CRYSTALLISING MEANING:
ATTITUDES OF LISTENING
TO ILLNESS NARRATIVES

Volume Two

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of the degree of Doctor of Philosophy

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The University of Melbourne:
Faculty of Medicine, Dentistry and Health Sciences –
School of Nursing and Social Work
and
The Victorian College of the Arts –
School of Dance
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Appendix One:
Autobiographies, biographies
and illness narratives

I gathered this list of illness narratives over many years. They are relevant autobiographies, biographies or illness narratives where the writer was personally engaged in the experiences. It is not formatted by End Note so that descriptive comments could be added.

Allende, Isabel. (1996) *Paula*, [Allende writes as she waits beside her deeply comatose daughter’s bed], Flamingo, UK.


Boden, Christine. (1997) *Who will I be when I die?* [Christine describes her journey with Alzheimer’s Disease, diagnosed when she was 46], Harper Collins, Australia.

Bone, Pamela. (2007) *Bad hair days*, [This journalist describes the experiences of suffering from multiple myeloma], Melbourne University Press, Melbourne.


Bradshaw, Delia. (2003) *Becoming Fine*, [an adult daughter’s tale of climate change in her relationship with her mother], Textcraft, Melbourne.

Casimer, Jon. (1999) *Naomi’s story*, [his baby daughter’s journey with a tracheoesophageal fistula, a father’s diary], Allen and Unwin, Australia.


Didion, Joan. (2005) *The year of magical thinking*, [Didion describes her first year of grief, when her husband of forty years died suddenly of a massive heart event], Alfred A. Knopf, New York.


Lewis, C.S. (1961) *A grief observed*, [reflections of a great scholar on the death of his wife], Faber and Faber, London.


McGowan, Diana. (1993) *Living in the labyrinth*, [a personal journey through the maze of Alzheimer’s Disease], Delta Trade Paperbacks, USA.


Sacks, Oliver. (1984) *A leg to stand on*, [a neurologist’s experience of severe leg injury], Picador, UK

Shepherd, Janine. (1994) *Never tell me never*, [the journey to recovery after severe injuries], Pan Macmillan, Australia.


Styron, William. (1992) *Darkness visible*, [a story of descent into deep depression], Picador, USA.


Appendix Two:
Ethics approval

23 December 2004

Dr L. Harris, Dr D. Asker & Mrs S Foster
Department of Social Work

Dear Dr. L. Harris, Dr. D. Asker & Mrs S Foster

Thank you for providing the additional information about the project.

I am pleased to advise that the Health Sciences Human Ethics Subcommittee approved the following project:

**Therapeutic Autobiography: Examining a process of constructing meaning, by including illness narratives within the context of collaborative life review**

Dr L. Harris, Dr D. Asker & Mrs S Foster

The Project has been approved for the period: 22/12/04 to 31/12/05. It is your responsibility to ensure that all people associated with this particular project are made aware of what has actually been approved.

Research projects are normally approved to 31 December of the year of approval. Projects may be renewed yearly for up to a total of five years upon receipt of a satisfactory annual report. If a project is to continue beyond five years a new application will normally need to be submitted.

Please note that the following conditions apply to your approval. Failure to abide by these conditions may result in suspension or discontinuation of approval and/or disciplinary action:

(a) Limit of Approval: Approval is limited strictly to the research proposal as submitted in your application.

(b) Variation to Project: Any subsequent variations or modifications you might wish to make to your project must be notified formally to the Human Ethics Sub-Committee for further consideration and approval. If the Sub-Committee considers that the proposed changes are significant, you may be required to submit a new application for approval of the revised project.

(c) Incidents or adverse affects: Researchers must report immediately to the Sub-Committee anything which might affect the ethical acceptance of the protocol including adverse effects on subjects or unforeseen events that might affect continued ethical acceptability of the project. Failure to do so may result in suspension or cancellation of approval.

(d) Monitoring: Projects are subject to monitoring at any time by the ethics committee.

(e) Annual Report: You must submit an annual report on this project at the end of the year, or, at the conclusion of the project if it continues for less than a year. Requests for annual reports are sent out by the Human Research Ethics Office in November/December of each year. Failure to submit a progress report at the end of the year will mean approval for your project will lapse.

(f) Auditing: All projects may be subject to audit by members of the Sub-Committee.

If you have any further queries on these matters, or require additional information, please do not hesitate to contact me on telephone no. 8344 2073 or e-mail k.murphy@unimelb.edu.au.

Please quote the HREC registration number and the name of the project in any future correspondence.

On behalf of the Sub-Committee I wish you well in your research.

Yours sincerely,

[Signature]

Kate Murphy
Executive Officer, Human Research Ethics

c.c. Chair, DHEAG, Social Work
Appendix Three:
Plain language statement brochure for therapeutic autobiography

Sandra Foster  MPC (Flinders) RN, RM, JW Cert.
Grad. Dip. in Creative Arts Therapy
(M.I.E.C.A.T.)

Sandra Foster has over 35 years experience as a Health Care Professional in Nursing and Palliative Care and has up to date qualifications in this field and Creative Arts Therapy.

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THERAPEUTIC AUTOBIOGRAPHY
Life Description and Life Reflection

Consultant Facilitator: Sandra Foster
What is Therapeutic Autobiography?

Therapeutic Autobiography provides a confidential process for telling, hearing, transcribing and then holding the stories of the important experiences of our lives.

We tend not to finish telling our stories, or take time to put them together. Therapeutic Autobiography is a process through which we review what we have learned and achieved, who we are and what we believe. It is like looking at a large picture from close up, seeing the pieces, and then stepping back in order to see the whole.

The experience of telling our stories and having them respectfully heard, and written down, can be very powerful and healing. The process gives us time to think, value our lives, and find new meaning in our stories. It can be like an archaeologist gently brushing the sand off a buried treasure, and uncovering layers of “how it was”.

Who does it help?

Anyone can gain comfort and healing from the process of telling their stories.
- Individuals with serious or terminal illness
- Their carers – family & health care professionals
- Palliative care workers as part of de-briefing
- Individuals with “ordinary” life stories who are searching for meaning

What happens?

The stories are collected by a series of audiotaped interviews. They are carefully transcribed and then returned to the storyteller for checking and reflection, and changes if necessary. I can provide support while you reflect on the meanings of some aspects of the story, if you wish.

What if you feel distress telling your story?

Counselling and support is central to the storytelling process.

What if telling your story affects your relationships with others?

You “control” your story and can alter it or withdraw it at any time.

What if you want to tell someone else’s story?

This process of Therapeutic Biography is similar and can be just as helpful. For example, as you collect stories about a loved one who has died, you may want to record them.
Appendix Four: 
Informed consent form

INFORMED CONSENT FORM

for participants in Therapeutic Autobiography with Sandra Foster.

I certify that I am voluntarily giving my consent to participate in Therapeutic Autobiography. The process, together with any risks to me associated with providing a story, has been fully explained to me by Sandra Foster.

I certify that I have had the opportunity to have any questions answered and I understand that I can make any alterations that I wish to my story. Also that I can withdraw my story at any time and that this withdrawal will not jeopardise me in any way.

I have been informed that the confidentiality of the information I provide will be safeguarded, Special conditions:.......................................................

........................................................................

Use of your story:

I may at some time in the future undertake further research in this area. It would be valuable to use themes or parts of individual stories in these studies. Your story will be treated with the strictest confidence. As you may share personal and perhaps sensitive information, neither your identity, nor those of others you mention, will be disclosed at any stage of the study. Use of your story is ensured of anonymity, and the anonymity of others who form part of your story. Pseudonyms will be used.

If you would prefer not to have any part of your story included for this type of study, please indicate by ticking the box.

I DO NOT want any part of my story included even anonymously in any research study   [   ]

Signed:...............................................................of

........................................................................

Witness:........................................Date:....................
Appendix Five: Themes across the literature searches for all five narratives

Kaye

1. Mothers and Daughters
   - An enduring bond of love and blood
   - Motherless daughters
   - Searching for the lost mother
   - The wild woman
   - In poetry
2. Suffering and grief
   - Anticipatory grief
   - Sadness
   - Shock
   - Spirituality
   - Touch and embodied experiences
   - Continuing bonds
3. Re-authoring lives
4. Values
   - Individuality
   - Creativity
   - Weakness and lack of courage
   - Concerns about ageing
5. Paradox and balance
6. Freedom
7. Telling the story
   - On writing another’s story
   - Equal voices
   - The collaborative story & methodological issues
   - History
8. Families
   - Kay’s father
9. Language and mirrors
10. Conclusions

**Sarah**

1. Between the ride and the story
   - Overcoming censorship of the story: telling the story so that the pain will not be wasted
   - They made her feel like a subject: medical discourse as power
   - I-It
   - The rise of experts
   - The moral problem of being a patient
   - Those who have the power
2. What is going on here?
   - How can they act like that
   - Explaining can heal
   - Pseudo participation versus creative participation
   - Standpoint
   - Sarah’s interpretation of her palliative care
3. Cultural soup
   - Untellable stories
4. Meaning making
   - Collaborative narrative relationships
   - Storytelling as ethical action in disrupted lives
   - Like a *testimonio*
   - Life’s normal tragedy: disease as entity
5. Listening to Sarah’s story
   - I-Thou and ‘hot’ texts
   - A shared community of value
6. Conclusions and closure?

Scott

1. Scott’s identity as a mathematician
   - Truth
   - Being a professor
   - Feelings
   - Separate worlds

2. Old age
   - Prayer and poetry
   - Inter/Intrasubjectivity
   - Giving Care
   - The dance of old age
   - The process
   - Asking the right questions
   - Oral hygiene enabling good communication, comfort and nutrition
   - Time
   - The family
   - Meaning
   - Isolation? Depression?
   - Listening in the silences
Bert

1. Alcohol induced dementia
   - Definition of alcoholism
   - The development of alcohol induced dementia
   - Wernicke-Korsakoff’s Syndrome
   - Confabulation
   - Differentiation from Alzheimer’s Disease
   - Alcohol and Isolation: non being

2. Narrative identity, personhood or sense of self, its loss
   - Narrative identity
   - Loss of story
   - Careful listening
   - Personhood or Sense of Self; power and disempowerment
   - In-valid: Loss of control
   - Silenced voice: this could be me!
   - To reveal all or respect doors that need to remain shut?
   - Bert describes himself as ‘Half a person’
   - Humour

3. Emotions
   - Raw emotions
   - Night Terrors and disruptive behaviour

4. Dementia care
   - Intro: being de-mented
   - The in-valid, and concepts of total care.
   - Confabulations beyond the physiological
   - Time and place, present & past
   - Making sense of dementia
   - Initiating conversations
   - Self-disclosure
   - Bert’s future
5. The staff of a dementia unit
   • The dialogues between staff
   • Staff stress and conflicting values
   • The staff’s surprise
6. Reminiscence & life review
   • Reminiscence in dementia
   • The reconstructed past
   • Valuing Bert’s presented world
7. Truth and values
   • A sense of place
   • Commemorating moments of value
   • Work ethic
8. Buber & intersubjectivity
9. Ethical considerations
   • Conclusion:
   • A tool to measure outcomes
   • The poetry
   • The benefits of the process

Elizabeth

1. Elizabeth’s narrative
   • A story of intensity
   • The story’s flow
   • A narrative shaped and measured by time and place
2. A sense of elf and belonging
   • Different cultures
   • Community support and connections
   • Making choices
3. Family and enduring relationships
   • Family ceremonials
4. Epiphanies
   - Elizabeth’s abortion
   - Elizabeth’s nervous breakdown
   - Elizabeth’s ‘hot texts’
   - Elizabeth’s near death experience
   - ‘It was not nice!’
   - A touch of kindness
5. Fraying around the edges
   - The deficits after Elizabeth’s stroke
   - Resilience
   - The end of Elizabeth’s narrative
Appendix Six:
Kaye

1. INTERSUBJECTIVE RESPONSE FROM SANDRA TO KAYE FOLLOWING TAPE 2

In order to help clarify for Kaye the clinical details of her mother’s death, in response to her confusion about ‘life support’ and when her mother actually died, I had a discussion with an anaesthetist (my son Dr James Griffiths). The discussion was limited to defining the medical situation. The following was my response to Kaye:

**ISR 3 Life Support:**

The patient is *ventilated*: there is a tube into the lungs, with an inflated cuff that stops the air from leaking out, and the ventilator breathes for the patient until such time as this machine is turned off, or the patient is able to breath for themselves.

**A drip:**

This is the intravenous line that gives the patient fluids into their vein, and also is a route for drugs to be given. ‘Central lines’ which go into the larger arteries and veins nearer the heart, are placed into the upper chest area.

**A Catheter:**

This is a tube usually in a patient’s bladder so that urine is collected for measurement of output, and to keep the person clean and dry.

When ‘life support’ or ‘machines’ are turned off, this means the ventilator is switched off. Now, in the new hospital ICU, the patient is moved into a quieter room where the family are free to stay for a while if they choose. The nursing care is still one on one.
There is a Patient Communication / liaison person available to help with this kind of information. They are able to access patient’s notes, to review the exact circumstances.

2. **KEY WORDS/PHRASES FROM TAPES OF KAYE’S INTERVIEWS**

These lists were selected from my intersubjective responses, prior to re-reading the transcripts or re-listening to the tapes.

2.1. **Tape 1:**

- 25 years: an intimate relationship
- Pivotal devastation - my mother is dead!
- 10 years: completely and utterly missing from my life
- Like a goddess of soulfulness
- a rare bird! on a pedestal in my mind,
- a really really good person
- She was unbelievably unique -
- Like a closed flower, she was rained on and opened

Finding out who my mum was might help me find out what life means, what love means, what family means, what everything means.

I can’t walk away from her and ‘let her go’
because I might loose her
she is such a part of me, part of who I am.

She was an emotionally abused child -
her father was a cruel tease
That’s filtered down to me
Coddled as a child - almost over-protected
that’s partly why I’m so immature now,
partly the wild Bohemian she wanted to be
I keenly felt single
total dweebs - why bother?
I wanted a really loving relationship -
like holding hands on the couch watching TV
Dad showered Mum with love.
I shower people with love
I’m so generous emotionally - this strength of love

Do I need to let go of her?
‘I’ and ‘my mum’
Are bound almost indistinguishably
How can I loose her when she is so inextricably part of who I am?

2.2. **Tape 2:**
I had no choice
This is a key
I’ve lost her
I said goodbye
her body was dead, cremated

I’ve got all these characteristics
I hate those pictures!
I was born from her,
I had 25 years of her energy

There’s been 10 years since I parted with her body!
The problem: yet she is part of me … the characteristics come with me
Her death was an up and down experience
In shock - I smoked a lot, I wanted to vomit
An in and out tray; the out tray: dead!
Down: the morgue, the ultimate
A visceral kind of feeling, an up and down motion
stainless steel surfaces
The 3 of us together, but separate entities
She was healthy, why did she have to die? Anger - NO!
Mum died twice
I look like her,
though there’s a clear genetic line from my dad to me
She was doe-like, I was so wild
I was on a self-destructive streak!

2.3. **Tape 3:**
I think backwards and forwards - I think too much
I don’t want to be here!
There is a line of obliteration, drinking and smoking
to obliterate the pain.
I have a depressive tendency in my physical body to equal
the pain in my emotional body
Feelings? Emotions? That’s a very hard thing to say:
frustration, confusion, anger.
Parallel experiences:
I will not let go of my ideals
the potential to be really happy
The pearl of great price or the bowl of glass marbles
Romantic love or pragmatic relationships
Honesty and freedom
Care, goodness, kindness
He: gave her the freedom - that’s what commitment’s about
Mutual respect no secrets, just pure light
He: covered it up, pretended it wasn’t happening
Absolute: weakness, dishonesty, lack of freedom, lack of courage
Mine: there from the beginning
Hers: evolved
I believe in love!
Relationships can change but still endure.

The things that I’m scared of:
Being single
Being alone
Being unloved
Not reaching my creative potential
Settling for the marbles
instead of the pearl

2.4. Tape 4: Side A
My whole life is story
I am a creative person in my essence
Creativity is one of the really high values
This is the lesson I have learnt from my mum’s death:
I do not avoid suffering now
From absolutely no choice, to two choices - to sink or swim
I am strong and brave, I know I will survive
I want to say ‘thanks for my life’
I am starting to wonder...
Does loyalty (or stubbornness)
mean my life’s work is to pursue her artistic endeavours,
to do what she didn’t complete?
My life’s my life, hard, painful, I suffer a lot -
Love is the only rational act
I absolutely don’t think pragmatic existence is enough!
The rational is the Love!
Compassionate rationalism -
Until you understand death you don’t understand life!
when faced with two choices, always take the hardest path

2.4.1. To P:
‘Follow your heart:’
I love you,
I think it’s the best thing that’s happened to us,
I’m really sorry and sad that you don’t feel the same way
all I can do is get on with my life, and let you go free’

2.5. Tape 4: Side B
My dad wants me to be happy
I thought I was unloved, unlovable,
It’s weird - I am actually quite happy!
and I’m learning to make decisions for myself
Nine, ten years, and Good King Wenceslas still brings tears
I haven’t got over my mum’s death
She was always there for all of my problems
even though they were pretty bad,
She is everywhere in this city, I’ve come home to my mother -
she is still present for me, I’m still as sad as the day she died.
But now ...
For the first time in my life I am finding my mother in me
Growing a sense of happiness, clarity, knowing and valuing myself
for the first time in my life I’m valuing the real human being
I want to see the whole person
‘valuing is creating’
Existence becomes meaningful when an individual’s creativity is understood,
to redeem suffering (Nietzsche 1997 edition )

2.6. **Tape 5:**
Sink (suicide/insanity) or swim (transform the experience)
creativity is innate in me
creativity in the context of life and suffering - the capacity to go way out
the creative use of suffering
life’s trajectory - you need to know what you want before you can be assertive.
I am the black sheep in the family - I’m the only one -
no career, no boyfriend, no children, no financial security
or can’t they see I’m incredibly lucky I’ve been given this gift?
the guts to search
2.7. **Tape 6:**

That’s what life’s like

The strokes.

They’re so confident, loose and beautiful

She could have become very abstract

It’ll be a beautiful big painting

flowers huge in one corner

then coming out into darkness,

the leaf, I can see it

It’d be amazing

like a jump-cut, in film

I chose the darkest corner!

The darkest corner

is next to the greatest light

There’s the very dark movement

then it becomes lighter, then it gets darker

there was a very sudden change

It went from the light to the dark very suddenly,

I don’t know how I managed to choose that particular corner,

very essential base type meaning - the unknown; inconsistency;

contradiction;

changes are what make life great

madness, confusion, loss, pain,

paradox - an essential part of human existence

Basic, bottom line survival

A fine balance between hope and despair

joy and suffering

You have to make decisions and act

Killing is part of life

I’d like to ride the fulcrum in the middle

But animals kill each other to survive

I don’t kill anything that I don’t have to kill

There is no sense - you have to create a position

I don’t know how you do it
Is this it?
My life was over -
The love didn’t work
I’m never going to love anyone again
I’m never going to be that happy again or have that incredible intensity
that I just love in my life, that richness, that stimulation, or that sort of wildness
It’s all over, maybe I’ve had it
I’m 36 years old, is it really worth living, if I’m not going to have these things?

And then!
I go to this big art meeting, I’m sitting there, there’s just me,
I was feeling like a pimple on a pumpkin,
What am I doing here, these people don’t know who I am,
‘Why would you match me up with a kid?
you don’t know me, you don’t know what my films are like?
You don’t know what I’ve done, you don’t know whether I’m any good.
She just attacked me:
‘this isn’t about the film industry,
you’re meant to be here, because you’re meant to be here,
you’ve had the courage to come here,
you’re supposed to be here’

She said ‘I liked you as soon as I met you,
you’re meant to be here,’ and I’m just going
‘has this turned into a self-help group for me?
I’m terribly sorry!’
I’m involved!
That’s what I want to do with my life!

We’re all getting old!
When you get to this age you have to grapple with ageing
Check this photo! I’ve got a photo of me, and I look like that!
I’m wearing the same sort of dress
Mum looks absolutely beautiful. I love that photo!
She said ‘your mother was an angel!’
everyone knew that my mum was different.
The relationship that we had with each other was just so different
I don’t think I know anyone who’s got the sort of relationship I had with
my mum
It’s just uncanny - she would look into your eyes
she just had some sort of quality about her
that was very non-judgemental, very caring,
she didn’t try to impose her views on anyone else
She didn’t try to impose her views on me, as her daughter,
which is what most mothers do

‘I get that from my mum and dad’
This is the problem
‘A Fine Balance’ is so profound (Mistry 1996)
These people are in the most extreme position,
They’re suffering a kind of dictatorship
They wanted to beautify the cities
so they knocked down all the slums,
made millions of people homeless;
pick up bus loads of people,
take them to a political rally
make them stand there for hours, regardless
They’d do these things to these people
In this incredible society there’s no certainty
because it’s over populated, urbanizing, everything’s breaking down
The caste system is inherently evil, it has to break down

And here’s me, you, everyone we know
in this affluent western society, we’ve come in here
we’ve ripped through the indigenous population,
roads, traffic, affluence, high education, privilege
Even within that context
because I’ve eschewed that
[abstain from, shun, avoid].
Suffering from middle-class guilt
I’ve had left-wing, socially orientated values
I get that from my mum and dad
I’m so proud of my dad
He’s very socially conscious

I am so sick of people making value judgments about people
based on these external things when they don’t really understand
that

person [yells]. I think that’s one of the biggest problems in the whole
world

I sort of went to university
I had this brain, I didn’t know what I wanted to do with it
there was a lack of fixety in my path, in my purpose
I left university, I went to Queensland
I got busted for drugs, I ran around
I went back to university, I left, I went back, I left

Then my mum died! I went off [yells]
I lived in Brisbane, I came back here, I left again, I’ve moved. I’ve been
evicted
I can survive financially, by myself, I’m on the dole, I’m working in a
café
I’m trying to get into a film related field
I’ve hardly ever had any long term relationships,
I’ve been on my own. I don’t have children

It seems to me that to a certain extent,
you’re only going to be free once you accept
that you can’t really have security or permanence
Freedom is when you start to say that’s all you know
And you don’t have fixety in your viewpoint
To be fixed in your viewpoint and to say ‘that means this’
The fear is insecurity, people are scared of being insecure
They’re scared of not having something to hold on to
Freedom comes from knowing there is no certainty
Happiness comes from knowing unhappiness
‘there’s so many things I want to talk to her about’
I’m so helpless they start to nurture me because my mum’s dead,
because I had this incredible relationship with my mum,
I really wish I had now,
I’ve been missing her really really badly,
party because I’m starting very slowly to kick arse
And if I kick arse, and I do something amazing like I do this project.....
I want her to know, I want her to know, I want her to see it
I want to be able to talk to her about these people that shit me!
It’s like I was having a conversation with someone
and I can’t have the conversation! I want to talk to her!
inconsistency, contradiction, change, madness
I think we misunderstand what normality and abnormality is in this
society
We are all flawed, and we all make mistakes all the time
3. FULL TEXT OF FOUR POETIC STATEMENTS: TIME, SPACE, SELF, OTHER

a) Time: (temporality) [van Manen, 1990, pp101-106]: subjective time as opposed to clock time. Past, present, future: the past changes under the pressures and influences of the present - I may reinterpret who I once was or who I now am.

My Mother Myself:

For 10 years she has been completely and utterly missing from my life,
I don't have her to refer to as a model anymore, I've lost her
I said goodbye, her body was dead, cremated
I feel that I watched her through my life, I watched her in her life grow
I remember a number of things about her
I will always believe I had this incredible relationship with my mum,
It's like I was having a conversation with someone
and I can't have the conversation

Probably one of the nicest moments for me,
which would have been really when I was sort of saying goodbye to her
I think I would have preferred to have stayed there next to her for the whole time
While the machines were actually removed,
because that was the last time I ever was going to be
in the presence of my mother's physical body
The way I dealt with walking away from my mum,
my mum died, I went off!

I am constantly striving for something I don 't achieve,
if my mum was there the edge would be taken right off it ...
which is where we started months ago

There was a lack of fixety in my path
I sort of went to university, I left,
I went to Queensland, I ran around
I went back to university, I left, I went back, I left again
I've hardly ever had any long-term relationships, I've been on my own
I was really in the experience
I think backwards and forwards, and I think all the time,
I don't want to be here!

It seems to me that to a certain extent you’re only going to be free
once you accept that you can’t really have security or permanence
Freedom comes from knowing there is no certainty
Freedom is when you start to say each day is as it is
There’s no future, there’s no past, there’s just now

I can tell that story anywhere any time really
I was born of this woman, and I spent 25 years with this woman around me
For the first time in my life I am finding my mother in me
I felt that my mum had become a certain person by the time she died,
she gradually learned;
For the first time in my life I can see the whole person
maybe what is happening is that I’m re-claiming that,
those things are actually becoming very very clear to me
for the first time in my life
I feel a sense of clarity developing, a sense of happiness,
a sense of knowing myself that I’ve never had before,
and a sense of valuing myself that I’ve never had before
I’m experiencing that [sometimes]
without even deliberately trying to experience it [It’s transient]
b) Space: (spatiality) [van Manen, 1990, p.102]: spatiality is felt space, mathematical space, the length, height, depth dimensions, distances, spatial dimensions of home, but lived space is largely pre-verbal, we do not ordinarily reflect on it, we become the space we are in. We know the space in which we find ourselves affects the way we feel. Home reserves a very special space experience which has something to do with the fundamental sense of our being. Home has been described as that secure inner sanctity where we can feel protected and by ourselves ... Home is where we can be what we are ... lived space is the existential theme that refers us to the world or landscape in which human beings move and find themselves at home.

I was born of this woman,
I spent 25 years with this woman around me
I was standing looking out the window above her bed
And I was just telling her what was out there
I think I would have preferred to have stayed there next to her for the whole time,
the actual just sitting there with the body;
that was the last time I ever was going to be
in the presence of my mother's physical body

I can remember these feelings that I had,
this up and down motion, feelings of stainless steel surfaces
I got a very strong visceral kind of feeling of those things,
they were key physical components of the experience.
I wanted to vomit
The way I dealt with walking away from my mum
I went off!
There was a lack of fixety in my path,
I sort of went to university, I left,
I went to Queensland, I ran around,
I went back to university, I left,
I went back, I left again.
Freedom is when you start to say each day is as it is
I had to come home
I hadn’t had a sense of home or family since my mum died
Home is something I have to establish within myself
The journey was coming home to my city
I drove into Melbourne, past the hospital where my grandfather died
I went past a place I’d attended for some gynaecological problems
She was everywhere in this city: I’ve come home to my mother,
It’s keeping me in Melbourne

I still live in a share house, without financial security,
I don’t have a lot of things, I don’t have a proper home
Maybe hiding under the bed, the parallel is like smoking the cigarettes,
and then being nurtured out, It’s actually right inside me

Joy and suffering are inextricably linked, a parallel journey
So it’s precisely about this experience I’ve been having of life,
where I see life as being just an ongoing parallel experience of joy and suffering
I chose the darkest corner, next to the greatest light
What we had was pure light ‘Your mother was an angel’
It went from the light to the dark very suddenly, almost like a jump-cut in a film
Almost like it had been clipped too early
I see both sides and flip from side to side
c) Self: (corporeality) [van Manen, 1990, p101-106]: The phenomenological fact that we are always bodily in the world. We first meet people in the world through their body. In our physical or bodily presence we both reveal something about ourselves and we always conceal something at the same time.

*Myself, motherless daughter:*

I don't have her to refer to as a model anymore, I've lost her
I said goodbye, her body was dead, cremated
I haven't got over my mum’s death
I remember a number of things about her
I find it incredible the misconceptions people have about death
I just think that's such crap!!!

I’ve deified her. What we had was pure light ‘Your mother was an angel’
I had this incredible relationship with my mum,
I’ve been missing her really really badly,
partly because I’m starting very slowly to kick arse
And if I kick arse, and I do something amazing,
I want her to know, I want her to see it
There’s so many things I want to talk to her about
It's like I was having a conversation with someone
and I can't have the conversation
I want to be able to talk to her about these people that shit me!

The big thing that I've definitely inherited from her
Massive problems with self esteem, huge,
that's coloured my whole life in relation to absolutely everything

I think I would have preferred to have stayed there next to her for the whole time
I was bowled over by that experience. I’m still as sad as I was the day she died
The way I dealt with walking away from my mum was
I think I might have touched her, it was hard to touch her, because I wasn’t brought up or taught,
society didn’t really teach me much about death
I am constantly striving for something I don’t achieve
I am so sick of people making value judgments
about people based on these external things
when they don’t really understand that person.
I absolutely don’t think pragmatic existence is enough;
with my pain of someone choosing pragmatics over idealism
But you have to make decisions and act
I’d like to ride the fulcrum in the middle,
I don’t kill anything that I don’t have to kill
I want to heal the world. You have to create a position,
I don’t know how you do it, and I do not like it
I don’t want to live like that, I want to live in a society that’s based on
love,
that’s all I’m interested in, and I’m interested in social justice
I will not let go of my ideals,
I think the environment should be vastly different,
I think society’s in profound crisis

My own chaos:
My mum died, I went off!
There was a lack of fixety in my path, in my purpose
I sort of went to university, I had this brain,
I didn’t know what I wanted to do with it. I left university,
I went to Queensland. I got busted for drugs,
I ran around, I went back to university, left, I went back, I left again
I’ve hardly ever had any long term relationships,
I’ve been on my own, I don’t have children
I can survive by myself, I’m on the dole,
I’m working in a cafe, I’m trying to get into film making
There is a line of obliteration, drinking and smoking, to obliterate the
pain
I have a depressive tendency in my physical body
to equal the pain in my emotional body
Feelings? Emotions? That’s a very hard thing to say:
frustration, confusion, anger, anxiety, hatred
I'm still as sad as I was the day she died

I'm a very experiential person, fiery, highly engaged
I was really in the experience
I'm optimistic and pessimistic sometimes at the same time,
but always extremely, never half-hearted
I think the extremes of the scale are normal
I am the black sheep in the family;
I'm the only one with no career, no boyfriend,
no children, no financial security
Coddled as a child; over-protected
That's partly why I'm so immature now,
partly the wild Bohemian she wanted to be,
so wild, self-destructive, and self-punishing
I really live, I think backwards and forwards,
I think all the time, I think too much, my mind's massively overactive,
I can get really manic, I've got a huge amount of energy,
but I think also I live at a very high level of engagement
I don't want to be here! I've learned a process like a meditation
I'm loud, that could be mistaken for assertive

Chaos is a part of life, important in the processing of growing
or dealing with a major issue
My chaos is my honesty
I'm honest to the world. I don't hide how I'm feeling
It's weird, kookie, fucked up thoughts,
incredibly perverse when someone dies,
dark, shit thoughts, honest not callous,
shock, bottom line experiences
I can tell that story anywhere any time really
I was born of this woman,
I spent 25 years with this woman around me,
so there’s an energetic kind of level, and there’s an energy
For the first time in my life I am finding my mother in me
I’ve got a photo of me, and I look like my mum!
I’m wearing the same sort of dress
She looks absolutely beautiful, I love that photo!
I think that one of the key points was to discuss
what values I inherited from her:
definitely ... honesty is very important, and freedom
I believe in love, I just felt that they were in love
I shower people with love, I’m so generous emotionally

I’m realizing that my life has value, that I’m \textit{absolutely amazing}!
I have a growing sense of happiness,
clarity, knowing and valuing myself
I’m experiencing that without even deliberately trying to experience it
[It’s transient]
Thank God I’m doing this process with you,
because it’s keeping me sane, I’m a flighty, flighty person
I’m under a lot of pressure,
I feel that the reason that things didn’t work out with him,
is partly because of this process, because this is more important,
this is giving me a reason to really be alive
This is really clarifying for me, it is absolutely what I believe.
I just feel I’ve been given the most incredible gift
It took the most incredible amount of courage, it caused a huge amount
of pain.
Yeah, yeah pain is part of it, it caused a huge amount of pain
Home and family:

I had to come home
I hadn’t had a sense of home or family since my mum died
Home is something I have to establish within myself
That’s what I came back for
I don’t know if I’d feel any differently now if she was alive.
I drove into Melbourne, past the hospital where my grandfather died
I went past a place I’d attended for some gynaecological problems
My mum was always there for me, I was crying
I’ve come home to my mother, she is still present for me
I had a long period where I felt that I didn’t have a family
One of the key things I did in response to my mum’s death
was to deny family, I felt a bit like the three of us were together,
but for me it was like we were three very independent entities
Dad took control, he made me move home
My dad wants me to be happy - this puts immense pressure on me
But I’m learning to make decisions for myself
He loves me so much, I’m so not what I think I’m supposed to be for him!
He’s the model I’ve had to refer to for 10 years
He said ‘you’ve got to get a proper job,’
he had a role in my low self esteem

I started the conversation by saying ‘I think we’re really lucky!’
We had great parents, and a great childhood,
we had a loving open emotional relationship with our parents
I can’t stand the idea of spending your whole life
being a victim of your childhood.
Mum is part of me, her characteristics come with me
I look like her, though there’s a clear genetic line from my dad to me
I was connected to my granny
I’ve come through a process where I’ve created a good relationship
with my father, my brother, my nieces
I’m blanketed by love, but I’m tired,
I’m getting older, I still live in a share house,
without financial security, I don’t have a lot of things,
I don’t have a proper home
I’m lucky enough to be able choose to live a slightly unconventional life,
but those things still do affect me, they’re the norms
I’m learning through this process that what gives me my strength
to exist and be happy isn’t those things
I’ve refused to make those things the basis of my life

The creative use of suffering:
I feel that I watched her through my life, I watched her in her life grow
My life’s my life; hard, painful, I suffer a lot
I had the guts to search, I valorise creativity
My whole life is story, I am a creative person in my essence,
creativity is innate in me,
whatever happens, my life is a creative process
I’ve chosen to live in a certain way,
I’m like a power house of spinning creativity
I do not avoid suffering now I am strong and brave,
I know I will survive
I want to say ‘thanks for my life’
The real joy of having an experience like that in your life
is that it gives you a stark realization of the real nuts and bolts of life.
I have to make my own decisions for myself,
I’m not going to do what you think I should!
I always seem to be taking the harder path. Why do I do this?
Maybe hiding under the bed, the parallel is like smoking the cigarettes,
then being nurtured out
I have to self-nurture now, because I don’t have a mother,
I’ve had to learn how to do that
This is the lesson that I learnt from my mum’s death

So if I never produce anything, I’ve made these subconscious
decisions,
as though I’ve been guided by some other force,
which I think is partly to do with my mum
Because, if I think about my childhood, it’s rubbed off on me
I have no doubt about it. So it’s not just that I valorise these things
for some abstract impractical kind of perverse reason,
it’s because it’s innate in me
It’s actually right inside me

Paradox and contradiction:
I contradict myself all the time
So it’s precisely about this experience I’ve been having of life,
where I see life as being just an ongoing parallel experience of joy and
suffering.
When I read through what I’ve said
I read a lot of contradictions and perhaps hypocrisy
I’ve been thinking a lot about basic survival
because of things I’ve been experiencing in my life
I’ve been thinking about religion,
I don’t think that I necessarily need to hinge my life
around some kind of external system of belief
that is encapsulated in some particular form.
I can never lose her in one sense, because 'she was who she was, that means I am who I am'
I chose the darkest corner,
I see both sides and flip from side to side
I can’t walk away from her and 'let her go' because I might lose her
I feel such intense loyalty to her, she is such a part of me, who I am
Do I need to let go of her?
My mum and I are bound almost indistinguishably
How can I lose her when she is so inextricably part of who I am?
I see everything as being kind of grey, I've got opinions, seeing it as grey, that's just another opinion

Feeling:
I thought I was unloved, that I was unlovable.
Fear of not being loved, of not reaching my creative potential,
of settling for the marbles instead of ‘the pearl’,
that's what I'm scared of now
I love him, and I thought he loved me,
I thought I'd found the person I was looking for, and now I haven't
That's been a really dominant theme for me
I'm so sick of having to fight my way around the world on my own
Yet I'm blanketed by love. I can see the silver lining,
I can see the positive side to the experience more clearly
I've had so much experience with being immersed in my own fear
I can remember these feelings that I had
of this up and down motion, feelings of stainless steel surfaces
I got a very strong visceral kind of feeling of those things,
you were key physical components of the experience
I wanted to vomit, I'm still as sad as I was the day she died

Most of my life I've been scared of being alone,
not having a relationship like the one that my parents had
I absolutely don't think pragmatic existence is enough!
Absolute: weakness, dishonesty, lack of freedom, lack of courage
I’ve been scared of that a lot, I feel a sense of hopelessness
What seems to happen for me is that the hopelessness is operating in tandem
with something else which is a kind of re-growth, regeneration or re-birth

Now I feel very pressed for time
I feel I met someone I loved, it didn’t work out,
I feel like it’s all over for me, I feel like I’ve missed my opportunity,
I suppose that is probably why I am clinging to that so much
I just can’t remember, prior to that night,
when I’d seen my mum before that, it’s all gone,
I can’t say that I saw her the day before, or the day before that
or we did something the weekend before, or I went over there ...
I can’t remember anything. Nothing!

I knew I was in shock over the weekend because of the letter I’d received,
I knew about it, in a way that I hadn’t known before
I won’t look in mirrors any more because I think I’m really aged,
that’s one of my key issues
d) Other: (relationality) [van Manen, 1990, p.101-106]: The lived relation we maintain with others in the interpersonal space that we share with them ... we approach each other in a corporeal way, through a hand shake, or by gaining an impression of the other in the way that he or she is physically present to us ... in a larger existential sense human beings have searched in this experience of the other, the communal, the social for a sense of purpose in life, meaningfulness, grounds for living as in the religious experience of the absolute Other, God.

My Mother, Myself

I remember a number of things,
the actual just sitting there with the body like that,
her feet were shaking, she had a tube down her throat, clearing out her lungs
she’d fart occasionally, and let out these breaths of air;
her eyes were open, her pupil was leaking
It was hard to touch her,
there’s this incredible experience of alienation
You’re actually with this body of someone,
it's not that person, it's cold;
people say touch her, hold her hand, kiss her;
you do it because you’re being told to do it,
but it doesn’t feel right, this person just isn’t!
That was the last time I ever was going to be in the presence of my mother’s physical body

The way I dealt with walking away from my mum was
I think I might have touched her, her body was dead, cremated
My mum died, I went off!
I just can’t remember, prior to that night,
when I’d seen my mum before that, it’s all gone,
I can’t say that I saw her the day before, or the day before that or we did something the weekend before, or I went over there....
She always didn’t want to go grey, she was looking at herself in the mirror
and she goes, 'oh, oh no, look, here's my first grey hairs!'
She felt that she’d never really been allowed to reach her potential
My mum was this *mega* intelligent person, really interested in art and ideas,
my mum was interested in social justice
It’s the most profound thing, it’s like,
if my mum was there the edge would be taken right off it

I had this incredible relationship with my mum,
I’ve been missing her really really badly,
if I kick arse, and I do something amazing,
I want her to know, I want her to see it
I will always believe that was probably one of the best
mother-daughter relationships that you could ever come across:
no punitive element, little disciplinary element
One of my main things about her dying is that I’ve deified her
What we had was pure light ‘Your mother was an angel’

That’s the hard part of it, this issue of loosing someone,
the key part of the experience, it’s a contradiction in itself,
I can never loose her in one sense,
because ‘she was who she was, that means I am who I am’
I can’t walk away from her and ‘let her go’
because I might loose her
I feel such intense loyalty to her,
she is such a part of me, who I am
Do I need to let go of her?
My mum and I are bound almost indistinguishably
How can I loose her when she is so inextricably part of who I am?
I was born of this woman,
I spent 25 years with this woman around me,
there's an energetic kind of level
My mum was always there for me. She was everywhere in this city
I’ve come home to my mother, she is still present for me,
I’m still as sad as I was the day she died
For the first time in my life I am finding my mother in me
I’ve got a photo of me, and I look like my mum!
I'm wearing the same sort of dress
She looks absolutely beautiful. I love that photo!
In terms of stuff to do with art, creativity, value systems, and love,
I think that we are talking about her,
I think that one of the key points was
what values I inherited from her: definitely
honesty is very important, and freedom
My dad showered my mum with love, he gave her freedom,
I just felt that they were in love

I find it incredible the misconceptions people have about death
You know people in the movies when someone dies,
they kiss them and they hug them and they hold them
I’m sure that happens and people do that
I think that the society’s crisis is really enunciated
in an experience of death,
I think one of the problems with death is
people can’t deal with it, they don’t talk about it
This is the problem: people are in the most extreme position
Here’s me, you, everyone we know in this affluent western society,
we’ve come in here, ripped through the indigenous population,
roads, traffic, affluence, high education, privilege
in this incredible society there’s no certainty,
because it’s over populated, urbanizing, everything’s breaking down
We had mouse traps in our house and they were set
Then there was note saying due to certain new perspectives
about killing mice, we’re not going to kill mice in the house
I am so sick of people making value judgments about people based on these external things when they don't really understand that person. Absolute: weakness, dishonesty, lack of freedom, lack of courage, he covered it up, pretended it wasn't happening. I don't think he should settle for pragmatics; businesses, houses, habit, comfort, her I think he should go for broke. Because I reckon that unless you're willing to go out on a limb, take risks in life, you're just living a half life, you're not really alive. I feel I met someone I loved, it didn't work out: I love him, and I thought he loved me; I thought I'd found the person I was looking for, now I haven't. 'I'm really sorry and sad that you don't feel the same way, all I can do is get on with my life, and let you go free’ Thank God I'm doing this process with you, I feel that the reason that things didn't work out with him, is partly because of this process. Because this is more important, this is giving me a reason to really be alive. This is really clarifying for me, it is absolutely what I believe. I just feel I've been given the most incredible gift. It took the most incredible amount of courage. It caused a huge amount of pain. Yeah, yeah pain is part of it. It caused a huge amount of pain. For the first time in my life I can see the whole person. I'm valuing the real human being.
*Home and family:*

I am the black sheep in the family;
I’m the only one with no career,
no boyfriend, no children, no financial security
partly the wild Bohemian she wanted to be,
It was almost 10 years since Mum died,
I hadn’t had a sense of home or family since my mum died.
I had a long period where I felt that I didn’t have a family
I don’t know if I’d feel any differently now if she was alive
I drove past the hospital, where my grandfather died
One of the key things I did
in response to my mum’s death was to deny family
I felt a bit like the three of us were together,
but for me it was like we were three very independent entities
Dad took control: he scattered her ashes without us there

My dad wants me to be happy, he made me move home
He has an incredibly strong paternal instinct, he loves me so much,
I’m so not what I think I’m supposed to be for him!
He said ‘you’ve got to get a proper job’
he had a role in my low self esteem
He’s the model I’ve had to refer to for 10 years

He couldn’t talk about Mum’s death
He’s an extrovert, multi-directional, he can concentrate,
be involved in a number of different activities at any one time,
he’s a good business manager, he used to get antsy,
he’s very pragmatic, quite shy, a real extrovert, gregarious, ribald like a clown
The grumpy thing’s a key - he wears everything on his face and in his body
My brother said ‘Nothing stands out in my memory’
Then he said ‘I feel annoyed with her that she didn’t assert herself’
Dad would make suggestions about what she should do
She wouldn’t assert herself and say what she wanted to do,
she’d do what other people wanted
He doesn’t think that we were lucky

Being an artist was not an option in Grandpa’s family
Grandpa never defined anything,
so you could never be certain about ownership, relationships
Mum is part of me, her characteristics come with me, I look like her,
though there’s a clear genetic line from my dad to me
I was connected to my granny
I’ve come through a process where I’ve created a good relationship
with my father, my brother, my nieces

I feel that I watched her through my life, I watched her in her life grow
I felt that my mum had become a certain person by the time she died,
I think that she synthesized a lot of lessons in her life;
I think that she had quite a creative approach to her own suffering
And that she gradually learned
I’ve been guided by some other force,
which I think is partly to do with my mum
Because, if I think about my childhood,
my mum was creating in an artistic sense,
all the way through my childhood
I’ve got my mum’s drawings in my room,
and she was potting, and what ever she was doing
she was always actually creating at a practical level
And it’s rubbed off on me

Where are we going from here?
4. **TWO STRUCTURAL NARRATIVES AROUND THE THEMES**

4.1. **Feeling**

The daughter thought she was unlovable and was afraid of loneliness and being alone, and of not being loved. She was also afraid of not reaching her creative potential. She thought she had found the love of her life, but this was not the case, so the relationship ended. She feels tired of the constant struggle of being alone and yet she can see that she is very much loved by family and friends. Her father showered her mother with love, the daughter showers people with love and is emotionally very generous. She has had to live with her fears.

She was always afraid of settling for a pragmatic relationship instead of the ideal, which she believed her parents had, and of not experiencing a relationship as good as theirs. She felt her partner settled for the pragmatic, was dishonest and lacked courage. This leads her to feelings of hopelessness, yet she can also feel this is happening at the same time as a kind of re-birth or re-generation. Failure of this important relationship brings a sense of pressure of time running out, and that she has missed her chance, which made it harder to accept that the relationship had ended.

She remembers the strong embodied feelings she had over her mother’s death: an up and down motion, and strong feelings of nausea. She has trouble remembering the end of her time with her mother - nothing remains in her memory of those last precious days and weeks prior to her mother’s collapse. She feels society deals badly with experiences of death, and television becomes our main source of knowing how to behave appropriately.

The daughter experienced shock when her mother died, and this in a way helped her when she received the letter which ended her relationship with her partner - she knew what it was she was experiencing. She remembers her mother finding with horror her first grey hairs shortly before her death. The daughter is afraid of looking in mirrors now, because she sees signs of her own ageing.

4.2. **The Creative Use of Suffering**

The daughter watched her mother’s growth. Her mother had gained wisdom by the time she died and a creative approach to her own suffering. The daughter’s own life is difficult
and painful, and she suffers but she can see that life involves suffering. Creativity redeems suffering, the daughter valorises creativity and had the courage to undertake this search for meaning.

Her whole life is story, she is innately creative, her life is a vibrant, pulsating creative process. She does not avoid suffering now, is brave, a survivor who is grateful for her life.

The good knowledge that came from the experiencing of her mother’s death was the understanding of the hard realities of life. She is now wanting to take responsibility for her own decisions. She is aware she often chooses the hardest path in life and sometimes wonders why.

When she was very young, the daughter used to hide under the bed when things went wrong, and her mother would nurture her out. The parallel now is her smoking and drinking, but because her mother died she has had to learn to nurture herself out. Ten years ago she had the worst possible experience when her mother died and she realized that she could choose to suicide or sink into mental illness, or transform the experience and nurture herself into survival. She chose the latter.

This was a creative decision, almost as if she was guided by her mother. Her mother’s artistic creations are precious possessions. Thinking about her childhood she realizes that her mother’s constant creativity has rubbed off on her. It is not just at an abstract level but at an embodied level deep in her being.

5. **THE APPLICATION OF THE LITERATURE SEARCH TO KAYE’S NARRATIVE [FULL TEXT]**

There was a great deal of literature connected to Kaye’s story, perhaps because her story is complex, and inextricably connected to others, as Crossley (1996) suggests. Also to ‘being fully alive’ as Kaye so deeply longed for. So the literature search became like Kaye’s life-search, incomplete, sometimes overwhelming and chaotic, often wonderfully affirming, and crucially for Kaye and for me, it is ongoing. I searched through my own library, especially around many issues of grief and bereavement. I did several internet searches, such as through google.com and relevant current literature available through amazon.com. I re-read the older feminist writings of Simone de Beauvoir, Collette, and
Virginia Woolf. I sorted the literature into a number of themes. There are many concepts, and the literature does not always fit neatly into one or another category. Kaye’s shouted responses are highlighted in bold. Each theme and the literature I searched is presented side by side with a section on my reflections in blue print.

1. Theme: Mothers and daughters
   - An enduring bond of love and blood
   - Motherless daughters
   - Searching for the lost mother
   - The wild woman
   - In poetry
2. Theme: Suffering and grief
   - Anticipatory or preparatory grief?
   - Sadness
   - Shock
   - Spirituality
   - Touch and embodied experiences
   - Continuing bonds
3. Theme: Re-authoring lives
4. Theme: Values
   - Individuality
   - Creativity
   - Weakness and lack of courage
   - Concerns about ageing
5. Theme: Paradox and balance
6. Theme: Freedom
7. Theme: Telling the story
   - On writing another’s story
   - Equal voices
   - The collaborative story and methodological issues
   - History
8. **Theme: Families**
   
   - Kaye’s father

9. **Theme: Language and mirrors**

10. **Conclusions**

Table 1. Literature search for Kaye’s narrative

<table>
<thead>
<tr>
<th>1. <strong>Theme: Mothers and daughters</strong></th>
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<tr>
<td><strong>Introduction</strong></td>
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<tr>
<td>There is much written about mothers and daughters. Manning (2002) pieces together the many tapestry-like shapes that make up mother-daughter relationships, with empathy as the common thread that binds them all into an elaborate quilt, rich with facts and stories. The powerful influence the mother-daughter bond has on a woman’s identity is described by Friday (1997) as affecting a woman’s relationships with men, and her self-esteem. de Beauvoir (1985) suggests that the connection we have with our mothers is sacred.</td>
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<tr>
<td><strong>My reflections</strong></td>
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<td>It is clear from the literature that the overwhelming significance of the relationship between a mother and her daughter is profoundly important when it comes to the mother’s death. It is a subject that I am looking forward to exploring further on completion of this study, especially as a daughter and mother. The writings I searched echoed the overriding theme of Kaye’s story, the special quality of the relationship she had with her mother, influencing her relationships with men, her self-esteem, and her deep grief that her mother died many years too early (Friday 1997; Manning 2002).</td>
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<table>
<thead>
<tr>
<th>a) <strong>An enduring bond of love and blood</strong></th>
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<td>There are significant references to the enduring bonds of love and blood. Born in France in 1873, Collette describes themes of childhood, family, and above all, her mother: vividly alive, fond of music, theatre, and books. Collette conveys the impact her mother Sido had on her community and her daughter (Collette 2002). Both written and visual portraits of women reveal both the diversity and the universality of this mother-daughter bond. The deeply personal experiences of women illuminate a relationship that is awe-inspiring and of deep importance. These</td>
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<td><strong>My reflections</strong></td>
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<td>The enduring bonds of love and blood between Collette and her mother, created a bridge for me connecting the devoted relationship that I heard existed between Kaye and her mother (Collette 2002). Kaye describes a relationship with her mother that is powerful and deep. Kaye’s story expresses these ‘universal feelings of tenderness, pride, and love so strong and complex that it is sometimes painful’ (Saline 1997). Kaye says:</td>
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   I think that she in her own way was a very spiritual person. I think she was unbelievably soulful ... I’m not sure, I
stories express universal feelings of tenderness, pride, and a love so strong and complex that it is sometimes painful (Saline 1997; Bradshaw 2003).

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<th>My reflections</th>
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<td>It is somehow reassuring that like Kaye, de Beauvoir’s (1985) account is not all pure and idyllic. Kaye’s mother did not die from cancer as de Beauvoir’s mother did. But that same feeling of being alienated from her mother’s body in the few days her mother lay unconscious in Intensive Care, was a significant part of Kaye’s experience. Kaye’s feeling that she has lost the physical connection to her mother is profoundly painful:</td>
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<td>You know people, you know in movies, they always show people like when someone dies, they kiss them and they hug them and they hold them. I just think that’s such crap!!! I mean I think, I think that sure, I’m sure that happens and people do that but there’s also this incredible experience of alienation...[shouts]</td>
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<td>You’re actually with this body of</td>
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Think this is probably one of my main things about her dying, is that I’ve basically deified her. But, yeah for example, I can tell you some pretty classic things like when I got busted. Me and my friend we got busted for drugs. Pot ... it’s an amazing story, fantastic story that one! And so we were in cells and so I ring my mum up, me and my friend are in phone boxes next to each other, and I go ‘Mum I got busted.’ And she goes [gentle voice] ‘Busted? What does that mean?’ [laughing] and I go ‘You know drugs Mum, busted for pot,’ and she goes ‘Oh I thought that might happen.’ [Kaye laughs heartily] And my friend’s in the phone box with her mum, who’s fiery, you know totally different style of woman. She goes ‘Mum I got busted’ and she goes [yelling] ‘You know you won’t be able to go to America!’... the contrast is just astonishing.

b) Motherless daughters

de Beauvoir (1985) gives an honest, raw account of her thoughts and fears as her mother dies. Not all of those thoughts are of love, pure and idyllic.

A mother’s death is of great significance to her daughter. Edelman (1995), in response to her own painful story, gathers the stories of many other women who as children or adults, lost their mothers. Her collection of stories uncovers the apparent ultimate inability of daughters to compensate for such a tremendous loss at any age. This book portrayed motherless daughters as victims, and the unique aspects of being a motherless daughter. Edelman suggests that many, if not most of the results of such a loss are going to be negative. Edelman (1996) revisits the subject of dealing with the pain of losing a mother. This book describes how the feelings of guilt, anger and sadness, create an incredible sense of loss, not only of a mother, but, in fact, of
family altogether. This means that a mother’s death become a life changing rite of passage for many if not most women. Ainley (1994) also gathered daughters’ stories about the deaths of their mothers, exploring the issues and emotions precipitated by their mothers’ deaths, describing a diverse range of emotions and experiences. Roberts (2000) writes about the connection and distinction between different generations of women, which seems also to be almost sacred.

someone and it’s not that person, and it’s cold and it doesn’t feel the same... It doesn’t feel right. You’re just going MAN! This person just isn’t!

Kaye describes her loss not only of her mother, but, in fact, of her family altogether:

K: Because I lost, I had a long period of time where I felt that I didn’t have a family.

S: You felt that the family was lost, not just your mother?

K: Absolutely! Because when my mother was alive I had a family. When my mother died my father created a new family and my brother created a new family and I didn’t. So they both had new families and I didn’t have a family at all.

The writings I researched suggest that many, if not most of the results of such a loss are going to be negative. However, after the process of sharing her story with me, Kaye could finally say there were some positive outcomes, ten years after her mother’s death (Edelman 1995; 1996). Over the time taken to tell her story and since then, Kaye has come to see some good things that have emerged from her experience, such as a deeper understanding of the ‘nuts and bolts of life.’

Kaye had not resolved many of the issues which arose around the time of her mother’s death, over the ten years before we began to record her mother’s life story. I believe that by the end of the process of recording her story, Kaye was beginning to see how far she had come in her journey of understanding the enormity of the impact of her mother’s death on her life and well-being (Ainley 1994).
c) Searching for the lost mother

It seems to be a common ritual search for meaning that leads a woman to explore the places and people who were significant in her mother’s life, in order to discover for herself the person her mother had been. Dowrick’s (1985) heroine Zoe Delightly’s mother dies early in her life, her mother’s death marking a turning point in Zoe’s young life. It was as though everything she loved and trusted died with her mother. She eventually escapes to Europe from her New Zealand homeland, and there she lives a dazzling life. But fleeing the past does not erase it. Her zany life continues until making peace with her ghosts, retracing her journey and re-finding her mother allows her to find peace within herself. Zoe says:

I believe that everything’s transitory, yet I can’t accept that, and I go on fearing the transitory nature of things.

Her friend replies ‘Everything’s transitory except, you could have added, the pain you feel about your losses, the death of your mother and the death of your hopes with Gabriel [her lover]. They don’t seem too transitory’ (p.342).

Modjeska (1990) also sets out to collect the evidence of her mother’s life. She follows the threads of history and memory into imagination. She travels to visit the places that were her mother’s past, and talks to the people who knew her mother. She needs to find out what had gone wrong in a family that everyone described as happy. She needs to find answers before she as the daughter can find her own peace in her own past. It is a story of the quest for the dead mother in order that the daughter may understand herself.

My reflections

One of the most interesting experiences for me in recording Kaye’s story, was when she described the feminist influences that impacted on her mother, as described by her aunt, whom Kaye visited to seek stories about her mother. As I was a few years younger than Kaye’s mother and aunt, this was fascinating for me, and illuminating for Kaye:

She said that Mum was interested in new scientific developments and they talked about ... things before they became proven. She was quite experimental, and very advanced ... she was really, really interested in women’s issues. Honesty in women’s issues, women’s health issues...

She then started to talk historically - which was really interesting, about women. She said in the thirties rich women did anything they liked, they travelled and things like that. And then in the fifties there was a post war backlash.

You were thrown back to a docile little life, of being a mother ... you know that era, that generation, women were married at the end of that compliant period, and so in the sixties there was this upsurge of change, you know, Vietnam, and The Women’s Movement etcetera.

It was perhaps because I had previously read many of these books that I encouraged Kaye to set out on a journey in order to discover who her mother had been, although she had in fact already begun this exploration. Kaye tells how she came back to Melbourne because this was her mother’s city and here her mother ‘was everywhere.’ It was fascinating that Dowrick’s (1985) heroine uses almost the same words as Kaye when Kaye said about life: ‘it’s transient.’
Kaye, like Modjeska (1990), sets out with me to collect evidence of her mother’s life, following the threads of history. She travels to the places that were her mother’s past, and talks to the people who knew her mother. Kaye also needs to find answers before she as the daughter can find her own peace in her own past.

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<td><strong>d) The wild woman</strong></td>
<td><strong>My reflections</strong></td>
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| Estes (1992, p.8) describes the wild woman. She suggests that once women have lost her and then found her again, they will struggle to keep her for good. Estes believes that wild women know how to walk away, and they know how to stay. | Kaye talks about the wild Bohemian woman that she believes her mother wanted to be. **Coddled as a child - almost overprotected, that’s partly why I’m so immature now, partly the wild Bohemian she wanted to be, so wild, self-destructive, and self-punishing.**  
I hear that Kaye is now developing a better knowledge of her own wild woman, and how to celebrate her as part of who she has become, hopefully less destructively (Estes 1992, p.8). |

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<td><strong>e) In poetry</strong></td>
<td><strong>My reflections</strong></td>
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| There were a number of relevant poems (Haldeman Martz, Editor 1987) For example ‘For My Mother’ by Michele Wolf (p.55): ‘I sharpen more and more to your likeness every year, your mirror...’  
and ‘ The Orphan’ by Seltzer (p.63): There’s no umbrella now to separate you from eternity... You’re a survivor with all the loneliness of survivorship. | The poems explored were all poignant reminders of Kaye’s loss and grief on the death of her mother. The poems, rather than being another theme, were exquisite and poignant sources of affirmation of the powerful impact on women writers over the years: of their relationships with their mothers, and the deep significance of the death of a mother on a woman’s life, whether it had been a good relationship like Kaye and her mother, or difficult like mine with my mother. This impact seems to occur whether the mother is young or quite old. The poems were separated and treated as a theme for convenience. The selection of themes for the literature searches, is further discussed in Chapter Two, 5. |
### 2. Theme: Suffering and grief

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<th>Bourdieu (1999, p.4) describes <em>ordinary</em> suffering as <em>la petite misère</em>, and one of his interviewees, Isabelle, remarks (p.596) that suffering can’t be measured, ‘you can figure out the temperature of water from a distance with a little wire, but suffering can’t be measured, there’s no point of reference.</th>
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<td><strong>My reflections</strong></td>
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<tr>
<td>Kaye and I talked a lot about suffering. She said:</td>
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<td><strong>My life’s my life, hard, painful. I suffer a lot, life is suffering.</strong></td>
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<td>She came to see that she had used her innate creativity to transform her suffering into meaning and value. We began the fourth interview by looking at what Nietzsche said about suffering, and this resonated deeply for us both. Kaye referred back to this reading a number of times throughout the interviews, in terms of how she was able to transform her suffering creatively, because this is what she had seen her mother do. Kaye quotes:</td>
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<td>‘Suffering is transformed when it is valued, valuing is creating ... This does not rid the individual of suffering, but transforms his or her evaluation of it. It becomes a criterion of oneness with the flow of all beings’ Nietzsche (1997, p.56)</td>
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<td><strong>And um ... the Buddhists say life is suffering and I have been very affected by that statement, and I really think that the only way to live your life is to face um ... you know, the monkeys on your back.</strong></td>
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<td>It was hard emotional work for Kaye to come to see the meaning of her suffering, but I believe that in the course of telling her mother’s story, she was able to reach a sense of knowing that in her suffering she could also celebrate her creativity (Luke 1987, p.123). Kaye’s story of her chaos resonated in Frank’s (1997) understanding. Kaye rose from within her suffering. She did this in the long run with great courage and in her own zany style.</td>
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<td>Helen Luke, Jungian scholar and counsellor, (1987, p.123) writes from the perspective of her eighty plus years. The Latin verb <em>ferre</em> means ‘to bear,’ ‘to carry,’ and ‘suffer’ derives from it, with the prefix ‘sub’ meaning ‘under.’ This is reminiscent of the term ‘undercarriage’ - that which bears the weight of a vehicle above the...</td>
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wheels - which is an apt image of the meaning of suffering in human life. Only when we suffer in the full sense of the word do we carry the weight. A person may say, ‘I am so terribly depressed, I can’t bear the suffering,’ when in fact they may not be suffering at all, but simply lying down under the weight of outer circumstances or inner mood.

Sociologist Arthur Frank (1997, p.144) suggests that the only resolution these stories offer is the achievement of the personal resolve to go on living with the continuing exploration of complex suffering. He explains that what we can hear in stories is not people rising above their suffering. Rather we hear people rise in their suffering, and in the process they teach the rest of society the necessary place of suffering in life.

Holocaust survivor and psychiatrist Victor Frankl (1984, p.11) says that one of our main concerns is not to avoid pain or to feign pleasure but rather to discern a meaning in one’s life and particularly in one’s suffering.

...to live is to suffer, to survive is to find meaning in the suffering. If there is a purpose in life at all, there must be a purpose in suffering and in dying. But no man can tell another what this purpose is. Each must find out for himself, and must accept the responsibility that his answer prescribes.

Sociologist Norman Denzin (1989b, p.15) describes significant life-changing events as epiphanies. He suggests there are four forms of the epiphany, the major form being where an experience shatters a person’s life, and renders it never the same again. The Macquarie Dictionary says an epiphany is a revelation of the basic nature of something, a perception of some essential truth (Delbridge 1987).

Haberecht and Prior (1995) explore grief as An event such as Kaye experienced at the death of her mother, is Denzin’s (1989, p.15) major form of epiphany, where the sudden, unexpected death of her mother shattered her life, and rendered it never the same again. It was an important step in the naming of themes, when Kaye owned the chaos as hers and named the theme ‘My own chaos’. Her chaos, and her understanding of it, flowed right through the whole process.

A chaos story such as Kaye’s, with its description of how awful her life got, threatened her health. Kaye’s story changes, coloured by a wisdom that came from starting with us being together, in the place where she was up to. Through telling her rich story, she was then able to move to a better place, of fuller life and more stable peace (Frank 1998, p.204). The disorder and confusion seemed unstable, but in the end were not completely negative. Chaos theory’s relevance to grief is the wave or trigger effect experienced by the grieving person where an infinitesimal incident can produce a massive result. As an example, Kaye was driving past the hospital where her grandfather died and the gynaecologist’s clinic she attended with her mother’s support, and this produced a wave of grief that was almost overwhelming:

I got into Melbourne ... I went past the place where my grandfather died, I went past a place I went for some gynaecological problem ... and my mum was always there for me. And I remember there was a surgery I must’ve gone to ... and I was crying ... and my mum was just everywhere in this city. Absolutely everywhere. And I was just going ‘phew!’ it’s like I’ve come home to my mother.

Many times, however, the pattern of chaos is not noticed until years after the grief. In Kaye’s case this comes after ten difficult years. Her pattern of pain and chaos are difficult, causing chaos in her whole life.
a state of spiritual chaos, and not merely a process of stages to be passed or worked through. They suggest that grief is inherently turbulent, a concept very different to the linearity of many available grief models.

Frank (1998, p.201-204) discusses chaos stories. He explains that paradoxically once the chaos story can be told it is no longer total chaos, and in that paradox lies a therapeutic opening. The chaos narrative that cannot be told is ‘about how thin the ice is that we skate upon, and how cold and deep the water we can suddenly sink into’. To deny the living truth of the chaos narrative is to intensify the suffering of whoever lives this narrative. The first thing a person in chaos needs is someone who will just listen, without attempting any change. Compassion means, literally, to suffer with the other.

This concept of chaos carries the implications of negativity and disordered confusion. Chaos intuitively seems to be essentially unstable, but in fact chaos theory holds that chaos and stability are each inherent in the other. Chaos is actually a mathematical concept and according to chaos theory, is a non-linear state. It is dynamic, turbulent at best, erratic and violent at worst, but is not necessarily negative. Chaos theory’s relevance to grief is the wave or trigger effect. The popular theories of grief, with their focus on phases and stages, represent a linear way of thinking that stands in opposition to the non-linearity of chaos. It is argued here that the experience of chaos in grief is spiritual chaos because it is that which gives us meaning, and our whole notion of connection to others and the universe is threatened by the process of grief (Frank 1998, p.201-203).

Golden (2000, pp.30-32) says that it is natural for people, and indeed all of nature, to oscillate from stability to chaos. He also describes how grief is not a pathological...
state; it is a normal life event that throws us into instability. This instability has its own pattern, and if we look hard enough we may get a glimpse of it. It is within this pattern that new and deeper parts of ourselves reside. Many times, however, the pattern of chaos is not noticed until years after the grief. The patterns of pain and chaos from our grief are a double-edged sword. They are painful and difficult, bringing chaos into our lives. But they also help us move into a more developed level of functioning.

Kegan (1982, p.170) suggests that those defending the imperial balance, may tend to feel that others are persecuting them, holding them too close, not giving them their freedom, trying to make them ‘feel guilty’. But life gets more destabilised before it can become balanced again, and this involves the actual reconstruction of the relationship between self and other. Phenomenological researcher Graeme Clark describes how we manage mostly to ignore death at a distance, while taking life for granted. When death enters our life, it is often confronting, shocking, even violent. Our grief demands our complete attention. We are incapacitated, numbed, stricken. Life as it has been, is broken. Our sense of innocence may be broken. And even if our innocence of death is long lost, our sense of safety in the world may be shattered (www.last accessed 2006).

As we tell our story, it is through sitting with others, recalling the good times and the bad, that we shape our changing relationship with the other and move through grief. By exploring the meanings of our loss, our self-reflection is deepened. We redefine and discover ourselves in the context of our attachment to the other and to the legacy we have been left. Clark explains that a core feature of grief and bereavement is the way in which our attention is called to meaning. Grief is at the core of human meaning. It brings us to

in this city.

Her absence, [or is it presence?] is pervasive. Kaye’s life as it has been, is broken. Her sense of innocence is broken (Clark www.last accessed 2006).

As Kaye told me her story, describing her loss, exploring the meanings of her loss, her self-reflection gradually deepened. She redefined and rediscovered herself. For Kaye, this was not able to begin until ten years after her mother’s death, as she and I began to unravel the story of her mother’s life and death. Through sharing her story with me, Kaye’s life was validated. In honouring past experiences with her mother, she could clarify for herself and for me, who she is and what was important and meaningful to her in her existence.

As Clark explains grief, it brings us to the core of our living as human beings, which Kaye describes as ‘the nuts and bolts of life’. It brought Kaye home to her city, and to telling her mother’s story:

K: It took the most incredible amount of courage.

S: It caused pain?

K: It caused a huge amount of pain.

‘Letting go’ was a huge issue for Kaye. There is much that follows in Kaye’s struggle with the issues around the restructuring of her relationship with her mother. I read Clark’s paper and had an ‘ah-ha’ moment, after which I wrote a poem for Kaye about her mother’s death and her shattered mirror image, freely quoting Clark. This became an issue between Kaye and I, it was a point of learning for me, and is further discussed later. I simply confess at this point to non-critically assuming that Clarke was writing about how it is for all people, it certainly resonated with my own grief. It was almost like Clarke and I were telling Kaye ‘there is one way of viewing things, A WAY of
the brink of non-existence, it also brings us to the core of our living as human beings. Grief is a deep experience. Our most profound motivations and reasons for living are touched and challenged. The pain of grief is deep, cutting through the superficial cloak of everyday life. Grief brings us to the depth in ourselves, by taking us to the very edge of existence. Ultimately, our struggle with grief may bring us home to ourselves. Clark asks some hard questions. Do we ever really ‘let go?’ For whom do we grieve? Primarily for ourselves, for the past we have known? (Clark www.last accessed 2006)

Although death disconnects our direct relationship, we maintain our connection with the other through our struggle to reposition them as a living memory in our ongoing life. Clark says:

Relationship is a living mirror whereby we know ourselves. Bereavement shatters the mirror, but we continue to know and discover ourselves as we sort through the broken shards.

Frame (1980, p.150) comments that we all see faces in the water. We smother our memory of them ... Sometimes by a trick of the light we see our own face. Frame says that remembering, she felt the longing that comes when the hovering dead finally withdraw themselves and return unopened all communications addressed to them (p.232). Niederhoffer and Pennebaker (2002, p.574) explain how we naturally search for meaning and the completion of events, to give us a sense of control and certainty over our lives. They suggest that it is easy to understand people’s inherent need to obtain closure and resolve emotional upheaval, and how individuals tend to ruminate, talk, and dream about things that are not resolved in their minds, or about tasks that

finding meaning’. I needed to listen more carefully and accept that Kaye had another interpretation of mirrors, and it was different to mine.

Frame’s (1980, p.150) ‘faces in the water’ resonated for me when Kaye related an important dream she had where her mother was present at a party:

Mum was there, and we were celebrating, and I think that if I could see my mum again, then what I would want to do is celebrate, um... I think my immediate reaction would be, I’d say thank you to her. I’d say ‘thanks’ this is great, like ‘thanks for this life’ cos it’s so great, and um ... I’d just want to celebrate that with her. I just think, what I’ve learnt, and where I’ve been, and you know everything that’s happened since she died... (Transcript, Tape 4.)

Perhaps this dream of saying thanks to her mother for her life, brings Kaye a small sense of closure, and a better completion of that which had previously felt not finished. Frame says that she felt the longing that comes when the hovering dead finally withdraw themselves and return unopened all communications addressed to them (p.232). Kaye later shared with me how much she wished to talk with her mother, and yelled:

there’s so many things I want to talk to her about

I had this incredible relationship with my mum, I really wish I had now,

I’ve been missing her really really badly,

partly because I’m starting very slowly to kick arse.

And if I kick arse, and I do something amazing like I do this project.....

I want her to know, I want her to
are not completed.

My reflections

Kaye describes a family outing to Phantom of the Opera, the night before her mother’s cerebral haemorrhage.

Oh and the other thing that happened that night was we went out to dinner … me and my mum went into the toilets together. And we were standing looking at the mirror in the bathroom … Mum was looking at herself, and she goes … because she always didn’t want to go grey … "oh, oh no", you know, "look, oh here’s my first grey hairs!" So I mean there was just this incredible combination of things that occurred on that day

I was sitting behind her, and I was looking at her head, I had imagined my mum’s death a lot. I don’t know if that’s normal for people to do, I think it is. I have imagined the deaths of a lot of people I know. And myself. And I was looking at her head … I was watching her head, and there’s this scene in the Phantom of the Opera where a huge chandelier drops down to just above the height of the people in the middle of the front stalls. And at that point, tears came into my eyes, like smarting into my eyes, and I basically imagined my mum’s death at that point. The night before she actually died.

a) Anticipatory or preparatory grief?

Fulton (1999) suggests that the current definition of anticipatory grief is of any grief occurring prior to a perceived inevitable loss, forewarming of loss, or anticipation of loss. Fulton states that it is now widely accepted that anticipatory grief is a normal grief reaction in response to an expected death. This view suggests that belief in an anticipatory grief that can mitigate the impact of ultimate death reduces the feelings of helplessness and personal vulnerability.

As Kutscher (2002, www. last accessed Oct. 2006) explains it, there are constant losses throughout life that become major and minor preparations for death, of both those who are important to us, and also for our own death. He argues against a theory of anticipatory grief as a kind of adjustment to the potential loss, or a theory of ‘the more anticipatory grief before the loss, the less the bereavement effects following it.’

Gilbert (2005, www. last accessed October 2006) describes the confusion and controversy that exists around the concept of anticipatory grief. She suggests that some studies have found that the ability to anticipate a loss results in an easier grief experience. Others have found no relationship between a period of anticipation and the severity of post-death grief.
Gilbert argues that anticipatory grief is not a device for completing the tasks of grief prior to the death, it does not substitute or necessarily lessen the post-death grief process.

Despite Fulton’s (1999) suggestion that anticipatory grief might mitigate the impact of the ultimate death there was no obvious evidence in what followed that this premonition or thinking was in any way helpful to Kaye.

I remember clearly an experience when I was about 12 years old. My father was working very hard and complaining of feeling unwell. In school assembly one morning we were singing a hymn and I remember being engulfed by a feeling of great concern and sadness that my father might one day die. My relationship with him was precious, he was a bridge between me and my difficult relationship with my mother. However he went on to live until he was 83, and our relationship continued to be very important to me.

In a later discussion not recorded, Kaye told me that whilst she called this a premonition, she had clearly had such thoughts before, and in these instances her mother had not died the next day. She rather thought that they were flights of imagination, perhaps ruminating on what the worst thing that could happen to her would be like. She felt that this particular occasion did not in any way prepare her for the actual experience.

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<th>b) Sadness</th>
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Greenberg and Safran (1987 p.174) suggest that sadness often helps us to reveal ourselves to ourselves. Strasser (1999, p.86) explains that sadness is distinct from other emotions due to the nature of its duration. It is less intense than other emotions and usually lasts a longer period of time. It can also be considered as an all-pervading mood, generally comprising being downhearted, lonely, and feeling isolated. Spinelli suggests that on the one hand, we strive for a sense of our own uniqueness, wanting to be singled out for

Kaye came to understand that her ongoing sadness, not always only related to her mother’s death, encompassed the knowledge that all her relationships with others are of a transient nature. She could yell ‘I don’t like it’ and know relationships were ‘transient.’ Kaye said ‘this is key’.

After we finished working together on her story, Kaye told me that she still felt lonely at times, and still deeply sad. I have been comforted since first reading Moore (1991, p.144) and his description of the core of sadness, that was perfectly reasonable to
recognition, status and love. On the other hand, however, our sense of separateness sometimes gives rise to feelings of isolation and loneliness (Spinelli 1989, p.77). Surgeon Tony Moore (1991, p.144) writes of his own core of sadness and that it was perfectly reasonable for it to remain as part of his ongoing journey:

I knew I would never be the same again. I had to accept the differences and begin to appreciate that the changes could help me forwards. Although my public humour and irreverence have returned, a core of sorrow remains, and it can’t be shifted.

c) Shock

McNamee (1992, p.186) understands that a person’s crisis is something that happens to the person. This external orientation portrays an impotent individual at the mercy of situational constraints. McNamee describes a crisis, as a moment in a person’s life, a lived segment in which vulnerability is ‘languaged.’

Greenberg and Saffran (1987, p.135) cite Polanyi’s distinction between tacit knowledge and explicit knowledge. In the first stage, the stimulus or event is coded and compared with long-term memory, the tacit knowledge about the event is still tacit, or implicit. In the second stage, the tacit knowledge becomes converted to explicit knowledge (Polanyi 1967).

My reflections

Kaye’s description of shock connects to McNamee’s (1992, p.186) understanding that a person’s crisis is something that happens to the person. McNamee describes closely how Kaye felt when her mother died. This recognition of crisis, (as Kaye named it shock), occurred for Kaye again when she received a letter from her partner ending their relationship. Kaye learned the meaning of shock when her mother died, and said she then recognised, or knew that it was shock she experienced again, on reading P’s letter.

d) Spirituality

The heart of spirituality seems to be experience, whether it is the experience of the transcendent, of the essence of our being, or of whatever it is that provides our life with meaning and purpose. Haberecht and Prior (1995, p.5) suggest that the focus of Western spirituality is finding different ways of working to expand spiritual

My reflections

Kaye told me that she did not follow any formal structured religion. However she was strongly influenced by Buddhist-type spirituality, with a deep commitment to the environment and ‘a world based on love’. If the heart of spirituality is experience, the work that Kaye and I did together involved careful analysing of our intuitive knowing,
knowledge and thus achieve wholeness. This involves the analysis of intuitive learnings, developing meanings from them, and the subsequent application of them in one’s life.

and our searching together expanded our knowledge, and brought some sort of wholeness for both of us.

e) Touch and embodied experiences

Abram (1996, p.45) tells us that our sadness is indistinguishable from our bodily feelings of that sadness, ‘the body is my very means of entering into relation with all things’. Abram explains that touching and being touched is the reciprocity of the sensuous. As Abram tells us, our eyes with which we see things are themselves visible.

My reflections

Kaye frequently refers to her experiences as they occurred for her at an embodied level. Her descriptions of ‘the up and down’ feelings of her time visiting Intensive Care, her feelings of nausea throughout her mother’s hospital stay, and her strong feeling of alienation from her mother’s disintegrating body, and her not wanting to touch her mother, regardless of the suggestions of the hospital staff that she should do so. These were difficult issues for her to resolve. As Abram (1996, p.45) tells us ‘the body is my very means of entering into relation with all things’, this includes for Kaye, the body of her dying mother.

It stands to reason that Kaye’s mother’s cold dying body bears little resemblance to the warm loving mother that she had previously been for Kaye. Kaye describes her horror at the haemorrhage that was distorting her mother’s pupils. Kaye recognised with abhorrence that these haemorrhaging eyes, which she had previously described as ‘doe-like’, could no longer see her or respond as her mother did. Was it any wonder that she felt that this was no longer her mother?

f) Continuing Bonds

I attended a workshop where Dennis Klass described his concept of building continuing bonds with the person who has died. Klass talks about not letting go, but in forming an internalised re-creation or reconnection to the person who has died.

My reflections

At the beginning of our fifth recording session, I described to Kaye with enthusiasm, the workshop I had attended that week, where Dennis Klass described his concept of building continuing bonds with the person who has died. Kaye more
(Klass 1996). Klass presented a model of how he worked with families helping to change the dynamics of how they dealt with a death in the family. Klass’s model (Klass 2001) shows the ‘points’ of the life, and how in his view you only had to change one of these points, and every other one changed in response. So you only had to restructure one significant aspect of how the person experienced their world and gradually their whole life-view was able to change and re-create the new relationship with the person who had died.

Anderson (1997, p.158) discusses the task of listening to the story. She believes that engagement in a dialogue in the language that clients use in their everyday problem descriptions and interpretations is critical to shared local understanding.

I once said ‘I don’t want to let her go. How can I let her go?’ I explained to Kaye: ‘what our task has been, and what I think we have done, is re-created or reconnected you to who your mother is, and then that goes into an internalised form if you like, and it allows you to be who you are, with her as your mother, even though you are absolutely aware of the reality of her death. But the bond is continuing for as long as you are alive.

That is so different to that model of letting go. And I think that probably this is a very new kind of paradigm where you’re not asked to let go, and in fact what happens then is that it turns around so that it’s not clinging tightly screwed up to who your mother is, you don’t have to, she’s internalised as part of who you are, and therefore your view of the whole of your life, becomes somewhat different’. (Transcript Tape 5)

While examining the model Kaye replies:

Absolutely. Yeah, in relation to this, [pointing to model] and I suppose particularly these, actually these three things here actually really resonate with me very strongly - how the universe works, place and power of the self, and bonds with transcendent reality. You know, I said to my flat mates a couple of nights ago that I felt almost as though I was having some sort of spiritual transformation (Transcript, Tape 5)

In the end I deliberately left unchanged Kaye’s sometimes colourful language as it had been said, for example ‘its fucked!’ ‘he gets antsy’ (Anderson 1997, p.158). At one point I asked Kaye to tell me exactly what antsy meant, as it was not one of my usual words. When I described her mother as fey, she asked me what that meant, and we looked it up in the dictionary. Anderson describes the need to validate a client by
taking their story seriously. It was not difficult with Kaye, her story was deeply engaging and her chaos and pain absolutely real to me, her ‘listener.’ At the end of the process, as she checked the ‘five verb’ reduction poem I had written, she remarked that she really liked it because it gave her a sense of value, and validated her life.

Before tape three, off-tape, I described to Kaye a story I knew from The Bible, about a man who was searching for a fine pearl, and having found the pearl of his dreams, sold all that he had to buy the pearl. This story then often came up in our discussions. Kaye suggested that her relationship with P was like the pearl, and that the pragmatic relationship that P left Kaye to return to, was like a bowl of glass marbles. This story was used by us both to deepen our understanding. Perhaps not quite in the way Bible scholars might have thought appropriate, but it was a parable we both understood (The Bible, The Gospel of Matthew, Chapter 13, Verse 45) Kaye said

what I’m discovering that in the context of the experience that I’ve had with P, where P says I won’t sacrifice, you know ‘I want the marbles not the pearl. And I won’t sacrifice my business and my wife and my, you know, things, for love.’

S: But the pearl?

K: But this is the pearl! [shouts]

S: The pearl, the pearl, is what you’re describing.

K: Yeah, I mean I’m not saying the pearl is, is......

S: he [Kaye’s father] is giving you a pearl of great price by being that honest with you.

K: But that’s always been the relationship that we’ve had.
| **S:** But it’s ... that’s what it is ... it’s a very ... it’s a pearl. |
| **K:** I guess what I’m establishing is my value system, where my value system comes from. There are elements in the love and the relationship between her and Dad that are part of what my value system is, and part of what I believe this pearl is, this love is. I’m not saying it’s an unrealistic thing, I’m saying it’s a real thing. |

### 3. Theme: Re-authoring lives

Freedman and Combs (1996, p.10) describe how Milton Erickson influenced their work, with his understanding of the importance of stories in shaping reality, that this was the way that he wrote and rewrote his own life story as he lived it, giving positive meaning to what others might have experienced as adversity. It was through Erickson that Freedman and Combs encountered the belief that people can continually and actively re-author their lives.

Anderson (1997, p.212) writes that postmodernism challenges the idea of a single, fixed core self that we can reveal if we peel away the layers. Rather it invites us to move from what Anderson calls verifiable reality, to a narrative social understanding or constructed reality of self. It asks us to concentrate on understanding how these givens or meanings emerge from our understanding. In this dialogical view, our self becomes a narrative self and our identities exist in relation to our perspective, a point of view that is related to our purposes. As Kaye says:

> Finding out who my mum was might help me find out what life means, what love means, what family means, what everything means. (Transcript, Tape 2)

**My reflections**

Freedman and Combs (1996, p.10) explain how telling her story to me, helped Kaye to re-author her life. Kaye says:

> Everyone has an opinion, this is just another opinion.
4. Theme: Values

**Introduction**

Freedman and Combs (1996, p.36) suggest that we inquire about where our beliefs come from and what processes of social constructions have brought people into those beliefs. They suggest we should try to be ‘transparent’ about our own values, explaining enough about our situation and our life experience that people can understand us as people rather than as ‘experts’ or conduits for professional knowledge. When an answer takes the conversation in an unexpected direction, we ask even more questions, following that new direction if it seems relevant. Efran and Clarfield (1992, p.203) tell us that:

> Conversation is nothing more and nothing less than the everyday, rough and tumble adaptational processes that enable us to live together on this planet ... conversations are not necessarily fragile events that require special nurturing.

**My reflections**

Kaye and I talked extensively about her values, and in our conversations my own values were sometimes discussed to balance the conversation. Kaye explains:

> K: I think that what I'm learning of, in this experience with P, and with my ideals, ... you know in a lot of ways I don't think I'm a very stubborn person, but I will not let go of my ideals! [loudly] That is one thing that I reckon's going to come out of this.

> K: I believe in love

> S: and in generosity of love?

> K: In generosity of love. I believe in giving love, and I believe in receiving it. I believe that I can give it, and I believe that I can receive it. And I think that's where he falls right down. And he knows that [loudly] and so when he fell in love with me, what he fell in love with was his own potential to be loved and to love. In a way that he just had never done before.

> S: And in a way he's said the cost of that is too great, and put it down.

> K: The cost of that's too high. And I disagree.

Sometimes Kaye and I lurched from one place to another in our almost chaotic conversations, and once she laughed and said ‘I thought for once we were going to go straight!’ (Efran and Clarfield 1992, p.203).
<table>
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<tr>
<th>a) Individuality</th>
<th>My reflections</th>
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<td>Bruner, J. (1986, p.41) explains that individuality is born out of the corruption in societies of selves:</td>
<td>Kaye was concerned about society’s values and how this impacted on her belief about the values she lived out in her own life. She was often distressed by the world’s seeming lack of concern for the impact of greed on the environment and third world countries. Because of her deeply felt global concern, Kaye was moved by a book that became the focus of some of our discussions of her world view. I was touched that she gave me a copy of it for Christmas so that I could take it on holidays to read (Mistry 1996).</td>
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<td>It begins with conscience and ends with consciousness. At its core is a contrast of <em>individual versus society</em>: an individual transcends and resists what is binding and oppressive in society and does so from an original natural position.</td>
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<th>b) Creativity</th>
<th>My reflections</th>
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<td>Bradshaw (1992, p.365) describes a Rogers study that revealed that people work most creatively when they are motivated from within. According to Bradshaw, Roger’s study confirms that the best environment for creativity is one in which we can respond to reality as it is grounded in the elements of childhood: wonder, curiosity, playfulness, spontaneity, resilience, and experimentation.</td>
<td>Creativity is an important issue for Kaye, and was discussed many times in relation to her own and her mother’s lives. Kaye said:</td>
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<td>I am a creative person in my essence, creativity is innate in me, whatever happens my life is a creative process.</td>
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<td>I’m like a power house of spinning creativity.</td>
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<td>‘Valuing is creating.’ Existence becomes meaningful when an individual’s creativity is understood, to redeem suffering’ (Nietzsche, 1997 edition).</td>
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<td></td>
<td>Creativity in the context of life and suffering - the capacity to go way out, the creative use of suffering.</td>
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<td>(from ‘Creative Use of Suffering’ theme worksheets)</td>
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c) Weakness and courage in classical literature

In ‘Jane Eyre’ Charlotte Bronte (1847) describes Jane as ‘poor, obscure, plain and little’ but she also possesses incredible strength and conviction. Rochester is her match in passion, a dark and complicated hero. In the beginning of the story Jane is weak and Rochester is strong, however at the climax, Jane says ‘I care for myself’ and it is Rochester who is weak.

My reflections

Kaye’s experience of the ending of her relationship with P caused her great anguish. However, she came to see in time, that P chose to accept a pragmatic return to an old, less than satisfactory relationship, in a way that she felt was weak, dishonest, and lacking in courage. Kaye comes to see that she is the one who had ‘the guts to undertake this search’ for meaning, but she realised this also caused her great pain in it’s experiencing.

It’s fucked!! And love is about freedom! And this love that these two share, is not about freedom.
(Transcript, tape 3, p. 4)

d) Concerns about ageing

Seedsman (1994, p.110) cites Sartre’s view that living teaches you that time is neither healer nor enemy. It is neutral and seamless and of steadily diminishing quantity. You alone are in charge of quality control. One can accept this transience and be grateful that the conditions of the lease include blazing sunsets, the spinning grandeur of seasons and the company of other species as well as your own, and laughter. Luke (1987) uses classical literature to reflect on ageing as she herself enters her eighties, and she finds wise and creative ways to celebrate the acceptance of a peaceful old age.

My reflections

One of Kaye’s greatest fears, reflecting her mother’s fear, is of ageing. This was illustrated by her story of the family outing two evenings before her mother died:

...we were standing looking at the mirror in the bathroom. And I won’t look at mirrors any more because I think I’m really aged, that’s one of my key issues. Yeah! no it’s really full on ... we were standing there looking in this mirror and Mum was looking at herself, because she always didn’t want to go grey, my dad’s not grey now and Mum hadn’t gone grey by the time she died. And she was looking at herself in the mirror and she goes, ‘oh, oh no, look, oh here’s my first grey hairs!’

One can accept Seedsman’s (1994, p.110) transience, grateful for blazing sunsets and laughter. But for Kaye and her mother, not grey hair!
### 5. Theme: Paradox and balance

The two greatest yearnings of human life, according to Kegan (1982, p.142) may be the yearning for inclusion, that is to be welcomed in, held, connected with, a part of; and the yearning for distinctness, that is to be autonomous, independent, to experience one’s own agency, the self-chosenness of one’s own purposes. These yearnings are in obvious tension. Gibran (1964, p.61) wrote about the balancing of sorrow and joy, laughter and tears, pain and growth.

> Some of you say ‘Joy is greater than sorrow,’ and others say ‘Nay, sorrow is the greater.’
> But I say unto you, they are inseparable.

Cecchin (1992, p.88) warns that paradox can be a way to gain control but at the same time it was a way to bring the battle to a standstill or to a kind of apparent truce. We could become experts in creating paradoxical situations springing from the intensity of our therapeutic relationship.

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<th><strong>My reflections</strong></th>
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<tr>
<td>Kaye yearned for inclusion, to be welcomed back into her family, to be held, connected with, a part of; and she paradoxically yearned to be autonomous, independent, to experience her own agency, the self-chosenness of her own purposes. These yearnings for Kaye were in great tension. Maybe it is this yearning and tension that for Kaye embodies her cry for freedom, her paradoxical wish to belong, and her grief that her mother is no longer there for her to help sort out the confusion and paradox (Kegan 1982, p.142).</td>
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<td>Sharing Gibran (1964) and his balancing of sorrow and joy, laughter and tears, pain and growth, were really joyful moments in Kaye’s and my time together. I think it was life’s paradox, and the understanding that without one you could not have the other, that was the deepest knowing that grew for us both, in the experience of recording her mother’s story. Kaye deeply understood after recording 93,000 plus words in the tapes, that her pain was the breaking of the shell that enclosed her understanding (p.61).</td>
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<td>To use her own words, Kaye’s story swung ‘from side to side’ with her ability to ‘see both sides of the picture’, but I do not believe this slowed our ability to reach a place where the paradox was known and could be accepted (Cecchin 1992, p.88). Kaye gained deep understanding by reading Mistry’s ‘A Fine Balance’, and we talked about it a great deal:</td>
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<td>And survival, there’s a particular line to it, a fine balance, the fine balance is between hope and despair. So it’s precisely about this experience that I’ve been having of life, where I see life as being just an ongoing parallel experience of joy and suffering.</td>
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### 6. Theme: Freedom

Frankl (1984, p.12) suggested that what alone remained for prisoners in the horror of the concentration camps was ‘the last of human freedoms’ - the ability to ‘choose one’s attitude in a given set of circumstances’. Frankl takes a surprisingly hopeful view of a human’s capacity to transcend their predicament and discover an adequate guiding truth.

Greenberg and Safran (1987, p.175) tell us that being afraid is human, and being able to tolerate being afraid is essential. It is important for people to recognise that they are afraid, in order to be able to confirm that this is acceptable, and to face and live through what they fear.

Heidegger’s definition of freedom as cited by Moustakas, (1996, p.107) is that ‘freedom is the letting be of what is’. Seedsman (1994, p.106) suggests that the fear of freedom is unfortunately real, and like it or not, a little courage is always required if we wish to be something different from what we have already become. To fear to venture by oneself or to reveal oneself, fear to set out one’s imperfect work before it is an opus, Estes (1992, p.11) suggests are all issues encompassing the search for freedom. Estes also explains that taking on the task of being on one’s own, letting die what must die, allows the new woman to be born (p.81).

Crossley (1996, pp.66-68) writes that one’s sense of self-consciousness as well as one’s sense of self-worth is dependent on recognition by those whom one deems worthy to recognise one, that is, structures of mutual recognition, such that selves require and seek out this recognition. To a large extent the self-process is routinely bound into our interactions with others, formed through an internalisation of our relationships with others. Selfhood is inevitably intersubjective, self is seen to be

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**My reflections**

Kaye remains ambivalent about whether her freedom and independence is a blessing or a burden. Frankl’s (1984) hopeful view of Kaye’s capacity to transcend her predicament and discover an adequate guiding truth, sits closely with her understanding of her ‘predicament’ and her ‘truth.’

The unknown, inconsistency, contradiction, change, madness, confusion, loss, pain, paradox - an essential part of human existence, are what make life great. It seems to me that to a certain extent, you’re only going to be free once you accept that you can’t really have security. You can’t really have permanence. Freedom is when you start to say ‘That’s all you know. And you don’t have fixety in your viewpoint. To be fixed in your viewpoint and to say ‘that means this’ The fear is insecurity. People are scared of being insecure. They’re scared of not having something to hold on to. (Transcript, Tape 6.)

Kaye recognises her own fears, and sets them out clearly. Kaye’s words ring with her growing conviction that freedom is about ‘the letting be of what is’. However it remains difficult for Kaye to be on her own in her life. She describes her ongoing struggle:

- The things that I’m scared of:
  - Being single
  - Being alone
  - Being unloved
  - Not reaching my creative potential
  - Settling for the marbles instead of the pearl (From Tape 3.)

Kaye yearns for a partner who would enable her to feel known, integrated and
achieved only in relation to another. loved, and this fits well with Crossley’s (1996, p.66) view that one’s sense of self-consciousness as well as one’s sense of self-worth is dependent on recognition by those whom one deems worthy to recognise one. Crossley also gives weight to Kaye’s profound sense of loss of selfhood after the loss of her mother, and followed by the loss of her relationship with her partner (Crossley 1996, p.68).

7. Theme: Telling the story

**Introduction**

We all are made of stories. Cottle (1999) goes as far as to suggest that they are central to our soul, intellect, imagination, and way of life. Whatever we understand to be our social fabric, our inheritance and culture, is founded in great measure on the stories we tell. For it is the story whereby we explain to others how we lead our lives, and what meanings we draw about the lives we have led. Cottle says that when I tell something, I feel something about what I am telling, just as what I felt becomes part of what I tell. In addition, I reason something out which clearly shapes my original definition of the event and now exists as part of that experience. Cottle suggests that it is evident that any autobiographical statement or story also contains its cultural and institutional trappings.

Crossley (1996, p.55) suggests that self is ‘a socially instituted and temporally mediated reflexive process’. It involves the subject ‘turning back’ upon themselves throughout time, to view themselves from ‘outside’ or rather, as another would view them. This reflexive process is made possible through the interaction of the subject with others. The me is often housed in an autobiographical narrative. Our sense of ourselves is based in stories which we

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**My reflections**

Kaye said ‘My whole life is story.’ One of her greatest difficulties following her mother’s death, was the feeling that it could not be talked about:

Yeah, not only ... well actually that’s interesting, not only other people, but Dad didn’t talk about it either.

Cottle’s view of the effect of telling, then feeling, and it then becoming part of one, strongly relates to Kaye’s descriptions of the last few days of her mother’s life, where her own feelings coloured the whole story of her life from then on. According to Cottle’s view, I listened then not only to Kaye’s individual or idiosyncratic stories, but also about her culture and social structures. Kaye says:

Thank God I’m doing this process with you, because it’s keeping me in Melbourne and it’s keeping me sane. Because I am a flighty person and I’m under a lot of pressure and I feel that the reason that things didn’t work out with him, is partly because of this process. Because this is more important, and this is giving me a reason to really be alive. This is really clarifying for me, it is absolutely what I believe. I just feel I’ve been given the most incredible gift ... the result is I’m sitting here with you and...
tells about ourselves, which exemplify the sort of person we feel that we are and which construct and sustain a sense of continuity over time. Autobiographies identify us both to ourselves and to others. Language is central to this process:

autobiography might be conceived as a special form of language game, which places certain demands upon the speaker and furnishes them with rhetorical devices for meeting those demands (p.59).

Claudia Brenner’s (1995) ‘Eight bullets’ is a powerful narrative. While out bush walking on a deserted trail, Brenner and her partner Rebecca, were spied on, and then shot with eight bullets by a homophobic man. Rebecca died from a bullet in her liver. Brenner, despite her severe injuries, managed to walk out for help:

The more I told the story ... the less power it had over me, and the more my sense of safety grew. I told it and cried about it so many times that it eventually began to heal into a memory. As a memory, it could be integrated into my regular world. I began to make sense of ... my life, my ‘self-story’. Integration did not mean that I was in less pain, but I did feel less split off from myself ... It was becoming a memory that was interwoven with everything else in my world, and that world was being transformed into a place where it was not inconceivable that I could be shot (p.159).

Phillips (1991) tells us that courageous mothering and daughtering involves esteem building in ourselves and in each other. She suggests that good self-esteem in daughters is accompanied by a strong feeling that they are self-responsible people (p.201). Phillips suggests that we cannot respect others unless we respect ourselves. That is why self-esteem is essential for a good

Brenner’s (1995) story had a powerful impact on me. I felt that Kaye could equally translate Brenner’s words into her own story of her mother’s death, it’s impact on her life, and her gradual integration of it into who she is, a person who now finds it conceivable that her mother might die suddenly and unexpectedly early from a ruptured cerebral aneurysm.

When her mother died, Kaye explained that she ‘went off’ and basically denied her family. The task she and I engaged in centred around reconstructing the story of her mother’s life, reconstructing as we went, the connections she had to remake with her family. We explored the reasons for her mother’s low self-esteem, thus enabling Kaye to come to see:

Low self-esteem. You know that’s the big one that I’ve definitely inherited from her. Massive problems with self-esteem, huge, like that is the thing that’s coloured my whole life. You know I’ve no doubt about it, it’s coloured my life in relation to everything. Absolutely everything.

Phillips’s (1991, p.201) suggestion that good self-esteem in daughters is accompanied by a strong feeling that they are self-responsible people developed in Kaye as the weeks of taping progressed.

The other thing about the experience that, what I’m realising is that my life has value, that my life’s incredibly valuable, that I’m incredibly valuable, that I’m absolutely amazing! [loudly] For the first time in my life I am finding my mother in me. Growing a sense of happiness,
relationship between a mother and her daughter (p.25). She explains that parents need good self-esteem in order to have children with good self-esteem (p.99).

It seems that by ‘inheriting’ her mother’s low self esteem, Kaye was perhaps able to see such ‘an incredible relationship’ with her mother. In this way her mother’s low self esteem did not come between them. Her brother ‘saw it differently’:

He said ‘Nothing stands out in my memory.’ [loudly] And I’ve written in brackets but it does! [shouts] And then he said, ‘well one thing stands out’, he said ‘I feel annoyed with her, that she didn't assert herself, she just took too much of a saint ... just took ...’ what he means there is - that you know Dad would make a lot of suggestions, you know that she would do what - you know she’d just go with - like she wouldn’t assert herself and say what she wanted to do, she’d do what other people wanted — (Tape 5, side B).

<table>
<thead>
<tr>
<th>a) On writing another’s story</th>
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Kiesinger’s (1998) paper examined her process of writing the story of a person suffering from bulimia. Kiesinger said that she wanted to write a story that did not deny her own particular feelings and responses. She wanted:

to write an account ... that acknowledges the extent to which my study of her is a reflection of my own inner life and experience ... in ways that acknowledge my self not as a contaminant to my portrayal, but as inherently part of it ... thus I must become vulnerable to my own inner experiences, those things I thought, felt, and experienced in response to Abbie’s life’ (p.84).

Kiesinger said she tacked back and forth between segments of Abbie’s story and her own, attempting to reflexively connect their experiences in ways that used Abbie’s life

My reflections

Kiesinger’s (1998) paper was important for my understanding of the nature of what was happening between Kaye and I. Kiesinger’s experience resonated with my working with Kaye. I would have felt uncomfortable had I not done so much work on my relationship with my own mother. Kaye’s story of her ‘perfect’ relationship with her mother, still managed to produce a tinge of envy in me.

Kaye said:

… I think this is probably one of my main things about her dying, is that I’ve basically deified her. You know I’ve put her up on a pedestal, like for me she’s like a god, and I think that that’s partly a mistake on my part, in terms of how, you know that I’m not treating this person as a human being, that I’ve sort of deified my mother.
story to challenge and deepen her understanding of her own life, and her experiences to heighten her understanding of Abbie’s story (p.72).

Kiesinger said she listened with her entire body:

I offered snippets of my own experiences to better connect with hers. From the outset I quickly became her conversational partner rather than her interviewer. In the few hours we spent together I was more her friend and confidante, than scholar and researcher. The emotional and relational investment I had to make in order to hear and then later write Abbie’s story was immense (p.76).

Kiesinger discovered that although transcription is a tedious, time-consuming, often frustrating task, she found it an invaluable step in the process of writing this lived experience. Doing her own transcription forced her to go through Abbie’s oral history repeatedly. Transcribing allowed her to hear Abbie’s voice over and over again and as a consequence she grew to feel closer to her experience. Repeated listenings reconnected her with the emotionality of her plight (p.92).

I needed to be clearly aware of, and bracket my own struggle to deal with the difficult relationship I had with my mother. I needed to set aside my preconceptions, theories, and my prior experiences that would interfere with listening to Kaye from her perspective, through her eyes and wisdom. (Further discussed in regarding my mapping and journaling in Chapter Two, 4.1.2, and regarding Bracketing in Chapter Two, 3.3.)

For as far back as my earliest memories, my mother suffered from anxiety and depression, and this deeply affected my family at least until she died. I had responsibility for my mother for the three years she lived after my father’s death, and this was stressful and demanding. After she died I was able to think through, write, meditate and resolve many of the difficulties and my resentment of the enormity of this task. The MIECAT Graduate Diploma was a time of consolidation and knowing that was very important for me, although it was always made clear that this course was not meant as personal therapy.

So how did this impact on my work with Kaye? I tried to carefully set aside my own experiences, however at one point in our conversation I said:

S: And the light has come for me now … with the work I’ve done for the last part of my MIECAT Grad Dip. I’ve understood, finally, no, not finally because I don’t think there is a final understanding, but I’ve understood with great clarity, what my relationship with my mother has brought to me. And it’s taken me a great deal of angst, and work to do that.

K: So I guess that this process that we’re doing here is partly about me establishing what my relationship with my mother has brought to me.
S: Absolutely … because she was your mother, you are the Kaye that is Kaye. Because my mother was who she was, which was a person suffering from depression and anxiety for all my life … that's made me into the person who I am. Now if my mother hadn't been my mother I wouldn't be who I am. Nor would I have learnt what I've learnt and I wouldn't have been walking this journey with you.

K: Mmm

S: … I can really value that now, despite the pain, and the abuse. And it's only now … so I suppose what I'm saying is that I think that this is the beginning of that walk for you of understanding, I don't think it's the end. I don't think there's a final forming. I don't think for me, that there is. I don't think I've reached the end of my understanding, I think that I've come a long way, and I think in a way I'd describe that like ... you're climbing a mountain range, and you've reached a peak, where you can see, but there's still other higher peaks to come. (Tape 2).

After much reflection, I do not think that my relationship with my mother ‘contaminated’ Kaye’s and my work together. On the contrary I think it enhanced and enriched my understanding and also Kaye’s, about the nature of our particular relationships with each of our mothers, and how that helped form us into who we are now.

Kiesinger worried about what her participants would say when they read her renderings of their experiences. This made me very conscious of the other people who are involved and affected by the processes of narrative work, and made me think about the ethics of a person setting out their story for reading by affected others, such as Kaye’s father and brother.
I think the most important thing that Kiesinger’s paper said for me, was that although transcription is a tedious, time-consuming often frustrating task, that she found it an invaluable step in the process of writing this lived experience. Repeated listenings reconnected Kiesinger with the emotionality of Abbie’s plight (p.92). This is of pivotal importance in my therapeutic autobiography work. People often remark to me that there are easier ways of transcribing, however it is this connection to the story as I transcribe, that brings me deeper into the story, and the understandings this then unfolds for me.

### b) Equal voices

Fine (1998, p.130) sets out the significance and difficulties regarding the survival of equal voices in the process of listening to, recording and transcribing, and then analysing, collaborative narratives. Gubrium and Holstein, (2002, p.21-23) echo this imperative.

#### My reflections

I felt a real concern that equal voices be heard in our work together, especially in the selecting and naming of the eight themes, and that the end result must be an equity of outcome, a sense that we have truly collaborated on this project. Fine (1998, p.130) confirmed this importance for me. I think it allowed me to see that the struggle Kaye and I had to produce the eight themes that felt right for us both, was both legitimate and necessary.

### c) The collaborative story and methodological issues

Moustakas (1996, p.27) describes how he listens to the range of voices:

- the variations of speech, the tones and textures, sounds of joy and anger, the mixture of sadness and laughter, the edgy, uncertain words of fear, the myriad facial and body expressions - the lengthy silences and continuous stream of words that seem never to stop coming, and all the ups and downs of ecstasy and misery.

#### My reflections

Kaye and I seemed to merge into a common purpose and place as we settled into each session of taping. It felt like what Moustakas (1996, p.27) expressed as a ‘unique pattern of our life together, the continuity and sameness’, and our conversations came to have value and meaning for us both. We developed a ritual, similar to that which Moustakas describes with his client. Before long into each session, Kaye would say she was hungry, and we would stop to share soup, cheese on toast, toasted sandwiches, as comfort food in between the work of storytelling (p.78-
He goes on to suggest that to fully know another person is a long journey of listening, feeling, sensing, risking, trusting, doubting, joining, wandering alone, confronting, loving, supporting, opposing, laughing, weeping. To be receptive means to let the other person tell a story in her own way, in its own process and unfolding. This would also fit into the Buber/Crossley (1923/1996) intersubjective honouring of The Other’s need for comfort whilst engaging in a difficult emotional task.

| 79). This would also fit into the Buber/Crossley (1923/1996) intersubjective honouring of The Other’s need for comfort whilst engaging in a difficult emotional task. |

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<thead>
<tr>
<th><strong>d) History</strong></th>
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<td>Denzin (1989b, pp.28-29) discusses his understanding of history, and its place in the processing of narratives. Denzin suggests that history enters the research process in a number ways. Firstly, the events and processes that are studied unfold over time. They have their own inner sense of history. Secondly, these events occur within a larger historical social structure. This structure shapes, influences, and constrains the processes under investigation. This includes language, micro and macro power relationships, and taken-for-granted cultural meanings that structure everyday social interactions and social experiences. Thirdly, history operates at the level of individual history and personal biography. Each individual brings a personal history to the events that are under investigation.</td>
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<td><strong>My reflections</strong></td>
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<td>At one point in the process I read Denzin’s (1989) understanding of history, and the place I should perhaps allocate for it in the processing of Kaye’s story. I decided to try to see Kaye’s story from a historical perspective. In working from this historical perspective, I chose five of the themes that seemed to be most important in the history of Kaye’s experience, and reassigned some of the material in this historical framing. It did not seem to produce more understanding for me, and I put it in place and moved on.</td>
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<th><strong>8. Theme: Families</strong></th>
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<td>Anderson (1997, p.219) describes a family as an interactional process. Tolstoy (1873) begins ‘Anna Karenina’ with the statement that all happy families are alike; each unhappy family is unhappy in its own way. Miller (1997, p.30) suggests that family stories must be told over and over again. ‘That is the way with family stories, they are told and retold to strengthen the tapestry’ (p.30).</td>
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<tr>
<td><strong>My reflections</strong></td>
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<tr>
<td>Kaye researched her mother’s history, trying to understand many of the family issues that had moulded her mother into who she was. Kaye spent time visiting various members of her family and friends to help her restructure the fractured story of family that she had lived with for the ten years since her mother’s death.</td>
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I relished Tolstoy’s (1873) comment in ‘Anna Karenina’. Perhaps it involves the powerful influence of one unhappy or disturbed person to throw a family into unhappiness, which then permeates several generations. This seemed to echo in Kaye’s mother’s family where one person seemed to have had a deep and long term influence on several generations.

she was so brilliant like - she could really draw, and she didn’t go to art college, or pursue an art career, you know as a young person. Was that because she didn’t have the opportunity? … I mean is that the key, that that was not really an option within the psychological makeup of that family? That’s what I’ve always thought or wondered about. I feel that sort of pressure too, and I don’t know whether I just inherited that sense of pressure, from the experiences that Mum had as a child.

Kaye and I had frequent discussions about who was like which parent, who inherited which characteristic from which parent:

My sister-in-law says ‘your brother’s like your mum, and you are like your dad.’ That really pisses me right off - I actually think I’m like my mother!

Dad always believed that he was not as smart as Mum. You know, I’m pretty sure I’m as smart as my brother, so, I don’t know whether that really is true, but that’s how we always operated in our family. And there was always a clear kind of genetic line down from my mum to my brother, and from my dad to me. So there was always a sense that I was more like my dad and my brother was more like my mum. Throughout my whole life, my whole childhood. And you know still, probably.
a) Kaye’s father

Phillips (1991, p.85) discusses fathers and their influence on Mother-Daughter Relations. The forgotten factor in mother-daughter relationships is the father. How he relates to the mother influences how his daughter values her mother and herself. While the father plays an important part in his daughter’s self-esteem through his attitudes and behaviours to her directly, research also indicates that fathers may play an influential role in their daughter’s self-esteem through their attitudes to their wives as mothers, as women and as sexual beings (p.88).

It is important that we construct stories about the important emotional events and experiences of our lives. Niederhoffer and Pennebaker (2002, p.574) explore recurring and overlapping emotional inhibition, cognitive and linguistic processes. They suggest that not talking about important emotional events engages powerful negative changes in each of these processes. However they believe that by constructing stories through writing or talking, these dynamics can be reversed.

My reflections

Kaye said about her father:

- He has an incredibly strong paternal instinct, he loves me so much, I'm so not what I think I'm supposed to be for him! He's the model I've had to refer to for 10 years.
- He’s multidirectional, he can concentrate, be involved in a number of different activities at any one time - he’s a good business manager.
- He said you've got to get a proper job, he had a role in my low self esteem.
- He’s very pragmatic, used to get antsy, he was quite shy - he’s a real extrovert, gregarious, ribald like a clown. The grumpy thing’s a key - he wears everything on his face and in his body. (From the ‘home and family’ theme work sheet)

Kaye talks a great deal about her parents’ relationship:

He fell sooo in love with her, he gave her support, showered her with love.


He said you’ve got to get a proper job, he had a role in my low self-esteem.

He couldn’t talk about Mum’s death.

9. Theme: Language and mirrors

Bruner, J. (1986, p.22) explains that in putting any particular expression together, one selects words and one combines them. How one selects and combines will depend

My reflections

Kaye was determined that her voice would
on the uses to which one wishes to put an utterance. According to Bruner, the selection of expressions must meet the special requirements of that special form of speech act that is this story. We characteristically assume that what somebody says must make sense, and we will, when in doubt about what sense it makes, search for or invent an interpretation of the utterance to give it sense (p.28).

Cecchin (1992, p.90) confesses how in his research, he struggled to give up hypotheses even though they were very attractive and looked like the truth. The hypothesis was a way of constructing a connection with the system and not a step towards the discovery of a ‘real’ story. It is in and through language that a person constructs a personal account of the self, who we believe ourselves to be is a linguistic construction (Anderson 1997). Self is discussed further in Chapter One, 2.2.

Freedman (Freeman and Combs 1996, p.27) tells how he sees ‘daffodils and azaleas’ and Combs sees ‘beautiful flowers’, that is, the different linguistic distinctions their families used in their youth. It must never be presumed that our ways of seeing are the same.

People carefully search for words to express themselves, for the words that are most meaningful for them. The nuances of their words and language contribute to shifts of the descriptions, understandings, and meanings that the language attempts to clarify (Cecchin 1992, p.64). Moustakas (1996, p.47) also notes this shift in language, that ends the self-destructive denials and enables the person to leap forth to the language of hope, determination, and possibility.

As cited by Freedman and Combs, (1996, p.46) Derrida explores the slipperiness of meaning. Derrida examines and illustrates how the meaning of any symbol, word, or remain alive in the processing of her story, in such expressions as ‘I am a flighty, flighty person’ and ‘it’s fucked!’ When I was writing the first creative synthesis I had deleted ‘fucked’ to perhaps raise the tone of the writing! However, Dr Jan Allen, as my supervisor at the time, suggested that ‘it’s fucked’ needed to be added back in, simply to be sure that Kaye’s voice was there, using Kaye’s own colourful language.

Kaye and I talked around her feeling that her mother ‘died twice’ and I thought we came to a clearer understanding of the events of her mother’s death. As a response to Kaye’s confusion, I spoke with a doctor (my son) who gave me exact definitions of life support, ‘turning off’ life support, and other terms that had continued to muddle Kaye for the ten years after her mother’s death. However Kaye later responds that she is still ‘never knew precisely’ when her mother died, despite the clarity offered by my presentation of medical information.

After reading a paper by Clark (www. last accessed 2006) I wrote a poem and e-mailed it to Kaye, pleased about the new meaning that Clark had uncovered for me:

Life as it has been is broken,
no longer to be taken for granted.
Innocence shattered, I am broken.
At the edge of existence, dangerous,
at the centre of life’s reality and meaning,
I enter the unknown.
I lost my mother - I am lost.

My mother was the mirror
through which I watched and knew myself.
Her death shattered the mirror.
I continue to re-know myself
as I sort through the broken shards.
I become bricoleur, remaking
re-creating the me who lost my mother,
transformed into the me who knows now
that because she was my mother
I am who I am.
In the face of her death, I am reborn.
I see now that in using the first person
Derrida and other deconstructionists believe that it is fruitless to search for the one 'real' or 'true' meaning of any text, as all narratives are full of gaps and ambiguities. The officially sanctioned or generally accepted meaning of a given text is but one of a great number of possible meanings.

Language, I was actually presuming to speak for Kaye. I was disconcerted when Kaye did not respond with enthusiasm to my poem, in fact found it difficult. It was a critical moment in our relationship. I had assumed she would find the meaning that I had found. For her, mirrors had quite a different connotation, to do with her mother’s and now her own fear of ageing. She says she now refuses to look in mirrors because it reminds her that she is ageing. I was in danger of subjugating her story if I was not careful. It was an important reminder for me. As I went on I kept bumping in to references to mirrors, and still do. Kaye and the mirror is a good example of the different ways of seeing something as simple as a mirror. It must never be presumed that our ways of seeing are the same (Freedman 1996, p.46).

10. Theme: Conclusion: Acting as midwife to Kaye’s narrative

An important idea from Golden (2000, pp.30-32) is that of ritual elders, those who have experienced the chaos of grief themselves and can create a space in which ritual will allow the chaos to be contained and workable. Golden says that the ritual elder helps provide a safe space to contain the individual’s grief, and acts as midwife to their experience of transformation out of spiritual chaos. Corradi Fiumara (1990, p.6) describes a philosophy of deep listening called *maieutics* that enables the birth of understanding and meaning (refer Chapter One, 2).

Kegan’s view (1982, p.229) of an evolving self, is echoed by Skolimowski (1994, p.223) who would suggest seeing the world differently, therefore changes relationships with other people. It is a spiral of understanding. By gaining a new dimension, one might change one’s way of being in the world.

Heron and Reason (1997, p.282) suggest that to heal means to make whole. We can

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**My reflections**

For Kaye I believe that I have acted like Golden’s ritual elder, or midwife to Kaye’s experience of transformation out of spiritual chaos. I could not ask for a more meaningful and privileged task, and one no less rewarding than when I worked many years ago as a midwife in labour ward with mothers in childbirth (Golden 2000, pp.30-32). This was an important connection for me.

As Kegan would describe Kaye’s evolving self, her new way of thinking is centred within a new orientation to contradiction and paradox. Rather than completely threatening her system, or mobilising the need for resolution at all costs, the contradiction becomes more recognisable for Kaye as contradiction; the orientation seems to shift to the relationship between the poles in a paradox rather than a choice between the poles. It is a much more
only understand our world as a whole if we
are part of it; as soon as we attempt to stand
outside our world, we fall into division and
chaos. Making whole necessarily implies
participation. A characteristic of a
participative worldview is that the
individual person is restored to the circle of
their community and the human community
in the context of the wider natural world.
Heron and Reason continue that

knowers can only be knowers when
known by other knowers. Knowing
presupposes mutual participative
awareness. It presupposes
participation, through meeting and
dialogue, in a culture of shared art
and shared language, shared values,
norms, and beliefs.

Kaye now sees the world differently and
therefore her relationships with other
people have changed. Her individual spiral
of understanding has changed significantly
(Skolimowski 1994, p.223).

Kaye says with great delight near the end of
our taping sessions:

I’m involved! That’s what I want to
do with my life!

The journey is coming home to my
city. I had to come home

Home is something I needed to -
have to establish within myself.

I’ve come through a process where
I’ve created a good relationship with
my father, my brother, my nieces
(Taken from ‘Home and Family
worksheets).

I believe this process of telling and
listening in a deeply shared and
collaborative relationship has enabled Kaye
to come home to herself, as she says ‘it is
transient’, but often a happy, and clearly
ongoing journey. I found it delightful and
important, that most of what Kaye so
painstakingly uncovered in the way of
meaning for her, was so superbly
represented by writers across many ages
and types of writing.

My voice as researcher and as a survivor of
my own mother’s life and death, helped
make Kaye’s work credible. Her story is
both biography and autobiography, its
major task being its autobiographical work,
that of finding for herself who she has been,
so that she might find her way into her
future possibilities. Kaye shared secrets,
courageously opened herself up and told
and understood her many layers of
consciousness and their confusions, gaining
wholeness and even happiness - if her
mother had to die, this made it worthwhile.
Kaye has gained the special knowledge called wisdom.

Kaye’s mother’s death challenged and redefined her health and wellbeing. Her autobiographical work became a possibility of becoming, a new habitual way of thinking for herself and in its developing understanding, extends this possibility to others, who must then do their own autobiographical work (Frank 2000a, pp.9-10).
Appendix Seven:

Sarah

1. **THE APPLICATION OF VAN MANEN’S LITERATURE SEARCH TO SARAH’S NARRATIVE [FULL TEXT]**

There are many connections to illness narrative literature in Sarah’s story, particularly in the writings of Arthur Frank. Many of the themes interconnect, interrelate and are difficult to untangle, so there is some overlap. Bold print represents Sarah yelling as best she was able with the bronchial stent and tumour in her trachea affecting her vocal cords.

1. Theme: Between the ride and the story
   - Overcoming censorship: telling the story so the pain will not be wasted
   - They made her feel like a subject: medical discourse as power
   - I-It
   - The rise of experts
   - The moral problem of being a patient
   - Those who have the power

2. Theme: What is going on here?
   - How can they act like that
   - Explaining can heal
   - Pseudo participation versus creative participation
   - Standpoint
   - Sarah’s interpretation of her palliative care

3. Theme: Cultural soup
   - Untellable stories
4. Theme: Meaning
   - Collaborative narrative relationships
   - Storytelling as ethical action in disrupted lives
   - Like a testimonio
   - Life’s normal tragedy: disease as entity

5. Theme: Listening to Sarah’s story
   - I-Thou and ‘hot’ texts
   - A shared community of value

6. Theme: Conclusions and closure?

Table 2. Literature search for Sarah’s narrative

<table>
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<tr>
<th>1. Theme: Between the ride and the story</th>
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<tr>
<td><strong>Introduction</strong></td>
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Frank (2001b) suggests that the ride is a figure of speech that describes everything that is not part of the real story as far as the ill person is concerned. The ride oversteps or surpasses the telling of real stories. Frank suggests that the medical system has neither time nor interest in who the people are who are on this ride.

The story needs conversation which is based in a mutual recognition of identity, which is defined in dialogue with significant others. Frank pleads that as health professionals, our vocation must be the ongoing struggle to know the ride as separate from the story. By clearly seeing each of them, we can offer better intersubjective relationships to those who are on the ride and who have little say or control over it.

| **My reflections** |

Sarah’s words, which I chose for the title of the final essence statement of her narrative analysis, and Frank’s (2001b) ‘Between the ride and the story,’ connect powerfully for me. Sarah said:

‘everything else keeps on ... you know ... you’re already on the annoying ride, you don’t stop, it’s express train ...’

Frank’s suggestion that the medical system has neither time nor interest in who people are on this ride is the sad, angry essence of Sarah’s cry. She even uses Frank’s words for this journey, as a ride that is so fast she does not have a voice in its management, and that:

I’m a nervous person anyhow. They don’t know me. They're getting to know me with my reactions with what they’re doing to me. Certain things are my characteristic, so its not just because I’m sick of it, I’m like this. I act like this if I’m not sick! Because that’s me!
Sarah’s anguish is centred in the fact that from her perspective the health professionals remained more interested in their ride than her story. While Frank says that the story needs conversation that is based in a mutual recognition of identity, Sarah feels this is denied to her, until she has the opportunity to describe the experience to me, in its context within her whole life story. If our identity is defined in dialogue with significant others, then Sarah recognised her dependence on both her family and the numerous health professionals who came into her life when she began the ‘annoying ride’. But they did not seem willing to pause and listen, so they might know who she was, or to recognise the life that was hers before it was taken over by her illness. In fact she felt this so strongly she said ‘they made me feel like a subject.’

### a) Overcoming censorship of the story: telling the story so that the pain will not be wasted

Stories call to be heard through the physical, emotional, psychosocial and spiritual aspects of the pain caused by censorship of the patient’s narrative of their experience. Being in opposition to the ride, gives voice to what is censored, by the logic of satisfaction. Lorde (1980, p.14) wrote that she needed to share her story so that ‘the pain would not be wasted’. Narrative work is a vital way for people to articulate for themselves, and for others who will follow, a knowledge that they have had to learn and discover from their own life experiences (Monk et al. 1997, p.23).

Frank, (2001a, pp.360-1) writes from his own experience of life-threatening illness, that he was not so much in need, but in mourning, grieving the life that he might not live as well he might have, and what his family might be forced to go through with

### My reflections

Sarah’s story is told through her pain, grief and anger at the overwhelming loss of control of her life. This was compounded by her perception of the system’s censorship of her pain. Sarah’s story being in opposition to the ride, gives voice to her anguish. Sarah’s simple yelling of

> [the oncologist:] ‘I’ve instructed!’ I said ‘WELL, I REFUSED! AM I ALLOWED TO?’

gave voice to her pain and anger, and her courage to describe her refusal of things that defied her common-sense and reciprocal recognition.

Sarah sadly reflected that it would never be the same again. Sarah’s suffering was censored by the unit’s system; she was required to be a good patient. She continued to feel unheard, and that ‘they didn’t care, it was not important to them.’ She was also concerned about her family in Israel, their distance, and the problem of.
him. Frank said that the censoring of his suffering would have added to his already extensive anxiety. Suffering is the subversive voice in the biomedical discourse, it is central among all the things that do not fit. In order to oppose the censoring of the things that do not fit, according to Frank, means writing or telling them without making them fit some explanatory schema.

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<td>them being informed about her illness. They became part of the fraught tangle that drove her anxiety, loss of control and grief. All the things that did not fit this unit’s system were censored as far as Sarah was concerned, the unit’s text allowed no space for their presence. Sarah could be seen as a subversive voice of suffering, according to Frank. Perhaps my deep engagement with Sarah’s story was in order to oppose the censoring of the things that did not fit, which by telling and then writing them makes her narrative successful (Frank 2001a, p.360-1). As Frank (2001b) suggests, Sarah’s narrative as she told it to me, succeeds over the institutional take-over of her body through an official, medical discourse that explains her body but denies Sarah’s voice as the person who is the lived body. In the end, her success is that she has at least told me what it was like for her, and expressed her anger and frustration. Sarah was concerned that, despite her lungs feeling full, she could not expectorate any of the rubbish she felt must be there after the bronchoscopies and having stopped smoking. She yells:</td>
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<td>I was asking the first one, second one, third one, fourth one, every sister in hospital, every doctor, every physio, I kept on saying, ‘the gunk has to come out, where is it?’ Why couldn’t they tell me its been sucked out! WHY? How come that they didn’t know! Or if they didn’t know why couldn’t they have found out! Because I kept on threatening I’m going to ring the guy who did my bronchoscopy and ask him. He’s seen my lungs, I’m sure he’s seen all the smoking gunk and the tar and nicotine and whatever! Probably he sucked as much as he could out! BUT DID HE TELL ME? NO! WHY? Phew! Can you explain that?</td>
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Sarah told me that she wanted her story shared with anyone who would read it. She wanted, like Lorde, (1980, p.14) to share it so that ‘the pain would not be wasted’. Sarah and her brother desperately wanted her story to be heard by the palliative care health professionals in particular, so that they might develop an understanding of what the experience of terminal illness had been like for her (Monk et al. 1997, p.23).

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<th>b) They made her feel like a subject: medical discourse as power</th>
<th>My reflections</th>
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<tr>
<td>Health professionals subscribe to a particular medical discourse by promoting certain definitions. This controls which people or what topics are most important or have legitimacy. The shift in concept from benign caregiver to oppressive professional is one that, fair or unfair, is implied. This means that to change this situation, health professionals of all varieties must look at how relations of domination and submission are built into the very assumptions on which their practices are based. They place the client/patient in a submissive place (Hoffman 1992, p.13-14). In terms of Buber’s (1923) I-Thou it creates a situation of a patient becoming an I-It. As Frank (2000b, p.357) argues it, the alienation created by an institutional take-over of the patient’s body through an official, medical discourse, explains this body in its physiological detail but denies the voice of the person who is the lived body. As a researcher, Ellingson (1998, p.498) recalls a study of physicians and their attitudes toward patients. Patients who insisted on asking questions and discussing options instead of simply following the physician’s advice were labelled ‘difficult,’ and the physicians complained that such patients wasted too much of their time. Zaner (2004, p.58) describes a patient who</td>
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<td>My reflections</td>
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<td>Sarah’s health professionals subscribed to a particular medical discourse, by adopting and promoting certain definitions. For example, Sarah was defined as ‘a difficult patient’, and the numb spot on her head was not allowed to rise to the significance she felt it deserved. Clearly this infuriated Sarah:</td>
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<td>So it’s like it’s not my body any more. The doctor wants me to take morphine, to calm me down. I refused, because this would be artificial calm, and not solve any problems. I still feel that sleep would give me more energy. I tried to explain to the doctor that my anger was not aimed just at him, but also at the medical profession, the nurses, and the world. Because I’m pissed off with everybody, right! I haven’t seen him since. It’s very nice that I’ve got the palliative nurses coming here, but you feel like a subject! Because they’ve passed information about you, they discuss you between themselves. Ok they’re doing the right thing, but I’m a subject. You know they report on me - fine! but they don’t realise that’s how they make me feel! And they report to him (Tape 1. transcript).</td>
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is elderly and vulnerable, where the physician had the advantage in this asymmetrical situation. The asymmetry was not merely formality of social structure, but an existential reality, a vital fact of life in this hospital and in these circumstances.

Bourdieu (1999, p.591-5) writes of his interview with Isabelle, who very quickly collides with the difficult reality of hospitalisation and then physical therapy. The total dependency imposed by the hospital, which the sick ordinarily see as just an interlude in their lives, becomes for Isabelle, always under the threat of dependency, an unacceptable ordeal. Isabelle sees the logic of the hospital, that sick persons with their suffering and their demands seem like one more obstacle to the smooth operation of an institution which, through all its members from the physician to the caregivers, expects total self-abnegation and submission from the patient. Isabelle says she feels reduced to ‘physical particularities’ at each new encounter, and she says that suddenly she had become an object!’

c) I-It

Buber argues that the It-form of conceptual knowledge is knowledge that is pursued by stating: ‘so that is how matters stand, that is the name of the thing, that is how it is constituted, that is where it belongs’ (Buber 1923, p.90). He also describes ‘the basic word of separation,’ as that which keeps apart I and It, and that life can then be divided into two neatly defined districts: institutions and feelings (p.92).

My reflections

Health professionals, whilst their intentions are caring, place the client/patient in a submissive position. I am sure this is what Sarah meant when she said they made her feel like a subject, or as Buber would say, the It part of an I-It relationship (Hoffman 1992, pp.3-14; Buber 1923). In fact Sarah felt this so strongly it negated any sense of their care, although she said to me that she knew she needed them and that some of them did care.
**d) The rise of experts**

Crossley (1996, p.140-141) discusses the overlapping concerns expressed by both Foucault and Habermas with the rise of experts. These scholars all suggest that being an expert serves to give authority to intervene and regulate affairs, in a range of different arenas, here mostly concerning healthcare settings. Crossley says many people would regard this state of affairs as reasonable and unproblematic. It is usual that doctors enjoy some privileges over our bodies, and we think that this is a good idea if it will help to alleviate our pain and perhaps help us live longer. Those who have power exercised over them are left with no choice but to act in specific ways if they wish to achieve certain things and to either reach or sustain a particular identity. Walton (2005, p.12) writes that fundamental reform in health service delivery is needed before patients can be treated by multidisciplinary teams who are as loyal to the patient as to their own profession, who share common ethics and respect the roles of all members of the team.

**My reflections**

In Sarah’s case, it was her palliative care arena where the experts’ expertise authorised them to intervene and regulate Sarah’s life and illness. This expertise so disempowered Sarah, and made her feel so lacking in control of her body, that she felt that her life was over, that her body was no longer her own. As I heard and understood it, Sarah’s feisty refusals and arguments with the health professionals were in order to sustain her sense of her own identity and some semblance of control over her life. With the tape turned off, Sarah laughingly told me that she heard their alarm bells ring as she began to walk up the path to her various appointments.

**e) The moral problem of being a patient**

Frank (1997, p.131) writes that serious illness creates a moral imperative for a person to do the right thing, and to rise to the occasion, accepting the role of patient, agreeing to be compliant in this role. Most tellingly, the role of the ill person, according to Frank, does not encompass the identity of the ill person. As a medical ethicist, Richard Zaner (1993, p.46, 148) suggests that the main moral problem is that most ill people face situations where it is not really clear what the ‘right thing’ is. Frank (1997, p.8) describes the conflict

**My reflections**

For Sarah the conflict grew from what the health professionals seemed unwilling to enter into with her. From her point of view they did not ever seem to provide her with enough medical information to make sense of her disease, particularly in the light of her knowledge of anatomy and physiology acquired from her training in Israel as a pathologist. She felt that her knowledge was upsetting for the health professionals. However, these were physiological issues she could not avoid because they were Sarah’s life.
between what the health professionals believe they should not need to get into with the patient, and the issues that the patient cannot avoid because they are her life. This is like a Pandora’s Box in which the ill person is living, which they cannot get out of, and a box the health professionals are determined to keep the lid on. But it is, for the patient, their life as they experience it.

Looking at the stories and covenants of physicians as healers in the ancient times of Asclepius, Zaner (2004, p.59) invokes a moral vision centred on the healer-patient relationship, wherein power speaks to vulnerability, the one who has power over, against the one made vulnerable by sickness. However these early healers such as Asclepius, vowed to be as attentive to the soul as to the body.

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<th>The oncologist told her that her disease was incurable, he could not operate, a stent was only a literal stopgap measure. The doctor, prior to her first bronchoscopy, told her it was a risky procedure, and she had a 50/50 chance of survival. She insisted on making a will in the theatre anteroom, which was her last will, though incorrectly witnessed. It is a poignant additional piece of the jigsaw puzzle that Sarah did in fact die in theatre having a subsequent bronchoscopy. Sarah accepted that her long-term heavy smoking was possibly going to end her life in this way, she knew her condition was serious, on one level she seemed to understand, but still felt she had not been told fully enough for it to make sense, so that she would not be in any doubt. In Frank’s terms, what the doctors seemed to want to keep the lid on was, for Sarah, the Pandora’s box that her life had become. She kept yelling that bad or good, she wanted to know what was going on and to be treated as an adult. I do not know if at any stage in the three weeks after we recorded the three tapes before Sarah died, someone did sit with Sarah, and spell out the fact that her lungs were full of tumour, and that indeed her life was rapidly coming to an end.</th>
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| **f) Those who have the power**  
Denzin (1989, p.30) states that knowledge is a belief, or set of beliefs, about a particular segment of reality. It is socially and politically constructed and is intimately related to power. Those who have power determine how knowledge about a situation is to be gained. They also define what is not knowledge. Under the interpretive paradigm, Denzin argues that knowledge can be assumed neither to be objective nor to be valid in any objective sense. Rather, knowledge reflects interpretive structures, emotionality, and the power relations that |

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**My reflections**

In Sarah’s case it was the health professionals who had the power, determining how knowledge about her situation was to be made available to her. They also defined what was not knowledge. For Sarah, I believe this was the greatest source of her distress (Denzin 1989).

In the biomedical model, it is understood that patients’ talk should be second-hand medical talk: close enough to the physician’s version to insure compliance with medical orders, but not so close as to suggest patients might make their own
permeate the situations being investigated. treatment decisions. Sarah shattered the biomedical model’s version of how a patient should talk by her prior knowledge, and by refusing to comply with their instructions when she thought that these instructions were ill informed or illogical:

> It's little things that piss me off, and make me feel that I'm not in control. Ok, I know there's rules. I'm the biggest stickler to the rule, that's the way I was brought up. But I like rules when they're logical.

However, her knowledge had its limits, she needed help to understand her test results, and help was not always given with good grace.

Sarah desperately wanted to make sense of what she was required to suffer. She also challenged her first general practitioner when she said that she believed her persistent cough and weight loss was lung cancer, and she preferred to expect the worst. He told her not to be silly, it could be a number of other things, but she was proved right. With a degree of grace this doctor then accepted his role as the one person in the system who would listen to Sarah’s emotional plea for support.

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<th>2. Theme: What is going on here?</th>
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<td><strong>Introduction</strong></td>
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<td>In asserting that stories matter, Charon (2002, p.79) asks what is going on <em>here</em>? <em>Here</em> being the ongoing social situation of the people at the scene of the actual storytelling, asking who are the key players or stakeholders in this narrative. Charon suggests that not only does the teller shape the story, but the teller’s plot is constructed so that what is going on in the narrative affects what is going on <em>here</em> where the story is being told or read. We need to pay careful attention to the ‘point’ of telling the story. Otherwise we might miss the crucial</td>
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<td><strong>My reflections</strong></td>
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<td>In the context of Sarah’s story, the key stakeholders in her story are Sarah, the health professionals, and her family. Charon’s <em>here</em>, for Sarah is her home and three hospitals, as the setting of her terminal illness story. It seems to me that the point of Sarah’s story was to finally make sense of her illness as part of her whole life narrative, to describe for herself its progress so that she might absorb it and accept it as something she couldn’t change. She also needed to tell who she was, so that <em>who-she-was</em> could be re-embedded in her</td>
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Charon writes that the plot of the conventional medical narrative focuses almost exclusively on details technically salient to medical care. Who the patient is, what she does for a living, her family, her values, and her life goals make little difference in the medical case. It is concerned primarily with the bodily malfunction for which the patient has sought help (p.81).

### a) How can they act like that?

The loss of the individual self is part of the admirable, but sometimes awful character of medicine. Frank’s (2002) paper ‘How Can They Act Like That?’ explains how for patients, the stakes of playing a particular game emerge from the distilling of personal histories with full and compelling self-evidence. Frank says that people can imagine themselves playing only this game; they cannot imagine themselves playing others. Health professionals each bring their own personal game to the contest. Frank suggests that in these games, the health professionals have little imagination of what they themselves look like as players in the other person’s game. The ethos of palliative care is to self-consciously allow the patient’s stakes to determine how the game will be played. Dialogue opens when each stakeholder is willing to become caught up in the other’s story, letting go of what has been their own story, even if provisionally (p.16).

### My reflections

Sarah fought the loss of her individual self with every ounce of her energy. Listening to the voices of the other participants of this story might throw more light on the narrative, but is not possible. It might have widened my perspective in the search for a durable understanding of this story.

Perhaps it illustrates an opportunity for further research in the future. A study could be centred around an illness narrative examined from the perspective of all the stakeholders, set in similar methodologies as this study, grounded in Frank’s (2002) paper ‘How Can They Act Like That?’ For a patient like Sarah, the stakes of playing her particular game emerge from the distilling of her personal history, with full and compelling self-evidence.

Sarah’s health professionals each brought their own personal game to the contest. Sarah’s story implies that the health professionals seemed to prevent her from ever determining how the game might be played, at least that is how she described it. After Sarah’s death I heard the voice of another player in Sarah’s story, that of her brother, and my conversation with him is discussed in Theme 2, d), Standpoint.
b) Explaining can heal

It has been said previously that in the biomedical model, a patient’s talk should be second-hand medical talk: close enough to the physician’s version to insure compliance with medical orders, but not so close as to suggest patients might make their own treatment decisions (Frank 1998, p.201). However van Manen (2002, p.14) writes that explaining, that is giving the patient sufficient information, can heal in the sense that it prompts us to be less anxious, and more reflective.

My reflections

In her distressed cry for information, Sarah felt hopelessly ignored by the health professionals. If explaining can heal, as van Manen suggests, Sarah said she did not want to calm down by taking morphine, she wanted to know what was going on, and would then sleep better. She said that if it was something that she couldn’t fix, then she would come to terms with it, and learn to live with it, but she needed to know (van Manen 2002). I’m unaware that anyone ever offered Sarah enough information so that she felt calmer or more healed.

As Sarah saw it, in her attempt to be ‘successfully ill’ she needed to have a full, physiological explanation that would help her to make sense of her rapidly progressing disease. She accepted the disease on one level, perhaps even before the ‘official’ diagnosis, but it was only after the radiotherapy oncologist spelt out the issues of her radiotherapy, that she thought:

Now it kind of dawns on me Hey! you’ve got cancer. I heard radio was the little thing, chemo’s the big thing! But what he told me, I thought shit! I can’t wait till chemo comes!! I might as well die! I don’t want this treatment.

By denying or skating around the information that Sarah’s future was bleak she felt that ‘everything I have to push for...’ Perhaps her ‘push’ was her own rising to the occasion Frank (1997, p.131).

c) Pseudo participation versus creative participation

Skolimowski (1994, p.156) calls it pseudo-participation, when we are led to believe that there is ample room for our creative intervention, while in fact there is none, or very little. This happens when there are

My reflections

Sarah angrily tells the story of her stay in hospital, where the problem of her medication and the times it was to be taken became an emotionally fraught issue for her. She feels that she is not trusted to take the medication if it is given to her ahead of
hidden internal rules within the game that only the privileged know, and through which they manipulate the game to their advantage. We have an illusion of participation. We ‘participate’ by giving our silent consent to the power game of others.

According to Skolimowski, co-creative participation occurs when we are allowed the freedom of not only following the rules but also of making the rules through which we can change the game as we go along. Our status as human beings is enlarged by the degree to which we are allowed co-creative participation. The more sophisticated the technology, the more it disengages us from life.

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<th>d) Standpoint</th>
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<td>Frank, (2000b, p.356) describes a standpoint as ‘a political and ethical act of self-reflection’. To take a standpoint means to privilege certain aspects of what your biography shares with others. Taking a</td>
<td>Sarah’s brother was a key ‘player’ in Sarah’s story. I had a long, sad telephone conversation with him after her death, when he came to Australia for her funeral. He had found the transcript of Sarah’s</td>
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<td>time, so that she might take it immediately after her meal as ordered. Instead it is locked in her bedside drawer:</td>
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<td>You come to them and an hour later she comes for you. I’m trusted here at home, but I’m not trusted in hospital. I have to sit there and wait when they have time, finishing with whatever other people they do, so they can give me the medication that I should eat. I mean its little things that pissed me off, and again makes you feel that you’re not in control. I think if I got my dinner I know that after dinner I should have a tablet, I’m going to be able to take my own tablet. I don’t have to sit and buzz and buzz and wait for them...</td>
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<td>I asked her did she explain that to them, and she replied:</td>
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<td>YES! - ‘We were busy!’ I didn’t doubt that you were busy, just leave it out. The next time I think it was by mistake it [the locked drawer] was open all the time, till one of the sisters saw and realised it was and ‘HHHHhhhh!’ and she quickly locked it! you know. MY GOD for two days it was open! You know? Nobody mattered. So I mean its ... they don’t themselves have control on, its little things.</td>
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<td>Sarah describes a loss of control that highlights quite the opposite of Skolimowski’s co-creative participation. The more sophisticated the technology, the more it disengages us from life, and for Sarah, from participation in her own life from then on (Skolimowski 1994, p.156).</td>
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A standpoint both reflects one’s own unique experience and asserts membership in a community of those who understand shared experiences in mutually supportive ways.

No two people can occupy the same place at the same time, they will not necessarily see the same things. There are many factors which might account for discrepancies in experiences, ranging from social position and cultural capital through to purpose, mood and momentary inclination. All of these factors may lead us to interrogate our environment differently. Perceivers can argue and debate about what they see and can show and teach each other how to see the same things in similar ways (Crossley 1996, p.30).

Apter (1996, p.40) says that we are possessive of the stories we tell about our lives, what we have suffered, what we desire, what we aim for, who we are. Apter asks who owns the knowledge, who has power to tell the real story?

Her acquisition of permanent residence status in Australia is a good story about the game she was prepared to play to get work in Australia, and how this acted in her favour to allow her to stay. It colours her unique experience and records it for posterity within her family story, marking her experience as a member of the Australian branch of her family. Frank suggests that biographies are singular, and yet can only develop within communities, in this case the community of Sarah’s Israeli and Australian family groups and the community that she and I formed for the time we shared together (Frank 2000b; Crossley 1996, p.30).

I do not know if Sarah’s brother was able to go on to tell the story from his own perspective. As far as Sarah and I were concerned, I do not think that there is, in this therapeutic autobiographical way of gathering a life-review, a deeper layer of knowledge that is the privileged information of me as researcher-listener. Here the aim is for acceptance of a reciprocal meaning that is available for both teller and listener, a shared and collaborative meaning (Apter 1996, p. 40).
Sarah’s interpretation of her palliative care

Denzin (1989b, p.11) writes that programs must be judged by and from the point of view of the persons most directly affected by them. That is, according to Denzin, everyday life revolves around persons interpreting and making judgements about their own and others’ behaviours and experiences. Many times these interpretations and judgements are based on faulty or incorrect understandings.

My reflections

In Sarah’s case, the programme she was interpreting was the palliative care services she was receiving. She had difficulties and conflicts with the service. Sometimes these interpretations and judgements are based on faulty or incorrect understandings. The palliative care service had great difficulty with Sarah’s interpretation of their programme and her criticism only makes any sense in the narrative of her whole life story. She said:

- they don’t themselves have control
- the nurses every time they came and saw me I kept on hampering them about that, [the numb spot on her head] so they passed it on to him. I think he eventually decided to do something about it.
- that’s the thing, I feel like it’s very nice that I’ve got the palliative nurses coming here, but you know what, you feel like a subject! Because they’ve passed information about you, they discuss you between themselves. Ok they’re doing the right thing, but again, I’m a subject, you don’t realise that that’s what they make me feel!
- most things are trivial to them, but they were not to me!

My question to Sarah: what would have made a difference?

- I think first of all, treating me as an adult.
- I don’t want to calm down. I want to know what’s going on!
- it’s not important, - I said. ‘IT IS’ (shouts)
• they always think its me! ... reacting! Some [nurses] are patronising, they still don’t tell you much, I don’t know if they’re not allowed to or they don’t want to. They treat you like you don’t have to know.

3. Theme: Cultural soup

The Macquarie Dictionary (Delbridge, ed. 1987, p.448) gives a sociological definition of culture as ‘the sum total of ways of living built up by a group of human beings, which is transmitted from one generation to another’. In working with narratives that describe lives, it is important to understand that the newborn child is at birth, instantly bathed in a *cultural soup*. From a narrative perspective, problems may be seen as floating in this soup. The problems we encounter are multi-sourced, and developed over a long period of time and they come together through the medium of language to construct and produce our experience. Externalising conversations helps to locate the problem within the beliefs of the culture from which the problem emerged (Monk et al. 1997, p.27).

**My reflections**

Sarah’s *cultural soup* became a signpost for me as I worked with her story after her death. She described in considerable detail, the effects that her families’ cultural values, experiences and ways of seeing the world, coloured and shaped the whole of her life. I felt quite strongly that in the end, Sarah’s *cultural soup* shaped her illness experiences. I heard how her childhood in a poor squatting house in Jerusalem influenced the rest of her life. Her bed as a child consisted of two armchairs pushed together at night, forming the lounge furniture during the day. Her task as a young girl was to assist in assembling the day and night states of the room. The kitchen and bathroom were shared with other families, one had one’s turn and left everything tidy for the next family. As one of my intersubjective responses to Sarah’s story I drew a pot of her *cultural soup*, and all the issues that occurred to me that belonged in it:

- **Self discipline**: ‘I just did it because that’s what was expected’;
- **Being uprooted and surviving genocide**: her parent’s journey from Europe to Jerusalem and Sarah’s journey from Jerusalem to Australia;
• No stories were told, we knew just that they did go through it [The Holocaust];

• Resilience; Independence; Hard work and parental sacrifice - there was always food on the table;

• Israeli Wars: adventure, hardship, needing to be endured;

• Great poverty: managing as best one could - all my clothes were hand-me-downs;

• A culture that celebrates: parties and dancing, in the one living room with high ceilings that made it seem bigger;

• Valuing human life: Jewish or Christian, one could have friends of either faith;

• Her birth was a happy occasion; her childhood was ‘basically very happy’.

For Sarah, on the surface the cultural soup she was born into on Jewish New Year seemed to be a happy one, where her birth was straightforward, she said that her mother basically dropped her, and went on with her life. Sarah needed me as listener, to hear the descriptions of her Jewish culture, as they gently and sometimes not so gently unfolded in her stories. Sarah’s story contained pictures of cultural events that affected her profoundly, and consequently her way of seeing and dealing with the world, and the way that she tackled her illness.

She told me that she did not like the term ‘second generation Holocaust survivor’. She said that she was a Holocaust victim, it was a pivotal part of who she was, she had no grandparents, cousins, aunts and uncles, she was deeply affected, no matter which generation. Externalising conversations
helped Sarah to express the problem within the beliefs of her Jewish culture from which her problems emerged (Monk et al. (1997, p.27). I expect Frank (1995, p.97) would see a connection between the chaos story of Sarah’s illness, her experiences with chemotherapy, and its connections back to the chaos stories of her childhood experiences of learning about the Holocaust, its profound effect on her family, and Sarah’s I’m a nervous person anyway.

Sarah described her recent visit to Europe, to one of the death camps. The great emotion between Sarah and her mother, who stayed in the bus and would not go into the camp, was powerful and painful. Sarah said:

I’m happy I’ve seen it, and that was it [said with great emotion]. You wouldn’t put animals in there! You go into a room, its half the size of this room and you have 150 people in it, you still can’t figure how 150 people fitted. But they definitely did! We stood there together, two girls, and we were counting and we said ‘I think I can fit 70 people here.’ But they had one hundred and fifty in that room. And they have the papers to show it, all the names, its not a fiction. Its a fact! (shouts) IT DOES NOT MAKE SENSE! And you say never mind how skinny they were, you still could not fit them there. THEY DID! My mother went through those things.

LeGuin (1981, p.192) cites a survivor of Dachau concentration camp who says that the SS guards took pleasure in telling them that they had no chance of coming out of the camp alive, a point they emphasised with particular relish by insisting that after the war the rest of the world would not

a) Untellable stories

My reflections

Shortly before Sarah returned from Israel to Australia just a month or so before we began to record her story, she travelled to Europe with her mother and visited one of The Holocaust camps. Her experience visiting the camp brought validity to her family’s experiences, and clarity to her
believe what had happened, there would be no evidence. Primo Levi (1979) managed to tell his own Holocaust story, as did many others, but many could not.

Barclay (1996, p.94-97) describes the awful pain, loss of identity and constant horror that occurs when a person lacks the language, coherence and ability to express the shocking outrage of a story such as The Holocaust.

So according to Monk et. al. (1997) we make sense of our lives in the context of our social history, shaping stories about the groups we belong to and about how we came to be who, how, and where we are. Such stories constitute one’s identity. We may sometimes feel that our lives are being storied for us by external forces. No person has total control over the meanings of their life and people need to make meaning through conversation with others. Within human communities, what can be said and who may speak are issues of power (Monk et al. 1997, p.39).

4. Theme: Meaning making

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<th>a) Collaborative narrative relationships</th>
<th>My reflections</th>
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<td>Wikan (2000, p.230) tells the story of a person who had at the forefront of her life, an illness story of headaches and stomach pain. Behind that physical pain was a life full of turmoil and despair. ‘Care of the self’ according to Frank (1998) is a practice of re-claiming a voice that bodily trauma and institutional treatment have more or less silenced. Dialogue improves the sense of being understood, the sense of belonging and feeling more hopeful. Anderson (1997, p.33) questioned some of her clients about understanding of the horror that her parents had experienced but could not ever talk about. The shocking outrage of a story such as Sarah’s mother’s personal experience of The Holocaust, meant that she had the embodied experiences of a concentration camp that were not ever conveyed to her daughter. A story so horrible that it could not be told. Sarah’s stories were a colourful picture of her childhood in Israel, very poor but basically happy. For a child who loved to learn, there was always food on the table, school to attend, and hand-me-down clothes with boots with reinforced toes which came in handy for keeping the boys in line! Such stories constituted part of her identity; they were the background context that brought the possibility of coherence to her life as she told it in its present, with her disease in progress, and her life now in Australia. As Sarah’s disease took over her life, she vehemently expressed Monk et. al’s suggestion that her life was being storied for her by external forces (Monk et. al. 1997, p.39).</td>
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In placing Sarah’s illness story first in our life review recording, it then allowed the rest of her life story to be free to emerge, with the illness story secure, but set aside for the time being. Sarah’s illness narrative, as the first part of her life story, became an occasion to describe herself as the centre of her self knowledge, a ‘care of the self’ according to Frank, a practice of struggle to re-claim a voice that she felt illness, institutional treatment, and her family had more or less silenced. Her articulate and feisty nature made this particularly meaningful for me; she had
this and their answer was that health professionals should try to listen. Later Anderson says that collaborative narrative relationships are grounded in not knowing. That is the non-arrogant, non-judgemental, non-powerful sense that it is the client who is the one who best knows her own life.

such a strong knowledge of her strengths and weaknesses (Wikan 2000, p.30; Frank 1998).

By setting her illness story in the context of her life story, Sarah was able to gain a better perspective of who she was. I remain sad that we were unable to complete the process that might have enhanced her understanding further. Anderson (1997, p.33) asks if dialogue improves the sense of being understood, the sense of belonging and feeling more hopeful. The anguished cry that Sarah gives to her GP was 'they don't listen to me!' Anderson’s next question is ‘what do the health professionals need to know?’ I believe Sarah would answer this with ‘they need to spend time in order to know me!’ (Frank 2001b).

c) Like a testimonio

John Beverley (2000) is a Professor in English and Communication. He defines a testimonio as an account of a life, in a novella length printed text, which needs a narrator and an interlocutor, who generally tapes the account and then transcribes it. As Beverley describes it, the narrator uses the possibility of a writer/researcher’s work as interlocutor, to bring her situation and dissatisfactions to the attention of those who might change feelings of loss of control. Beverley suggests that the direct narrator is often a person who is illiterate or not a professional writer.

My reflections

This need in Sarah to tell and publish her story so that others might hear it is akin to Beverley’s (2000) testimonio. As Beverley describes it, the narrator, in this case Sarah, is terminally ill rather than illiterate. She uses the opportunity of my work as interlocutor, to bring her situation and dissatisfactions in the palliative care unit to the attention of those who might change her feelings of loss of control. In Sarah’s case, the rapidly increasing debility of her terminal illness, means that she is unable to undertake the task of writing her story for herself.

d) Life’s normal tragedy: disease as entity

Howell (1998) states that meaning goes beyond the surface reactions of the individual to the very depths of the person’s soul, and can be a source of despair and suffering. Individuals may have two reasons for their symptoms or illness

My reflections

Howell’s (1998) statement that people might have two reasons for their symptoms or illness experience, the medical reason and their own private version such as punishment, connects when Sarah says:
experience, the medical reason and their own private version such as punishment. As Trautmann Banks (2002, p.222) suggests, health professionals, and perhaps people in general, don’t want to accept into their innermost understanding, all the elements of life’s normal tragedy. Because it might seem that the world, and therefore the people themselves, are out of control and liable to depression and despair. Trautmann Banks suggests that by denying this reality of life, people thereby miss out on the personal growth available through tragedy. They also render themselves unable to be part of the humour surrounding such events, which Trautmann Banks suggests is to do with continuance, community, and cathartic calmness.

van Manen (2002) discusses how we see disease as an entity, as:

something that confronts us, something that stands before us as it were, and hence the experience of object, the disease as entity. When we sense something conspicuous then we tend to worry. It is when this relation remains disturbed in a disquieting manner that we exist in a protracted state of ‘dis-ease,’ literally uneasiness.

Chapple, Ziebland and McPherson (2004), researchers from the Department of Primary Health Care at Oxford University, examine the stigma, shame, and blame experienced by patients with lung cancer, in their qualitative study. They concluded that the pattern of stigma they identified is probably stronger in the population of patients with lung cancer. There have been suggestions at times that smokers might not be able to receive treatment until they agree to cease smoking.

Sarah was quite prepared to accept that after years of heavy smoking, lung cancer was a real prospect. Yet the GP told her not to be silly when she voiced this acceptance. Sarah told her life story, with its tragedies embedded in a clipped, articulate humour like a paradigm that blanketed and embraced its Jewish origins and grief (Trautmann Banks 2002, p.222). Sarah sees her disease as an entity, as she said:

I wanted to stop this cough which controlled me, I felt like ... I’m not joking, you know the devil was there, I don’t believe in those things, but I felt I needed an exorcist. It took me over, I could not do a thing about it (van Manen 2002).

I’m living with it because that’s what a million others who’ve lived with it, because that for me is my punishment, my time is come, I’ve been smoking, I’m being punished, whatever!

One cannot help but wonder if Sarah’s care was in any way affected by the kind of stigma described by Chapple, Ziebland and McPherson (2004). As she describes above, she was in no doubt that her smoking and family history was the cause of her disease. She did not express the view that it affected her care as a direct result of her smoking, as this paper suggests. She appreciated the support of The Quit Line when she rang them. She was more satisfied with their explanations than she had managed to extract from her oncologist and surgeons.
5. Theme: Listening to Sarah’s story

<table>
<thead>
<tr>
<th>a) I-Thou and ‘hot texts</th>
<th>My reflections</th>
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<td>Buber’s (1923) challenge is for us to see a Thou in the Other, as a reciprocity of care and mutual meeting of selves. Gilgun (1999) suggests that in some cases researchers cannot emerge unscathed from close analysis of ‘hot’ text, that is, narrative material that most people would find deeply disturbing. Gilgun (p.203) understood that if she had left herself out of the account she prepared, she would have provided an incomplete narrative.</td>
<td>I heed Buber’s (1923) challenge that unless I see a Thou in the other person, I cannot be a Thou for them or an I for myself. It is, as previously argued in Chapter One, a relationship of Being-to-Being that is important. If there had been an understanding of this reciprocity of care and mutual meeting of selves within the palliative care unit, Sarah’s story might have had a different telling. She then might have felt that her health professionals had seen her, a more respectful notion of dialogical reciprocity rather than the Health Professional-patient subversion Sarah yelled about. I found working with Sarah challenging, and working on her story later, a kind of healing balm to the ‘hot text’ issues. I could then hear her voice in its context of her culture and personality, and know that as she suggested, she was a perfectionist and life could never be perfect, thus allowing or explaining the tension for her. I have read a number of Holocaust narratives, and each one is, for me, barely readable. Primo Levi’s ‘If this is a man’ (1979) was perhaps the most difficult, and required a degree of persistence to complete. And like Gilgun (1999, p.188) Sarah engaged my deepest subjectivity, in that she brought a very personal Holocaust narrative for me to engage with, and to find reciprocity within. Like Gilgun, how Sarah perceived me affected how she represented herself, and I certainly responded to her self-representation. I am sure that if the work we had been able to do together had included the distilling of Sarah’s story to its end point, there would have been much more evidence of this reciprocity and the struggle to reach a deep, intersubjective understanding.</td>
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### b) A shared community of values

Winslade, Crocket, and Monk (1997, p.63-72) suggest that because we value our encounter with what is there, we know how to symbolise it in words, and therefore our statement has the value of truth.

### My reflections

I was the audience for Sarah’s life-story. I was drawn into the telling, noticing and acknowledging Sarah’s presentation of her story. The significance of telling a story and having another human being listen closely, is incredibly valuable. My response was not contrived, I found myself laughing, filled with tears, horrified, sad.

Drawn into the rhythm of humour in the description of Sarah’s first day at school, I convulsed with giggles, and the more I laughed, the more funny she allowed herself to become in the telling. I acted as reviewer, clarifying statements that sharpened her awareness of the significance of what she was saying. Sarah knew how to do justice to a valued experience, and to use it’s telling to assert a shared community of value, a shared way of delighting in and valuing the world as encountered. So in the description of her first day at school, Sarah knew that together, we were engaged in reliving her valued experience as one.

### 6. Theme: Conclusions and closure?

Charon and Montello (2002, p.83) suggest that cases need closure, and that aesthetic closure occurs when a reader or listener has ‘the expectation of nothing.’ This is the moment of stasis when readers feel that nothing more can be added to a work. This conclusion occurs at the end of the interpretive process or the literal end of the story. These writers state that interpretive closure is achieved when there are no more questions to be answered, a satisfying wholeness has been achieved in the teller’s and listener’s sense of what has happened. Interpretive closure is reached when the narrative can account for the anomalies revealed in the course of the investigation, the narrative answers questions raised, and makes room for new information.

### My reflections

Perhaps in Sarah’s story interpretive closure is an impossibility, she is not here for me to check that I have got my interpretations of her story anywhere near right. Sarah herself said:

> I’m by nature a perfectionist, and I expected everything to be perfect, and of course nothing is perfect, even in hospital with doctors and the patients, so nothing’s changed has it! Nothing! I haven’t learned all those years! I still haven’t learned!

For Sarah and for me, ‘the ongoing communication between simultaneous differences’ included her Jewish and my
Frank (2000) sees that autobiographical work is about seeking wholeness. Dialogical autobiographical work recognises that the relevant wholeness is never for oneself alone but always for oneself with another. Wholeness comes to mean the ongoing communication between simultaneous differences. The ethical challenge is to live in the space of those tensions.

non-Jewish cultures, her smoking, and my non-smoking, her terminal illness and my health, and ground we did not discuss, my never-clarified status as a health professional and her status as a patient. Perhaps that is all that can be concluded, and must be enough for me to feel closure to Sarah’s story. Perhaps I might need to concede my desire to bring order to what seemed to be moral disarray. Sarah certainly seemed to die as herself, with integrity, maintaining her courage and her voice until the end of her life. I celebrate her story, admire her style and courage, and am grateful to have known her.

2. LETTER FROM SANDRA TO SARAH AFTER TAPING OUR FIRST SESSION

Dear Sarah,

I want to thank you from the bottom of my heart for the extraordinary gift that you have given me. Firstly, you trusted me enough to share with me the agonies of your journey. Secondly, you have been prepared to share your wisdom and insights into our Health Services.

I feel you have a gift that is, as you say, ‘not always good’ or comfortable. Your personality and culture allows you to see straight into the discrepancies and holes in our system, the little things and the bigger disasters that happen all the time. If we can but ‘listen’ to the things you see, and ‘hear’ the realities, maybe they can be done better.

While listening to your moving story, I seem to hear that somehow you are focused on the small and often irritating picture. While this is of huge importance to you, I wonder if it slows you from seeing the big picture, the ‘tapestry of your life’. I can sense this bigger picture, and it shows me a lovely colourful, warm, feisty, very intelligent lady, with an amazingly rich wisdom to be shared with those around you. A person with a superb worldview that is both educated and intuitive, and of great value to the world.

Sarah, thank you. I sincerely appreciate your gift to me, and look forward to hearing more of your story.

Sandra Foster.
3. LETTER TO SARAH FOLLOWING FINAL TAPING SESSION

Dear Sarah,

Gather your hours into a glass and drink: you will enjoy your past a second time.

Gather your days into a book and read it: you will discover chapters of meaning and insight.

Gather your years into an album and browse: you will discover that you are an episode in a dynasty of life that holds and blesses you. (Leonard Mason)

I came across this over the weekend. As I read it, it reminded me of your story, and the great pleasure I had in sharing it with you. I had many smiles as I transcribed it all, and sometimes tears. You are a powerful storyteller, with such an interesting story to tell. I hope the transcript is ok, and the process has been enjoyable for you too, and given you some clarity and understanding of the colours of the tapestry of your life.

Sandra Foster.

4. TWO E-MAILS FROM SARAH’S BROTHER IN ISRAEL

[ANNONYMISED]

Dear Sandra

Thank you very much for your letter, I am very sorry you had to go to so much trouble finding my correct address. I would certainly appreciate if you will send me a copy of the revised interview. Please try to send via email as an attached word document ... the address you have used is the correct one in Israel.

I don’t understand why you have to use another name - I would use Sarah’s and the hospital’s name if it is permitted. Thank you again, and please let me know if you want me to add or amend anything.
As confirmation of Sarah’s brother’s on-going consent for me to include her narrative as part of my thesis after transferring into The University of Melbourne’s PhD programme I e-mailed him. He replied immediately:

Dear Sandra

Thank you for your letter – frankly speaking I was surprised – in recent years I have very little communications with AU and every time I see an email that ends with .au it moves me and brings memories. I have no objection that you will use Sarah’s story as she told you. It is definitely her story as she understood it and I know for a fact that she gave you her consent. As for me I will respect any of Sarah’s wishes including this one – just tell me what to do. Do I need to sign this form with a witness?

I would like to add that if any of this is did good to Sarah you have my blessing and full support. All the best.
1. SOME OF SCOTT’S LITTLE STORIES:

*Story One:*

[in Germany] ‘One evening as we arrived at the youth hostel, three boys were sitting on the gate and singing with perfect harmony. That was an experience quite different to any I’d had elsewhere.’

*Story Two:*

[in Moscow, at a mathematics conference.] ‘There was notice of a day trip to Leningrad, to be done by plane. The people who wanted to go were got out at 8 o'clock in the morning and sat in the airport for hours and hours, and watched a repair gang take a wheel off the aircraft that was going to be used. And eventually, I suppose it might have been between 11 and 12 midday, the flight began. I can’t remember what was remarkable about it, but having started off somewhere near midday, we arrived in Leningrad at...oh...3.30, something like that, and we were taken to a ... oh what’s the name of it ... The Ermitage ... a great museum or art gallery in Leningrad. By that time Leningrad had changed it's name, it’s now back to St Petersburg, and as I said we were taken to The Ermitage, and refused admission, at 4 o’clock in the afternoon. They weren’t going to admit anyone.

We didn’t get in. The woman at the front door was very imperious, and said ‘Nyet!’ which I think is Russian for ‘no,’ and waved her hands and so on, so we didn’t get anywhere there, which I believed was a great pity, it’s said to be an important art gallery. It was rather a frustrating trip, especially as having started off at 8 o’clock in the morning, and arrived back at 10 o’clock in the evening.’
Story Three:

I had to return to England for things to do with Cambridge, and so we got married and went to England by ship, and then ... well that journey divides itself into parts, and the first part was to India, to Bombay and Calcutta, at both of which we had some friends, people who had been in Australia. And then going on from Calcutta to Delhi, and from Delhi we flew across Pakistan, but not going down into it, and I'm uncertain where that flight ended, but it was probably in Beirut, in the Middle East.

One interesting trip that we had from Beirut was to the ... City of ... um ... Pink Stone or Pink Rock, I can't quite remember that exactly. And they have a So-called-city, it was a shambles out in the desert. We got a taxi to drive us there 150 miles or so I suppose, and perhaps three or four hours on the way, three or four hours there in this So-called-city ... Now it's So-called because hardly any one lives there. It evidently was a pearl at one time. We'd read about it, and that's why we made our way there.

Sandra: And did you stay there, or just went for a day trip?

Just for a day trip. I doubt if there was anywhere to stay there or near there. I doubt it ... it was reached through a narrow passage between cliffs, high cliffs, and there were men with horses at the beginning of the passage, and that didn’t worry my wife, she knew enough about horses, and she rode a horse while I walked there. So we had a good look around there.

Sandra: It was peaceful, ... you weren’t worried?

Oh yes, yes, completely peaceful. Beirut nowadays is not a place you might want to go to, because of the tension in the Middle East. But it was perfectly peaceful then. We walked along the treed main street, and found, to find a well ... travel agency which would take us to Petra, and that was about all that we saw of Beirut, but it was interesting.
There were, here and there in the Middle East, there were camps occupied by refugees, we were told, but refugees from what, I don’t know, possibly religious persecution or something there might have been like that.

**Story Four:**

Sandra: Did you ever go to Norway?

Yes we did. We were there in 1938. And that trip was part of our honeymoon. And we walked around in the hills, and also met various people in the course of these travels. And it was very nice to have such friendships.

Sandra: So did you go out onto the waterways?

Well yes, in the neighborhood of Flom. Sometimes the weather was very overcast, but then we saw the same thing in better weather some time later. Yes, well their ferries take you across the fiords and so on. One trip we had to transfer from one ferry to another, they came to stop in the middle of the fiord and linked up together and people ... like changing trains.

Sandra: So how far north would you have gone in Norway?

Oh, Trondheim, but I think further than that. Yes, we went to Narvik, where there had been a great navel battle in the war. There were cemeteries all around there.

Sandra: And did you enter into that different kind of culture of trolls and Norwegian myths.

Well we were aware of it. But didn’t go far into it. In some areas in the hills mentions were made of what the ... trolls had done, and where their lairs and their tracks were.
Sandra: It’s a very beautiful country?

Yes, yes, with the valleys and fiords and, yes it is a very pleasant land. Picturesque.

Sandra: Did you see the other Scandinavian countries, Denmark and Sweden.

We were in Copenhagen at one stage. Sweden we were in for a long time traveling from Stockholm to Narvik. Narvik is in Norway but the railway that runs northward from Stockholm through Sweden is evidently the simplest way to reach Narvik. We returned from Narvik to Oslo but that was a journey made up of bus trips and so we got out every now and then and met some of the people who were on the bus. Yes it was an interesting trip, that is - going southwards from Narvik was primarily in Norway itself.

Sandra: I found the people in Denmark very friendly. The people in Sweden and Norway were comfortable with English speaking people?

Well yes. They were. Different groups of them anyhow, we got talking with, like many European people they wanted to try out their English on us and learn more from us. In - ... I can’t get the name of the place yet, it rained heavily and we went into a McDonalds or one of those, and had a cuppa. There were two schoolgirls who came to us there in the cafe and asked could they talk with us in English and this was a sort of vacation exercise. I don’t know that they would have found many more English speakers. But anyhow this was quite an experience, and they enjoyed it very much and so did we.
2. THE APPLICATION OF THE LITERATURE SEARCH TO SCOTT’S NARRATIVE [FULL TEXT]

The literature following my work with Scott illuminated many of the issues that were uncovered by my journalling and mapping as I worked. I identified two key themes in Scott’s narrative, each containing a number of minor or sub-themes. These themes and sub-themes became the framework for my literature search that helped me to make sense of Scott’s narrative.

This particular literature search demonstrates that the bias and intrasubjective leading of the researcher means that the literature searches are quite idiosyncratic. If the literature search following Scott’s narrative had been comprehensive I would have explored the mathematical concepts that Scott and I discussed. But because they are outside my ability to comprehend, I did not search the literature around this subject. This could be seen as a significant omission given mathematics’ central position in Scott’s story, for example Scott saying ‘One of the most central parts of mathematics is the Binomial Theorem’. Or perhaps it was simply my intersubjective decision that our connection would be enhanced if I did not spend too much time floundering in my lack of mathematical intelligence, and focused more specifically on Scott’s search for universal truth.

Each theme or sub-theme contains the relevant literature references side-by-side with an outline of my personal reflections on how these particular readings have contributed to my understanding of Scott’s life narrative. The ‘literature’ column is in black print and my reflections are in blue.

1. Theme: Scott’s identity as a mathematician
   - Truth
   - Being a professor
   - Feelings
   - Separate worlds

2. Theme: Old age
   - The poetry of growing old
   - Inter / Intrasubjectivity
• Giving Care
• The dance of old age
• The process
• Asking the right questions
• Oral hygiene enabling good communication, comfort and nutrition
• Time
• The family
• Meaning
• Isolation? Depression?
• Listening in the silences

Table 3. Literature search for Scott’s narrative

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<tr>
<th>1. Theme: Scott’s identity as a mathematician</th>
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<tr>
<td><strong>Introduction</strong></td>
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<td>Our understanding of who we are, or our self identity is, according to Holstein and Gubrium (2000, p.114) narratively constructed. Anderson (1997, p.218) tells us that selves can be determined, brought into awareness, and described by others as well as ourselves. The self becomes the encompassing entity that somehow underlies, supports, and is the basis of all that we engage in, such as emotions, feelings, thinking, and acting. Helen Luke, Jungian scholar and counsellor, wrote much about one’s understanding of oneself. In ‘Old Age: a journey into simplicity’ (1987, p.49) Luke writes from the experience of her own ageing, that the first breakthrough to our realisation of the meaning of our life, is the conscious discovery of the work we love to do. Bourdieu (1999, p.600) discusses one of his interviewees, 80 year old Louise who had been a social worker, and how in her stories</td>
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<td><strong>My reflections</strong></td>
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<td>Scott’s obituary describes him as a person of integrity, a fine teacher, an important influence, a ‘mathematical physicist’. This is how Scott sees himself, and wants to be seen by others. Affirming Luke’s understanding, Scott describes his love of mathematics, his success as a schoolboy, and his dislike of other subjects in contrast. Scott stated firmly, right at the end of his life, ‘I have to call myself a mathematician’, and this sets his identity in this role primarily, for the remainder of his life, long past his retirement from the university. Scott’s narrative identity, therefore, continues to be that of a mathematician. I reflect on the multifaceted selves of Ceglowski (2000) and Spinelli (1989) described more fully in Chapter One, 1.2 and 2.2. We are a series of selves, we become what the situation demands. Here Scott sees himself entire and single-faceted as a mathematician, not father, no longer</td>
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she always portrayed herself in her role as social worker. Bourdieu’s interpretation is that by repeatedly coming back to this role, Louise seeks to reaffirm a professional and social identity that everyone has forgotten: at the hospital, where she feels like a cumbersome package, in her building where she lives, and even in her own family for whom she no longer exists except as a ‘problem.’ Louise’s suffering is all the greater because as a social worker, like all such professionals, she has concerned herself with other people’s problems all her working life.

husband, though clearly moved and engaged in the memories of his beloved wife.

**a) Truth**

Human beings are perpetually engaged in the search for a sustaining, sustainable truth. Frank (1997, p.142) describes a ‘perpetually questing truth-in-flux’, rather than an eternal, fixed-for-ever truth. This is like Lett’s (2001, pp.135-136) *temporary approximation to meaning*. Skolimowski (1994) cites Popper, who invented the notion of approximation to truth (p.306). It changes and evolves as we move through our lives. Anderson (1997, p.37) believes that doing away with the idea of ‘truth’ as such, does not mean that the alternative is that ‘nothing exists’, whilst Skolimowski (1994, p.298) suggests that truth is an intersubjective entity. Skolimowski says that truth was described by Plato as a living dialogue, that is, words made true in the light of the whole situation, of the whole context within which they are embedded in a given time.

Skolimowski (1994, p.320) also discusses *participatory truth*. When it is envisaged as part of the realisation of human meaning within the cultural context, he calls it *cultural truth*. Participatory truth that is created when we construct new logical and mathematical theorems and proofs is called *formal* truth, and appears to be remote from everyday reality. *Practical truth*, refers to

**My reflections**

Scott’s search for mathematical or universal truth was his lifelong passion. Reality and truth are further discussed in Chapter One, 1, and Chapter Two, 3. Scott and I had a number of discussions about truth. Despite his weakness and approaching death, I think he still struggled to think about mathematics, or perhaps worried that his engagement with mathematics no longer seemed possible.

Skolimowski’s (1994, p.320) *formal* truth appearing to be remote from everyday reality, perhaps explains that it was this remoteness, and its bottom-line, non-negotiable universality, which attracted Scott’s mind and work. It lured and enticed him away from his everyday reality, over many years. He believed that more study would reveal more truth, and that it would be a universal, healing and uniting truth that could be global in its application and understanding.

Perhaps it was his family who supported this remoteness, and believed in his mission, enabling his mind to soar in search of this perfect, formal truth. Scott and I discussed his feeling that he had worked to gather a view of life as a whole. He said ‘The mathematical world is a life time’s
such outcomes as for example, when we spray crops, uncovering long term harm to human beings and the environment.

The ancient Greek philosopher and mathematician Pythagoras is said to have made significant contributions to our knowledge of mathematics, astronomy, and music. Pythagoras sought to shed light on the essential questions of our existence: What is the purpose of our being? What can we know? And what constitutes the good? It is asserted that through numbers, Pythagoras sought to discover that which is universally true. He found truth in mathematics, geometry, and science (<www.goodwriters.net/apiervichpythagoras.html> last accessed 2005).

Philosopher John Caputo (2000, p.2), describes Radical Hermeneutics, and studies the deconstruction theories of Derrida in particular. Caputo cites Husserl’s view that we are not tuned into something calling to us like a mystic voice from a better world, ‘here is the truth’. Later (p.30) he cites Foucault as defending the impossibility of reducing us to truth. Caputo suggests that Foucault abandoned the truth of truth, in favour of the ‘cold truth’ of the truth that there is no truth of truth (p.35).

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<td><strong>b) Being a professor, or living a professional life</strong></td>
<td><strong>My reflections</strong></td>
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<td>The Macquarie Dictionary defines a professor as a teacher of the highest order. It involves not only teaching, but professional service to the university, research, and perhaps an international reputation. Ingmar Bergman’s classic film <em>Wild Strawberries</em>, (1957) is cited by Coleman (1986, p.45) in the context of examining reminiscence therapy for elderly people. The film describes the ageing of a bad tempered Swedish professor. I acquired this film as a DVD. The cantankerous</td>
<td>At my first visit to Scott in his elegant hostel, I wanted to establish with him that I accepted that this was his space I was entering. I began by asking what I should call him. I knew he was generally known as ‘Professor.’ I told him that on arrival at the hostel I had asked for Scott, as he was called there. He smiled and replied ‘I usually warn people that this is how I am addressed here, it is convenient’, but I could decide what I called him. However he brightened and was clearly pleased to be in control of this detail.</td>
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Professor Isak Borg, at the end of his life is able to find peace, and is reconciled with his family from whom he had been alienated. Up to that point he was suffering from guilt and depression as part of his reminiscing. He experiences a number of stark, troubling dreams, presented in the film as separate dream sequences.

Psychiatrist Robert Butler (1963, p.69) suggests that not every life review has the successful outcome of the professor in *Wild Strawberries*. In the film, Borg, ‘realises the non-affectionate and withholding qualities of his life. As the feeling of love re-enters his life, the doctor changes even as death hovers upon him.’ Coleman warns that some people will continue to feel guilt and depression, and may refuse the process of telling their story altogether, if it seems too difficult for them.

Professor Peter Underwood, from Murdoch University Western Australia, read a poem he had written about his father, also a professor, on Radio National’s Science Show (19/4/2003). Professor Underwood remembers as a little boy, asking his father what a professor did. His father replied, ‘Son, a Professor professes.’ Later the poem says:

As I grew up
often he repeated
(as if it was his creed)
*a professor professes,*
sometimes even adding
(surprised, a little sad, a little angry)
that from time-to-time however
he had struck a fellow-tribesman
who was non-professing.

There are dissimilarities between Scott and Ingmar Bergman’s Professor Borg (1957). Scott said he had no regrets, he had quite a positive feeling about his life as he described it, and he was not alienated from his family. I reflected on the process of life-review outcomes for Scott in the light of Coleman’s warning. I cannot be sure how helpful the process was for Scott, although he sincerely thanked me for my work, and clearly enjoyed much of our conversation and his reminiscing and ‘armchair travelling’. I think perhaps the greatest benefit came from making this final tangible story available for his family, rather than it bringing him peace. I think Scott was perfectly able to move into a realm where he was peaceful and comfortable, with or without our work. Perhaps he struggled to tell his story as a gift for his family.

Professor Peter Underwood’s poem resonated for me, and for Scott’s daughter when I shared it with her. Scott’s surprise was that his sons did not follow in his mathematical footsteps, and sometimes in his university life he didn’t understand points of view that some people had. I asked ‘So their philosophy didn’t match yours?’ and he replied ‘That was the case occasionally’. I continued ‘Is it possible to define what that philosophy was, where you met people who had a similar outlook to yours?’ And his response was ‘In some ways a pacifist outlook’ (Tape 7, transcript pp.9-10).

c) Feelings

Psychotherapists Greenberg and Saffran (1987, p.7) writing about emotion-focussed therapy, argue that emotion is an ally in the change process. They define feeling as the union of emotion and cognition, as they are

My reflections

Scott explains that in the end he thought it might have been better if he had sometimes expressed his feelings, but that this is still something that he finds difficult. Greenberg and Saffran (1987, p.7) argue that emotion
experienced inseparably in the moment, and that emotion, cognition and behaviour are interdependent and inseparable (p.45). In Gendlin’s (1982) view, there is a bodily felt dimension of meaning. Gendlin believes that authentic possibilities for change can be formed only from this felt sense of how one is living in one’s situations. Greenberg and Saffran (p.177) suggest that

‘sadness can be a deeply experienced sense of loss or pain, or it can be a secondary reaction to feelings of unexpressed or unrecognised anger or possibly fear.’

(and I add that this includes its expression) is an ally in the change process. My conversation with Scott proceeds:

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<tbody>
<tr>
<td>S: Did you ever loose your temper?</td>
<td>Scott: No doubt! [smiling]</td>
</tr>
<tr>
<td>S: No doubt?</td>
<td>Scott: Maybe.</td>
</tr>
<tr>
<td>S: So did you say you were angry at times or just go very quiet?</td>
<td>Scott: I went very quietly.</td>
</tr>
<tr>
<td>S: So how did you deal with anger?</td>
<td>Scott: Generally I realised that it often does not succeed in anything useful.</td>
</tr>
<tr>
<td>S: Did you express overt anger with your children? Do you remember?</td>
<td>Scott: Yes.</td>
</tr>
<tr>
<td>Scott: Yes.</td>
<td>S: I wonder if they remember? [laughs]</td>
</tr>
<tr>
<td>S: How does that feel now?</td>
<td>Scott: I expect they do. [wry smile]</td>
</tr>
<tr>
<td>Scott: I went very quietly.</td>
<td>S: So were you good at expressing feelings? Scott: No. [hands tightly clasped]</td>
</tr>
<tr>
<td>S: And is that still hard to do?</td>
<td>Scott: Yes I think so. [looking sad, long pause]</td>
</tr>
</tbody>
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Scott’s body language as he talked about this difficulty in expressing his feelings, seemed tightly held in, yet perhaps sadly known.
**d) Separate worlds**

Academic life is described as having the potential to separate the academic from his ordinary self, making him remote from the other people who are part of his life outside the university. Arthur Bochner, Professor in Communication Studies, (1997) poignantly describes his own father’s death. He was attending a university conference at the time he was told of his father's death, and he writes that he had normally split his academic self from his personal self. Here at this conference, with the news he had just received, the two worlds within him collided, and he says ‘I was stunned to learn how tame the academic world is in comparison to the wilderness of lived experience.’ Bochner goes on to see the academic man within, standing face-to-face with the ordinary man, and that the sad truth was that the academic self was frequently cut off from the ordinary, experiential self. Bochner, through the experience of his father’s death, came to see that his academic world was not in touch with his everyday world of experience.

Bruner, J. (1986 pp.13-15) describes a paradigmatic mode of relating experiences, as contrasted with a narrative mode. Bruner says that the paradigmatic mode:

> ‘seeks to transcend the particular by higher and higher reaching for abstraction, and in the end disclaims in principle any explanatory value at all where particular is concerned.’

Bruner explains that the narrative mode leads to good stories, gripping dramas, and believable, though not necessarily ‘true’ historical accounts. Bruner states: ‘The same claim can be made for science and mathematics: they reveal most plainly and purely the deep structure of paradigmatic thought’.

**My reflections**

Scott hinted that he was aware that he had often retreated into his academic world of mathematics, and that this perhaps left him unavailable for the ordinary world of his family life. He said when there was tension between these worlds he simply got on with both, and ‘it was not difficult’.

The essence of Scott’s life, as it descriptively distilled through my process of reduction, seemed to suggest that his family held and cared for him throughout his career, enabling his professorship, his travels, and allowing him to soar higher and higher to seek his mathematical ‘universal truth.’ It seemed to me to be rather like a person on the ground, anchoring a kite by holding the string firmly so the kite could soar as high as possible without actually blowing away. As Scott told it, it seemed to be his wife who held the string, so ‘it was not difficult’ for Scott to move from his world of mathematics to his world of travel. But I sensed a sad remoteness from Scott’s children, particularly his sons, which perhaps made their lives difficult at times. It was in the light of this understanding that I drew an intersubjective response of Scott’s three separate worlds that helped me to see more clearly the nature of this gentle man’s life.
2. Theme: Old age

a) The poetry of growing old

Richardson (2002) comments that poetic representation is a useful device for capturing the essence of a situation. In the light of Scott’s and my connection through poetry, this theme in the literature review begins with two moving poems focused on ageing, the first written by the poet Judith Wright (1994). I love the poem’s entirety but quote only the first and last verses and one line from the fourth verse.

Prayer

Let love not fall from me though I must grow old.
To see the words fade on the fading page,
to feel the skin numbing in fold on fold,
the mind and the heart forgetting their holy rage –

... I pledge to the night and day my life’s whole truth.

And you, who speak in me when I speak well,
withdraw not your grace,
leave me not dry and cold.
I have praised you in the pain of love,
I would praise you still
in the slowing of the blood,
the time when I grow old.

Another moving poem titled Growing Old (Matthew Arnold 1822-1888, 1966 edition), partly states:

It is to suffer this,
And feel but half, and feebly, what we feel.
Deep in our hidden heart
Festers the dull remembrance of a change,

My reflections

Judith Wright’s poem, (1994) seems to encapsulate the essence of Scott as he sat in his elegant, quiet hostel room and shared his story with me. There seems little to add to the poem’s poignant beauty, and its reflection for me of Scott in his chair, just a few months from the end of his life. I ponder Scott’s life’s whole truth and consider my own. Is there something that can be articulated and known as a life’s-whole-truth? Or are the meanings fleeting, just temporary approximations to meaning: at the time, not whole-of-life-meanings, fixed or settled? Arnold’s moving poem also reflects for me, the old, frail, dying, but gentle, and always quietly dignified Scott, who told me the stories he could still remember, and agonised over how much he had forgotten. I wrote for myself, after one session where I deeply felt the sadness and impact of old age:

‘Old age’

He is eighty nine years old next week
his body is slowly dying
his memory is failing
his ability to communicate is almost finished
I feel he is sad,
but it seems he feels it is too late,
or too difficult to say so.

And while The Manor is upmarket
it is not where he wants to be.
There’s not much joy in the end of his life
even if I see care, and hear rich stories of what has been experienced.

I don’t think I like this picture of old age and seeing myself being like that.
But no emotion - none.  
Both poems capture the essence of the pain, sadness, regret and yet wisdom possible in the slowing of age.

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<th><strong>b) Inter/Intrasubjectivity</strong></th>
<th><strong>My reflections</strong></th>
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<tr>
<td>One of my lecturers at MIECAT, psychologist Jenny Hill (1997, p.1) defined intersubjectivity as</td>
<td>For me intrasubjectively, a theme of old age and how mine might be for me, was starting to gain my attention and gather significant central meaning. Yalom, (1999) and Zable (2001) enhanced the essences and approximations to meaning growing for me in Scott’s story, and the formation of responses I would later offer to Scott and his family.</td>
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<td>a deeply empathic-intuitive sharing of the feeling of a personal response, which acts as a mirror to the other. Through this mirroring and witnessing of the other’s material the other is challenged to own their own knowing. The goal being to clarify meanings of experience through dialogue.</td>
<td>So there was a blending of Scott’s storied experience of old age and dying; my prior experiences, such as my parents’ deaths at ages 83 and 86, supposed to be bracketed and set aside, but never possible completely in reality; the writings of Yalom, Zable, and Luke; and my fears about how my old age might be for me. I thought about Scott and his situation at The Manor, an upmarket place by most standards, and yet I felt a quiet, carpeted solitude when, once past the clatter of the dining room and kitchen, I entered the passage to Scott’s room. All other residents’ doors seemed to be shut. Was this a privacy and dignity he wanted, or isolation? He spoke of ‘home’ in L. Avenue. However I believe he made the decision himself to stay at The Manor and was not pressured by the family.</td>
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<tr>
<td>In other words we experience the world as an intersubjective world, a world of shared meaning (Crossley 1996, p.4).</td>
<td>Scott told me a number of beautiful stories where he was peacefully transported back into a place where he seemed to see, feel and almost touch the past experiences he was describing. They were like Zable’s (2001) beautiful story about the character Laizer.</td>
</tr>
<tr>
<td>Psychotherapist Irvin Yalom (1999) and Melbourne Jewish author Arnold Zable (2001) were important to me in my literature searching around some of the issues raised for me by Scott’s narrative. Yalom’s (1999, p.20) mentor/patient Paula, talks of the absolute isolation she feels when she knows that she is dying. Zable (2001, p.76-77) tells a beautiful little story about how the character Laizer has a luminous moment, where in the forest of Siberia, on a work party in the freezing winter snow, he has a hallucinatory vision of a village suspended from the sky, floating in the early light of a crimson dawn. As he tells the story, years later, he is again transported back into that vision of beauty.</td>
<td>I was inspired by Helen Luke’s writings, especially about ageing, and encouraged to see its possibilities and hopes. Scott</td>
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<tr>
<td>The writings of Helen Luke, Jungian counsellor, especially her book of essays centred in her own ageing, called ‘Old Age: a journey into simplicity’ (1987) shares her</td>
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grace and courage, and describes creative ways of growing old gracefully. Luke died in 1995 at the age of 93 (Bedford 1995, www last accessed 02/06). Luke spent much of her life probing the hidden meanings of religion, mythology, folklore, and literature. In her book Old Age, she draws on the writing of Homer, Dante, Shakespeare and T.S. Elliot. Luke utilizes her appreciation of storytelling as the way to talk about deep truths. ‘If you want to die a true death it will come out of a true life lived with a final vision of what is divine and material. You can’t speak about it except in story.’ In writing about Odysseus in his final preparation and rites, Luke suggests that Odysseus affirmed the wholeness of his life’s journey, and his readiness to die (p.23).

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<td>reflected much of Luke’s courage and positive gratitude for the good life that he had lived. This furthered my own view of the possibilities for a good old age. Scott certainly seemed to enjoy drifting into the dreams of former lovely times with his beloved, on his travels, enfolded within the poetry he loved. I will read these authors again and again as I age, and hope they will give me the courage that I need to grow old gracefully.</td>
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<th>c) Giving care</th>
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<td>The simplest dictionary definition of care seems to be that of being concerned, solicitous, looking after, making provision for. In the context of nursing, Arndt (1992) describes caring as everydayness, and Frank (2004a, 2004b, p.110-111) describes relations of care, and in Palliative Care at its best, engaging in polyphonic caring, that is hearing the contribution of many caring voices. van Manen (2002, <a href="http://www">www</a>. last accessed 2005) suggests that the other, is given to us as ‘an ethical event’, in our immediate recognition of their vulnerability and weakness. The ethical experience of the other body’s call is always in the concrete, in the situation in which this vulnerable other bursts upon our world. Intersubjectivity in this sense is not something that one creates or gives shape through some kind of decision to be personally responsive in one’s own body awareness. One simply cannot help but feel that the other person has made a claim on one’s responsibility. And then the question reflected much of Luke’s courage and positive gratitude for the good life that he had lived. This furthered my own view of the possibilities for a good old age. Scott certainly seemed to enjoy drifting into the dreams of former lovely times with his beloved, on his travels, enfolded within the poetry he loved. I will read these authors again and again as I age, and hope they will give me the courage that I need to grow old gracefully.</td>
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<td>There were two occasions when I felt a need to care for Scott in a ‘nursing care’, physical sense. Once, when he was clearly feeling cold, I offered to cover him with a spare blanket, and as I tucked it around him I wondered if I was invading his space. He expressed his gratitude for my care. On one occasion when Scott seemed frail and distant, I actually thought that as he drifted off to sleep he might not come back. I looked around to see where the call bell was. I asked myself how I would respond if Scott died while I was sitting there. Would I just sit for a while and allow him to peacefully drift away without intervention, or would I alert the staff, who I am sure would have a protocol to ‘call a code,’ or at least an ambulance. van Manen suggests to me that Scott, as the other, was given to me at this point, as an ethical event in my immediate recognition of his vulnerability and weakness. As van Manen explains it, Scott made a claim on my responsibility, so that the question was reflective.</td>
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becomes: what is one going to do about this call? This is where ethical reflection may enter. Moustakas (1996) discusses ‘being-with’ and Skolimowski, (1994, p.162) writes that one of the crucial requirements of participatory research is empathy, which he describes as dwelling; belonging; sharing; giving and taking. So as Skolimowski sees it, (p.182) the dance of participation involves compassionate consciousness, without which it cannot succeed.

‘what should I do about this call?’

The first situation was easily resolved, I cared for him by offering him the warmth of the blanket, prepared to accept the risk of invading his space. The second situation was more complex, though in the end did not require resolution, as after a period of sleep, Scott woke by himself and we went on as if nothing had happened. It was then that my ethical reflection could be shaped. My dilemma was: should I have behaved as I would have had Scott been my father, that is, with a gentle, dignified, peaceful non-intervention? Or did I have a nursing duty to alert the staff and provoke ‘a code,’ given that my brief was simply to be there to record Scott’s life review?

I’m glad that I did not have to decide, but I think I would have sat there for quite some time without taking any action other than accompanying him calmly and quietly with my caring presence, choosing Moustakas’s (1996) ‘being-with’. My prior palliative care experience had prepared me to do this without fear of Scott’s death. I can still picture myself in Scott’s room at the times I have described above, and my feeling was one of taking care of him in the moment. Was it as a nurse or researcher, or simply as a companioning human being, a connected

My reflections

Chodorow’s work was helpful in my understanding of Scott’s place of residence in The Manor. To reflect on this dance theme, at one point in my journalling after leaving Scott I wrote:

d) The dance of old age

Joan Chodorow, a Jungian Analyst, (1991) uses a dance theme, where she encourages us to observe the body language and movements of the people we are trying to communicate with, to enable us to experience more fully the expression of the

My reflections

Chodorow’s work was helpful in my understanding of Scott’s place of residence in The Manor. To reflect on this dance theme, at one point in my journalling after leaving Scott I wrote:
feelings of the person we are engaging with. This means seeing the whole being, not just what is said, but the stance, posture, actions and other expressive behaviours.

I witnessed the tide of residents arriving in the dining room as I walked through to the front door, to leave The Manor. All were frail, mostly with walking frames, some in wheelchairs, the embodiment of old. It was like a bizarre kind of ballet, where the performers all shuffled along, frail and attached to upmarket walking frames and chairs.

Their bodies are well cared for here the surroundings are expensive, elegant but what about their minds, their souls? Who listens to them? hears their stories? connects the space between them? helps them find knowing and peace?

e) The process (and its difficulties)

This theme addresses the processes and difficulties of recording life stories with the frail aged. I searched the literature for writers who might illuminate the process of reminiscence and life review in older frail people, whose ability to remember and fluently relate these memories, might now be difficult for them.

Norrick (2000, p.2) describes the interrelated roles of verbalisation (that is, telling the story) and remembering, as ‘purposeful contextualization of something remembered’. Norrick says that far from simply recapitulating past experiences, storytellers seem to relive, re-evaluate and reconstruct remembered experiences. Adams (1994, p.89) recounts witnessing a struggle between two opposing facets within the character of a person he was working with: the need to share her stories wrestling with her strong natural reserve.

My reflections

Scott’s long pauses, time out for naps, and slow responses, made recording the interviews quite a difficult process. There were many occasions where I waited patiently (mostly) for Scott to seemingly relive the experience in his memory, and then dreamily reconstruct it in the telling. As I re-listened to the tapes prior to commencing to process them, I understood that the hardest thing required of me, was to slow myself down to the pace of this tired, frail, quiet, dying man, in order to hear and be present to his mind. He was a private, introverted person. However he willingly offered and seemed to enjoy sharing his stories despite his worry that he had forgotten so much. I think Scott did enjoy telling me his stories, but he also wrestled with his strong natural reserve.
<table>
<thead>
<tr>
<th>f) Asking the right questions</th>
<th>My reflections</th>
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<tr>
<td>The differentiation between therapeutic autobiographical work and therapy is discussed elsewhere, however, it is relevant here that Anderson (1997, p.146) argues that the therapist’s task is to ask the right question and find the right tool to move the conversation to where more might be uncovered about the person’s experiences. So by listening carefully, the next question emerges from within the dialogue.</td>
<td>When Scott recited The Rubiayat, we went on to talk about poetry and my knowledge of The Rubaiyat that Scott loved. I had to learn especially with Scott to ask open-ended questions, or he would give me simple one-word answers that did not move us anywhere in particular. I then had to extend the question to ‘unstick’ the conversation. I got better at it as we progressed:</td>
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<td></td>
<td>S: did you have a car?</td>
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<td></td>
<td>Scott: no.</td>
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<td>S: so you travelled on the trains or by bus?</td>
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<td></td>
<td>Scott: Ah, well, largely we walked, but of course, that is limiting,</td>
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<tr>
<th>g) Oral hygiene enabling communication, comfort and nutrition</th>
<th>My reflections</th>
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<td>Killick and Allan (2001, p.130) emphasise the need to question patients as to why they are not eating. If this questioning is neglected, it may not ever be discovered that the person’s dentures are a problem, and that attempting to chew causes pain and discomfort. Mouth ulcers and fungal infections also need attention, and plenty of fluids to avoid a dry mouth, which would cause problems with talking. Butler (1963, p.72) suggests that the personal sense of meaning from within the person’s life, is more clearly available for those who have nearly completed their lives. A sore, dry mouth will restrict the flow of the narrative, and add to the misery of the sense of loss of function. The person may present as being depressed, when it is simply painful for them to talk.</td>
<td>Not long before I met Scott he had begun to lose weight, ate very little, and had several falling incidents. He was readmitted to hospital but no specific problems were found. Finally a staff member asked him why he was no longer eating, and he explained that his dentures were fitting so badly that eating hurt his mouth. He was then provided with vitamised food, and his denture was repaired. I was struck by how Killick and Allan’s (2001, p.130) discussion of the need for excellent oral hygiene so clearly reflected in Scott’s situation.</td>
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### h) Time: Life review facing death

Butler (1963, p.74) argues that life review should occur for the aged, regardless of their situation. Butler believes that the aged, in particular, need a participant observer, professional or otherwise, to record their life review. Butler argues that ‘a constructive re-evaluation of the past may facilitate a serene and dignified acceptance of death’. Butler suggests that a person’s life-review, being Janus like, involves facing death as well as looking back.

**My reflections**

When it came to a discussion about feelings, Scott said that despite his lifelong difficulty in expressing his feelings, it may well have been better if he had done so. I think there were several other insights that he may have gained, despite the lateness of our work together.

Scott said that he was satisfied with his life, it had been a good life. He had initiated one conversation about his death, not long before he and I began to work together. He began a conversation with his family saying ‘when I die ...’ as he felt his breathlessness indicated this was imminent. Regarding Butler’s suggestion that a person’s life-review, being Janus like, involves facing death as well as looking back, it was never clear that Scott still had the capacity to see his life in such a time-structured way. Perhaps he mostly did not wish to talk about it (Butler 1963, p.74).

### i) The family, the setting and the value of life review

Reminiscence therapist John Adams (1994, pp.84-95) talks about life review in a hospital setting. Adams writes that the written text simply cannot convey the intensity of the experiences of making the recording. The reminiscences are especially useful in that they can be passed on to the following generations, including some of the enduring values and wisdoms the person has gathered.

Teacher of writing, Bernard Selling (1990) in teaching people to write their life stories, states that the process of telling one’s story for the next generation, describing events and actions accurately, was mostly warmly accepted by his students’ families. Their narrative would be a valuable asset to the family in the years to come.

**My reflections**

Scott’s hostel was not a hospital, nor was it like his familiar, well-worn, comfortable home. I agree with Adams that the written text simply cannot convey the intensity of the experiences of making the recording with Scott, especially the day I had a car accident in the gateway to his hostel, and the day I forgot to turn the tape recorder on. I think that my journalling, and attempts to record as part of the transcript the pauses, glitches and difficulties of the process with Scott, perhaps simply reminds me of some of this colour and intensity. I know that Scott’s family values the narrative that he and I created together, and I believe it is something that his grandchildren will read and value over the years (Adams 1994, pp.84-95).

Scott’s family’s experience of my work
DeSalvo (1999) uses the term *story-truth*, which sits comfortably with any problem of memory loss and loss of accuracy.

Chodorow (1991, p.123) talks about the complexity and confusion of family emotions that are involved in the months of a loved family member’s decline towards death.

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| Chodorow (1991, p.123) talks about the complexity and confusion of family emotions that are involved in the months of a loved family member’s decline towards death. |

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| was important, since it was due to their referral that I recorded Scott’s story. They were closely engaged in Scott’s care and well being, and expressed satisfaction with the transcription. Some material was known already. Some was the expression of feelings that seemed to be surprising and new. |
| Off tape Scott and I had a conversation about truth, whose truth it was, and story telling. *Story-truth* sits comfortably with Scott’s memory loss. Scott clearly had some degree of confusion and expressed his frustration with this loss: ‘I can’t remember. Oh, I can’t remember!’ Scott’s daughter had journaled other conversations with her father from 1993 until the present, and these were transcribed and included with the family’s final document, allowing readers to find their own version of exactly how and when it happened. Chodorow (1991, p.123) accurately describes the complexity of family emotions that were involved in the months of Scott’s steady progression towards his death. This complexity involved each of Scott’s children seeing his deterioration from within their personal perspective of who he was for each of them. There were issues for them as to where he would die, in the end he moved from The Manor to a nursing home nearer his daughter in the country. |

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| j) Meaning: the value of constructing the story |
| My reflections |

I listened to Arnold Zable (2001) discussing his book *Café Scheherazade* on ABC Radio National’s *Books and Writing* (16/3/01). Zable describes what he believes makes a good story. Over many years he had developed a relationship with the characters who met at Café Scheherazade, in Acland Street St Kilda, Melbourne, and he listened to them deeply. He offered them drafts of his stories to read, and they said ‘No, no, there is something missing’ |

My eight meetings with Scott uncovered some new meaning, but in this limited experience I did not feel a deepening of Scott’s understanding, and it left me feeling something was missing. But perhaps I was assuming that this understanding was necessary or possible for Scott, or for that matter for everyone. |

Unlike Zable, it was not possible for me to return again and again to Scott to clarify and deepen the story. Reason’s (1998,
and they went on together to uncover deeper layers of meaning. It is this depth of meaning that Zable has captured in his book. Reason, (Reason and Hawkins 1988, p.83) suggests that the best stories are those which stir people’s minds, hearts and souls and by doing so give them new insight into themselves, their problems and their human condition.

### k) Isolation? Depression?

Depression in ageing might be seen as sitting alongside and resulting from social isolation.

Professor of Anthropology Robert Murphy (1990, p.230) writes about his own serious illness and decline. He found one of his most difficult struggles was against the isolation of his life as an increasingly disabled paraplegic with rapidly progressing spinal tumours. Murphy argues that it is this isolation and the gradual slide into dependency that pulls people backwards into their inner selves. However he also suggests that life is a process which has a litany to be celebrated.

### My reflections

Perhaps we should not make assumptions about depression in the aged. I felt Scott expressed a much more peaceful acceptance than Murphy describes. Murphy was considerably younger (in his early fifties) at the time of his decline. I think that in his own gentle, quiet, unassuming way, some of the time at least, Scott was celebrating his life. It had been good; he was satisfied. He seemed also perfectly happy to withdraw into a different world of memories and the presence of loved ones who had died before him, particularly his wife and his mother. So even if Murphy raged, I don’t think Scott did. At the time I wrote:

Perhaps Scott is not stuck in his room bowed with depression.
Perhaps he is peacefully occupying one of his other worlds, able to do so by his reduced physicality.

So maybe it is a depression in his physicality rather than a depression in his soul. Perhaps it’s a comfortable, enjoyable place for him to spend his time, as the end of his life approaches. Perhaps this is a state to be accepted: here, feelings may remain unexpressed, Scott can just be, in a world of his choosing.
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<tr>
<th><strong>l) Listening in the silences</strong></th>
<th><strong>My reflections: valuing Scott’s peace</strong></th>
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| Killick and Allan (2001, pp. 141; 163) explain that silence can be awkward, embarrassing, and one might feel it must be filled. ‘In order to respond in the most helpful way it is necessary to develop sensitivity as to why silence is occurring’. Following a conversation of meaningful connection, the person lapsing into silence may indicate tiredness. Silence may mean that the encounter is over. Moja-Strasser (1996, p.99) writes of the phenomenology of listening, especially in the therapeutic relationship. She suggests that good listening allows moments of silence, without the therapist fidgeting or interrupting the silence because of their own discomfort. Holstein and Gubrium (2000, p.223) discuss the clarity of one’s moral horizons and how one practices one’s social self. Kenyon (Kenyon and Randall 1997) writes that ‘it would seem that so long as we are alive, we still have a story to tell and we still have a past, present, and future.’ The Psalmist cries ‘Do not cast me off in the time of my old age, do not forsake me when my strength is spent’ (The Bible, The Old Testament, Psalm 71, Verse 9, 1989). But the poet Kahlil Gibran perhaps describes it best when he says:  

You talk when you cease to be at peace with your thoughts.  |

These readings helped me to frame how old age and one’s decline might be interpreted or misinterpreted by those who witness silences, quiet acceptance, physical decline and frailty.  

There were a number of instances when Scott seemed to be transported back to the beauty of places he remembered visiting. I could hear Scott’s pleasure in his own special memories. I suggested one day to Scott that it was such a hot day that a shady tree to sit under would be a good idea. He gazed into the distance as if I was no longer there, his voice became quiet and dreamy, and he began to recite:  

Here with a loaf beneath the bough,  
a flask of wine, and Thou  
With thee beside me in the wilderness;  
the wilderness is Paradise enow  
(from The Rubaiyat by Omar Khayam)  

He seemed to be transported into the presence of another. I held my breath and sat still and allowed this special time to extend for as long as he wished. I learned as I went along with Scott that these silences often led to beautiful gems of wisdom that I needed to wait for. Sometimes they simply led to him drifting off to sleep for a while. Silence sometimes meant that our meeting was over, Scott brought the sessions to an end when he was ready. This was our agreement prior to the first recording.  

I needed to decide how long was reasonable for a silence to extend. During the first session I switched the recorder to voice operated mode. Scott sometimes slept for as long as 5 minutes, then woke, and began talking again, refreshed enough to voice some special gems of wisdom that I valued. The spoken words grounded in Scott’s stories, and his yawns and beaming |
grins, peaceful head-scratchings, and especially his jokes, were all part of our I-Thou/Being-to-Being encounter, which to me was precious, given the rapidly approaching end of his life (Buber 1923).

I interpret Gibran as implying that if one is absolutely at peace with one’s thoughts one has no need to say anything. But in speaking one’s thoughts, perhaps one’s intention is simply to indicate and share one’s acceptance and peace. I had a strong feeling of measured significance, in what Scott did have to say.

I believe that Scott’s moral horizons were clear, he was sure of his identity as a mathematician with a pacifist world view, he negotiated his worlds of work, travel and family in a way that brought him satisfaction and approval from others he met along his way. Therefore he could die in peace, his life complete.

Scott remarked that there were places he might like to return to, and places he clearly enjoyed revisiting in his armchair travels, places that had meant much to him throughout his life. He was cherished and valued by family and colleagues, and received respectful, dignified care in his failing months, in stark contrast to the pleading of the The Psalmist’s ‘Do not cast me off in the time of my old age, do not forsake me when my strength is spent’. Despite some confusion as he deteriorated, Scott seemed to peacefully understand that he was well loved and cared for.
3. **JOURNALLING MY EXPERIENCE OF WORKING WITH SCOTT [FULL TEXT]**

Meeting Scott

I arrived at Scott’s residential care facility feeling slightly nervous about how I would proceed, and how much Scott would be able to participate. When I arrived in his room he was sitting quietly in an armchair gazing into the distance. He told me that he had read my ‘Therapeutic Autobiography’ brochure, and understood the reason for my visit. He told me that he felt it would be a useful and interesting thing to do. I explained that he was in control of the sessions, and should tell me at any time if he wished to stop. He signed a consent form which he understood enabled me to use the material for further study, in a confidential manner. He seemed quite pleased with this idea, and we talked about my study plans.

In order to establish with him that I accepted that this was his space I was entering, I began by asking what I should call him. I said I thought of him as Professor, though I had asked for Scott at reception. He smiled and replied that he usually warned people that this was how he was addressed here, it was convenient, but I could decide what I called him. However he brightened and seemed clearly pleased to be in control of this detail. I felt in awe of his academic aura, perhaps he sensed this.

He said that as far as his travels were concerned, it was a problem to know where to begin, and then he launched immediately into a starting point, of a holiday he remembered in England. Although I felt barely settled into the room, I switched on the recorder, and without hesitation we were away.

Taping anxiety

Scott’s voice was always very quiet and I was immediately anxious that the microphone would not be powerful enough. A short while into the first session, in agony at the thought that I might not be capturing such a rich story, I moved the microphone closer, so that it rested on his jumper, at waist level. I was always nervous about invading his space, he seemed such a private person. I arranged a tape on the microphone cord, for subsequent sessions. Pinning it onto his jumper at the beginning of each session was as
close as I came at any time to touching Scott, as to do so would have felt invasive, uncomfortable for him, and inappropriate. He did not seem to want hand shaking and I tried to remain careful about his comfort. The microphone made a terrible noise if he fiddled with the cord. On several occasions when I got back in the car and my ‘tape anxiety’ surfaced, with trepidation I checked to see that it had recorded. A flood of relief to hear the voices!

I was very annoyed with myself that the fourth session began with me forgetting to turn the microphone on for the first fifteen minutes. I remembered Warren Lett teaching us that if one was fully engaged and present, what had been said would be easily recalled, and I quietly jotted down the things we had talked about, confident I had remembered it well, but it did start me off on the wrong foot.

*Transcription*

Transcribing the tapes, (408 minutes of tape time) took more than four times the tape time. It went quicker when Scott’s voice was stronger. Transcribing offered me time to re-experience what was there in the stories, and it was often here that indwelling took place and uncovered essences and themes (refer Chapter Two, 3.2.3 on narrative methods). I tried to transcribe each session before the next, which was difficult when I was doing three visits per week, which I later reduced to two.

As I transcribed the second session, I realised there was tangible evidence that there was a change in Scott’s demeanour, it was not just my feeling. The first tape went for 40 minutes, and took me just over double the time to transcribe. The second tape went for 45 minutes before it ran out, and there were 3 hours 40 minutes of transcription of much denser conversation. The experience was enlivening Scott, and therefore I felt more confident.

There were often times when Scott seemed to be yawning, and grimacing, struggling to find a word. It took me a while to get used to this. The curtains in the room were usually almost closed, and the room often felt stuffy to me, but he did not like the ceiling fan on, even on quite hot days. It was a struggle not to yawn myself and feel claustrophobic.
At the first session, towards the end of the tape Scott asked to be excused, and lurched to the toilet. When he came out of the bathroom, he thanked me for coming, and was clearly dismissing me. He asked how long it would be before I came again. He clearly showed me to the door. I felt some wry amusement that he had taken me at my word and decided for himself how long the session would last. Perhaps he tested that there were boundaries, and they did work.

On my entrance to the room on the third morning, Scott was alert and bright. The conversation flowed, at first with some confusion, and at the end of the tape, although I saw Scott was tiring, I did turn the tape over, as I sensed he hadn’t quite finished, and felt this should happen when he felt ready, not when the tape ran out as previously. He talked for a further 4 minutes, and seemed to me to get progressively more shaky. Finally he asked to be excused to go to the toilet, and I stopped the tape. When he came back into the room he was breathless and needing a rest.

I commented on having seen King Canute, lying in his glass sarcophagus in the basement of Odense Cathedral in Denmark. I said that I didn’t think I would like generations of people looking at me after I had died, Scott laughed and said ‘still, it would be an interesting point of contact!’ I loved being able to keep up with the places he had been, like London, because I had been there, and follow his quoting of literature and poetry, especially The Rubaiyat, because it was so special to my own father. I decided to find my father’s old copy and selected several verses to give him next time. He seemed pleased with his recitation. He always received my offerings of literature with obvious pleasure.

My input and intrasubjective responses

As I transcribed the first session, I reflected critically on my own input into the conversation. Was it different from a clinical sitting-in-silence? Did I over-prompt by jumping too early into a question? Did this stop a flow that might have led somewhere else? While I think some input really did help the flow, some of it was clearly my own intrasubjective response to my own travels. I felt I had lots of stories I wanted to include! Scott spoke very slowly and at times seemed to drift off altogether, so there was plenty of time for me to think about what was said and to make careful decisions about when to put in another question or prompt.
The second session began with a discussion with the nurse on duty, who told me that Scott had difficulties swallowing, so all his food was now vitamised, and he was not to be given dry food. She told me that Scott had been very low recently, and they had not expected him to pull through. She said that he was up and dressed this morning, but that he did have bad days. I wondered if she was hinting that she didn’t think it was a good idea that I bothered him.

When I knocked and entered his room, he was sitting in his chair with my letter on the arm of the chair. He looked up and seemed pleased to see me. He appeared bright and alert. I asked him if he was able to read my letter, and he smiled and said that what I had written were ‘very suitable words about our first conversation’. I assembled the recorder and set it going. As the subject of his wife came up, he gazed off into space looking pensive for a while, with his hands clasped gently on his lap, his knees crossed. I felt as if he were not really there with me but he seemed peaceful and I waited quietly. He seemed to enjoy talking about his wife, rather proudly, I felt.

The tape ran out after 45 minutes, and I sensed that he had tired, but he really would have gone on a little longer, I think. I suggested that I was able to the next day. With much more animation than on the previous visit, he thanked me for coming and, smiling, said that he would like me to come tomorrow. He hoped the stories weren’t disappointing. I said that I was really enjoying them. He said he’d had a wonderful life. His wife was somewhat reluctant to travel, but she got used to it and attended conferences with him and made friends with other spouses. He smiled as I looked back when I was shutting his door. I felt more comfortable, and reassured that he had also enjoyed the session. I felt very pleased with the richness of the stories we had recorded and was just as pleased with the long silences which I allowed to continue and he ended without my prompting.

I noticed that each place we ‘visited’ produced my own intrasubjective response, such as my experiences in that place, and sometimes it seemed appropriate to share simple experiences from my own travels, to keep it like a conversation rather than ‘therapy.’ I needed to think carefully before doing this, as it was easy to confuse him, and cause him to ‘loose his place.’ I could see this process clearly enlivening him, and providing him with meaningful re-experiencing of his life.
The sixth session began with a minor accident to my car as I entered the driveway to The Manor. This left me to begin the session feeling shaken and cross. Then Scott was not in his room, but had gone for a walk with his carer to a fairly distant sunroom. By the time he shuffled back to his room he was breathless and seemed almost too tired to go on. I thought at times that as he drifted off he may not come back and I looked around to see where the call bell was. I asked myself how I would respond if Scott died while I was present. Would I just sit for a while without alerting the staff, who I am sure would have a protocol to ‘call a code,’ or at least an ambulance.

After one side of the tape, with some lengthy pauses, but some good connected dialogue and re-experiencing material, I suggested that he should rest before the lunch bell disturbed him again, and he thanked me; I think it was for allowing him to rest, rather than for coming! At one point when he seemed far away, I made a suggestion that he seemed to have developed an ability to work throughout his life alongside the varied customs and cultures of others without discomfort. He immediately opened his eyes, sought direct eye contact with me, and said firmly, ‘Yes, quite so!’ It was a lovely connection in the morning that felt a bit damaged, and where engagement had been difficult.

3.1. Access to experiencing by using literature

Scott explained his interest in Peer Gynt, a Norwegian story. But he could not remember the story, other than Peer Gynt’s journey, which then prompted a discussion of Scott’s own epic journey. I decided to search out Grieg’s Peer Gynt Suite and play it to him and also find the story, and this was quite a time consuming task. I found a synopsis, from Oxford Companion to Literature, and photocopied it as a response to give to Scott (Ibsen/Watts, 1966). His daughter also gave him a longer synopsis, and the two versions confused him somewhat.

I remembered that I had read something of the Pink City that Scott talked about. Eventually I went to four fairly battered second hand travel books by Richard Halliburton that I had bought as a teenager. In the smallest, most faded of these, ‘The Flying Carpet’ (1950), I found the chapter entitled ‘The Enchanted City.’ With pleasure I photocopied it, enlarging the print so Scott could read it. I hoped it would trigger further memories of his
trip to Petra. I remembered discussion in class at MIECAT about how selected pieces of literature would be appropriate to offer as further access material.

After discussing bridges in London, and the Wordsworth poem, I typed up the poem ‘Upon Westminster Bridge,’ so that I could enlarge the print and offer it as another piece remembered and loved, with which Scott could sit and re-connect. I also enjoyed reconnecting with this poetry of my schooldays.

3.2. Emerging themes

After the fourth session, I began reading Yalom’s ‘Momma and the meaning of life’ (1999). Yalom’s ‘mentor/patient’ Paula, talks of the utter isolation she feels when it is known that she is dying. I pondered Scott and his situation at The Manor, an up-market place by most standards, and yet I felt a quiet, carpeted solitude when, once past the clatter of the dining room and kitchen, I entered the passage to Scott’s room. All other doors to resident’s rooms seemed to be shut. I would feel incredibly lonely living there. Is this privacy and dignity that he would wish, or isolation? He spoke of ‘home’ in L. Avenue. His daughter had told me that Scott made the decision himself to stay at The Manor and was not pressured by the family.

I could see various themes starting to emerge in my own response to Scott, and in his responses to his own stories. Dealing with my own intrasubjective response that week I journalled:

I witnessed the tide of residents arriving in the dining room as I walked through to the front door, to leave The Manor. All were frail, mostly with walking frames, some in wheel chairs, the embodiment of old. It was like a bizarre kind of ballet, where the performers all shuffled along, frail and attached to up-market walking frames and chairs.
The questions / theme followed:

Their bodies are well cared for here
the surroundings are expensive, elegant
but what about their minds, their souls?
Who listens to them?
hears their stories? connects the space between them?
helps them find knowing and peace?

A theme of old age and how it might be for me, was starting to gather core meaning. And reading Yalom (1999) and Zable (2001) enhanced the essence statements that followed later, the approximation to meaning for myself, and the formation of responses I would later offer to Scott and his family.

As I re-listen to the tapes I understand that the hardest thing that was required of me was to slow myself down to the pace of this tired, frail, quiet, dying man, in order to hear him and be present to his mind. He was a private, introverted person who willingly offered and seemed to enjoy sharing his stories despite his worry that he had forgotten so much.

Scott’s wife had recorded colourful stories of her early life experiences. Since her mother’s death, her daughter had not felt able to listen to her mother’s voice in order to transcribe them. I volunteered for this task. This work brought me a deeper resonance to the family as a whole. I felt that these stories would contribute substantially to the gathering family story, and felt pleased and privileged to be able to help. They were not able to be approved for inclusion with Scott’s narrative, because his wife had not given her consent. They simply belonged to the family, to sit alongside Scott’s narrative.

The family also have slides in boxes and these can be sorted out to match the places Scott and his wife visited, scanned and then included with Scott’s narrative, so the possibility is growing of a detailed record of this man’s interesting life. I began to see a picture of Scott’s whole life after the seventh session, and indwelling this (refer Chapter Two, 3.8), I wrote an intersubjective response called ‘A Number of Worlds,’ which I gave to Scott at my final session and also sent a copy to his daughter.
**Difficulties**

I continued to battle with the difficulties of a tired, breathless person who drifted off to sleep. Or was he meditating? How should I sit with that? For how long? I was there to access Scott’s stories. How long was reasonable for a pause to go on before I prompted further conversation? Clearly sometimes Scott was slowly pondering an answer and I interrupted. Sometimes he drifted off to sleep, and I think he sometimes felt I was being pushy when I roused him. When I used the voice-activated recording on the tape recorder, I lost the depth of pauses, which I have always thought are important to understand. I decided this probably has to be intuitive at each particular time with each particular individual, especially those who are terminally ill.

To understand this balance, and how much I said overall, I used the computer to count the words. Of the total, Scott said two-thirds of the words. This was better than I had thought. In comparison, in my previous experience with Sarah, (Chapter Four) who was also terminally ill, she said 96% of the words.

I was aware of my own travel reminiscences producing little anecdotes that took me back to places and people with whom I had connected. I had written these stories down, and in an effort to trigger Scott’s memory of people with whom he had connected, I took what I felt was a risk and gave him three little stories from my travels. I felt that this confused him, and I felt disappointed, although he said he enjoyed reading them. As I thought about my disappointment that my little stories did not work for Scott, it dawned on me that there were little stories embedded in Scott’s tales that were equally important to him. Scott actually says, in the final session, ‘it has been interesting to bring some [of his travel] experiences back into focus.’ *Interesting* and *significant* are two words Scott uses to give positive meaning.

As I indwelled all the material we had recorded, I began to form a picture of this interesting life, and a sense of the essence of the philosophy and values that underscored Scott’s lived experience. Firstly I described this growing feeling to Scott, and then came home and formed an intersubjective response ‘A good life’ to give him at the final session the next week. This felt quite meaningful to me. It was seeking to amplify what Scott had told me, connected to my own experiences, but more related to my own empathic response to Scott’s story. Without difficulty, because I had been deeply engaged in Scott’s
experiences, I felt a resonance, a being-in, and being-with, as described by Moustakas (1996).

The final session found Scott not as well as previously but still able, occasionally, to access depths of meaning and understanding. I began by reading him my intersubjective reflection, which he listened to very carefully, and he responded that it was good, and accurate. At the end of the session he commented that while the worldview I described was correct, it failed to include another world he inhabited, that of his work in mathematics, and this world was quite separate from his worlds of travel and family. He saw this separation of worlds as being essential for his work to have progressed, and felt there was no great difficulty in keeping the separate worlds spinning but apart: ‘I just kept up with each’. Perhaps this brought him understanding and clarity. It certainly gave me much to think about as I pondered the balancing of these separate worlds, and the effect that might have had on Scott’s family.

As I indwelled this final view, I created a pastel representation of Scott’s three worlds, with a background world of grey feelings which he said remained too difficult to express. While feeling a strong need to be accurate, I recognised that some of this was ‘surmise’ on my own part. The art conceptualisation was mostly for Scott’s daughter, since probably it would now merely confuse him. It resonated with her, and she said that her brothers would also find it helpful. This seems to fit ‘complex family emotions’ (Chodorow 1991, p123) where clearly, the worlds occupied by Scott did indeed impact on his family.
I also began to reflect on a theme that resonated for me in this work with Scott:

*Old age*

He is eighty nine years old next week
his body is slowly dying
his memory is failing
his ability to communicate is almost finished
I feel he is sad,
but it seems he feels it is too late or too difficult to say so.

And while The Manor is up-market
it is not where he wants to be.
There’s not much joy in the end of his life
even if I see care, and hear rich stories of what has been experienced.
I don’t think I like this picture of old age and seeing myself being like that.

For his family, and acknowledging my own intrasubjective response ‘old age,’ I wrote a deeply felt essence, an approximation of meaning: The family responses are continuing to emerge but they express delight with Scott’s improved demeanour and brighter appearance.

Perhaps Scott is not ‘stuck’ in his room
bowed with depression.
Perhaps he is peacefully occupying
one of his other worlds,
able to do so
by his reduced physicality.

So maybe it’s a depression in his physicality
rather than a depression in his soul.
I think this might be a comfortable place
for him to spend his time,
as the end of his life approaches.
Perhaps this is a state to be accepted:
Here feelings may remain unexpressed
Scott can just **be**,
in a world of his choosing.

Dr Warren Lett later commented to me in personal conversation that what is possible depends very much on the capacities of the teller, and not just memory. Perhaps Scott was not used to reflection to a point of meaning. Dr Lett continued that this was an interesting problem: ‘Should one assist this or just stay with the story as told? And how will you find the answer to such a question except by testing it? And is there a diversity of ways of responding’?

As I prepared to process Scott’s story for my thesis, I felt the usual sense of nervous anticipation, almost reluctance to embark on this re-entry. I woke at 4am and the day’s task of beginning processing Scott’s story was in my mind. I drifted back to sleep and Scott’s room, his presence and his story permeated dreams that were relaxed and peaceful. I woke at 7am with a pleasant anticipation of getting back into his life review. The re-entry was fascinating, not difficult or painful.
Appendix Nine:
Bert

1. THE APPLICATION OF THE LITERATURE SEARCH TO BERT’S NARRATIVE [FULL TEXT]

Introduction

To this point I had little experience of dementia, so it was a steep learning curve for me to enter Bert’s world and his narrative. From outside Bert’s dementia, I needed to consider the problems and risks in his dementia unit setting, wondering how I might attempt to understand a world I knew so little about, and to see the similarities between Bert’s world and mine, rather than being overwhelmed by the differences. Carolyn Ellis (Ellis and Berger 2002, p.857) reflects on her research writing about the experience of suffering from bulimia, as a participant who did not engage in the bulimic behaviours she was seeking to understand. Because I drink very little alcohol, like Ellis I reflected on my work with Bert from the position of a collaborative inquiry participant who did not engage in his alcohol-induced-dementia behaviour, which I nevertheless set out to understand. The literature was illuminating for me, and in the end I could see Bert’s personhood shining through his dementia, which was a poignant discovery.

It is interesting to note that I did not research the other narrative’s illness physiologies and clinical perspectives to the same degree that I explored Bert’s alcohol induced dementia. Because of my previous nursing and palliative care experience I felt that I had adequate understanding of the clinical issues involved in for example, Elizabeth’s stroke and multiple organ failures, Kaye’s mother’s ruptured cerebral aneurysm, and Sarah’s small-cell lung cancer.

I focussed on books, by Killick and Allan (2001) and Kitwood (1997) from the many related specifically to dementia care. John Killick worked for nine years in a dementia unit as writer-in-residence, and his insights are invaluable in my understanding of Bert’s
narrative. He refers to ‘people with dementia’ as the one condition, rather than the probable group of conditions, which perhaps should be called ‘dementias’. Kate Allan helped develop his writing from her background of clinical psychology.

Kitwood (1997, p.1) expresses his concern at the ‘rising tide of dementia’ that is inevitable with our ageing population. His experience with dementia began by meeting a frail old lady who became a friend to Kitwood and his wife. He was at that time an academic psychologist, but then began his work with and for people with dementia, finding to his surprise that he liked people with dementia, admired their courage, and could interact with them and understand something of their predicament.

1. Theme: Alcohol induced dementia
   • Definition of alcoholism
   • The development of alcohol induced dementia
   • Wernicke-Korsakoff’s Syndrome
   • Confabulation
   • Differentiation from Alzheimer’s Disease
   • Alcohol and Isolation: non being

2. Theme: Narrative identity, personhood or sense of self, its loss
   • Narrative identity
   • Loss of story
   • Careful listening
   • Personhood or Sense of Self; power and disempowerment
   • In-valid: Loss of control
   • Silenced voice: this could be me!
   • To reveal all, or respect doors that need to remain shut.
   • Bert describes himself as ‘Half a person’
   • Humour

3. Theme: Raw emotions
   • Night Terrors and disruptive behaviour
4. Theme: Dementia care: Being de-mented – a troubled perspective
   • The in-valid, and concepts of total care.
   • Bert’s confabulations beyond the physiological
   • Time and place, present and past
   • Making sense of dementia
   • Initiating conversations
   • Self disclosure
   • Bert’s future: leaving him and walking away

5. Theme: The staff of a dementia unit
   • The dialogues between staff: staff stress and conflicting values
   • The staff’s surprise

6. Theme: Reminiscence and life review
   • Reminiscence in dementia
   • The re-constructed past
   • Valuing Bert’s presented world

7. Theme: Truth and values
   • A sense of place
   • Commemorating moments of value
   • Work ethic

8. Theme: Buber and intersubjectivity

9. Ethical considerations

10. Conclusion
    • Approximations to meaning
    • The poetry
    • The benefits of the process
Table 4. Literature search for Bert’s narrative

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<th>1. Theme: Alcohol induced dementia</th>
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| The literature search for Bert begins in the domain of his alcoholism. The only medical information I was given by the Activities Co-ordinator was that Bert was a person with alcohol induced dementia, and that his psychotic attacks were controlled by medication. | **My reflections**

The descriptions of the progressive changes due to alcohol induced dementia would explain much of Bert’s situation as I experienced it over the ten weeks we worked together. The presumed damage to Bert’s frontal lobe as described by the literature, fits what I saw. Understanding the effects on memory impairment, with the preservation of word meanings and other verbal symbols, illuminates Bert’s ability to ‘play’ with words, and his skill at telling a good, credible story. I believe Bert was skilled at filling the gaps in his memory with plausible stories, which fits in with the literature’s views on confabulation. It also explains how Bert clearly still remembered events that occurred in his distant past ‘as if it was yesterday’. His short-term memory and planning capacity, such as when our next appointment was scheduled, also seemed to be reasonably intact, though sometimes anxiously obsessed about.

Somehow this doesn’t feel like the complete picture of Bert’s confabulations. I suspect that he was always a good storyteller, he enhanced his stories to make them more interesting, and he read broadly, so the knowledge of what he had read previously, such as Paul Brickhill’s book The Dam Busters, (1955, Ballantine Books, USA), is now confused or blended into his own story as he tells it today. Oscar-Berman, Shagrin, Evert and Epstein (1997) appear to be describing a situation like Bert’s, where his overall intelligence has not deteriorated significantly, because the information in his narrative is more involved with long term memory. However I have no knowledge of Bert’s drinking history other than that alcohol seemed to

|  |
|  | a) Definition of alcoholism

In the American Psychological Associations Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-1V) the term alcoholism refers to the criteria for alcohol dependence defined by: a craving for alcohol, possible physical dependence on alcohol, an inability to control one’s drinking on any given occasion, and an increasing tolerance to alcohol’s effects (Oscar-Berman, Shagrin, Evert, and Epstein 1997, p.65).

|  |
|  | b) The development of alcohol induced dementia

Dementia comes from the Latin ‘de mens’ meaning ‘out of mind’, which refers to a group of conditions typified by memory impairment, intellectual function and eventually personality change (Bloch and Singh 1997, p.180). Alcoholics often develop personality changes, social and personal neglect, confabulation, and lack of empathy, insight, and emotional control (Brun and Andersson 2001, p.288). Frontal lobe damage causes problems in engaging in ordinary cognitive, emotional, and interpersonal activities. Disruptions to these frontal lobe networks release previously inhibited behaviours (Oscar-Berman and Marinkovic 2003, p.128). Hersh (1997, p.850) suggests that delirium persisting beyond several weeks should be considered |

|  |
|  |  |
dementia. Bloch and Singh (1997, p.180) propose that the most damaging psychological long-term effect of alcohol abuse is cognitive impairment, or brain damage, which if left unchecked, leads to progressive dementia.

c) Wernicke-Korsakoff’s Syndrome

Alcohol dementia is also known as alcohol-induced persisting amnesic disorder, or Wernicke-Korsakoff Syndrome. Wernicke’s Disease involves damage to nerves in both the central and peripheral nervous systems. It may also include symptoms caused by malnutrition, especially lack of vitamin B1 or thiamine, which contributes to brain damage leading to severe cognitive deficits (Oscar-Berman and Marinkovic 2003, p.127). Korsakoff syndrome or psychosis involves impairment of memory and intellect or cognitive skills, its main symptom being confabulation (Hersh, Kranzier, and Meyer 1997, p.848). Dalla Barba, Cipolotti, and Denes (1990, pp.525-534) describe deficits in episodic memory, where information about temporally dated episodes or events is stored, and in semantic memory, where the organised knowledge that one possesses about the meaning of words and other verbal symbols and facts are preserved. These authors suggest that in Korsakoff’s Syndrome, it is the episodic memory that is significantly impaired.

d) Confabulation

Confabulation is the symptom that distinguishes alcohol induced dementia from Alzheimer’s Disease. Confabulations are defined as ‘the falsification of memory occurring in a clear consciousness in association with an organically derived amnesia’. In other words the person makes up detailed, believable stories about experiences or situations to cover the gaps in their memory. The underlying
neuropsychological mechanisms are not clear (Dalla Barba, Cipolotti, and Denes (1990, p.525).

In Korsakoff’s syndrome, it is possible that intelligence and memory for past events is relatively unaffected. It is this memory deficit, called anterograde amnesia which leads to confabulations, where the gaps are filled in with fabricated or imagined information (Lishman 1990, p.640 Oscar-Berman, Shagrin, Evert, and Epstein 1997, pp.67-69).

Korsakoff’s Syndrome destroys short-term memory, but spares long term memories formed, or knowledge gained, before the onset of prolonged heavy drinking. Thus, according to Oscar-Berman, Shagrin, Evert and Epstein, (1997, p.67) overall intelligence, as measured by IQ tests, does not deteriorate, because this information involves long-term memory. These authors suggest that the outcome for patients varies according to the age at which problem drinking begins, the family history of alcoholism, nutritional deficiencies, and liver disease. Family history of alcoholism can influence such things as tolerance for alcohol and the amount of consumption needed to feel alcohol’s effects (Oscar-Berman and Marinkovic 2003, p.125).

e) Differentiation from Alzheimer’s Disease

Signs of severe brain dysfunction may persist after cessation of alcohol consumption, and is then known as Alcohol Amnesic Disorder. This mimics Alzheimer’s Disease, and a study comparing patients with the two disorders revealed that memory impairment is similar, whilst their overall profiles are different (Sullivan and Marsh 2003, pp.1716-1719). Alzheimer’s Disease is a slowly progressive degenerative disease of the brain’s outer layer, the cortex. A definitive diagnosis can only be confirmed

My reflections

Bert’s family culture of alcohol consumption and its rules, such as not drinking alone, fits Murphy’s picture, which I heard from Bert as an expression of solidarity and mateship. Bert only sometimes gave me clues to his sadness and the losses brought about by his drinking. He describes his mother and grandmother as strong women who by their hard work and use of available resources, carried the family through the depression, as Bert says ‘rather well.’ However they both, according to his story, consumed a
by examining brain tissue post mortem, where characteristic deposits of amyloid are seen in the form of plaques between brain cells, and as tangles within the cells themselves (Bloch and Singh 1997, p.190). The course of the disease varies from person to person, as does the rate of decline. On average, Alzheimer’s patients live for 8-10 years after they are diagnosed; however, the disease can last for up to 20 years (DeBaggio 2002, p.6).

f) Alcohol and isolation: non-being

Whether dementia is described according to perspectives from clinical medicine, psychology or sociology, people with dementia are vulnerable to social isolation, estrangements and loneliness (Gibson 1994, p.46). Robert Murphy, a professor of anthropology, (1987, p.72) describes excessive alcohol consumption as a way of asserting or protecting a fragile masculinity. Murphy describes this as an attempt to maintain the myth of male superiority, and he deplores its cost to both males and females. It may start in conviviality, but ends in brooding isolation. Murphy (p.131) describes the kind of social limbo where these people often end their lives. He sees (p.227) his own aloneness as being a facet of non-being, as he faced progressive deterioration from a spinal tumour which rendered him paraplegic and eventually caused his death.

My reflections

The story Bert tells, in his suffering from alcohol induced dementia, illuminates his self-defining. His life was the narrative he told me, including the stories he crafted and integrated within his overall life-narrative, not his restricted, unhappy life in the quart (1200 ml) bottle of port between them, every day of the week. Murphy describes his own ‘brooding isolation’. It was this image I saw of Bert in his room, where I was first introduced to him by the Activities Co-ordinator (AC). She was concerned that he did not want to leave his room for anything other than meals. Murphy could be describing Bert, in a state of non-being, as he is left standing outside the formal social system - he is in trouble in the unit which is his home: with the staff because of his night terrors; he is alienated from his family, who have perhaps abandoned him for the remainder of his life; nor can he fit into the community of the other dementia patients, who intellectually do not match him either. If our connection to others is the utterly core concept of being human, then Bert’s separation from others means he is deprived of being fully human. He is indeed isolated, a non-being. Is it any wonder he grasped with enthusiasm the opportunity to tell his stories to me, and to be heard as a person of self-worth?

2. Theme: Narrative identity, personhood or sense of self, and its loss

a) Narrative identity

A life-review narrative is the consciously formulated, premeditated and coherent account of a life’s story. When defined this way narrative involves recognition of its author as capable, self-defining, and intellectually able (Wiltshire 1995, p.81).
Freedman and Combs (1996, p.77) argue that narratives are not ‘about’ life, they ‘are’ life as we know it, life as we experience it. Oliver Sacks (1985, p.105) comments that we each have a life story or inner narrative:

whose continuity, whose sense, is our lives. It might be said that each of us constructs and lives a ‘narrative’, and that this narrative is us, our identities.

Damasio (2000, p.196) explains our *knowing* arises from within the stories we tell:

in extended consciousness, the sense of self arises in the consistent, reiterated display of some of our own personal memories, the *objects of our personal past*, those that can easily substantiate our identity, moment by moment, and our personhood.

Damasio’s view echoes in much of the literature on narrative that is reviewed in Chapter Two, 3.

dementia unit. Telling *his* life, gave him back his integrity, and a renewed sense of self-worth.

Damasio (2000) underlines the importance to Bert of telling his story. From Damasio comes the understanding that Bert’s sense of himself, and his rage at his loss of personhood are perhaps calmed by the narrative process itself, of him telling his story, and knowing he was being heard by me. His passion for the photographs on his wall of his childhood home, validate and affirm for him that from within the stories of his place, comes his sense of identity, who he is. Bert has quite a strong memory of who he has been, and where he has come from, and his experiences along the way. He says much less about his present, and who he is today. This is where his confusion dominates.

I hope somewhat forlornly that having recorded Bert’s story, it might help the staff of his dementia unit to recognise the narrative integrity and coherence of his story, whatever the difficulties his night terrors might present to his carers. Bert used almost the same words as Freedman and Combs (1996, p.77) when I asked him if he enjoyed the experience of recording his life narratives he answered:

*Yes, well, put it this way, it's life, so it's not much good in saying no, you don't enjoy it if it's your life, or my life. You only get one chance. Yeah.*
### b) Loss of story

Linde (1993, p.20) in her work on life stories and the creation of coherence, suggests that ‘part of the interpretive equipment furnished to us by our culture is the idea that we have a life story, and that any normally competent adult has one’.

**My reflections**

Linde (1993) leads me to ponder that if Bert is seen by the staff of his unit as lacking competence or coherence, then this would mean that he is also cut off from his life-story. If in Linde’s sense the life story means something like ‘the events that have made me who I am’ then this leaves Bert without a story in the place that is now his home. Without a voice, or any sense of meaning, despite the story he told me.

### c) Careful listening

According to Bruner and Feldman (1996, p.291), we need to understand narrative structure in order to understand how the process might be used. They suggest that in autobiography, as in other narratives, the product is a highly constructed one. The second point these authors make is that narrative patterning does not get in the way of accurate autobiographic reporting or interpreting, but rather, provides a framework for both telling and understanding.

Brough (1998, p.2) writes poignantly of the experience of caring for a close friend as he deteriorated into Alzheimer’s Disease. Brough says

> to my shame I was often far too slow to tune into what was the real and most important issue of the day. Once I learned to treat what he said as the relating of a dream, once I listened for images and took them very seriously, we were able to explore very deep reserves within each other.

**My reflections**

Clearly Bert constructs and arranges his story so that despite his dementia, it makes coherent sense. I think this happens through the mist of his dementia. Bert’s narrative pattern does provide a framework for the telling and understanding of who he is. It can be revealed by listening very carefully to the story and its possible meanings, that lie deeper than the confusions and confabulations that cloud the surface (Bruner and Feldman 1996).

There were a number of occasions when I felt quite disappointed because I had been slow to ‘hear’ what Bert had said to me. One day I brought home a paper-towel story Bert had written for me, entitled ‘Promoting Group Harmony’ and I kicked myself that I had not noticed this heading when he gave it to me, and the next visit was too late to comment. Brough’s (1998) confession comforted me, it was a difficult task.
d) Personhood or sense of self, power and disempowerment

Kitwood (1997, p.8) discusses the idea of personhood, seeing it as

a standing or status that is bestowed on one human being by others, in the context of relationship and social being. It implies recognition, respect and trust. Both the according of personhood and the failure to do so have consequences that are empirically testable.

Kitwood expresses grave concern over the possibility of excluding people with dementia from the ‘personhood club’ (p.9). Kitwood believes that we are all in the same boat, and there can be no empirically determined point at which it is justifiable to throw some people into the sea. He pleads for enhanced awareness and understanding in the context of dementia.

Freedman and Combs (1996, pp.37-39) discuss the politics of power, as proposed by Foucault, who suggests that there is an inseparable link between knowledge and power and that those who control the discourse, control knowledge. In conversing with Australian narrative therapist Michael White, (cited in Freedman and Combs 1996, p.39), White argues that even in the most disempowered of lives there is always lived experience that lies outside the domain of the dominant stories that have marginalised and disempowered those lives.

My reflections

Kitwood’s warning (1997, p.8) highlighted and validated my feeling of Bert’s having ‘been thrown into the sea’ of the dementia unit. I strongly felt his disempowerment as described by Freedman and Combs (1996, pp.37-39). In Bert’s case it is the staff who determine his disempowerment resulting from his behaviour. They have power over his precious possessions, which they throw out each morning when they are messed up by his night storms. It might empower him if a box or shopping trolley was presented to him each evening for him to pack his precious writing and books in, which could be removed from his room and returned to him safely next morning. His clothes were treated this way, but not the things that he saw as most precious, his messy books and papers.

The dominant stories of Bert in the unit are those of his disruptive night behaviour. At the afternoon presentation of the completed life review, the staff marvelled and exclaimed ‘did he really do all this, we had no idea’.
### e) In-valid: Loss of control

Zola (1982, p.76) writes about how staff are ‘too busy’ to pay attention to patients’ personal problems. Zola relives his own experiences and agonises over his losses, explaining that as he saw it, loss is loss, no matter the nature of its cause (1982, p.125). Zola expresses the hope that through reflection, we can bridge the gap of understanding of the disabled and so restore some of the universality of the human condition (p.194). Kitwood (1997, p.1) describes a ‘rising tide of dementia’ as it increases in our ageing population. Kitwood warns that in risking being close to a person with dementia, we may see some terrifying anticipation of how we ourselves might become (p.14). Zola’s final indictment is that ‘anything that separates and negates those with a chronic condition will ultimately invalidate not only them, but everyone else’ (1982, p.238).

### My reflections

One weekend Bert was very upset by a staff member who, as he saw it, threw out all his precious papers, (which he had probably soiled). Bert was still very distressed telling me about it days later:

> They took everything, ooh gee did I give ... I went and showed whoever was in charge - ‘don’t know anything about it’ they said ‘that’s your own private business.’ Just took ... ooh gee, I was ... .

It took an effort on my part to hear Bert’s pain and distress sufficiently to address the situation with promises of more copies, which I delivered on the following visit. Only then was he calm enough to go on with his stories. How many staff on Bert’s unit could identify his enormous loss, including his connections to his family and his freedom? Zola’s hope of bridging the gap for disabled people can only grow from understanding, and adequate staffing of dementia units like Bert’s. Kitwood’s (1997, p.1) ‘rising tide of dementia’ makes me all too conscious that one day this might be me, even if my dementia would probably not be alcohol induced (p.202). My journalling of my experience with Bert gave my voice to this concern. I would not like to end my days in a place like that, no matter how accredited it is! This is further discussed in the section on the mapping and journalling of my experience of working with Bert.

### f) Silenced voice: this could be me!

Holstein and Gubrium (1995, p.21) explain that words used such as demented, or difficult, can categorise people as narratively incompetent. As a result, their voices and the particular experiences of their lives will not be heard. Kitwood

### My reflections

Bert’s horizons were as broad as his travel, his war experiences, and his childhood experiences of surviving the depression. As interviewer I actively probed the linkages between the places, and experiences of Bert’s life. The quality of life in Bert’s...
(1997, p.79) suggests that to get close to the experience of dementia, we might draw on our own stock of emotional memories and create an inner narrative that has at least some resemblance to living with dementia. Kitwood thinks that as we create such a role we begin to make contact with our own supply of dementia-like experiences, together with the accompanying feelings of intense anxiety, fear of abandonment, generalised rage, dreadful feelings of bewilderment, boredom, betrayal and isolation.

Holstein and Gubrium (1995, p.58) suggest that the primary objective of active interviews, (refer Chapter Two, 3.2), is to promote the visibility of linkages and horizons. According to Holstein and Gubrium, the interviewer actively probes the linkages between the places and experiences of the person’s life. These writers believe that the quality of life in the nursing home takes on its meaning in relation to the lifelong experiences of the patients, but only when they are listened to beneath the crust of confusion (p.67).

Zaner (2004, p.87) in his musings on the possibility of his own suffering from dementia writes poignantly:

Dementia, unasked for and undeserved, is cosmically unjust. It ought not be. But it is, and since it is, so must I respond by doing all I can to undo its cosmic marks, to undo what has now befallen you, my comrade and fellow being. I must help you, ease your pain, assuage your suffering, ensure you are never abandoned. And with that, I know, is the other half of that thought, that recognition: I must prepare myself to be not merely giving, but be on the receiving end of those giving care, if it be me, not thee, who falls to dementia.

I embraced Kitwood’s (1997, p.79) suggestion that in order to get close to the experience of dementia, I should draw on my own stock of emotional memories and create an inner narrative that has at least some resemblance to living with dementia. I did this via my journalling, feeling deeply how I would hate this to be me, and this unit to be my ‘home’. I began to feel what Bert’s life would be like, with feelings of anxiety, fear of abandonment, generalised rage, dreadful feelings of bewilderment, boredom, betrayal and isolation. I tapped in to those feelings, journalling them throughout my work with Bert. They are discussed further in the following section on my journalling of working with Bert.
<table>
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<th>g) To reveal all, or respect doors that need to remain shut?</th>
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<tr>
<td>Frank (2001a, p.358) warns that research practice and perhaps psychotherapy are situations where it is usually required of participants that all is revealed or spoken.</td>
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<td>My reflections</td>
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<td>I found Frank’s (2001a) suggestion helpful, that there are aspects of suffering that might most generously remain unspoken. Bert’s two youngest sons seemed unable to be spoken about, although they were named, and I think caused Bert sadness. I needed to allow him the private space where they could remain undisturbed. In my own intrasubjective response about Bert’s children as I transcribed the tapes, I drew four doors, two for the first two children he could talk about, and two doors that we tacitly agreed would remain shut, the two doors that represented the two sons he did not wish to discuss. And that was where it rested, I did not push, I drew them as doors that could remain shut.</td>
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<th>h) Bert describes himself as ‘half a person’</th>
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<td>Murphy (1987, p.92) describes an individual’s concept of himself as a reflection, or like a refraction in a fun-house mirror, of the way he is treated by others. Murphy explains that if a patient is treated with ridicule, contempt, or aversion, then his own self worth is diminished, his dignity and humanity are called into question. Sarbin (1994, p.25) echoes this view, that when people become a ‘mental patient’, or a ‘dementia patient’, they become non-persons as the result of legal, medical, and nursing routines. They are ‘sectioned’ or involuntarily admitted to secure care facilities, and like it or not, are then subjected to the routines of these establishments. Zaner starkly puts it ‘this is a prison, plain and simple, and to make matters worse, they treat you like a child (Zaner 2004, p.78).</td>
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<td>My reflections</td>
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<td>I heard deeper than the words of Bert’s story ‘yet to be written’, ‘The Two Dozen and a Half, Not Two and Half Dozen’. Bert said ‘the half is a person, written in first person tense, I have put myself down as the half, he’s been promised a million pounds if he could rehabilitate himself, get back to a normal straight course’. He said ‘that’s definitely what the plot is about’. He strongly expressed his wish that he could be restored to a better way of living, so that he would be free to resume his life in South Australia. As ‘half a person’, Bert’s night terrors are a source of anger and resentment for the staff who have to don gloves and gowns and scrub his room clean each morning. Bert’s reflection of himself is a reflection of the way he is treated by others. His self worth is diminished, (perhaps halved in his eyes), his dignity and humanity are called into question (Murphy 1987, p.92; Sarbin 1994, p.25).</td>
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### 1) Humour

Killick and Allan (2001, p.86) suggest that the use of humour shows a sense of personhood and a useful method in the attempt for a person to come to terms with their condition.

**My reflections**

I enjoyed Bert’s dry, witty sense of humour and saw that his use of humour was evidence of his personhood, used in his attempt to come to terms with his condition. Bert’s funniest joke to me, which was so dry I almost missed it, was at the end of recording the last tape, when I ask him how long he had been there in the nursing home. His instant reply was ‘two’, said with a cheeky grin. ‘Two months or years?’ I asked. ‘No, too long!’ We both enjoyed his joke.

### 3. Theme: Raw emotions

Kitwood (1997, p.72) writes

> at one extreme are men and women who move into dementia with very little insight. When things go wrong, they tend to blame other people, or develop delusions, perhaps of theft or mysterious interference. Eventually their dementia envelops them, like an impenetrable fog. In some instances powerful, raw emotions break through with an agonising intensity as psychological defences collapse.

**My reflections**

Kitwood’s understanding seems especially relevant to Bert’s feeling that the staff honkey-tonked his possessions, when they simply threw out the mess of soiled books and papers that accumulate through Bert’s overnight raging storms (Kitwood 1997). Bert was probably a person who was never aware of the power of his raw emotions.

### a) Night terrors and disruptive behaviour

Crossley (1996 p.155) argues that as long as people are denied the dignity of recognition, particularly at an institutional level, they will always be potentially opposed to their situation, and that situation will consequently be unstable. Kitwood (1997, p.136) suggests that all so-called problem behaviours should be viewed carefully as attempts at communication, related to the person’s need. Then it is possible to understand the message, and engage with the need that is not being met.

**My reflections**

Bert’s state of dementia seemed to filter out emotional reflections, so whilst he readily shared humour, sadness and anger were either controlled or absent, somehow almost ‘blanding down’ the stories he told. The anger then perhaps is what emerged uncontrolled in his night terrors, that distress and disturb his relationship with the staff who have to clean up after his storms.

Bert’s night terrors seem to highlight Crossley’s (1996 p.155) description of loss of dignity and recognition. I was not invited
Moss (1989, p.197) describes an unequal relationship where the patient somehow absorbs from professionals, an attitude of self-judging, and self-discounting, which health professionals in particular tend to re-enforce perhaps unintentionally without understanding how it can be so destructive to the patient’s sense of self-worth. Moss suggests that it is the patient’s own world of experience which should be the proper context in which his actions are interpreted. This, in the case of dementia, might be quite difficult but must be understood if it is ever be implemented.

by the staff to talk about or contribute my insights to any care plan that might alter this situation and perhaps improve Bert’s prospects for a more peaceful existence at night.

How can Bert fit into the world in which he now finds himself? His ‘night terrors’ and room wrecking are what construct the person the staff know, not the person of the stories he was able to re-construct with me. These stories described a very different Bert, from a very different perspective, unknown and surprising to the nursing staff (Bruner, J. 1986, p.39).

It would be difficult for the staff not to re-enforce the destruction of Bert’s sense of self worth. It means that as Moss suggests, it is Bert’s own world of experience that should be the proper context in which his actions are interpreted. But the staff other than the Activities Co-ordinator of the unit appeared to know little of Bert’s world or his life experiences before his admission. His own response to my praise and encouragement was always a deprecating ‘Oh well’ (Moss 1989, p.97).

4. Theme: Dementia care: Being de-mented – a troubled perspective

Introduction

Richard Zaner, Medical Ethicist writes that dementia means that you no longer mens, or mind, as you are now de-mented, de-witted, de-minded. Zaner asks ‘can I lose my soul as I apparently can lose my mind?’ (Zaner 2004, p.77). He bleakly writes:

Truth be told, for most people today the de-mented just don’t count as much as the rest of us, whatever the cause and etiology, as the ways in which we typically ‘manage’ them, in institutions or hospitals or at home demonstrate (p.80).
‘do the demented count less than the rest of us, the non-demented? Or is that widespread, deep-lying sense of no longer counting, no longer needing to be reckoned with, expressive instead of a deep malaise within contemporary society. We do think less of them, but should we?’ (p.81).

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<th>a) The in-valid, and concepts of total care</th>
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<td>Zola (1982) describes missing pieces and diminished people in his account of disability and chronic illness, although he does not specifically refer to people with dementia. Zola sees it starkly as two worlds, the valid, and the in-valid (p.25). Speaking from his own experience, Zola asks of these long-term institutions how they can be accredited, and claim to give ‘total care’. Zola suggests that this ‘total’ refers to their control over the lives of the residents, not to the potential fullness and wholeness of care they might offer.</td>
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<th>My reflections</th>
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| Sadly, perhaps even with his stories told and written, Bert will remain in-valid in his current setting, however much he might need to reside there. Zola’s question of how a unit like Bert’s can be accredited, and claim to give total care is a fair one. I see Zola’s ‘fullness’ for Bert as: honouring his still strong work ethic; providing him with a typewriter to use under gentle, respectful supervision during the daylight hours; and removing the things he values but will destroy over night, and returning them to him in the mornings. Perhaps this honouring of his wholeness or fullness, might lessen the impact of his night terrors, tiring him enough so that he will settle and sleep more. There is not time for the staff to meet these non-physical needs, and no money perceived as available for this sort of care. Less than total care devalues the person, exacerbates anxiety, rage and grief, and these emotions themselves produce mayhem and chaos (Kitwood 1997 p.101). My narrative work with Bert demonstrates a way to positively improve the care of people with dementia (Kitwood 1997, p.101). 

Bert beamed and seemed to physically expand, with such simple validations as showing him a photocopy of the page in the postcode book that confirmed his story of Booboorowie, a remote town in South Australia. |
Well Booboorowie Road was - I'll be drawing it out on a proper map the size of that type of thing [pointing to A3 map of SA] because that was right opposite the railway station, going out to Booboorowie.

S: I found that, that's the postcode book.

B: Oh good gravy! Yes. Oh yes, now I - yeah, Booboorowie, 5417. Oh yes, the post code, yeah that's right, yeah. I realise that, yeah.

b) Bert’s confabulations beyond the physiological

Jane Crisp, an Australian lecturer in communication, (1995) describes her mother’s journey into dementia, and discusses the issue of confabulations or pseudo-reminiscences. Crisp suggests going beyond a negative estimate of confabulatory stories based on their apparent confusion of past and present, truth and fantasy, to a more positive estimate of them as complying with the norms of narrative. They then become functional for their teller as tools of interaction and of reconstructing an identity. This attitude also allows for identification of certain predominant themes, which may help one to grasp the general sense of such stories.

Crisp (1995) asserts that people who are dementing are not wilfully lying. For them past and present, fact and fantasy get jumbled up together, much as happens in dreams. Thinking of their stories as waking dreams may help make them seem less strange and may suggest ways of understanding them better (p.133). Crisp suggests that no matter how fantastic a story seems, carers should stay open to its potential significance. She explains that

My reflections

Crisp (1995) helped me to make sense of Bert’s confabulations. They were a vexed issue for me in my work with Bert. I seemed to accept on one level what Crisp suggested regarding confabulations, but still quite late in my analysis of Bert’s story, found myself feeling guilty for checking on the internet, certain verifiable facts in his story, such as in the substantial archives of the Department of Veterans Affairs. I constantly asked myself why I needed to check?

So many of Bert’s stories described him as resourceful, coping, not scared, doing the job that had to be done, being rewarded for exceptional courage, in other words the person he wished to be. I gathered some evidence that some of his claims simply were confabulations, and then found myself asking ‘but what did happen?’ However overall, I had to agree with Crisp, it was the substance and essence of Bert’s whole story that allowed me to meet who he was, through his coherent narrative, albeit enhanced to turn it into a better yarn, as I guess I have done myself on occasions!

Bert’s pride in his family’s coping through the depression by using all the available resources, is an example, his proud ‘and as a result we managed rather well,’ affirmation of his own training at coping
the relevant criteria would no longer be the literal truth or fabrication of the details but such aspects as the credibility of the story line, the pleasure and amusement it gives the tellers and their listeners, and the overall point of the story - the underlying message or thematic and metaphorical meanings it suggests to us (Crisp 1995, p.135).

Crisp also suggests that it is worth noting that an account of the past which is not objectively true to the facts, may nonetheless be genuinely expressive of how that past seems to the person giving the account (p.136).

Killick and Allan (2001, p.106) write that confabulation could be regarded as an example of a creative response that gives clues to the underlying concerns of the person, and is therefore an important resource for communication.

Bert’s delight was touching, when I confirmed and validated parts of his stories, like the Booboorowie postcode and that there was a horse called Foxami.

A friend of mine was heading off in her car to wander around the Clare Valley in South Australia and I gave her a list of places she might visit further out, taking photos of the places Bert had mentioned. She took a film of photos of these places. His delight in the photos was wonderful to share. He destroyed the first set, so they were reprinted and then laminated and placed high on his bedroom wall. He turned his room around to face them, and drew the attention of everyone who entered his room to his place, his identity, focused in these places from his past. He used the word remember 284 times over all the tapes, mostly it was I can remember that! It was as if the photos assured him some parts of his story were verifiable (Killick and Allan 2001, p.106).

I wondered what Bert was trying to tell me when he related that his father held an important political office in South Australia, which was easily established via the internet as confabulation. Perhaps Bert was telling me of a time when his family were important and had power, in the light of his present feelings of powerlessness, and the ‘half-person’ he now described himself as being. In my intrasubjective response (refer my journalling in Appendix Nine, 2), after one visit I emotionally drew Bert as a fractured soul. Perhaps his memories and confabulations allow him, as Killick, Allan, and Crisp suggest, to hang on to his sense of coherence. My being with him, listening carefully to his stories, honouring them by reproducing them in print, and the intersubjective honouring that my responses brought him each week, must have made some difference to his well-being (Killick and Allan 2001; Crisp 1995).
c) Time and place, present and past

If we are able to help people to have rich experiences, then we manage to support the maximum functioning of the person’s memory. Consistency in time and place are helpful tools for encouraging better memory function (Killick and Allan 2001, p.113).

There is a possibility, however that the person could feel tested to remember. The power we as people without dementia wield in our interactions might imply that the value we place on the interaction depends on their being able to remember specific information (Killick and Allan 2001, p.114).

Killick and Allan (2001, p.104) explain that talk about the past features in conversations with people with dementia, as indeed it does with all of us. We need to pay careful attention to distinguish meanings that relate to the past and those that refer to ongoing situations. Killick and Allan talk about incidents and information that are connected by an emotional bridge.

My reflections

Bert described to me in great detail his delight in the fish, chips and strawberry milkshake meal he relished on one of his precious Thursday outings with the Activities Co-ordinator. This visit included Williamstown, where Bert once lived, so he became the ‘expert’ for the time they were there. This fits Killick and Allan’s description of rich experiences. A photo taken on the day and included in Bert’s copy of his story, shows a beaming, happy Bert. Regarding Killick and Allan’s suggestion that consistency in time and place are helpful tools, I know I confused Bert by changing the days of our meetings and missing one week because of The Melbourne Cup Day holiday. However this in itself, when we rode through the confusion, brought out his own stories of The Cup, (refer Chapter Six, 2.4.1) which added colour to the overall picture.

Bert’s anxiety to please me by remembering his stories, seemed sometimes almost subservient. It worried me. I hope he didn’t feel pressured as if he was being tested, as Killick and Allan (2001, p.114) warn.

B: I may have - being the first time I may have just misled you accidentally I notice I've got the ship, one particular ship I've got down twice where it should have been 2 different ships. Being the first time see,

B: I was about to tell you something and you interrupted me! Now I can't remember.

S: Oh ... I’m sorry.

B: It doesn’t matter! You're here to ask questions, and for me to answer. But, I forget what I was going to mention to you about.
On one occasion I think Bert was talking about the situation in his nursing home, where he believed for a time that it was another patient rather than the staff who were interfering with his things. He would not have been able to sort this out if I had asked him, so we in fact simply moved on. I think this conversation was a clear example of conversations about incidents and information that are connected by an emotional bridge. Bert seemed unable to comprehend that it was his own doing that destroyed the things in his room each night, and that it was this that made his relationship with the staff so fraught (Killick and Allan 2001, p.104).

Bert said at one point:

I'm glad you had this ‘I'll never stop being interested in learning something' - well that's quite true, I go by that every day, I, whatever I'm reading, or doing, or whatever I'm putting down on a bit of paper, I'm interested in learning from what I'm doing.

It was almost as if they were now my words, he seemed not to recognise that he had said them himself (Killick and Allan 2001, p.194).

<table>
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<th><strong>d) Making sense of dementia</strong></th>
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<tr>
<td>People who do strange, incomprehensible things are by their very nature disturbing. Killick describes the fear he felt initially working in the dementia unit, when the people with dementia behaved in a confronting way. They seemed frightening because he was unable at first to empathise with their motives and therefore saw them as fundamentally different from himself. One unsatisfactory solution of societies in this situation, is to lock these people away and to ignore them (Killick and Allan 2001, p.120).</td>
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<th><strong>My reflections</strong></th>
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<td>At times I felt confronted by the noisy intrusion of the other residents in the unit, such as Larrie with his constant pacing and yelling. I also acknowledged to myself, my fear that this might happen to me. This is Bert’s permanent home, where he clings to his own space in his room. It was all too easy to think, ‘what if this was me living here?’ Over the weeks I visited the unit, with staff changes and only an ‘acting’ Unit Manager, I did not have any kind of meaningful conversation with anyone other than the Activities Co-ordinator (Killick and Allan 2001, pp.120; 140).</td>
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### e) Initiating conversations

Killick found that it was seldom difficult to initiate conversation with residents (2001, pp.170, 176). They recommend that attempts are made to preserve the character of one-to-one meetings because of the unique benefits it brings to the person, but that interruptions by other residents were sometimes difficult to manage.

**My reflection**

Bert clearly wanted to talk, and therefore echoing Killick’s experience, did not require much direction. After following a general opener which Bert himself suggested should begin with his conception, he was off and running. Occasionally other residents interrupted us and this altered the dynamics of our concentration temporarily.

### f) Self-disclosure

Once a relationship is established there may be times when answering questions about oneself or offering information is helpful. Killick and Allan (2001, pp.177, 226) suggest this makes its own significant contribution towards affirming the person with dementia. They also suggest that photos are gifts to storytelling, that pictures and objects might help the person to engage more fully in their narrative by encouraging more memories, and enhancing the feelings of acceptance and validity.

**My reflections**

On one occasion I gave Bert a photocopy of a family photo of my grandfather’s Hupmobile car, with me in the photo as a young child. I had some misgivings about doing so, probably due to my strong nursing training not to self-disclose. I found Killick and Allan’s advice reassuring, and Bert clearly enjoyed the photo.

### g) Bert’s future: leaving him and walking away

In a dementia unit the outcome of collaborative work might well provoke vulnerability and the risk of further hurt. It is related to the continuity of what we seek to provide, and the danger of arousing expectations that cannot be met (Killick and Allan 2001, p.178). There can be difficult issues around the act of leaving someone behind when you finish the work, especially if you know that they are unhappy in their situation (p.190).

These are the moments when our efforts to make sense of the complexity of life operate at their

**My reflections**

I asked myself whether my collaborative work with Bert might have had the effect of provoking his vulnerability in such a way as to put him at risk of further hurt. The fact of my being able to walk away and return to my life highlights the gulf between my life and Bert’s. If, as Killick and Allen say, these are the moments when our efforts to make sense of the complexity of life operate at their deepest, and we can value such experiences for these promptings, I’m not sure that this was as easily absorbed as it was to write! I felt a continuing sense of responsibility for Bert in the aftermath of his telling me his story. I am unable to act other than by responsibly sharing his story.
deepest, and we can value such experiences for these promptings as part of my thesis (Killick and Allan 2001, p.190; Ellingson, 1998, p.3).

<table>
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<tr>
<th>5. Theme: The staff of a dementia unit</th>
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<tr>
<td><strong>a) Dialogues between staff: stress and conflicting values</strong></td>
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<tr>
<td>The sharing of insights between staff members is a particularly important aspect of giving care in a dementia unit. Killick (2001, p.140) observed that it seemed often to be in the discussion of specific incidents with others that new ideas and perspectives in the search for meaning actually emerged. Murphy (p.130) suggests that ‘contradictory reactions of kindness and rejection help make the treatment of the disabled the arena of enormous conflicts of values.’ Killick (2001) and Kitwood (1997) discuss the fact that the staff who were most caring towards the patients in dementia units seemed to seldom stay long.</td>
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<td><strong>My reflections</strong></td>
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<tr>
<td>I sensed ambivalent feelings on the part of the staff of Bert’s unit, and this is discussed further in my journal of my experience of working with Bert. The Activities Coordinator clearly struggled to find ways of improving Bert’s life. The staff who were most caring towards the patients in this unit seldom seem to stay long, reflecting the experience documented by Killick (2001) and Kitwood (1997). The Activities Coordinator left several weeks after my work with Bert finished, suffering from burnout, enormous distress and a deep sense of failure.</td>
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b) The staff’s surprise

In Killick’s (2001, p.16) work with people with dementia, staff were often surprised at the writing that emerged. This experience is also echoed by reminiscence therapist Gibson (1994, p.56), who explains that staff were accustomed to labelling people as ‘confused’ and as a consequence dismissed seemingly incoherent conversation as confabulation, and they often failed to listen acutely and to empathise appropriately. The patient’s records were simply a few lines, and the staff had no idea of the rich and interesting lives their patients brought with them. Gibson (1994, p.58) writes that involvement in her research project helped staff to acknowledge their ignorance of the people in their care. Gibson explains that the staff became intrigued and determined to discover and then to use the information they gathered through their reminiscence work with the patients. The staff grasped the possibility of using life-history as a working tool to enrich the quality of social exchange in the present.

Killick (2001) was starting to work with the nurse manager of ‘his’ unit, to see how his life review-writing work could be incorporated into care plans, and how he might give staff guidance on how to use life history work in their care of people with dementia. Exploring this idea further might enhance the care of many people with dementia, and thereby also enhance the well-being of their care givers (p.19). Killick argues that the very strangeness of the situations in which we force people with dementia to exist is likely to cause further disturbance to the sense of selfhood (p.23).

My reflections

Holstein and Gubrium’s (1995, p.21) words resonate with Bert’s situation in that labels applied to him by the staff as difficult or disruptive affect the way he is listened to, and might even result in him being dismissed as incapable of contributing anything worthwhile. When the staff of Bert’s unit read the folder of his stories, their apparent amazement that he was competent to tell such stories, surprised me. They seemed to have little concept of his previous life.

I would like to think that with Bert’s photos on his bedroom wall, staff might simply talk with him about his interesting life. It would be encouraging to see resources allocated for more of this type of care in units similar to Bert’s. I cannot help but wonder if withdrawal, and challenging behaviour like Bert’s at night, rather than being due to brain damage, is actually the result of the deprivation of opportunities for real communication.
## 6. Theme: Reminiscence and life review

### a) Reminiscence in dementia

Gibson (1994, p.46) explores the contribution of reminiscence to people with dementia. She warns that there needs to be careful appraisal of reminiscence work for its rich potential, so that it might be used effectively for people with dementia. Regarding the work of life review, Crisp (1995, p.136) writes that it seems possible that having a positive attitude towards being at the end of one’s life may depend not so much on what one has actually achieved as rather being able to make some sort of order and sense out of one’s past - in other words, being able to turn it into a satisfactory narrative … by asserting that one has been and still is a person of worth.

Crisp (1995, p.137) sees the fragments of stories that form together into a life review as scraps, pieces of a patchwork that survive from the past, joined together by narrating and organising themselves into a new whole around a central person. Crisp sees the importance of these narratives at a time when one’s sense of who and where one is are falling apart.

narrative provides a means of bringing the fragments together, and constructing an active identity for the narrator.

It may be that the act of transcribing and actually writing the words of the person, has the effect of reinforcing their sense of who they are (Killick and Allan 2001, p.194).

### My reflections

Gibson (1994) affirmed my understanding of the importance of Bert’s reminiscence work. Bert’s stories were indeed fragments that formed into a patchwork whole, organised and narrated into a sense of who he was, creating an active identity for Bert in his present situation (Crisp 1995).

Dementia patients like Bert, in an institution become just one of many. Bert’s confabulatory storytelling might be his strategy for survival, a way of propping up his threatened ego, a relationship where the balance of power is on Bert’s side. Bert knew what was involved in a good story, and this is what he offered me, the person to whom his story was being told (Crisp 1995).

Like Crisp’s mother’s favourite narratives, where she is very much the heroine, Bert was very much a leading part of his family’s coping strategies. I hear Crisp’s mother’s ‘it’s nice to know there are some things I can still do!’ and Bert’s ‘I can remember that!’ as being somewhat the same.

As Crisp writes it, Bert’s stories provide a sense of power to counteract his present confusions and loss of independence. They describe achievements due mainly to himself as the hero of the story. He guided lost planes home, rescued a drowning child, was in charge of war planes, received medals and awards, picked the best mushrooms and drove the mutton-birding team (Crisp 1995 p.139). Bert’s stories supported Kitwood’s (1997) argument for reminiscence work as being much more significant than simply revisiting the past.
Crisp (1995) explains that

for those in an institution, there may be the oppressiveness of regimentation and community living, of becoming just one patient among many … confabulatory storytelling can be seen as a strategy for survival, a way of propping up one’s threatened ego … a relationship in which the balance of power is on the side of the storyteller (p138).

The boasting theme running through many of Crisp’s mother’s favourite narratives, where she is very much the heroine, can be seen as a means of giving herself a powerful role to offset her actual state of powerlessness and dependency as proclaiming a right to be treated as someone of importance.

Stories built around solving a problem can also be seen as providing a reassuring sense of power to counteract present confusions and loss of independence. They describe achievements due mainly to the teller, who is the hero of the tale. Crisp says

sometimes these are fantasised qualities of strength, activity, resourcefulness and power which serve to compensate for an actual position of weakness and dependency (Crisp 1995 p.139).

Kitwood (1997, p.42) argues that at this point in history it is not convenient for any government to take the ‘rising tide’ of dementia seriously because it has such momentous implications for health services and social care. In discussing reminiscence, Kitwood (p.56) suggests that there are ways in which biographical knowledge could be incorporated into care planning and practice. Although dementia involves major losses in cognitive ability, it is known that long-term memory often remains relatively intact.
### b) The re-constructed past

Linda Garro, a professor of anthropology, (Garro and Mattingly 2000 p.70) discusses how in describing their experiences, people reconstruct past events in the light of their present situation. The present is explained with reference to the reconstructed past, and both are used to generate expectations about the future. Garro says that

> narrative accounts convey the effort to make sense of the past from the perspective of the present. In going beyond a recitation of what merely happened, these accounts point to meaningful connections among events and states of affairs.

Garro also assures us that literal recall is ‘extraordinarily unimportant’ (p.71).

#### My reflections

Bert talks about his yearning to return to his beloved South Australia in a future in which he has somehow rehabilitated himself. I wonder if, as Garro suggests, Bert’s constant references to the culture of drinking in which his life seemed to be saturated, is expression of his struggle to explain how his admission to ‘this little nursing home’ came about, and how in understanding that, his way out might be found, though as he puts it: it will take a million pounds. In response to a destructive downfall like Bert’s alcohol induced dementia, the reconstruction of the past in accounting for his illness, and dealing with his admission to the secure unit in the present, and his hope for escape in the future (‘next year, after Christmas’), are often closely connected. Through the fog of his confusions and confabulations, Bert does this through his stories. Garro reassured me that in Bert’s world his literal recall is ‘extraordinarily unimportant’.

### c) Charm and beauty: valuing Bert’s presented world

Reason and Rowan (1981, p.32) affirm that in using the process of collaborative inquiry, a person’s presented world is valued. It can be valued for its own language of charm and beauty. Abram (1996 p.155) writes of the storied earth in the landscape of language, and that the Apache Indians like to pronounce place names ‘because those names are good to say.’

Psychiatrist Robert Butler (1963) describes in his life review-reminiscence work, how older people report the revival of the sounds, tastes, and smells of early life.

#### My reflections

Bert’s presented world was valued when I listened and responded to his love of South Australia. It was valued for its own language of charm and beauty, such as when with a deep sigh of longing Bert said

> The Barossa Valley was, it wasn’t north of Adelaide, Barossa Valley was north-east. I’d like to have a photo around, or two, or one anyway, of the Barossa Valley. Oh, the Barossa Valley. [big sigh] Yeah....... 

Bert and I had a number of discussions around the names of places in his beloved South Australia, The Wildongaleechy Pub, Booboorowie, Whyte Yarcowie, Terowie, to name a few. I remarked that I had trouble pronouncing them, he said he had heard
little else over the years, in other words, they were part of his cultural language. Like the Apache Indians Bert loved those names, they represented his place in his storied earth (Abram 1996, p.155).

Reading Butler’s (1963) comments of how older people report the revival of the sounds, tastes, and smells of early life, brought to my mind Bert’s description of the mushroom sauce his mother used to make from the mushrooms the children collected for the short season they were available:

there was such a place in - oh only 6 or 7 weeks of the year, as you know, in the mushroom period. About Easter time. But we used to know a particular spot there, and we used to get them and I’m not joking or pulling a lie, you know the old kerosene tins, this high, we used to, each of us, we’d have them full up and take them back home and go back again ... You know mushroom syrup ... You look in your recipe book you’ll find it, ketchup, mushroom ketchup, mushroom syrup. Oh yes, it tastes terrific, just like the mushrooms. Oooh, beautiful! Yeah, but I can remember coming home with these - and sometimes we’d come home and then go back, there was only about 6 weeks of the year.

7. Theme: Truth and values

Introduction
Bruner, J. (1986, p.12-14) discusses the vexed issue of truth. He says that a story’s aim is to endow experience with meaning, which is the question that preoccupies both the poet and the storyteller. The imaginative application of a narrative mode leads instead to good stories, gripping drama, believable though not necessarily ‘true’ accounts. To move on with life, the

My reflections
So many of Bert’s stories reflect his journalistic ability, humour and simple story telling skill. To move on with life, the future needs to be reorganised, and in this reorganisation, space is created for new and different thoughts about one’s life. This fits well with Bert’s ‘hoped for end’ (refer Chapter Six, 2.2). Any grasp of reality now possible, requires Bert to come
future needs to be reorganised, and in this reorganisation, space is created for new and different thoughts about one’s life (Butler 1963, p.74).

Anthropologist Crapazano (1980, p.5) describes his work with Tuhami, a Moroccan, which he describes as ‘an ethnographic encounter’. His book is about his own need to make sense of the story that Tuhami, an illiterate Moroccan Arab tilemaker, related to him with the help of a field assistant. Crapazano expresses the difficulty he feels about parting with any of the fragments of Tuhami’s story. It seems to Crapazano that Tuhami’s tale expresses the desire to be recognised as exceptional (p.10). Crapazano describes the privilege of his re-encounter with Tuhami, and confesses that he cannot resist finding reality in Tuhami’s story (p.42). In the end Crapazano notes that his work with Tuhami shifted from fascination and joy to concern and worry. He was coming to know Tuhami as a person and beginning not only to sympathise with his condition but to empathise with him. Care had entered their relationship (p.141). Crapazano explains it is an active granting of importance - importance for oneself - to the Other’s subjectivity. The Other must matter in one’s own self-constitution; he must not simply be an object of scientific or quasi-scientific scrutiny.

John Heron (1981b, p.32) explains that because we value our encounter with what is there, we know how to symbolise it in words, and so our statement has the value of truth ... it presupposes a shared community of value of delighting in and valuing the world as it has been encountered.

to grips with a great deal of modification to his expressed wishes, if he is to have any sense of peace and acceptance at the end of his life. His residence in the locked dementia unit is not changeable as far as I could ascertain. For this acceptance to happen, Bert will need to make space for new and different ideas about his life, which can then be incorporated into his identity. I sadly fear that it is too late for this to happen for Bert (Butler 1963, p.74).

I felt many connections in my work with Bert, to Crapazano’s (1980) work with Tuhami. More than any of the other narratives in this study I felt it was almost impossible to choose which stories of Bert’s to ‘let go’ in the final essence. Bert’s story seems to ask me to recognise his ability to manage very well, to express himself very well, and to use resources very well. Unlike Crapazano and Tuhami, the privilege of re-encounter was not available for me, with Sarah, Bert, or Scott. Another comforting, similarity for me, Crapazano cannot resist finding reality in Tuhami’s story (p.42). I could not resist searching for reality in Bert’s story. Like Crapazano, I struggled to deal with my own feelings in my journalling of my work with Bert. My connection through the literature to Crapazano and therefore to Tuhami, was reassuring.
### a) A sense of place

Social commentator Hugh Mackay wrote in The Age Good Weekend Magazine (October 15th, 2005) that he suspects that much of the uneasiness, anxiety and moral uncertainty of modern urban societies can be traced to our loss of a strong sense of continuous connection with the places that help us to define ourselves. Places shape us, the places according to Mackay, where we feel the magical sense of belonging and being connected.

*My reflections*

Bert described his strong sense of connection to his beloved South Australia, remembering many of the details of his life there. It was his way of describing his appreciation of the world he valued more than any other, ‘where I wish to be’. Heron (1981, p.32-33) explains that this sets out the truth-value of Bert’s story, and behind that lies the being-values of Bert’s world. His story has such a ring of sincerity that I have no doubt about his intention, I hear his valuing of his beloved South Australia. I could rejoice in Bert’s love of South Australia, I have been there often enough to picture what he describes, I value what he values. He expresses his longing to return to the place where he feels he belongs. His clinging to this sense of his continuing connection is poignant in the face of his need to remain in the confines of ‘this little nursing home’ where he will have to end his days. The photos on his wall are all that remain of his connection to his definition of himself (Mackay 2005).

### b) Commemorating moments of value

In The Good Weekend Magazine in The Age, an article by James Hillman (1999, pp.53-56) suggested that geriatric psychology finds that older people spend more and more time doing their ‘life review’ as work of recovery not from the past, but of the past. It is the work of ageing. Hillman suggests that if past time is not to be lost time, one must give it presence. He writes that as we age, something in us wants to return to distant halls and dusty mirrors. Hillman suggests that character consolidates by commemorating moments of value in oneself. Old age gives time to commemorate our achievements, and those people we were involved with. Hillman

*My reflections*

It is perhaps my valuing that Bert absorbs into himself, that draws him out of his room and into the relationship we construct to collaborate in recording his stories. The Activities Co-ordinator told me that he had previously seldom left his room willingly. I did not ever need to encourage him. Bert’s work ethic could be thoroughly satisfied with the effort he put in to telling his stories. In Bert’s case the stories that drew him were of favourite food and farming, where they managed resources very well. Hillman’s suggestion that character consolidates by commemorating moments of value in oneself is important in understanding Bert’s confabulations. He seemed to need to tell a story where he was
saying that life review attempts to turn events into experiences, to draw out their emotion and gather them into patterns of meaning. Memories can warm, become more pleasant, not hurt as much, musing may even make them amusing.

Bert’s snake bite story enabled Bert to be a sort of hero, surviving by knowing to ‘suck and spit, suck and spit’ and allow the humour he included at the end of the story to enhance his coping style, ‘I wasn’t scared.’

S: What happened to the snake? [laughing]

B: Oh it probably lived, led a happy life! Probably had some snakettes! [laughing] Oh incidentally, snakes don’t have - lay eggs at all. Snakes don’t lay eggs of course.

c) Work ethic

Kitwood (1997, p.83) explains that:

To be occupied means to be involved in the process of life in a way that is personally significant, and which draws on a person’s abilities and powers ... The need for occupation is still present in dementia ... the more that is known about a person’s past, and particularly their deepest sources of satisfaction, the more likely it is that solutions will be found.

My reflections

Bert’s still active sense of work ethic can be heard in this section of transcript:

B: I’m not going to do it straight away, but I do intend to write a book each in, completely in French, and one in German.

S: That will be challenging.

B: Yes. But then again, it’s been done by others so ... [laughs] it won’t be a first.

S: No. Mm - so you’ve got a lot of work to do ... 

B: Oh well, if you do a little bit each day, you don’t go and do everything all in the one day, by any means. Like today when we’ve finished here, then I’ll go and get absorbed in the maps and so forth, and make a few notes, and write a few notes out.

I asked Bert if he enjoyed writing. Bert replied:

B: Oh yes, still do. Oh yes, I’m looking forward to getting my typewriter though. But today being Friday I’ll have to wait now till next
8. Theme: Buber and intersubjectivity

Moustakas (1990, pp.173,181) explains that inter-human conversations were able to open what otherwise would have remained unopened. Here Moustakas is referring to the work of Martin Buber (1923) and his understanding of the need for us each to see the ‘other’ as a ‘Thou’, in order for us to become an I to ourselves.

Kitwood (1997, pp.10-11) also discusses the work of Buber, suggesting that daring to relate to another as Thou may cause us anxiety or even suffering. Buber sees it also as the path to fulfilment and joy. Kitwood writes about one of the most famous of Buber’s sayings that ‘all real living is meeting’. This requires openness, tenderness, presence (present-ness) awareness, and for Kitwood the word that captures the essence of this meeting is grace. In a meeting where there is acceptance, with no attempt to manipulate or overpower, that is, a meeting of equality, there is a sense of an expanded way of being (p.11).

Kitwood (1997, p.12) suggests that Buber gives absolute priority to engagement and commitment. In discussing intersubjectivity and its limits Kitwood reminds us poignantly that no one has returned from this particular journey of cognitive impairment in order to tell us what it is like. He explains (p.71)

> If we try to describe the experience of dementia in ordinary prose, we are using the calm, detached and highly ordered vehicle of language in order to convey impressions of a state of being that is often fragmented and turbulent.

Here, as Kitwood sees it, in Buber’s terms, a problem arises in the repeated failure to

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**My reflections**

Moustakas (1990) provides a framework for Bert’s narrative by explaining that the conversations that Bert and I recorded were able to open what otherwise would have remained closed. It seems that very little of Bert’s story was known by the staff of the nursing home which is now his home for the remainder of his life.

Kitwood’s (1997) discussion of the work of Martin Buber suggests that daring to relate to another as Thou for the staff working in units like Bert’s, may cause anxiety or even suffering. In Bert’s situation, for myself I add anger with the system. I hope I achieved a state of acceptance and grace with Bert, I think we established a degree of trust, but it was often difficult (p.11).

Sadly, it seemed to me that I sensed from the staff that Buber’s I-It was simply what Bert ‘deserved’ in response to his ‘bad behaviour’ at night. Perhaps Bert had never developed a personal ‘feeling language’ through which to contain or comprehend the range of his experience. Throughout my journalling of my experience of working with Bert, poetic statements were a mode of expression I found helpful. I think Bert’s most poignant story was a description of his ‘next book,’ and I re-formed it in this way, in the third person, so as to change its appearance and grasp what it was saying to me:

> The title of his next story is Two Dozen and a Half, not Two and a Half Dozen.
> The half is a person, he’s written it in first person tense, he put himself
meet a person as Thou, and therefore there is an imposition of an I-It way of relating (p.89). Kitwood writes that the stories people tell about experiences in their past are often rich in metaphor related to their present situation (p.74). He continues that one way of understanding dementia is through the use of our own poetic imagination (p.76). Kitwood says poetry allows an essence of the experience to emerge.

Whilst Kitwood (1997, pp.86-87) suggests that there is better dementia care than ten years ago, the plea for even better care still, can be noted. An ethic of respect for personhood pleads for it. Kitwood (p.118) argues that it is common for staff to be poorly supported, undervalued, and given little opportunity to develop their potential. He continues that as soon as people with dementia are seen as merely ‘behaving’, an essential feature of their personhood is lost.

The following is another inter/intrasubjective response I wrote in poetic form, called ‘For Bert’. I did not expect that at that stage he would read it, however it was written in order for me to see more clearly what Bert’s life was like:

When you were at home to yourself, in South Australia;
when you were who you were, when you worked and then shared a drink with someone and had a meal.
Once you were an important person, who knew important people -
You can remember that.

It can be seen that Bert’s ability to sustain his first taped narrative over 90 minutes, and then express his disappointment when the second tape ended at 60 minutes, demonstrates a need for long, engaged conversations. In my experience of working in Bert’s unit, it seemed that the empathic, caring staff did not remain working there for long, they soon burnt out and resigned, and less skilled staff continued, not able to meet the psychosocial needs of the residents. In Bert’s case, his destructive overnight rages cause him to be seen by the staff as ‘behaving badly’, and therefore an essential feature of his personhood was lost. (Kitwood 1997 p.118).

9. Theme: Ethical considerations

Killick and Allan (2001, p.39) argue that people with dementia are so much less powerful than people who do not suffer from dementia. Their words are assumed to be confused, and their preferences and choices likely to be disregarded or treated down just for the story as the half, the person in the first tense, just using himself, he’s been promised a million pounds if he could rehabilitate himself, get back to a normal straight course.

My reflections
Killick and Allan’s (2001) argument that people with dementia are treated as irrational or unreliable felt to me exactly how the nursing staff saw Bert. I found it
as irrational or unreliable. Killick and Allan (2001, p.39) continue that the access that people with dementia have to resources such as money, goods and the kind of interpersonal contact we all take for granted, is often severely restricted. They suffer not only from the immediate consequences of these limitations, but also the indignity and injustice of the knowledge of them. Killick and Allan (p.40) suggest that personhood is formed and maintained through relationships, and that relationships are inherently reciprocal.

There are a number of ethical issues around working in narrative life review with people with dementia, mostly in their lack of control over the documents produced. According to Killick and Allan (2001, p.206) it cannot be respectful to the person to distribute highly personal information within a staff group without any consideration of privacy. Killick and Allan admit that this is a minefield, and that always being sure of having done the right thing is probably impossible. In working with people with dementia, Killick and Allan believe that it is best to leave the words used as they are spoken (p.198). Medical ethicist Richard Zaner talks about the ground of ethics being closely bound up with the form of reflexive relatedness to and with the other person (Zaner 2004).

Sad when he referred to the simple act of buying the newspaper each day, that in reality he is unable to enjoy this simple pleasure and freedom:

B: I used to have an Argus, when I was in Melbourne, I mainly had The Argus and The Daily Austen.

S: And what do you get to read now?

B: The Age. Over here. But I get a South Australian Advertiser occasionally when I'm down the street. Like it's Friday tomorrow, I'll be going for a walk down the street again. Tomorrow.

I checked, and no such trip was possible. I wondered if Bert’s feelings of powerlessness fuelled his frustration and anger, and so his night terrors? Is it for Bert a perpetual circle of more night terrors → more staff anger → his frustrations and anger → more night terrors? Do we as a society see people with dementia as having nothing to give us, therefore our relationships cannot be reciprocal? Bert not only gave me the very best of his story telling ability, but he put in a great deal of work over the weeks to write his stories, albeit on the paper towel provided. One of these stories was poignantly called ‘I am Offering a Slice,’ which strikes me as an extraordinary reciprocal gift for our collaborative work together, he is offering me a slice of himself and his life. It was this that made it all worthwhile for me.

Bert gave written consent for our work and my study, with enthusiasm and apparent understanding. A copy of Bert’s life review was put away for his family if ever they should visit, even after his death. I worried about the security of this document from an ethical standpoint, but there was little I could do about it other than hand it over to the Activities Co-ordinator and Nursing Unit Manager. I think his family might have some difficulty coping with his confabulations, and that it might not be
such a positive outcome for them, unless they are able to read the essential meaning beneath his words (Killick and Allan 2001, p.195).

Given Killick and Allan’s warning of a minefield, (p.198) Bert’s story did not seem to me to contain information that might be really damaging to anyone, which gave me some comfort, and he seemed proud to share it with anyone who showed interest. The outcome was a collaborative effort between us, and I think it enhanced his sense of self-worth for at least a time. I transcribed Bert’s tapes with meticulous care. There was only one word in the whole document that I changed deliberately, and this was an unfortunate word that Bert had mispronounced. I felt as if I was protecting his dignity by doing so.

10. Theme: Conclusion

a) Approximations to meaning

Lett (2001) and Reason and Rowan (1981, pp.43-51) suggest that *approximation to meaning* might not sit with the standard psychoanalytical model or psychology training, but it sits well with collaborative inquiry.

*My reflections*

It was necessary to listen carefully, hear and understand what was deeper than Bert’s words.

b) The poetry

Parts of Judith Wright’s (1994) poem ‘South of my days’ seemed poignantly to reflect and resonate with Bert’s experiences and presence:

... a story old Dan can spin into a blanket against the winter.  
Seventy years of stories he clutches round his bones.  
Seventy summers are hived in him like old honey.
... he shuffles the years like a pack of conjuror’s cards. True or not, it’s all the same; ...

... I know it dark against the stars, the high lean country full of old stories that still go walking in my sleep.

c) The benefits of the process

Killick and Allan (2001, pp.115) suggest that it is not so much the activity itself that dictates the nature and meaning of the experience, but rather the way that it is done. In Gibson’s (1994) studies, she wrote (p.57) that the most obvious outcomes for the people in her project who received concentrated personal attention informed by detailed knowledge of their life histories, were undoubtedly increased sociability accompanied by decreased aggressive or seemingly attention-seeking behaviour.

My reflections

I’ve had a number of conversations with academics and fellow students who suggested my need to develop a tool to measure outcomes of my research, such as an improvement in depression scores. I grew into my understanding of approximation to meaning (Lett, 2001). It took me quite a while to gain understanding, like a flow of approximations, or developing meanings, over many years. Almost daily my own approximations to meaning change as I reach deeper levels of understanding (Lett 2001, Reason and Rowan 1981, pp.43-51).

When I asked Bert ‘how has this process been for you, have you enjoyed telling me the stories of your life?’ he replied ‘it’s not a matter of enjoyment, or non-enjoyment. This is my life!’ What is behind his answer, for me, is:

I have told you who I am. Not the person here in this place, but the person who shares these stories, not the physical wreck you see before you, but a person who has lived and had amazing experiences.

How could I have presented him with a questionnaire that asked it better? I needed only to listen carefully, hear and understand what was deeper than his words, the essence that would emerge given time.

I agree with Killick and Allan (2001) that it is not so much the activity itself that
dictates the nature and meaning of the experience, but rather the way that it is done. I think the end result of my work with Bert was an overwhelming improvement in his feeling of self-worth, no matter how short lived that might have been after we finished. The photos on his wall were a continuing reminder to him of the person he had been. I have recently heard that the photos are still on his wall and still the focus of his attention.

It was clear that Bert had enjoyed the process. It also brought him out of his room and thereby improved his socialisation. I continue to wonder if Bert’s night terrors and isolation might have gradually improved, if his “work” of telling his stories could have continued. I know I gained a great deal from knowing Bert, including learning about the ravages of dementia. I would like to think that my work with Bert enhanced the unit staff’s knowledge of Bert, and of alcohol induced dementia.

2. MY JOURNALLING OF MY EXPERIENCE OF WORKING WITH BERT [FULL TEXT]

I went to the dementia unit to meet Bert and the Activities Coordinator (henceforth the A/C). It felt slightly confronting entering the locked door, and I did not dwell on the other residents shuffling by, needing to focus on the meeting with Bert. I was impressed with the pleasant surroundings, in soft colours, with art work decorating the walls.

The A/C and I agreed that we would record three sessions initially and then review the situation. As he happily scratched his head and shuffled through his papers, intense with anticipation, Bert told us some beginning stories about his childhood. By this time I was full of enthusiasm, feeling a sense of anticipation, and wishing we could begin sooner. I felt encouraged and enthusiastic for the process, and full of hope that Bert’s family would value the stories we would record.
I felt a sense of excitement and possibility
that I would be drawn
into the stories of this
interesting man.
Alcohol induced dementia maybe,
but his stories are alive and well,
Like fruit, ripe and bursting to be picked.
The taste of the visit lingered with pleasure,
though I pondered his truth, his confusions,
his unrealities.

As I indwell (refer Chapter Two, 3.8) the task ahead, I wonder how much I will need to
believe that the stories Bert tells me are more or less accurate, or merely fantasies of his
dementia. I remember and re-read Crisp (1992). I remind myself that Bert will find value
in telling the stories, and I will see this in other ways than his necessarily telling me of this
valuing in words. And it is not necessarily important that the stories are accurate
historically, this is not their most important value.

So as I transcribe, the MIECAT process will help me to indwell Bert’s stories, and
experience their essence, allowing their meaning to be recognised, and valued by Bert,
me, and readers of my study.

Crisp (1992) sees the weaving of her mother’s narratives out of fragments drawn
indiscriminately from the real and the fictional is likely to be seen as evidence of
‘confusion’ rather than as duplicating the process of *bricolage* where by any narrative,
fact or fictional, is constructed. I discussed the word *bricolage* with a French-speaking
friend and came to understand the picture of fragments, or pieces of scattered stories,
forming together to create a new picture, like lots of torn up fragments of many pictures
being used to make a new art work of new value and new meaning. A bricoleur is a
person who uses only the tools or materials at hand to achieve a purpose.

Narratives are an offering, a gift to the person to whom the story is being told; they
involve interaction with others, one should regard the sharing of memories, whether
fantasised or real, *as a form of personalized gift*. This says: I have something interesting
to tell you - a story means I am a person who has achieved these worthwhile things; who has had these special relationships; I am still worth having as a friend. The double agency such narratives give their teller - as teller and as major figure within the tale - would seem to function as a means of empowering someone in an otherwise massively disempowering situation like Bert’s.

2.1. The first session [90 minutes]

Bert was waiting for me and the A/C said he had been excited for days, anxious to know if I would keep my word and appear when I said I would. He eagerly left his room for the ‘relaxing room’, which amazed the A/C as he had previously been very reluctant to do so. We began by discussing the consent form, which he readily signed. When I explained the anonymity process he waved it aside, saying he did not mind, he was only telling it as it had been.

We used a photocopy of a South Australian road map to ‘find’ the places in the stories. As Bert focussed and entered into his early life, the noises of the other residents became less intrusive. They wandered past the window and even peered in, but the focus was not disturbed (at least at this visit). Several times we came to a pause and we’d both look at one another and say ‘where to from here’ and almost instantly could plunge back into the stories.

I loved watching his long, pale, thin hands describing his story as he went along. His gentle grin caused his badly fitting denture to fall in his mouth, giving him a rakish appearance. He so enjoyed the experience of being in his own stories he quietly glowed. His reminiscences resonated with an authority of his own knowing, though I was still silently seeking my own validating of the facts.

As I transcribed I felt my intrasubjective responses surface. The early Hallet stories brought memories of my own childhood, which although quite some years later than Bert’s, still depression/war affected. However my pacifist self began to react to Bert’s almost complacent acceptance of bombs and mayhem in his war stories and I needed to bring these feelings to the surface of my consciousness. I wrote:
Being just post-New York terror,
I want to scream ‘No! you were young men,
So were ‘the Japs’ as you called them, so were the people of The Ruhr Valley
whose dam walls you biscuit bombed.

Our world hasn’t yet found a way other than violent.
I feel a sense of drowning in despair for the world,
my dam wall breached by terrorism!

He told me how he coped. He had a job to do, he focussed on that, didn’t think about the
rest, shrugged his shoulders and got on with it. He smiled as he told me that his tears were
for interrupted leave, rather than my expectation of death of comrades! I wondered if he
was playing deliberately cool.

I rang the A/C to confirm my next appointment with Bert. She said he was ‘full of it’ after
I left, expressing his hope that I would go on. She said he had a real spring in his step
after I left. I was pleased, but it felt like a huge task to absorb it all.

After about 12 hours of transcribing I felt weary and overwhelmed by the constancy of
the transcription task. Various people suggested that sixty-minute tapes were better, and
would lessen the impact of transcribing. I felt a sense of relief deciding this was a good
way to go. I had heard a finish in our first tape at about the one-hour mark but then re-
opened the conversation, where it could have quite comfortable ended.

2.2. The second session [60 minutes]

Spring was bright and sunny outside
Inside felt locked in.

Bert was pleased to see me and came happily from his room to the ‘relaxing room’. He
seemed delighted with the folder I gave him, most especially with the map. He showed
me his atlas and told me a certain member of staff ‘who would remain nameless’ had
removed the pages he wanted. I wondered if he tore books and if this was why he seemed
to only have paper towel to write on. It was the first sign of his paranoia I had seen, and I
steered him briskly back to getting started. I’m not sure if that was the right approach,
but we could have spent our hour down that path. He appeared scruffy and crumpled, hair
on end, mouth dry, as if he had no regard at all for his bodily appearance. He constantly scratched the top of his head.

He gave me his response to last week - a wad of paper towel with neat printing, delightful caricatures, and said it was for me (rather shyly I felt), or if I didn’t want it he would send it off to The Advertiser. I accepted it with delight and said I would try to scan it into my computer. He was pleased, and urged me to read one funny story he had written, and was clearly pleased, with a big grin on his face when I laughed at the end of reading it.

The reduced tape time went quickly, full of light and confidence, clearly I am gaining his trust. He wanted to go on when I pointed out that the tape had clicked off, and we talked for a few minutes - he had lots of ‘work’ to do to draw and write for next week - he checked a number of times that I would come back and I wrote it in my diary clearly in front of him. My diary prompted him to ask how much such a book would cost. Last week he asked about the cost of the multidirectional microphone. Does he want them? Is he prevented from having books?

As I opened the door to leave, there were 2 staff members outside the room serving afternoon tea. They looked astonished as Bert breezed out, cheerily thanked me for coming, said he would see me next week and added that he would do his hair for me next time!

As I transcribed at least two identifiably separate stories from this second tape, I heard again a joy and excitement in Bert’s telling of the story, and the pleasure I felt in listening to them. His voice went up several notches, he laughed, and at the end when I made a comment about my enjoyment, he shrugged it off with his usual deprecating remark that it was just how it happened!

The costing questions (diary and microphone)
the paper towel writing and the story about the missing pages from the atlas,
struggled to the surface feeling to me like a lack of knowing.

Is the paper towel the best Bert can have to write on for his safety?
I felt the urge to find him
a diary for his own use.
Was I needing to rescue him, expand him?
Would writing our appointments in his own diary
reassure him of my commitment?

I feel a need to know more
from the health professional care team’s
point of view.
Am I needing to see myself aligned with the health professional team?

Or should I be just meeting
with Bert and I in that room
Two people with his stories,
ordinary and real.
If I had professional knowledge
would that distance me from him?
Surely not.

2.3. **The third session [60 minutes]**

I felt a sense of acceptance and acknowledgement from the staff when I arrived and was leaving, and also from Bert, but particularly from the A/C. The process is so clearly having an enlivening effect on Bert, and he told me how much he was enjoying it, he said he could not do without it now! The A/C has asked me for a copy of what we have done so far, so that the Director of Nursing might apply to Veterans Affairs for funding. This feels affirming not just for me, but for the value of the work for Bert. The A/C wanted to call it reminiscence therapy. I am concerned about the confidentiality aspect. The A/C is also hopeful that Bert’s family might be interested. Somehow I have doubts about that. Bert just seems to want his stories to be heard and doesn’t care who reads them. If they appeared next week in his beloved Advertiser I think he would be pleased!

Bert told me two quite emotional stories today, of the demise of his first marriage, and also the death of his second wife, and I think this was a real measure of the trust that has grown between us. He allowed himself to be quite sad in the telling, which was a change
from his brisk matter-of-fact norm. Today it was really obvious that Bert had trouble speaking because of his dry mouth and poorly fitting dentures. They kept dropping down and he was holding his hand over his mouth, it was bothering him. He had his papers spread all over the table, and much of the time his hands were comfortably behind his head as he talked.

I ask the A/C about the books and why the need for photocopies, and she told me he sometimes soiled them, or in his messy ways tore pages. When I saw the state of our work, and the cover of the folder I had given him, I could see what she meant! However he told me he really appreciated the things I brought him each week that I had looked up for him. The A/C offered to copy anything while Bert and I are working, such as The Dam Busters next week if I can borrow it from the library. He was really pleased, almost a bit embarrassed to be so pleased about the ‘Honeymoon Story’ I had separated out from the transcript (refer Chapter Six, 2.4.1). He looked at it with delight to find that particular bits of the story were there; he was beaming with pleasure. When he read my intersubjective response with the line he said about never stopping learning, it was as if I had made it up but he resonated with its accuracy - he said how glad he was that I had put that bit in.

It hit me like a ton of bricks when I got home and was sorting through the papers. Bert has called the paper book that he presented me with ‘Promoting Group Harmony’ - why have I only just noticed that? What did he mean? What else is there for me to see?

I hear again in this 3rd tape how much focus in Bert’s life has been placed on alcohol. The Coopers beer in Hallet, The Willdongaleechy Pub, the brewed hop beer, over and over stories about alcohol. Is this the life of ‘those days’ or is there way more alcohol than in my experience? Perhaps there’s a Post-Methodist voice of disapproval in me that needs expression. Do I see Bert’s predicament now, with alcohol induced dementia, as a result of a life of hard drinking? Am I being judgmental, or is it just like smoking related lung cancer?
2.4. The fourth session [60 minutes]

There were nuances of sadness and disconnection throughout today’s session that left me feeling disturbed, unsettled and needing to re-focus on what it is I am trying to achieve with Bert, at a financial cost to myself, and a not insignificant physical demand. He was upset when I arrived and started immediately to tell me how his folder had been damaged, leaving him with an incomplete set of transcriptions. He seemed most upset about the missing title page, and I promised to bring him another one. He had done work on the corrections, and some of these pages were missing. He described it as being done by a member of the weekend relieving staff, and when he complained to the staff he was not at all reassured, he said they had told him it was his own private business. I wondered if he had done it himself, or if another resident had visited his room.

I felt sad for his distress and anger and assured him it was all easily replaceable. It all felt disjointed and muddled, and Bert’s confusion was evident in the transcription. These confusions were clear evidence of the reasons for his living there. But his wish to revisit the Melbourne Cup, Wonthaggi, South Australia, all impacted on me with this feeling of loss of control of his life, and his lack of ability to finish his life with any sense of freedom or control. However at the end of the session he bounded off to his room with a really cheery ‘goodbye and thank you!’ There is no doubt about his enjoyment and the value the process had for him.

My conversation with the A/C was not really encouraging. There is no money available for such work, she impresses on me. She photocopied The Dam Busters, quite a chunk of it, we both having decided to give it to Bert in instalments. She came with me to take it back to him in his room. He was sitting pouring over his books, and was clearly delighted with the photocopy. He just lit up and recited ‘Oh squadron 317 and 617! I will enjoy reading this!’ I left feeling he would be happily absorbed by it over the coming week. That night I had a powerful and disturbing dream.

In the dream there was confusion and mess everywhere. When I woke up the feeling was of the shattered dreams and illusions of the time in my life the dream represented. I felt it connected somehow to Bert’s sadness, buried under layers of his normal, almost gruff exterior. I realised that I left the transcript before I went to bed, in the place where Bert is
describing the shattered remnants of his first marriage and I think, the un-stated relationship to his own sons, particularly the youngest two.

I can hear Bert clearly set out the no-go area as we talked about his sons. I sensed his disconnection from them, he was very quiet and sad as he described the end of his first marriage, and didn’t describe how it was for him being separated from these youngest boys, who he perhaps hardly knows. I felt his sadness.

At this point I wrote and drew my 4th intra-subjective response, with 4 doors, one containing the two sons he does not talk about, which seems to be a door that is firmly closed. I shared this with my collaborative research partner Jane Gorey, to be sure that my respecting this door and not knocking on it was the best response, given my lack of understanding of Bert’s paranoia. Perhaps it is simply that he does not have any stories about these two boys.

I sense a hard life with little in the way of softness or love, and it occurs to me that I haven’t heard Bert mention love once. I search through all the tapes and find myself saying ‘love of trains’ ‘lovely little stone churches’ ‘lovely story’ and then I find Bert saying ‘I’d love to get into contact with...’ But that’s it, no other mention of love.

2.5. The fifth session [60 minutes]
Bert was sitting in his room lost in his reading when I tapped on the door. He smiled broadly and said he was waiting for me, and would join me in the relaxing room.

He arrived there visibly upset because his satchel ‘had been taken’. He said he had been told that another patient had taken it to hospital, and that Bert could not have it back until that patient returned. It contained all his precious papers and preparations for this session. He was angry and restless. We began in a muddle of missing pages and those he had spread in confusion over the table. He told me he had spent much time building corrections into the transcript, such as spelling of place names.

I turned on the recorder, and felt touched, comforted by his statement that he was now more interested than ever in this process. I felt that I had turned the recorder on too early, but had I not done so I would not have captured that lovely affirmation of how Bert felt about my visits and the work we were doing. However it was a while before we both
really settled into the story. As we settled I felt myself being drawn into the story and we were both surprised when the first side clicked off. At the end of the tape I suggested to Bert that the tape must have been going around faster! Surely an hour couldn’t go that fast!

Am I giving him too much factual stuff? This week I seemed to have gathered quite a lot - about the Beaumont children, about The Melbourne Cup winners, about Harold Holt’s drowning, one of my family photos of my grandfather’s Hupmobile car, and a brief account of the disappearance of Sir Charles Kingsford Smith’s plane, with mention of the Melrose son that he talked about. The Melrose name from the internet seemed incredibly important to us both - a solidification of his story. He seems quite delighted, it is almost as if the facts in print from me give validation and value to his previous story, and confirms the dates even when he (and I) have got them wrong in the telling. I hear his oft repeated ‘yes I remember that’ as affirmation to himself that his memory is still working, this did happen. Confirmation of his story, (more or less accurate doesn’t seem to matter) brings a happy ‘yeah, I remember that!’ Like it has affirmed that at least part of his brain is still in tact.

The interruption with his sandwiches and tea, which Bert seemed embarrassed about, felt like a bureaucratic intrusion to me. He dunked the sandwiches in the tea and tried to swallow them quickly and quietly. Why did they bring them this day and not the other days? It felt rather as if the person who came into the room wanted to see what we were doing with the door shut. Or Bert might have perhaps grumbled about missing afternoon tea while we were working. I won’t ever know unless this door to communication with the staff and Bert’s history is unlocked and I am nearer to being seen as part of the team. I grumbled to myself that Bert’s meals in this institutional setting were more sacred to them than the work we were doing. It does not feel to me as if the staff know what we are doing, or understand my part in it. I hear later this week that there is no Unit Manager, Liz is just ‘acting’ and did not want the job - perhaps this accounts for the lack of managing!
I ‘saw’ as I transcribed:

Some stories we tell together
a common re-membering
like the Fowler’s fruit preserving.
Shared memories of how it was done
what part as children we were required to play.
We were connected in the remembering and telling.

Talking with Bert about his values: I think I was struggling to express my question to Bert in a way that he would understand. He ‘got’ the doing what had to be done part. I’m not sure whether the values beyond that were part of his understanding or not - I can hear values in there but the question feels like a bit of a dead end - I think he wants just the pragmatic this is how it was in those days sort of stuff. As I transcribed the work first then relax part, I can hear a work ethic in there, I didn’t hear it when he was saying it, but is it just my interpretation? Is the search for values for me, or for Bert?

I hear:

until I die
I’m going to live to at least 100
I’ve got at least 30 years to go.

Company’s the main thing
company’s the main thing, repeated.

Values - I’m not particularly interested,
facts: if I remember it,
and you establish it did happen,
even if it’s just the post code.
I still have integrity
and worth as a person

I enjoyed his joke about blackberrying and being careful not to pick up snakes! Towards the end of the transcription I re-experienced a feeling of drag in the story, he apologized for sounding uncooperative, but said it was because he had lost his bag and all the work
he had done to prepare for the day. Somehow I wondered if it wasn’t me focusing on things that were just vague concepts to him, like his best pieces of writing, his heroes and mentors etc, rather than the life of the further back past that he could be-in more peacefully.

My husband John and I talk about the concept of having choice in our old age, and I wonder how choice can be felt by Bert as he sits forever locked in. He talks about his life in the future beyond the nursing home, being free to visit various places, and as far as I have been able to find out this is just imagining, and not a real possibility.

I wonder how to bring closure to these sessions, and decide that they should finish before Christmas, giving us room to complete 10 sessions, though I’m not sure how another 5 sessions could go. I see the last 2 being involved with final corrections with the tape running or not, and presentation of the finished volume at the last session. That gives us 3 more sessions of stories and I’m not sure if we won’t just go over and over what is already told, unchanged. I indwell how this might be for Bert, and if it is possible to shift in closer to his now. As I try becoming him as suggested in Moustakas’s ‘Heuristic Research’ (1990, p.172-173). I read: you must be the thing you see and I write:

Locked up
powerless, surrounded
not free to choose, controlled,
angry, upset

I disengage from this me in now
and flee to the me
in Hallet, Barossa,
beloved South Australia
another time in
my favourite place.
In Hallet life flows,
life is creative, resourceful
we survive rather well
I ponder what the A/C would make of it, what Bert would make of at least the second half. I think he is not reflective enough to make a connection between the locked up and the fleeing in imagination. I think: the A/C would be uncomfortable with me suggesting Bert was angry.

2.6. The sixth session [60 minutes]

When I turned the tape off at the end of this session, Bert and I chatted for a few minutes before he began to briskly pack up while talking about next year back in South Australia. I asked him how long he had been here, and he grinned and quickly said ‘2’. A bit perplexed I asked ‘2 what, years or months? ‘No, too long!’ This brisk and witty humour just added to the complexity of the day and my subsequent digestion of it. We both giggled!

During this session there were three interruptions by staff into the room, which were disruptive and disconcerting, and Larrie made a great deal of noise outside the door, with no apparent effort on the staff’s part to quieten him or move him away. Is this because the A/C is away while the session is underway and she only gets back when we are finished?

I went out laughing after Bert’s joke, and found the A/C. We had a longer and more useful discussion at a depth that helped me, informed me, but was also disturbing. When I arrived to begin today, the Acting Nurse Manager, Liz, had taken me down to Bert’s room. Outside the door I asked her if his satchel had been found, and she told me that it had been thrown out, because he had messed it up. I was not at all satisfied with this answer, but it was clearly all I was going to get. However the A/C was quite disturbed, and told me that when she had asked Liz the week before about Bert’s satchel and papers, and Liz had said, ‘You don’t know what goes on at night here. In the mornings the staff go in to Bert’s room with gowns and gloves on and throw out all his stuff because he has soiled everything with urine and faeces.’

The A/C says Bert has nothing left in his room, which of course means all the intersubjective stuff I have given him, has been thrown out. She repeats sadly ‘he has nothing, he has nothing!’ She was relieved to know that I had a copy of everything, and she had also been making copies, so that a full copy of our work is preserved.
This means that outside his room (and his control) a copy of our work is available for staff to read (as far as I know). The confidentiality issue here concerns me enormously. It’s almost as if he is being punished by having any control of his life removed, even that which is preservable. The first thing I want to ask is that if this night raging is a recurring thing, why can’t they give him a box, and pack his things, saying ‘we’ll mind them for you in the office overnight so that they will be safe’ and return them to him when it is daylight. I came to feel his complete disempowerment, and how his rages feed into his disempowerment, and maybe that his work with me has stirred these issues in his mind so that, at night, they explode into uncontrollable dementia.

And then again I want to ask ‘Why can’t he have medication to control this situation at night?’ Surely that is possible. Are the staff cross with him so he needs to be ‘punished’? As I agonized over these issues, I felt a picture of a fractured soul emerge into my awareness, with the fracture line seeming to run through the line between night and day. I drew an art representation of this, and I saw that my work with Bert might inflame this rather than soothe it:

Figure 1. My Intrasubjective response: A fractured soul
The A/C told me that Bert arrived at the dementia unit in a terrible state, filthy, unkempt, malnourished, and that he is there permanently. Given that his sons must have seen him in this prior-to-admission state, it is not surprising that they have disconnected from him. She says he seems much better than when he was first admitted, and she greatly values the work I am doing with him. We talked about his refusal to talk ‘now’. The A/C said she had read that some forms of dementia showed no signs of physiological brain cell changes on autopsy; people seemed to just choose to retreat to a place and time where they were happier, such as Bert in Hallet. Obviously Bert would clearly have brain cell damage due to his alcoholism, and we talked about the significance of alcohol in Bert’s various stories.

I told Bert and the A/C that I could see an end to the stories, and the A/C and I talked about how we could bring some closure to the experience for Bert. We agreed that his sons might not honour the stories until after Bert’s death, but that they should be preserved and available for them then. So before Christmas we will have a presentation of a folder to Bert of his stories, and make a copy to be kept for his sons.

The A/C had 2 great photos of Bert taken eating his fish and chips meal of several weeks ago that he had described to me with such obvious enjoyment. I will scan them into the stories. The happiest of the two should go at the beginning. Somehow, looking into them, I could see the man he once was: red-headed, intelligent, funny, articulate, feisty, maybe even handsome. This seeing of the person who he had been, made it all the more poignant.

I transcribed the story of Booborowie, and how the road was directly opposite the Hallet Railway Station, and on further peering at the map, having told Bert that Booborowie wasn’t there, I found it further south, nearer to Burra and Spalding. I felt a persistent urge to go and visit Burra, Booborowie and Hallet and The Willdongaleechy Pub, as I transcribed this session. To visit the railway station:

A journey of validation, affirmation, confirmation.

Seeing with my eyes
Feeling with all my senses alive
to the essence of his place.
Photocopying the paper towel offering this week gave me, from Bert:

‘A text for today’ - about Kelpies
The precious maps of Hallet
The title: ‘I am offering a slice’... of himself. I wonder?

2.7. The seventh session [60 minutes]

I went to bed the night before this session filled with horror at the callous, inhumane attitude of our politicians to the treatment of refugees (The ‘Children Overboard’ Event). I woke just before 5am after a vivid and disturbing dream. I was so disturbed I needed to get up and get a cup of tea. As the jug boiled I looked out into the park that ajoins our backyard. It was misty and beautiful and I realised yet again that it is nature and the nurture of ‘the warm gloves’ (images in my dream) that sustain me. I stood and read the Wendell Berry poem on the refrigerator door and it comforted me:

When despair for the world grows in me
And I wake in the night with the least sound
in fear of what my life and my children’s lives may be -
I go to where the wood-drake rests his beauty on the water
And the great heron feeds.
I come into the peace of wild things
who do not tax their lives with fore-thoughts of grief.
I come into the presence of still water
And feel above me the day-blind stars
waiting with their light.
For a while I rest in the grace of the world
And am free.’  (Berry, W. 1957-1982; 1985).

As I drink my tea and focus, I am connected to current situations in my life where I feel a strong sense of powerlessness and loss of control, the loss of choice, an inability to do what I would choose to do. This includes the dawning day’s visit to Bert, and the attitude of the nursing staff as I feel and observe it. As I write this I suddenly remember the dawn dream images described in both Frankl (1984) and Zable (2001) in Cafe Scheherazade.
I connected strongly again to my dream images when a nurse offers to lock us into the ‘relaxation room’. A number of staff seemed to be around the office area when I arrived, but none who seemed to know who I was. I went down to Bert’s room and he was pleased to see me; he was sitting reading the transcripts. I claimed the relaxation room and one of the staff came over and said she would lock us in, which would save the interruptions, but she must have sensed my reluctance to be locked in. She assured me that the door could be opened from the inside, which I tested before agreeing. Several people tried to get in but went away on finding the door locked. Therefore in this session there were no interruptions.

Bert arrived with a bulging cheek that affected his ability to talk and laugh. His speech was distorted and he continually put his hand over his mouth and I inwardly groaned thinking of the loss of clarity and the difficulties this might pose to the transcription. I wondered if he had had a tooth removed and it was a pressure dressing or something similar. At one point it almost fell out, so he fished around and removed it and glared at it and said ‘that’s disgusting’ and put it in his pocket, and I realised it was probably a piece of meat from his lunch! (As he would say ‘Good gravy!’)

I asked him how the process of Life review had been for him, as I realised that this would be the last tape we did, there was a feeling of completion to the stories. He replied it wasn’t so much a matter of liking it or disliking it, it was his life. I hope the presentation of the finished book will give him a sense of closure and enjoyment.

A long de-briefing with the A/C left me sadly beginning to understand that working there is very difficult for her and she also feels unsupported by the nursing staff who seem to feel little for the patients, or if they do they do not stay long. So she has enjoyed our de-briefings, giving her some added insights into the patients just through sharing experiences and my reflections. We pondered together what had contributed to Bert’s present dementia, and his abuse of alcohol. Was it the loss of his second wife, the role modelling of his father’s drinking, his war experiences, the hard life of a journalist? Bert is not able to think these issues through any more, if he ever could.

The conversation with the A/C wakes me again at 2am, and re-connects me with the previous night’s dream. I uncover another layer of the situations where the A/C as a
member of staff, feels deep loss of control over the level of care of the residents she loves, despite her yearning to give quality care. She has no real sense of team support. She is traumatized herself by the nurses seeming lack of connection to their patients - it wounds her deeply and I can’t see how her health can survive - so she will leave as does everyone else who cares. Which of course further disempowers the patients.

We discussed Bert’s loss of his beloved possessions, and the A/C told me how the staff deal with that. I asked if it would not be possible for his things to be packed up and kept safe over night for him. She said they were - the things that the staff saw as most important - that is his clothes!! I stabbed at the computer keyboard in my anger as I wrote this. No respect or understanding for the things that made him into the person that he is. None! Just a person who made a mess and a noise at night who required them to clean up in the mornings. Liz was angry with him for his night terrors, and maybe felt that telling his stories to me fed the night terrors and dementia. The staff (as I felt it last night), seemed to allow the rages to destroy his precious papers and books. This morning I wonder if that is not perhaps a bit too harsh a judgment of them.

I delivered the finished document to the A/C and waited while she made 2 copies for me to get bound, one for Bert and one to keep safe for his family. I sat in the office and waited while she attended the end of a staff meeting. It felt changed somehow, warmer, friendlier, I felt comfortable talking to the patients who wandered around, not so intimidated. I wondered if it was a different lot of staff on duty, or the effect of the new unit manager, who I had not yet been able to meet. Or was it because I was ‘in the office’ and seemingly part of the staff?

Dear souls wander with lack of purpose.
Althea, who tells me I look a nice person,
my hair is pretty and I have nice breasts!
She seems troubled and tells me ‘the others are being silly’
Louise wrings her hands in anxious searching.
But today the staff seem kind and the troubled souls seem cared for.
Larrie zaps around in noisy, crazy circling unrest.
2.8. The Presentation!

The A/C had gone to so much trouble to make the room pretty and the occasion special. Althea kept trying to brush the rose petals from the tablecloth - still the housewife. Beside Bert sat a grey-haired gentleman, Greg, dressed in clean hand-knitted jumper, shirt and tie, immaculately groomed hair, such a contrast to Bert’s scruffy, unkempt wild, chaotic look. He looked every bit the retired banker, but spoke in a barely audible constant monologue, while smiling with great courtesy.

A number of the staff came, and the A/C told me that she had constantly told them of the work I was doing with Bert, with seemingly little response, but somehow it was as if now it had clicked, and they saw. They borrowed the book from Bert, and poured over it with some amazement and genuine appreciation, humour and acceptance of the work we had done. They were impressed by the work involved in transcribing the tapes. Their response amazed the A/C. My brief ‘speech’ was not heard because several of the patients wanted to know what all the talking was about when there was food to be devoured, and cake at that! The A/C said that my enthusiasm and presence in the stories was transparent. Bert made a presentation to me, (a wooden box of herb seeds) from The Unit, and it was hard to imagine that any other patient there could be as articulate and able to do that. However he was most uncomfortable out of his room, and soon escaped back there. I went down to say goodbye to him, and he was pouring over the book.

The A/C phoned me later to tell me that she went down there to say goodbye to Bert, and he was still totally absorbed in it, and she didn’t like to interrupt him. She tells me the process has given him back his identity. She had invited his son, who said he was too busy to come on a Friday but that he would call in this evening (which he didn’t!). She suggested, and I hadn’t thought, it may well be his grandchildren who make the connection into seeing Bert as a person, and perhaps that it is too big a task for his sons. Anyway the copy is there for them if and when.

If this process has given Bert a sense of his worth, identity and integrity back,
If this process had enabled his stories to be available for his children or grandchildren if and when they are ready,
It has certainly given me a huge understanding of the impact of dementia,
(that I didn’t have to experience with my parents, I suddenly see with gratitude).
It has filled me with a greater understanding of the importance of the stories for the person, and for their integrity regardless of their historical accuracy, and for the pure shining worth of the human soul that glows through the obscuring screen of dementia, with all it’s noisy, de-humanizing, less attractive images.
And maybe if even a few of the staff can see that, and value the people with dementia, it is perhaps not quite so bleak for them, they are cared for even if not by all of society, or even all of the staff.

It has been of enormous value to me!

Precious valued golden knowing
Life - colourful, full-blown, locked away, often noisy, sometimes smelly, mouthfuls of meat-in-cheek reality,
But golden human connection in story, in care given, care received, reciprocal humanity.

The housewife, still the housewife, fussing, tidying,
The banker, immaculately groomed, still the business man,
Muttering, muttering, but smiling graciously,
Bert, the scruffy, chaotic ‘journo’ in colourful disarray,
With inarticulate uncomfortable silence, happiest when writing or reading alone in the privacy of his room.

As I woke up next morning I instantly ‘clicked’ into my feeling yesterday of ‘let down’ and disappointment, that washed over me as I drove home. Now I’d had some sleep it was possible to separate out the various strands of feeling:

- I was all too conscious of the imperfections of the finished book - still some typos, the binding not all that robust, certainly not as strong as it needed to be. I had the feeling that Bert would wreck his copy quickly, perhaps even last night.
- It was a huge task over the 10 weeks, 7.5 hours of taping, 60 hours of transcribing, almost double Sarah’s story. I felt exhausted relief that it was done.
• What will keep Bert together now, if he is in fact now more himself as a result of this process - the A/C will not have any more time to give him, she is so stretched as it is.

2.9. New Year’s Eve

This morning reading Reason & Rowan Chapter 4, on methodological approaches to social sciences, I remembered a conversation I had with my friend Peg (M.A Psych) about the need to develop a tool to measure outcomes of my research, such as an improvement in depression scores, and I replied that if a measurable outcome was expected then I was not interested in doing the research. I grew into MIECAT’S approximation to meaning. I thought about how long it had taken me to gain understanding, like a flow of approximations, or developing meanings, over my epic journey of over twelve years, and how almost daily my approximations to meaning would have changed. It might not sit with the standard psychoanalytic model of training, or Peg’s psychology training, but it sits much more comfortably with me.

I pondered how uncomfortable I am with survey questions, where my answers are so often between the lines, and the questionnaire requires a choice of one definite answer or another. I cannot say my answer is different from both, or even sometimes one and sometimes another. I guess this has been an issue with me for many years, and now I see that heuristic research, and phenomenology, using MIECAT-model processing, is something that sits with my philosophy and belief system. I remembered Bert when I asked him ‘how has this process been for you - have you enjoyed telling me the stories of your life?’ and he replied: ‘It’s not a matter of enjoyment, or non-enjoyment. This is my life!’ I marvelled at his answer. This morning what is behind his answer for me, is ‘I have told you who I am. Not the person here in this place but the person who comes with these stories, not the physical wreck you see before you now, but a person who has lived and loved and had amazing experiences.’ How could I have presented him with a questionnaire that said it better? I needed only to listen carefully, hear and understand what was deeper than his words.
Appendix Ten:
Elizabeth

1. INTERSUBJECTIVE RESPONSES FROM SANDRA TO ELIZABETH

1.1. Intersubjective responses to Tape 1: a poetic summary

A very pleasant life: Father was the bank manager,
practically nobility in a country town, a maid and bank clerks who spoiled.
First school experience, a class of three sitting around the fire,
a sepulchral cough to be petted; Phyllis with ringlets, and Mr B the teacher.
Carnations growing over the septic tank, a warm place to lie in the sun.
Held down for hair-washing, water poured from a copper jug.
The crystal baptismal bowl broken, the revolver ready for robbers.
Pumping the organ, learning hymns, a treasured brooch thanks for Mother’s organ
playing.

Father moves up, the family is sad to leave.
This inner suburb is not a pleasant place, a sad neighbourhood, Father’s bank is refuge
from fighting with sister or mother, flashing red lights advertising whisky,
Drunks on the pavement, poor men, unemployed, frightening.
Mother playing bridge, and fun at the fire brigade.

‘College’ a penny tram ride from the bank,
a big move for a bright little girl from a small country grade.
A ‘mother’ to settle a lonely little show off. Gratitude for music as escape;
good hymns with descants, shiny navy tunics, bucket hats,
and any excuse to avoid gym. Betty (who was very Christian),
and finally a welcome to the group; with books, books, books,
a dedicated bibliophile is happy. Elizabeth talked, talked, talked, always talking
And is awarded the Bible Prize!
Holidays with Grandmother by the sea.
The sisters’ rivalry grows: she was six years older, had boyfriends, was pretty, and went to Queensland with Mother.
Serious illness, screaming pain, hospital, surgery, fighting ether anaesthetics.

Emily McPherson College, boring, non-impinging.
A first boyfriend, the beginnings of womanhood, measles and pneumonia.
A good move to Kew, and the war begins.
Mother goes to America, and returns with lovely things.
Big sister leaves home, bringing some relief of tensions, and finally marries her charming British naval captain.

Finally Elizabeth enrols at university with languages, literature, fun, boyfriends, little work but wonder-full reading, writing, drama and choir.
The Anglican Church becomes a focus for music and getting to know God.

1.2. Intersubjective response to Tape 2, Side A: a poetic summary
I was at university having fun, not doing any work.
falling in love, finding the church,
I remember my seventeenth birthday party, dancing the Lambeth Walk.
My sister had a boil on her face, and wouldn’t come to the party,
she gave me a wallop, I had a beautiful backless dress,
there was the mark of my sister’s hand on my back.
Mother was very hospitable and good at making homes into pleasant places,
There were German prisoners of war working near by,
one came and ate with us for a long time.
Our house is still there, there was a lot of music around,
I went to SCM, and joined the Anglican Church, the middle one,
*ut omnes unum sint* That we all may be one.
I thought that was the nearest thing, and I still think it probably is.

I learned about Bach if only you could play it! I love it, it’s like a puzzle, mathematical.
I never wanted to play in public, only ever for myself.
It shames me when I hear stories about lack of food during the war,
the awful things that happened; I didn’t know that, I was a happy seventeen year old,
I preferred not to read the headlines.

At an SCM conference, when I was about twenty, lo and behold
there was a beautiful soldier in uniform, I remember chasing him like mad!
I fell over and sprained my ankle, the dear was the only one with strength enough
to pick me up and support me. He lent me a handkerchief, and then came to dinner!
I only knew him about three weeks all together, we corresponded with many loving
letters.
He was trained in Holland as an Administrator
to The Netherlands East Indies, in Java, in New Guinea, fighting Japs.
Oh, I could go on and on about him.
I was violently in love with him, it was a very lovely time,
Mother always loved him, Mother said ‘he is the man for you.’
I began to do some work at university about the end of ‘45.
I knew I was going to get married. I thought I’d better finish my degree.
He had his beautiful [doctorate] degree, I’d better have something.
I began making my trousseau.
About two o’clock in the morning he rang and said
‘I’ve got a few questions to ask you, only answer yes or no.’
The first one was ‘Will you marry me?’
We could marry by proxy, then I could go to Indonesia as a married woman.
1.3. An art representation

Figure 2. Second response to Tape 2: A long bridge between lives

1.4. Intersubjective response to Tape 5, Side A: a poetic summary

Back in Australia, one day I saw an advertisement for land ‘with un-build-out-able views.’
We’ll go for that, it looked such a pretty street, I said ‘that’s ours!
That’s for us, gum trees and all,’ I’d so missed gum trees.
That was six hundred and forty pounds, we went straight in and bought it.
It was really quite a slope.

Young architects, they were going to build something really special,
‘I want all the light I can get, all the windows I can get,
all the view from everywhere.’ Everyone came to look at it.
I wanted the top sitting room bigger, he said ‘space costs money! SCM!’
We had the entire roof purple, the bedroom was bright yellow,
we used to wake up in the morning hit in the face by the sun shining on the yellow.

For about a year I hated it. But then I thought - ‘well how silly,
it’s what you wanted’. It was, it is what I wanted. It felt that I made it! I did it!
I organized it, I was the main person. Nothing clicked, it just grew on me.
I would have liked to have had modern furniture, but
I inherited things and I couldn’t bear to throw them away.
I realized it did do what I wanted, it does do what I want.
The light and the view always. It’s bonded to the land?
Oh it is, that’s one of the things I said in the brief,
I said I wanted it to lie on the ground, to lie on the ground.

I thought ‘lets get pregnant again’. Between my oldest and youngest daughters there’s nine years. The oldest took a lot of responsibility for the youngest.
I did a teaching degree, then I taught for five years, at two high schools then a private girls school, my time there was a disaster!
It was a bad time, it really was, I had a nervous breakdown,
I had such plans, I’d done such a lot of work on new systems,
I think now I was really advanced but certainly that school wasn’t.
Later I did a librarian’s degree, it was a very boring course, but we all got through it.
They said ‘The High School is building a new resource centre, how about that?’
So I said Right! It was very pleasant, a very good seven years there.
I belonged to the Mothers Club, my dear friend next door was President of the Mother’s Club, I was Vice President.
We were very close, we’d hop over the fence to each other all the time.
We travelled a lot then, we were very lucky to travel, I think Innsbruck’s my favourite.

1.5. Tape 6, Side B: a poetic summary
I got to hospital, after about two days I felt better, everything seemed to be ok,
that night I was taken to the Intensive Care, I’d had a heart attack.
This is very fragmentary from then on, part of the time I was conscious, part of the time I wasn’t, there was chaos and trouble.
The doctor said to the family ‘I think you’d better prepare yourself, because I don’t think she’s going to make it.’

They decided to deprive me of water, I can’t think what fool did that, it was agony!
I begged horribly for the nurse to give me some water, she was horrible, she didn’t say anything about why I was being deprived - but ‘No! No!’ Just that.
And by that time I was blind, I knew I was going to die.
My husband came in, I said ‘Darling if I’ve got to go, I want you to ...’
I heard him give a big sob, I thought ‘oh well, I’d better start trying to get better’.
So I said ‘I’ll try and come back if I possibly can.’ I was perfectly clear in my mind,
I told my oldest daughter ‘I don’t mind dying but I’m worried about your father.’
I can remember the things I said quite clearly.

You felt you had a choice? No, not really, I don’t know what happened,
but I’m quite sure if they looked at my chart I improved from then on.
Only because he was so worried and so miserable, I’d never heard him sob. Never!
I remember I thought I would like to have a priest, he came, the only trouble is
he’d turned Roman Catholic, he couldn’t give me The Last Rites,
in the end he just said a prayer. By that time I think I was over the worst of it anyway.
My grand daughter told my youngest son that I was dying, he’d better come quick.
I couldn’t see any of them but I knew their voices
My oldest son was massaging my feet, the sweetie, apparently they were black.
I just knew I was just hanging on, I couldn’t do anything.
You were peaceful? Oh yes. I wasn’t disturbed,
except that I was worried about my husband. My oldest daughter was a great support.
When I came home, she lived here for a while and looked after me so sweetly.
I had to be trained to do everything. I had a birthday soon after,
the family came very, very carefully, I remember the boys would barely touch me.
I think I was very fragile, terribly fragile! I probably looked very fragile,
I could always talk, I couldn’t see, I couldn’t read. That was terrible.

My left arm’s worse than my right when I try to play the piano.
That’s the biggest penalty, not being able to play the piano? Yes, quite big.
I’ve got double vision a lot, but I can read, that’s the main thing.
My husband would walk with me and every week or so I could walk a little better.
These stairs helped me immensely. I had to go up and down.
I trained myself to knit again. The first efforts at knitting, oh dear me!
Now I can knit fairly evenly but I can’t properly count for a pattern.
I still have difficulty with money, I can’t count it properly any more.
I have no sense of direction or balance, I can’t possibly drive a car,
I drove it once or twice after I’d been ill, but after that, I knew I couldn’t.
I had a few little things I did with the car that were not altogether a good idea.
You had to let go these independences? Yes, oh yes, terribly much.

I used to accompany all the Christmas Carols always, we had such fun,
I haven’t accepted giving up the piano, but it’s no use.
We treasure every day, we are healthy and can manage together.
Funnily enough grandchildren are important, but great grand children
I haven’t quite come to grips with! They’re cute but are they mine?
I think I’ve finished my story! Every day we feel we are so lucky and blessed
just being healthy and being together. It’s a happy ending if either of us dies now,
the other will be terribly miserable, but we’ve both had a very good life,
full of adventures, full of love for each other, so we’ve been lucky.

2. THE APPLICATION OF THE LITERATURE SEARCH TO ELIZABETH’S NARRATIVE [FULL TEXT]
The literature for Elizabeth’s story follows many of the themes and issues uncovered in
her narrative, such as her family and its influences and structures, her illness narrative, her
resilience, her soul crisis, and lately her grief concerning her frailty and loss of
independence. Elizabeth’s narrative covers many rich, complex life issues and
experiences, and so it is not possible for the literature review to be comprehensive, or the
themes entirely untangled. My reflections on the literature are in the right hand column in
blue.

1. Theme: The narrative
   - A story of intensity
   - The story’s flow
   - A narrative shaped and measured by time and place

2. Theme: A sense of self and belonging
   - Different cultures
   - Community support and connections
   - Making choices
3. Theme: Family and enduring relationships
   - Family ceremonials
4. Theme: Epiphanies
   - Elizabeth’s abortion
   - Elizabeth’s nervous breakdown
   - Elizabeth’s ‘hot texts’
   - Elizabeth’s near death experience
   - ‘It was not nice!’
   - A touch of kindness
5. Theme: Fraying around the edges
   - The deficits after Elizabeth’s stroke
   - Resilience
   - The end of Elizabeth’s narrative

Table 5. Literature search for Elizabeth’s narrative

<table>
<thead>
<tr>
<th>1. Theme: Elizabeth’s narrative</th>
<th>My reflections</th>
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<tbody>
<tr>
<td><strong>a) A story of intensity</strong></td>
<td>Many of the things said at Arthur Frank’s workshop (2004) resonated with Elizabeth’s story for me. There were many intense moments in Elizabeth’s story that evoked the pain of these experiences for her:</td>
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<tr>
<td>Early in 2004 I attended a workshop entitled ‘Working with Narrative: Health and Illness Stories’, at Epworth Hospital in Melbourne, lead by Arthur Frank, visiting Professor of Sociology from Calgary, Canada. Frank suggested that stories were like images that invoked the world of the storyteller with great intensity.</td>
<td>It was a thrombosis of the lateral sinus. And oh! I was in terrible pain for days and days and days. No, no sulphur drugs, no. Nothing could help it, I remember terrible pain, terrible pain. It was screaming pain.</td>
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<td></td>
<td>So, no anaesthetic, nothing silly like that. I lay across the bed, and I remember the doctor stood back and p</td>
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<td></td>
<td>They decided to deprive me of water. I can’t think what fool did that, but they did. It was agony! I begged</td>
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<tr>
<td>English</td>
<td>Chinese</td>
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<tr>
<td>Horribly for the nurse to give me some water, she was horrible, she didn’t say anything about why I was being deprived - but ‘No! No!’ Just that.</td>
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### b) The story’s flow

Permut (1989, p.56) in describing her own journey with Systemic Lupus Erythematosus, says that naming things is a way of owning them. Spinelli (1989 pp.97,101) discusses the problem of retrieving the stored data in our memories. Spinelli’s findings suggested that all experiences from our past can be stored permanently and are capable of being remembered.

Antonio Damasio, professor of neurology, (2000, p.172) discusses the autobiographical self, based on autobiographical memories. The invariant aspects of an individual’s biography form the basis for autobiographical memory which grows continuously with life experiences but can be partly remodelled to reflect new experiences. Each reactivated memory operates as a ‘something-to-be-known’ and generates its own pulse of core consciousness. Thus, according to Damasio, the result is the autobiographical self of which we are conscious.

### My reflections

Elizabeth’s story is told with an honest sense of the flow of her life-experiences, and a confident certainty of her sense of understanding of her remembered past, even though sometimes she recognised that some events were muddled in time. The flow from her childhood to the present makes sense of her life-experiences, her place in the world now, and her sense of the meaning that has flowed along throughout her life. Elizabeth seems to have no hesitancy in naming any of the experiences both good and bad that happened throughout her life.

She had within recent times suffered a life threatening stroke that caused major organ failures. As she described her life, albeit as I helped her to structure or keep her place in that flow, she seemed to have no overt sense of reshaping or reinterpreting, but simply that these experiences were given, and that many were ‘not nice’ when they occurred.

### c) A narrative shaped and measured by time and place

Bruner and Feldman (1996, pp.291-298) describe how a group’s highly constructed narrative structure provides the framework for telling and understanding the group’s story. These writers explain that each autobiographer creates a life story centred around themselves under particular constraints that are shared with no one else. They suggest (p.293) that events are shaped for narrative purposes with a view toward

### My reflections

Bruner and Feldman’s words resonated with many of the descriptions Elizabeth had given of her life, which seemed to be almost lived and measured through her sense of time. I wrote an intersubjective response for Elizabeth, anchored around van Manen’s (1990, pp. 101-106) view of time.
meaning and emphasising the significance of the events, not toward the end of somehow preserving the facts themselves. Bruner and Feldman state how different groups have different stories and interpretations of the same events, as narrated by the framework of their differing cultural perspectives. Describing one of the groups they studied, they say

‘Theirs is a kind of adventure tale, one that recruits a lot of words of place and time. They tell their story sequentially, moving from a defining origin through a great many specific places where they have been over time. Their words are of time and place ...’

van Manen’s (1990 pp 101-106) view of time (temporality) is subjective time, as opposed to clock time. Past, present, future, the past changes under the pressures and influences of the present. I may reinterpret who I once was or who I now am.

She experienced lovely, pleasant, happy times,
She loved books and music all the time, although some times were hard.
There were times of confusion, times she now gets mixed up, terrible, worrying times, bad times, horrible times, times so difficult she didn’t want to remember them, and has almost blanked out their memory.
In the end, she is thankful most of all for loving shared times,
For relationships that have stood the test of time.

2. Theme: A sense of self and belonging

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<th>Introduction</th>
<th>My reflections</th>
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<td>Crossley (1996, pp.65-67) discusses the importance of the identification of our self and our citizenship. He describes a sense of ‘membership’ and communal belonging. People do not always feel a part of a situation and do not always feel integrated.</td>
<td>Crossley’s (1996 p.65) sense of ‘membership’ and ‘communal belonging’ sits with Elizabeth’s sense of being ‘at home’ in her early experiences, her time at university, and later on, in the home she and her husband built. Elizabeth’s childhood experiences of living in inner Melbourne where the drunks were abhorrent to her developing values, again in Holland, and later at the private girls’ school, and even in their own home with her difficult teenage daughter, were instances where she strongly felt that she was ‘not at home’ and did not belong. Crossley’s view illuminates a clear effect on Elizabeth’s inability to go on working in the girls’ school, and her destabilised</td>
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mental health. She had what she describes as ‘a nervous breakdown’. From Crossley’s perspective one could say that what was interrupted was Elizabeth’s sense of herself, which belonged to both her intersubjective order and her moral order. Particularly at the girls’ school, she felt she was not trusted, and could not teach in the way she had developed, a way that sat comfortably with her sense of her own integrity.

At one stage I was very hurt, I marked them according to what I always marked fourth form, on their essays. Their teacher came to me, no, I think it was even the principal and said that they'd always had much higher marks than that. And I said ‘but I'm marking the same as I marked at high school.’ And she changed that, they had to have better marks

S: Whether they did better work or not?

E: That’s right.

So Elizabeth fell apart. The experience left her feeling untrusted, misunderstood and undervalued. She simply could not go on, especially coupled with her teenage daughter’s ructions at home, there was no place where Elizabeth felt integrated.

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<th>a) Different cultures</th>
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<td>Bruner and Feldman (1996 p.302) argue that we need to get beneath ‘culture in general’ to the intimate personal mini-culture of the face-to-face groups with which an individual engages, to see something of the variety of ways that people make their autobiographies, in relation to the way they make the story of their community. Crossley (1996, pp.92-3) writes about the way we make sense of different cultures and group life. He</td>
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| Elizabeth has a very strong sense of her communities throughout her life, and her destabilisation experiences come when this sense is challenged. Elizabeth’s groups began in the small country town where her father as bank manager was ‘almost nobility’ along with the doctor and solicitor. Then at school in Melbourne Elizabeth says of her life-shaping membership of ‘the group’:
explains how the group’s rules and habits are acquired through trial and error, through personal acquaintances and experiences, and that much is learned in education of both a formal and an informal kind. David Reiss is a psychologist, and researcher in Family studies. In ‘The Family’s Construction of Reality’, (1981, p.173) Reiss writes that specific shared explanations or understandings which families developed are important in shaping the ongoing values of the family members.

Crossley (1996, p.94) goes on to suggest that community assumptions are shared. Crossley says a sense of disorientation and anxiety results ‘when visiting alien cultures, what we take for granted isn’t, while others take for granted what we don’t’. Crossley suggests that ‘thinking as usual’ is the style of thinking which is accepted, valued and which works in a particular group. He explains that ‘stocks of knowledge are socially distributed and tied to particular roles in the community, they do not assume a general form which would be accessible to an outsider.

Different members of a community, assuming a relatively complex division of labour and social differentiation, have different practical knowledge. Their knowledge relates to their own specific position or role within the community. This may be spatial in the sense of a geographical orientation based around their own home and the various landmarks of their life, but it is also social. They have their own areas of expertise. This inside knowledge cannot be applied to the outsider since they are not part of the community and have no place within it from which to be oriented. Even if they have a social ‘map’ of the community, they have no place on that map and thus cannot use it. There is no ‘communion with otherness’ as Buber (1923) would describe it.

Betty was very Christian ... she was really my saviour, she took me into a large group of about eight popular, well thought of, get-ahead girls. And from then on I was pretty good.

Elizabeth was encouraged to join the Student Christian Movement, where later at a house party, she met her future husband. Here at this private school, Elizabeth’s standards and values were shaped, and then confirmed as she went on to university:

There were the religious rules, the alcohol rules, the sex rules, but they didn’t worry me really. They were rules, but you lived within them.

Illuminated by Reiss (1981, p.173) Elizabeth says:

My grandparents and mother were very anti drink. And I still don’t like it, people drinking at all. I cannot stand people drinking.

Elizabeth’s sense of herself was set securely enough that she could survive the dramatic change that her marriage-by-proxy drew her into. However, moving to Holland after five years in Indonesia, she was thrown into a sense of being unwelcomed, unwell, and not at home. Elizabeth explains this sense of disorientation not being at home and its resulting anxiety:

I remember hearing the teacher at the kindergarten say ‘she’s just a foreigner!’ And I felt distinctly less foreign in Bali. I was just a stranger, and it was unfortunate that I spoke Dutch, because they thought I thought like the Dutch and I didn’t.

Crossley’s ‘thinking as usual,’ fits the large Dutch family that Elizabeth had joined. Her Dutch in-law family had their identified place in this group, and their status or standing was recognised. Whereas Elizabeth felt that ‘they said about me “we don’t know what we have in her.”’ Thus
Reiss (1981, p.187) explains standing, where ‘old line’ families maintain high status and influence on the community, and are high status links. They help to perpetuate the family’s sense of itself as contained, ongoing, and confident. Because of its importance in Elizabeth’s narrative, this is further explored in Theme 3 regarding ‘family and enduring relationships’. This book was a very useful resource on family function.

Drewery and Winslade (1997, p.48) suggest that what most people do is muddle along, making sense as best they can, making decisions and acting on them in the face of uncertainty, and complexity in the life situations that are constantly arising and demanding response. These authors propose that as complexity increases, we recognise ourselves with more difficulty. They emphasise that we also must learn to forgive ourselves.

Elizabeth’s sense of

I was not considered to be doing the right thing, mostly I went out too much I think, and I didn’t do the spring cleaning when I should do it.

I’d been looking forward to cooking for myself. But Tante Nell had arranged for a girl who would help me, she needed training. You have to realise this is fifty years ago ... then it was very standing conscious, standing is where you came in the hierarchy of people ... Pieter’s family was enormous, good bourgeois, solid citizens, not religious, but they always had money and standing. And it was quite strange to me. Standing was very important, and your name was important and they didn’t know anything about me.

Crossley’s ‘hierarchy and status/standing’ impacted heavily on Elizabeth’s sense of not belonging. No wonder that Elizabeth longed to leave Holland for Australia, where she might reorient herself and reform her sense of coherence. Outsiders were not on the map of Elizabeth’s adopted Dutch community, there was no ‘communion’ with otherness as Buber (1923) would describe it. For Elizabeth the best thing about Holland was the other wonderful countries that could easily be visited from there.

Elizabeth’s in-law family in Holland, were an ‘old line’ family who maintained high status and influence on the community and these high status links helped to perpetuate the family’s sense of itself as contained, ongoing, and confident.

It was not surprising that Elizabeth made the choice to abort the pregnancy that would have changed her husband’s mind and prevented them from leaving Holland to return to Australia. Drewery and Winslade (1997, p.48) illuminate the no-win decision that Elizabeth had to make, and its continuing resonance in her ongoing...
life. Elizabeth says:

Then I had a bad thing, I was pregnant. And I couldn't bear that. I told the doctor 'I'm not going to have this child.' Because I knew what would happen. You see we had a good job in Holland, my father had left us some money but we had no prospects in Australia … So I had an abortion, which was done by a doctor, but I was very ashamed. I knew that Pieter would insist that we stayed if I had another baby.

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<th>b) Community support and connections</th>
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<td>Reiss (1981, p.177) writes that the family’s social environment contributes to its management of stress. The community, together with the family, forge links or bonds of a particular quality. The nature of these bonds supports and sustains the family.</td>
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<td>Elizabeth describes many links and bonds with her Australian community, she says:</td>
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After the car accident Dieter was taken up by one of the neighbours a couple of doors up and he was all right.

I belonged to the Mothers Club. My dear friend next door, we managed to get an entirely new resource centre built there. I was Vice President I think, and my friend was President.

We could talk over the fence in those days, it was wonderful! We used to share our dishes, and we always said to each other we could never have a party together because we needed each other’s dishes!

I had another neighbour who died more recently. I didn’t know that she was an alcoholic. I’m so sorry I didn’t know ... I didn’t know what was going on. Finally one day, considerably later, the police rang me. They said ‘Mrs M’s in hospital, and she’s dying.’ So I held her hand until she died. Fortunately she died fairly quickly, without a struggle. But it was hard. |
And after her stroke:

I couldn't see, I remember Pieter trying to get some of the ladies from the church to come and read to me because I couldn't read. That was terrible.

c) Making choices

Robinson (1996, p.21) tells us that such major decisions as choosing a career or a partner have irreversible consequences, and the reasons for making those choices impact on one’s sense of identity and the coherence of one’s life story.

My reflections

Elizabeth’s choice of partner for life was a dramatic one. They had spent a total period of three weeks together, over the two years prior to their marriage-by-proxy. He was in Indonesia just after the Japanese had left, and this form of marriage enabled her to travel to Indonesia to be with him. Her parents liked him and supported her decision:

I was violently in love with Pieter - but no sex, we were nice people in those days. Pieter endeared himself to my father, and Mother always loved him, Mother said ‘I know you won’t take any notice of me, but Pieter is the man for you."

Elizabeth allows no room for doubt:

Father M had organised a little service for me to be married by myself! It was frightening, really. I promised to love honour and obey him, when he wasn’t there.

S: Did you ever have any doubts?

E: No, funnily enough, no. It was strange, I said to Pieter the other day ‘Didn’t you have doubts about me?’ He said ‘No.’ I said ‘well I didn’t have any doubts about you either.’
3. Theme: Family and enduring relationships

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<td>Reiss (1981, p.155) writes about the significance of family structures. He describes how the family plays a central role in providing understanding and meaning for one’s life experiences. It offers a framework on which to hang explanations of the world for its members. This then serves as the basic organiser of experience, the family provides a strong model to follow (p.263). Reiss (1981, p.169) describes the family’s extraordinary role in the creation of a sense of order, balance, and coherence in its life. Family members weave this out of memories of the past from their own childhood, and out of their survival by their own struggles. Reiss defines an event as stressful by virtue of a common social construction that it will produce substantial changes in the life patterns of an average family (p.177). Reiss (p.269) describes status, representing a special stringing together of the influence and prestige of the entire family. Influential families can command many of a community’s resources and are well known by everyone. Status is the combined result of the family’s skill in making itself well known to others and indispensable to the community. Another of Reiss’s architectural aspects of status is the openness of the family’s boundaries to people and experiences in its social environment. By openness he means the relative freedom of people to enter the family. Non-members are readily welcomed and can form various kinds of ties with one or more members of the family group. Reiss describes families who have great difficulty admitting strangers, are rebuffed and made to feel like outsiders.</td>
<td>Reiss throws light on the significance of the family structures that coloured and grounded Elizabeth’s life story. As the art conceptualisation of Elizabeth’s life review made clear to me, her resilience was strengthened by the core stability of her early family experiences, and then by the strong, enduring relationship forged with mutual determination in her marriage. In Reiss’s terms, Elizabeth’s family has a resilient quality. Her family is strong basically because of the parents’ determination. Elizabeth and her husband bonded with each other in the first five years of their marriage independently of either of their families of origin. This cemented their relationship perhaps more strongly than most, and strengthened their determination that their marriage would work. She said: I only knew Pieter - we worked it out once, about three weeks all together, to see him. But we corresponded regularly, with much loving letters. It all came together because of Pieter, he was wonderful, especially when my mother died. I really can’t say enough about what a wonderful husband he is, it made everything easy. Reiss’s (1981, p.169) description of the family’s significant role in the creation of a sense of order, balance, and coherence in its life woven out of memories of the past from childhood, and centrally for Elizabeth, out of survival by their own struggle. Her family did survive its many struggles, with both order and balance. For Elizabeth, Reiss’s ‘stressful events’</td>
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would include many of the incidents she describes as nasty: the birth of her first child; the malnutrition and failure to thrive of her first two babies in Indonesia; the lack of acceptance she felt in Holland; the abortion; the miscarriage; and her gynaecologist’s subsequent demand that they leave their two children and have a much needed break. The only place available for the children, since there were no suitable relatives to mind them, was a children’s guesthouse, which was a less than ideal situation for the children. The list goes on: the car accident and subsequent agonising birth of their third child with Elizabeth’s bilateral fractured pelvis; her experience of feeling not trusted at the private girls’ school; culminating in her nervous breakdown and her feeling of distress endured during her second daughter’s difficult teenage years. Having survived all these, one would have to assume either strengthened this family’s resilience, or brought about its failure to survive. The proof of survival is that the family appears to be robustly alive and well (Reiss 1981, p.177).

Elizabeth describes her mother as very interior, she fixed the home very beautifully, Father was very proud of that. Mother was very good at houses and homes. Making them a pleasant place. Always anyone who wanted to come and eat with us, she was very hospitable.

And her grandparents

Grandfather we always knew was an important figure, he was a Councillor - he was a very impressive man. He was a very good man, an elder of the church, they were very upright, God-fearing people. Grandmother was very important to us. In her very quiet way she ruled the family I think, with Grandfather being the much-respected elder statesman in the background. Nobody would ever
speak back to either of them, ever!
They were very influential for me.
So they represent a strong model for
Elizabeth to follow, a family that achieved
high standing. She perceives her family as
influential in their neighbourhood, and on
her own life. This early family model is
challenged by Elizabeth’s later experience
in Holland (Reiss (1981, p.263). When she
arrived in Holland:

The new bride and with two baby
children I had thought I would be
welcomed and taken into the family -
I wasn’t!
As Reiss explains it (p.269) the first aspect
of this Dutch family is the conspicuousness
of the family within the larger social unit.
Elizabeth says:

We went to Holland, and he was
immediately taken up by the family ... they were a very large and
supportive family and they took him
on immediately to be company
secretary to a large engineering firm
on the docks ... I was just a stranger.

It doesn’t necessarily happen now
but then it was very standing
conscious. You know, standing is
where you came in the hierarchy of
people, and his family was
enormous, and good bourgeois, solid
citizens, they always had money and
standing. Standing was very
important, your name was important
and they didn’t know anything about
me. Did I have family? Probably from
convict stock, you see! [laughs] ...
They said about me ‘we don’t know
what we have in her.’

Elizabeth did concede that ‘one of Pieter’s
aunts was very kind’, however overall
‘there were no tears shed when I left’. One
cannot help but contrast the family of
Elizabeth’s early years, grandparents who
were strongly influential in their
community and on her own life, and a
mother who was hospitable, compared to
this powerful Dutch family where she knew she was not known, understood, or welcomed.

*a) Family ceremonials*

Riess (1981, p.246) suggests that ceremonials, reaffirm a family’s assumptions about awareness and the world through explicit, intense and focussed awareness on particular family processes.

My reflections

Elizabeth describes the deficits that her stroke has left, which changes her role in the family considerably, and means she is no longer able to actively bind the family together as she has previously done.

I used to accompany all the Christmas Carols always, we had such fun because all the children have got nice voices

Ceremonials, like this family’s singing of carols together reaffirm the family’s assumptions about awareness and the world through explicit, intense and focussed awareness on particular family processes (Riess 1981, p.246).

4. Theme: Elizabeth’s epiphanies

*a) Elizabeth’s abortion*

Echoing Drewery and Winslade (1997), Reiss (1981, p.159) writes that explanatory systems are stabilised by their relationship to general or framing assumptions, and in most cases personal explanatory systems cannot deal with the fine texture of everyday experience. So what Reiss calls ‘ad hoc derivations’ are almost always required to make especially difficult decisions.

Greenberg and Saffran (1987, p.180) write that guilt is technically a judgement rather than an emotion, one judges oneself and this results in feeling sad, angry, or ashamed. Melbourne psychologist/theologian, post abortion grief counsellor, Anne Lastman (2004) describes the psychological wounding following

My reflections

Elizabeth made her own decision to abort her untimely third pregnancy. Her feelings of disequilibrium and guilt closely fit those described by Drewery and Winslade (1997), Lastman (2004), Reiss (1981), and Greenberg and Saffran (1987 p.180). Elizabeth says:

I've been ashamed ever since. I was wrong. I feel I was using a very selfish reason. Oh it was legal, a doctor did it, and it wasn't painful. I went to confession, afterwards, when I came back to Australia. Then I had a nasty miscarriage, at about six months, it wasn't pleasant. I was rushed to hospital bleeding all over the car. I rather thought it was a sort of punishment for the abortion I'd had. I'd confessed to Father M in the
elective abortion, that creates a disequilibrium that is challenging to the person’s assumptive world, fracturing the inner being of the person.

Those experiencing grief after a termination of pregnancy, do not generally have the social supports that are present when the ending of a pregnancy is by miscarriage. Lastman says that this type of grief, because it is unacknowledged and unsupported, then becomes what she calls disenfranchised, and the work of mourning is obstructed. This then is ‘problem grieving’, and resolution is difficult. Lastman cites DSM-IV stating that ‘trauma is apparently more severe and longer lasting when the stressor is of ‘human design’. Lastman argues that incomplete mourning results in impacted grief, which has the potential to be expressed in family structures well into the future (transgenerational grief).

Psychologist Sue Nathanson (1989) writes poignantly of her soul crisis following her termination of pregnancy. Nathanson says ‘my pain has nothing to do with the external, physical world’ (p.43). Nathanson suggests that her pain was brought on by her own choice, she was the cause of her own suffering. She sees that decisions in these painful domains (and here Nathanson includes suicide and euthanasia) arouse nearly unimaginable anxiety because they ‘border on darkness’ (p137). Nathanson describes our human need for a loving attachment to a mother who has the power to buffer and protect us from an awareness of the vast, indifferent universe in which we must survive. ‘This need is so profound that we unconsciously demand that mothers provide perfect care for their children. No matter that such perfection is impossible. It is this unalterable fact that Nathanson calls a soul crisis.

hospital, that made it a little better. I said I thought it was probably a punishment, and he said ’yes, it probably was!’

Reiss (1981, p.163) would perhaps suggest that Elizabeth voluntarily and passively accepted an explanatory system offered to her by the church and its spokesman. Elizabeth was not only denied support in Holland, but was also unable to talk about it when she returned to Australia. Elizabeth says she never got over feeling guilty.

Elizabeth would agree that her abortion decision was her own. I heard in Elizabeth’s explanation that she had no physical pain, but that it might have felt better if she had. Perhaps Nathanson touches on a number of difficult issues in Elizabeth’s life - her own mother, even when present on a number of painful occasions in Elizabeth’s life, such as the birth of her first child in Indonesia, could not protect her from it’s terrible pain. And throughout her ongoing life with her own children, neither could she offer them protection from their own suffering, which saddened her enormously. It is this unalterable fact that Nathanson calls a soul crisis, which seems to fit Elizabeth’s story so well, and brings a requirement for her to accept a permanent alteration in her sense of herself.
b) Elizabeth’s nervous breakdown

Melbourne psychiatrists Bloch and Singh (1997, p.6) describe an acute stress reaction as a temporary but severe state which develops in a previously well person in response to exceptional stress. This is what many people refer to as a nervous breakdown.

Reiss (1981, pp.170-173) suggests that family disorganisation entails the failure of previous modes of construing the environment. Reiss looks at periods of crisis in a family’s history as conceptual cornerstones. The path to recovery or reorganisation of the family begins with the crisis construct, where the family recognises that it is in crisis and begins to develop a shared concept of that crisis, and the pathways, if any, open to it for resolution of that crisis. Reiss explains (pp.213-215) that in resolution of the family crisis, a genuinely collective position does not require that each individual understand everything that other members of the family are feeling and thinking. What is critical here is that each individual identifies at least a single aspect of the other’s experience. This single aspect serves as evidence that if she wanted to she could enter the other’s experiential world.

Charlotte Linde, a sociolinguist, anthropologist and narrative researcher (1993, p.134) describes a sense of the loss of coherence brought about by disruption to our life’s story. Gaylene Becker is a Research Anthropologist (1997, p.107) who explains that families may both aggravate disruption and create continuity, according to Becker, engaging in a form of generational continuity.

My reflections

Elizabeth had many ‘not nice’ stressors, the later ones seemed to be the lack of trust she felt as part of the staff at a private girls’ school, and the difficulties with one of her teenage daughters. Elizabeth says:

And then I got ill, I think I had a sort of a nervous breakdown. It was very nasty ... I thought my time there was a disaster, and after about a year I quit mainly because I had a nervous breakdown and I wasn’t well at all. I remember the doctor coming to the door. I said ‘I’ve got to go to school.’ He said ‘You can’t go to school, if you go to school I’ll put you in Larundel.’ It was a bad time, it really was.

Elizabeth describes how her youngest daughter reacted to this time of disorganisation

She was being rather difficult. She was about fifteen, and she was rather playing her father off against me ... I don’t think I did the right thing ... I’m having the nervous breakdown and I’m not very nice to live with ... But anyway, Pieter finally said to her ‘Look, you’re disrupting our marriage. How about you go somewhere else.’ And she was very angry at that, and she went.

Reiss’s (1981, pp.170-173) description of periods of crisis in a family’s history as conceptual cornerstones seems to fit many of Elizabeth’s crises, such as her abortion, her miscarriage, the family’s car accident and then her nervous breakdown. In Reiss’s terms this would mean that in the meeting of the challenges of Elizabeth’s crises, changes of coherence, and possible strengthening of the family’s resilience could emerge. Recovering from her breakdown, Elizabeth left the family and travelled to England for time out. Elizabeth said to her husband ‘I have to go, I just
have to’. The time away refreshed and replenished her, ‘it really set me up,’ and she returned after about three months to begin a librarianship diploma and build a new career path.

Years later, the recognition of each other’s pain came to both Elizabeth and her daughter when they could agree. ‘She said I was very depressed, and very needy and I think she was right.’ Describing her intergenerational conflicts, between herself, her mother and sister, and later between herself and her daughter, Elizabeth, according to Becker, engages a form of generational continuity (Becker 1997, p.107).

Linde’s (1993, p.134) description of a sense of loss of coherence, to a degree matches with Elizabeth’s story of her abortion and later her ‘nervous breakdown’. Something seems to be missing in Linde’s overall view as it sits with Elizabeth’s story. It is my perception, not suggested by Elizabeth, that at this point in Elizabeth’s life many of her previous losses of self coherence came together in a mass destabilisation. The abortion, the grief over her mother’s death, the struggles with her children’s births and health, the family’s car accident, the struggles with her teenage daughter, all then brought to a head by the girls’ school scenario, and her feeling of failure, her sense of loss of trust and therefore integrity.

Elizabeth requested a further conversation as she re-read the work we had done, in order to finish her story. It related to this previous paragraph in particular. This conversation is fully described in Chapter Seven, 2.5. Elizabeth said that she felt that I had made too much of the abortion continuing on to be part of her nervous breakdown. She had ‘squashed’ the abortion by her confession, and also by going on to have more children. She said it was a pity she had done it, but it wasn’t part of the nervous breakdown. When she had the breakdown, the abortion was too far
away, too long ago to be part of the cause. The abortion was not ‘a lifelong grief or guilt, I got over it.’

She now feels that the things that have happened since have supported her decision to have the abortion. I asked if the emotional scar of the abortion would always be there, and she replied that ‘it is only a scar, it doesn’t do anything’.

c) Elizabeth’s ‘hot texts’

Gilgun, a Social Worker, (1999) describes narrative texts where researchers cannot emerge unscathed from close engagement with ‘hot’ texts, that is, narrative material that most people would find deeply disturbing.

Johnson (1989, p.374) proposes that purposes are destinations, journeys often involve obstacles that must be overcome or dealt with. This gives rise to an *agon*, the basic struggle or tension that gives the story its character.

My reflections

The stories of Elizabeth’s difficult forceps delivery of her first baby in Indonesia, without anaesthetic, in appallingly primitive conditions, the subsequent malnutrition and failure to thrive of her two children, and, later on, the excruciatingly painful birth of her third child when she was suffering with multiple fractures, including bilateral unstable pelvic fractures, were all texts that I found ‘hot’ - difficult to transcribe and fully engage with. However much I could enter this text, I still was not able to fully comprehend the agony that Elizabeth had endured (Gilgun 1999).

Perhaps Elizabeth’s own hot text was, for her, the story of her stroke and near death experience. Whilst it was central to our initial agreed purpose of telling her life story, she kept putting off the point in the narrative when she discussed her illness. Finally when there was little left until it was faced and told, the time became right. She says

I think I should tell you about being ill, that’s about the end of me, I think the end of my story. I have to describe the illness that was really very traumatic.

And she seemed then to launch herself into this part of her story, fitting Johnson’s (1989, p.374) explanation that purposes are destinations. Elizabeth’s journey involved obstacles that needed to be overcome and
dealt with, giving rise to the basic struggle or tension that gives her story its character.

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<th><strong>d) Elizabeth’s near death experience</strong></th>
<th><strong>My reflections</strong></th>
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| According to Becker (1997, p.48) near death experiences reawaken our awareness of our mortality. Such experiences bring about a confusion of thoughts, emotions and feelings, and a need to find meaning within these experiences. Near-death-experiences researcher Atwater (1992) describes ‘heaven-like scenarios with visions of pure light, vibrant landscapes as if in springtide, blindingly open clear sky’. Atwater claims that when one keeps a person’s life in context with his or her brush with death, you cannot help but recognise connections between the two, threads that seem to link what is met in dying with what that individual came to accept or reject about the depths of their living. Surgeon Sherwin Nuland (1993, p.16) in his book about how we die, gives a pragmatic view of the physiologically produced effects of the shutting down of organs, and how this ‘turns down’ sight, consciousness, and commences the ‘spiral into oblivion’. Nuland says that it is not sensible for us to dismiss the many credible stories of near-death experiences. He remarks that many of these experiences report a sense of peace and well-being (p.137-9). Byock (1992, p.233) also describes a nearing death awareness. The Tibetan Book of Living and Dying sets out the ‘exciting dimension’ that with the advent of modern medicine, there are many descriptions of people who have been revived from ‘death’. Rinpoche (1992, p.320) explains that no two people have the same experience, there is no common pattern, but that a ‘core experience’ seems to appear. | I searched Atwater’s (1992) description of near-death experiences that might throw some light on Elizabeth’s experience. Elizabeth ‘knew’ she was dying, she couldn’t see, she was floating in and out of consciousness, but still felt a sense of connection with the family she loved who were surrounding her bed. She still felt a deep sense of responsibility for her husband’s well-being, she could not leave without knowing his care was in place: I said to Pieter ‘Darling if I’ve got to go, I want you to ... I heard him give a big sob. I thought oh well, I’d better start trying to get better. So I said I’ll try and come back if I possibly can.’ I was perfectly clear in my mind. But I was blind, and I just knew I was going to die. S: Were you worried? E: No ... I said ‘I don’t mind dying but I’m worried about Pieter.’ I can remember the things that I said quite clearly. S: So you felt you had a choice? E: No, not really, I don’t know what happened but from then on I’m quite sure if they looked at my chart I improved from then on. Only because Pieter was so worried and so miserable. S: Did he say he didn’t want you to go, or he wasn’t..... E: He sobbed, I’d never heard him sob. Never. Atwater’s ‘heaven-like scenarios with visions of pure light, vibrant landscapes as if in springtide, blindingly open clear sky’,
do not fit Elizabeth’s experience. However Atwater’s claim that when one keeps a person’s life in context with his or her brush with death, and that you cannot help but recognise connections between the two, seems to connect with Elizabeth’s deep commitment to her relationship with her husband. This was strong and abiding, and perhaps explanation enough. She heard how much it would hurt him if she died, so somehow she was able to turn around before it was too late.

Nuland (1993, p.16) in his book about how we die, presents a pragmatic view that would explain Elizabeth’s experience as physiologically produced by the shutting down of her organs, and that this ‘turned down’ her sight, consciousness, and commenced her ‘spiral into oblivion’. Physiologically, perhaps the restricting of her fluids allowed her kidneys to begin working again, and gradually her heart and other vital organs recommenced their functions. Nuland says that it is not sensible for us to dismiss the many credible stories of near-death experiences. He remarks that many of these experiences report a sense of peace and well-being (pp.137-9). Byock (1992, p.233) also describes the nearing-death awareness, that Elizabeth was apparently experiencing.

Elizabeth’s description correlates with Rinpoche’s first step in his ‘core experience’, that of ‘an altered state of feeling, of peace and well-being, without pain, bodily sensations or fear,’ (Rinpoche 1992, p.320).

e) ‘It was not nice!’

LeGuin (1981, p.193) suggests that the human condition and our normal existence is made up of an unbroken series of ordeals, deaths and resurrections.

Bourdieu (1999, p.600) discusses one of his interviewees, Louise, an 80 year old

My reflections

Elizabeth remembers past events that I would have described as horrific, or almost unbearable, in her words as simply ‘it was nasty’ or ‘not nice’. When I asked her about this almost blanding down of the horror, she said that the events had happened long
woman who had been a social worker. Louise uses a ‘chatty tone of voice’ to describe her suffering, as Bourdieu interprets it, as if Louise wanted the levity of her tone to hide the pathos of her situation.

ago, and that they had now lost their sting. In fact, in describing a much more recent event, that happened at the same time as her near-death experience, she says

I was in Intensive Care, that was the night that they decided to deprive me of water. I can't think what fool did that, but they did. And it was agony! I begged, I begged horribly for the nurse to give me some water, and she didn’t say, she was horrible, but she didn’t say anything about why I was being deprived - but ‘No! No!’ Just that.

f) A touch of kindness

In his book ‘The renewal of generosity: illness, medicine and how to live’ Frank (2004b, pp.69-73) discusses a story about the deeply ill Vanessa, who says ‘no one reached out to touch me.’ Frank (2002c, p.15) calls this a ‘how can they act like that?’ story.

In her book titled ‘Old Age’ writer Helen Luke (1987, p.109) suggests that a true nurse is always deeply concerned, she is compassionate, which means objectively ‘suffering with’ but not invaded by emotional reactions. According to Luke, a true nurse is herself changed by the experience through the love that lives beyond her own emotion.

My reflection

Frank’s (2004b) story about Vanessa, resonated for me in Elizabeth’s story. One might well ask what led Elizabeth’s nurse to make the situation worse, engraving its horror on Elizabeth’s mind for the rest of her life. Perhaps a simple touch and word of compassion might have made the situation better and at least understandable for Elizabeth, no matter how legitimate and sensible the medical reason for withholding fluids may have been. In Frank’s ‘Vanessa’s story’ that I saw reflected in Elizabeth’s story, the focus of Elizabeth’s nurse was the implementation of instructions that might kick-start Elizabeth’s failing organs. Elizabeth’s own narrative fell outside this medical imperative, this nurse simply saw what fitted into her nursing orders. How could any human being not see Elizabeth’s ‘agony’ and offer her a word or touch of comfort, and perhaps ice to suck or oral hygiene? Elizabeth’s story then became about her distress, and the failure of the nurse to listen to, hear and honour her suffering. Frank’s book (2004b) ‘The renewal of generosity: illness, medicine and how to live’ is in my view, a cry to all health professionals to see/hear more than just their own narrative, or the medical
imperative’s narrative, to embrace the narratives of all the stakeholders in the story, such as Elizabeth and her family. It is a reasonably simple, inexpensive act of kindness that might have made a difference for Elizabeth.

5. Theme: ‘Fraying around the edges’

a) The deficits after Elizabeth’s stroke

Zola’s (1982) Missing pieces is a poignant book about living with disability. Zola, a sociologist disabled by the after effects of polio, describes among others, the neurologically damaged. as diminished persons (p.8).

Murray Parkes (1971, p.103) suggests that certain crisis situations and events can lead to the stars as well as to the grave. He describes our assumptive world as the only world we know and says that whether we construe a particular change as gain or loss, it still requires some effort to absorb into our life-space. He calls these major changes psycho-social transitions, bringing changes to our view of the world. The transition involves giving up one set of assumptions about the world and establishing another, and grief is the inevitable consequence (p.107). Each person’s assumptive world is unique to themselves, and painful insight is required if we are to recognise a discrepancy between our assumptions and our actual life space.

Becker (1997, p.53) suggests that in looking at how strokes affect lives, especially in older people, we are encouraged to re-shape the meanings associated with impairment. We are also might explore how impairments foreshadow death. Becker explains that stroke ‘lends itself to this exploration, because of its potentially devastating effect on people’s bodies and their lives’. One of Becker’s storytellers cites her great loss at

My reflections

Elizabeth struggles to come to terms with the physical deficits and the huge loss of independence she has now to learn to live with. It is how she is in her world at the time of recording the life narrative:

They still help me up the steps at church, but it isn’t that that’s wrong with me, it’s that I sometimes sway ... I’m quite strong really but I have no sense of direction or balance. And that’s awkward. That’s the reason I can’t possibly drive a car.

S: That took a bit of coming to grips with?

E: Mm, I still haven’t - but yes, it did.

S: That loss of independence?

E: Yes. Well I drove it once or twice after I’d been ill, but ... after that, well I pretty well knew I couldn’t, especially in ill, but ... after that, well I pretty well knew I couldn’t, especially in traffic. I had a few little things I did with the car that were not altogether a good idea. But ... oh boy!

S: They were actually points of you having to let go these independences?

E: Yes, oh yes, terribly much.

S: Deliberately saying ‘ok, I won’t challenge this any longer.’

E: Yes, yes, yes.
not being able to play the piano anymore. This person describes this as the ‘one thing that has killed me, and broken my heart’ (p.55).

S: The piano still hurts?

E: Oh, I keep thinking, you see if I can teach myself to knit, couldn’t I teach myself to play again. But I’ve tried and tried ... I don’t want to listen to other people’s music, I want to make my own, but I can’t ...

S: So they’re all things that need to be given up, and accepted giving up?

E: Yes I suppose so, mmm, I haven’t accepted giving up the piano, but it’s no use ...

Murray Parkes (1971) suggests that certain situations and events would account for some causes of Elizabeth’s ‘nervous breakdown’. These events include bereavement - the death of her mother while she was isolated in Indonesia; childbirth - the traumatic forceps delivery; changes of occupation - the difficulties at the private girls’ school; migration - which would cover Elizabeth’s experiences in Indonesia and Holland; and major physical illness - covering Elizabeth’s severe injuries in the car accident and subsequent childbirth with unstabilized fractures. As Murray Parkes describes it, crisis can lead to the stars as well as to the grave. It seems to me that it describes Elizabeth’s resilience, that after she left the problematic job at the private girls’ school, she journeyed to London and gathered herself together over a period of three months, and returned home restored, with a decision made to do a graduate diploma in librarianship, which went on to bring her years of happy employment. It was perhaps harder to resolve the relationship with her youngest daughter, this was not achieved until the last few years.

Elizabeth, over a number of years, had quite drastic, shattering experiences that fractured and brought changes to her assumptive world. She often described experiences that were ‘not nice’. So
Elizabeth’s fractured sense of not being-at-home with her teenage daughter, and her sense of not being-at-home in the girls’ school where she felt not trusted, were significant triggers for all the difficult life experiences she’d had up until then, lumping together to totally rupture her senses of self equilibrium. One of Becker’s (1997) storytellers cites her great loss at not being able to play the piano anymore. This person describes this as the ‘one thing that has killed me, and broken my heart.’ (p.55) I am sure Elizabeth would agree, it is that devastating.

b) Resilience

The Macquarie Dictionary (p.1447) defines resilience as elasticity, resilient action, the ability to rebound, the power of ready recovery, buoyancy, springing back, and returning to the original form or posture after being stretched. Deveson (2003) is intrigued with the capacity some people appear to have of dealing with adversity, of being able to cope with great problems in their lives, and yet to come through, and bounce back. It is an almost mysterious quality that enables some people to rise above their adversity, and to still be able to find hope and meaning in their lives.

For Deveson, this meant facing the difficult issues in her own life including the disruption and eventual death of her schizophrenic son, being prepared to confront things that other people might not. Deveson says (p.109) that people do survive, by many means, such as hope, luck, adaptability, a reconnection with family and friends. Deveson says that sharing profound experiences such as birth and death, exposes us to confronting the universal questions about the meaning of life, and its inextricable connection to the meaning of death (p.206). Deveson and LeGuin (1981) describe Primo Levi’s (1979) resilience to survive the death of his family in the Holocaust.

My reflection

This concept perhaps for me, best describes Elizabeth’s life. Deveson (2003) is intrigued with the capacity some people appear to have of dealing with adversity, of being able to cope with great problems in their lives, and yet to come through, and bounce back. This seems to be part of Elizabeth’s personality, things that would daunt most people, she seemed to spring back from. Yes, they were nasty, but you simply had to get on with life.

There are times when to be resilient means to be able to let go and to allow others to take care of you. In Deveson’s (2004) view you learn from the things that happen to you, but every now and then it is simply human to fall down in a heap. Elizabeth did this a number of times, but particularly when she says

I was recovering from a nervous breakdown and in fact I told Pieter I had to go, I had to go away. I had to.

Love brings strength to resilience, and there is little doubt that the enduring, loving relationship that began in such an unusual manner for Elizabeth and her husband, was absolutely pivotal in her strong spirit of resilience that brought her through the difficulties her life encompassed. Elizabeth
camps of The Holocaust as being deeply embedded in his need to survive to tell the story, to bear witness to the horror that he had experienced.

Deveson (2004) suggests that we cannot be resilient all the time. There are times when to be resilient means to be able to let go and to allow others to take care of you. In Deveson’s view you learn from the things that happen to you, but every now and then it is simply human to fall down in a heap. Deveson also assures us that love brings strength to resilience.

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**My reflections**

Elizabeth and I considered the benefit of the process of therapeutic autobiography to us both. She thought that I had credited her with more courage and strength than she had, because what she did was a necessity. She sums up her story with ‘I did what I had to do, always. The key word is necessity.’

I asked her with a smile if there were no ‘pats’ for herself. She replied that she liked what she did, she likes the shape of her life except when it starts fraying around the edges. She says her intellect is alive and well, though her analytical prowess is not what it was. But she can still talk! She had read her story with a sense of pleasure, ‘this was me, I said that, it was true.’ She said that our conversation had been fun.

I sensed a benediction in Elizabeth’s ending to her life review

**E:** I think I’ve finished my story!

**S:** You’ve come to the end?

**E:** I think so, just as I say every day we feel we are so lucky and blessed just being healthy and being together.

**S:** Mm. It’s a good place to end.

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**c) The end of Elizabeth’s narrative**

In discussing the parameters of a narrative, Frank (2004 workshop, personal notes) says that the purpose of a narrative is to arrange events in an order that seems to make sense and end correctly.
E: As I say it’s a happy ending if either of us dies now, well the other will be terribly miserable, but we’ve both had a very good life, full of adventures, full of love for each other, so we’ve been lucky.

S: it’s a beautiful story

E: I think so.

S: I’m very privileged to have listened to it.

3. MY EXPERIENCING AND JOURNALLING OF ELIZABETH’S STORY

I connected deeply with many parts of Elizabeth’s story. Her love of literature and music, her breadth of fascinating life experiences, and her determined survival in the face of the struggles she faced throughout her life, all impacted deeply on me. They somehow became bridges to many of my own experiences. I admired Elizabeth’s courage and spirit. Her earthy sense of reality and humour seemed to be refreshing and open alongside others of her generation in my life experience. I had up until then thought that many of the previous generation were experts at secrets - my own family seemed held together with stories that could not be spoken. Elizabeth told me that all her family of origin had now died. She said that she could not think of anything that she would not want told, it reminded her of Holland, where everyone kept the curtains open at night, and when she commented on this to Dutch women, their response was ‘what have you got to hide?’

Elizabeth meticulously corrected my typographical and spelling errors, and we had various telephone conversations about the correct Dutch and Indonesian words and their spelling. Her polished, comfortable use of Dutch and Indonesian languages impressed me as a person with only one language. Each morning, as we got to the end of recording the first side of the tape, Pieter would appear with a tray of delicious coffee and Dutch biscuits, served with gentle courtesy. It was a lovely experience to be with them both and share their rich and compelling stories, and devoted relationship. I enjoyed the taping sessions in their interesting home. I had entered another world, a pleasant adventure for
me. I entered into Elizabeth’s world as much as I could while she was telling her story. It was later as I transcribed the tapes, and allowed my inter and intra subjective responses to form, that my own connections surfaced. Again I realised how strongly other people’s stories bring us back to our own experiences and stories, through which we interpret, reflect and respond to one another.

In 2004 I attended a workshop entitled ‘Working with Narrative: Health and Illness Stories’ lead by Canadian sociologist Arthur Frank. Many of the things he said that day resonated with Elizabeth’s story for me. Frank suggested that stories were like images that invoked the world of the storyteller with great intensity. There were many intense moments within Elizabeth’s story that evoked the pain of these experiences for her, colourfully and strongly resonating with me. Her almost bland ‘nasty’ and ‘not nice’ confused me - they often seemed like horrible experiences to me. When I questioned Elizabeth about this she said they happened a long time ago, and the intensity had softened for her, so nasty and not nice were enough.

Here again with Elizabeth I was experiencing Gilgun’s (1999) hot texts. Gilgun says that researchers cannot emerge unscathed from close engagement with ‘hot’ texts, that is narrative material that most people would find disturbing. The stories of Elizabeth’s difficult forceps delivery of her first baby in Indonesia without anaesthetic, in appallingly primitive conditions, the subsequent malnutrition and failure to thrive of her two children, and later on the excruciatingly painful birth of her third child when she was suffering with multiple fractures, including bilateral unstable pelvic fractures, were all texts that I found ‘hot’ - difficult to transcribe and fully engage with. However much I could enter this text, I still was not able to fully comprehend the agony that Elizabeth had endured.

On one occasion Elizabeth described her gynaecologist’s demand that they leave their two children and have a much needed break together after her traumatic miscarriage. I felt annoyed at her gynaecologists’ lack of insight into this family’s circumstances. This meant leaving the children in formal care, and sleeping in their car because they could not afford accommodation. I reflected on the painful, exhausting, never-ending commitment that parenting demanded, and the toll that it placed on parents’ health. I could well identify with this exhaustion and sometimes an overwhelming necessity for the parents’ needs to be met.
Elizabeth describes her mother as ‘very interior, she fixed the home beautifully’, and again listening to her story as I worked with it I was brought to reflect on my own mother, who was also very good at homemaking and was also very hospitable. And Elizabeth’s grandparents played an important role in the shaping of her life, as did my own. I thought that one day I would stop working on others’ stories and join together the many reflections I had written about my own family of origin. I wanted to argue with Reiss (1981) when he states that the family’s social environment contributes to its management of stress. That sounds positive! I saw that in a much more negative light in Elizabeth’s family, and probably Sarah’s, Kaye’s and my own. Reiss says the nature of these bonds supports and sustains the family. I think it also sometimes nearly destroys them.

Elizabeth ‘fell apart’ in a teaching position where she felt she was not trusted, and could not teach in a way that sat comfortably with her sense of her own integrity. The experience left her feeling untrusted, misunderstood and undervalued. I remembered a work experience where my illusions were shattered and I soon left what I thought would be an excellent long-term job, feeling similar sorts of feelings that took me many years to work through. Again I ponder the need to bracket my own experience, to acknowledge its presence in my sitting beside Elizabeth’s distress recounting her experience. Perhaps my experience simply enhanced my empathic listening to her experience. I did not disclose my bad experience to her.

At school, she was encouraged to join the Student Christian Movement, which stabilised and transformed her enjoyment of secondary school and led later to her meeting her life’s partner, as a university student attending an SCM camp. My own experiences of SCM were much less favourable and were not very successful for me.

Elizabeth described the rules of her girlhood years. There were the religious rules, the alcohol rules and the sex rules, but they didn’t worry Elizabeth. They were rules, but you just lived within them. I certainly could identify with similar rules although, some twenty years later, they were changing. Perhaps they change with each generation - Elizabeth and I enjoyed discussing these rules that guided our growing years. I acknowledged my annoyance with rules that to me didn’t make sense.
3.1. Elizabeth’s abortion

I found it quite difficult to engage in Elizabeth’s story of her abortion. I had not ever really needed to deeply consider this issue before, though I had previously had some discussions with several friends who had abortions without seeming to experience the long-term guilt that Elizabeth described. So now I needed to read broadly around the issues that Elizabeth described, as part of the literature search after I had finished her story, before reaching its essence statement. I wanted to be fully informed as to what it might have been like to have made this decision around 50 years ago, for Elizabeth. Not so that I might explain, but rather to try to immerse myself in the issues Elizabeth described, so that I could more closely feel her perspective of her particular experience, that sounded to me like a continuing soul crisis.

So as she described her abortion on the tape, as I re-read and re-listened, and transcribed, as fully as I could I entered and indwelled her pain, guilt and grief. I needed to feel informed, to find some firm ground to rest on, before I could sit with her in her as yet unresolved crisis. [I wrote this before Elizabeth and I had a further conversation about this issue.]

It was slippery hot text, and it was hard to grasp her perspective. I could forgive her far more readily than she could forgive herself.

If I hadn’t ever formed a view, how could I see it with her eyes. My pre-reading perspective seemed to be that the God-Jesus I’d been taught about would have seen her intolerable situation, known her pain and understood in deep love, the decision she had made.

So in the end there were two collaborative positions: Elizabeth’s, which still felt guilt, shame and grief, and mine, which saw her pain, grief and anguish and also saw possibilities for her to find her own forgiveness; and seeing that, for me then to ‘allow’ or stay with her ‘NEVER!’

I read extensively. Reiss (1981, p.159) talks about ‘ad hoc derivations’ which are almost always required to make especially difficult decisions. Elizabeth was adamant that she
made this decision for herself, and that it was a selfish one, even though I could hear or understand reasons that supported that decision for her two existing children’s wellbeing. I had to listen carefully to Elizabeth’s story and bracket my own feelings and interpretations, and in this particular story it became the most difficult of all the life reviews.

I wished that Elizabeth could forgive herself for making this decision at this time in her life, and not continue to this day to see it as a wrong one, deserving God’s punishment. Greenburg and Saffran (1987, p.180) write that guilt is technically a judgement rather than an emotion, one judges oneself and this results in feeling sad, angry, or ashamed. Lastman (2004) describes the psychological wounding following elective abortion, which creates a disequilibrium that is challenging to the person’s assumptive world, fracturing the inner being of the person. Elizabeth says

I've been ashamed ever since. I was wrong. I feel I was using a very selfish reason. Then I had a nasty miscarriage, at about six months, it wasn't pleasant. I was rushed to hospital bleeding all over the car. I rather thought it was a sort of punishment for the abortion I'd had. I'd confessed to Father M in the hospital, that made it a little better. I said I thought it was probably a punishment, and he said 'yes, it probably was!'

I felt cross with the priest’s lack of compassion! Reiss (1981) would probably suggest that perhaps Elizabeth voluntarily and passively accepted an explanatory system offered to her by the church and its spokesman. That still manages to make me angry - how intrasubjective is that!

As Elizabeth said (up until she modified this aspect of her story in our final conversation) that she never got over feeling guilty. I really wanted her to see that the lack of support and the priest’s judgement forced her to carry this pain all the way through the years until her ‘nervous breakdown’ and then beyond until now. But that is how it was and is for her, that was her story.

It was difficult to find a copy of Sue Nathanson’s (1989) book, where she writes poignantly of her own soul crisis following her termination of pregnancy. Echoing
Elizabeth, Nathanson says ‘my pain has nothing to do with the external, physical world’. She sees that decisions in these painful domains (and here Nathanson includes suicide and euthanasia) arouse nearly unimaginable anxiety because they border on darkness. Now I was reading *explanations* that helped me to make sense of Elizabeth’s experience [for myself!]. Nathanson explains our human need for a loving attachment to a mother who has the power to buffer and protect us from an awareness of the vast, indifferent universe in which we must survive. This need is so profound that we unconsciously demand that mothers provide perfect care for their children. No matter that such perfection is impossible. Perhaps this touches on a number of distressing issues in Elizabeth’s life. Her mother, even when present on a number of painful occasions in Elizabeth’s life, such as the birth of her first child in Indonesia, could not protect her from the terrible ordeal. And throughout her ongoing life with her own children, neither could she offer them protection from their own suffering, which saddened her enormously. It is this unalterable fact that Nathanson calls a soul crisis, which seemed to fit Elizabeth’s story so well, and brings a requirement for her to accept a permanent alteration in her sense of herself. It is here that I can finally see and acknowledge the bridges to my own painful experiences, my relationship with my own mother, with her depression and anxieties.

### 3.2. Elizabeth’s near-death experience

It was my fascination with near-death stories that drew me to Elizabeth’s story in the beginning. I searched Atwater’s description of classifications of near-death experiences that might throw some light on Elizabeth’s experience for me. Elizabeth said she ‘knew she was dying’, she couldn’t see, she was floating in and out of consciousness, but still felt a sense of connection with the family she loved who were surrounding her bed. She still felt a deep sense of responsibility for her husband’s well-being, she could not leave without knowing his care was in place.

Atwater’s ‘heaven-like scenarios with visions of pure light, vibrant landscapes as if in springtide, blindingly open clear sky’, did not seem to fit Elizabeth’s experience. However Atwater claims that when one keeps a person’s life in context with his or her brush with death, you cannot help but recognise connections between the two, threads that seem to link what is met in dying with what that individual came to accept or reject about the depths of living. Elizabeth’s deep commitment to her relationship with her husband
was strong and abiding, and perhaps explanation enough. She heard how much it would hurt him if she died, so somehow she was able to turn around before it was too late. This made sense of Elizabeth’s experience for me, especially in the light of my own Palliative Care nursing experience, sitting beside many dying people, who seemed able to determine the right time for themselves to let go. It always struck me as remarkable when some people seemed able to get the timing to fit certain specific requirements, such as waiting until someone special arrived to say goodbye.

3.3. A touch of kindness

At his public lecture the evening before the workshop in 2004, Arthur Frank discussed a story from Canada, a verbal reference later discussed in his book (2004, p.69-73). In Frank’s story, the deeply ill Vanessa says ‘no one reached out to touch me.’ These words resonated for me with Elizabeth’s story. I wanted to ask what lead Elizabeth’s nurse to make this situation worse, engraving its horror on Elizabeth’s mind for ever. Perhaps a simple touch and word of compassion might have made the situation better and at least understandable for Elizabeth, no matter how legitimate and sensible the medical reason for withholding fluids may have been. In his discussion of Vanessa’s story, Frank explained and I then heard reflected in Elizabeth’s story, that the focus of Elizabeth’s nurse was the implementation of the instructions that might kick start Elizabeth’s failing organs. Elizabeth’s own narrative fell outside this medical imperative, this nurse simply saw what fitted into her nursing orders, that is ‘withhold all oral fluids’. Frank (2002c) calls this a ‘how can they act like that?’ story. How could any human being not see Elizabeth’s ‘agony’ and offer her a word or touch of comfort, and perhaps ice to suck or oral hygiene? This was a story then of Elizabeth’s distress and the failure of the nurse to hear and honour her suffering. Frank’s (2004) book ‘The renewal of generosity: illness, medicine and how to live’ is in my view, a cry to all health professionals to see more than just their own narrative, or the medical imperative, to listen to and embrace the narratives of all the stakeholders in the story, such as Elizabeth and her family. It is a reasonably simple, inexpensive act of kindness that might have made a difference for Elizabeth. And of course, here again, it links into my own story in the Introduction, that I needed to bracket, but acknowledge and make transparent its presence.
3.4. **Resilience**

I felt that this concept perhaps best described Elizabeth’s life, though perhaps I exaggerated its significance. Elizabeth certainly thought I did! The Macquarie Dictionary defines resilience as elasticity, resilient action, the ability to rebound, the power of ready recovery, buoyancy, springing back, and returning to the original form or posture after being stretched. Perhaps this is what Elizabeth ideally would have done. I think she suggests that I exaggerated her spring and bounce! Elizabeth expresses a deal of sadness and depression in how it has all panned out in her life. She survived, but perhaps ‘spring’ was rather more a slow gentle moving on.

Deveson (2003, 2004) says that people do survive, by many means, such as hope, luck, adaptability, a reconnection with family and friends. Elizabeth would say that her faith carried her through, and her relationship to her husband. Significantly, Deveson suggests that we cannot be resilient all the time. There are times when to be resilient means to be able to let go and to allow others to take care of you. In Deveson’s view you learn from the things that happen to you, but every now and then it is simply human to fall down in a heap. Elizabeth did this a number of times. I could resonate with that!

3.5. **The continuing deficits**

I could fully empathise with Elizabeth’s distress that her stroke had curtailed her life and left significant deficits. She was distressed by her inability to play her beloved piano, or to maintain the independence of driving her car. At my age I cannot help but wonder how my own health will pan out over the next twenty years or so, and how I would deal with similar issues. So Elizabeth’s grief and her coping and struggle to improve, and indeed to accept that some of these restrictions and deficits were permanent, impacted on me deeply.

3.6. **The benediction**

When Elizabeth said ‘I think I’ve finished my story!’ I agreed, it felt finished. It was a beautiful story, beautifully told, in pleasant surroundings, I really did feel privileged to have listened to it. It is a lovely narrative to include in my thesis.
Appendix Eleven:
Speculative possibilities for better listening: enabling better outcomes

1. POSSIBILITIES WHERE BETTER LISTENING MIGHT HAVE ENABLED BETTER OUTCOMES FOR THE FIVE NARRATORS

In the Introduction and throughout the thesis there is discussion about what constitutes good listening. I now reflect on how each of the five participants in my study on a number of occasions seemed not to have been listened to by various healthcare professionals. The following are my speculative thoughts about ways the quality of listening might have been improved and contributed to better experiences. This better listening might have helped the narrators find a better coherence, a less damaged sense of self-identity and less sense of loss of control of their lives, in the difficult experiences they describe. In each case I am suggesting intersubjective or I-Thou/Being-to-Being connections and communication, which might have led to different interventions and better outcomes. After considering each of the five narrator’s experiences, I also consider possibilities of how I might have listened differently, as a critique of my methods and my listening in the study.

1.1. KAYE: Possibilities of listening at the time of her mother’s death that might have made a difference to Kaye’s well-being

Kaye stated that she was by nature ‘a flighty person’. The nature of her mother’s unexpected death was the trigger that launched Kaye’s ten-year self-destructive trajectory: ‘my mum died and I went off like a rocket’. Kaye described herself, her father and brother as ‘three completely separate entities’, as they struggled through the three days
her mother spent on life support in the Intensive Care Unit. Each seemed isolated in their individual grief. For Kaye, it was ‘an incredible experience of alienation’.

Privacy in a warmer, softer setting than the stark, cold and sterile ICU Kaye experienced, would perhaps have softened Kaye’s bleak images of her mother’s last three days. A softer setting is now available in a refurbished unit at this hospital, for at least some patients who are acknowledged to be dying in ICU. ‘Room One’ is where patients are moved prior to the ventilator being switched off and the patient being extubated. The room has carpet, flowers, a couch for family members to sit on, and nice curtains.

However ICU units remain stressful places with often frantically busy staff. If a patient is expected to survive until the next morning, the family are asked to leave, there is no provision for them to stay overnight. Wros (1994, p.271) suggests that some nurses soften these difficult situations and are concerned for the primacy of the family needs over the demands of the institution or the physician. In the unit where Kaye’s mother died, for security reasons, and the fact that this room can only be entered by going past four other ICU beds, visitors are limited to two at a time. Critical bed shortages also limit how long a family can stay with their loved one in this room after death, prior to transfer to the mortuary - an even less pleasant setting (Personal conversation with my son Doctor James Griffiths, who trained and worked at this hospital 7/2/07).

Wros (1994, p.257) asks ‘what are the interpersonal concerns and background meanings of bereaved family members related to nursing care during the time the patient is dying in critical care?’ A shift of focus for the health professionals at this point would change their way of listening to what was happening. It is not just a difficult task to be done, rather a journey to travel with the family. It requires the utmost in gentle, sensitive, unhurried listening to this family as a whole, and its individual members who are each, as Kaye expressed it, separate entities suffering their own personal crisis. Kaye describes a shattering life-crisis where she felt left out of the decision-making loop. The requirement for time, listening and sensitivity is a big ask in such a busy unit, but to not meet this need may perhaps trigger ten year destructive trajectories like Kaye’s, that cost far more in terms of suffering for families. Pastoral care is of great value, but it also requires the training and sensitivity of all the health professionals involved. One nurse’s comments are related by Kaye ten years later:
‘At some stage I was sitting with my dad in the ICU next to my mum, and the nurse said ‘you know it’s genetic, you could have it too.’ Which is the most Fucked thing to say. To, particularly to a father who’s sitting there with his daughter, and his wife’s just died…”

In Chapter Eight, 10.1, I reflect on how Wros’s paper led me to soften my stance by allowing the voices of Kaye’s mother’s ICU’s nurses to be present in Kaye’s story in a less critical way than I perhaps presented in Chapter Three.

What is needed is a co-ordinated team effort. However in Chapter Eight, 10.1, I described imagining the voices of Kaye’s mother’s nurses, after reading Wros (1994). This helped me to acknowledge that my suggestions are perhaps presumptuous and I have nothing other than Kaye’s story and my son’s descriptions of this particular ICU on which to form my speculative ideas.

It might have helped Kaye if a pastoral care person had offered to support her and enable her to stay with her mother when life support was withdrawn, listening carefully to how she was coping at the time. Kaye felt pressured by her father’s edict that they would all leave before this happened. Kaye has always regretted his decision but was not able to challenge it at the time. Skilled pastoral care and listening might have enabled the verbalisation of her desire to stay. Kaye said

I mean I didn’t actually see my mum properly dead.

S: You left before?

Yeah I was a bit pissed off about that actually. I mean there’s a couple of things in ... what happened around my mum’s death that I’ve had some real problems with.

However skilled pastoral care and listening whilst respecting this family’s lack of religious affiliation, might have helped Kaye manage these horrendous three days with less dire, long-lasting effects. Perhaps individual follow-up might have supported Kaye, such as a phone call and the offer of counselling and information. This required the recognition by the staff of the ‘three independent entities’ of Kaye, her father and brother, and their individual styles of grieving.
It cannot be known how much Kaye might have responded to better listening at the time of her mother’s death. Perhaps I-Thou/Being-to-Being engagement and ‘ethically mindful’ listening might have softened the experience for Kaye and reduced the power of her flight into ten years of chaos (Guillemin and Gillam 2006, pp.29-40). It would have involved listening to her carefully in order to hear her confusion, and pain and misunderstanding about her mother’s death. This skilled and engaged listening ten years earlier might have helped Kaye find a less destructive pathway through her grief.

1.2. SARAH: The possibilities of her carers listening to Sarah over the last weeks of her life that might have allowed her a more peaceful death

Sarah’s illness story was a litany of occasions when health professionals listening differently might have made a difference to Sarah’s sense of loss of control of her life. Sarah’s perception of her relationship with the many and varied health professionals she had dealings with, was that they did not really know her or care about her as a person. This was despite her also knowing that she needed them. Her resulting anger and frustration further damaged these relationships and therefore further accentuated the despair she felt with the downhill progression of her disease. Her family’s interventions however well meant, added fuel to this fire:

I was overwhelmed by visits from my brother. He took charge and I became the little sister. He said to the doctor ‘I want to talk to you! You tell me what’s going on!’ My life is gone!
I asked Sarah what would have made a difference for her:

I think it would have made a difference if they had treated me as an adult … And treating me as smart enough. And I can hear people saying ‘you’re too smart for your own good.’ I know! I’ve come from a medical background, so they’re not treating a nit-wit that doesn’t even know what the lungs look like. I’m a pathologist … so I know maybe a bit more than the Tom, Dick and Harry who go to school and don’t know what the functions of the body are. I’m a person who wants the facts clearly sorted out and correct, and I would like the doctors and nurses to tell me, and to explain … if I don’t understand, explain it to me again.

It took time and empathic, open, engaged listening to hear how Sarah’s life experiences set the scene for her final battle. I sensed this battle as almost her own personal Holocaust. She was asking the health care professionals to take seriously ‘the small issues that were big to me’ and to talk to her about them as if they mattered:

… funnily enough, it’s my nature, I’m one of those who pay attention to very minor details, and I also get irritated by very minor details, so I’m saying this is really minor, this is really stupid, you know, concentrate on the big stuff, but this is my nature. I’m trying to teach myself to change it but there it is, little things annoy me … Most things are trivial to them, but they were not to me!

As she expressed it, seeing her as an adult who was recognised, and given information, repeated as often as necessary, at a level she could digest and understand, would have made a difference.

Transposing Kleinman’s (1988 p.xiv) story of his little patient into the context of Sarah’s care (refer Introduction): I visited Sarah and in effect said ‘tell me about who you are who comes to need this care. What is this illness experience like for you?’ A simple enough question that needed my willingness to listen in a deeply engaged way, walking with Sarah as we constructed her life narrative in the way she needed to tell it. I can only hope it made a difference to Sarah. It certainly made an impression on my life and its narrative.
This deep impression reflects the reciprocal recognition and trusting mutually open nature of this model of listening that has consequences for both narrator and listener.

1.3. **SCOTT: Possibilities for enhancing his care by listening to and reflecting on his needs**

By listening to Scott’s quietly told life review stories, I could sense his withdrawal into his own peaceful inner world. It gradually seemed to me it was not a depression he wanted or needed to be encouraged to leave. Rather it was a transcended place where he was peacefully preparing for his approaching death. To reach this understanding took me weeks of careful, lengthy listening, gently encouraging Scott’s musings about his life’s experiences. After reaching this understanding, I was able to share my feelings with Scott’s daughter. It was a peaceful withdrawal that I had witnessed before in my palliative care experiences.

It is sometimes difficult for a family to accept this withdrawal. Some families try to jolly the person back into being present with them (for example, my mother with my father). Scott’s daughter understood that her father was dying, and therefore Scott was able to talk or peacefully rest without his family feeling that he needed treatment for his depression. This understanding prepared Scott’s family for his peaceful death a month or so later.

Shortly after we finished recording his narrative, Scott moved from his special accommodation to a nursing home near his daughter’s home in the country. In the nursing home, Scott’s daughter told me how a physiotherapist cajoled Scott to walk with a walking frame, and he struggled valiantly to oblige her. But he never did anything like that again. The Director of Nursing of this unit eventually recognised that Scott should not be pushed.

However sometimes in his bed/chair he was pushed out to lie in front of daytime television, which he had always abhorred. Staff listening differently to Scott would have uncovered that this was something Scott would definitely not enjoy. It might have been what others in his situation might find soothing, but he was, as described by his son-in-law, ‘by no means a common denominator person’. This individuality resonates in the other narratives in my study - it is listening deeply to this person, and their way of being in the world, that becomes the key to giving better care.
1.4. **BERT: Listening to Bert, honouring his stories, self-worth and dignity**

There are a number of practical actions that might have followed the process of listening to Bert’s life review narratives that might have enhanced his wellbeing and the staff’s morale:

1. Helping Bert keep his precious books and writing safe, eg. a shopping trolley for storage, removed from his room overnight. If he had been encouraged, he was physically able to undertake this action for himself, which might have given him some semblance of self esteem and control over his possessions.

2. Understanding that listening to Bert is valid therapy, equal to drug regimes, worthy of investment of time and resources, and more creative than the current cycles of rages → unpleasant room clean-ups → staff anger → Bert ‘punished’ → rages *ad infinitum*.

3. The staff’s engaged acknowledgement, listening to Bert’s stories of the past - maps and photos of South Australia on his walls. In other words the staff’s ongoing interaction with Bert’s ‘place’, recognising his value as a person with dignity.

4. Facilitating Bert’s writing and his still strong sense of work ethic:
   - Provision of a typewriter (calm, quiet supervision, removed from the room at night)
   - A paper supply better than paper towel, also removed at night
   - Valuing Bert’s writing and drawing despite his confusions and confabulations

5. A daily newspaper of his choice, engagement in and discussion about his love of Channel 31, peaceful negotiation of television sound levels. The provision of headphones might resolve this on-going tension, also needing to be removed at night.

6. Bert told me that he has always woken at 4am. Rather than allowing his destructive rages to begin then, giving him one-to-one attention at this time each morning. A personal care attendant could encourage him to talk and write, enhancing his sense of self worth. This would be action that followed listening, enhancing Bert’s dignity and self-esteem, nipping in the bud the soiling of his room.
7. Possible outcomes arising from listening to Bert:

- The staff actively engaged in creating a more peaceful and positive existence for Bert.
- Bert less bored, better occupied therefore sleeping soundly, hopefully less night rages.
- The possibility of reduced anti-psychotic medication and its consequent dry mouth.
- Staff morale boosted by constructive care for Bert’s self-identity and wellbeing.
- Better understanding of the many dimensions of dementia care contributing to the wellbeing of other patients and staff, improving staff retention rates, particularly the roles of Unit Manager, Activities Co-ordinator and other visiting therapists.

The wellbeing of Bert, enhanced staff morale and their informed and supported enthusiasm for dementia care, with reduced unpleasant cleaning, outweigh any perceived costs. This would enhance the wellbeing of all participants in the unit - patients, families, staff and management, and model possibilities for dementia care at its best.

It is a given that at the time of writing these ideas at the end of processing Bert’s narrative, Bert has probably declined in his dementia to the point where some of them would no longer be possible. They are, therefore, the speculative considerations of how I see the implementation of simple strategies in similar situations, in order or improve the self image of people suffering from Wernicke-Korsakoff’s Syndrome, who are residents in Dementia units where most of the other residents suffer from Alzheimer’s Disease. This could improve the morale of these units as a whole.

1.5. ELIZABETH: Possibilities of better listening that might have lessened Elizabeth’s suffering

I will not discuss the many difficult health crises that permeate Elizabeth’s life narrative, and how she might have been heard differently in each of them. I will focus on the event that brought us together, Elizabeth’s recent ‘near-death’ experience, and the bitter memories she still has of that experience. She had left this ‘horrible’ story until the end of
her life review. She did not want to revisit the experience, but she felt that it had to be told:

That night I was taken to the Intensive Care Ward. I suppose, I don't know what happened but I'd had heart failure. And this is very fragmentary from then on, because part of the time I was conscious and part of the time I wasn't . . . And there was chaos and trouble . . .

that was the night that they decided to deprive me of water. I can't think what fool did that, but they did. And it was agony! I begged, I begged horribly for the nurse to give me some water, and she didn't say, she was horrible, but she didn't say anything about why I was being deprived - but 'No! No!' Just that . . . but it wasn't pleasant at all.

I rather angrily wrote in my journal, after listening to Elizabeth’s description and transcribing the tape, (following Frank 2002; 2004)

‘Elizabeth’s narrative fell outside the medical imperative, the nurse who upset her only saw what fitted her nursing orders. How could any nurse not hear Elizabeth’s ‘agony’ and offer her comfort? This nurse failed to hear her suffering.’

Restricting Elizabeth’s fluids was almost certainly intended to reduce the load on her heart and to ‘kick start’ her failing organs, particularly her kidneys. So these ‘orders’ followed by the nurse were probably physiologically speaking, responsible for her survival, perhaps alongside Elizabeth’s decision to ‘come back’ if she could. She was not cut off entirely from awareness of what was happening, she knew the various family members were around her bed, and would have been able to know and recognise gentle kindness and care from this nurse had it been offered. Soothing explanations, good oral hygiene to ease her thirst, ice to suck if this was permitted, were surely all acts of compassion that I always thought were the imperatives that undergirded the skills of nursing care. There are strong resonances between Elizabeth’s ‘horrible’ story, Kuhl’s (2002, pp.45-46) story of Marjorie, and my own story in the introduction.
As I considered these possibilities of listening differently in these situations, having also acknowledged the stressful conditions of working in an Intensive Care Unit in Kaye’s narrative, I read Giullemin and Gillam’s (2006, p.47) comment:

… what is the remit of health professionals; can they take (equal) care of all dimensions [of care/treatment]? One way to think about this is to consider different health professions as specialising in different dimensions of wellbeing. But we need to be clear that this does not mean they can be cavalier about the others … this does not mean it is ethically acceptable to ignore the possibility that medical treatment might cause psychological suffering.

Elizabeth’s healthcare professionals might well be pleased that their skill had brought her back from the brink of death. But this one point of not listening to Elizabeth’s suffering still causes her distress, and is what she remembers most clearly. If this nurse had been willing to engage with Elizabeth’s suffering, to listen and acknowledge her ‘agony,’ it would have changed this story into a more positive one where Elizabeth remembered the staff’s presence as supportive and compassionate.

2. POSSIBILITIES FOR ME LISTENING DIFFERENTLY

[EXPANDING THE DISCUSSION OF CHAPTER EIGHT, 4.9]

There were times when I did not listen - or at least did not hear, sometimes re-connecting with what was said as I transcribed and thinking ‘Why didn’t I respond to that at the time?’ With hindsight I have gained perspectives on many ways of listening, the environment for listening, the types of dialogues I experienced and how better to maintain them, reflections on the forms of responding, the multi-modal aspects I used, and ways of extending the concept of narrative to include other forms of expression or languages.

2.1. Kaye

It would have been better if I had discussed in depth with Kaye before we began, the method of reduction to an essence statement, so that she would not have felt so anxious about the deconstruction or reduction of our precious creation. In other words I needed to get past my ‘system’ and understand deeply her perception of the ‘fragmentation’ of my
process of reduction to essence. However, being the first narrative I processed in this way I was not really sure at that stage how it was going to flow. I could not see any way to make sense of the narrative meanings other than to go through themes seeking an essence of crystallised meaning for us both.

My own intrasubjective responses to Kaye were sometimes strongly represented in our conversations. I needed to constantly remind myself to listen intersubjectively and not be overwhelmed by what I wanted to say, or what I wanted Kaye to know. Sometimes I was aware that I did not hear Kaye at first, but because she was open and able to move within conversations from place to place, or idea to idea, we could mostly return and sort out where I had said too much or imposed my views, either at that time, or at the next session after I transcribed and heard my not listening. At one session I spent considerable tape-time describing Dennis Klass’s (2001) Interactive Web model of changed meanings (refer Chapter Three). In the end this turned out to be helpful for Kaye and she volunteered how much her view of the world had been able to change through our conversations. But it was her story and I agonised that I had said too much.

I was always anxious of losing Kaye’s voice in the process of ‘descriptive analysis ending with the essence of experience’ (Douglass and Moustakas 1985, p.42). I was relieved and delighted that, in the end, for Kaye the essence rang true and affirmed her experience, and was validating and important for her. It turned out to be a risk that worked.

2.2. Bert

With Bert, it would have been helpful for me to understand the nuances of the unit’s structures and philosophies, and to be seen as part of the professional team, rather than an ‘odd’ visitor who spent time in the quiet room recording the ramblings of one of the most disruptive residents. It was only at the end of our work together where the staff saw what we had produced, that they perhaps briefly supported the work Bert and I had done. I have only minimal hope that our work substantially changed the way they saw and heard disruptive residents in this unit.

In Chapter Six I also note how I did not see the titles of the precious paper-towel booklets Bert gave me until I got home and took time to look at them and absorb their significance. The two titles, ‘Promoting group harmony’ and ‘I am offering a slice’ would have been
interesting ideas to have explored with Bert. By the time I had seen them it was too late. It is simply not possible to notice everything and respond to every significant piece of the narrative.

2.3. Sarah

Because the staff of Sarah’s palliative care unit saw me as ‘siding with’ her difficult patient issues, they withdrew from supporting the work we were doing and simply observed from a distance. It was not possible to seek feedback from them for their voice in Sarah’s story. It was her brother, not the unit staff, who notified me that Sarah had died three weeks after we finished recording her life review.

I developed skill at forming the intersubjective responses as I continued in my study at MIECAT. As a result I felt disappointed that for Sarah, the first narrative I recorded, the responses were not poetic reflections written myself, but were using the words of others. There were pressures because Sarah’s life was rapidly running out, and what I sent her was the best I could manage at the time.

I used three ninety-minute tapes for Sarah because of the urgency, and worked hard to transcribe them as quickly as possible, but this was not ideal. I think it reduced the time for my inter and intrasubjective reflections to ‘brew’. With Sarah’s narrative, they emerged later during the processing, after Sarah had died. This perhaps partly accounts for the fact that I did not respond to Sarah’s description of rape about halfway through our second interview; it was only later in a supervision conversation that its significance came to the surface:

I was a virgin until I was, I think I was in the army already, till I was nineteen. And that was also a big mistake. It wasn’t, even with my consent. I was kind of virtually what you can call even raped.

How could I have missed some response to it, other than that the quality of good, totally absorbed concentrated listening has limits and probably as practiced in most therapeutic sessions an hour is the limit. Another consideration was that Sarah talked with a sense of great urgency and I seldom interrupted the flow of her story.
2.4. Scott

Scott taught me about really listening and waiting in silence for what might possibly emerge. His best wisdom often emerged quietly after long pauses. I got better at waiting. I kicked myself when I was transcribing and heard myself jump in too early or be too pushy, causing Scott to ‘lose his place’. With Scott I also learned to accept that recording is fraught with human errors like not turning the recorder on, and that perfection is mostly impossible. I was relieved to get into my car after recording an interview, press ‘play’, and hear that I had been successful. I had to learn especially with Scott to ask open-ended questions, or he would give me simple one-word answers that did not move us anywhere in particular. I then had to extend the question to ‘unstick’ the conversation. I got better at it as we progressed.

The variety of multi-modal responses were interesting. These ranged from ancient poetry and literature re-typed to enlarge the print size for Scott, to the many maps for Bert and the simple photo-copied page from the postcode book that offered him affirmation and validation. Deep listening, especially when transcribing, enabled these ideas to arise in my awareness. Some were more challenging than others. It took some effort to locate the synopsis of Ibsen’s play Peer Gynt in The Oxford Companion to Literature (Ibsen/Watts, 1966). I then photocopied and enlarged the print so Scott could read it comfortably. The only time I felt that I had ‘missed the mark’ with responses was with three of my own small travel stories that I gave to Scott. I felt they simply confused him. However they led me to see the small travel stories that Scott himself had embedded in his narrative, and I had pleasure in separating them out and sharing them with his daughter.

The recorder I used for the five interviews was a small analogue type with an omni-directional microphone. There were some difficulties in being sure of what had been said, which required repeated listenings. In recording Scott’s narrative where there were long pauses, I used the voice-activated facility, which minimised the recording of the noises outside Scott’s room when he was not speaking, but prevented the measuring of the length of pauses.

As I struggled to come to grips with the thesis, early in the processing of the narratives, particularly Sarah’s, I wrote a poetic reflection called ‘I do not know who I am: that is who I am’ and this concludes Appendix 11:
3. **POETIC REFLECTION: I DO NOT KNOW WHO I AM:**

**THAT IS WHO I AM**

I read with a sense of laughing delight, Caputo’s (2000) *radically hermeneutic* wisdom that we do not know who we are, that *is* who we are.

Perhaps a serious illness: the healthcare professionals’ interpretation tells us ‘you are a body with --- ---’, whatever disease they have diagnosed, defined and labelled.

Perhaps the process of describing our lives in response says ‘I do not know who I am.
You have described the *what* you see that my body is.
You offer me Derrida’s Absolute Secret, you tell me that you know who I am.

I describe my experiences
my feelings and emotions - as much as I am able.
This is who I have been, what I have done and experienced.
It’s a much less fragmented, more complex description of who I am.’

The therapeutic value of deeply engaged listening to the stories, and finding that the absolute secret is that there is no Absolute Secret, tells me that whilst I understand that I cannot really know who I am, I can claim back my whole life, all the experiences I *can* remember, and see that *this* is who I am *for now*.

Kaye became *a flighty person whose mother had died*.
Bert’s dementia defined him as a fractured soul - *he doesn’t know who he is*.
Scott the professor was simply a dying, sad, tired old man, maybe sometimes rather confused.
Sarah was a *fiesty, difficult patient*
with lungs full of tumour.
Elizabeth saw that some of it *wasn’t nice,*
some of it was even *horrible.*
Like a crystal rotating so that the myriad facets might catch the light,
each of them willingly described their complex life journey to me as trusted audience.
Parts of the descriptions were funny,
parts were incredibly painful and sad.
But in the whole description, the telling, and the listening,
they could be whole.
They could describe the

*I don’t know who I am,

and see the but this is who I am!*

By describing their lives and experiences to me,
they were able to give voice to their innermost, unique selves.
Appendix Twelve:
My journalling summary

A synthesis of my own experience across the stories from my journalling process

Seeing a Thou in Kaye, Scott, Bert, Elizabeth and Sarah, enabled me to be fully I for myself, a comfortable, deeper, richer place for me to be than before I began. I love that their stories remain alive in me; they are part of who I have become. We are perhaps able to go on, even in a story beyond our lives, with dialogical, creative new meanings (Frank, 2005). I have learned more deeply that to feel heard and understood is perhaps the most precious gift in life. There is no story without a listener, for my story or these Others. Just listening with all my heart, all my soul, and all my intellect has brought blessing and meaning. I see now I cannot do more, I cannot give less (Stein, 1998; Buber, 1923).

I was midwife to the stories, rather like Corradi Fiurama (1990) suggests

Not only was I helping to co-author the narrators’ stories, I was also giving birth myself to the overall understanding and meaning. I struggled to anchor the collaboration of the voices in a way that would satisfy the narrators, me, and my peer researchers. My sense of responsibility created feelings of anxiety in me. I felt pressure and concern, especially recording and transcribing, which was time consuming but invaluable. Experience taught me that clarity of recording impacted on ease of transcribing. I got better at it!

Reduction beyond a certain point caused some pain and anxiety, both to me and especially to Kaye. I wondered how I could find the essence of each person’s story in a manageable shape and size without reduction. I invariably had the feeling that reduction was impossible, then experienced a happy ‘clunk’ as the essence emerged or fell into place. I was concerned for the impact of the story on the family of the narrator, recognising that there were more voices than the storyteller’s to be considered in this process. I worried about how equal, multiple voices in the stories could survive the process with integrity. I was joined with my storytellers in a creativity of becoming. I
worried about me assuming that my meaning was their meaning. Kaye pulled me up on that one! I tried not to need to impose order on what seemed like disarray in their stories.

I entered into their stories
I facilitated the building of bridges and connections between us. My dream world rocked with tangled images of their stories and mine, our messy, shattered illusions. I was without doubt engaged! I caught Kaye’s chaos, Elizabeth’s birth stories, Sarah’s anger and grief. I sat in Sarah’s desperate loss of control, and in so doing revisited my own illness experience of silenced voice, my anger and grief for loss of care-giving, especially in nursing. I saw that the most difficult thing required of me was perhaps the greatest gift Scott offered me: that to build a bridge between us, I had to become slower, older, quieter, if I wanted to hold and know his wisdom. I felt great anguish as I tried to become Bert, I felt locked up, powerless, not free to choose, controlled, angry, upset. I wonder again and again how my health will pan out over the coming years (Moustakas 1990).

My emotions were stirred
I felt sad that I couldn’t finish the work Sarah and I began. There was so much I wanted to ask her. I felt disquiet and frustration with her story. Did she simply leave out the beauty and happiness in her life narrative in order to contain her story because of her approaching death? I felt Sarah’s hurt that Palliative Care simply closed ranks and didn’t want to know her anguish. Her voice was silenced. This evoked my anger! Sarah touched a wish in me to speak for many silenced voices. My deep engagement with Sarah’s story made me want to oppose the censoring of the things that didn’t fit the professional/hospital narrative (Frank, 2001).

I needed to be listener, rather than defender of health professionals. I needed to deeply hear Sarah’s sad, lonely cry for help, to walk alongside her suffering. If the health professionals had been able to hear Sarah’s story, there might have been meaning in her suffering. Perhaps my years of study have aimed at ways to amplify silenced voices so they might be heard (Frank, 2001). I felt Bert’s disempowerment so strongly my anger and despair was again called forth. Elizabeth’s experiences finally jelled it all together to make me see and know my ‘silenced-voices’ passion! It was so hard to bracket my
feelings and interpretations. I hoped I made them clear and transparent. It felt like Buber’s I-It, my mission being to hear and tell the stories so that a different, better way might emerge.

*I felt delighted with the essence statements, and the narrators’ responses*

Kaye’s feeling of being valued and validated; her fresh running with her own journey, felt very satisfying to me. I felt delight as from each person’s story an undercurrent of meaning slowly welled up. Kaye said that together we’d created something beautiful and meaningful.

*I was delighted to understand that there is no ‘finalising discourse’*

All of us remain unfinalised, even Sarah, Scott and Bert (Frank, 2005). The dialogue Sarah began continues in me, as a narrative we created through our dialogue, and in the work I continue to do. Sarah still speaks through me, not assimilated into me, but as a new possibility of compassion and identification. The experience of our dialogue influences how I see the world. I find that deeply satisfying. I was delighted to witness Scott’s clear enlivening in the early days of our working together. I was delighted that my knowledge of literature, poetry, music and places enriched our talks. It didn’t matter in the end that I lacked mathematical intelligence (it’s lack has always been a great embarrassment to me). I was delighted and moved seeing Scott transported into the presence of his beloved, as he recited the words of The Rubaiyat, a reconnection for me to my father and ‘his’ poem. I was delighted when I grasped the reciprocity of Bert’s and my gifts to one another. His ‘I am offering a slice’, paper towel gifts to me of his stories, his ‘this is my life!’ My time and commitment were my gifts to him. It was for me ‘precious valued golden knowing of life’s colourful, full-blown, locked away, often noisy, sometimes smelly reality, accepting the cost, anger and anguish; knowing I-Thou Being-to-Being connection in the story, in care given, care received, reciprocal humanity’. (refer Bert’s Chapter Six)

*I found literature that encouraged me*

Other writers affirmed my task, ‘heard’ me, and echoed my despair. The difficulties others wrote about reassured me: Frank, Kiesinger, Klass, Yalom and Zable, Nathanson’s
abortion story; Killick and Kitwood enlightened me about dementia. They all helped me know I needed to be fully present, aware of my own previous experiences that brought me to see things through the lens of my own perceptions, and to bracket them as fully as I could.

*I struggled with the issues of confidentiality*

Often this seemed to be outside my control, for example some of the staff’s lack of respect for Bert’s story. All the narrators seemed happy to share their story with whoever wanted to read it. Where did that leave me? With some anxiety I accepted there is an ethical dilemma in narrative work (Josselson, 1996). I needed to engage with their *cultural soups*, I learned about the impact of our cultural perspectives (Monk et al. 1997, p.27; refer Chapter Two, 2.7).

*The narrators’ relationships with their parents re-engaged me with my relationship with my parents*

I wanted to care for and comfort Scott as he re-engaged me with my father’s dying. Elizabeth pushed me to re-engage with my own childbirth experiences, my intrasubjective responses needed to be transparent, my pain, my grief and shattered illusions needed to be revisited, and my self cared for. I re-experienced my family pain, deepening my own meaning, it was deeply satisfying. Elizabeth talked about living within rules, I’ve always hated rules I thought were patriarchal or stupid! I had to engage with my views on abortion; smoking/lung cancer; alcohol/dementia; as a Post-Methodist-Ladies-College-Methodist! Some taboos and judgements were taught well and had lodged deeply. Each pushed me to arrive at an approximation to meaning for myself.

*What did I gain?*

In learning about each person’s life, I was learning more about my own, who I was, my life’s values, and meaning. Like Myerhoff (1979, p.19), I see older people now in a new way, as part of me, not ‘they’. I loved the feisty, feminine narratives from Kaye, Sarah, and Elizabeth. I was able to hear and understand life’s normal tragedy; I could know Frank’s twin G’s, The Grendel Monster of fear, chaos and mayhem, and The Holy Grail
of healing and meaning that we all seek (refer Chapter Four, 2.7; Frank, 2005b). The stories make sense, and allow meaning to emerge. I am thankful for the gift of their stories and their creative meeting with my stories; we became a communion or community of minds and souls.
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