

# In our own words

Younger Onset Dementia



Alzheimer's  
Australia  
Living with dementia

A collection of very  
personal stories

# Foreword

This collection of very personal stories contains insights into living with younger onset dementia. I am deeply grateful to all those who have contributed to this publication. I know from personal experience how important, and how painful, it is to share such experiences.

There is no cure for dementia whether you are young or old. Yet there is so much that could be done, even now, to improve the quality of life of those with younger onset dementia. A good start would be to promote awareness among medical professionals and other care staff that people as young as 35 years old may have dementia. The wider community equally needs to know that Alzheimer's disease and the many other causes of dementia are not confined to older people.

It is heartbreaking that so many people experience such trauma in the diagnosis of dementia. This may involve years of uncertainty and misdiagnosis with depression and other conditions before a diagnosis of dementia is made. If there is one message to policy makers and the wider community from this moving publication, it is that early diagnosis and greater understanding of younger onset dementia among medical professionals is critical.

It is equally important that policy makers and the wider community understand that life goes on after a diagnosis of dementia, even if it will never be the same. For the younger person, there may be family and financial responsibilities to manage. There is a critical need to ensure ongoing social engagement and involvement in activities that have been a lifelong interest. Respite care and other services including residential facilities for people with younger onset dementia need to respond creatively to their special needs to be active and involved.

Let me thank again all those who have shared their experiences in this publication. I hope their courage will promote a better understanding among Australians of the needs of people with younger onset dementia and, the responsive services that are needed to assist them and their family carers to enjoy a better quality of life through what will inevitably be difficult years.



**Ron Sinclair**

Chairman, Alzheimer's Australia National Consumer Committee



**An Australian Government Initiative**

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# Younger onset dementia

## What is younger onset dementia?

While dementia is often perceived as part of the ageing process it can also affect younger people. Younger onset dementia is the term used when the person diagnosed is under the age of 65. In Australia today, it is estimated that about 10,000 people with dementia are under the age of 65.<sup>1</sup>

While Alzheimer's disease is one cause of younger onset dementia, there is a much higher representation of rarer dementias in the younger groups compared to the over 65's. The symptoms, as a consequence, are more varied and may include loss of practical function and emotional and behavioural change before memory loss.

## The needs of people with younger onset dementia

Younger people with dementia have different needs compared to their older counterparts due to the life stage at which the disease becomes evident. Demotion, early retirement, diminished superannuation, lack of future legal planning, outstanding mortgages, significant debt, young and adolescent children still at home, physical fitness and relationship breakdown are often part of the complex picture that creates other layers of difficulty for younger people with dementia that may not be there for older people with dementia. Care partners also have greater levels of psychological distress with higher carer burden. Children and parents of a parent with younger onset dementia also face many unique challenges that are different from those of people with late onset dementia.

## Links to other chronic conditions

Dementia can be the consequence of other chronic conditions in younger people including Multiple Sclerosis, HIV AIDS, alcohol and drugs, Motor Neurone, Huntington's disease, Down syndrome, stroke and Parkinson's disease.

## Alzheimer's Australia

Alzheimer's Australia is committed to the prevention of Dementia, while valuing and supporting people living with dementia. Alzheimer's Australia has developed national partnerships and strategic alliances with other peak consumer bodies, stakeholders and the Commonwealth and State Governments. This approach has enabled the development of complex dementia programs and services that are considered leading edge in the international field of dementia support services. Alzheimer's Australia has a strong consumer focus with people living with dementia, their family and carers actively contributing to policy, management and running of the organisation. In accommodating younger residents with disabilities.

1. Access Economics, Dementia Estimates and Projections: Australia States and Territories, February 2005.



## Marian

## Western Australia

*"Make the most of the precious time together and to make each moment count as you don't know how long it will last." Jan*

### Main issues

- Inaccurate diagnosis – stress
- Delay in treatment
- Lack of appropriate respite service
- Financial loss – wife gave up work to take up caring role

### About Marian

Marian was born in 1945 and was formerly a TAFE lecturer teaching metal trades. He is a boilermaker by trade and had been teaching for over 25 years. We have been married for 40 years and have two sons and three grandchildren.

### A change

Marian was diagnosed with Alzheimer's disease in 2004 when he was 59. He noticed something was amiss when he found he couldn't remember his students' names and was given a hard time by them.

He went to see a doctor who treated him for stress and encouraged him to give up teaching. He went back to the metal trades industry but there were times when he was sent to a job but suddenly realised he did not know how to get to the location.

Gradually Marian lost confidence and one afternoon, when his shift ended, he was so disorientated that he didn't even know how to get home. His employers noticed the problem and sent him for some tests.

I noticed something was wrong with Marian and took him to see a neurologist.

Eventually, after many trips to the doctors and numerous tests, Marian was diagnosed with Alzheimer's disease.

Our family were devastated when they heard the diagnosis but at the same time, we were

relieved to get a diagnosis. We approached Alzheimer's Australia WA and attended the Living with Memory Loss program where we met other couples in the same situation.

### Changes

As Marian's Alzheimer's disease progressed, he went from being a very outgoing person to someone who is quiet and withdrawn. He gets fatigued easily and is no longer able to do anything around the house. He is slowly losing his short term memory and has trouble with his speech. Depending on whether it's a good day or not, he can still sign his signature.

I was forced to give up work to care full time for Marian and we now rely on the pension, our super and the carer's allowance.

The demanding caring role meant I soon lost contact with my work colleagues and friends and friendships tapered away. Relatives too have begun to distance themselves from us.

Marian now attends an Alzheimer's Australia WA Friendship Club for those diagnosed with younger onset dementia.

### Respite

Marian's first experience with respite was 10 days of overnight respite which he hated. He felt the residents in the facility were much older than him and he felt very out of place. The residents were unable to do things on their own and Marian had to help the nursing staff with their tasks. He would have preferred a place that caters to the younger age group.

It is important to pursue a diagnosis if you know something is not right. It's hard to see the person you fell in love with change before your eyes and become a stranger. **Jan**



## Linda

### Western Australia

*“The biggest thing was accepting the diagnosis. It was especially difficult at such a young age.” Linda*

#### Main issues

- Too young for dementia sentiment by family and doctors
- Inaccurate diagnosis – depression
- Delay in treatment

#### About Linda

Linda was born in 1950 and used to work as a dress maker and a costume designer. We married and together have two children, Daryl and Althea, as well as two beautiful grandchildren. Linda used to care for her elderly mother who was staying with the family. After Linda was diagnosed with Alzheimer’s disease, the family had to place her mother in a permanent care facility.

#### A change

Linda was diagnosed with Alzheimer’s disease two years ago when she was 56. However, she first noticed something was amiss a few years before when she began to struggle doing what she had done for many years such as sewing which she had been particularly good at.

She went to see a number of doctors at the end of 2005 who all told her that she was suffering from depression and was prescribed antidepressants. By the middle of 2006, there had been no improvement and things started getting worse.

She soon lost the ability to tell the time, read and write and could not remember things she had done, such as what she had cooked for dinner the night before.

She thought she was going mad and didn’t understand what was going on. She would cry a lot and become very anxious and withdrawn as she could not make sense of the things around her. My son and I didn’t notice what was happening to Linda as we thought she was too

young to have Alzheimer’s disease. As we were always around her, we were unable to notice her gradual decline.

#### A confirmed diagnosis

When my daughter Althea returned home after spending some time overseas, she quickly noticed the change in her mum. She remembered that her grandfather (Linda’s dad) had Alzheimer’s. She then went on to the internet to read about it and found the symptoms Linda displayed matched what she had read.

We took my wife for several memory tests at a memory clinic in Fremantle and within a month, she was diagnosed with Alzheimer’s disease and put on medication.

After Linda was diagnosed, we contacted Alzheimer’s Australia WA to seek help and advice. We went on to attend the Living with Memory Loss program where they met others in the same situation. When we finished the program, we felt more empowered and more open about the diagnosis.

Soon we started to understand and accept the diagnosis and adjusted our lifestyle to fit Linda’s needs. I still work to support the family while Althea spends more time with Linda.

There are times when Linda feels it is hard for her children as they are still very young and probably don’t have many friends whose parents have been diagnosed with Alzheimer’s. **Robert**

*Dementia in younger people is much less common than dementia occurring after the age of 65. For this reason it can be difficult to diagnose and its incidence in the community is still not clear.*

## John

### Queensland

#### Main issues

- Slow diagnosis
- Cost of diagnosis

My husband, John, was diagnosed with Alzheimer’s disease in February 2008. John had just turned 64. The diagnosis, when it finally came, was a relief to both of us.

For John, it finally explained the problems he was experiencing and the frustrations he was feeling particularly at work. For me, I was able to stop questioning what I was doing wrong and realise it wasn’t me and I couldn’t fix it.

While John can look back 20 years or more and recognise that he had problems with his memory, it was about 10 years ago when we relocated to Brisbane that John started having real difficulties coping with his work environment and responsibilities.

John became a regular visitor to our GP trying to find answers to the way he was feeling. He was sent to various specialists and underwent several investigations.

I learned that there are many different ideas about how to diagnose and the costs were enormous.

Eventually, because no physical problem could be found, John was referred to a psychiatrist for depression early in 2007, even though testing by a neuropsychologist showed his memory was poor.

John was put on a very high dose of anti-depressants which exacerbated his problems at work.

In November particular signs started to emerge and I noticed that John was not able to navigate and was doing a couple of other odd things. When I visited the GP with these issues, he was not surprised and said he had thought for some time that John may have had Alzheimer’s disease or the like. I could not believe that he had had these suspicions and not pursued them further.

Getting an absolute diagnosis of this disease then became another issue and I soon became very frustrated.

*A diagnosis that is as early and as accurate as possible has undisputed value for someone of any age. For a younger person, it is likely that the onset and diagnosis of dementia will bring about a great number of lifestyle and unexpected changes, so early diagnosis is especially important.*

#### An early diagnosis is essential to:

- Eliminate the possibility of other conditions that may have symptoms similar to dementia and may be treatable, including depression, chest and urinary infections, severe constipation, vitamin and thyroid deficiencies and brain tumours;
- Eliminate other possible causes of confusion, such as poor sight or hearing, emotional changes, bereavement and loss, or side-effects or interactions between certain drugs;
- Allow early access to advice, information and support from Alzheimer’s Australia, social services and other voluntary agencies and support groups;
- Allow the prescription of drugs that are effective in slowing the progression of certain types of dementia (e.g. Alzheimer’s disease) in the early to middle stages, but are ineffective for other dementia types. An accurate diagnosis of the type of dementia is also important because drugs prescribed for other conditions could be detrimental to those with dementia (e.g. prescribing neuroleptics for mental health problems has very dangerous side effects for those with dementia with Lewy bodies); and
- Allow the person with dementia and their family to plan and make arrangements for the future such as writing a will, establishing an enduring power of attorney, writing advanced care directives (a living will) and planning for financial management.

#### Alzheimer’s Society UK.

It was only through my questioning, calling various institutions and general perseverance that I learnt about the memory clinic and it was here that John was finally given the diagnosis. Thankfully we avoided the extensive psychiatric testing and invasive lumbar puncture tests recommended by a neurologist, saving us more than just money. I believe now it is only when you become aware of the symptoms yourself, you realise how simple it should be. **Gail**



## Susan

### Victoria

*“It didn’t occur to Susan’s colleagues, even as medical professionals, that there might be a genuine medical reason for her memory loss.” Robert*

#### Main issues

- Slow diagnosis
- Lack of professional knowledge
- Lack of facilities for younger people

#### Susan’s story

For Susan, it was constantly leaving lights on and doors open, losing keys and repeating things in conversation. Then she had a car accident because she couldn’t judge the distance between her car and the car in front.

Susan was just 58 when she was diagnosed with Alzheimer’s disease. Her symptoms began showing when she was in her early 50s, but it took years and many medical appointments to get a proper diagnosis.

Susan was working as a nurse in Canberra when her colleagues noticed that she was starting to forget things. Her boss decided that she needed to be retrained, even though she had a long history of being a nurse. Possibly due to lack of understanding about younger onset dementia, it didn’t occur to Susan’s colleagues, even as medical professionals, that there might be a genuine medical reason for her memory loss.

I am her husband and main carer. I work from home, helping my son with his computer business, and Susan spends four mornings a week with a carer.

Susan is reliant on me for assistance with daily tasks, and having carers visiting the house means that I have the freedom to work a few hours each week. Communication from the carers can be limited however, sometimes they don’t turn up and offer no warning or explanation.

Recently Susan experienced delusional episodes and wandered from the house a few times. One time, a police helicopter was despatched to find her. Soon after this, Susan was admitted for a short time to an aged care facility. It was a scary and confusing time for both of us. Thankfully, she stabilised and is now back at home.

During this difficult time, I found it extremely hard to find the medical and crisis services needed to help Susan. When she disappeared one day, I couldn’t find a number for a crisis team anywhere. I eventually remembered that I might be able to access it through the local hospital, and after several phone calls managed to find the right people, but feels that services like these should be easier to find, especially given that people are often calling in a time of crisis.

Susan is now unable to read for long periods, change the TV channel, or talk on the phone for more than two minutes. But she loves people and she still wants to be involved. I am constantly searching for ways to keep Susan stimulated and involved in activities that interest her, and have tried respite day programs in the local community. I find that they are usually designed for older people, not for people like Susan who are fit and active.

The experience of living with dementia has had its positives. It has brought us closer together. We have reached out to other people by sharing our story in the media and helping to raise awareness about dementia in younger people. We are a wonderfully close team.

We live in Melbourne. We have two adult sons, David and Stephen, who live interstate.

**Robert**



## John

### Victoria

*“Eighteen months prior to getting a diagnosis of dementia, John became increasingly frustrated with his inability to perform well at work.” Liz*

My husband, John, would set about trying to get organised but never succeeded. He’d sort pens into different colours then put them back together into the container. Then he’d start all over again. He’d try to tidy up the garage – putting things into piles, then putting it all back the way it was to start with.

John was a university lecturer and he wasn’t coping at work either. I began to worry about his ability to organise and manage tasks. John also started to struggle with expressing himself verbally – often he couldn’t find the right words or would regularly forget familiar names. There were lots of ‘thingamebobs’ and ‘thingamajigs’ in conversation.

John was 54 when he was diagnosed with fronto-temporal dementia, and he died in June 2007 at the age of 62.

Eighteen months prior to getting a diagnosis of dementia, John became increasingly frustrated with his inability to perform well at work. He was eventually diagnosed as having depression and he took sick leave from his job. I found this diagnosis hard to believe because John was always upbeat, although I did acknowledge stress as a problem.

Over the next six months, John was assessed by a Cognitive Assessment and Dementia Management Services clinic, visited a psychiatrist five times, had an MRI scan, and was finally diagnosed as having dementia by a neurologist.

The diagnosis was both a shock and a relief for us, because at least we knew what we were dealing with. Later, we went on a Living With

Memory Loss retreat with Alzheimer’s Australia Vic, and were interested to hear that many other people had experienced the same long period between first seeking medical advice to getting an accurate diagnosis.

For the first couple of years, I cared for John at home with the help of our daughter and a government funded EACH (Extended Aged Care at Home) package. He sometimes went into respite care to give me a break. The respite facility didn’t cater for the needs of a younger person with dementia and John was expected to sit in his room and watch TV all day.

John was then recommended for an acute psycho-geriatric facility because of his changed behaviours. He stayed there for one year before moving to a high care facility for six months.

The worst times were when John was in the acute psycho-geriatric facility, because the care staff were poorly trained and had low morale, and there were no activities for the patients. This particularly impacted on John because he was a young, active and fit man. He was expected to watch TV all day or pace outside in the courtyard.

The experience of living with dementia was not all bad. Our family became much closer and had frequent contact with each other. We had time to sort out our finances, wills and power of attorney. We enjoyed many holidays together as John’s illness progressed, including camping adventures which he loved.

I have three children – Murray 34, Julie 31, and Stephen 27. I live in the Victorian country town of Warragul. **Liz**



## Michael

### New South Wales

*“I currently juggle five different part-time care services for Michael per week, so I can work, and he can stay at home.”*  
Joan

#### Main issues

- Respite care
- Severe financial impact

My husband, Michael, was diagnosed with frontotemporal dementia at the age of 66. The symptoms first appeared at age 60 and it took six years to gain an accurate diagnosis.

#### Financial Impact

His condition has had a massive financial impact on our lives, as he hasn't been able to work for the past ten years.

Our children were still at school when he was diagnosed, the youngest was 13, and we have a mortgage and a house to maintain.

I've been the major breadwinner, with a full-time job and my children both began part-time work as soon as they could.

#### Juggling respite services

I currently juggle five different part-time care services for Michael per week so I can work and he can stay at home. There are no long-day

care (8am to 6pm) services for younger onset dementia in our area. The best service is the recently started Ella Younger Onset Dementia Group, run by Haberfield Uniting Care. It offers two half days per week.

It's a very positive and socially engaging group, and Michael, who is the most physically capable member, feels he is able to make a contribution. It's the high point of his week.

Michael goes to a day care centre for the aged one day a week. But the clientele are older and frail and he's the least happiest there.

We are currently facing losing care in the home four half days per week. The home care program is facing closure as it is not financially viable. But we want to keep Michael at home for as long as possible, and are not sure what the future holds.

Joan

## Shirley Tasmania

I am a nurse practitioner and clinical consultant nurse, working in the medical and psychiatric areas. This included three years in New Guinea then another six years once our children all left home. Most people would find the remoteness and conditions challenging but comfortable jobs are not for me. After my husband had a stroke we had to come back to Australia. Before accepting a position in Tasmania, I was managing a drug and rehabilitation centre in Warburton, just outside of Melbourne.

When I became physically unwell, and began to find it difficult to do nine things at once, I attempted to cut down my working hours, took leave owing but nothing changed. Initially I was told there was nothing wrong. I could not remember my staff's names! Different doctors and many different opinions followed. Having worked with people with Alzheimer's disease it suddenly occurred to me that I had the symptoms. It was not until I went to a psychologist, who knew me and my past abilities, that dementia was diagnosed. I trusted and felt comfortable with her as she allowed me to talk and actually listened.

The lesson in my life has always been do what you have to. I am aware of what is happening and how quickly I am losing my abilities. It is random. I am not the same every day. Each day I look at what I can do. It is difficult at times talking to people because I lose words. Talking about the past is easier. I do not want to look silly and do not trust my own judgment. I have learnt to keep things short but I like to talk, so that makes it difficult. I now choose to keep busy helping others which is a lifetime habit of mine. **Shirley**

## Leo Tasmania

My energy, excitement and passion, which I call my juice, comes from interacting and influencing people, not only as a boss but as a listener and a coach. My career as an organisational development consultant and more recently as an executive and managerial coach involved working in many countries, including China, Japan, Singapore, Germany, UK, Ireland and Canada (just a few that I can remember at this time). My juice also comes from fly fishing, which I have taught, along with fly tying both in the US and Australia. Cooking is another passion.

When leaving my doctor's surgery one day I could not find my car. I did not know where I was. Eventually, I was able to make my way home. This is when I suddenly thought, 'This is what happens to people with dementia.'

A call to my doctor eventuated in a CAT scan and blood test, but the nightmare of obtaining a diagnosis had begun. The feeling I was not being listened to so distressed me at one appointment that I became lost when sent to have yet further tests. Centrelink was another hurdle. Their response was, and, I quote, 'We are not saying you don't have dementia but medication may help to make you better then we will rehabilitate you.'

Independence has featured strongly throughout my life. I now depend on my wife, Ellie, to oversee any decisions I make. I find this very difficult. Timing and how you say things is very important, but my sense of timing is now lost. Say it now or forget it. People have disappeared from my life. It is like going through a divorce. I fear making a fool of myself. Being at home alone allows me to feel normal. **Leo**

## A correct diagnosis is important

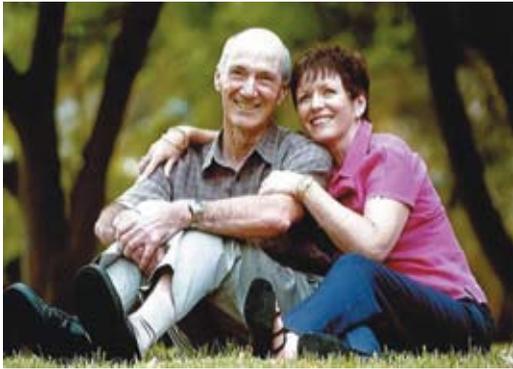
*Consulting a doctor to obtain a diagnosis is critical at an early stage. A complete medical and psychological assessment may identify a treatable condition, or it may confirm the presence of dementia.*

#### A diagnostic evaluation might include:

- A detailed medical history, provided if possible by the person with the symptoms and a close relative or friend. This helps to establish whether there is a slow or sudden onset and its progressions.
- A thorough physical and neurological examination, including tests of the senses and movements to rule out other causes of dementia and to identify possible medical illnesses which may worsen the confusion associated with dementia.

- Laboratory tests including a variety of blood and urine tests sometimes called a "dementia screen" to test for a variety of possible illnesses which could be responsible for the symptoms. The dementia screen is available through a doctor. Other specialised tests including a chest x-ray, ECG and CT scan may be recommended.
- A mental status test to evaluate the range of intellectual functions such as memory, the ability to read, write and calculate which are often affected by dementia.

- Psychiatric assessment to identify treatable disorders such as depression, which can mimic dementia, and also to manage any psychiatric symptoms such as anxiety or delusions which may occur in conjunction with dementia.
- Neuro-psychological testing to identify retained abilities and specific problems in areas such as comprehension, insight and judgment.



## Ralph

### South Australia

*“All future plans have gone out the window. We live just a day at a time.”*  
Jenny

#### Main issues

- Slow diagnosis
- Lack of professional knowledge
- Lack of facilities for younger people

When Ralph was diagnosed with Alzheimer’s disease he was 55 and a manager with a large department store. Our two young adult children were still living at home. We also had responsibility for my elderly parents. I was working part time.

The impact of Ralph having to give up work was huge – to lose the main income in the family, let alone the loss of confidence, self-esteem and dignity for Ralph. Two years after Ralph’s diagnosis I stopped work to stay at home to care for him. After five years, I still continually worry about money, because in my 50s I could live another 30 years, and will require residential care for Ralph along the way. I have had to learn to get help and advice to set up our finances to our advantage.

At first it was hard finding activities for Ralph as most programs for people with dementia catered

for older people in their 70s and 80s, whose interests were very different than Ralph’s in his 50s, having just left work.

Ralph now attends a council program making wooden toys for the Royal Flying Doctor Service and is part of Photography Group with other younger men with dementia.

For Ralph, the loss of independence of not being able to get out and around is huge.

Ralph gave up his driver’s licence voluntarily, but he has always hated the fact that he can’t drive any more and has to rely on me to take him places.

My children are both now interstate and don’t see Ralph often. It’s hard for them to accept the changes in their father and how it has affected our lives. I feel as if I’m doing this all on my own and I miss having them around.

All of our future plans have gone out the window. We live just a day at a time. **Jenny**

- Judging the speed of other cars
- Reaction time
- Hand-eye coordination

*Having a diagnosis of dementia doesn’t necessarily mean that a person will need to stop driving immediately. In most States and Territories drivers or their families have an obligation to tell their licencing authority of any medical condition such as dementia that might affect their ability to drive safely.*

## Driving with Dementia

*The prospect of having a driving licence cancelled can be extremely upsetting but the issue of driving and dementia has to be addressed because dementia can affect driving ability in a number of ways, including:*

- Finding your way around
- Remembering which way to turn
- Judging the distance from other cars and objects



## Robert

### Queensland

*“Are we the only people in Australia facing these problems?”* Karen

#### Main issues

- Long and complex diagnosis
- Financial burdens
- Long distances to specialist appointments
- Stress placed on wife and family due to the decline in Robert’s health.
- Age – access to services including assessment, diagnosis, treatment and placement for the younger person.

I am the wife of a 43 year old man who has been diagnosed with younger onset, frontotemporal lobe dementia. We live in rural Queensland, have two adult sons and two grandchildren.

My sons first noticed the changes in their Dad’s behaviour on a deep sea fishing trip. Robert began repeating stories word for word to anyone who would listen. Later he began playing practical jokes, often unsafe, to the extent our grandchildren, whom he adores, became quite frightened of him.

Eventually Robert lost motivation, which was uncharacteristic as he had always been a hard worker. Our GP was indifferent and queried depression and sleep apnoea which was investigated. Before long, his employer approached me about his inability to complete work tasks. He has not worked since. An application was made to Centrelink for payment, but with no definite diagnosis, the application was denied. Centrelink payments started five months after our initial application.

After countless referrals and specialist’s appointments, often involving trips of up to 400 kilometres from home, Robert was still being treated for sleep disorder. Robert was trialled on several different types of medication to no avail. In desperation and frustration with lack of continuity, assistance and blasé attitude to Robert’s condition, we attended the local hospital again after he became extremely agitated. Robert’s medication was increased, but with little effect.

Four months after Robert finished work we started

to receive superannuation payments. This involved endless paper work and a monthly visit to the GP, to also complete paperwork. This assisted to relieve our hardship but by this time my frustration and exhaustion had reached critical levels. Robert was admitted to an extended care unit in Brisbane for two weeks for assessment and medication review.

Robert’s driving licence was cancelled but he had difficulty in understanding the concept of no longer being able to drive. Robert started wandering and in one instance took a neighbour’s car from their garage and drove to my parents home some streets away. This was traumatic for everyone concerned but would have been worse had we not lived in a small rural community, where most were aware of his condition.

Robert and I have been married for 25 years. He has been in care since November 2008 as his behaviour and day to day needs became too challenging and exhausting for one person. My sons and I brought Robert home for Christmas but found he was no longer interested in family or friends. In the short four day period he was hospitalised for one night due to insomnia and behavioural problems.

We can no longer live together, but because we are married Centrelink takes my wages into account when calculating Robert’s pension which I need to pay for Robert’s placement. I need to work to support myself. I have reduced my hours so not to interfere with his pension and allow flexibility to visit him. Robert is in care in Brisbane awaiting placement closer to home. The 800 kilometre round trip is taking a toll on me and my family both emotionally and financially.

This is a very brief account of our ordeal. The process from onset to present has taken fourteen months but living through the progression has been arduous.

**Karen**



## Annette

*Annette ALTREE-WILLIAMS is a retired science graduate with work specialisations in Pathology and Occupational Health. Her last years in the workforce saw her as editor and co-author of the Australian Encyclopedia of Occupational Health and Safety, published by Standards Australia in 1998. Four years ago, at age 55 years, Annette was diagnosed with Alzheimer's.*

### Main issues

- Abrupt reduction in short-term memory
- Affected many other life capabilities
- Impacted on management of diabetes and heart disease

I was born in 1949, married for 38 years and have two adult sons. I have been an insulin-dependent diabetic since the age of 3 and have had heart disease for 22 years. I had never missed an insulin injection (4 per day) or doubled up on one. Suddenly in 2004, I found myself forgetting an injection and, on occasions – particularly when tired, forgetting I had already had my needle and injecting twice. I only discovered the mistake when my husband, Stephen, brought me out of a severe hypoglycaemic reaction.

I was the co-author and managing editor of the *Australian Encyclopedia of Occupational Health and Safety*. It was during the time of embarking on the second edition of this book that I found myself lost, unsure of what to do and how to do it. Eventually my fellow two authors agreed with me not to go ahead with the second edition.

I have embroidered all my life and in the 10 years prior to diagnosis had learnt needle lace and bobbin lace. Suddenly, I couldn't remember how to undertake needlework and lace projects.

### Diagnosis

By early 2005, I had become increasingly concerned about my memory. I found myself missing appointments, both social and medical, which was uncharacteristic.

I mentioned my memory problems to my GP (of many years standing) who made the preliminary diagnosis of dementia after testing over three consecutive visits. I said nothing until I got back in the car and then began to cry and questioned

Stephen: "Does this mean that I have dementia? Only old people get this and I'm just 55. I think it's a mistake." Referral to a geriatrician followed with a further battery of memory tests, blood tests, MRI scan and an ACAT assessment. Shortly after my ACAT assessment, my geriatrician diagnosed Alzheimer's.

### Living On

Unfortunately, I discovered it was not a mistake and there was no magic cure. In a similar way to my experiences with diabetes and heart disease, I got on and developed my own means of coping. My GP suggested it would be of value to seek help from Alzheimer's Australia. With the support and help from these wonderful people things have improved for me.

On bad days when I feel tired and unwell it may take me longer to find something to do that I can cope with. On other days when things appear normal the basic cross-stitch embroidery or bobbin lace activity works out well. Often what I do does not always appear in the pattern sheet but if it looks alright it remains.

I have developed a tick-box list of all my medications, including insulin needles and the times I need to take them. I tick each item as the medication is taken.

Although I wish I didn't have Alzheimer's, I have accepted it and life does still go on. Activities may take longer or I may forget all about them. I know all the people who mean so much will be there on this new life journey. It is important for anyone dealing with a person with dementia to understand that we still feel things deeply (such as hurt, rejection, criticism) and that we wish to be treated as before the diagnosis. **Annette**

## **Different needs of people with younger onset dementia**

A person with younger onset dementia will need extra consideration because the dementia appears at an earlier stage of their life when they are likely to be more physically and socially active.

When diagnosed the person may be:

- In full time employment
- Actively raising a family
- Financially responsible for the family
- Physically strong and healthy
- Have young children

Changed behaviours that are associated with dementia may be more difficult to accept and cope with in a younger person. For family members who are caring for someone with younger onset dementia there are a number of issues that may arise:

### **Loss**

The sense of loss for the person with younger onset dementia and their family can be enormous. Unplanned loss of income if the person with dementia was earning an income can be a major problem for the family. This can be made worse by the loss of the self-esteem that usually comes with working, and the loss of a purpose in life. Future plans, perhaps for travel or time with children or grandchildren may no longer be viable.

### **Caring**

The task of caring for someone with younger onset dementia can be difficult, and at times may feel a bit overwhelming. The first step is to contact Alzheimer's Australia in your State or Territory or the National Dementia Helpline to find out about Alzheimer's Australia services or support services offered by other agencies.

Some services, although aimed at older people, welcome people with younger onset dementia and their carers. There are currently few specialised services specifically for people with younger onset dementia.

### **Respite care**

Respite services need to be flexible to respond to the unique needs of younger age groups.

Contact a Commonwealth Respite and Carelink Centre on 1800 052 222 for help

### **Resources**

Further resources and information about younger onset dementia are available at [www.alzheimers.org.au/youngeronsetedementia](http://www.alzheimers.org.au/youngeronsetedementia)



**Alzheimer's  
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Living with dementia

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An Australian Government Initiative