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# RELATIONSHIPS AND DEMENTIA

**ALZHEIMER'S AND DEMENTIA**  
**AUSTRALIA AND HOPE**  
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Alzheimer's Australia NSW respectfully acknowledges the Traditional Owners of the land throughout Australia and their continuing connection to country. We pay respect to Elders both past and present and extend that respect to all Aboriginal and Torres Strait Islander people who have made a contribution to our organisation.

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# CONTENTS

Acknowledgements	2
Executive summary	5
Introduction	7
How does dementia impact on relationships?	8
Role and identity	10
Emotional and physical intimacy	12
Grief and loss	15
Positive impacts	18
Support needed	19
Conclusion and Recommendations	21
Further reading	22
Appendix – Alzheimer’s Australia NSW support services	23
References	25



## EXECUTIVE SUMMARY

# “I love her for who she becomes...”

***“I love her for who she becomes ... I learn to re-love the person she becomes [as dementia progresses] ... She’s still her, she’s just different.”*** Woman caring for her mother with younger onset dementia

Our intimate and family relationships are complex. Living with dementia increases this complexity, so relationships need to be reframed and constantly renegotiated as dementia progresses. The dementia journey is different for everyone and is influenced by a range of factors. Each individual with dementia, their carer/s and family will experience different challenges as dementia progresses and relationships change. This is not a linear process; it is unpredictable.

Alzheimer’s Australia NSW has produced this discussion paper in response to consumer requests to raise awareness of issues which are most often dealt with privately. This paper gives voice to people with dementia and carers who are living with the impact of dementia on their relationship. We use their words throughout the paper to illustrate the relationship difficulties, challenges and struggles they divulged to us, as well as the positive impacts they identified. The research findings are divided into four themes:

- role and identity
- emotional and physical intimacy
- grief and loss
- positive impacts.

Dementia can impact on the roles people hold and their sense of identity within their relationship. People with dementia experience a loss of independence as responsibilities they held within a relationship are taken on by others. Children caring for their parents often feel the roles are reversed and they are now parenting their parent with dementia. Some people caring for a spouse or partner with dementia also feel like they are in the role of parent, describing their loved one with dementia as child-like, while others feel like a care worker, rather than a partner. Such role changes can impact on an individual’s sense of identity within the relationship and, perhaps, more broadly. How you perceive yourself, your role and your worth is often in relation to other people. If your role within a primary relationship changes and the partner in the relationship is also changing, what does that mean for your sense of self?

Dementia impacts significantly on emotional intimacy. Carers in particular can feel they have lost their life companion and confidante. Several carers told us about the impact of the loss of verbal communication by the person they care for. Effective communication is key to working through relationship problems, so how can such issues be dealt with when communication capabilities and short-term memory are diminished?

Our research participants also discussed the sadness experienced as a result of the loss of sexual relationships and intimacy between couples. The move to residential aged care has an immense impact on intimacy, particularly in large facilities where rooms are shared by two or more residents. Aged care managers and staff have an important role to play in enabling intimacy between couples to continue when one partner moves into care.

Carers of people with dementia described the grief and loss they experience as their loved one’s dementia progresses. This ambiguous loss is felt when a person with dementia is physically here, but may not be

## EXECUTIVE SUMMARY CONTD.

mentally or emotionally present in the same way as before. People with dementia and carers can both feel grief and loss for the person they were, the role they had, their relationship, their shared history and the future. Guilt, as well as anger and resentment, are normal emotional reactions associated with this grief. People need to be supported to work through these emotions, for example, by receiving counselling or joining a support group.

While many of the stories we heard were about challenges, struggles and loss, research participants were also able to identify the positive impact of dementia on their relationships. For some, dementia had provided opportunities to reconnect with loved ones and establish new relationships with the person they care for. Some carers described how the emotional connections with their loved one with dementia are evident; even if the person with dementia does not appear to know them, there still are moments of connection and recognition which they cherish.

This paper has two key messages. Firstly, society needs to recognise, acknowledge and understand that people living with dementia, their carers and families face relationship difficulties and challenges. Secondly, we need to ensure they are well supported in order to maintain their relationships as dementia progresses. This paper has only just scratched the surface of this complicated and multifaceted issue. Further work is needed to better understand the variety of ways in which dementia impacts on relationships.

*“The relationship [with my husband] has changed. I am more enclosed in myself. I don’t feel I want to speak about things. I have hated losing my independence and having to rely on someone. I don’t feel as attracted to him. I feel guilty that I’m changed. I am more changeable in my emotions. It is hard for him. I feel he speaks down to me.”* Woman with dementia on her changing relationship with her husband

### RECOMMENDATIONS

1. The Australian Government funds quality respite services to support carers to continue caring for loved ones with dementia at home and avoid premature entry into residential aged care.
2. The Australian Government increases funding for counselling services for people with dementia and carers.
3. The Australian Government funds a pilot program of telephone-based support groups for carers of people with dementia (especially for people from rural and remote areas).
4. The Australian Government fund further research and knowledge translation activities on the impact of dementia on relationships in order to improve provision of targeted, relevant support services.
5. Residential aged care facilities provide support to people living with dementia and carers to maintain relationships and enable opportunities for physical intimacy within aged care homes. For example, organisational policies and staff training to address these issues.

# INTRODUCTION

Intimate and family relationships are by nature multifaceted and constantly changing. A diagnosis of dementia and the progressive symptoms of the condition almost certainly result in relationships being different and more complex. As this is an issue that is rarely discussed publicly and people deal with privately, Alzheimer's Australia's consumers requested we write this paper to increase awareness, create a public discussion, and draw attention to the ways in which dementia impacts on relationships. To find out more, Alzheimer's Australia NSW conducted qualitative research via an online survey which received 193 responses (176 carers<sup>1</sup> and 17 people with dementia) and follow up correspondence (emails and telephone interviews) with 32 of these respondents.

We appreciated the openness with which people shared personal and intimate details with us, in order to shed light on their situation and to help others. This paper frankly discusses the relationship difficulties, challenges and struggles that people with dementia and carers told us about, as well as the positive impacts they identified. The paper explores how the relationship between the person with a diagnosis and their primary carer/s changes and shifts as dementia progresses, and what support is needed to help people cope with these changes. Importantly, this paper gives voice to people with dementia and carers as they grapple with the impact of dementia on their relationships. Their moving descriptions of their experiences and emotions are directly quoted throughout this paper. Who better to explain the impact than those who are living it?



1. Including current and former carers

# HOW DOES DEMENTIA IMPACT ON RELATIONSHIPS?

Dementia is the term used to describe the symptoms of a large group of illnesses which cause a progressive decline in a person's functioning including a loss of memory, intellect, rationality, social skills and physical functioning. There are many types of dementia including Alzheimer's disease, vascular dementia, frontotemporal dementia and dementia with Lewy Bodies. In 2017, there are more than 413,106 Australians living with dementia (184,868 (45%) males and 228,238 (55%) females). Without a medical breakthrough, the number of people with dementia is expected to be almost 1,100,890 by 2056<sup>i</sup>. There are currently 1.2 million Australians involved in caring for someone with dementia<sup>ii</sup>.

The symptoms of dementia are varied: how they are expressed is dependent on the individual and the type of dementia they have. Some common symptoms of dementia include short-term memory loss, personality changes, apathy and social withdrawal, communication difficulties (for example, aphasia), poor decision-making capacity and changes in behaviour. These symptoms of dementia can impact significantly on people's interactions and relationships. For example, behavioural changes associated with dementia – such as suspiciousness, paranoia and aggressive behaviour – can put relationships under considerable strain<sup>iii</sup>.

Dementia impacts on relationships in a number of ways and there is no roadmap for how this will occur. The dementia journey is different for everyone and is influenced by factors such as symptoms, progression, personalities of both the person with dementia and their carers, past experiences and levels of resilience. Each individual and their family will experience different challenges and issues as dementia progresses and relationships change. This is not a linear process, it is not predictable. People have to adapt as dementia progresses and as roles within relationships change. Relationships need to be reframed and constantly renegotiated as dementia progresses.

Only a few participants in our research indicated that their relationship was challenging or difficult prior to dementia. Most participants described their relationship, pre-diagnosis of dementia (or prior to the onset of symptoms), as loving and caring. Partners talked about working as a team and sharing responsibilities for different aspects within the relationship, while parents and children described their relationship in terms of the parent being "in charge" and a confidante or guide to the child. These descriptions of relationships change markedly as dementia progresses.

The following discussion of our research findings is divided into four key themes. These are:

- role and identity
- emotional and physical intimacy
- grief and loss
- positive impacts.

We then discuss the support people need to help them deal with the shifts in their relationship and conclude with recommendations for governments and service providers.

*"Our relationship has changed on every front, except that I still love and care for my wife and she is still to me the same lovely person despite her dementia."* Man caring for his wife with dementia





# ROLE AND IDENTITY

Dementia can impact on the roles people hold and consequently their sense of identity within their relationship. People with dementia will likely experience a loss of independence as responsibilities they held within a relationship are taken on by others. They may also fear burdening others with a carer role or other responsibilities they once managed<sup>iv</sup>.

*“Most people have a partner or parent [but] mine have all passed away and I am very determined to try not to be a burden. I’ve only been diagnosed for two years and speech and memory are the main things deteriorating ... I have two sons and my greatest fear is being an invalid and burden. I hope to be able to live independently for as long as possible with the help of available services. All in all I may be mistaken and they will step up. It may be their fear of what is to come that they never speak of my illness.”* Man with dementia

*“My daughter may take on a stronger parenting role ... if my memory becomes very confused, then there is no chance of our relationship staying exactly the same. I will need much more support and a lot more understanding. Also, I will have to accept help. This may be confronting for me and I will probably be somewhat resentful and she will be rather annoyed. She may become more bossy than I would like, and I know that this could be a burden for her as it could end up stopping her getting on with her personal life planning.”* Woman with dementia

Carers may gradually have to take on more responsibility for decision-making which they may find overwhelming, resulting in feelings of resignation or resentment.

*“We are still in love and get on well, and we still both have the same sense of humour. But I feel I am losing my life’s partner and companion. The relationship has changed in that my husband relies on me completely. I am now responsible for everything, including banking and business affairs, daily activities and arrangements. He does not want or expect to make decisions or organise what we do. So it’s more like a parent/child relationship now.”* Woman caring for her husband with dementia

Children caring for their parents often feel that the roles are reversed and they are parenting their parent with dementia. This experience is challenging, confronting and upsets the natural order of relationships – no one wants to feel as though they are parenting their parent.

*“I went from being the child to being the parent. My role went from being supported to being depended upon for every aspect of life. This had initially resulted in a lot of resentment on my part. I struggled to understand why my mum couldn’t just be how she was before. I have always known it wasn’t her fault, but there was no one else to hold responsible for the very dramatic and heartbreaking change in our lives.”* Woman caring for her mother with younger onset dementia

Some people caring for a spouse or partner with dementia also reported feeling like they were in the role of parent, describing their loved one with dementia as childlike:

*“We’re no longer two individuals. It’s evolved into more of a parent/child relationship.”* Woman caring for her partner with dementia

*“I am the leader, decision maker, and ‘mother’ after being the younger wife all our 54 years of marriage ... I hate it.”* Woman caring for her husband with dementia

*“I have become his mother. He has the capacity of a five-year-old. I am his rock. We don’t have a marriage. I feel like my husband has gone.”* Woman caring for her husband with younger onset dementia

Others described feeling like a care worker rather than a partner:

*“My husband has become a shadow of his former self who no longer knows who I am or where he is. There is no longer a relationship as such except to the extent that I am his carer.”* Woman caring for her husband with dementia

*“I am starting to feel more and more like a carer and less and less like a partner in this marriage ... It’s hard to feel that emotional connection to someone when you feel like a worker and not a partner or lover.”* Man caring for his partner with dementia

For both partners and children caring for a loved one with dementia, such role changes can impact on their sense of identity within the relationship and, perhaps, more broadly. How you perceive yourself, your role and your worth is often in relation to other people and influenced by your connections with people who are important to you. If your role within a primary relationship changes and the partner in the relationship is changing, what does that mean for your sense of self?

### **CASE STUDY - Kayla<sup>2</sup>**

Kayla’s mother, Heather, was diagnosed with younger onset Alzheimer’s disease three years ago at the age of 55. Her speech has been significantly affected, and she also experiences anxiety, paranoia and confusion. Heather is aware and scared of the changes she is experiencing.

Kayla, aged 31, told us how dementia has changed her relationship with her mother and as a result she can no longer rely on Heather for guidance and advice.

*“Mum was my mum, you know. I went to her for support, but we can’t have those conversations now.”*

Despite acknowledging that her mum has changed, Kayla still feels a deep emotional connection to Heather.

*“I love her for who she becomes ... I learn to re-love the person she becomes [as dementia progresses]. She’s still her, she’s just different.”*

Kayla also described the positive impact of dementia on her immediate family as they have reunited to care for Heather.

*“It has brought my family back together. We’ve realised how important family is and we’re such a solid unit now”*

Her advice to other carers of loved ones with dementia is to be patient and adapt. Planning for the future is hard for Kayla and her family as it’s uncertain how Heather’s younger onset dementia will progress. Kayla would like there to be more community awareness about younger onset dementia. She also needs support to deal with the emotional impact and grief associated with Heather’s decline.

*“[I need] more accessible information on how to constantly mentally adjust to the change. Every time she enters into the next stage I grieve the loss of that person and learn to love the new person. At first that was extremely hard to deal with.”*

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2. Pseudonyms are used in all case studies presented in this paper.

# EMOTIONAL AND PHYSICAL INTIMACY

*“There is no longer any reciprocal appreciation of my emotional needs, and no empathy from him for the load I carry on his behalf.”* Woman caring for husband with dementia

*“I no longer have the two way intimacy, communication that was so precious in our marriage. However, we still love each other deeply, it is just expressed in a different way.”* Woman caring for her husband with dementia

Intimacy can be defined as feeling close to your loved ones, sharing and accepting feelings, and being emotionally vulnerable and available. Relationships Australia notes that intimacy often doesn't need words, but the ability to put feelings and experiences into words makes intimacy more likely to occur<sup>v</sup>.

Dementia impacts significantly on emotional intimacy. Alzheimer's Europe observes carers can feel that the heart of the relationship is lost and they have lost their life companion and confidante. As a result of communication difficulties and memory loss it can become increasingly difficult to share experiences and memories<sup>vi</sup>.

Several carers told us about the impact of the loss of verbal communication by the person they care for. This is particularly difficult when conversation and banter were cornerstones of their relationship, as these women caring for their husbands explained:

*“The relationship has changed dramatically. I can't confide in my husband, as he can't follow the conversation. He doesn't have the same insight and he forgets all 'conversations'. I'm now thinking for two people, and often, it feels like I'm living with a young child.”* Woman caring for her husband with dementia

*“The emotional and physical side of our relationship has suffered drastically. I tell him as little as possible, bend the truth, pretend a lot and generally try to survive with him as easy as possible. Our social life together is almost non-existent and I prefer to have time away from him if possible instead of doing things together. It has just become too hard as so many people just don't understand. The changes [to our relationship] are too many to list.”* Woman caring for her husband with dementia

Moreover, effective communication is key to working through relationship problems. How can such issues be dealt with when communication capabilities and short-term memory are diminished? For carers of loved ones living with dementia, this is a major challenge.

In addition, an important component of relationships is the shared history – remembering, reflecting and reminiscing about the good and bad times. Carers told us that it can be difficult to feel connected as dementia progresses and the person with dementia forgets this shared history. Perhaps a way to deal with this is to shift the focus of the relationship to a 'shared present' as this man caring for his wife with dementia explains:

*“Our relationship has changed so that I am now more a 'carer' than I am a husband. It has forced me to become more flexible, less pedantic and to live 'more in the moment', because that's where my wife lives. I have found that exceedingly difficult. We have very little shared memory or experience remaining. Our conversations are all about what we can see NOW, what we are feeling NOW, what we hear NOW, what we are touching or tasting NOW. Our experience of a couple of minutes ago is gone, last week and any time earlier very unreliable.”* Man caring for his wife with dementia

Although carers reported challenges in feeling connected, for many the connection remains despite it constantly shifting. As one young woman caring for her mother told us: “... they [people with dementia] are changing, so you need to change with them”. The impact of memory loss is also keenly felt when the loved one with dementia intermittently or permanently does not recognise their carer.

This decline in emotional intimacy can leave people feeling very lonely and socially isolated. Previous research by Alzheimer's Australia found people with dementia and carers are significantly lonelier compared to the general public. People with dementia reflected that friends became more distant after

their diagnosis and symptoms of dementia make it harder to connect with people. Carers felt friends and family were confronted by a diagnosis of dementia and withdrew, while the nature of caring left them with less time to socialise<sup>vii</sup>.

*"We don't have a normal relationship. Everything is about his needs. We can't have a normal conversation. Everything is difficult. We no longer have any social life. Life is very difficult, lonely and depressing. We are just existing."* Woman caring for her husband with dementia

*"I can't respond the way my caring wife would like me to. We also have no sex life."* Man with dementia

Dementia also impacts considerably on sexual intimacy in relationships. While much of the literature on dementia and sex focuses on either an increasing sexual desire or inappropriate sexual behaviour of people with a diagnosis of dementia, our research participants primarily discussed the sadness experienced as a result of the loss of sexual relationships and intimacy between couples.

*"Our physical relationship continued until two years before she went into care. Then it became more about comfort and cuddling. The sex faded away. And that's after half a century together, so that's very sad."* Man caring for his wife with dementia

*"No-one talks about sex. We used to have a reasonable love life, now it is only occasional and at my instigation. It is no longer as fulfilling for me, but I also feel guilty if I masturbate. How do I take care of those very normal human needs?"* Man caring for his partner with dementia

The move to residential aged care also has an immense impact on intimacy for couples, particularly in large facilities where rooms are shared by two or more residents. The simple act of lying in bed together to have a cuddle becomes a challenge in this instance, as these women told us:

*"Our once lively and gratifying sexual relationship is now reduced to my initiating simple touch, such as hand and foot massages and holding his hands. He is now in permanent care and comes home once a week. The most wrenching experience has been parting with him to stay in permanent care and no longer being able to snuggle together at night."* Woman caring for her husband with dementia

*"We had a sexual relationship right up until not long before he went into the nursing home ... But the emotions don't go and physical contact was still important. In the nursing home, he was sharing a room with three other men so it was difficult to find space to have a cuddle."* Woman who cared for her husband with dementia

Managers and staff of residential aged care facilities have an important role to play in enabling intimacy between couples to continue when one partner moves into care. There should be organisational policies in place and staff training to ensure that a comfortable and supportive environment and culture is provided.

Intimacy and sexuality are important contributors to the quality of life and well-being in older people. There can be negative consequences to social relationships, self-image and mental well-being when people are denied the opportunity to sexually express themselves<sup>viii</sup>.

*"Sexual relations are tricky ... that's hard in a marriage; it's a special part of your bond. My advice to others would be to try to keep that part of your relationship active."* Woman caring for husband with younger onset dementia

Carers and people with dementia acknowledged that emotional and sexual intimacy are important for bonding in their long-term relationships. Whilst conversations about intimacy and sex in older people are not commonplace, given a safe and anonymous opportunity people chose to divulge very personal, intimate aspects of their lives to us.

## **CASE STUDY - Rachel**

Rachel cares for her husband, Frank, who has dementia. Rachel has struggled emotionally as Frank's dementia has progressed, especially as their relationship was on rocky ground prior to his diagnosis.

*"We weren't really close. We both lived our separate lives and just talked about the kids. There wasn't a lot of joy or laughter."*

In particular, Rachel has struggled with her perception of who Frank is with dementia.

*"Up until the diagnosis I thought of him as a partner, but my perception of who he was to me changed when he was diagnosed ... I've struggled with trying to overcome that. It's taken me four years to realise that he hasn't really changed and I'm starting to see him for who he is."*

Attending a support group has helped Rachel deal with the changes in their relationship. Rachel says the support group members have given her insight into where things are heading and how she will cope with the future. When asked what advice she would give other people who are caring for a partner with dementia, Rachel replied:

*"I would tell others that when you get the diagnosis, today isn't different from yesterday. They are still the same person but they have a disease. The core of the person is still there and you have to try to find that and nurture that."*



# GRIEF AND LOSS

*“As the disease progresses there will eventually be no relationship. Relationships depend on give and take, not all one way. She will eventually not be the same person I loved.”* Man caring for his wife with dementia

Many carers told us about their stresses and frustrations, as well as their guilt and grief surrounding their relationships as dementia progresses and their caring role intensifies.

*“Dementia is a very cruel disease as the person you love and respect is slowly changing into a dependent and less fully rounded personality. It can be very lonely.”* Woman caring for her husband with dementia

The grief experienced by these carers could be categorised as ambiguous loss. Ambiguous loss is different from the loss and grief of death, because the grief cannot be fully resolved while the person with dementia is alive. This ambiguity and the mixed feelings associated with it are common for carers of people with dementia. It is the loss felt when a person with dementia is physically here, but may not be mentally or emotionally present in the same way as before. This is very different from the loss and grief of sudden death, for example, where loved ones clearly know the person is gone and they are more likely to get support from family and friends. Closure is also more achievable through traditional mourning rituals and the natural grieving process. Ambiguous loss complicates grief as it is continual, difficult to recognise and confuses relationships<sup>ix</sup>.

*“Dementia is a really cruel disease. It leaves your loved one an empty shell but still outwardly the same. A person dies of dementia long before they stop breathing. My wife was my best friend and I am slowly losing her. I see her every day but it is not the same person.”* Man caring for his wife with dementia

*“How can you accept the person you have loved for 52 years personality and cognitive skills disappearing before your very eyes ... it's a heart-breaking grief.”* Man caring for his wife with dementia

The emotional impact of the person with dementia moving into residential aged care is substantial. Previous research by Alzheimer's Australia NSW found the experience of placing a person with dementia into an aged care home is often characterised by stress, emotional upheaval and feelings of relief, loss, grief and guilt. For the person with dementia, moving into care can be disorienting, disempowering and emotional<sup>x</sup>. Carers may experience sadness because they feel their carer role/identity is taken away. Yet the experience may also have a positive impact on a relationship, because the intensity of day-to-day personal care tasks such as showering and toileting becomes a staff responsibility, so family members can identify with their original roles of partner, child and so on.

People with dementia and carers can both feel grief and loss for the person they were, the role they had, their relationship, the shared history and the future. Guilt, as well as anger and resentment are normal emotional reactions associated with this grief. We need to acknowledge these responses and support people to work through them in a way of their choice, such as joining a support group or individual counselling. However for people living in rural and remote areas, accessing support groups can be difficult due to their face-to-face and location specific nature. We need to develop alternative ways to assist carers to connect with and support each other.

*“I still think of myself as married, but there will come a time when I won't. I will just be being with a person with dementia.”* Woman caring for her husband with younger onset dementia

## **CASE STUDY - Trish**

Trish, aged 75, cared for her husband Daniel who was diagnosed with frontotemporal dementia in 2007. Daniel moved into residential aged care in 2012 and passed away in 2016 at the age of 78. Trish reflected on how their relationship was affected as Daniel's dementia progressed.

During their 30-year marriage, Trish and Daniel had a loving and communicative relationship. Prior to the onset of dementia, they had lots of common interests and would have thought-provoking conversations which went on for hours. Daniel lost the ability to communicate verbally quite early on in his dementia, and the lack of verbal communication between the couple and the increasing social isolation impacted greatly on Trish.

*"Coming to grips with dementia was like clutching at clouds ... and there was loss everyday. They call it an ambiguous loss and it's so true. The man I knew was gone, but he was still there."*

Trish felt this ambiguous loss of Daniel acutely and grieved throughout the progression of his dementia.

*"You have to forgive yourself a lot. It's normal to resent the situation sometimes and you need to express your feelings."*

Trish would advise other carers of people with dementia not to feel guilty about moving a loved one into residential aged care. She found her relationship with Daniel improved when he moved into care as the day-to-day tasks of caring were performed by care staff and she was able to spend more quality time with him.

*"Much of my husband's frustration and aggression stemmed from the humiliation of having to be helped with simple tasks like showering, dressing and toileting. When he entered the aged care facility, however, the staff took over these tasks and coped with any outbursts, and we were able to get back much of our former loving relationship. My role became one of the companion who walked hand in hand with him, read to him, played him music and helped with his meals. To know that this can happen might help someone with the inevitable guilt that comes with the entry into an aged care facility."*





# POSITIVE IMPACTS

*“Dementia has actually helped our relationship. Our relationship is stronger as I am the only one of our family that can care for her on a daily basis so we have had to learn to get along and communicate better. We still fight but there are a lot of better moments.”* Woman caring for her mother with dementia

While many of the stories we heard were about challenges, struggles and loss, participants were also able to identify the positive impact of dementia on their relationships. For some, dementia had provided opportunities to reconnect with loved ones and establish new relationships with the person they care for.

*“It is a beautiful, nearly-romantic relationship. We seem much more open with our feelings. I think he has lost many inhibitions in regard to life in general ... His lovely sense of humour remains, in fact has increased as he doesn't have to worry about things. He smiles lots and I love him dearly.”* Woman caring for her husband with dementia

Carers also spoke about how the emotional connection with their loved one with dementia remains; even if the person with dementia doesn't appear to know them, there are still moments of connection. For example, one man told us about the experience of dancing with his wife at her nursing home and although she doesn't remember who he is, in that moment she knows how important their relationship is. It can be a look in their eyes, a smile and knowing glance, or shared laughter.

*“We do very well making tears into laughter and sadness into joy. Our relationship has changed so much already I live with a total stranger, but our memories and the integral man who once shared our lives will remain and be respected for the person he was and the person he has become.”* Woman caring for her husband with dementia

Some carers told us of the satisfaction they received from caring for their loved one and their appreciation of the opportunity to spend time with them.

*“There's a deep joy in putting yourself second and focusing your efforts on the comfort of someone else, emotional or physical.”* Woman who cared for her husband with younger onset dementia

## CASE STUDY - Wendy

Wendy cared for both her mother and father with dementia. Her mother was diagnosed with dementia in 2008 following a number of strokes, and her father was diagnosed with Alzheimer's disease in 2011. They both died in 2014, aged 89 and 93.

Wendy described her relationship with her parents prior to dementia as “not too good”. Her mother was manipulative and always negatively compared Wendy to other people, while her father was an angry and aggressive man. Yet, despite their strained relationship, Wendy wanted to look after her parents and she found her relationship with her parents improved as their dementia progressed.

*“The relationship was easier [with dementia] because it was one-way....It was like they had a second childhood and it was less complicated and easier because they didn't argue and were more settled.”*

For Wendy, the time spent caring for her parents was an opportunity to rebuild a more positive relationship with them.

*“I'm glad I spent time with them. Enjoy the time while you can. Put aside your differences. I didn't want to not look after them and regret it later.”*

# SUPPORT NEEDED

Many survey respondents felt that nothing would help them deal more constructively with the changes in their relationship. Nor could they identify what might help them in the future apart from 'a cure' or 'to not have dementia'. However, other research participants, especially former carers, provided advice for others to help them cope with the changing nature of their relationship as dementia progresses. This advice from carers can be summarised as:

- get as much support as possible
- don't be too afraid or too proud to ask for help
- make the most of available support services
- plan ahead for the future
- recognise that things will change and residential aged care may be necessary
- attend support groups
- use respite services
- see a counsellor
- don't be too hard on yourself!

*"We had a good close relationship and we worked closely together... We are now two separate people. I don't think she knows who I am ... I've had to develop a life without her and that's okay."* Man caring for his wife with dementia

For people caring for a loved one with dementia, there are complicated issues to negotiate as the person who they love is still here and they still have a relationship with them, yet the relationship is constantly changing. To be resilient and deal with this, carers need an understanding of the condition and the reasons for the constant changes, as well as support in their caring role. Counselling sessions with counsellors skilled in dementia can assist carers to understand what is happening, work through their emotions and develop their capacity to care for their loved one. Respite is also an important service to maintain caring relationships. Good respite services provide a meaningful activity or enjoyable experience for people with dementia, while allowing carers to have a break from the day-to-day tasks of caring. Alzheimer's Australia NSW has a range of support services to help carers and people with dementia (see appendix).

## CASE STUDY - Peter

Peter and Margaret, both 75 years old, have been married for 55 years. Margaret had been experiencing symptoms of dementia for five years before being diagnosed with Alzheimer's disease in 2011. Peter recalls that Margaret struggled to accept the diagnosis and was adamant nothing was wrong.

The couple enjoyed a very happy marriage. Peter told us:

*"We had a wonderful relationship. We worked together, travelled together, we did everything together. I couldn't have wished for a better relationship. She was a wonderful mother, a wonderful teacher ... I was very proud of her, and her of me."*

Margaret's dementia "added an edginess to their relationship", but Peter remains devoted to his wife. Peter made use of the available services to support his care for Margaret at home for as long as possible. Margaret now lives in an aged care home and Peter visits her every day.

*"Despite her dementia Margaret is still her lovely self, for which I am very grateful. We still have as good a life together as possible. My life now revolves around Margaret, her care and the friendship of the other residents and the staff who care for them all. It's my extended family."*

Peter is now an advocate for greater awareness and support for dementia, and is undertaking studies in dementia care. His advice to other carers of people with dementia is:

*"Get as much help as you can. Don't think you can do it all. Join a support group and don't knock back help."*



# CONCLUSION AND RECOMMENDATIONS

## CONCLUSION

*“I will be there for my wife. But it will be increasingly from a determination to “do my duty” to her rather than for our relationship being enriching for either of us. I am a realist, but at the same time a sentimentalist in the best sense of that word. Love for one who has been so much a part of one’s life does not end in their absence.”* Man caring for his wife with dementia

It is difficult not to be moved by the rich, thoughtful and frank responses so openly shared by carers and people with dementia. This discussion paper has merely scratched the surface of a complex issue. We hope that it generates a public discussion and enhances community understanding about the ways in which dementia impacts upon family and intimate relationships.

More research is required to unpack this issue further. The link between the symptoms of undiagnosed dementia and relationship breakdown has been largely unexplored and the diverse experiences of people from Aboriginal and Torres Strait Islander communities, Culturally and Linguistically Diverse (CALD) backgrounds, and Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) communities require greater focus.

The response we received for this social research project indicates this is an issue people with dementia and carers want to talk about. It also suggests more work is required to better understand the multifaceted ways in which relationships are affected as dementia progresses in order to develop, improve and tailor support services for people with dementia, carers and their families.

## RECOMMENDATIONS

Alzheimer’s Australia NSW recommends the following:

1. The Australian Government funds quality respite services to support carers to continue caring for loved ones with dementia at home and avoid premature entry to residential aged care.
2. The Australian Government increases funding for counselling services for people with dementia and carers.
3. The Australian Government funds a pilot program of telephone-based support groups for carers of people with dementia (especially for people from rural and remote areas).
4. The Australian Government funds further research and knowledge translation activities on the impact of dementia on relationships in order to improve provision of targeted, relevant support services.
5. Residential aged care facilities provide support to people living with dementia and carers to maintain relationships and enable opportunities for physical intimacy within aged care homes. For example, organisational policies and staff training to address these issues.

## FURTHER READING

If you have a diagnosis of dementia or are caring for a loved one with dementia, you may find these resources helpful. You can access these through the Alzheimer's Australia NSW library – phone (02) 9888 4218 or email [nsw.library@alzheimers.org.au](mailto:nsw.library@alzheimers.org.au)

*Dementia - Support for Families and Friends* by Dave Pulsford and Rachel Thompson

*Living Your Best with Early-Stage Alzheimer's* by Lisa Snyder

*Loving Someone Who Has Dementia* by Pauline Boss

*To Love What Is: A Marriage Transformed* by Alix Kates Shulman

*Ten Thousand Joys & Ten Thousand Sorrows: A couple's journey through Alzheimer's* by Olivia Ames Hoblitzelle

*Come Back Early Today: A Memoir of Love, Alzheimer's and Joy* by Marie Marley

*Green Vanilla Tea* by Marie Williams

*One Day at a Time: Sharing Life with Dementia* by Dorothy Webb

*Jan's Story: Love Lost to the Long Goodbye of Alzheimer's* by Barry Peterson

*A Funny Thing Happened on the Way to the Nursing Home: A Different Handbook for Carers of Dementia Patients* by Jim Connor

# **APPENDIX:**

## **ALZHEIMER'S AUSTRALIA NSW SUPPORT SERVICES**

Alzheimer's Australia NSW services are available to support people with dementia and their carers throughout their dementia journey and can provide advice and guidance about how to deal with changing relationships as dementia progresses. These include:

### **The National Dementia Helpline**

The National Dementia Helpline is a free confidential phone and email information and support service which provides:

- information about dementia and memory loss
- information on how you may be able to reduce the risk of getting dementia
- information about government support services (including My Aged Care, the Carer Gateway, Centrelink)
- information about services in your area
- emotional support to help you manage the impact of dementia.

The Helpline is for anyone who is concerned about their memory, has been diagnosed with dementia, cares for someone with dementia or works with people with dementia, or who wants to know more about dementia.

### **Living with Dementia program**

The Living with Dementia program is an early intervention program for people living with early stage dementia and their carer/support person. It is facilitated by trained professionals and uses a psycho-educational model based on group work theory and practice. The program allows participants to reflect on their individual situation, learn from both the program content and the group experience and to practice and incorporate this learning into everyday living.

### **Counselling services**

Counselling gives people an opportunity to speak confidentially with a professional counsellor about issues relating to dementia. The counselling service is free of charge and is available in person, by telephone or Skype. Some topics that people talk to a counsellor about include: adjusting to a diagnosis; understanding dementia and its impact; caring for someone with dementia; responding to changed behaviours; family issues; loss and grief; and planning for the future.

### **Education sessions**

Alzheimer's Australia NSW runs free courses and workshops for family carers and friends of people with dementia. We work with a close network of community partners to deliver education sessions and help participants to access a variety of services specific to their needs. Our carer education programs are designed to help with practical strategies for managing day-to-day. Options include in-depth one-day, two-day and three-day courses, evening seminars, topical workshops, as well as programs for sons and daughters and extended family.

### **Carer support groups**

Support groups give carers an opportunity to meet with others in a similar situation to share experiences, learn new ideas for skills for living with dementia and engaging in mutual problem solving. Support groups generally meet monthly for about two hours at a local venue. They can have an informal, social focus or be more structured with an aim to educate and inform. The groups work to foster a friendly environment where there is laughter and camaraderie as well as learning. Group members can choose how much they talk about their own experiences.

## **Alzheimer's Australia Resources and Help Sheets**

- Caring for Someone – Intimacy and Sexual Issues [https://www.fightdementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone19-IntimacyAndSexualIssues\\_english.pdf](https://www.fightdementia.org.au/files/helpsheets/Helpsheet-CaringForSomeone19-IntimacyAndSexualIssues_english.pdf)
- Residential Care – Caring Partnerships [https://www.fightdementia.org.au/files/helpsheets/Helpsheet-ResidentialCare03-CaringPartnerships\\_english.pdf](https://www.fightdementia.org.au/files/helpsheets/Helpsheet-ResidentialCare03-CaringPartnerships_english.pdf)
- Family and Friends Matter [https://www.fightdementia.org.au/files/NATIONAL/documents/FamilyAndFriendsMatter\\_english.pdf](https://www.fightdementia.org.au/files/NATIONAL/documents/FamilyAndFriendsMatter_english.pdf)



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DEMENTIA  
HELPLINE**  
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Queanbeyan, Harden,  
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