

**UNDERSTAND ALZHEIMER'S  
HELP AUSTRALIA**  
FIGHTDEMENTIA.ORG.AU

# **THE LONG AND LONELY ROAD**

*Insights into living with  
younger onset dementia*

Alzheimer's Australia

This publication was made possible by an unrestricted grant  
from Janssen-Cilag

# CONTENTS

<b>INTRODUCTION .....</b>	<b>1</b>
<b>FRANCES AND BRADLEY .....</b>	<b>3</b>
<b>ANNETTE AND CHRIS .....</b>	<b>4</b>
<b>KAYE AND DAVID .....</b>	<b>5</b>
<b>RON AND SANDY .....</b>	<b>6</b>
<b>ELIZABETH AND ALLAN .....</b>	<b>7</b>
<b>MAVIS AND PHIL .....</b>	<b>8</b>
<b>DI AND JOE .....</b>	<b>9</b>

# THE LONG AND LONELY ROAD

**This collection of case studies provides some insights into living with younger onset dementia.**

**Alzheimer's Australia is grateful to all those who have been willing to share their experiences.**

**There is no cure for dementia. Commonly, people associate Alzheimer's and other causes of dementia with 'old age'. This is not so as these stories demonstrate, and the trauma of dementia may be even greater when it occurs in younger people.**

The most common response made when the word dementia is mentioned is: 'old age'. One person, diagnosed with dementia at age 58, put it quite well when he said it was because we still think of it in terms of the phrase 'senile dementia'.<sup>1</sup>

There is no quick or easy fix to change these cultural and cross-generational associations between age and dementia, but the best place to start may be with the medical profession.

Indeed, one of the most frequently voiced concerns of people in these case studies relates to the average doctor's lack of knowledge and understanding about the various forms and symptoms of dementia.

*"Getting the diagnosis is so important and that doctors understand.... When David was diagnosed by the specialists, our GP said 'I can't understand it, he's too young."*

**Kaye, whose husband was diagnosed with dementia at age 53**

For many people, this lack of recognition of the signs of dementia in younger people causes considerable stress.

When there is not an accurate diagnosis, much time (and money) may be wasted trying to link behavioural and other problems with the wrong causes.

---

<sup>1</sup> It is equally incorrect to assume that dementia is a natural part of ageing.

Even when specialist medical practitioners are involved, such as neurologists, there is sometimes a lack of appreciation of the outward signs of dementia. People with dementia and their carers understandably get angry and frustrated if their personal and daily observation of behaviour changes and loss of skills are dismissed because scans and other technological tests do not support them.

As one of the contributors to the case studies said after waiting almost a year for his diagnosis: "At long last I know I have something – that I am not going mad".

Early diagnosis is important to the person with dementia, their families and carers for a number of other reasons. It enables, for example, planning of finances and future care needs. Advantage can be taken of medications now available that benefit the majority of people in the early to moderate stages of dementia. There is no cure for dementia but the quality of life for many will be improved for a period with these medications, through improved cognitive function and increased capacity to cope with every day life.

**Alzheimer's Australia believes that there are now some 24,000<sup>2</sup> people under the age of 65 with a diagnosis of dementia in Australia. There may be many more with undiagnosed dementia given the problems reported with early diagnosis.**

For people diagnosed with dementia at a younger age and their partners, there are many very personal and difficult emotional issues to address. The burdens imposed by a breadwinner no longer being able to work often seem insurmountable. The household suddenly has to come to grips with substantially reduced income, creating extreme concerns about matters such as mortgages and the costs of everyday living. These worries are made worse when there is a young family involved - with children at home and dependent on their parents.

In short the family environment is changed forever with a diagnosis of dementia. In many cases, children find it more difficult than their carer-parent to come to terms with the fact that their other parent is no longer the person they have depended on all their lives.

---

<sup>2</sup> Dementia in Australia, AIHW, 2012

In some cases, the ill parent may no longer recognise his or her own children – a potentially traumatic situation for a young child or teenager to have to cope with.

Even worse is the fear that the dementia may be of a genetic origin, creating considerable fear within the family – a fear that is real for relatives beyond the immediate family. In these situations it is critical to have properly trained, compassionate and understanding counsellors who have experience of the stress that dementia brings.

*“You expect this sort of thing only happens to older people. You can’t take it in – you can’t visualise what’s going to happen. That’s why I think counselling is vitally important. You’re trying to cope with loss of income, possible loss of your partner and, as well, loss of freedom.”* **Chris, carer.**

For the carer, there is the emotional distress caused when long planned holidays, or the enjoyment of a normal retirement, suddenly are no longer possible. Instead, a spouse or partner becomes a full-time carer, often without proper guidance and help.

Carers may find that their friends ‘drop off’ and, while they may still need to work for financial reasons, they can only do so part time because their work availability is restricted. Social isolation and a 24 hours each day caring role can leave carers emotionally and physically exhausted.

As one carer who took part in these case studies put it: “I look out of the window and I see all these people living in a normal world and I want to join them, but I can’t”.

With younger onset dementia, the carer’s role may be made more difficult by the demands of a person with dementia whose physical fitness is unimpaired.

Regular activity is a necessity, but appropriate day-care programs are not always readily available and younger people with dementia frequently have to join in groups of older people whose physical needs are usually different. In these situations the result is likely to be increased irritability or other behavioural problems, including aggression. When this happens, the ‘offender’ may be asked to leave the group - throwing him or her back on the carer spouse or partner.

The eventual placement of a person with dementia in residential care will be traumatic for the person with

dementia, their families and carers. The trauma of this experience can be exacerbated by the problem of accessing appropriate care and the additional financial strains it can involve. The carer will often want to go on being very much involved but whether this is made possible will depend on a good partnership with staff in residential care.

Through these case studies we can sense that every person with dementia is a unique individual who has individual needs and relationships. Those with younger onset dementia are, for example, in an age range where they are more likely to relate to the Rolling Stones and Elvis Presley than Vera Lynn and Bing Crosby. But whatever their likes and dislikes, the point is that they are individuals.

Today, greater scope exists for medical interventions and care management that enhances quality of life for people with dementia, their families and carers. There is a much greater appreciation now of how effective care interventions can be managed. Terrible though Alzheimer’s and other causes of dementia are, the message is that with a positive approach the quality of life for many can be improved for at least a time.

**FOR INFORMATION AND  
SUPPORT FOR PEOPLE  
WITH DEMENTIA, THEIR  
FAMILIES AND CARERS  
CALL THE NATIONAL  
DEMENTIA HELPLINE:  
1800 100 500**

## FRANCES AND BRADLEY

*“Nobody wants to be confronted with the fact that they are losing their abilities. They’ve got to acknowledge the problem themselves and that’s the only way they can feel as if they are still in some sort of control over what is happening to them.”*

**Frances’ husband Bradley was diagnosed with Alzheimer’s at age 59.**

“Bradley was a Mechanical Engineer and had run three businesses. He would write up computer programs and set up all kinds of systems” Frances recalls.

At age 56 Bradley began to get pains in his head, shoulder and arm. His hand was weak for a long time but a neurologist found nothing untoward. Later he noticed his ability to process information declining and he was starting to get slower and slower. By 1999 costings for jobs that used to take him two days were now taking a month. “In effect he was getting two days wages for a month and that was affecting us financially” said Frances.

“About the middle of 1999 he had a genetic test done that showed that Bradley had Alzheimer’s. It took a long, long time to get the results, more than six months. The Doctor wasn’t concerned which type of gene he had. Frances said “From our point of view it helped put aside our fears, knowing the type of gene he had showed Alzheimer’s didn’t run in families”.<sup>3</sup>

When they were told Bradley had Alzheimer’s Frances says there were mixed feelings. Bradley said he was disappointed to find out he had something that wasn’t going to go away, but at least there was the knowledge there was something wrong - that he wasn’t going insane.

Frances said “For me it was depressing – being confronted with something that was only going to get worse, not better. We had been looking forward to Bradley stopping work sometime so that we could do the things we had been talking about.”

Frances believes that Alzheimer’s Australia has provided an important support base for her and Bradley. “Once you get into a structured group with a counsellor or some professional person who can give you information and advice, it creates a very good and understanding support system. It means you’re in a group with people who have similar problems to your own.”

Frances said “We still do quite a few things but, for instance, the thought of travelling overseas would be really hard to contemplate. Bradley obviously feels more comfortable in his own familiar surroundings – at least he knows where everything is.”

Frances said that while they have no real financial concerns, she has had to learn to manage a dramatic lifestyle and emotional change. “I try to let Bradley do things on his own, but when he’s obviously having difficulty working something out, I haven’t quite worked out how to always react and direct without getting annoyed. I find though, if I try to give too much direction, I might as well have not tried at all because it just becomes confusing for him. The simple message is the best.”

For Frances, her ideal would be for Bradley not to have to go into residential care. “We would like to be able to have the sort of help that would enable us to stay in our own home. It is also very important for carers to have respite available so that when they need to they can get a break, knowing that their partner is being looked after properly”.

Frances’ final advice is to be realistic and positive. “My attitude is to enjoy doing the things you do and don’t bother yourself with the things you can’t do. I like to think I’m responsible for what happens in my life and try not to let things that happen outside my control get to me.”

---

<sup>3</sup> A number of variants have been identified which run in families.

## **ANNETTE AND CHRIS**

*“You’ve lost the person you love. There is still a person there, but you’ve no idea who that person is.”*

**Annette’s husband Chris was diagnosed with Alzheimer’s disease at age 55**

Annette has been living with Chris’s illness for more than 15 years and is very concerned about the future – for herself and for Chris.

“I need placement for Chris now. He needs to go into residential care. There are no appropriate residential facilities for this minority group with younger onset dementia. I’m tired and I’ve forgotten how to function in the normal world. To keep Chris in a calm environment everything’s got to be structured. The burden of care has become too great and I am desperate to regain my life.”

Although she has support with day programs and “a carer comes in five times a week to shave and shower him” Chris exhibits challenging behaviour which can be impossible to address.

A major issue for Annette is their financial situation. Chris was retrenched at age 55 and was not paid out his full superannuation. Annette had to engage the services of a solicitor for this entitlement to be paid. Unfortunately not all entitlements were paid out. Due to the caring role she also had to cut her hours in the work force to a minimum. Because of Chris’s illness and the cost of maintaining the home she decided to sell and downsize to a unit.

Annette and Chris, like so many others affected by younger onset dementia, spent a long time trying to get a diagnosis. GPs in particular tend not to recognise that younger people can have Alzheimer’s disease. “You know that something is wrong but don’t know what to do or where to go. Chris went to the doctors many times. He was prescribed vitamins and advised his problems were due to stress.

“It was almost four years before Chris was referred to a neurologist. I was advised that Chris had a mild memory problem. Neither the GP, the neurologist nor the neuropsychologist informed me about Alzheimer’s Australia. Alzheimer’s disease was not mentioned.”

“We actually got help from a clinical trial of a drug that was advertised for younger participants. Chris was tested and accepted and finally they said he probably had Alzheimer’s disease. The doctor in charge was extremely supportive and put me in touch with Alzheimer’s Australia.”

Annette says that Chris enjoys going to his activity groups, but even this presents worries for her. “When younger people with a need for physical exercise get into groups with older, frailer people they become frustrated and show challenging behaviours. You can then get a phone call saying they can no longer attend the day care programs. If Chris can’t attend the programs, then I can’t cope with him at home. I live on the edge waiting for the phone call”

“I look out the window and I see all these people living in a normal world and I want to go and join them but I can’t. Chris’s focus is on me – I’m his security blanket and I have no private space. He can’t watch TV, he is unable to read and it is very difficult to meet his needs.”

“The current situation is that day programs closed on Chris and he was assessed as unable to fit into mainstream care. He is currently placed in the ‘mental health system’, in an interim ward for the frail aged.”

“I spend many hours each day meeting Chris’s special needs. Unfortunately I have had to retire from the workforce due to my depleted physical energies and ongoing burden of care.

My endless journey still continues ... when can I regain my life?”

## KAYE AND DAVID

*“I used to associate dementia with old age. I had never known anyone young with dementia before David.” Kaye*

David was a successful executive with an importing firm. He had suffered with severe depression and had been on medication for years but, after the family moved to Perth for David’s work, his wife Kaye began to think there was something more seriously wrong with him.

“At the start, maybe he did have some idea that he had dementia but he was not admitting it. He knew he wasn’t coping but he couldn’t see why. He’d go to work every day but it didn’t seem to click that he wasn’t doing his job.”

“Those times were a nightmare. We never knew from one day to the next what to expect.”

“When you have a successful man at the peak of his career who suddenly is unable to be the breadwinner, it is distressing but understandable that he is most likely going to take out his frustration on those nearest and dearest to him”, Kaye says.

“The company was marvellous. They kept him on until one day I received a phone call saying that David shouldn’t come in any more. Unfortunately it was left to me to tell him.”

Eight years after moving to Perth and a three-year constant round of trying to find the underlying cause of his problems, David was finally diagnosed with fronto-temporal dementia. David was just 53 years of age.

“Getting the diagnosis is so important and it is also important that doctors understand how to manage their patients. When David was diagnosed by the specialists, our GP said ‘I can’t understand it, he’s too young.’”

In order to be closer to the rest of their family, Kaye, David and teenage daughter

Tory moved to Canberra where Kaye became full-time carer to David.

David had always been keenly involved with cars, but now he had to give up driving. “At first he wouldn’t accept it, but he seems to have come to terms with not driving. It’s been a long slow process and it’s only now that he’s accepted he’s got dementia.” Kaye says.

“He takes the dog for a walk on one particular route and I’m tempted to go with him in case he loses his way. But if I do that it will take away the one little bit of independence he still retains. It’s a constant battle all the time. How far do you let him go – before you say, no, you can’t do that - or that’s not quite right?”

“Probably in the last 12 months his language has started to be affected whereas, with Alzheimer’s disease, language is affected earlier. He doesn’t initiate any conversation and it’s very demeaning for him not to be able to find the words to explain.”

“I guess we’re very lucky here because Alzheimer’s Australia gives a lot of support. I know lots of cases where people are not so well supported and they don’t get the care we do. Without the support Tory and I have received from Alzheimer’s Australia there is no way we could have coped.”

“It’s all those little things of everyday life we take for granted until something like this happens. It’s frustrating and very emotional, but you get to understand a person in a lot more different ways. When something like this happens you get to talk to each other and relate to each other differently.”

“You get highs from little things. Like the first time that David actually laughed at himself or laughed at something. I hadn’t seen him laugh at anything for probably two years.”

## RON AND SANDY

*“He’s very determined that he’ll do absolutely everything he can. He tries very hard.” Sandy*

Ron was just 56 when he got his diagnosis. Sandy recalls that for the previous 18 months it was very frustrating for both of them.

“It was an accumulation of the little things like losing concentration, withdrawn, non-communicative, losing things. One day he lost a chequebook – another time I sent him down to the bank to deposit some money and he somehow put it in the wrong account.”

“Ron had been under a lot of stress in his job in local government which was very high profile. He finally had to resign and it was very traumatic.”

Ron knew there was something wrong but he wasn’t able to handle it. “My doctor said it was low testosterone - which he treated, but it didn’t do a damn thing.”

Ron and Sandy decided to move to Canberra to make a fresh start. Sandy’s wish was for Ron to find a middle level management job – not too much stress. “We’d buy a house and do some travelling. We’d be able to live very nicely on his navy pension. He’d been quite high in the navy when he retired.”

“But he just fell to pieces. Just to go to the corner store he’d get lost.” One day he went to golf and he didn’t come home. Sandy and her mother, who lived with them, didn’t know where to start looking and finally he rang, very distressed, from the local shops. This was the trigger for getting him to a neurologist who gave him the proper scans and, finally, the diagnosis. For Ron it was a relief. “I knew I was not going mad, that I had instead an illness.”

While Sandy recalls Ron as being “quite thrilled” about the diagnosis, her first reaction was quite different.

“I saw my whole future gone. I just saw all of our plans going. But, once you get over the initial shock and start seeing the possibilities, it does get better.”

Ron and Sandy are both involved with Alzheimer’s Australia. Sandy says she couldn’t have survived without the support and the activity programs they provide.

For Ron, the main message is activity. “In the Alzheimer’s groups they say, ‘we’ve gotta get you guys out there and doing something and working your brain ‘cause you lose your brain if you don’t do it.”

“I get angry and wish I didn’t have my illness but I’ve got to get out. A lot of these people all they’re doing is sitting down and doing nothing. And that just irritates the hell out of me.”

“If I didn’t have these groups, Sandy would go bananas. It’s harder on her than on me because I know what’s going on inside my head – she doesn’t.”

“I know things have changed over the time since I was diagnosed, but I’m happy with it. I don’t get frustrated – well sometimes I do when I can’t do what I want to do.”

Sandy agrees. “The thing that bothers me most about Alzheimer’s is you lose your ability to learn. It may sound cruel to an outsider but I make him do things that he can still do. I’m afraid that, if I don’t, he will lose even those basic skills.”

“I accept that as he deteriorates I’ll have to reassess. As far as the future is concerned, I don’t know.”

“The biggest issue right now is time alone. When I have time alone I can sort of re-charge and I’m better with him then.”

## ELIZABETH AND ALLAN

*“My experience in nursing gave me a good understanding of dementia, but I am now able to view the problems from a different perspective.”*

**Elizabeth, whose husband Allan was diagnosed with Alzheimer’s at age 54.**

Allan was diagnosed with Alzheimer’s in 1997 and is in full-time institutional care. Like others, arriving at the final diagnosis of Alzheimer’s was for Elizabeth and Allan a prolonged and difficult process, with initial opinions being that Allan was suffering from depression.

A key issue for his wife Elizabeth is the lack of adequate training in dementia care in institutions.

“While Allan is well looked after - it’s a new facility and the hygiene is excellent - there are not enough people with dementia training. You have to have people with basic dementia training and, importantly want to do that type of work. Having good carers – it’s like getting a good babysitter.”

Elizabeth also has concerns about the role families play in institutions.

“They don’t embrace the family. They think they do, but they don’t realise that with dementia they are getting the whole family - where we are all concerned about what kind of care the person is getting. This can be demanding stuff, but the plus is that the family’s services can be utilised.”

“I’d like families to be made to feel part of the team - being more welcomed. In paediatrics and midwifery they’ve embraced the family, but it hasn’t quite spread through other facets of medicine and certainly not with mental health - because they’re a bit of a law unto themselves.”

Allan’s dementia has been more severe than many younger-onset cases.

Within three years of having to leave work because of non-performance, he had reached the stage where he had to be showered and dressed and had become incontinent.

He was attending day care programs, without which Elizabeth says she could not have coped, but his behavioural problems led to him being rejected by them one by one.

He then went into a nursing home for respite where, despite its security, he got out on more than one occasion and headed straight for a nearby beach. Elizabeth says they couldn’t cope with Allan because he wasn’t happy being there. As a result he would get angry and become difficult to control.

“I realised that there was no way he could stay there, but the mental health system was the only place that would take a person like him and that’s where he’s ended up – in a mental health ward.”

Elizabeth says she would like to see more of the available money put into home care support, because she says, it keeps more people happy.

“Most feel more at ease at home. But where it falls down is in the day-care centres which, generally, are not equipped to deal with challenging behaviours. The minute someone causes trouble, you get a phone call saying don’t come back. So where do you go? No matter how much you love them you can’t get away from that 24 hour care. If you get the right sort of care, then it’s much easier to cope and you can go on for a while.”

Elizabeth says she’s found her focus in being a member of the local council. “That, and the research effort that I’ve put into my belief that Allan’s dementia is caused by excess iron levels in the blood (haemochromatosis). These interests have helped me cope with things.”

## MAVIS AND PHIL

*“I try and utilise the abilities I still possess. If you accept the fact that you are suffering from memory loss, then you can deal with it.” Phil*

“I was about 50 at the time and I was also feeling that my judgment was sometimes failing me. But you try to give yourself reasons for these lapses. Perhaps it’s just laziness, overwork. Perhaps it’s just getting older. My doctor said, ‘Don’t worry Phil, we’re all getting older.’”

Phil was a senior member of the scouting movement and used to give a lot of talks – he says he used cards as cues for the points he wanted to make, but then he started to forget some of the points.

Mavis first became aware in about 1994 that Phil had a problem.

“One day he would remember something and the next day he would forget it. I just thought it was tiredness, maybe the ageing process. When I look back, there were signs. He would forget the grandchildren’s names, or he would forget his own sons’ names. He would cover it up by saying ‘number one son’ or ‘number two son’.”

“When, in 1996, he finally got the diagnosis, I was very worried because the neurologist told me he had five to seven years to live. I thought, I’ve got to start dealing with this and my first reaction was to come home and phone Alzheimer’s Australia to get help and find out about Alzheimer’s – because I didn’t know anything about it. Now, I know pretty well what’s going on and how the disease is going to progress.”

“My main role as a carer is to try and keep life on a pretty even keel. I guess that, as the disease progresses, I will have more contact with carer support groups and probably with Alzheimer’s Australia. There we can discuss our common problems and find solutions that help each other.”

For Phil, rejection has been one of his major problems. “I don’t have a great many friends. There tends to be a ‘pushing away’ when you find out you have an illness – perhaps they fear they’ll catch it from you. It’s caused by a lack of knowledge of dementia and, to a certain extent, fear.”

“The popular view, through movies and TV mainly, is of people sitting in a wheelchair, staring out at the wide blue yonder, dribbling at the mouth and unable to recognise or communicate. When people see that they assume all people who have dementia are in that stage. These are the stereotypes and we need far better (public) understanding”

Phil’s dementia has progressed very slowly, thanks to a trial drug he has been on for several years and Mavis says she is able to cope quite well but she worries about what will happen when Phil finally has to go into a nursing home.

“If you’ve got the money there seems to be no problem, but there are so few ‘free beds’ available at the moment that you could be on the waiting list forever.”

“But, I try to remain positive and take each day as it comes and I try not to think too far ahead. Up to now I’ve found it fairly easy. I guess I’ve been fairly fortunate with how well Phil has been in the last five or six years.”

Phil agrees. “It’s like a person who is an alcoholic. Until they say ‘I am an alcoholic’ they can’t deal with the illness.”

“The abilities I have lost – they are still pleasant memories – they’re part of history. If you can accept this, you can then work out ways of dealing with it.”

## DI AND JOE

*I'm still teaching two days a week and that's important. It gives me the break I need.*

**Di, whose husband, Joe, was diagnosed with Alzheimer's at age 54.**

Di remembers the first signs of a problem were in 1997 when Joe began to have difficulties with his short-term memory. At the time, she says, she didn't worry about getting medical attention because, "You know, I thought, we're getting old – that sort of thing."

"I could relate to myself doing similar sorts of things although perhaps not to the same extent. Then a friend suggested it could be something else, but maybe treatable. So we went to a specialist and Joe went through all the tests, scans and so on, really detailed. It took almost a week doing it."

"The diagnosis at that stage was that it could be depression, but I had my doubts. Joe had finished working and I knew he was looking through the job ads and cutting them out, so I thought maybe he was missing the work routine and was not adjusting to retirement."

Joe had been an Olympic rower and was doing voluntary rowing coaching, so Di suggested that, as they were financially secure, Joe should not worry about working and just keep on with the coaching.

It was another friend who suggested Di and Joe should seek a second opinion and, after consulting a doctor who was doing research work on dementia, it was he who identified Joe's problem as Alzheimer's.

For Di and Joe, the diagnosis was a shock - as Di says, "We basically knew what the future path was and we were a bit upset."

"As far as getting any real guidance for planning the future was concerned, we didn't get all that much help from the doctors."

"It has been Alzheimer's Australia that has helped us pick up so much information and how to cope. That has been really important. The other thing is that you don't feel isolated, because you meet other families and see how they are coping. To me, some of them were having more difficulties and more complications than we were."

For Di, it is the emotional effect on her and her children that has been one of the harder aspects of Joe's illness. "I acknowledge it", she says, "But I try not to dwell on it."

"It is sad that sometimes he can't remember things in the past although it helps in that you do get warning signals. Something might happen and not happen again for a month. Then you realise he can't do that anymore. You know you are going to have to make some changes, so the next time it happens, we'll do it another way."

One of the biggest disappointments for Joe was having to give up driving. "He really did enjoy it", Di says, "But I could see that while he did still have some skills, his ability to carry out a sequence of tasks, like indicating, was gone."

Di sees her main role as carer for Joe is to try and find things that he enjoys doing.

"Joe doesn't watch much television, apart from sports and then only for half an hour or so before his attention goes, but he seems to like going to the movies. And he is still very physically active. Everybody at the Alzheimer's groups seem to be impressed by the fact that he still plays tennis and golf and does a lot of bike riding and walking."

Di's advice for carers is simple. "Keep doing the things you enjoy. If something's working, keep doing it. Make these things the highlights – but also be realistic."

And finally, "Carers need to look after themselves if they are going to look after someone else."