



Supporting people living with dementia to find meaning in their lives

Roland Manderson, Deputy Director, Anglicare Australia

2nd Amity Senior Service International Conference and Elderly Social Work Conference

Nanjing 16 October 2015

I'd like to begin by thanking the Amity Foundation for inviting me to the second international conference on elder service. This is my first time in China and I'm delighted to be here in Nanjing. I feel very privileged to be able to be a part of this conversation.



My mother in her new home

This is a painting of my mother Mardi by Jackie Adcock, my sister in law.

When I was visiting my mother in a dementia unit near the end of her life, she told me quite a few times that there was no point in her life. That seemed to be a fair comment.

People were sitting around waiting for food. Or something. Mum was often anxious and confused, and she was frail and quite blind.

I know the residence where my mother was living had a thoughtful program and approach to caring for people with dementia. It's just that it seemed a rather unevenly pursued. And we, I mean the members of the various families of all the residents in the unit, weren't always clear about how that approach was meant to work. Or how we could all be a part of it.

And there is another side to the issue of "what the point to it all" was. What did this stage of mum's life mean to me? And extrapolating from that, what does it mean for us as a society more generally to live with age, frailty and dementia?

Australia

Australia is a 'developed' country facing demographic changes. Its population of people post-retirement age relative to those in the workforce has risen from 1 to 7 in the 1970s to 1 to 4.5 now, and is expected to rise to more than one person of retirement age to every three in the workforce by 2050. And from now until then, the number of people with dementia is projected to increase threefold.

So how there is a big change happening, as we've all been saying at this conference and how we deal with that as a society, as communities, is the question.



The Anglicare Australia network

Anglicare Australia is a network of 40 organisations, all separate but united in a commitment to care for the most vulnerable and disadvantaged. Most of the largest organisations in our network provide care for the elderly: running residential care facilities, offering services to people in their home, and providing specialist services for the homeless and people living with addiction, illness and disabilities.

All Anglicare Australia's member organisations articulate, in different ways, an essential Christian belief in the inherent value of every living person.

Meaning for the person and meaning for others

In this presentation I look at two things, meaning in the life of people with dementia, and what those lives mean to others.

Firstly, how – in the provision of different services across the Anglicare network – we are looking to support people to find (or keep hold of) the meaning in their lives.

The various forms of dementia raise challenges for people who provide care. But we know there are ways that family members and professional care givers can connect with people who have lost some – even much – of their coherence, and their capacity to engage with the world and recall things in their lives.

I am particularly interested in how that approach is sustained through the organisations, and how it is shared and understood by families and by residents or customers, the elderly, themselves.

Secondly, I touch on some of the ways we are making those external links, so that we – as individuals, family members, volunteers, community groups – find meaning ourselves in our connections and relationships with people in these circumstances.

I look briefly at how the privilege of caring for people at the end of their life might play out in a life affirming way. And while often that relates to the mission or purpose of the organisation, it is rarely overt, nor is it seen as a major part of the dementia care project.



The Montessori method for dementia care

Anglicare SA describes the Montessori philosophy as a perfect mission statement for dementia care:

“To enable individuals to be as independent as possible; to have a meaningful place in their community, to have high self-esteem; to have the chance to make choices and meaningful contributions to their community.”

I won't go into it in full detail here, but there is a body of work and expertise on [Montessori for Dementia](#). The outcomes – in regard to better sleep, lower demands on staff, improved wellbeing, lower medications use, fewer problematic behaviours, greater family involvement – are substantial.

This approach starts from the understanding that much of our meaning in life comes from the daily activities we are involved in. And for people living with dementia, as I'll explain, thoughtful design of their facilities can support those meaningful activities. Anglicare SA presented at our national conference recently on how they are designing residential facilities to support this Montessori practice of care.

For example, when bedroom doors are painted in different colours, it is much easier for people to recognise their own room. Handrails and door handles are in contrasting colours so people can see them and use them. Artworks and memorabilia are used as landmark objects that signal to people where they are in the building. So they don't feel lost.

There needs to be large spaces so residents can be a part of the cooking and the cleaning, and have room for arts, crafts and group activities. And the spaces are kept open and clear to make it easy for people to move around.

Lighting is important. Shadows and reflections can make things are difficult or confusing for people living with dementia so there is lots of natural lighting and non-reflective glass incorporated into the design.

Meals of course are very important too. So dining spaces are kept small and relatively quiet, in rooms of no more than seven people. The food is served on coloured plates, so residents can see and understand the food they have in front of them.

Also, when it's time to get their food, they are able to move around and point to the dishes that they want, and to serve themselves as much or as little as they choose.

You would be interested to know that that process has seen *everyone* put on weight, and food waste has been significantly reduced.

And you might know many people see themselves as they were in say their 30s or 40s. They will feel at home in their own rooms if they have recognisable pictures of themselves, as they think they are, on their walls, and not mirrors.

So you can see how appropriate design helps people remain active and independent.

The other part of the project is really about sharing this understanding.

All staff need to focus on incorporating people into the activities of their day, rather than delivering them the medication or the laundry or the meal. And family and friends need to understand too, be invited to participate. To be guided to be involved.

So the communication strategy is as much a part of the concept as the design.



The care conversation

Staff at Anglicare Southern Queensland establish the respectful relationship that they want with the people they care for through a conversation. They begin by asking that person, in their own words, to describe their life and what's important to them. How they are going? What they would like to do, and what might help them? The more clinical part of the discussion comes later.

Of course this can be a challenge to some staff, because of their many years of practice assessing people's medical and daily support needs. Also, because it's a shift in the balance of power.

But in Australia, that balance is already changing. We are moving from government determining the care and support that someone will get, to the person themselves choosing the care they want and who they get it from. And this change in the aged care system resonates with an approach to dementia based on the individuality of the person and the relationships they develop with their caregivers.

As in the Montessori method, at a practical level we are talking about a shift for staff from feeding people to working with them in preparing meals. The outcome may not be the orderly delivery of food, but it will be the companionable or purposeful work of meal times.

And when I reflect on visiting my mother in her aged care home, when a plate of food was just put in front of her, I now understand why she was so keen to have me eat some of it. It was probably the only useful thing she could do - ensuring that I ate too. At the time I thought it was just that she didn't want to eat it herself.

Another element for Anglicare Southern Queensland staff members is their interest in helping people to do things they've always wanted to do. While they still can. One example they gave was giving someone the opportunity to ride a horse. All of that is about paying attention to the person: it's about investing in opportunities for them, and recognising the dignity of their risk rather than simply focussing on the duty of care. It grows out of the concept of 'relationship'.

As Anglicare Southern Queensland itself put it, *"We nurture essential, ethical, effective caring relationships with clients, along the continuum of care."*

That notion is already fundamental to Anglicare Southern Queensland's strategic plan. It is now being built more formally into the detail of their aged care systems.



A capability approach

I drew some similar lessons from the Brotherhood of Laurence, particularly regarding a respite and social support service they run.

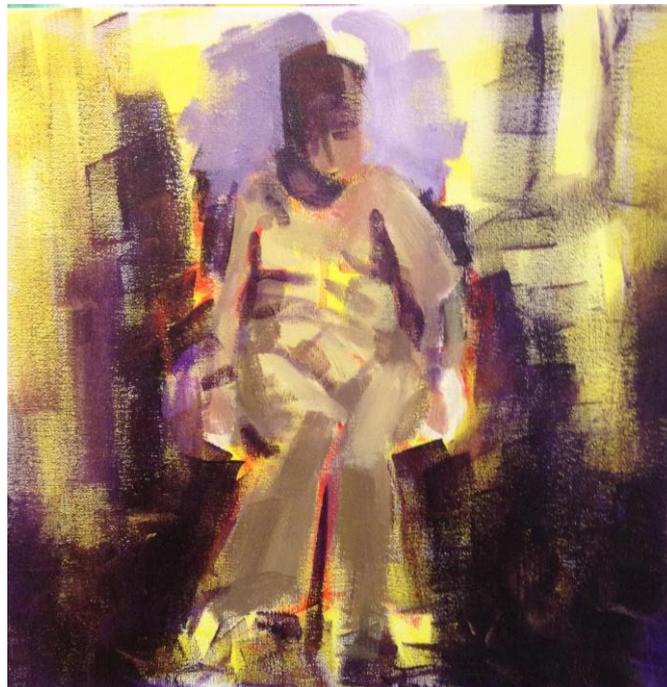
In talking about the programs, staff members describe their approach as drawing on people's capabilities. It is about learning from people (and their families perhaps), what they can and want to do – which is very often about remaining connected and engaged in the world around them - attending dances, working in the community garden, making wooden toys. Once that becomes clear, the project becomes about changing expectations of the people with living dementia and changing the expectations of what happens around them.

For care staff that can be a kind of jigsaw puzzle, where they then have work out what *their* responsibility is.

One instance of that independence is the Younger Onset Dementia Group (YOD) which has been active in co-designing and evaluating its own programs. Members of the group have appeared on television advocating for everyone to see the person rather than the dementia, and they have developed and conducted a program of engagement with local schools.

The point I'm heading to here is that kind of close connection needs a supportive work culture.

At the respite service, staff members reflect on their own practice, and plan accordingly. They reflect together on events, group activities and individuals. They also acknowledge and offer feedback on each other's contributions. Importantly they are themselves listened to, allowed to create, learn and be courageous. Just as they aim to do with people living with dementia, and as they encourage them to be.



Cared for just for who I am

Finally, I'll touch on *Benetas*, an Anglicare Australia member's pastoral care approach. We've seen that personal connection and individual responsiveness are key to the wellbeing of people living with dementia, and to their capacity to find meaning in their lives. And we know that people living with dementia can be hard to make that contact with.

This image is another of Jackie's paintings of my mum. When, if she was out of bed, she was in wheelchair for the last few months of her life.

Pastoral Care is particularly focussed on the deepest sense of meaning for the individual. Quoting from *My name is Joe, not Dementia* a key presentation, or paper, from the Benetas pastoral team:

"At the centre of a pastoral approach, is the capacity to meet the person where they are, and allow the person to take us along with them. Let us walk alongside the person living with dementia and gain a sense of what this journey is like."

Spirituality is that part of a person to which pastoral care particularly attends, but as we've already heard at this conference, spirituality is a broad concept. While the basic questions of spiritual wellbeing – who am I? where am I going? why? – are constant for us all, Benetas connects them to the domains of the world around us (the environments), the arts, our personal relationships and (where relevant) our religious practice and heritage.

Whatever the anxiety, or limited cognition, or pain, or uncertainty someone might be living within, they can still be as touched by physical contact, by companionship, by prayer, by the sunset or by music as they could ever be.

And while it is essentially an individual journey we are talking about here, few people find or hold meaning in their life alone. Pastoral Care for that person, as Benetas describe it, extends to "the emotional and spiritual needs of residents, clients and families."

To make the real difference through pastoral care we must not trivialise what people are going through. Here's another quote from *My name is Joe*:

"... it is social inclusion that is perhaps the most central need, and this can only be addressed if we first, with great honesty, acknowledge the painful reality of aloneness and abandonment for many people living with dementia."

Reflecting pastorally on the experience of the person living with dementia enables us to reframe our understanding of a person by seeking to gain a real sense of the person's story, as well as our own. For the question, 'who am I?' is ultimately framed not only by the stories we tell about ourselves, but also by the stories that others tell about us. In telling you something about who I am, in pining for you to share with me something of how you feel about me, what I am really yearning for most of all, is that I am cared for just for who I am."

"even if" as John Swinton expresses it, "who I am is difficult for me and for others".



Meaning in our lives

Now I want to turn this question around.

I thought about the value we espouse across the Anglicare network. That every one of us is valued. That in our life we all have meaning.

In much of my discussions with Anglicare colleagues we talked also about the role people with dementia play in the lives of others. A number of the Anglicare services have extensive volunteer programs. People come in to brush hair, or do the fingernails or just play draughts with people living with dementia. And they will tell you, as we all will, that it's a privilege to spend that time with someone. To be with them in this simple way.

And we know there are examples of the value, the meaning that comes from bringing the old and the young together. Of finding a place for the stories and the experiences to be passed on. Of bringing life and connection into the minds and hearts of others with fairly simple things like pets, and song.

And some of the principles that I've already described are in essence about spending the time, the moment, with someone. Whether they can talk about it or reflect in any conscious way. The trick is to find enough time to do it.

The modern world might be throwing us some demographic challenges linked to an ageing population; it is also speeding up and over complicating our work life in the meantime. There are not many places where being still, listening, simplifying, or focussing on the present is what we have to do.

At the Reina Sofia gallery in Madrid, many floors above the busy Guernica gallery, is a room with maybe eight paintings by Miro and Picasso towards the end of their extraordinary

painting careers. Picasso's paintings were of the artist and the model. Direct, visceral and intense. Miro's were of landscapes. Also simple. Bathed in light. This one is *La danse des coquelicots*, the dance of poppies. To paraphrase the gallery, this painting reflects Miro's progressive simplification of his universe, and his return to a basic theme of the reality of the earth.

I'm not suggesting that this Miro is a parallel to life with dementia. But it is a reminder of the value and the power of that essential simplification.

There is meaning for us others who are learning how to spend time with someone who has lost or is losing so much of their usual attributes and capacities, if we are – as John Swinton would have it – prepared to care for them however they are.

The most profound things we can do might very well be the simplest.

END

Special thanks to

Lesley Jeffers, Acting General Manager, Active Living	Anglicare South Australia
Susan Cooke, Director Service Delivery	Anglicare Southern Queensland
Jennifer Marshall, Practice Development Consultant	Anglicare Southern Queensland
Mary McConochie, Service Leader, Residential Care and Retirement Living	Anglicare Sydney
Pam Storey, Senior Pastoral Care Practitioner	Benetas
Lisa Astete, Senior Manager	Brotherhood of St Laurence
Kylie Levett, Program Coordinator	Banksia Centre, Brotherhood of St Laurence