



An Australian Government Initiative



The Good, The Bad and The Brilliant



Lessons from the journey of living with dementia

A Dementia Community Grant Project

An Australian Government funded project helping Australians with dementia and their carers



The Good, The Bad and The Brilliant – *lessons from the journey of living with dementia*

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Images in this book are for illustrative purposes. Persons appearing in photographs are not necessarily people living with dementia. Image page 30 and repeated back cover courtesy K Swaffer.

Aboriginal and Torres Strait Islander people are advised that this publication contains reference to a deceased person.



Foreword

Living with dementia can be complex. The experience of being the person who supports the person living with the condition is also complex. As Australians live longer lives, more of us will experience dementia, either through having the condition or caring for or knowing someone who does.

Like so many Australians, I have been closely touched by dementia, and as I read the personal stories in *The Good, The Bad and The Brilliant*, there were many things that resonated with my experience.

Arising from conversations with a number of carers and people living with dementia, this document aims to capture the uniqueness of each journey, while exploring the shared experience.

As the authors point out, many people talk of the experience of living with dementia as a journey. They also observe that no one on the path ever planned to take the journey, or spent much time thinking about what it would mean to them. This means that when a person finds out that they have dementia, or that their partner, family member or friend has dementia, they want to find out more – there are so many questions.

I believe that reading this document will be of great help and encouragement to those starting, and already on, the journey with dementia. As they read the words of the people who are living or have lived the experience, they will be able to connect, and it will answer some of the questions that people ask. It points to some of the challenges that are likely to arise, but also emphasises the room for positive and happy moments.

This cohesive set of personal stories comes together as a balanced narrative that explores the good, the bad and the brilliant along the way. It should be read by all people touched by dementia, and even those who are not.

Sue Pieters-Hawke
Sydney
24th May 2012

Each journey is unique



Acknowledgements

The ideas in this book have been gathered from interviews with 17 people; carers and people living with dementia – those most capable of telling how it can be done; the expert informants; those with the lived experience. Participants came from diverse backgrounds and had a wealth of information and knowledge to share. They included women and men, were from a range of ages and came from metropolitan and regional areas. Each person was open, honest and willing to tell their story. It was not always an easy task for people to talk about their experiences but they did and, in their telling, stories arose of regular, everyday people who were experiencing and doing extraordinary things. We acknowledge and thank every one of those individuals.

Thank you to the members of the project steering committee: Valerie Sandlant, Philip Ellison, Sue McKechnie and Lynn Openshaw, Resthaven; Alison McLeod, SA Health; Rosie Ranford, carer; Deb Treherne, Alzheimer's Australia SA; Rosa Colanero Multicultural Aged Care and Tracey Watters, Palliative Care Council SA.

Thanks also to Norman Radican, of Alzheimer's Australia SA, for reading drafts and contribution of comment.

Philip Ellison and Valerie Sandlant

Snapshot of the people who were interviewed

Christine Bryden has younger onset dementia and her husband, **Paul**, is her carer or, as they say, he is Christine's enabler. Christine has had dementia for 16 years and also tells her story through being an author.

Pam Correll was the carer for her husband, **Phil**, who lived at home before moving into a residential aged care facility. He spent the last weeks of his life in hospital, dying in 2011 from younger onset dementia, of the Alzheimer's kind. Pam is still the carer for her mother who has vascular dementia, and lived in her own home before moving into a residential aged care facility in early 2012.

John Harris is the carer for his wife, **Marge**, who lived at home with the support of some in-home services and respite until early 2012, before moving into a residential aged care facility.

Colleen Kirby is the carer for her husband, **Patrick**, who lives at home with the support of some in-home services. They remain closely connected with their friends through their joint love of music.

Ron Klose is the carer for his wife, **Shirley**, who has lived with dementia for more than 10 years. Shirley lived at home with Ron, until moving into a residential aged care facility in 2011. He remains her carer and misses her living at home.



Carla Mastrangelo is the carer for her mother, **Angela**. Carla's parents migrated from Italy before they met and were married in Australia. At the time of the interview, Carla was committed to keeping her mother living at home. However, due to her own health issues, Carla made the difficult decision for Angela to move into residential care in late 2011. Earlier, Carla and Angela had been carers for Carla's father and Angela's husband, Francesco, who lived at home with dementia before moving into residential care. Francesco died some years ago.

Jenny Potter is carer for her husband, **Ralph**, who has younger onset dementia and was living at home when Jenny was interviewed. While Jenny was committed to Ralph living at home and not being separated, she has found that she is no longer able to support Ralph at home and he is now living in a residential aged care facility.

Rosie Ranford lived with and cared for her mother, **Margaret**, and her father, **Reg**, who both had dementia and died at home. Rosie had substantial support from her family and from community services, which enabled her to continue to work full time.

Chris Smith was the carer for her Aboriginal husband, **Stan Karpany**. Stan had dementia and lived at home until he died, in 2011. Chris and Stan had five children together and the youngest three, aged under 18, still lived at home.

Kate Swaffer has younger onset dementia, remains living at home and is supported by her husband, **Peter Watt**. Kate and Peter are committed to Kate remaining living at home and living a full life. Kate challenged herself to write daily in a blog on the internet as a way of documenting and exploring her experience.

The following participants are identified using pseudonyms to protect the privacy of individuals.

Edith was the carer for her husband, **Bill**, who was of Greek descent and grew up in Egypt, before coming to Australia and settling in Mount Gambier in 1951. Bill married his Australian born wife, Edith, in 1960. Bill died in 2011, during the writing of this book, after two weeks in a residential aged care facility.

Eileen is the carer for her mother, who lived in her own home with Eileen's support and some community based packaged care services, before moving to live in a residential aged care facility in 2011.

Elizabeth is the carer for her mother, who has dementia and lives in a residential aged care facility. Elizabeth is a lesbian and identifies as a member of the gay community.

Gwen and her daughter were carers for Gwen's partner, **Paul**, until he died at home during the writing of this book.

Rae is the carer for her husband, **Don**, who lives at home. As a home mum Rae, with four sons, was also the carer for two of their sons who have disabilities. The last of their sons living at home has recently moved to supported accommodation.

There is a life to be lived



■ “You live until you die, don’t you?”

There is life after diagnosis

Dementia is something people are hearing more about. By 2050, it is estimated that 981,000 Australians will have dementia (Attwood, 2011). While dementia is not a natural part of ageing, the older you are the more likely you are to experience having dementia. Not all people with dementia are older, and some people are being diagnosed with dementia in their 40s and 50s.

This book has been written in the hope that it will challenge attitudes and the dominant belief that people get old, get dementia and need to move into a nursing home. The messages in this book may be of value to carers, family and friends, who want to support a person living with dementia to stay living at home until they die. It is also anticipated that it may be useful for staff working alongside people living with dementia.

The key message emerging from conversations with people living with dementia and their carers was that when someone is diagnosed with dementia, there is a life ahead; a life to be lived fully, until death. Kate Swaffer put it in simple terms: “Well, you live until you die, don’t you?”

Christine Bryden said, “People need to understand we had a life before; we have a life during. It’s not instant when you get a diagnosis that you’re no one. You’re never no one. You are someone all the way through.”

Peter Watt’s thought was, “You do have the time that you have now.”

“You can get carried away by the music.”

Colleen and Patrick share a great love for music. Patrick has a lovely voice and still sings. He remembers all the words to the songs, but can’t remember what happened five minutes ago. They have music playing in the house all the time. As Colleen said, “You can get carried away by the music.”

Colleen can’t imagine life without Patrick or without music. Sometimes, Colleen can see in his eyes that he is lost. She knows it is going to get worse but not how. She would like more information and believes it would be useful, but just hasn’t had the time to find it. She often lies awake in bed wondering what is going to happen. “You know something is going to happen and get worse in the future, but you don’t know. You just don’t know. I need to look into it rather than worrying about it. I do really want to know, but I just haven’t done anything about it.”

Keeping Patrick at home maintains their togetherness; he’s her husband and they, “should be together.” Having in-home respite has helped Colleen by enabling her to keep up with all her musical commitments.



Respecting the person living with dementia

Each individual is a person; with dignity, rights, feelings and the ability to connect with another human being. Participants expressed the value and importance of assuming that the person who is living with dementia is still a thinking, feeling individual, with the capacity to laugh, smile, cry, sympathise, empathise, feel joy and elation, hurt and humiliation. A strong theme emerged that what is wanted and needed by people living with dementia, and by those who support them and enable them, is the opportunity to remain engaged with life.

Each person with dementia has a life experience. Each person developed skills, capacity and expertise. Respecting individuals for their expertise enlivens them: “When you ask Paul a question about something technical, you can see his eyes light up.”

A person who appears to be quite disconnected and unaware to a casual observer might actually be very engaged. Carers are the closest observers of the actions and feelings of the person living with dementia. The connection is deep and well-informed. The carer is an expert in this area. “Most people just think that Ralph is at a stage where he would know nothing, but that’s far from it.”

Talking about any person while that individual is present is devaluing. This can cause the person with dementia to respond with behaviours of concern, which are often a response to being ignored. Behaviours are generally caused by pain or an unmet need; understanding this can change the way the person is viewed, and the response to the person.

“Start looking inside the person; we are still human. Yes, we struggle, but we are not less human because we don’t function as well,” said Christine, who lives with dementia.

“Each person living with dementia needs to have the best environment for them around them for their journey. We are quite vulnerable, as we go down this path with dementia. We all have different journeys and it would be an awful journey if we weren’t getting on well with our carer and family. A person’s experience of dementia is based in how people respond to us; our so called ‘challenging behaviours’ are often a response to what has been done to us. If in a stressful, unpleasant environment, we wouldn’t want to be there.”

Paul, Christine’s carer, added, “We must enable the person with dementia, as they still have heaps to contribute.”

It's a learning curve



■ The Journey

A unique journey

In interviews, people mainly described the experience of living with dementia or being a carer for someone living with dementia as a journey. People who were interviewed said that the start of the journey came as a surprise and a shock. Each journey is unique and there is no map. The road may have numerous detours and some blind alleys. There will be profound experiences: joys, sorrows, grinding exhaustion, elation, a roller coaster ride, attended by indescribable feelings of love and commitment.

“It’s a learning curve that becomes more intense the deeper you get into it.”

There are *good* stories of courage and determination. There are stories of *bad* experiences often at the hands of the system. There are stories of *brilliance*; of carers who gave everything they have in the quest for a better life for the person they support, and stories of sadness and feelings of guilt for those carers who could no longer care for the person, despite their dream, vision and hopes.

In the rare moments that the carer has to contemplate things, an understanding of how to support a person living with dementia emerges. The insights from these lived experiences are invaluable in helping others who find themselves taking the ‘journey’. For some, it is fast, for others, slow. Some people have lived with dementia for more than 16 years. “We were told that Ralph would be dead in five to seven years, but it’s been nearly ten years now.”

Dementia is not curable. However, medications may slow the progress of some types. As with many terminal illnesses, the person with dementia may die from something else, due to a weakened immune system.

Pam had an idea of where Phil’s dementia was heading, “We knew Phil had Alzheimer’s; no one spelled it out that he wouldn’t get better. When the doctor said, ‘I’m so sorry to give you this news,’ I had no idea it was going to be fatal, and yet seven years later, it was.”

Early signs

Typically, in the early stages of dementia, the person appears different or to be forgetting things that they otherwise might not forget. Sometimes they lose skills that previously came easily. A person’s emotional state or their capacity to cope with changes, noise, crowds and other stimulation, might change.

“I had been worried for probably about 12-18 months. For me it was his word finding. When he wanted to put together a sentence he would say, ‘Ummm, ummm,’ quite a lot and was unable to find the word. When driving, his judgement of where cars were was poor. Beforehand, he was a very social person. I noticed he was not joining in and would go off on his own. I found this embarrassing when we were trying to be sociable. Those were the areas that I really noticed.”

“In hindsight, in the beginning, Phil showed signs that things weren’t right. He could always give a plausible explanation for why something happened, but the little things added up.”



Diagnosis

For everyone interviewed, diagnosis was a key point in the journey. For some, it came as a relief; an opportunity to put a name to the condition and have an idea of what they were dealing with. For others, it came as a, “huge blow,” but, getting the diagnosis early meant, “we were lucky and he was put on medication straight away. I’m sure that has slowed down his decline.”

Some people described experiences with health professionals that they found challenging; often feeling their concerns were minimised or dismissed, or the condition denied. Some others reported health professionals who wanted to “tell it like it is”, and this was a negative experience.

“Shirley was diagnosed in April 2002, following 12 months of denial at the hands of medical professionals. They didn’t want to know. They didn’t want to recognise that Alzheimer’s was present. We did a circuit of ‘the commercial medicine’. We were referred to a psychiatrist who was very cruel. He said, ‘Well, you have got two to five years.’”

“It took three years from the early signs to diagnosis. It’s not like when someone has a stroke and they are immediately affected by it. I didn’t realise I was doing so much to help Phil cope; it was such a gradual decline. When he was diagnosed, I found it easier to put my head in the sand and live in denial. Our children made the first start and pushed for support.”

“I hear that, for people who have younger onset dementia, there are huge issues with getting a diagnosis. Some of them go on for years. For some younger people, the condition is misdiagnosed as depression. That’s what happened to us.”

“It was a challenging 50th birthday present, is all I can say. I felt a very deep sadness that I don’t really seem to feel any more.”

Some people described getting discouraging advice on diagnosis; that the person with dementia and the carer should ‘call it a day’, find a place at the first available nursing home, admit the person and wait for the end. People described the sense that they had been told that life was over now; that the person should lower their expectations of themselves.

“The impression I got was; drug him up, sit him in the corner and wait for the inevitable; look after him; give him what he needs. That was not Paul’s life. He was very active. He was intelligent. Just because someone has dementia doesn’t mean that they don’t have a mind and they don’t work things out. There are some amazing people with dementia; they handle things sometimes better than those of us who don’t have dementia.”

Christine had been having migraines for six years when the doctor did a brain scan and found significant signs of dementia: “It was there up in lights.” Christine was a senior public servant advising the Prime Minister on science and technology. The advice to ‘give up work immediately’ implied that she shouldn’t be in a ‘responsible’ job. She says that, at that point, she cried a lot; but she was a single mother of three, so had to get on with life. Christine has since remarried, and has been living with dementia and getting on with life for 16 years.

Thinking of the first signs of Stan’s dementia, Chris described an event that indicated something was different. “He was away camping with family and friends and he said he looked up into a tree, and saw a man in the tree, a tribal man, and all these birds just flew off as soon as this man appeared. Stan felt that spirit man had got him, and that’s where his trouble started. His friends had never seen

There's a lot of stigma attached to having dementia



him in that state before. He was upset and aggressive.” Chris said, “Even after this event, which was thought to be the result of a stroke, it took about 18 months before a diagnosis of dementia and a further two months after that to get any assistance.”

Rae told us that Don had always had trouble connecting with his two sons, both of whom had a disability. Rae feels it was their son Andrew, who has autism, who first recognised Don had changed, perhaps because Don became more affectionate. Rae thinks Don is lucky to finally have the opportunity to appreciate their son. Rae realised that there was something up when she and Don were on a bus trip interstate: “He was most peculiar; he was confused on the bus – not himself. Since he was diagnosed with Alzheimer’s, his mind hasn’t broken down that much, but his body has. It feels like he’s not my husband anymore. It feels terrible – frustrating. I feel very lost and very alone. We’ve been married for 57 years.”

Living at Mt Gambier made access to health professionals and eventual diagnosis more difficult for Edith and Bill. “City people don’t realise that country people don’t have access to things that might be needed immediately. Mt Gambier is a five hour drive from Adelaide. You have to go the day before the appointment and pay for accommodation. It’s a lot of time and expense, and so much travel.”

■ Where do we go now?

After diagnosis, most people sought information about dementia and learned as much as they could. Jenny said: “Ralph was very open to wanting to know what was out there for us. I think it was the next day he was up at Alzheimer’s wanting to know all about his condition and what help can we get; what’s out there for us. We found out about an education program and did that together, which was great for us. There were a few others in that group who became our support group following the course. We meet monthly. Support groups have been the most important thing for us.”

“It is important to have the knowledge of what is available, but how do you impart that knowledge on to carers? I did an eight-week course where lots of different guest speakers came and talked to us about their services. The group has formed a small support group and we meet monthly. From this, I’ve picked up one or two things.”

Following the diagnosis, Chris said, “We walked out the GP’s door, thinking, ‘Where do we go now?’ What do you do? You jump on the Internet.” She said it was hard to find support in understanding dementia and how to find services. She felt there was no coordination of information. Chris said that carers are too busy and too tired to manage all of the available services, and suggested that what is needed is a coordinated response; one person to be the main contact.

Chris believes it might be useful for carers who have been through the experience to assist carers new to the journey. “If you’re a carer and don’t understand dementia, issues arise. You need carers who have been through the experience to be a guide to people, and assist them to find help.”

Chris felt there wasn’t access to the right counselling that would, “understand the Aboriginal way.” She also felt that if she sought counselling through government agencies for herself or her kids, there would be referrals between agencies and no guarantee of privacy and confidentiality.

Pam said, “Everyone says help is out there, but where do you find it? As we went on the journey with Phil, Alzheimer’s Australia gave us tapes and DVDs, but I didn’t want to watch them. That



would have meant I was accepting his situation; how stupid I was! I did end up watching them later, but by then we'd gone beyond what they were saying. If I had watched them in the first instance, I could have learnt something."

Stigma

"There's a lot of stigma attached to dementia – probably as much, if not more, than with mental illness. I sent out emails to about 180 people. I got less than five replies. Then, when you want some help, you don't want to ask those people who didn't reply. You need to make new friends. Having dementia is a really isolating experience. Yet when I had a brain tumour my husband was inundated by enquiries. It was a big contrast. With dementia it feels like no one wants to know."

"When this first started, I can remember the horrified looks on the faces of the family: 'What's Dad done to bring this on himself?' At one stage nobody would accept Paul because he didn't fit in. He didn't fit any mould. He would talk incessantly and that was challenging."

"And then there's this idea that the person needs to be shut away and they must live in an institution."

"I thought that Ralph might be able to use the community bus to go to the supermarket, do the weekly shopping and come home on the bus. But as soon as it was mentioned that he had dementia, that was it. They just simply would not have him on the bus."

"As soon as that dreadful word 'secure' was mentioned [the residential aged care facility] didn't want to know me," said Ron.

"I told everyone close to us that Phil had Alzheimer's," Pam told us. Staff at the school where she worked were told, and the response from the principal was, "Are you going to resign?" She explained that she hadn't planned to and was asked, "Well how are you going to look after Phil and do your job?" These questions scared Pam; the idea that people thought having dementia meant the carer was immediately unable to work anymore.

Christine felt that, "Once diagnosed, you become a whole bag of things; behind a wall, totally to be feared, so much fear that people find it hard. A common experience is that this fear of the unknown results in a loss of friends and close acquaintances. I only have two people in my life now from my previous life, but we have made many new friends through me having dementia."

When thinking about attitudes to dementia, Christine reflected, "I get so angry with this: If people die with cancer, they've had a brave battle. But if I battle my dementia and fight it until the very end, it's not believed that I have dementia. It's not credible. I'm not supposed to have this illness if I can battle it, because I'm meant to lack insight. I've been trying to beat this for 16 years."

Being a carer

Being a carer is a life changing experience. It can be very fulfilling but has its challenges. The relationship between the carer and the person being cared for often becomes very close and it can redefine relationships in other ways.

Being a carer is a life changing experience



Peter's take on being a carer was that the carer is there as a support without living the person's life for them. "There's a limit to which you can intervene. She lives a life of dignity; she's her own person; it's her struggle and I'm there to support her and advocate for her in situations that she can't, but I'm not there to live her life. I think it would be incredibly insulting to do anything else."

The motivation of the carer

Few people plan to be a carer, but those who find themselves in the position are able to explain why they choose to continue. Amongst the carers interviewed, a strong theme was the motivating power of love. There is no choice. This is here. This is now. This is happening. I love this person and I am here for the long haul. I'm not walking away. "It's happening to us, not just to Kate," said Peter.

All carers interviewed appeared to have a central belief that the person living with dementia had a right to live a fulfilling life until death.

Some carers supported their parents and spoke of the unconditional love that was offered to them as a child. Rosie reflected that her motivation was imparted to her by her parents: "That care, that love, that understanding of people with difference has been passed on to me. It was that love and nurturing given to me as a child, and then later as an adult, that motivated me. When I was asked the question, 'Why?' and, 'Why did you do it twice?' My answer was, 'Why not?'"

Rae explained that she wanted, "to keep Don at home, because I feel that I can still do it; because I want to do it. I'd feel guilty putting him into a nursing home, because I know that's how I felt when the boys had to go into care. I cared for them and now him, out of love. I can get a bit frustrated at times, but he's an easy man to handle."

Edith was the carer for Bill for six years. "I just looked after him. I was one of the lucky ones, because he had such a beautiful nature; he never became nasty." In the final year, when Edith had to help him in the toilet and dress him, it became physically hard work. She said that it was just normal to her, and there was no way she wouldn't have done it. "Bill had lived his life for me and the family and his friends; he never did anything for himself. I knew Bill would stand by me whatever happened, and this made it very easy to look after him." They were married for 52 years and, "Our love didn't lessen; it got stronger."

Pam says she was lucky because, "Phil wasn't so bad. He still had his fine motor skills; he could write with a pen but he couldn't walk. I didn't think once, 'This is so hard.' I thought, 'It's just your life with Phil and you're just doing what you have to do.' Phil was placid and happy to go along with anything; he just laughed and smiled right up until when he died."

Stan lived at home with Chris and their three children aged under 18 years from the time he was diagnosed with dementia until he died, aged 78. Chris said, "It was important for him to be at home with his kids, so he could still teach them about their culture. You would never know when he would come up with a story about his life or Aboriginal culture. Being at home helped the children benefit from this spontaneity. Stan had a great fear of hospitals, institutions and being locked away. He felt safe and secure at home. It was hard, but I did it for love and for the children and because I knew it was what Stan wanted. Family life is the most important thing."



Paul's partner, Gwen, believes that, "The nursing home environment was not for Paul. Let's face it, nobody can give him this situation that he has here at home. So, while Paul's needs can throw the house into turmoil, it revolves around him. He was a very reasonable man but, at one point, he pounced unexpectedly on me like a commando on a mission: 'What are you doing here?' I feared for my safety. But, I said, 'It's me. It's Gwen.' You had to be calm. But, you know, that passed. You can't expect other people to understand that. I feel that staff in the nursing home only have limited time."

The carer experience

The carer experience is complex, diverse and ranges across the spectrum – it's best explored in a selection of comments made by carers.

"You're in a different world."

"A lot of the things that you thought were really important when you were younger are not important at all, I think you learn that because the person you love is going to die. All I can do is stand there with her as she goes through her journey, day by day, and it puts all of those material things into a stark perspective."

"Sometimes we would go to the hospital and we would tell them what was concerning us. Say something like, 'Shirley has an odour on her breath; I think that she's having another downward step,' and they seem to ignore what you have to say."

"I often think, 'I wonder what's going to happen after this?' And I wonder where I'll be; what I'll end up doing."

"I had to give up some of my interest in committees and gave up some golf that took up large slabs of time – four days a week then – and I haven't played since."

"I felt very sorry and sad and helpless. I was angry that I was having to give up my life."

"I think this experience has strengthened our relationship. Over time, she came to rely on me a lot more. We have been friends, best friends, for a long time. That has become stronger through this."

"I had a really difficult night and day; I just wanted to put a blanket over myself and hide. I took it step by step and slowly moved through the day; showering Mum first, then dressing her. The last thing I had to do was wash the dishes. All of a sudden it felt like a load had come off me; it was really eerie. I physically felt a load had lifted."

"I used to think that I was impatient and that bothered me. When I heard the experiences of others in some group discussions, I realised that I wasn't as impatient as I thought. I was experiencing what others experience."

Stan didn't understand his condition. He would ask, "Why am I like this?" Chris would explain as best she could: "You have been working all of your life, used your brain all of your life, then you gave up work, didn't use it as much, it's just going in a different way." Chris said family and friends outside of the household would initially say, "He hasn't got dementia," and she realised they didn't understand what dementia was, either.

I was experiencing what others experience



“I need to initiate everything; the way she looks at me, the way she stands, I know she needs to go to the toilet, so I need to suggest it. Last night I almost fed her all her meal. I get her ready, drop her off, go to work and pick her up and come home. This is our routine. She’s been very restless these last few weeks; the other night we had about one hour’s sleep. She got up and started ranting. I tried to be as gentle as possible, but I was firm with her in the end, and got her back into bed, and she went back to sleep. The next morning when she woke up, she whispered to me, ‘I’m sorry,’ and that broke my heart.”

Pam felt her son judged her as being reactive instead of proactive, but she found it took something to happen to respond to it: “You didn’t know what the day would bring; you just went with it. You can be proactive when you have a geography you can map. But with dementia, you are just being prepared to be prepared and develop the capacity to respond.

“Phil’s Alzheimer’s was in the middle of our lives. It wasn’t Phil anymore; it was Phil with Alzheimer’s. Phil had been the mediator; he stilled the waters. He would calm everything and, all of a sudden, the calmer was gone. Our son said to me, ‘I just wanted to ask someone how to fix a tap in my house, and Dad wasn’t there to ask.’

“Things became very negative between the children and me; I felt judged. They told me I couldn’t treat Dad like that, but they didn’t live here and didn’t understand. Finding things like the dirty dishes from the dish washer put back in the cupboards. I’d think, ‘OK, you’re losing your memory, but can’t you see the dishes are dirty?’

“It was a huge learning curve for me. I thought he’d just forget my name or my face but not all the rest, like how to swallow, how to speak.”

Many carers interviewed talked of an enhanced relationship; a special love that came from the experience of needing to manage living with dementia. This experience creates a unique bond between the carer and the person living with dementia. When each carer reflected on their experience, no one regretted the time and energy they had spent being a carer of the person with dementia.



How to live through it: “Go to sleep in the wool department.”

For Edith, the hardest thing was the sleepless nights. She would settle her husband, Bill, by holding his hand in bed, and always slept with her head on his shoulder. Something she now finds difficult is to learn how to use a pillow again.

Most nights, Bill would get up. Edith would cover her eyes with her hand, watch through her fingers and, if he wasn't too restless, she'd let him go. Edith found it was best to let him go or he'd get frustrated. So she watched from afar, never having a full night's sleep. Edith had learnt to anticipate the dangers around the house from experience; constantly thinking, “What is he likely to do with that?” For example, she hid all the sharp knives following a night when Bill tried to open a can with one. “To cope on a daily basis, you can't be rigid. Every 24 hours turns into 48. You go all the time. You don't stop.” One night, Bill covered his head with shaving cream and as she took it off, he asked, “Why are you belting me up?”

One morning after a restless night, Bill tried to help with breakfast. In doing so, he spilled yoghurt and milk, then walked through it with his walker. Tired, Edith must have sounded sharp when she suggested he leave it to her. He did, and she presumed he had gone off to the garage for a smoke. But when Edith went to see if all was well, he had gone. Luckily he was not too far down the road and she was able to get him to turn around. Now arrangements had to be made to secure the house. Later that day, a home support worker asked Bill why he had left. He said, “She's not always that cute, you know!”

Edith enjoys driving, and when she'd get really frustrated, she would go out with Bill in the car, play classical music and drive for an hour. This relaxed her; gave her a release. However, Edith found long trips were not a good idea. “Never take a person with dementia from Mt Gambier to Rockhampton. I was a nervous wreck when we got there! You need to know where all the accessible toilets are in each town, and be able to park close to them.”

Edith found great comfort in a support group of other women who care for their husbands who have dementia. She says people who are going through the same thing really understand. They share their experiences and they all learn from them.

One of the hardest things Edith found after Bill's death was that the staff who had been such a constant in their lives just stopped coming. Whilst she understood why this happened, it didn't make it any easier. The staff had been with them through so much. Then, suddenly, nothing.

On the first anniversary of Bill's birthday following his death, Edith had the inner strength to say, “I'm not going to sit here and be miserable,” and went for a drive. As she drove, she remembered all the things they did together: where she would have parked for Bill to have a cigarette, where they walked together and where they stopped for lunch. She shed quite a few tears.

Live for today and what happens today



Dealing with challenges

“Stan would often have hallucinations. One night he wouldn’t go to bed because he thought there was a woman and her child in the bedroom. He told me this and I said I’d fix it, so I went into the bedroom and told them to leave, loudly and firmly and that they mustn’t come back. This worked!”

“There was no information that told us how to cope with hallucinations, delusions.” Chris found that she adapted herself, learning to be in Stan’s moment and experience, going along with what he was seeing or experiencing and dealing with that so that he felt better. “We never knew what was coming next.” Stan needed to feel secure; he often hallucinated about police coming or taking him away. Sometimes he thought home was a police station and needed to be convinced he was safe. I had to ask some road work vehicles with flashing lights to move away from the front of the house because they caused Stan such fear and distress.”

Chris described how one night she noticed Stan missing at 4.00am. Stan’s nephews found him and brought him home at 7.00am. Chris took him to hospital, where staff suggested Stan’s injuries were the result of a fall. Chris asked for x-rays, which showed that Stan’s injuries were most likely as a result of being bashed. Chris was referred to the Aboriginal advocate through Aged Rights Advocacy Service (ARAS), who arranged for a motion alarm for the door to alert when Stan went out.

Pam said her mother, Thelma, who has dementia, used to refuse to have Pam in the house, and became very angry with the people visiting every day. Thelma argued with everyone who came into her home and showed them the door to get out. If Pam rang, they would have a lovely conversation, but if Thelma saw Pam, “She would go off. It hurt initially but I realise she doesn’t know who I am; she thinks I am her sister. I even tried apologising for what I may have done that upset her but that didn’t work.”

Guilt

Most of the carers interviewed expressed feelings of guilt around the need to have a life of their own. While it is important for the carer’s wellbeing and their capacity to maintain their role, this is still a tough one. “To go away without him or to put him into respite and walk away, knowing that you’re going to be doing something enjoyable for yourself, oh, they’re awful feelings.”

“I will never forget that first time when Ralph went to respite; it was the worst thing and the hardest that I’ve ever, ever had to do. To walk out and leave him behind was just shocking. I just ‘lost it.’ I was looking forward to it but, while I had all these plans, I didn’t know what to do with myself. It was a massive loss. My counsellor said that I was going through grief and loss. And that’s exactly what it was. I hadn’t imagined that I’d feel like that, but I did.”

In the last few weeks of Stan’s life, Chris described a fear and guilt that she was not providing adequate care, as Stan wouldn’t eat. She would dip some swabs in beer and place them in his mouth; just the taste seemed to give him satisfaction.



Sense of loss

The journey of dementia is one that, in almost every case, the person and those closest to them never planned to take, and spent little time contemplating. “It’s something that happens when you might be thinking, ‘The kids have left home; we’ve got time together; we can do things together.’ And if you’ve made it that far, most people think, ‘It’s plain sailing from here and we’ll just grow old together.’ So it’s a real shock to the system [when your partner is diagnosed with dementia].”

Kate told of feeling, “My future has been stolen.”

Peter suggested that, “When you are aware of what’s happening, the future is not a notion to dwell on, because all of your dreams and desires feel as though they’ve been lost. I feel that sense of loss for what we had planned to do together. But you have to put things in perspective, because you do have the time that you have now. Then there’s the memories that are lost. The other night, we had poached eggs on toast as an easy dinner. I mentioned that it was just like when we used to sit down on a Saturday night with the kids and watch our favourite TV show... for Kate, the memory was completely gone. That’s devastating.”

A difficult carer experience is loss over time. While most people have experienced the pain of sudden loss, carers talk of a different experience. Their journey is punctuated with points of loss. “I have a friend who says it felt like her mother died before she physically died. That would be hard.”

Live for the moment

“Why cry now? I can spend my time grieving for the future or what might have been. Sure, bluntly, she’s going to die at some point and I’ll have plenty of time to grieve and cry after the fact, so I refuse to spend too much time now grieving and crying. While people might refer to it as a journey, it’s really the present and, even though we are aware that it’s getting worse, we try to focus on now, not on the past or what’s been lost. When you see what’s there in the future, the present becomes much more important – live for today and what happens today. If we don’t want this condition to define us, that is how we need to live. I think we came to that point of view gradually. You need to constantly adapt – just when you think you’ve got a line on this thing, it changes, so you have to be ready to adapt.”

Paul and Gwen had never been on a cruise, so they went for it. It was early days and no one on the cruise realised that Paul had dementia. It was a memorable trip, something that was shared and the source of many stories.

Colleen and Patrick continue with their life, seizing the opportunity to continue a rich involvement in music and culture. Their friends were told about Patrick’s dementia, and they accepted and welcomed Patrick’s ongoing participation in their group activities.

“Phil was in hospital for five weeks at the end and wasn’t eating. I thought, ‘If only he would eat.’ The medical staff told us we were wasting our time: ‘What’s the point of doing this; he’s going to die anyway.’ One of the nurses told me, ‘He’s going to get an infection, and then another, and die.’ She’d say we weren’t facing the facts and living in a dream world. I knew where this was going and didn’t need to be told all the time. I just wanted to make the most of him while he was here. Even

There are plenty of opportunities to share a laugh



though his brain was impaired we still had some communication, if his eyebrows moved he was connected. I don't remember that man who couldn't do anything, I only saw the Phil I knew." Then, "palliative care stepped in and they were just marvelous. They didn't treat Phil's end of life as a medical issue. It was the whole family; they were treating all of us."

A sense of humour

While it can be tough, there are still plenty of opportunities to share a laugh and appreciate the humour of the situation. It is alright to laugh sometimes.

Most of the people we interviewed could speak with humour about events and situations from their journey. Gwen couldn't stop herself from laughing out loud about Paul's exploits hot-wiring cars, after his licence had been taken away. "I'd hidden his keys, but he used to hot-wire cars parked in the street."

Rosie entwined many humorous anecdotes in a story that ran the full range of emotions. She told with fond love and respect of the time when she found her Dad sitting very proudly with a slipper on his head, convinced that it was a hat.

Pam chuckled as she recounted that Thelma thought her son was her husband and when he went home, she said, "He went to live with that other woman... but she is very a good cook."

Edith reminded us that, "keeping your sense of humour is so important. One day, Bill came out of the bedroom saying he couldn't find his feet. I suggested looking at the bottom of his legs, to which he replied he had done that but they weren't there. He was looking for his socks!"

Family, friends, connections and communities

Family and friends understand things about the carer and the person with dementia that are unique and provide support that can be provided by no one else.

"For Dad – who really loved his dogs – we had 'doggy wash' come every fortnight on a Saturday. Quite a few of my friends would bring their dogs as well. That was a social event and I'd cook pancakes. It meant that he was seeing different people and they would have a conversation. So, even though he couldn't go out, it was that normal life continuing." This approach recognised the value of Rosie's dad and the things that matter: real life, real connections, real relationships.

"I needed to work to have contact with other people as well. There are quite a few people at work who know Mum, and we can sit and talk about her. A group of people around you who know you and care for you is really important. I need that network of people, and to be home with Mum. I need that balance. I don't have much time for myself, but Mum is all I have. My wellbeing is dependent on Mum's wellbeing. When she's sad, I'm sad. It's hard for me to see her sad, because I can't do anything."

"Ultimately, you need to seek out people who are empathetic, who are willing to learn and to try to understand the condition. In the end, we did find some friends but, beforehand, we had quite a few friends who were casual and many of those just disappeared as things deteriorated."



“We’ve also met some fantastic friends in our support groups and so on along the way. They support each other so much and care about each other. I think some of the people we met like this will be lifelong friends. We’ve shared so much.”

Colleen and Patrick have a strong social network of friends who regularly gather to enjoy and play music. Patrick’s dementia is out in the open; he talks about it, and their friends talk about it too. This was done purposely, so there would be no talking behind his back. Colleen said, “You know it’s not going to get better, but having friends and people I can talk to, to find out what happens and when, will help me.”

Many of the people interviewed found that dementia evoked apprehension in people who they knew. “In the beginning we had quite a few friends and many of those just disappeared. Not many people come here, I can tell you. I tried to avoid people who didn’t understand or didn’t want to know what the condition was about, and there were a few of those.”

“Friends fell by the wayside and I hear that so much when I’m in carers groups and support groups. Friends drift away from you and I think because it’s dementia – they see a person with dementia and they don’t know how to handle it. With dementia, there’s not a lot of knowledge or understanding or acceptance of it out there. Now I think it’s improving, but there is an awful long way to go.”

“Our friendship network would provide support”

Elizabeth spoke of the strong network of her community. “If you are a gay person and have never been married or had children, then you don’t have that part of care giving. Not taking for granted that your children will look after you. Our friendship network would provide that support. I know a lesbian friend who is dying and, while some support is provided by family, the bulk is done by friends. So the friendship group is hugely important. I feel that I’d depend on friends more than family; even the extended gay community, the fabulous gay network that is very inclusive. Our community has experienced a lot of discrimination. We know what it’s like, so I don’t think there would be that attitude of, ‘Well they have dementia, so I’ll avoid them.’

“The gay network is strong. The community reinforces itself. I think some of that comes from the shared experience of not being accepted – everyone has had their own level of rejection from family or work. People trust their group because they are not going to reject them.

“I have complete confidence that, if my partner or I were diagnosed with dementia, as partners, we’d support and care for each other. It goes without saying. I know that we’d be supported by others as well; that’s how my community works.”

Elizabeth has experienced this support as a carer for her mother: “If I need help with Mum, I can call on my gay group. They all love Mum. When I went on holiday, they all went up there and visited her. She couldn’t remember it, but I thought it was great.”

Home is where the person wants to be



Staying living at home

Carers and people living with dementia held a strong belief that home was the best place for a person to live for as long as they could and, preferably, until death. People can, and have, with the appropriate support, remained living at home with advanced dementia until they died. Any move into residential care is not inevitable, although the goal of living at home until death may, for many and varied reasons, be difficult to see through. It can be considered successful to have managed to remain at home ‘as long as possible’, as long as it fulfils the best interests of both the person living with dementia and the carer.

“Home is where the person wants to be; even now. Home is the right place – there’s no doubt about that. Home is familiar.”

“Mum’s lived there for 65 years and she knows every nook and cranny. She could get up in the middle of the night and find her way in the pitch black to the bathroom. She knew where everything was; knew every squeak and sound. If she goes in to a new environment the sounds are new; if it’s dark it frightens her. Strange sounds affect the way you sleep.”

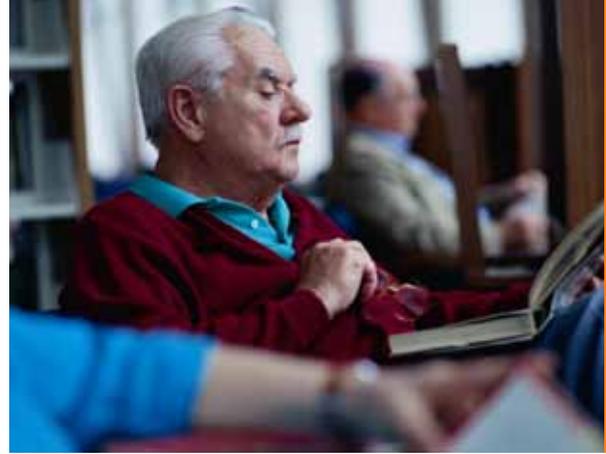
“My objective is to keep Marge at home as long as possible, because she won’t be as comfortable anywhere else as here in her own environment. It’s better for family and friends to keep contact. We have a very loving family; my son and daughter are marvellous.” John has been committed to the principle of living at home as long as possible for many years. When considering what was best for his parents some years ago, he said, “My brother, sister and I did everything possible to keep them in their own home after selling the farm.” He held the belief that as long as a person is well supported, “They’ll never be happier than in their own home and, while we can cope, let’s do it.”

For John, remaining living with Marge meant that they could more naturally carry on with life, like going to weekend sporting fixtures to watch their grandchildren play. This maintained a link to their life before dementia. It helped maintain links with family. John was absolutely sure that Marge loved going out to see sport. “Matter of fact, sport was how we met.” This deeply embedded and long term personal history is very important to the couple. They feel that it is a bond that would be weakened by Marge’s living anywhere else but at home.

“When you’re at home, you can deliver a type of care which is loving and recognises the individual and their needs. I put myself in the person’s shoes and try to think what it is that I would like; what sort of affection, what sort of direction. These are the things that can’t come from a stranger. They have to come from a family member.”

“It’s the familiarity of home; your routine is established, you know where everything is. Although I’m not sure if it’s the right place to be in end stages of dementia. Not everyone likes it, but for some people, residential care is the best thing they’ve ever done. But, the idea of me going to live in a residential aged care facility horrifies Pete. I think he feels that he should be able to look after me at home.”

“Home is where you can do what you like, when you like, and that’s one of the things that keeps me going.”



“Staying at home gives Paul a will to live. He’s tough, and there are plenty of times where it’s been said he won’t get better... and he has. I believe that’s about him knowing he has a home here. Also, I’m a little bit selfish and I want him to be here. I’d miss him if he wasn’t.”

Chris spoke about her decision to support Stan to stay living at home: “The kids had to pitch in and help; without that we wouldn’t have been able to have Dad home. Hospitals are not the place for Aboriginal people; Stan wanted to sleep on the floor but the hospital wouldn’t allow it.” She said it was often she who picked up on medical issues and this was an advantage of having Stan home. Chris found it hard living on just a couple of hours a sleep at night. She always waited until the household was calm and all were asleep before she went to bed, then was up in the morning before anyone else to prepare for the day.

On choice, self determination and living and dying at home

Rosie was the primary carer for both her mother and father, each of whom had dementia of differing types, and each of whom lived with dementia at home and died at home.

Rosie’s mum had a stroke and subsequently experienced a form of dementia in which the most striking manifestation was psychosis, evidenced by fear of having done things wrong or being negligent in her care of her husband. She also had a deep fear of losing her husband. “Dad was the person she adored most and she feared would be taken away from her.”

Rosie worked full time during her time as a carer, and felt pressure to have her parents live in a residential care facility: “So you can get on with your life.” But she decided that she would do everything she could to see that her parents lived and died at home. For Rosie, there was no choice: “Why would I abandon them at that point? They had made it very clear that they did not want to live in a nursing home.”

Rosie’s decision rested on the belief that it was best for her parents to remain living at home in a familiar environment as her parents had each been assessed as having a different level of support need. She believed that a move to live in a residential aged care facility would have separated the life partners and been severely distressing to them both. They never wanted to live apart. Rosie believed that this would have seen an effective separation of her parents that would have had significant negative impact on their emotional welfare, mental health and physical wellbeing: “That would have fed into Mum’s psychosis.”

Rosie felt that living at home meant that she and her parents had direct influence over the flow of the day and this self-determination was central to quality of life. Home provided security. “They spent three-and-a-half years in bed together. Mum was too scared to leave her bed. Some days, Dad would climb in with her. They’d hold hands all day and their little dog would lie between them. Her security and her domain was that room.” This is something that Rosie felt sure would not have been achievable in a residential care setting.

Home is where you can do what you like when you like



On the evening before Rosie's mother died, her eldest nephew came and supported her to settle her Mum for the night: "Such a supportive act of kindness."

Then, "Mum and Dad slept the night facing each other and holding hands with their little dog with them. When Mum passed away, even though Dad had Alzheimer's, he tried to give her mouth to mouth. When he realised that Mum had died we lay either side with her and watched the dawn come up. That was a really powerful time – there they were together. That's how they wanted to go – together. That moment is a cherished moment that I have. For me, it was all about those special moments together; whatever they may be."

Even with the best practice and the best of intentions, Rosie feels that her mother's death would have been quite different in a residential care facility.

Rosie's story includes numerous experiences where the barriers encountered seemed to be system related, where organisations and individuals are required, through regulation and bureaucracy, to act as gatekeepers instead of the gateway. It is a story of commitment, persistence, determination, energy and advocacy. Her experience is not unique – each carer interviewed shared these characteristics.

On hearing Rosie's story, the question was unavoidable: "Why did you do it?" Rosie's response was simple: "Because we cared for each other. They had cared for and nurtured me. They got me through some tough times. And when the going gets tough, it's not about bailing out and abandonment. Even to put them into residential care ... I could not have left them there."

Having returned from the hospital for the last time, "Mum took another seven-and-a-half weeks to die", and she was, "surrounded by love, with her husband; she had come home. It was a warm place; there were lights on, people there. It was that hub of what life's about. So I could come home, get into my trackies and life continued around them."

Rosie had some of the difficult conversations with her parents; finding out what their feelings were about how they would die, what sort of medical interventions they would accept. She saw the fulfilment of these expressed wishes as ultimately honouring not only her parents' individual wishes, but her parents themselves.

Rosie said that her parents, "had the richest life that was possible, with whatever they had. For me, that was the most important thing. It wasn't all hunky-dory. At the end of the day, I did the best I could. Basic nurturing, love and care, their personal needs were looked after and their dignity was respected."



Support to stay living at home

In keeping the person living at home, there often comes a time when the carer needs support to look after the daily needs of the person. There are services that may be available, such as in-home support, that can help the person have a shower and look after other personal needs. Support may also be available for the daily tasks of running a home, such as cooking, washing and cleaning.

Having people unknown to you in your home can be difficult. “Taking that step was a huge culture shock. The comings and goings and acceptance took me six months... knowing that someone else was coming in to shower my husband was a huge hurdle to overcome.”

Often things settle in time: “I love the person who does my cleaning; she really respects our personal privacy. It’s about the right attitude and the worker needs to have that understanding of what it would be like for them to have someone come into their home.”

A partnership is built on a feeling of mutual goodwill and respect. Sometimes things may not click and it is important that it is managed sooner rather than later. All service provider organisations aim to assist their clients get the best service. Many encourage feedback, but it can be difficult: “You’re very appreciative of the support and don’t want to be rude or complain. Often you may feel like you’re sacking the person. I felt awful that I had to make a phone call and complain.”

People commented on the value of a good connection with a support worker. “They connected; not only to Shirley, but to me. And when they came here it was like having a visitor – sometimes we’d sit down and talk. I think it’s probably one of the best things in the provision of services for carers, the respite and the relationships that grow between the person and the support workers.”

Chris talked of the differences between the services that they received at home from various staff. With some she felt her privacy was invaded; they would make unsolicited remarks about notices on her fridge or books she was reading. Others were like family and would use the same greeting every visit, so that Stan would recognise who it was. It was difficult, at times, to find sufficient respite to enable the whole family to be together. The respite allowed for a few tasks to be done, but not really for enough family time. Chris also commented on the difficulty after Stan died, when services just stopped. “One phone call of condolence, then nothing.” Chris felt this was especially hard on the children, who felt cut off and experienced this as yet another loss.

Rae has support from four different organisations, which makes it difficult for her when she needs to change something. She found them all very valuable in being able to continue to have Don live at home. “I’m getting a lot of help; without it, I couldn’t do it.” Rae and Don used to go away on driving trips around Australia and when they couldn’t any more, they joined a touring company and have found them very good. “They work around us, pick us up from home and drop us back. They have two or three mystery trips each month and other trips for special events, like the Melbourne Cup. This is like the holidays we used to go on.”

Carers valued the relationship with their coordinator: “I wouldn’t have handled Mum at all if it hadn’t been for Annalees. She was great. She thought of things that I simply wouldn’t have thought of. Sometimes, I needed her to encourage me to make good decisions that I found hard to make. She’d say, ‘Think of your Mum; what would she want?’”

Taking time out can be whatever the carer chooses



Carers valued respite. “I think it’s probably one of the best things in the provision of services for carers – the respite. I could not have done this without that help; without respite. She would come away from those activities happy every time. She really liked one on one support.”

Carla was offered two hours of in-home respite a week. She negotiated to have this in four hour blocks once a fortnight instead, so that she could continue with night owl lawn bowls.

Pam was apprehensive about help. “Getting Phil to accept help was hard, and the coordinator’s suggestion for someone to come in to work alongside him was brilliant; in Phil’s mind they became friends. It wasn’t such a tragic path.” Phil’s helper would take him on a dolphin cruise or go into town for the morning. Pam said it was a relief for her to see two men doing ‘blokey stuff’. They would clean the gutters together, maintaining the ‘man stuff’ around the house and they had fun.

Christine previously described Mondays as her worst day. Before respite, even though Paul would leave a message on the notice board saying where he was and when he’d return, he’d come home to half drunk cups of tea all over the house and the vacuum cleaner cord in a tangle. The garbage from under the sink would be somewhere else and he was faced with a very anxious Christine. Now they have some support for companionship and cleaning every Monday. There are two different support workers and Christine hopes they will remain constant. They have worked out what Christine needs over time and that has been helpful. Cleaning sends Christine into a frenzy, something she is not used to. In her position as a senior public servant, she always kept her cool. Now, she becomes very anxious worrying about when the sheets and towels should be changed.

Carla is her mother’s primary carer and she realises this is a big responsibility. “I need support, because if I get sick, who’s going to look after Mum? My sister does what she can. Mum had an ACAT assessment. This will be the next step; just a little bit of help at home will help me.”

Carla described being anxious about people coming into her home as she was worried they would judge her. Her caring role takes priority and because of this she had had to let the garden go and things in the house were perhaps not as clean as her mother would have them.

Carla explained that, “We hit a crisis point in the middle of 2010; Mum could no longer be left alone. I took six months off because she wasn’t coping. She was frightened and afraid. I needed to do something. I started to investigate how I could go back to work and look after Mum at the same time. I contacted an agency and they sent me all the information. I just had to read it and choose what to do. I contacted a respite cottage. With my sister’s encouragement I took up two days of respite services. Mum enjoys going there. There are other people there and it gives Mum a different aspect on life. I want her to be as active and stimulated as possible.”

In keeping the person living with dementia at home, there may be additional costs to consider. Rosie said: “My last electricity bill with Dad at home was \$1200 for three months. We would never have done it any other way, but I don’t think people realise the cost of running a washing machine four or five times a day because of the wet clothes, the bedding. Power’s on almost all day; heating, cooling, lighting, TV. My water bill would have been what you’d expect for having eight people in the home.”



Time out for the carer

Taking time out doesn't need to be complex. It can be whatever the carer chooses it to be, as long as it frees up some time and helps the carer relax.

When asked what people want from taking time out, each person had a different response. John said, "I'd be happy to walk on the beach or sit and read or even catch up with housework or tidy up the back room."

Time out helps the carer continue: "I really feel that if I could get respite every two months, it would make a big difference to me."

"I have been very, very much aware that I have had to do things for me to keep me going and to keep me healthy and to keep me on track. I have a massage once a month, walk on my walking machine each day, relaxation each day, which we do together."

"I still go to dinner and catch up with the girls I used to work with. I still do things I like and someone comes to be with Ralph when I do that. I need to do it to keep in touch."

Paul said he'd give up going to the prison as a Chaplain if he had to, but also acknowledged that he needs, "something other than dementia. I can't have my entire life focused on Christine's illness." Christine thinks it is important too, and supports him to continue. "I can't help Christine unless I'm well; not just physically but in the head, so I have to do things that are not related to dementia."

"I'd been told that it was important to look after myself and I was given a list of places where I could go for respite. I was on the phone for hours. I started off taking notes and then realised I was getting lost in the mire. It wasn't really until one of my neighbours told me about a respite cottage. They really put an emphasis on the carer – they don't just tell you to look after yourself, but give you some options."

Home-style respite settings

Respite is support for the carer to have a break from their caring role. This can occur in their own home, with support workers spending time with the person living with dementia in their home environment while the carer goes out or has a rest, or it may be when a support worker takes the person living with dementia on an outing. Respite can also be provided where the person with dementia spends some time at a home-style, centre-based respite house in the community.

"We found the stay at the respite house was very successful. I stayed too and that was good. Immediately we said we'd like to accept a booking, we were invited to come along to the monthly carers' meetings. I was told, 'You bring Marge and we'll care for her while you're at the meeting, then you pick her up and go home.' They also provide other opportunities for carers to relax and spend time together."

"Within 24 hours of Ralph going to home-style respite, I received a call from the coordinator saying that he was adamant that he was coming home and that it was agitating him to think that he would be staying. I asked to speak with Ralph and just let him know that I needed a break and that I needed his support in doing that. I asked the coordinator if I could get a text once he had settled and within an hour I'd got the message that all was well. I think this is something that worked well because of that homelike setting and more personalised attention."

My caring role changed but didn't go away



“We’ve been to a respite cottage in the country for a weekend holiday. We can go together and they look after Don and take us out and they pick you up. Don goes to another respite cottage in Elizabeth for four or five nights a month. I appreciate this. He enjoys it and I’ve got over feeling guilty about it. I’m not getting out enough myself. There is another respite cottage where we can go together or Don can go alone. There are only four bedrooms and during the day, they take you out for a drive. This all means we can continue to have holidays together.”

Residential respite

“I was keen on one place – I’d heard good reports. It would have suited us because of our family and friends living in the area. I made enquiries and the lady said, ‘Oh yes we’ve got a spot for two or three weeks.’” John said he was very impressed with the place but was disappointed when he realised his wife would be sharing a room with two other people. “I felt I could not bring myself to put her in there.”

Jenny talked about her experience with residential respite. “It was difficult for both of us because he thought I was going to leave him there. The care is wonderful there, but it’s that he’s away from home and me and everything that’s familiar to him.”

Transition to residential care

Despite the commitment and desire to keep the person living with dementia at home and support them in this environment until they die, sometimes it is a goal that is unable to be achieved. The thought of the person going to live in a residential aged care facility can be challenging for carers and families.

“I can’t let go. I know that. I know I’m fighting with myself in letting him go. That is probably why I’m not doing it.”

To long term partners, this experience may feel the same as being separated. “The separation is tough for me. Even though Shirley would often go to bed at half past seven and I’d sit out here by myself, she was there, you know, but now she’s not there. It’s like she’s died.”

“My caring role changed, but didn’t go away.”

Pam explained, “You are handing over your loved one to someone else. It didn’t change my life. I was there two hours every day. My caring role changed, but didn’t go away. I had a lot of guilt. He was walking when he first went in. Then he stopped walking. Weekends I’d go in both afternoons and watch DVDs with him. You lose them more than once. I grieved more at some of these changes than when he died. When he died it was like, ‘You poor bugger; you don’t have to put up with this anymore.’” The family could see him deteriorating and to keep the connection, Pam would wheel Phil down to the local pub and have a party with all the family once a fortnight.



One of the most common reasons to decide to take up residential care is to take pressure off the primary carer and it proves successful in achieving that. However, some people noted that when the person is moved into care, carers still wanted to be involved. “When Mum was living at home alone, I could ring up and check to see if she was fine. If I didn’t get an answer, I’d wait a bit and call again and if I didn’t get an answer, I’d go around. Now that she’s in care, it’s harder to keep in touch and it’s harder to be there for her; to get around and see her and make sure she’s going OK. It’s quite difficult to get there every night, but you want to be there to make sure she’s not worrying.”

Carla said, “Mum and I cried for joy when Dad was accepted.” Francesco had Alzheimer’s and became aggressive. It was decided that he go to live in a residential aged care facility. “It had become very, very hard. I still feel guilty about doing it. Mum does too, when she remembers. While he was there Mum and I tried to convince ourselves he was in the best place. We put his favourite paintings in his room; places painted by his godson of his home town in Italy.”

The carer remains a carer even when the person moves into residential accommodation. The welfare of the person remains their central consideration: “Yes, I’ve ‘relinquished care’ in that I don’t have to do the shopping, and so on, but I still take her to the doctor to see what they have to say. Her daily needs are met, but I want to go there and make sure that everything’s on an even keel. I need to know that she’s being cared for.”

When the person living with dementia dies

Finally, each carer is left without the person they have cared for and this is a remarkably bereaving experience. Some of the people we spoke with took a moment to speculate: “I think it must be awful at the end. It must be shocking when this is all over. There must be a massive void.”

Others have lived through the death of the person they supported and, while their experience is unique, it tells a story to the rest of us about what it might be like. Rosie told us, “One of the biggest struggles that I’ve had since my Mum and Dad died is coming home to an empty house. It’s a really lonely place; it’s dark, it’s cold. When they were living at home, it was a warm place, there were lights on, people there. It was that hub of what life’s about.”

After Stan had passed away, there was lots of “spiritual” activity in the house, so the family moved. Chris said the kids were concerned; they wanted, “Dad to come with us to the new house.” She reassured them they would leave the door open so he could come. There was still a sense of spiritual activity. Chris said, “He is calm now; at peace.”

Remember... there is life after death



Remember ... there is life after death

When the person with dementia dies, the carer inevitably experiences a loss that goes beyond the loss of a loved person. No matter how much respite or time to themselves that a carer has, life begins to centre on the role and on the needs of the person living with dementia. The role of carer becomes very consuming. Many carers find that they have defined themselves substantially through their role and that their day-to-day life has become focused on the person with dementia and their needs. The carer experiences a multiple bereavement; the loss of the person and the loss of a role and lifestyle and, if they have had support in their home, often there is an abrupt loss of the staff and personnel who have been supporting them.

It becomes very clear that, through the journey, maintaining social and emotional connections beyond the role and relationship with the person with dementia is important. These are the things that will help the carer sustain themselves through the loss.

Rosie has a view to the future: “I’m very close to my eldest nephew, who has four children; I call them my sunshine and my joy in life; they give me purpose. I’ve sold the car that was able to transport wheelchairs and now I have a seven-seater people mover. I have two dogs and I always make sure that I do something on the weekend.”

Edith is now almost ready to look for a voluntary position. She finds life empty without Bill. “The house looks after itself and the washing isn’t the same.” She needs to be doing something. She knows the importance of having a life outside of her experience with dementia.

“It hasn’t been easy.”

Elizabeth thought that, ideally, it would have been better if her mother could have stayed living at home. In talking with her mother, various options were considered, including employing full time support and buying a home with detached accommodation so that Elizabeth and her mother could live on the same property. Some community nursing services were engaged, but these were not reliable or punctual enough to suit Elizabeth’s mother’s expectations and this upset Elizabeth’s mother.

The situation became such that Elizabeth felt her own mental health was at risk. She received numerous calls from her mother during the day and spent much of her day worrying. This brought Elizabeth to the conclusion that perhaps the best choice was to suggest to her mother that she go into a residential facility. Although initially not well received by Elizabeth’s mother, with support from her uncle, the path was smoothed. When a place became available, the opportunity was taken up immediately.

From there, Elizabeth said it had been a long, hard slog. “It hasn’t been easy, but at least now she’s safe, and that’s reassuring.” However, it was not what Elizabeth described as an ideal experience. She kept in close contact through visiting, but noticed that her mother’s friends no longer kept in touch and that was a negative experience. Elizabeth also talked about the uncertainty of staffing. Her mother’s anxiety responded to individual staff members. “If I did it again, I would have had somebody live in and look after her full time. I think she would have been happier.”



■ Some tips from carers

Patience, routine, learn new skills...

Rae's advice is, "Don't lose your patience; have a routine. You need to look after yourself. I'm noticing it more this year. I'm feeling more tired. I need to look after myself so it is not such an issue for the family; not so much for them to do."

Peter said, "You learn some interesting stuff. They say that living in denial is bad for you, but I reckon denial is good. Facing up to things is important, but you can only take so much at a time and you need somewhere to hide. You can't live thinking about it all the time – it just becomes too much."

Colleen says that in order to cope, "You need patience; underneath I'm feeling it, but I'm not letting it out. It wouldn't be right, because he can't help what he's got." Colleen has routines that help the day flow as well as possible. She gets Patrick's clothes out each morning and gently guides him verbally to have a shower and get dressed. One day he was having difficulty remembering what he should be doing. When Colleen went to check on him, he had very neatly put all his clothes away. "You need to take what comes; there isn't anything you can do about it except manage and cope with it."

Be prepared to deal with personal support needs and incontinence – at advanced stages of dementia, the person is likely to experience episodes of incontinence. This can be extremely challenging to the carer. "That was a terrible time; I was forever cleaning up a mess."

The changes in people can be very difficult to come to terms with. There are strategies to help you cope. Ron said, "I had to constantly remind myself that this was not Shirley; it was the disease and that was the thing I clung to the whole time."

Be prepared to learn some new skills: "I surprised myself in learning the household skills and management as well as caring for Shirley. I'd never done any of that before. When it came to it, I found that I stepped up to the plate."

Talk things through

Talking about things, thinking them through, opening up, crying, laughing, getting things off your chest, explaining yourself, feeling understood, creating understanding – it is all part of the journey.

Many of the people interviewed emphasised that when they shared their feelings and how their experience impacted on them, they felt better. Often they said that their unique journey was best understood by someone who had lived the caring experience. Joining a group can be valuable to most carers; promoting their capacity to live through their experience.

Speaking to a counsellor may also help. Jenny says, "I have a counsellor through Alzheimer's Australia and I find it really helps. I go once a month now; I used go every couple of months."

Pam and her children have had counselling through the Palliative Care Team and they found this invaluable. It is helping them to gel as a family again. They are being treated as a whole unit; coming together and understanding what they've been through.

Have as much fun as you can, while you can



Talk about the future

“Get organised early – Power of Attorney, Power of Guardianship, Wills, advance directives and so on. Then it’s all sorted. It’s one less thing to worry about.”

“One of the practical things I have is Enduring Power of Attorney and Guardianship, which covers everything, medical and lifestyle. This is really important to do before the person you are caring for loses competency.”

It is wise for the carer to find out as early as possible what the intentions of the person with dementia are in terms of disposal of property, who they would like to speak for them if they can’t talk for themselves, and what medical treatment they wish to allow or not allow in case of an accident or when they can no longer indicate their wishes and intentions.

Although conversations around this topic may be difficult, they will help to ensure best outcomes for the person with dementia. Knowing the intentions of the person ultimately shows respect for their intentions and respect for the individual as a person.

“We were lucky we had those conversations, due to our professional backgrounds and experiences. It made things clearer for me and gave me another basis to make decisions. It was sort of a gift that they gave to me about what they wanted end of life to look like. They wanted to be together, surrounded by family, and, ‘Dear, if you can make me a nice pot of vegetable soup, I’ll be happy to the end.’ It was about how they wanted the end to be and whether we were able to do that or not.”

In talking about the future, Paul said, “It doesn’t worry me if I go before her, because Christine has three wonderful daughters who have enough love and concern for Christine to take care of her; they’d be fighting to have her.” Christine said, “We’re planning for the future; tomorrow, next week, next year to reduce my levels of anxiety. Little by little we think about the future; putting things in place as we go. We always talk positively about the next few years. We don’t sit down and specifically say, ‘What if?’ We don’t do life planning about what should happen if...” Paul reminded Christine she has an Advance Directive, and has donated her brain to science: “Oh that’s right; Paul is my memory.”



Keep active

Many of the people we spoke with talked of the experience at diagnosis, where it was suggested that a nursing home place be found for the individual, that the person should stop all work and basically settle down and wait... to die. This is something both carers and people living with dementia refused to do. “With Mum, when diagnosis came, I didn’t say, ‘Too bad, so sad.’ I would always help her to remember and help to make her think.”

“In those first seven-and-a-half years, we did all sorts of things. We went to Africa which is something he’d always wanted to do.”

“We found that the most important thing was to find things that were worth doing; to keep active.”

“I felt a very deep sadness. My husband and I are walkers, but at that point I started to run. I wrote at the time, ‘The faster I run, the less I feel. When I stop, the tears are gone and I feel renewed; mentally invigorated and alive.’ I think that helped me stay engaged with life, because if I hadn’t done that or something to relieve the anguish and tears, I think I might have given in to it.”

Christine has always embraced life and Paul supports her. They built their home three years ago, designing it exactly as they wanted everything to be. They call it their ‘grandparenting home’, as it is large enough for family to stay. Christine feels like she has, “finally unpacked for the first time in her life.”

For some people, having dementia can bring some real positives. Kate said, “Having dementia has created a whole lot of other wonderful opportunities that I’ve never had before, and it opens doors into other areas that I’ve never explored before.”

Kate’s story: “Have as much fun as you can, while you can!”

“I was advised – like others – to give up study, give up work and give up pretty much anything that made me think and ‘enjoy’ my life. This is what all the doctors, the neuropsych and even service providers and support organisations had to say. Well, I think if you’re not doing the things you like, you’re giving up. I’ve seen other people, who have now become friends, take the standard advice and I think I’ve seen them deteriorate.

“I did give up work, but I did not give up study. I used the supports available at uni and that has helped keep me engaged. Other people I know have worked hard at staying engaged with life and they have lived half again as long as it was predicted they might.

“When asked, my advice to people is to stay engaged, stay connected; don’t give up your usual activities – including work if you can still do it effectively. Or, if you can afford it, take the time off to engage in other productive and challenging activities; exercise; read books that will extend you; maybe learn an instrument or another language.

“Do whatever you can to keep your mind active. I like to do things to push my brain. So I write – I think that writing is profoundly therapeutic. Based on the advice of a professional therapist, I started writing a journal many years ago. I didn’t want to do it at first, but I came to learn about the value of writing. I advise people to keep a journal and write about life and their ideas.

“Have as much fun as you can, while you can!”

Resources



■ Resources

Places to go

Alzheimer's Australia – National Helpline – Freecall™ **1800 100 500** from anywhere in Australia to access your local office. www.fightdementia.org.au

Carers Australia – Freecall™ **1800 242 636** from anywhere in Australia to contact the local Carer Advisory and Counselling Service in your State or Territory. www.carersaustralia.com.au

Palliative Care Australia www.pallcare.asn.au

Commonwealth Respite and Carelink Centre – Freecall™ **1800 052 222** www.commcarelink.health.gov.au

Agecare Alternatives – **08 8271 3888** (in South Australia) www.agedcarealternatives.net.au

Centrelink – **13 27 17** www.centrelink.gov.au

Web

Dementia from an Insider's Perspective – <http://www.christinebryden.com/>

Having been diagnosed with Alzheimer's Disease at age 46, Christine has written two books and travels widely, with the support of her husband, Paul, talking about her experience of living with dementia.

Living Longer. Living Better.

Australian Department of Health and Ageing website – <http://www.health.gov.au>

Follow the links > For Consumers > Ageing > Living Longer Living Better

Australian Department of Health and Ageing website – <http://www.health.gov.au>

Follow the links > For Consumers > Conditions and Diseases > Other Health Issues > Dementia

American Alzheimer's Association – www.alz.org

British Alzheimer's Society – www.alzheimers.org.uk

Alzheimer Society Canada – www.alzheimer.ca/en

Alzheimer's New Zealand – www.alzheimers.org.nz

Respecting Patient Choices for information on advance care planning – www.respectingpatientchoices.org.au

Blog

Creating Life with Words <http://kateswaffer.com/>

Kate Swaffer has dementia that was diagnosed in 2008, the year she turned 50. In her blog, Kate aims, "to keep tabs on my life, my thoughts and my philosophies so that later on, I can remember what it is I was thinking or doing." Her blog considers a wide range of topics, including reflections on dementia from someone travelling the journey.



YouTube

Dementia in Australia

Dementia My Story, Kate Swaffer

Some suggested reading

Australian Government Directory of Services for Older People

Australian Government Department of Health and Ageing (DoHA) (2011). Canberra: DoHA

Web download available at: www.health.gov.au > Home > For Consumers > Ageing > Publications

Caring for Someone? A guide to your options and our services

Australian Government Department of Human Services, Centrelink (Centrelink) (2011).

Canberra: Centrelink

Web download available at: www.centrelink.gov.au > Home > Publications

Dancing with Dementia

Bryden, C. (2005). London, UK: Jessica Kingsley Publishers

Dementia, Lesbians and Gay Men

Birch, H (2008) (2008) Australia: Alzheimer's Australia

Web download available at: <http://www.fightdementia.org.au> > Home > Research and Publications > Ageing > Alzheimer's Australia Numbered Publications > Paper Number 15

Live Well, Die Well

Resthaven Incorporated (Resthaven) (2012). Adelaide: Resthaven

Web download available at: www.resthaven.asn.au > About Us > Publications

National Framework for Action on Dementia 2006–2010

Australian Health Ministers Conference (AHMC) (2006). Sydney: AHMC

Web download available at: www.health.gov.au > Home > For Consumers > Conditions and Diseases > Other Health Issues > Dementia > National Framework for Action on Dementia

South Australia's Dementia Action Plan 2009-2012: Facing the Challenges Together.

Office for the Ageing, Department for Families and Communities (OFTA) (2009) Adelaide: OFTA

Who will I be when I die?

Revised edition

Bryden, C. (2012). London, UK: Jessica Kingsley Publishers

With a Little Help ... How family and friends can support a Carer

Resthaven Incorporated (Resthaven) (2011). Adelaide: Resthaven

Web download available at: www.resthaven.asn.au > About Us > Publications

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Attwood, A. (2011). Editorial. *The Big Issue*, No. 389 13-26 September 2011. p4

Dementia a National Health Priority



Definition of some terms

Carer – a person such as a spouse, a partner, a family member or a friend who provides regular sustained support to another person without payment.

Person living with dementia – the person who has dementia.

Support worker – a person in a paid position who provides direct support, including personal care and domestic support.

Nursing home – nursing homes are also known more formally as residential aged care facilities in which care and support is delivered.

ACAT (Aged Care Assessment Team) – the assessment carried out by a member of this team is generally referred to as an ACAT (pronounced ay-cat). An ACAT is required to see if the person has support needs that warrant Government-subsidised assistance at home or to live in a residential aged care facility.

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