

## **Love and Dementia: Small Acts of Love**

This was the title of a two day National Symposium held recently in the regional city of Ballarat, Victoria. The theme of love was a deliberate focus on the small acts of love which enhance life for people with dementia as well as their carers, partners and friends, shifting the emphasis from the measurable task oriented care that characterises much of the aged care industry. It is hoped that the phrase “small acts of love” will gain worldwide acknowledgement and be affirmed as a valid and efficacious approach to dementia. The Symposium was an extraordinarily powerful and poignant experience, given that everyone present was touched in some way by the realities of dementia.

Some of the themes that suffused the presentations were:

- the importance of including rather than quarantining people with dementia;
- the need to create useful and productive activities for those with dementia that cater to individual needs and gifts rather than the collective, generic activities offered in most residential care facilities;
- the significance of ongoing relationships rather than abandonment of the person with dementia (one younger man with early onset Alzheimers spoke about the devastation of the experience of most of his friends falling off and not coping with the disease)
- and the desire to make communities overtly “dementia friendly”, a particularly crucial task given the huge increase in expected rates of dementia in the next twenty years or so.
- the reality that “small acts of love” are demanding and sometimes gruelling in the face of the terrible havoc wrought by dementia

Speakers included Sue Pieters Hawke, ambassador for Alzheimer’s Australia, daughter of Bob Hawke, former Prime Minister of Australia and Hazel, who died a few years ago, and whose experience with Alzheimer’s was well documented. Virginia Hunter Sampson from Texas, USA, spoke of the need for self-compassion in the torrid realities of caring for her husband who died from a form of dementia. Anne Zubrick from Western Australia, who is a Quaker and academic, reflected on her experiences of aged care facilities from her differing perspective as a volunteer and a board member. One of the most informative sessions was presented by a group of police officers from Ballarat, whose experience with dementia in the community has led to a special unit being established to assist vulnerable senior citizens.

A family from rural Victoria spoke about the impact on each of them of last year’s diagnosis of early onset Alzheimer’s for the husband and father who is in his early fifties. Very inspiring indeed was the story of how the Catholic high school of which he has been Deputy Principal is endeavouring to accommodate him, and how the school community- staff and students-has been counselled and educated about what to expect and how best to assist him.

Mercy Associate Anne Tudor shared the story of her partner Edie Mayhew's journey with early onset dementia and how this has changed their lives and their relationship. Anne spoke candidly about the stresses and the graces of dementia. Edie herself presented a segment on the joys and challenges of caring for her official Dementia Assistance dog Melvin, a beautiful specially trained Labrador.

The co-ordinator of the conference, Dr Catherine Barrett, who is Director of an organisation called Celebrate Ageing ([www.celebrateageing.com](http://www.celebrateageing.com)) founded to challenge ageism and enhance respect for the elderly, had read a poem that I wrote about a friend, a Sister of Mercy, who has Alzheimer's. The poem, titled [\*The Dance of the Seagulls\*](#), can be read on my website. Dr Barrett invited me to speak at the Symposium and reflect on the nature of ongoing friendship with someone with dementia, as part of a segment about caring for people in residential aged care.

One of the ongoing interests of some of us who attended the Symposium is Dementia and Spirituality: how to assist those with dementia in their devotional and spiritual practice, and what might be developed to enhance that experience. I am keen to hear from anyone who might have some suggestions, experiences to share on the subject, or would like to link in with this ongoing conversation. If you, a friend with dementia, or care worker you know are interested, please get in touch.

My presentation at the Symposium, titled *The Four Rs of Dementia*, can be read below. I share it because I believe we need to be more attuned to the needs of people with dementia, more inclusive of them in our community situations, and more informed about a condition that affects many around us. Sr Patricia Kenny rsm has generously given permission for her story to be shared, and so we trust it to your gentle reading.

## **THE FOUR Rs OF DEMENTIA**

My friend Patricia, known as Pat, is 90 years old and was diagnosed with Alzheimers in 2013. She was told the disease would initially mostly affect her short term memory. When I asked Pat's permission to speak about her condition and our friendship, she said, "Yes of course, it may be helpful to other people."

For the thirty years prior to her diagnosis she was the co-ordinator of a community for homeless and addicted people in Adelaide, known as Hesed Christian Community. She only retired at the age of 86. Pat's skills as a qualified teacher, social worker and nurse all came into play in running a structured recovery program and safe home for hundreds and hundreds of vulnerable people. She had phenomenal energy and stamina.

I met Pat in 2003 when I was asked to come to Adelaide to help collate a magazine for the 20<sup>th</sup> anniversary of the community. Despite our age difference we immediately clicked- we were both Sisters of Mercy, we had a shared interest in the

homeless, and we had other interests that drew us together. Over the next ten years, although I lived in Melbourne, I became involved on the Board of Hesed, and my friendship with Pat deepened. In 2012 the community began a period of discernment about its future, and it became clear that I needed to articulate to Pat my awareness as her friend and as Chair of the Board that her short term memory was beginning to fail her.

In 2014 Pat moved into an aged care facility. Pat and I speak each day on the phone – sometimes more than once depending on how she is that day and if she has forgotten that we have just spoken. When she is having a particularly bad evening and she rings five or six times, I give up the thought of pasta al dente. Sometimes this can be wearing, but at various times in my life Pat has been immeasurably supportive and caring of me, so in the scheme of things soggy pasta is tolerable! And I suppose it is true to say that, given her age and condition, I consider time with her is precious. I visit her once every six weeks and we usually head for the sea and her favourite lunch of King George whiting. Over time, these lunches have become much less chatty and more contemplative- enjoying the sea, the passing parade of children, dogs and the seagulls. We just sit gently in one another's company.

As I write this I recall recent conversations with Pat: last night she was her familiar caring self when I told her I had a sore foot; last week though, the staff murmured the ominous word “progression” after Pat had several days where she spoke angrily of being imprisoned and punished. For the moment she still emerges from these darker times, but I dread the day that she may not.

In those dark times, I talk quite honestly with her about the effect of the disease and the additional compromises exerted by, for example, urinary tract infections, to which she is prone. Honesty seems to me absolutely vital. I tell her she has a physical disease of the brain which affects her memory and her emotions. After we've talked this through for a while, she usually comes to a sense of peace or reassurance. We can laugh when I tell her she is like an old car with dodgy spark plugs. She trusts me to be honest with her.

Mostly though, she is a kind of pale version of herself: frail and confused. She knows that “something is not right in her head” as she puts it, but she is mostly still able to enjoy talking and having a gentle laugh and reflecting on life in simple ways. Sometimes she can become very anxious about things that would previously have not presented any challenge to her at all, such as how to put her nightie on. But then the next night we might have a little chat in French, which we both studied at university.

As a poet, I seek meaning in what is the randomness of why my friend should come to end her life in this fraught way, and I try to find metaphors and images that help me to cope with and understand it all in some small measure. I am speaking about one unique person, and it seems unwise to generalise about dementia given its myriad forms, but for what it's worth I share some of my ways of coping and caring.

I have come to think of dementia as more like a revolving door than a steep ski slope. That is, while there is the inevitable and terrible “downhill” process, in my experience it is not a clear and straight decline: it is more like a revolving door where some memories and capacities swing in and out, in and out. Some eventually get left on the pavement, but with no particular sequence or sense, and some get swept in again and again. And just when you think some capacity or skill has fled from her it makes a re-appearance. I am always receptive to being surprised in the good sense.

To digress for a moment. Some years ago one of our elderly Sisters in Melbourne was in hospital. She had broken her hip and surgical intervention was not possible. She had advanced Alzheimers. I took her some flowers, her favourite colour. Now, Mae had not been able to speak coherently for some time. She used to verbalise in what we might term gibberish, seemingly attempting to communicate, but mostly there were no real words. When she took the flowers in her hands she uttered a stream of this incoherent gibberish, but towards the end of it there was one word that I recognised, as clear as a bell. “Purple” she said, and beamed with delight. Her favourite colour and the colour of the flowers. That word purple taught me never to discount what is going on inside the beleaguered brain of someone with dementia.

Back to my friend Pat.

One of the huge challenges of our relationship is that she lives in Adelaide and I live in Melbourne: seven hours drive away. She has a speed dial on her phone with my number. Communicating mostly by telephone is demanding for both of us, but so far it is still possible. But not being present in the same room, not being able to communicate through touch or pick up visual cues and so on, does complicate matters for us sometimes. Pat refers increasingly to being glad to hear my voice. Somehow my actual voice seems to offer her stability and solace, and I have become much more conscious of using my voice to calm and reassure her, almost like a lullaby.

It seems very important to her to hear and engage with a voice she knows and trusts. My voice seems to anchor her to reality. As long as she knows my voice, we are ok. For people in aged care facilities familiar voices and faces are paramount, surrounded as they are by “strangers” whose names it is often too late for them to learn, and whose accents they sometimes cannot understand. And naturally, staff members, even the kindest and most caring, perceive my friend in her reduced present. They do not have a grasp of her past, of the nuances and complexities of her history. When Pat first moved into the facility she was sometimes uncooperative about taking medication. I suggested that rather than just presenting Pat with the medication without explanation, they might try telling her what the medication was for- “this is an analgesic; this green and white one is an antibiotic...” As a nurse, Pat responds to that. It gives her information; it gives her a sense of control in a largely uncontrollable environment, and it acknowledges her life skills.

I would like to share with you what I call my four **Rs of Dementia**. They act as beacons for me in my relationship with Pat. I am conscious of adapting to her changing capacities and frailty, and have to keep myself alert for how she is and what might really be going on when the surface messages are somehow distorted or unclear. These four **Rs** help me to care for her.

My first R for Dementia is **Realignment**. This has to do with sadly acknowledging the shifting balance in our relationship. Where once we enjoyed a mutually encouraging and caring friendship, increasingly I find that I do not and cannot expect as much of Pat in my regard, and her needs are much more pronounced and fundamental. I have had to adapt my expectations of her, who was once a rock of strength and encouragement to me. However, I try not to close off altogether from sharing some of my needs with her, and as already mentioned she is still very caring and loving in her manner. She just won't remember very often what I've told her, beyond the moment.

So, I have become much more maternal in my care of Pat, unashamedly more directive about the little daily things. I give her cues sometimes so that she can feel she is in touch with my needs, and I suppose too so that I can feel her express care for me. For example, I tell her my birthday is coming up, and then on the actual day I remind her. It's simple in a way, but a huge re-alignment from her previous capacities. It's not about me demanding her care but rather enabling her to demonstrate her old thoughtfulness, of respecting who she is.

Inevitably, I make allowances now for her. Sometimes her perception of reality can be skewed, as in the recent episode when she thought "they" were punishing her and that I had colluded with "them" and I too had "betrayed" her. Within myself I seem to have erected some protective mechanisms against this kind of fleeting condemnation. It is an indication of that re-alignment of expectations and of my sense of her diminished responsibility. However, I am not sure how I would cope if the day were to come when there is no flicker of recognition. That would be very tough.

Re-alignment is not just a psychological ploy. There are some very practical and physical examples that have proved helpful. Dealing with Pat's dementia is like being involved in a game of sorts, where the rules and guidelines change rapidly, and as her friend I think it is incumbent on me to try and creatively solve difficulties or alleviate distress if possible. What can help? What can make life clearer and reality simpler for her?

The kinds of things I am referring to in regard to re-alignment are these. One of the most traumatic aspects of life in a dementia specific unit for Pat is her sense of being locked in. The fact that she is not a wanderer but has been kind of homogenised in the care situation to have to deal with the same restrictions as those who *do* wander is another whole issue, but one that surely begs for research and attention! Let's protest against homogenisation! All her life Pat has had a profound respect for the

rituals of greeting and farewell, and for her not to be able to accompany a guest to the entrance and wave them off, is quite distressing for her. At some point it occurred to me that the situation could be addressed simply. Before exiting the secure unit, I now accompany Pat to one of the large dining room windows that look out onto the parking area and the entrance canopy where taxis pull up. So now, instead of standing at the “prison door” we say goodbye happily by the window, I disappear for a couple of minutes then reappear outside in her line of vision, and she stands there waving until my taxi drives off. Realignment. Distress lessened and Pat peaceful.

Another example of this is to do with her bedside table. On her bedside table Pat had a radio, a clock radio, (black) a telephone, (black) and at night her personal alarm pendant. At some stage it became clear that she was getting a bit confused with all these objects and their functions. And every so often the respective words would not come to her. I find it fascinating that a few times she has referred to the phone as a piano. At first this sounds weird, but there is a kind of “keyboard” logic to it. You have to think laterally sometimes to grasp what someone with dementia is really intending. Anyway, after some thought, I took the clock radio away and replaced it with a retro style clock with hands. Now, for the time being anyway, we don’t have any confusion about which is the phone.

My second R word for dementia is **Reassurance**. There are issues here about distinguishing between loss of confidence and loss of competence. With Pat, I often find that because of her awareness of her deficits there is a lack of confidence, an erosion of certainty about many ordinary skills and social interactions. It requires a delicate approach to know what capacities have actually gone, and what just need coaxing with a bit of encouragement. Again, trust seems the key. And time. And patience. Having the skill is one thing; the effort of focussing is quite another.

Social interactions, especially with large groups, have become almost too exhausting for Pat, but she craves one to one conversations. Recently we had a gathering of about sixty people for her 90<sup>th</sup> birthday. The night before the party she told me that she was very scared at the prospect of meeting so many people, and unsure about how she would cope. We talked for quite a while about it and came up with two resolutions: she asked me to sit near her to prompt her and give her cues to set her in motion, as it were, when people greeted her; and she asked me to tell people in my speech for the occasion that she does have memory problems and sometimes finds the world a frightening and confusing place these days. She wanted me to thank them for their understanding. As it was, Pat rose to the occasion and it was a lovely celebration. I am not sure of the cause and effect here, but certainly Pat was able to relax and enjoy the party. I think reassurance and encouragement can make a big difference to helping Pat maintain her self-respect and dignity.

My third R for dementia is a very obvious one: **Reiteration**. In my interactions with Pat I have entered a strange universe of repetition, and I have become a master of demonstrating surprise even if I have heard the same thing twenty times. In Pat’s speech patterns now I detect that sometimes she is on what I call a “long loop” and

sometimes a “short loop” before the same questions or comments recur. When she asks me within twenty seconds “and how are you?” for the tenth time, I know we are going to have a bad night. I just try and live in the moment with her, which of course is not always easy, and stretches one’s patience. I’m having a conversation with a friend; it’s just a modified kind of conversation. In musical terms it’s more like a round with recurring phrases than a straightforward melody. I find thinking about it like that helps.

Interestingly, the other aspect of this R for **Reiteration** that I have noticed is how I modify my own speech pattern in talking with her. I now almost automatically repeat information for her, or give her repeated cues to enable her to converse. For example, assuming that she will not necessarily remember, I remind her that my uncle died recently rather than feel slighted or upset that she might have forgotten. She will then be able to retrieve some of the story, and pick up aspects of it from previous conversations.

Perhaps the most important R of dementia in my relationship with Pat is that of **Reminding/Re-minding**. I consciously hold many of Pat’s memories for her, and bring them to her attention and engage her in talking about them. I find that while she seems not to initiate the act of recollection or day-dreaming herself, when I prompt her she is able to speak quite extensively about earlier days, particularly her childhood.

I hold in my imagination many of her photos and stories she has previously shared about life on the family farm at Streaky Bay. So, for example, sometimes when I ring her we play a little game where I say her full name: “Am I speaking with Patricia Mary Josephine Kenny?” And then I ask her where the names came from, and so on. Sometimes in the evenings when she is a little anxious I guide her via the telephone to glance around her room and look at the photos on her wardrobe. Her room is her safe haven and memory repository, crucial as the externalisation of her fading interior recollections. We will talk about her brother Dan playing the accordion, or the photo of her as a child riding her favourite horse Jumbo. Increasingly now there are some genuine blanks and losses for her, but there are still enough flickers of recognition that give her a sense of her story and her belonging. I feel this is a very precious role for me as her friend.

In the Celtic tradition there is a term for a deep spiritual friendship called anamcara—friend of the soul. I feel privileged to have Pat as an anamcara, even as her conscious mind diminishes, and I hope that at this crucial time of her life, I can in some meaningful way be an anamcara for her too. In the Celtic tradition, one of the roles of the anamcara was to accompany the person on her journey to death and the beyond, and dementia is surely a protracted journey for the person and those around her. I told Pat I was going to use the word anamcara to describe our friendship to you. We talked about how memory is only part of such friendship, that it is deeper than memory, deeper than conscious thought. She agreed.

I believe that in the downsized, straitened world of dementia “small acts of love” are crucial: noble in their ordinariness and poignant in their faithfulness. My role as Pat’s friend is increasingly to support and protect her in her vulnerability, and to be present for her in whatever the future holds. My intention is to foster gently her identity as a unique individual. When all else fails, love endures.

Mary Wickham rsm

E: [mary.wickham@mercy.org.au](mailto:mary.wickham@mercy.org.au)

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