LIVING WELL WITH DEMENTIA

TALKING ABOUT ALZHEIMER’S ACROSS AUSTRALIA
FIGHTDEMENTIA.ORG.AU
ACKNOWLEDGMENTS

The Alzheimer’s Australia NSW Policy, Research and Information Department would like to thank:

- Southern Cross Care
- Catholic Healthcare

Project advisory group members:
- Catholic Healthcare: Carmel Court, Sonali Pinto, and Grace Chan
- Southern Cross Care: Paul McMahon and Jillian Patience
- Alzheimer’s Australia NSW: Lyndell Huskins & Barbra Williams
- Dementia Advocates: Pauline and David Doig, Linda and Michael Bryan, and Trevor Crosby

Suggested citation

Alzheimer’s Australia NSW respectfully acknowledge 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.

© Copyright: Alzheimer’s Australia NSW, August 2016
The information in this publication is the copyright of Alzheimer’s Australia NSW. Subject to the inclusion of acknowledgment of the source, any written material, visual images, tables and graphs in this publication can be reproduced in whole or part for personal or in house use, without formal permission. Reproduction for purposes other than those stated above requires written permission from Alzheimer’s Australia NSW.

ABN: 27 109 607 472

2 Alzheimer’s Australia NSW
CONTENTS

Acknowledgments 2
Abbreviations 4
Executive summary 5
Purpose 8
Project methodology 9
Background 10
Research findings 14
Discussion 25
Conclusion 27
Recommendations 29
References 30
ABBREVIATIONS

AIHW  Australian Institute of Health and Welfare
ATSI  Aboriginal and Torres Strait Islander
CALD  Culturally and Linguistically Diverse
DQoL  Dementia Quality of Life Questionnaire
LGBTI  Lesbian Gay Bisexual Transsexual and Intersex
QoL-AD  Quality of Life in Alzheimer’s Disease Questionnaire
QoL  Quality of Life
RACF  Residential Aged Care Facility
EXECUTIVE SUMMARY

The primary purpose for undertaking this research is to reframe the conversation around dementia to be more positive and empowering. Much of the focus in research on dementia to date has been deficit focused and done little to address the stigma attached to dementia. It is hoped that the quotes and words of people with dementia and their carers that are contained in the paper serve to change this narrative.

The research aimed to help build the evidence base regarding living well with dementia by identifying key concerns and potential solutions to the challenges faced by people with dementia and their family carers in the Australian policy and service delivery context.

While there is an existing body of research looking into the quality of life and wellbeing of people caring for someone with dementia, there are few resources voicing the thoughts, views, and opinions of people with dementia and their carers in terms of living well with a diagnosis of dementia. The research identified issues with the predominant model of assessing quality of life. By adopting the seven domains of wellbeing of Allen Power, the research sought to understand perspectives on wellbeing as described by people with dementia. Power’s seven domains of wellbeing are:

1. Identity
2. Meaning
3. Connectedness
4. Growth
5. Security
6. Autonomy
7. Joy

Identity emerged as the most important of the seven domains of wellbeing, however, it also emerged that the domains are all mutually interlinked. Attaining, or living, a life filled with joy was expressed as an outcome of successfully living well with the other six domains.

Maintaining personhood is the underlying foundation for quality of life and wellbeing for everyone. This is particularly the case for people with dementia for whom this is made more difficult by the disease process underway and society’s stigmatisation of dementia. One person with dementia described personhood as ‘the nucleus of it all’. Communication and cognitive functioning are critical elements to maintaining personhood at the individual level.

One underlying message that emerges from the research is that people with dementia don’t want to rather they want to be supported as long as they can. Being afforded aforementioned personhood were felt most participants in the research of fully delivering on. Stigma and forward as everyday experiences hinder progress of the community to

“Having dementia isn’t joyful, but your life with it can be enjoyable”
Person with dementia

Participants described the current policy settings as placing serious constraints on people with dementia, carers, families, service providers and professionals to deliver on human rights commitments to people with a disability. There was even concern expressed that policy settings are regressing in how we care and support people with dementia in comparison to the advances being made for people with a disability through the National Disability Insurance Scheme. The emphasis in the NDIS on the individual, autonomy, empowerment, dignity of risk and person-centred approaches are advances that the aged care system is at risk of missing out on.
The aged care system is ripe for innovation, disruption and boundary-testing by people with dementia being more demanding and not accepting care and support that diminishes their personhood. Government policies and accreditation models that support this shift would free the industry from the constraints of a risk-adverse culture that stymies the ability of many stakeholders to support people with dementia to live well.

People with dementia described it is a life and death matter and they asked that policy makers treat their lives with the seriousness and gravity that they deserve.

Arising from this research, Alzheimer’s Australia NSW makes the following recommendations:

**People with Dementia and Carers:**
1. Fill your life with things you enjoy.
2. Be present focused and practice mindfulness.
3. Don’t accept things that diminish your personhood – be your best advocate and be more demanding!
4. Document your life and wishes against the Seven Domains of Wellbeing as part of forward planning.
5. Stay active, be busy and keep connected to others.
6. Give things a go and don’t be afraid to try new things.
7. Find opportunities to mentor others and support them.
8. Look after yourself – find a support group, café, a mentor, counsellor, make time for your needs – whatever works for you.

**Government:**
1. Invest in making Australia a dementia-friendly nation
2. Apply the UN Convention on the Rights of People with Disability to policies for people with dementia
3. Increase investment in aged care programs to adequately resource providers to deliver on psycho-social needs of people with dementia, not just biological.
4. Progress the consumer directed residential aged care model pilot for people with dementia
5. Foster innovation that disrupts the current predominance of residential aged care as the only accommodation model. Co-design the innovative models with people with dementia and providers who are eager to implement new models.
6. Invest in new programs that support people with dementia to live well between the existing early intervention services and the home support programs.
7. Develop a policy approach that stimulates improved responses from GPs to supporting their patients with dementia to live well.
8. Embed the framework of living well into the quality care indicators and accreditation model of the Quality Agency.

**Aged Care Providers:**
1. Lead organisations that foster a culture of supporting the implementation of care philosophies which help people with dementia to live well. Philosophies/models of care build on dignity of risk and sustaining personhood.
2. Provide purposeful and meaningful activities for people with dementia, particularly in residential aged care where greater choice is needed.
3. Pursue increased levels of collaboration with consumers and other stakeholders to improve practices and approaches to care and support of people with dementia.
4. Use the Seven Domains of Wellbeing as a framework to base case management / nursing / activities / therapeutic / allied health practices around.

Alzheimer’s Australia NSW
PURPOSE

This Alzheimer’s Australia NSW discussion paper provides an overview of the factors contributing to high quality of life and wellbeing for people living with dementia and their carers. The primary purpose for undertaking this research is to reframe the conversation around dementia to be more positive and empowering. Much of the focus of research on dementia to date has been deficit focused and done little to address the stigma attached to dementia. It is hoped that the quotes and words of people with dementia and their carers that are contained in the paper serve to change this narrative.

As government policies and programs shift to emphasise choice, control, and wellbeing, it is important that service providers are aware of what is important to people with dementia in order to live well with their diagnosis.

Alzheimer’s Australia NSW conducted a research project which aimed to:

• Identify what ‘living well with dementia’ means to people living with dementia and their carers
• Identify how people with dementia regard the seven domains of wellbeing proposed by Allen Power
• What people with dementia and their carers expect from service providers in order to get the most out of the service environment and lead enriched lives
• Identify potential barriers that stand in the way of improving quality of life for people with dementia
• Encourage stakeholders to take action to enable, support, and encourage wellbeing for all people with dementia.

Selected quotes are provided in a story-telling narrative approach which can serve as examples for service providers, family carers and people with dementia. Names have been changed to protect the identity of respondents. Practice and policy recommendations, developed in consultation between Alzheimer’s Australia NSW and the Project Advisory Committee, are also provided.
Alzheimer’s Australia NSW reviewed the existing literature on wellbeing and quality of life for people with dementia. Our review found that there were few studies focused on quality of life and wellbeing for people living with dementia. The review also highlighted the need for a measure of wellbeing for people with dementia specifically. As a result, it is important that Alzheimer’s Australia NSW present the views and opinions of people with dementia along with their carers.

The research team conducted a mixed-methods research project using a convenience sample in early 2016. The research occurred in the following phases:

**Surveys**
Online surveys were conducted with people living with dementia as well as family carers throughout NSW. The surveys investigated the experiences of people with dementia and family carers in relation to the seven domains of wellbeing for people with dementia proposed by Allen Power2. The surveys also highlighted their opinions about what is needed to live well with dementia and what service providers can be doing to help people with dementia live a higher quality of life. 48 valid survey responses were received; 85% of responses were family carers, while 15% were people living with dementia.

**Interviews**
Semi-structured interviews were conducted with people living with dementia in NSW and their family carers. Participants expressed their interest in participating in an interview through a portal offered at the end of the online survey. The informed consent of all participants was obtained prior to conducting interviews.

The interviews were designed to further explore the experiences of participants living with dementia in NSW, including what they believe could be improved and what they think needs to happen to ensure they live the best possible quality of life. Twelve people participated in the interviews including six people living with dementia and 6 family carers of people living with dementia.

**Focus Groups**
Focus groups were held with various service providers who registered their interest in participating in the project. Alzheimer’s Australia NSW conducted a focus group with eight service providers including residential aged care, home and community care, and community health.

**Project Advisory Committee**
A project advisory committee was established to provide the research team with a greater insight into what is important to people living with dementia and their family carers; promote the research; assist in recruiting research participants; review the research findings and analysis; and contribute to the development of recommendations.
BACKGROUND

There are currently more than 353,800 Australians living with dementia, with this number expected to increase to 400,000 in less than ten years. With the ageing of the Australian population, we are likely to see a steep increase in the number of people with dementia, which has the potential to increase the demand for informal care. The effects of dementia extend further than just those living with the disease. The lives of families and friends of people living with dementia are also affected by their diagnosis.

Common misconceptions such as ‘dementia is a normal part of ageing’ have resulted in a situation where dementia has not been a priority for health policy makers. As the Australian population continues to age, it is important for governments and policy makers to factor in the consequent increase in the incidence of dementia. Dementia is not a normal part of ageing, and as a result it has the ability to significantly lower the quality of life and wellbeing for all those living with it in comparison to people of the same age and life experience living without dementia. It is important that people living with dementia and their families are supported and encouraged to live their lives as the rest of the population does. This is consistent with the United Nations’ principles and rights of people with a disability that Australia is a signatory to.

“You can’t just sit and cry in your soup for the rest of your life, because there won’t be much of a life if you do that.” Person with dementia

“If the federal government actually acted on basic human rights and various UN charters on the rights of people with disabilities rather than paying lip service to them we could start. The rights of all individuals need to be respected, and people with dementia are more commonly the norm. Social inclusion needs to start at the bottom in local communities. Rather than looking up for direction we need to look around at our communities to promote and respect all.” Person with dementia

Personhood, Quality of Life, and Wellbeing

Personhood

According to Thomas Kitwood, personhood is “a standing or status that is bestowed upon one human being by others, in the context of social being. It implies recognition, respect, and trust.” Person-centred care in a gerontological nursing and service provision context is generally based on the promotion of personhood as a means of heightening one’s quality of life. However, when physical or mental anomalies appear, maintaining personhood can become challenging. Previous research suggests that the two primary individual attributes affected by dementia are communication and cognitive functioning, both of which are critical elements to maintaining personhood at the individual level. There are a number of models of personhood.

One model suggests that there are three levels of personhood that need to be considered in applying person-centred care practices in order to improve quality of life and wellbeing for people with dementia. The three levels of personhood are:

- Biological personhood
- Individual personhood
- Sociological personhood

The model provides a structure for organising existing person-centred interventions and strategies in dementia care in a residential setting while considering the fact that personhood changes and develops over time and varies from person to person according to a multitude of personal factors. Essentially, it suggests a ‘one size does not fit all’ approach and highlights the need to consider the person’s biological, individual, and social needs from a number of perspectives. It can therefore be said that in order to attain a high quality of life and wellbeing, personhood must be maintained through all three levels of personhood i.e., attending to the biological needs of the person (nursing and health care), to the individual needs (wants, preferences, choices, security, love and joy) and social needs (communication, maintaining connections in life e.g., friendships).

10 Alzheimer’s Australia NSW
Person-centred care is an important determinant of quality of life and wellbeing in all care settings. A 2012 study investigated the association between person-centeredness and resident wellbeing in dementia care units. The findings suggest that person-centred care was associated with an increased ability for residents to perform activities of daily living with minimal assistance. The research also found that those receiving higher levels of person-centred care rated their quality of life higher and performed activities of daily living better compared with residents receiving lower levels of person-centred care.

While there is a body of work about improving quality of life and wellbeing for people with dementia in residential aged care, there is scarce literature about living well with a diagnosis of dementia in the broader community. Much of the existing literature focuses on maintaining personhood in a residential care setting from a predominantly biological needs perspective.

**Wellbeing and Quality of Life**

While there is a widely accepted definition of personhood, wellbeing is a concept significantly more difficult to define and measure. The main discourse on wellbeing is that it can only be determined by each individual for him- or her-self. Lawton’s model has been the most pervasive conceptualisation of quality of life in dementia, encompassing: behavioural competence, objective environment, psychological wellbeing, and perceived quality of life.

Two newer, well-known, and well-used self-report quality of life questionnaires for people with dementia are the Quality of Life in Alzheimer’s Disease Questionnaire (QoL-AD) and the Dementia Quality of Life Questionnaire (DQoL). The QoL-AD measures physical health, mental health, as well as social and financial domains and provides an overall Quality of Life rating in a single score. On the other hand, the DQoL includes five domains: self-esteem, positive affect, absence of negative affect, feelings of belonging, sense of aesthetics and a global measure of QoL.

There are a number of biological factors that can contribute to positive wellbeing in people with dementia. They include remaining physically active, well-nourished having good sleep and the absence of pain.

“If you don’t eat, you die. None of the other stuff matters if you are malnourished.” Younger Onset Dementia Key Worker

“Being pain-free for a start” Person with dementia

There is research that suggests that walking is an appreciated routine amongst people with dementia. Some research suggests that walking, as a routine, reinforces wellbeing and provides a sense of meaning and continuity in life. Another study investigated the effect that intentional physical activity has on the maintenance of wellbeing and selfhood in people with mild Alzheimer’s disease. It found that physical activity can be an effective way of sustaining wellbeing and selfhood, while also improving physical and cognitive functioning. Previous research by Alzheimer’s Australia NSW on both topics of nutrition and exercise highlighted not only the impact on biological wellbeing, but also that both physical activity and nutrition have social effects as well. Both papers found a high value in being active and eating in the company of others for people with dementia.

“Just ensure that you’re doing things that are constructive, pleasurable, keeping you fit both mentally and physically and challenge you as a person. Make sure you challenge yourself. Yoga is a classic example, all the people in my class are at different levels, but are addressed appropriately by the instructor. It’s all about taking yourself slowly to the next level without incurring pain at your own pace. Just push yourself to a comfortable level. It’s amazing what it does to you. Your inner being and overall health feeling...it’s very hard to explain.” Person with dementia

**Recommendation 1: Fill your life with things you enjoy**

Power disputes the notion that quality of life is determined by the presence or absence of disease or by a measure of functional or cognitive abilities. Instead, he suggests seven independent domains that
are believed to contribute to individual wellbeing. They are: identity, connectedness, security, autonomy, meaning, growth, and joy.

Our review of the literature found scarce Australian research on wellbeing and quality of life of people living with dementia both in residential aged care and in the wider community. Most of the international research in this area consists of small scale qualitative studies. Australian research in this area has focused on residential aged care, not people living in the community which seems ill-focused given that 70% of the population with dementia lives in the community19.

Scales on wellbeing and quality of life can be limiting in scope due to personal definition differences, limited in terms of time of response and progression of dementia, rely on proxies for response, domains for quality change with progression, and the tension between objectivity and subjectivity20. Despite the difficulty in defining and measuring wellbeing, there are a number of philosophies that when drawn together form a theory that can readily be applied to real life situations.

The Seven Domains of Wellbeing

Power suggests seven independent domains that are believed to contribute to individual wellbeing21. They are: identity, connectedness, security, autonomy, meaning, growth, and joy. AlzNSW has utilised this framework to: overcome the difficulty of using quality of life measures; incorporate a qualitative, story-telling approach from people with dementia and carers thereby eliciting their perspectives; present the information in a positive frame of reference; and apply it to dementia and how personhood can be sustained through focusing on the seven domains. The seven domains are:

1. Identity
2. Meaning
3. Connectedness
4. Growth
5. Security
6. Autonomy
7. Joy

Erin is 63 and has been living with dementia for the past five years. While she has had to retire from her position as a teacher’s aide, she has filled her spare time working in a similar role in a volunteer capacity. She keeps herself busy both socially and physically through her involvement in her weekly cycling group, by walking her neighbour’s dogs and by attending a dementia café on Sunday mornings. “I never used to be this active in the community. Call me strange, but some people would say that this is the worst time of my life, but I don’t think I’ve ever been happier.”

Recommendation 5: Stay active, be busy and keep connected to others.
The Seven Domains

This section discusses the research findings aligned to the seven domains.

Identity

Identity is described as being well-known, having personhood, individuality, respect, wholeness, and having a history. Although identity is an important contributor to wellbeing, there are a number of both intrinsic and extrinsic challenges posed to maintaining identity for people living with dementia. The forgetfulness that is associated with dementia makes it difficult for a person to reflect on their personal history, their past occupations, relationships, social roles, and their spirituality – posing a challenge to maintaining a strong grip on individual identity. In addition to this, societal values, perspectives and the stigmatisation associated with dementia can generate a devalued view of a person living with dementia, which is thought to contribute to the erosion of one’s identity even more so.

Maintaining identity was very important to both carers and people living with dementia. Eighty-five per cent of respondents living with dementia believed their identity had been maintained while living with dementia. Some attributed this to maintaining their sense of humour, while others hinted that this was possible because very few people knew about their diagnosis.

One person living with dementia said:

“Frontotemporal dementia may contribute to a process of self-reflection and re-evaluation of personal priorities. It may also have decreased my inhibitions about expressing myself [helping me maintain who I am].”

Similarly a carer said:

“He certainly knows who he is. It is other people in the family whom he confuses.” Wife of man living with dementia, in the community

On the other hand, a carer of a person living with dementia in residential aged care felt that her husband’s identity was being compromised:

“I don’t think my husband’s identity is being maintained very well because staff attend to do everything for him, treating him like a child instead of stimulating him to do the things that he can for himself.” Wife of man with dementia living in RACF

One respondent expressed frustration at residential aged care staff not understanding the importance of appearance to some residents:

“When my mum was moved into residential aged care there seemed to be this attitude that maintaining the way a person dressed and presented themselves was no longer important. Mum was always dressed nicely, with hair done and a bit of makeup. That’s what she liked. But on entering care the clothes are washed within an inch of their lives and not ironed or put away nicely. So what she was wearing was inevitably crumpled, stretched or damaged. They didn’t think about coordination of clothes, or doing her hair or nails or a bit of makeup. We tried to maintain this but when you’re not there all the time it is hard to do. If mum could have seen herself she would have been devastated. Prior to this I made sure she was always dressed well, did her nails and made sure her hair was done (to the best of my ability).” A daughter of a woman living with dementia in RACF

“In aged care homes minimal attention is paid to who they were other than in lifestyle programs and their past experiences are narrowed down to a few general concepts. For example, music from the war years continued to feature in lifestyle programs when the current population there lived through the music of the 1950s and 1960s. It wasn’t a good fit.” Son of man living with dementia in RACF

14 Alzheimer’s Australia NSW
There was realisation from carers that an individual’s identity was able to change with the progression of dementia and that this needed to be accepted by family and care staff:

“His identity has been partly maintained only. Managing the finances was a big part of his identity but he can no longer do this. A new part of his identity that has developed is his participation in an ART (Art Respite Therapy) group.” Carer of man with dementia, living in the community

Qualitative survey data also revealed that it was important to both people with dementia and their carers that their identity not only be maintained, but respected as it changes.

“My mother-in-law is adamant that people should treat her with respect. Today when I visited her in the nursing home she told me she scolded staff when they just opened her wardrobe without first asking her if it was okay to do so, demonstrating her awareness of her belongings and her self-esteem.”

The research also revealed that while identity was important, stigma was a barrier to it being maintained, particularly for those living in the community.

“We try hard to keep things normal and help mum keep her identity, but with changes in behaviour and severe paranoia, we noticed people (friends, neighbours, services) treat her differently. I noticed some health professionals dealing with mum not as we know her but as someone with dementia, not our mum, nan, husband, active community member.”

Interview participants provided a number of suggestions as to what service providers could be doing to better maintain the identity of people living with dementia:

“Residential facilities need to put more time and effort into helping people maintain the way they like to present, the activities they like to do (whether social or otherwise), their cultural choices, likes and dislikes, relationships etc. All the things that make up a person’s identity. There needs to be a thorough discussion with the person and/or carer/partner/family of choice about the person’s identity and how they can be supported to maintain this. This could include having a simple “plan” that sits in the person’s file or in a private place that staff can access in the person’s room. Something that can be referred to and used. Staff should also have a lengthy introduction to new consumers rather than relying on notes or ‘hand over’ and training on what identity is, why it’s important and how to support people to maintain their identity even if it’s something that the staff member themselves might not personally agree with. It’s about the person they are working alongside not what they think is okay. In addition staff should be supported to be advocates for a person as sometimes the way a person identifies themselves is not supported by their family of birth.”

Recommendation 3: Don’t accept things that diminish your personhood – be your best advocate and be more demanding.

Meaning

Meaning can be defined as significance, heart, hope, import, value, purpose, reflection, and something sacred amongst people living with dementia. The medical model of care tends to strip away meaning in terms of the physical environment and delivery of care. A person-centred approach has the ability to infuse meaning into every aspect of care. Structuring days by activities that are meaningful can enhance pleasure for people living with dementia.

“I live here on my own. I keep myself as active as I can. When I was diagnosed I didn’t know how I felt. Then after a while, I told myself there’s no use sitting around…you kind of have to just get up and move on with your life.” Person with dementia

All respondents living with dementia indicated that living a life full of meaning was very important to them. Eighty-five per cent of respondents living with dementia believe it is possible to live a life full of meaning, while 90% of carers believed it was possible to live a life full of meaning with a diagnosis of dementia.
“To live a meaningful life, my husband does as much as possible for himself. He prepares the meals, showers, shaves and dresses himself and sorts out his tablets but checks with me before taking them. It’s important to let him do this as it gives him purpose.” Carer

Some carers expressed concerns about the lack of purposeful and engaging activities offered by service providers and the community:

“The activities offered by the Respite Service do not have a purpose. They are just entertaining/fill in the day. From my perspective, they seem more like a baby sitting service.”

“People with dementia can and should live a meaningful life, but quite often don’t as there isn’t the support and infrastructure for them in the community.”

Case Study: Man living well with dementia

Bill is a member of a lawn bowls club and that is his major interest. He really feels at home when he is there and plays Pennants (competing with other bowls clubs). People there understand what is going on with him and he is fully accepted and liked. Bill and his wife attend regular barbecues and dinners at the bowls club with our Happy Hour group of friends. He also goes twilight sailing in summer as a crew member on a friend’s boat. They too are aware of his dementia and are watchful - he is an appreciated crew member.

He enjoys gardening and reads a little when he goes to bed. He likes to stay as fit as he can and walks most days with his wife and dog; goes cycling in the cooler weather, and enjoys travelling.

He participates in family events and has a good social life, both in our local community through the bowling club and through gatherings with our other good friends. Bill and his wife entertain friends and family at home frequently as he is a good host. His conversational skills have declined, but he just likes ‘being there’ with other people.

Bill and his wife go to classical concerts, an occasional movie, see plays and plays music at home. He is aware of the ‘use it or lose it’ principle, and plays chess in the local chess club - most of the members are also bowlers. Sudoko is always on the go and he plays various other mind games. Bill’s wife said ‘We have a good life, thus far.’

Respondents also put forward suggestions regarding what needs to be done in order to provide people with dementia with the opportunity to live meaningful lives.

“We need flexible service delivery at home to enable the person to do what is truly meaningful to them. Taking them out to meet with their friends, not just with the care worker, enabling holidays with family where a care worker can come on holidays and help care for the person as they would if they were at home. Thinking out of the box and being innovative and flexible with what the services can do is essential. Everyone is an individual.” Carer

Carers again stressed the importance of providing engaging and stimulating activities and tasks for people with dementia to maintain meaning and a sense of purpose in their lives. Empowering people with dementia and their carers to manage packages of support will contribute to their determining flexible services that meet their needs. Models such as the NDIS and consumer-directed care are therefore supported by this research as they provide people with dementia the opportunity to make choices and have control.

“I think stimulation is really important and it’s not hard to find interesting things to do - even simple things. Making the most of what the person living with dementia can still do is another good thing as it helps with self-worth and allows the person to feel they can make a contribution.” Carer

The responses to what could be done to improve meaning overwhelmingly emphasise increased social

---

1 All names have been changed for confidentiality reasons.
interaction and engagement in meaningful activities.

**Recommendation 2: Be present focused and practice mindfulness**

**Connectedness**

Connectedness can be defined as a state of being and feeling connected, alive, belonging, engaged, involved, not detached, connected to the past, present and future; connected to personal possessions, place, and nature. Connectedness is particularly important in residential aged care settings where a strong connection between the resident, the staff and the family helps empower and enable the resident in participating in meaningful activities and decision making.

Communication within the dementia care triangle is integral to ensuring people living with dementia feel connected. Research suggests that improving communication skills in dementia care has the potential to significantly improve the quality of life and wellbeing of people with dementia and their family carer, while also increasing the likelihood of positive interactions in a variety of care settings.

**Figure 1: The Dementia Care Triangle**

Both people with dementia and their carers rated connectedness as an important contributor to wellbeing. Carers expressed frustration at the poor levels of communication in residential aged care between staff members, family members and the resident.

"There is a serious issue of communication in residential aged care. I understand that the staff work in shifts, but the handover needs to be done a lot better so that the residents and their families don’t miss out. They make it really difficult to stay connected to mum." Daughter of person with dementia living in a RACF

Survey respondents agreed that maintaining friendships and community ties is an important factor in maintaining wellbeing, but felt that there wasn’t enough being done to ensure that those ties were maintained.

"As far as friendships are concerned, they ‘fall away’ as soon as the diagnosis is known. You lose your self-worth in the eyes of the community." Person living with dementia

"Communities need to become more dementia friendly and supportive so that people with dementia can spend as long as possible living at home with access to everything they enjoy. If I’m moving into residential care, the service needs to make their service much more home like and far more in tune with my needs and wants than they currently are." Person living with younger onset dementia in the community.

Many carers also felt that the person they care for could be better connected to friends, family, and the community with increased awareness about dementia:

"More knowledge has to be spread in the community among the general public, but more importantly to carers about what is the best ways to make the person feel connected to the people around them. How to interact, what is the best way to manage them conversations and issues that may come up, etc. “ Carer
One person with dementia outlined the steps they have taken to ensure they remain well connected:

“Inclusiveness in social events is extremely important to me. To feel part of a group is vital. If people around me understand that I have dementia they put themselves out to make me feel welcome and one of the crowd.” Person with dementia

“I think the answer in many cases is that people don’t know how to address the news and so they clam up and avoid you. It’s your job to get out there and tell them, ‘Right, Fred. I’ve got some bad news. This dementia business is a bit of a pain in the butt. But I live with it, and I need your help to live with it’. By telling people, I think they gained a lot of respect for me.” Person with dementia

**Recommendation 7: Find opportunities to mentor others and support them**

**Growth**

The person-centred model of care provides people with dementia opportunities to learn and grow. However, the capacity for growth faces both personal and operational challenges in a variety of contexts. Segregated living poses a great challenge for people living with dementia as their dementia becomes the defining factor of the living area. Meaningful activities are not only central to the wellbeing of people with dementia, they are also integral to the enablement of the individual and the growth of capacity and social networks.

Only half of respondents living with dementia were satisfied with the number of opportunities they were provided with to learn new things, while 45% of carer respondents believed the person they care for is provided with enough opportunities to learn and grow.

Many carers pointed out that their loved one was too busy enjoying the things they already do, while others believed they were unable as a result of their dementia:

“She continues her hobbies that really interest her and she has been doing them for a long time. Her level of interest is high and any new learning is about what they are already doing. Trying to learn something new has not been very successful due to memory issues.” Carer

Other respondents highlighted the need for more opportunities, particularly from respite and home care providers:

“There needs to be a large variety of programs for people with dementia to participate in. There are a lot of people who won’t attend respite groups because they don’t like the activities offered – this makes it hard for carers to encourage them to go.” Carer

People with dementia expressed their understanding of growth:

“To me, growth means challenging yourself and throwing yourself into things like the living with dementia program or advocacy work. I’ve also started playing bridge. I’m not very good at it, but I haven’t been thrown out of the bridge centre - yet. It’s all good fun.” Person with Dementia

Others expressed their frustrations at the limitations being imposed on them by others.

“There are a number of physical challenges I would like to take part in, but everyone around me is telling me I shouldn’t do it because it’s too dangerous. I’m fitter now than I’ve ever been in my life. If not now, when?” Person living alone with Younger Onset Dementia

Having capacity to decide what they take part in and do/don’t do is important for people with dementia from both an autonomy and growth perspective. Decision-making about things that impact people with dementia is something that should be encouraged for as long as possible.

“I am consulted with any decision-making...I should continue with activities of all kinds that I’m interested in and am always encouraged to do whatever I can possibly do.” Person with Dementia

“I like to take part in new and exciting things, but my wife thinks they’ll do me more harm than good. I...
understand the risk involved, but it’s what I want to do.” Person with dementia

Recommendation 6: Give things a go and don’t be afraid to try new things.

Security

There are many aspects of this domain. They include freedom from doubt, anxiety or fear; feeling safe, certain, assured; having privacy, dignity and respect. As a result, security refers to more than just environmental security and the locking of doors. It revolves around ideas of familiarity and comfort with one’s surroundings and the way in which they interact. Security can also refer to the certainty that one’s identity and lifestyle will be maintained.

“As a carer, you want to allow them to maintain as much independence as possible, but it’s difficult to make choices sometimes. It was easier for me because I knew very well what mum was capable of doing and what she wasn’t, so I was more sure of myself.” Carer

Being free from abuse is a critical element of living well. The heightened potential for abuse, particularly financial abuse, is a cause for concern as expressed below and covered extensively by Alzheimer’s Australia NSW previously.

“There is a need for legislation which includes penalties for those who knowingly and/or deliberately take advantage of someone with a known condition - this includes the forced reimbursement of any money inappropriately taken by the individual (e.g. a tradesman who overcharges someone because they know of the person’s problem and they then take advantage of the situation - it has happened to me more than once as of late).” Person with dementia

Planning ahead is one strategy to reduce vulnerability to abuse and neglect, but also having your wishes respected.

“I have put in place my power of attorney and advanced care directives so I have security and peace of mind that when I am no longer able to make decisions myself, they will be made on my behalf the way that I would have made them. This relieves my fear for the future a little bit.” Person living alone with dementia

There is a natural tension between security, risk and dignity for people with dementia. Removing physical risks or risky activities from one’s life may involve removing components of life that are valued and thus may compromise quality of life. This may be doing more harm than good to people living with dementia. People have the right to be wrong, to make mistakes – these are natural human rights.

Recommendation 4: Document your life and wishes against the Seven Domains of Wellbeing as part of forward planning.

Autonomy

The literature suggests that of all the seven domains for wellbeing, autonomy is most treasured by people living with dementia. Exercising the right to choose our life’s path and to make decisions both large and small is a fundamental human right. The term itself refers to liberty, self-governance, self-determination, and immunity from the arbitrary exercise of authority, choice and freedom.

‘Living well means being able to have the shots called.’ Person with dementia

35% of people with dementia who responded to the survey said they were not happy with the level of involvement they have in making decisions in their lives. This mirrors the 65% of carers who believe the person they care for is happy with the level of involvement in decision-making.

Some respondents expressed their frustrations with limited decision-making at end of life.

“I would like to have a say about end of life decisions. The federal and state governments should ‘man up’ and put in place clear and unambiguous autonomy for end of life decisions. I can be prosecuted

20 Alzheimer’s Australia NSW
for not euthanizing a dog’s life if they are in intractable pain. Why can someone not be prosecuted for allowing people to exist, with no quality of life, with debilitating, intractable and chronic pain that will never improve who wish to die. It is wrong.” Person with dementia

“Dying well is just as important as living well.” Person with dementia

“Quality of death reflects the quality of life.” Carer

“Being respectful to their wishes, within their disease. Writing down the things they like to do, and not setting them up for failure. Nice to be in small groups of people with similar interests, rather than having one blanket task for a huge group, when individuals may not like doing that activity.” Carer

Carers reported the reality they confront with diminishing capacity, but steadfastly believe in the value of maintaining the capacity, involvement and respect for the person with dementia. Encouraging people to make plans and decisions for as long as they can, in areas that they are able, recognises and supports the personhood of people with dementia. At some point in the progression of dementia, people will stop being able to do this and it is important that we encourage autonomy and push this time out as far as possible.

“With the loss of memory, it will be easy for family to refer to me about decisions. I feel my husband needs to be involved, even though he finds it difficult to make a decision.” Carer

“It is important for him to have had a break away from me, as much as I need my space. Working on what he has and is still able to do, minimally now, within his capability at the time, and recognising when he is unable to do the activities. It’s important to keep focusing on him as an individual, and working on a 1:1 basis.” Carer

Personal, operational and physical barriers exist in the maintenance of autonomy in people living with dementia. In addition to the stigma attached to older adults in general in terms of decision-making, people living with dementia are further disempowered through aspects of life and care in terms of exclusion in discussions and the creation of regimented living schedules. Autonomy can also sometimes be compromised by the risk-averse attitudes and practices of carers and service providers.

Joy

In Power’s model of wellbeing, joy is happiness, pleasure, delight, contentment, and enjoyment. It is basically a term that describes the best, most elusive dimensions of human experience. Research suggests that when personhood is maintained, wellbeing is likely to occur and, in this case, manifests itself through positive or happy mood.

The concept of joy received mixed reviews from people with dementia with some arguing that ‘enjoyment’ is a more important contributor to wellbeing than ‘joy’.

“If you get involved in something you get pleasure and enjoyment from, I guess that means you’re experiencing joy to some extent. Having dementia isn’t joyful, but your life with it can be enjoyable.” Person with dementia

Sixty-five per cent of people with dementia carers responding to the survey believed that they experience enough joy in their lives, while 65 per cent of the carer respondents agreed the person they care for experiences joy.

“If I did not have dementia I would be short on joy as there would be more time in my life and less focus on how every moment of life is precious.” Person with dementia.

One respondent suggested a simple recipe for experiencing joy while living with a diagnosis of dementia:

“If you don’t like it, don’t do it. It’s a simple philosophy.” Person with dementia

Other respondents suggested that joy is not an important contributor to wellbeing and that engaging in

ii Note that this is the view of one respondent and not a representation of Alzheimer’s Australia NSW views on the matter.
purposive and meaningful activities was more important to people with dementia:

“My husband is not interested in doing anything that might bring joy... he only wants to do things he knows he can succeed in which is going for a walk and doing sudoku.” Wife of man with dementia

“What helps me live a good life? It’s that cocktail of exercise, activities and mental stimulation and the help that I obtain from Alzheimer’s Australia NSW ...stirred, consumed, lovely, beautiful.” Person with dementia

Recommendation 8: Look after yourself – find a support group, café, a mentor, counsellor, make time for your needs – whatever works for you
WHAT CAN SERVICE PROVIDERS DO TO SUPPORT PEOPLE TO LIVE WELL WITH DEMENTIA?

The concept of wellbeing can provide a framework for reimagining the role of service providers in supporting people with dementia as fully as possible. In order for wellbeing to be enhanced and quality of life to be maintained, it is necessary for all staff working with people with dementia to adopt attitudes and care practices that ensure the self-esteem, independence, and personhood of the person with dementia are maintained.

There is no denying that in order to provide optimal care that maintains quality of life for all people living with dementia, there is a need for a cultural change within organisations – from ‘doing to’ to ‘enable for’ and from ‘this is how we do it’ to ‘how would you like it to be?’.

Findings of the focus group conducted with service providers reveal the aged care sector can articulate best practice and person-centred care that aims to improve quality of life and wellbeing, but their inability to implement this is argued to be the greatest barrier to ensure this outcome for people with dementia.

“Successful implementation of this needs a whole-of-organisation approach. Managers need to provide their staff with the resources (knowledge, time, and support) to do this.” Service provider

This statement is further supported by the Australian Aged Care Quality Agency.

“The ability to articulate a philosophy of care but being unable to implement it can be a major challenge for service providers in achieving quality. Successful implementation of a quality culture requires a ‘whole of organisation’ approach.”

Focus group participants referenced organisations using interpretation of legislation as a ‘shield to hide’ from delivering better care. Coupled with a funding environment that is seeing reduced subsidies in residential care, uncertain future around home care funding, and activity based funding that does not accommodate the additional needs of a person with dementia in hospital, the participants also made reference to the need for macro-level policy changes that will support better practice. Should this occur, it is thought that:

“There is no reason why people with dementia’s wishes (to live well) can’t be fulfilled” Residential Aged Care Service Provider

Barriers to achieving quality in aged care identified by the focus group participants are presented by themes in the table below:

<table>
<thead>
<tr>
<th>Themes</th>
<th>Barriers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Workforce related issues</td>
<td>Education and professional development of staff is an ongoing challenge. There is also a need to change staff attitudes in order to recognise that people with dementia have a basic human right to make choices about their life. Specific issues mentioned included: an ageing workforce, attracting new workers (including creating more pathways for younger people), difficulty finding and retaining the right staff with the right attitude and aptitude. Participants were concerned about whether there will be sufficient investment in staff development will take place in a consumer-directed funding environment.</td>
</tr>
<tr>
<td>Lack of resources and capacity</td>
<td>Engagement in community life which caters to individual preferences would be enhanced through additional resources and capacity, including financial, workforce and technology.</td>
</tr>
<tr>
<td>Balancing risk while supporting choice</td>
<td>The issue of ‘dignity of risk’ emerged as a consistent theme – balancing safety and risk of harm against the right of consumers to have autonomy, control and make their own choices. Enabling consumers to flourish by pursuing their choices is made more difficult in a risk-averse culture in which the use of litigation is perceived to be growing.</td>
</tr>
</tbody>
</table>
Fear of what can happen ‘if something goes wrong’ This acted as a brake on innovation, provider willingness to allow consumers to take greater risks and for consumers to exercise freedom to engage in community life. Staffing limitations and concerns for the safety of consumers were seen as key factors that could contribute to social isolation of consumers.

The focus on clinical care While acknowledging the necessity of this for people with serious health issues, it was felt that this focus results in decreased attention given to psychosocial and spiritual needs. This has a detrimental impact on the quality of life of people with dementia who the providers support.

Funding driving behaviour The Aged Care Funding Instrument (ACFI) was singled out for its focus on tasks and needs/deficit based model of funding. This means that care becomes task driven, rather than focus on those factors that drive quality for individuals (i.e. communication, engagement, choice, caring) and incentivising innovation and psychosocial needs.

“Spirituality should be given a high priority in terms of ensuring the care context incorporates meaning, purpose and connectedness in a way that is relevant to the older person.” Let’s talk about quality – online provider response 2015

Focus group participants described the enablers to living well with dementia that service providers should implement. When analysed and put into a logical flow, a framework for creating a leading provider of dementia care was articulated.

Participants strongly argued for a need to change the focus in human service delivery from measurements/ KPIs to improving the care and quality of life outcomes. They speculated about whether the increasing choice offered by consumer-directed care will lead to innovation, responsiveness, dignity of risk and improved lives for people with dementia. This will be an interesting area to observe as the policy reforms occur.
This paper has highlighted: the need to understand wellbeing from the perspective of people living with dementia; that it is difficult to create an objective measurement of wellbeing; and that expectations and perceptions about wellbeing will change over a person’s life. The paper cautions against the concept of linking disability caused by the dementia with a person’s quality of life. This problem parallels the disability paradox: the symptoms of dementia only lower quality of life when they adversely impact on the person. By focusing on wellbeing through a story-telling narrative, this research has presented a different perspective grounded in the words of people with lived experience of dementia.

Wellbeing is a broad concept that extends beyond the biological definition of ‘absence of ill health’ and having food, nutritional and hydration needs met. The pioneering work of Kitwood and Buron in extending the scope of supporting people with dementia beyond attending to the biological needs of the person, to include the individual needs (wants, preferences, choices, security, love, joy) and social needs (communication, maintaining connections in life) continues to have contemporary relevance and shapes organisational approaches to person-centred care.

This paper has also reaffirmed findings from other research in unearthing disagreement between what carers and people with dementia think and say – in this case regarding the concept of Joy. It is very important to focus on the person with dementia and not always rely on carers as proxy voices. This research demonstrated this by conducting primary research simultaneously with both groups to elicit their perspectives.

The comments from people with dementia in this paper reveal that adaptation over time is important in order to accommodate and respond to the progression of dementia. The reality of dementia is that Growth is going to be difficult due to the nature of the disease and progressive decline, and the comments reveal a very positive attitude of focusing on a short-term timeframe. Growth cannot be ignored, nor assumed that it can’t happen. This finding should spur people with dementia, carers, family members and services providers to facilitate and create opportunities to learn, grow and continue to live a life filled with purpose.

Felicity’s mother, Grace, has fairly advanced dementia. Although she can no longer speak, Felicity still ensures that Grace is provided with the best possible opportunity to express her wants and needs. “I got her an iPad and created pictures on her homepage for her. That way she can point to what she wants to do.” Felicity keeps her mother active by setting up simple obstacles for Grace to take part in and gives her small tasks to do around the house. “You can tell she’s content with herself after she’s helped me bake a cake or tidy up, there’s a sort of look of pride on her face.” Felicity also keeps her mother physically active by joining Grace for walks around their gardens three times a day. “Sometimes we pick some flowers, she loves smelling them and putting them on display on her dresser.” In order to help her mother live well with a diagnosis of dementia, Felicity feels it’s important to provide her with purpose, “We all have a purpose in life, she’s forgotten hers. It’s my job to give her a new one and keep her going.”

Having Meaning and purpose in life – a reason to get out of the bed in the morning – was a very strong theme in many responses. This positive mindset and seeking to get the most out of every day clearly has a very beneficial effect on the people who responded in this way. This included trying new things, continuing to do old things they enjoy, taking risks by doing something they have never done before, or joining groups they would never have considered joining. Where people demonstrated this open-minded pursuit of things that are life-affirming and give purpose to them, it was clear that they felt they are living well with dementia.

“There weren’t many people who wanted to employ someone who was even mildly affected by dementia. My life changed radically in a short period of time. I quickly realised that I needed to fill it with things that both Janet and I enjoyed doing. I decided to fill my life with things of a sporting nature and testing my memory on a regular basis with crosswords and puzzles. I decided to focus on the very short term. ‘Tomorrow is the best day of your life’ you need to live on that basis. By adopting that more positive approach and sharing my story with friends and experts, I was able to fill my life with things I
like to do like playing cricket, doing yoga, playing golf, and just recently taking on Bridge. I figured, if I couldn’t do they physical stuff later on, you don’t have to be too mobile to play Bridge.” Person with dementia

One of the most encouraging developments in the last decade has been the emergence of the dementia-friendly community movement. Dementia-friendly communities provide the positive environment and settings where people with dementia can be more active, participate and be engaged in activities from which they previously would have been excluded. These activities are essential for sustaining and improving Connectedness and reducing the stigma attached to dementia. We are social beings and living in a community that is accepting, welcoming and inclusive of people with dementia will contribute in a large way to them being able to live well.

“Everyone has different interests, so all it needs is to look around. Try something different. Go out and do nice things. Have a picnic! Take a ferry trip!” Person with dementia

As Australia reforms its aged and disability care systems to a consumer-directed care approach that is focused on empowering, enabling and allowing choice for people with dementia/disabilities, it will be interesting to see how providers of these services respond to supporting people with dementia to live well. The consumer-directed care model encourages the concepts of Autonomy and Growth and this is supported by Alzheimer’s Australia NSW, as the alternative approach has not always achieved this in practice in the past.

This research has revealed that there are potential barriers to empowering people with dementia, such as carers and aged care staff making decisions about what is ‘in the best interest’ of the individual focusing on Security, rather than focusing on what the person with dementia ‘wants/needs’ as revealed in the quotes in this paper, which gives the person Meaning, Autonomy and Joy. The words of people with dementia eloquently describe how they want to be respected, treated with dignity and be allowed to make mistakes. How providers and carers respond to this expressed need of people with dementia will have implications for how well they are facilitating people to live well with dementia. For providers, the need to change to such an approach may also have implications for their ongoing sustainability and viability as consumers take their portable funding to providers who meet this need for them.

From a policy perspective, this paper has highlighted three principle themes:

1. The value attached to, and the effectiveness of, early intervention approaches to enabling people to live well with dementia. This includes: information at the right time; access to support such as counselling, support groups and education; occupational therapy and home modifications; and cognitive therapy.

2. The need to pursue a ‘whole-of-life course’ approach to living well, including the trajectory from diagnosis to death. This includes: meaningful and engaging programs that are tailored to the individuals’ wishes and abilities; sustaining sleep, exercise, hydration and nutrition; and planning ahead to ensure wishes are fulfilled in palliative care and in death through wills, Powers of Attorney, Enduring Guardian appointments and Advance Care Directives.

3. The persistence of policy settings that act as perverse disincentives to what consumers want from their aged care system. This was highlighted by the Productivity Commission in 2011 and there has been no change in the intervening five years. Settings may contravene the UN Convention on the Rights of People with a Disability with services like dementia specific units and special care units representing discrimination on the basis of disability, which is a violation of the inherent dignity and worth of the human person. The focus group with service providers revealed the persistence of approaches driven by policy settings that ‘compensate for loss’, fear of consequences unknown leading to risk-aversive care practices, an overemphasis on clinical care and low investment in leadership and staff training. This culminates in cognitive dissonance for staff because providers often are unable, or unwilling, to implement the strategy, vision and care philosophy that is articulated to clients, families and the broader community.

26 Alzheimer’s Australia NSW
CONCLUSION

Australia is a signatory to the *UN Convention on the Rights of People with a Disability*, however, this paper highlighted concerns from people with dementia, carers and service providers that the country is not making progress for people with dementia.

Progress, while slow, is being made in new policies enabling choice, control, dignity of risk and autonomy. These changes should bring about changes that sustain the personhood of people with dementia. The frustration that is conveyed in the quotes from people with dementia and their carers is that this change is not happening fast enough, or in all parts of the health and aged care systems.

While Government and service providers move through these changes, the paper has identified key messages for people with dementia and carers about how they can live well with dementia. These messages will support people to: remain independent for as long as possible, engaged in purposeful activities, have meaning in their lives and be present-focused.

“Denial is fairly detrimental to your quality of life. Accepting your diagnosis is the first step to leading a good life with dementia.” Person with dementia

This paper is timely in light of the Australian policy context and international shifts in how people with a disability, including dementia, are supported, enabled and have their basic human rights enshrined.
RECOMMENDATIONS

People with Dementia and Carers:
1. Fill your life with things you enjoy.
2. Be present focused and practice mindfulness.
3. Don’t accept things that diminish your personhood – be your best advocate and be more demanding!
4. Document your life and wishes against the Seven Domains of Wellbeing as part of forward planning.
5. Stay active, be busy and keep connected to others.
6. Give things a go and don’t be afraid to try new things.
7. Find opportunities to mentor others and support them.
8. Look after yourself – find a support group, café, a mentor, counsellor, make time for your needs – whatever works for you.

Government:
1. Invest in making Australia a dementia-friendly nation
2. Apply the UN Convention on the Rights of People with Disability to policies for people with dementia
3. Increase investment in aged care programs to adequately resource providers to deliver on psychosocial needs of people with dementia
4. Progress the consumer directed residential aged care model pilot for people with dementia
5. Foster innovation that disrupts the current predominance of residential aged care as the only accommodation model. Co-design the innovative models with people with dementia and providers who are eager to implement new models.
6. Invest in new programs that support people with dementia to live well between existing early intervention and home support programs.
7. Develop a policy approach that stimulates improved responses from GPs to supporting their patients with dementia to live well.
8. Embed the framework of living well into the quality care indicators and accreditation model of the Quality Agency.

Aged Care Providers:
1. Lead organisations that foster a culture of supporting the implementation of care philosophies which help people with dementia to live well. Philosophies/models of care build on dignity of risk and sustaining personhood.
2. Provide purposeful and meaningful activities for people with dementia, particularly in residential aged care where greater choice is needed.
3. Pursue increased levels of collaboration with consumers and other stakeholders to improve practices and approaches to care and support of people with dementia.
4. Use the Seven Domains of Wellbeing as a framework to base case management / nursing / activities / therapeutic / allied health practices around.
REFERENCES

2. Ibid
6. Ibid

Alzheimer’s Australia NSW


24. Ibid.


OUR OFFICES

ADMINISTRATION
Alzheimer’s Australia NSW
Macquarie Hospital Campus
Building 21, Gibson-Denney Centre
120 Cox’s Road (Cnr. Norton Rd)
North Ryde, NSW 2113
PO Box 6042 North Ryde, NSW 2113
T: 02 9805 0100
F: 02 9805 1665
E: NSW.Admin@alzheimers.org.au
W: www.fightdementia.org.au

NORTHERN NSW
Central Coast* 02 9805 0100
Coffs Harbour: 02 6651 6415
Forster: 02 6554 5097
Hunter: 02 4962 7000
Port Macquarie: 02 6584 7444

SOUTHERN NSW
Bega Shire: 02 6492 6158
Eurobodalla Shire: 02 4474 3843
Bateman’s Bay: 02 6492 6158
Cooma, Bombala & Snowy Mountains Shires: 02 6452 3961
Yass, Young, Goulburn, Queanbeyan, Harden, Upper Lachlan & Palerang Shires: 02 6241 0881
Moss Vale: 02 4869 5651
Wagga Wagga: 02 6932 3095
Wollongong*: 02 9805 0100

WESTERN NSW
Orange: 02 6369 7164

SYDNEY REGION
North Ryde: 02 9888 4268
St George/Sutherland: 02 9531 1928
Blacktown*: 02 9805 0100

NATIONAL DEMENTIA HELPLINE
1800 100 500
This is an initiative of the Australian Government

Alzheimer’s Australia NSW
ABN 27 109 607 472

WWW.FIGHTDEMENTIA.ORG.AU