Garry’s Dream

Creating services for people with Younger Onset Dementia

A Lovell Foundation/Alzheimer’s Australia Vic Initiative
The Lovell Foundation and Alzheimer’s Australia Vic have set an objective to promote the development of a quality long term accommodation facility for people diagnosed with Younger Onset Dementia.

We gratefully acknowledge the support of families living with Younger Onset Dementia in telling their stories and identifying their needs. Thanks is also extended to members of the Younger Onset Professional Advisory Group from Alzheimer’s Australia Vic, National Ageing Research Institute, Neuropsychiatry Unit of Royal Melbourne Hospital and the Eastern Cognitive Disorders Clinic for their advice and support.

There is an estimated 2,500 with Younger Onset Dementia in Victoria. Currently, for people at an advanced stage, the only residential care option available is in aged care facilities. We are working to introduce a best practice accommodation outcome for people with Younger Onset Dementia.
Hello

I’m Garry, I’m 48 and I have dementia.

This booklet is about my dream.

It is normal to think of dementia as an old person’s condition and that’s mostly true. But there are people like me in their forties, fifties and sixties (and some even younger) with dementia. In fact around an estimated 10,000 in Australia.

Unfortunately there are very few services available to support people with younger onset dementia. And at the advanced stage the only real care option is placement in a nursing home with older people.

We need to do something about this.

Mandy (my wife) and I are working with a group of supporters and others living with younger onset dementia to find a solution.

My dream is to find a residential provider organisation to work with us to create a best practice residential care facility for younger adults with advanced dementia.

Come with me on the journey to make it a reality.
So what do the books say about Younger Onset Dementia?

Dementia is a clinical syndrome used to describe the symptoms of a large group of conditions that result in a progressive decline in cognition.

People associate dementia with loss of memory, but there are many other consequences, including decline in reasoning, communication skills and the capacity to organise daily life.

There are over 100 different forms of dementia, with Alzheimer’s disease being the most common.

Dementia is a terminal condition for which there is no current cure.

Younger onset dementia (affecting people less than 65 years) is uncommon and it is commonly poorly diagnosed.

Younger onset dementia has some significant differences. The types of dementia can be very diverse with many rare forms and characteristics. For example, the main characteristics of fronto temporal dementia (FTD) relate to changes in personality and behaviour rather than memory. Other variants affect language, mood, reading, communicating and motor skills. The rate of progression of these diseases may be more rapid and the symptoms more severe than occurs with dementia in elderly people.

Commonly people with younger onset dementia will have been well established in jobs and at the peak time of raring their families. They may have limited opportunity to link to other people with similar conditions. Often it will take extended time to diagnose that the condition is dementia and people may live with inaccurate or incomplete diagnoses.

It is not accurately known how many people have younger onset dementia, but it is estimated to be around 10,000 people in Australia and about 2,500 in Victoria.
This is really what Younger Onset Dementia is...

This is the story about my Mum. It should never be repeated.

Mum was only 50 years old when we first noticed that there was something wrong with her memory. She became easily confused when we gave her instructions to do something, and would become frustrated when she couldn’t remember things or what she had been doing. She rather quickly lost her independence being unable to drive because she would become lost, and was unable to continue working.

She was diagnosed with Younger Onset Dementia when she was only 51.

She told me at Christmas time that she hoped that my brother and I didn’t have the dementia as well—her father was in his forties when he was diagnosed, as were several of his brothers – there appeared to be a clear family history in our case, and she was scared that she too had passed it on.

At first we assisted Mum by having support staff come into the home. We later needed staff to do sleep-overs, until it became clear that Mum required a higher level of care. Mum trialled a respite service for two weeks at a time, but she needed ongoing care. She was admitted to a nursing home where we thought that she would be staying for a long time. But over the next ten years she was moved from home to home because her needs could not be met. In fact over the 10 years she was moved 11 times.

Mum died in 2001

This is just one story.

Let me tell you about the lives of some others I know ...
And here is Jane and Rob’s story

Rob is 53 years old and was diagnosed with Posterior Cortical Atrophy (PCA) six months ago.

PCA is a rare atypical Alzheimer’s disease, which initially affects the visuo-spatial functioning. Rob is an architect, and thankfully he is still working, but his capacity is now limited to specific tasks.

We first noticed that his driving was deteriorating, and soon after his ability to move furniture within space diminished and his computer skills deteriorated markedly. This accompanied a general lack of motivation. Despite a variety of tests it took two years to be diagnosed.

He is passionately admired and loved by his family. His two teenage daughters accommodate his deficits, which it seems by stealth, have altered his capabilities. Much shared humour accompanies his irregular ways, with Rob quietly leading the laughter.

He is an elegant and caring man. He tires easily so life is becoming progressively simpler.

We are very concerned that as his condition progresses we may not be able to care for him ourselves. We would be so relieved if we knew that future care (be it respite or residential care) when we require it will be responsive to the needs of us all as a family, as well as Rob as an individual.

We think that probably the most crucial component of good care is staffing – well trained in younger onset dementia - and numbers of staff adequate to provide time for him.

We would like Rob to be with people of his own age, who share a similar experience and who may also have a young visiting family.
... and Linda and George\(^1\) have a story

George was diagnosed just before turning 41. He was diagnosed with frontotemporal dementia. We have two children aged 8 and 10. George had a long career as a general manager but his career ended 5 years ago.

George was always a high achiever, proud, a very kind, loyal, helpful and loving husband and father. This is what made me notice the changes so much, as he began to change into the total opposite personality to the George I knew. George hasn’t driven since late 2009. He cannot go anywhere on his own and we have to have all doors locked at all times.

The illness has impacted our family dramatically. We cannot leave George alone and socially we can’t do a lot of things. Nothing is normal at all in our day-to-day living. I honestly have to take it day by day as it is such a rollercoaster.

I worry a lot about what is going to happen to George in terms of the illness and permanent care when I can’t manage George at home anymore. It breaks my heart to watch someone I love deteriorate so much and become a shadow of themselves, and then to be faced with placing him somewhere - especially as he is so young. I worry a lot about the children’s and my wellbeing visiting George with the children in these places too.

This illness can make his care needs change in an instant - there is no specific stages to this illness and it’s unique to each individual. 

There just needs to be more for these people in all areas from activities, support and care for the families.

\(^1\) fictitious names
This is what we need

In 2010 we drew together families living with younger onset dementia.
We asked them to dream about a place for they can live when the dementia becomes advanced.

This is what they want ...

A place where we can LIVE ...

• A place where life is as normal as possible
• Where we can participate in activities of daily living, including cooking
• Where dignity and privacy is respected in our care
• Where intimacy is still possible
• A place that respects belief, faith and cultures
• Where our families can sleep over
• With pets
• Where we can still have IT links to our families
• With outdoor spaces and gardens, vegie patches, roses, and a men’s shed
• A staff that has specific training in younger onset dementia care issues
A place that keeps the family together ...  
• Where the family remains involved in our lives in all sorts of ways (volunteering, part of the home, helping with meals and outings, a part of our social life)  
• Where families can come and go when they wish, and stay over if they want to  
• Play areas, animals and everything else that is part of our family life now

And the place needs to work with our capabilities ...  
• Quiet zones and activity zones  
• Hubs/pods/units for our own space.  
• Mini apartments would be nice  
• Light and airy  
• Single storey  
• Clean and hygienic  
• Courtyards and garden areas for walking  
• A place where our needs are all met (no moving)

In a word ...  
• As close as possible to a home away from home
There is a solution – others have already done it

We have done our homework. There are a few places where people with advanced younger onset dementia can live in dignity and we have visited them. But there are none in Victoria.

Hammond Care, Horsely, NSW

We visited the The Hammond Care facility at Horsely, near Woolongong, south of Sydney to find out about its operations.

It is a complex of 6 units, one of which has been recently opened primarily to people with Younger Onset Dementia. The remaining units are for usual aged care.

At the time of our visit, threeresidents had moved into the YOD cottage, with 12 beds remaining, four of which were being designated respite places.

You enter the single storey unit through a traditional looking front door (doorbell and keypad) into a large open plan space. There is a kitchen to the right which is open to residents at all times, a dining area to far right, a lounge area to the far left. To your immediate left is the separate games and TV room, complete with a Wii unit and Play Station for children, used during family visits for some privacy.

Corridors to both left and right are where the residents rooms are – eight one way and seven plus a private bathroom the other. Each room has a corner ensuite – toilet (light over toilet for night) and shower.

Residents can decorate to their taste. Hospital style single beds provided. Mattresses for children can be offered. Outside each room is a cabinet for photos to identify the resident.

At end of each corridor is a computer station, window seat and there is access to the garden walk at the back of the cottage. The corridor and the garden walk create a circular walk. The garden is small with a gazebo and a washing line for residents washing. There is also a covered paved patio area for BBQ’s which opens out from the central open plan area of the cottage.

The Dales Nursing Home, Bradford, UK

The Ribblesdale Unit for younger people with dementia is the grounds of The Dales Nursing Home. It is operated by Bupa Care Services.

Mandy and I visited there in 2011 and we can report that...

Upon conversion, the original 22 bed unit (which included double rooms) was reduced to 12 beds – this meant that room sizes were increased and some could be considered mini apartments with both beds and sofas.

It is single storey, has a large open garden/lawn area at the rear, a sunroom, and a communal lounge area. There are several small dining tables, a television and DVD player and sofas. The unit also has a small family room when privacy is required, and a small kitchenette with 24 hour tea/coffee facilities and toast making available. The rooms have their own toilets, but the unit has a shared bathroom with a large modern bath/shower with hoist to assist with mobility. The units décor creates a low stimulation environment.

The co-location of this unit at the nursing home site enables laundry and meals to be prepared onsite and shared across all units. A cook can prepare a variety of meals and cater to individual needs if required.

The staff ratio has been kept high. Staff were selected because of an interest in working with younger people with dementia, and trained extensively. The unit manager is certain that training of staff has been the key to this unit’s success.

There are no designated activities staff. Activities tend to happen on a one to one basis quite spontaneously through the day depending on the mood and needs of the residents. The staff take residents to the local shops at times. Spouses and family members are made welcome and contacted regularly to be kept informed by both residents and staff. Spouses can stay; the unit is dealing with the dilemma presented over the use of only single beds at present. Staff have been trained to be aware of issues of intimacy and sexuality.

For more details: www.bupa.co.uk/individuals/care-homes/find-a-care-home/the-dales-nursing-home-thornbury
About The Lovell Foundation

Mandy and I established the Lovell Foundation with one major aim in mind:

**To provide a quality long term accommodation for people diagnosed with younger onset dementia and their families.**

The establishment of The Lovell Foundation Inc. in 2009 was in direct response to their family’s difficulties with the placement of my mother. In consultation with Alzheimer’s Australia Vic, the Lovell Foundation has worked with a team of professionals experienced in younger onset dementia, worked with families to identify their needs and identified and investigated the few appropriate facilities that exist for younger people with dementia.

The Foundation has been consistently contacted by carers, as well as clinical staff from a range of organisations who support the idea that an alternate solution needs to be found for placement of younger people with dementia within Residential Aged Care Services.

In April 2011 a consumer forum at Alzheimer’s Australia Vic for those diagnosed with younger onset dementia and their families clearly identified the dissatisfaction, fear and concern regarding the current for residential and respite care options available to them, and proposed many alternative suggestions, with a clear message that they would prefer a place of care dedicated to younger residents with dementia, and more inclusive of their younger families.
Trevor Mast has been a well known entity in the Victorian Wine Industry. With a particular interest in cool climate winemaking, he took up a position first at Seppelts, then at Bests Great Western and in 1987, with Ian Menzies and later Riquet Hess as partners, purchased Mount Langi Ghiran Vineyards best known for its cool climate Shiraz.

In the mid-90s together with his wife Sandra, Trevor launched the well-known ‘Four Sisters’ wine company named after their four daughters.

Trevor’s life was a full and busy one. In 2003 he was named a finalist in the Australian Winemaker of the Year Awards. In the same year he was also honoured as the annual Legend Winemaker of the Melbourne Wine and Food Festival.

In 2006 having celebrated 30 years of winemaking in the Grampians and having sold the business to the Rathbone Family, owners of Yering Station, Trevor was diagnosed with Alzheimer’s-type Dementia. He was 57.

Last year Trevor and Sandra became aware of The Lovell Foundation and after contacting Mandy and Garry Lovell and being inspired by their vision regarding accommodation for people with younger onset dementia, decided to contribute to the foundation by offering part of their personal wine collection for sale by auction.
I invite you to a conversation

We are seeking to identify a residential care service provider who is interested in a best practice residential care project for Younger Onset Dementia.

This would be ideal for a provider who is planning the development, extension or redevelopment of an aged care facility.

Our concept is the incorporation of a unit or wing or stand alone facility designed and managed to provide responsive, quality care for permanent residential care and respite for people with younger onset dementia.

This would be a best practice demonstration project. It would be the first such residential project in Victoria.

Demand and viability are clearly key issues. For this reason, our vision is for the development of a younger onset dementia unit linked to the management, administrative, staffing and support services of an aged care facility that stands separately, but connected.

Our timing? Yesterday.

This is my dream.

Are you able to work with the Lovell Foundation and Alzheimer’s Australia Vic to make it a reality?
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