

10 July, 2010

Dear Members of the Productivity Commission's Inquiry into Caring for Older Australians,

Thank you for offering to consider a submission in the form of a letter. I have been involved in aged care policy both from within government and from the voluntary sector. I attach a brief one-page CV and also a paper I co-wrote which responds to our need to remain recognized as uniquely valuable especially in our later years.

I think that the care we offer older frail Australians fails to respond to this need in a number of ways. Firstly I will endorse the well-documented views of other analysts and then I will offer my own personal view of how this has happened and how it might be remedied.

I am very moved by the valuable work of the organization called 'Aged Care Crisis Team'. Their summary of the issues is helpful and I will briefly consider those that appear on their website.

Whilst I appreciate that it would be impossible to close down *profit-making* Aged Care Facilities immediately I believe that we should work towards a community-based system of aged care similar to community-based child care. I do not think we should endorse the establishment of more profit-based centres and I do not think any good can come from places whose primary responsibility should be care but whose focus is also on profit. The profit-approach focuses people's attention on superficial assets like numbers of chandeliers and private rooms but conceals the abusive interpersonal experiences which occur behind closed doors and which continue to blight the lives of our frail elderly citizens in aged care facilities on a daily basis.

Of course I believe that there should be *total financial transparency* concerning the sources of resources and expenditures of profit-based organizations, and for all aged care facilities I believe there should be a body established for the receipt of *complaints which is totally independent of the Department of Health and Aging*. I think the findings of Merylyn Walton and Dr Judd should be taken very seriously.

From here on I will make a number of brief points arising from my overview of social policy...

I believe that it is foolish to put any disadvantaged groups in *ghettoes* on the edges of suburbs and cities, far from the people and facilities which they know and love. The whole experiential universe of these residents is fractured by such a change which occurs at a time when they are most vulnerable and when they need their known world in order to continue to function in it. In such aged care ghettoes most residents are less able to adapt to each other than they have been when they were younger. In many cases they actively persecute each other because their tolerance and understanding of the wider world has been diminished.

I have had occasion to visit a man who had to share an aged care facility room with a man who urinated on the floor as a matter of course. The hands of the man I visited were frequently brown from the effort of pushing his own faeces away from his

buttocks. These two men were left for most of the day together with no help or supervision from any sane carer. The facility concerned was given a good evaluation report within the period I am speaking of. I look back with envy on the days of large wards when at least a number of people could see what was going on and remedy any major problems.

I see the current movement to the provision of all private rooms as a retrograde step: certainly some people go through a stage of needing privacy but for others, especially toward the end of life, being put in a room of one's own can be like being prematurely put in one's own tomb. The sound of human voice is very comforting to most human beings and its absence can only result in *profound loneliness*.

Such aged care ghettos are understaffed because the profession of aged care is undervalued by the community and hence by our government. It is easy to see that, when a person can earn more by stacking the shelves of the local supermarket, the overall calibre of aged care workers will be low. Of course there are some wonderfully generous workers in the field but this does not in any way excuse the *shockingly low rates of remuneration* which these people receive. This has been documented in a number of studies to which I know the Commission would have access. The work is demanding and the emotional intelligence required by it would be higher than that used by many of the multi-national CEOs who have brought us to the brink of national economic disaster in recent years.

The lack of professional dignity in the wake of these humiliating levels of pay means that *very few people are interested in doing the work except in extreme circumstances*. I have known a dignified ninety-year old woman who was determined to age and die in her own home. She needed regular help to get up in the morning and to go to bed at night and her care coordinator undertook to arrange this so that she could remain in the inner city suburb where she lived. However each day of the week my aged friend had to cope with a different carer and she grew exhausted and confused explaining to often newly-arrived refugees what had to be done. Understandably she also found herself trying to listen to their problems as well. She asked if she could have the same person for several of the days at least but was unable to achieve this.

Ideally volunteers who could be *friends and neighbours* could contribute to support such a person in their own home or in a nearby aged care facility but these days it is extremely difficult to do this. I personally volunteered to help in one such facility in my own suburb. I completed a number of forms and applications so that my request could be processed and the requisite police checks be made. This was over six months ago and I heard nothing... not even a polite refusal. I know there have been studies to show that country nursing homes provide the highest quality of care and this is not surprising because the people who work in these homes tend to be local people who are known in the community. It is this need to be known which is mostly ignored by aged care facilities. We need financial incentives to encourage friends and neighbours to retain a role in the care of frail aged persons with whom they have a connection.

Recent studies of the needs of people in a city have highlighted our need for '*relatedness*' (see the Cities Project of the Grattan Institute). Thoughtful economists

from around the world are recommending that instead of measuring our national progress via economic measures such as the GDP, we should consider using a measure which focuses on health and well-being such as the Genuine Progress Indicator (see Clive Hamilton etc). I endorse the concepts of relatedness and well-being as playing a central part in our caring for older Australians and I suggest that we should provide incentives at every level of planning and administration to keep older people geographically and psychologically related to the people whom they have known throughout their lives and to measure the well-being of our older frail Australians as part of a new national GPI.

Yours sincerely,

Gillian Sutton

***Koula Poulos, Jill Sutton: a Paper presented at  
The 3<sup>rd</sup> National CAPS Conference, September 06***

My background is Greek and as such, I share something with the Ngunnawal people. Just as our indigenous friends find life's meaning in their narratives about the dreamtime, my father brought me up with the stories of Greeks who went on long adventurous sea journeys. He could barely read so he told us his stories from memory, over and over again. He told them in the way that, Rachel Remeni[i], that famous physician and writer celebrates in her book 'Kitchen Table Wisdom'.

Rachel says, 'Most parents know the importance of telling children their own story, over and over again, so that they come to know in the tellings who they are and to whom they belong. At the kitchen table we do this for each other. Hidden in all stories is the One story. The more we listen, the clearer that Story becomes. Our true identity, who we are, why we are here, what sustains us, is in this story'.

The Greek poet Cavafy's poem 'Ithaca' (you see a few lines of it on the screen) reminds us to pray that our journey will be a long one, full of adventure and discovery. I regard it as great good fortune that I now run story-telling groups for people in aged care facilities who have *all* been blessed with long journeys and it is a privilege to be present at those many sacred moments when a story is shared and recognised.

This presentation will be in three parts. Firstly, I will continue to introduce my practice of pastoral story group work. Then I will give a few examples of my groups in action and I will finish with a development of the theory of my work, using some of the current literature on aging and spirituality.

What I call my practice of 'pastoral story group work' has grown out of my clinical pastoral education studies and work in counselling, welfare management and hospital chaplaincy. I had come to feel that, in one-to-one counselling, I was missing important opportunities to connect people with each other. I had noticed that, if we got together and shared a story in a group, people became much more open to me as individuals. I realised that it is when people feel most vulnerable, as they often do in

a hospital ward or residential facility, that their deepest and most in-vulnerable understandings and truths become ripe and ready for sharing. I agree with the worker who said that, when insights are aired in a group, it is as though you open a window to let the sun shine in on them. I discovered that hearing stories not only brings healing, but that it can generate, in a group, what Remen has called a 'deep trust of life'...a trust which evolves as we realise we are not travelling alone.

It is worth discussing here why I choose to begin with *reading* stories to a group rather than insisting on the telling of their *own* stories in their own words. I am certainly aware of Elizabeth MacKinlay's good work on spiritual reminiscence groups<sup>ii</sup> but I find that a simple shared story helps people to get in touch with the universal themes they have in common. Elaboration of these stories with colourful personal details or insights seems best triggered by a story which is read out to the group first. As we near the end of our lives, our capacity to articulate our particular story may decrease but the recognition of commonalities in our lives through stories becomes more valuable. Even if a story is forgotten immediately after it is told, its sharing can become a sacred moment in the 'now'.

I have chosen my collection of simple stories so that they can inspire almost anyone, whatever their religion or culture. We chat about our stories, jokes, poetry and we sing our old songs together lustily. I encourage people to get to know each other as they pick up themes or details in their own lives and I celebrate their diversity too. Residents are thirsty for gradations of colour in all the sense dimensions. They love the times when the budgerigar sits on my head while I'm talking, when the dog makes approving growls from under the table or when my friend's grandchild does an impromptu fairy dance.

I am not afraid to project my story in a loud voice, so that hard-of-hearing residents claim they can 'hear every word'. Having lived with a deaf father helps me overcome the reluctance of many educated people in our culture to speak up! As we know, some people who have lost their capacity to speak can still respond to a shared story with facial expression, a nod or by remaining in earshot. The sound and cadence of the human voice, telling a story with a beginning, middle and end, can be a great solace to most human beings. Many of us oppose the isolation of refugees in detention centres, and I sometimes wonder if it is because the frail aged *are unable* to tell us about their experience of loneliness that we remain deaf to their suffering. Sometimes I feel that the provision of private rooms is like entombing old people before their deaths. One of my friends in an aged care facility sits in the corridor rather than in her room. She strains there to catch the stories of staff and of visitors on their errands and her greatest joy is a pair of socks the son of someone else's visitor sent her. I love these corridors and public spaces so much I've included this slide to remind us of how we have an urgent need to be with each other in public. I find that there is more story-sharing where residents have easy access to a common area which becomes like the village square. Research shows that we communicate at intersections. How sad to find ourselves in dead-end rooms where there is a reduced opportunity for the incidental meetings which are the stuff of life. And, as we are finding, bad things can happen between carer and resident when there is no one to watch or remind us to be sensitive to their needs.

I have a friend who recently complained about this sense of alienation among residents in her response to a meeting about some plans for expensive aged care facilities. She pointed out to the smartly-dressed men who addressed the meeting that it was the care that was provided which mattered more than the style of their purpose-built residences. She reminded the meeting that these places were staffed mainly by women paid at the disrespectfully low rate of about \$15 an hour. The only people who congratulated my friend for insisting on speaking up in this way were the tea ladies who served the supper. This slide is to celebrate the wisdom of tea ladies who know a lot about listening.

...But on with the second part of this presentation. Let me give you a few examples of the kind of transcending moments that occur in my groups. One day, I was telling a story about a boy on a fishing trip who asks his father if we can 'ever *see* God' and his father replied, 'It's getting as though I can't see anything else'. This prompted Greg in my group to remember a *droving* trip, long ago with *his* father. As they lay looking up at the night sky and counting the stars his Dad had said that it was like seeing God. For a moment, in our mind's eye, we all lay there with him, in awe of the shared beauty and vastness suggested by this image of stars which you now see on the screen.

After a story about a Greek grandmother being like a 'bulwark' despite losing all her offspring to far-off countries and never seeing them again, group-member Mary found new strength as she told us that 'We *all* need to remember we are bulwarks and that we are in a line of steadfast people, all of whom have been bulwarks'.

After a Dale Carnegie story about his mother who had always said that she believed that things would work out in the end despite a chain of calamities, Hatty began to remember her *own* mother. She wept as she told how her mum had lost five sons in the war and then lost her faith and died in her forties. But, Hatty reassured me about the regeneration of her *own* love, focussed always on her children and grandchildren.

After the 100 monkeys story which is about the contagion of an idea when a critical number of a species has shared it, Ruth got thinking about war. She told the group that it made her think that wise old women should get together so that their impulse for peace might reach a critical mass too. Like the 100 monkeys she vowed that their sheer numbers could, in some way we don't understand, ignite the action of women *everywhere* to bring peace to the world.

I tell a story about a man who repayed the kind offer of a glass of milk in his childhood with a life-saving operation when he grew up to be a surgeon. This triggered a conversation about the way we can never know the difference our small kindnesses might make in the long run.

People like my story about a group trapped in a lift on Christmas eve. They relaxed and shared their wine, cheese and stories for a whole five hours. This made group-member Margaret recall the London Blitz. She remembered how, as her neighbours hid underground, they felt much less frightened because they were all able to talk together. Perhaps Caravaggio's famous painting of Christ's friends, entranced around the table as he speaks to them, captures this magic of such shared listening.

The story retold in Remen's book about the re-emergence of all the animals who'd befriended King Arthur when he was a boy is a favourite too. They came back to help him pull the sword from the stone. This reminded Margaret of the way her dead mother's voice comes back to her when she needs strength or comfort. We talked about that 'tuck in time' when friends from the past all join us in the present.

I could go on, but I would like to spend some time sharing evaluative comments which show the value of these moments. Quite often my more articulate group members will explain to me that the initiative of the story-telling groups has transformed their lives in the nursing home... that they would now talk to each other about the stories after I had left and that they had suddenly become interested in how other people saw life's dilemmas. One woman reports that she looks at people's faces in the group and that they become radiant as they listen. Another woman has said she'd never been read to as a child. She told me, 'I've never realised how wonderful this could be'. Joan confides, 'I hope I can find some inner contentment instead of keeping everything in separate compartments'. Groups often ask when I will be coming back and staff have reported that previously agitated residents can be calmer after my stories. Martha had said to me that she thought that a story group wasn't for her but after she attended she said, 'I didn't realise how wonderful it could be'. 'We all sit here enchanted.' Those were *her* words. .

One day I started a group of eight people by asking them to say what makes them feel blessed. Bob just responded that nothing made him happy and what's more, he wanted to know why such terrible things happen in the world. Then as luck would have it there was some loud drilling in bathroom and Bob, in his gloomy mood, found in this irritating noise a metaphor for life. Things go wrong all the time, he said, and Maria added that the worst thing is seeing your loved ones suffer. I just let the general gloom hang over the group as we pondered life's tragedies. Then, we shared some songs and brighter stories and, all of a sudden, Bob took an initiative... 'I know', he said, 'It's *life itself* which is the blessing, that's really it.'

As Judith Leiii[iii] has reminded us in the words of Kierkegaardiv[iv], 'being aware of despair is not something that is depressing... for it views each of us through the lens of eternity's demand on us, that we be spirit'.

People sometimes ask me how I choose my stories and it's hard to reply. They are usually short, about 500 words and they have a spiritual dimension, chosen with a multi-faith community in mind. They are often humorous and, as Elizabeth MacKinlay v[v]reminds us, humour can bring with it 'enhanced self-esteem and mastery'. More often than not the stories contain some simple colourful details that catch the imagination like a red piano or a blue hat. I re-use much of my material if it works well and people seem to like to recognise the old favourites. The stories usually have some potential for meaningful resolution which can be expressed in the cadence of my voice for those who can't catch the sense.

Finally, to place my work in the context of some of the literature, I would first mention Michael White's work with narrative therapy. As you all know, he is keen to use 'texts of literary merit' to encourage people to dramatically re-engage with their own life experiencesvi[vi].

As Dostoyevsky suggests in *Brothers Karamazov*, there is nothing better than ‘a good sacred memory preserved from childhood’. He advises that, ‘If one carries such memories into life, one is safe to the end of one’s days’. An Hebrew prophet, Jeremiah, puts it well as he concludes his musings with ‘And this I call to mind... and therefore I have hope... the compassions are new every morning’. These ‘memories’ don’t need to be real in the sense of factual, although they often are. As Ricoeur has explained, ‘we can alter our existence by *changing* our imaginations’ as we are always ‘groping our way toward the creation of new images’ vii[vii]. It is my view that the images and meanings which we stretch toward in story groups not only confirm individual identity but also encourage us to become ‘prophets of our own existence’, as Maria Harris suggests in her book about religious imagination. I have included this wonderful slide of indigenous art to remind us of the way a shared image can transport us to a new and sacred space.

Sometimes I wonder if we should be talking about a new human right... the right to die among people who know some of our stories. If we die far from our childhood home, as my own mother did, we need other people around us with whom we have had some chance of sharing our stories. Perhaps Socrates didn’t mind drinking his fatal dose of hemlock because he had already taught his stories and philosophy to his friends who surrounded him.

I often recall the story of a friend whose scientific father had progressed far into his dementia illness. He was agitated about a research paper which was incomplete and below standard. He obsessed about it, long after he could speak grammatically, and in the end my friend took him out for a walk in the park in his wheelchair. She sympathised with his problem and then suggested that perhaps he and she could collaborate in fixing it up so it could be published. He was delighted and as they returned from their walk he turned around in his chair. He became confidential and said, ‘that would be very kind of you, as you see, I would really only be a sleeping partner in the publication... you would do all the work.’

I suppose my story groups are a short cut to ensuring that such residents at least have a chance of building the meanings for which they inevitably yearn... but I would love to see more participation from the staff in the activities of my groups. When I invited a staff member to join us as we sang a well-known song recently, he said, ‘O no, that’s not what I do and I haven’t got time.’ I know he is right, but I also know that, if we have *not* been connected to any part of a person’s story, it is easier to be unfeeling when working with that person. Technical expertise can often take priority over a readiness to engage in laughter and sharing.

But, many of us agree that it is not really that we have unfeeling *employees* in aged care but that we have inherited an unfeeling *culture*. We have a society which is collapsing under a terrible outbreak of ‘affluenza’ as Clive Hamilton and Richard Dennissviii[viii] have called it. Nursing homes are the victim of this culture which expects some of its most important work to be done by underpaid staff who struggle to meet the regulations and financial restrictions of their governing bodies. No wonder the churches are increasingly withdrawing from this work and refusing to continue to sponsor residential provision in its present form.

Robert Colesix[ix] has suggested that what makes us human is the telling of stories and recognising the grace of meaning which they bestow. Our conclusion is that we should not limit our precious tales to oblivion or to personal therapy sessions. Groups enable us to share 'the abiding things'x[x], as Bishop Burgmann called them long ago, and the more we share, the more grace we bestow on the people around us. As Judith Leexi[xi] has explained, our dependency reminds us 'that mutuality is the deepest of our needs'. Our tea-ladies know that we've *all* 'been there', even as they serve the next cuppa.

Thank you.

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i[i] Remen, Rachel, 2002 *Kitchen Table Wisdom: Stories that Heal* Pan Macmillan, Australia, ppxxvi-xxvii

ii[ii] MacKinlay & Trevitt, 2006 'Finding meaning in the experience of dementia; a learning guide' report in *CAPS newsletter*, V4, no 1, June 2006

iii[iii] Lee, Judith, 2003 'A Village of Old Children' *J. Relig Gerontology*, V15, No3

iv[iv] Thompson, Heather, 2004 'Spirituality of Later Life' *J. Relig Gerontology*. V16, Nos3/4

v[v] MacKinlay, Elizabeth, 2004. 'Spirituality of Later Life' *J. Relig Gerontology*. V16, Nos3/4

vi[vi] White, Michael, 2005 'Michael White Workshop Notes' cited on 3/6/2006 at [www.dulwichcentre.com.au](http://www.dulwichcentre.com.au)

vii[vii] Harris, Maria, 1991, *Teaching & Religious Imagination* p4, 5, Harper Collins, NY

viii[viii] Hamilton, Clive and Denniss, Richard *Affluenza*

ix[ix] Coles, Robert, 1989, *The Call of Stories* Houghton Mifflin, Boston

x[x] From Bishop Burgmann's quote outside the Centre for Christianity and Culture

xi[xi] Lee, Judith, 2003 'A Village of Old Children' *J. Relig Gerontology*, V15, No3