

Committee Secretary
Standing Committee on Family, Community, Housing and Youth
PO Box 6021
House of Representatives
Parliament House
CANBERRA ACT 2600
AUSTRALIA

Alzheimer's Australia would like to thank the Committee for this very important opportunity to comment on the issues that face those who support people with dementia. We welcome the focus on identifying ways to better support these family carers to remain in employment and otherwise participate in their communities.

We have attached three documents for your information:

- *The Long and Lonely Road: Insights into living with younger onset dementia;*
- *Dementia Manifesto 2007-2010*, endorsed by our National Consumer Committee in 2007; and
- The 2005 National Consumer Summit on Dementia Communiqué.

In dementia, it is particularly important to consider how carers are best supported when the individuals for whom they care have access to quality dementia care services and other dementia-friendly services. Therefore this submission does address, in places, the needs of the 'care dyad' i.e. people with dementia and their family carers.

Please contact Anne Eayrs (telephone 02 6254 4233 or email anneeayrs@alzheimers.org.au) if you require further information.

There are no sections in this Submission which are confidential and we agree to the submission being published in its entirety.

Glenn Rees
National Executive Director
Alzheimer's Australia

17 July 2008

Ron Sinclair
Chairman
Alzheimer's Australia
National Consumer Committee

17 July 2008

**Alzheimer's Australia Submission to the House of
Representatives Standing Committee on Family, Community,
Housing and Youth
Inquiry into Better Support for Carers
June 2008**

Terms of Reference

Carers play a vital role in sustaining Australia's current system of community-based person-centred care. However, they are often at increased risk of becoming socially isolated from their peers and disconnected from mainstream employment. Many carers also have significantly worse health outcomes than the general population (both in terms of physical health and psychological wellbeing) and endure problematic access to services and support. Carers also often face increased financial pressures, having limited opportunities to accrue savings, accumulate superannuation and save for retirement.

To obtain an improved understanding of the challenges facing carers and their support needs, the committee will inquire into and report on:

- The role and contribution of carers in society and how this should be recognised;
- the barriers to social and economic participation for carers, with a particular focus on helping carers to find and/or retain employment;
- the practical measures required to better support carers, including key priorities for action; and
- strategies to assist carers to access the same range of opportunities and choices as the wider community, including strategies to increase the capacity for carers to make choices within their caring roles, transition into and out of caring, and effectively plan for the future.

In examining each of these issues, the committee will also inquire into the specific needs of particular groups within the caring population including new carers, younger carers, older carers, Indigenous carers and those with multiple care responsibilities.

For the purpose of this inquiry carers are defined as 'individuals providing unpaid support for others with ongoing needs due to a long-term medical condition, a mental illness, a disability or frailty'.

Summary

In 2008, there are an estimated 227,360 people with dementia. By 2030 this figure will have more than doubled to 465,460 and by 2050 this figure will reach 731,030. There are more than 1000 new cases of dementia each week.

Currently almost half of the Australian population know a family member or friend who has dementia. As the numbers with dementia grow, the demand for informal care and the impact on family and friends who provide support will also grow. Many carers of otherwise healthy older people with dementia may provide care at home for extended periods.

Carers of people with dementia need:

- Support in the form of dementia-friendly and/or dementia-specific services and sufficient income to be able to access these;
- the knowledge that support is available to help them;
- information about how to access that support; and
- equitable access to support regardless of their location and cultural background.

A carer's continued involvement in their normal activities of daily living, including employment, is predicated on

- Seeing this pathway as possible and an acceptable option;
- Understanding and support from the general community - and employers in particular;
- Access to services that provide flexible, affordable and quality support at the appropriate point as needs arise.

This submission is organised under the following headings:

- Case study;
- Recommendations;
- Impact of dementia;
- Consumer priorities;
- Caring for a person with dementia;
- Value of caring;
- Cost of caring;
- Supporting carers to remain employed;
- Supporting carers in caring;
- Enhancing family carer skills;
- Consumer Directed Care;
- Younger people with dementia;
- Advance Planning;
- Overcoming discrimination experienced by carers;
- Improving quality of life for carers.

The following case study encapsulates how the care of a person with dementia involves significant and ongoing sacrifice, including physical and psychological demands, 24 hour vigilance, restrictions on contact with friends and social networks, and lost opportunities within the retirement years.

Case study

Michael was a small business owner. After selling his business he took a job in the city and found it very confusing to catch the train to work. He was diagnosed with dementia at 60 years of age and ceased employment. He subsequently resigned from his local Greek Cultural Club Committee and rapidly lost the ability to participate in his passions of gardening and dancing. He became dependent on his wife to care for him 24/7.

For 13 years, **Cathy** has cared for her husband. It is a physically and mentally demanding role and one she finds extremely difficult as her own health declines with diabetes and osteoarthritis. Michael lost the ability to speak many years ago and Cathy is the only person that he now responds to.

Because Michael was young and physically fit, there have been many years of wandering, both day and night. Police helicopters have been used to search for him. Cathy would be up and down all night with his sleep disturbances, wandering and then his incontinence. Each night she gets up to empty his urinary catheter bag after years of washing sheets, clothing and the use of inadequate continence products.

Now that Michael is immobile, Cathy is physically unable to cope with his care and her daughter, Carol, who has her own young family, gave up her job to manage the financial affairs of her parents and assist with the day to day care of her father.

Each day they together physically lift Michael out of bed to shower, change his urinary catheter bag, dress him, spoon feed him breakfast, administer his medications (the catheter causes frequent urinary tract infections), shave and clean teeth.

The only opportunity for Cathy to leave the house is while Michael is at day care. She doesn't like to ask her daughters too much as they have young children to care for. There is no weekend social activity and friends have dropped off visiting.

Carol wishes that her Mum could have a proper break and someone look after her for a change:

My mother tries to keep positive but the years of caring for my Dad have worn her down. These could have been great years for her. The best form of medicine for my Mum would be for her to have a getaway, to be pampered. She needs timeout from this pressured lifestyle with all the emotional and physical strain. She shouldn't have to continually chase for services, be scrutinised and rejected. It would be just great if someone would organise something for the carers themselves. Mum has her own health issues she struggles with, even if there was assistance with her dentistry, podiatry, physio or the carpets being cleaned, that would definitely help.

Recommendations

Strengthen care support

Strengthen current community and residential care arrangements, for example, through:

- Doubling the funding available to community care (from \$2 billion in 2008 - 2009 to \$4 billion in 2013 - 2014) to better meet the needs of family carers for support and the wishes of individuals to remain for as long as possible in their own home;
- Increasing the funding available to aged care assessment teams so that waiting times for assessment are reduced and access to advice on planning care is improved;
- Reducing the impact of inflexible program boundaries on family carers so that support is available to respond to a range of needs;
- Improving the planning arrangements for community care including respite;
- Improving the range of community care packages to provide a continuum of care;
- Extending the coverage of services in rural and remote areas;
- Establishing a network of services tailored to meet the needs of people affected by younger onset dementia, as well as those from Aboriginal and Torres Strait Islander communities and culturally and linguistically diverse backgrounds;
- Providing greater choice in respite and other services through the incorporation of the principle of Consumer Directed Care to provide people with dementia and their family carers with the option of taking control over their lives either through cash or individualized budgets held by the service provider; and
- Providing ongoing funding to successful pilots so that these services can continue to support existing clients and be extended to assist others with the same needs.

Improve income support and other financial arrangements

Identify opportunities to overcome existing discrimination, discontinuities and unintended consequences for family carers within the current taxation (and income support) review. Areas to be addressed should include:

- Ways to support family carers to continue to contribute to their retirement income, for example through a carers superannuation scheme or changes to existing superannuation arrangements; and
- whether Centrelink arrangements and requirements accurately recognise the needs of carers throughout the care journey, including at transition points like entry to residential care.

Provide carer skills education

Provide recurrent funding to extend the Dementia Caring Project to provide skills enhancement education and training activities for carers and families of people with dementia.

Normalise advance planning

Support family carers of people with dementia in future care by:

- Implementing the recommendations on substitute decision making made in the September 2007 Report by the House of Representatives Committee on Legal and Constitutional Affairs on *Older People and the Law*;
- Developing an education campaign to inform the Australian community of the benefits, issues and processes involved with advance planning for their health, their money and their lives; and
- Facilitating national consistency and mutual recognition in advance care planning legislation, including enduring powers of attorney, across the Australian jurisdictions so that the law and documentation are nationally consistent, user friendly and readily available.

Understanding the caring role

Develop a comprehensive information and education program to

- Improve community understanding of the caring role, including the impact on employees and employment;
- assist in reducing residual stigma; and
- encourage family carers to seek support and negotiate changes in their employment as well to remain active participants in their communities.

Valuing carer input

Strengthen the role of family carers in program development and evaluation and priority setting.

Strengthen the evidence base on care

Strengthen the evidence base on caring and carer support by:

- Targeting funding to address identified gaps in carer research, such as the needs of carers of people with younger onset dementia;
- Investigating what sustains individuals in the dual roles of employment and caring to minimise the effects on those prepared to care;
- Involving family carers in priority setting for research; and
- Supporting the dissemination and take up of research outcomes in service delivery and care practice.

Alzheimer's Australia submission

Impact of dementia

I'm tired and I've forgotten how to function in the normal world. To keep Chris in a calm environment everything's got to be structured. The burden of care has become too great and I am desperate to regain my life. (Family carer of person with dementia after 15 years in the role.)¹

In 2008, there are an estimated 227,360 people with dementia. By 2030 this figure will have more than doubled to 465,460 and by 2050 this figure will reach 731,030. There are more than 1000 new cases of dementia each week.²

Dementia is a devastating condition which causes progressive Neuro degeneration, leading eventually to death. There is currently no cure for dementia and limited medications, although there are preventative strategies which may reduce the risk.

Life expectancy is roughly halved for people of all ages after a diagnosis of dementia.³ Many carers of otherwise healthy older people with dementia may provide care at home for extended periods.

While dementia is not a normal part of ageing, it is more common as people age. The vast majority of people with dementia are over 65, however some 10,000 Australians have younger onset dementia including people in their 30s.

Currently almost half of the Australian population know a family member or friend who has dementia.⁴ As the numbers with dementia grow, the demand for informal care and the impact on family and friends who provide support will also grow.

Consumer⁵ priorities

Alzheimer's Australia is committed to a strong consumer focus in which people with dementia, their families and carers actively contribute to the work of the organisation according to their interests, needs and abilities.

At the first National Consumer Summit on Dementia in October 2005, the 50 people with dementia and family carers who participated identified the following priorities:

1. Improve the assessment and diagnosis of dementia.
2. Improve the responsiveness of acute care so it better meets the needs of people with dementia.

¹ The Long and Lonely Road: Insights into living with younger onset dementia (Alzheimer's Australia 2003), available at <http://www.alzheimers.org.au/upload/LongLonelyRoad.pdf>

² Access Economics "Dementia Estimates and Projections: All States and Territories" (Report for Alzheimer's Australia, 2005) available at <http://www.alzheimers.org.au/upload/EstimatesProjectionsNational.pdf>

³ Larson E et al, Survival after Initial Diagnosis of Alzheimer Disease, *Ann Intern Med.* 2004;140:501-509. available at

<http://www.annals.org/cgi/reprint/140/7/501.pdf?ijkey=9c04ce54e660b544f3c710958dae09cbebbc01e0>

⁴ Pfizer Australia Health Report Issue 40, 'Looking at dementia', available at www.healthreport.com.au

⁵ The following section focuses on priorities identified by the 'care dyad', ie people with dementia and their family carers.

3. Ensure easy access to quality community care services.
4. Provide more flexible responses to supported accommodation in the home and in residential care facilities.
5. Increase the recognition and understanding of the financial cost and legal implications of dementia.
6. Promote and ensure greater public awareness and understanding about dementia and risk reduction.
7. Increase investment in dementia research.

Participants identified fundamental principles which underpinned the priority actions identified:

People with dementia and carers need support that will help them to maintain their quality of life.

- Respect, compassion and humanity are fundamental. People with dementia and carers are people first and foremost, and their essential human dignity must be respected and valued at all times.

People with dementia need to be supported in their homes.

- Identified by all in attendance as the primary need, people with dementia must have easy access to support that is focussed on assisting them to stay in their homes as long as possible.

People with dementia and carers need to be recognised as partners in decision making about care options.

- Care must be person-centred, planned and involve people with dementia (as far as is possible) along with their carers and family.

People with dementia and carers need access to contemporary quality care provided by trained, accredited and appropriately remunerated workers.

- Whether in community, residential or acute settings, people with dementia and their carers want staff who are providing them with care and support to be appropriately trained and have an understanding of contemporary dementia care.

People with dementia and carers need to see a national symbol for cognitive impairment so that people with dementia are treated appropriately particularly in the delivery of service.

The underpinning principles applied 'equally to all people living with dementia – people with dementia and families and carers who are from culturally and linguistically diverse backgrounds; people who are living alone; people with younger onset dementia; people with a disability, people from Indigenous backgrounds and people from rural and remote communities'.⁶

⁶ National Consumer Summit Communiqué (Alzheimer's Australia 2005), available at <http://www.alzheimers.org.au/upload/Communique2.pdf>

In their recent *Dementia Manifesto 2007-2010*,⁷ the Alzheimer's Australia National Consumer Committee identified seven priorities for action:

1. Improve the diagnosis of dementia by GPs.
2. Expand community care services for people with dementia and their carers.
3. Improve access to quality dementia care in residential services.
4. Improve access to appropriate care for special groups.
5. Ensure a workforce able to deliver quality dementia care to all people with dementia.
6. Promote advance care planning for people with dementia.
7. Increase dementia research funding.

In a recent submission to the National Health and Hospital Reform Commission, Alzheimer's Australia pointed to the fundamental changes needed in the health and aged care systems to improve quality of life and health for the growing number of people with dementia and their family carers. The submission included detailed recommendations, including the need to double Federal Community Care funding over 5 years to \$4 billion, a recommendation that is picked up in the recommendations in this submission.⁸

Caring for a person with dementia

Families and carers of people with dementia share many of the same concerns and issues experienced by other carers. However there are issues that appear unique to family carers of people with dementia which are associated with the unpredictability of the condition and the physical and emotional demands of living day-to-day with a person with dementia.

'A person with dementia often appears perfectly normal so (the) public is not made aware of the disability as would typically be the case for a person with a physical disability.' (Family carer, WA)

Dementia can be a particularly isolating condition. As the condition progresses, many primary carers are unable to balance care and employment. Friends and family may withdraw their support and visit or call less frequently. In the absence of broad community education around dementia and its implications, lack of understanding and stigma associated with loss of capacity remain.

The situation is exacerbated for particular groups of carers who may experience additional difficulties in accessing suitable services and other support:

- Carers of people with younger onset dementia (those under 65 including people as young as 30);
- carers living in regional and remote areas;
- carers from culturally and linguistically diverse backgrounds;
- carers in Aboriginal and Torres Strait Islander communities; and
- younger carers including those who may wish to maintain employment or study.

⁷ Dementia Manifesto 2007-2010 (Alzheimer's Australia 2007), available at <http://www.alzheimers.org.au/upload/Manifesto0710.pdf>

⁸ Available at <http://www.alzheimers.org.au/upload/HealthHospitalReformMay08.pdf>

Social isolation can be minimised if people with dementia and their family carers have access to support services which help **both** to go on with their lives after diagnosis and maintain their daily activities.

A 2005 article by Brodaty et al identified the priorities for action as ‘raising community awareness on the availability of services, normalising service use, de-stigmatising dementia and encouraging processes of referral’.⁹

Value of caring

Access Economics estimated that the total costs of dementia in 2002 were \$6.6 billion, which was around 1% of GDP. Costs were projected to reach 3.3% of GDP by 2051. The direct health costs in 2002 were estimated to be \$3.2 billion compared with indirect financial costs of \$3.2 billion. The value of carers was estimated as just over \$2 billion of the indirect cost estimate.¹⁰

Family carers support people with dementia to remain in the community for as long as possible. After individuals enter residential care, many family carers continue to provide care, social or advocacy support. The distance between their home and the aged care facility may add to the burden of this ongoing support.

Carers do not feel that their contribution and expertise is understood or valued by either governments or the general community. Service providers and, in particular policy makers, need to engage family carers in the process of developing new service models. They also need to assess whether the services are meeting the needs of carers on a routine basis.

Cost of caring

‘Caring costs about \$800-1,000 each month. This excludes medication, incontinence aids, etc. It does cover care services, day care, 4 weeks residential respite a year, increased costs for additional laundry etc etc. To help with income support, it could be possible to raise the non-taxable income level for carers and people with dementia. Carers need to know clearly what financial assistance they and their person with dementia are entitled to.’ (Carer, NSW)

The cost of care can be high in terms of the direct costs of services and support and the indirect cost of lost employment opportunities. The latter is particularly true for younger carers including those affected by younger onset dementia.

‘Carers can incur high costs as a result of their caring responsibilities, particularly through lost employment, reduced salaries, and lost pension entitlements.’¹¹

⁹ Brodaty H, Thomson C, Thompson C and Fine M. (2005) *Why caregivers of people with dementia and memory loss don't use services*, International Journal of Geriatric Psychiatry, 20:537-546

¹⁰ Access Economics “The Dementia Epidemic: Economic impact and positive solutions for Australia” (Report for Alzheimer’s Australia, 2003), page 50, available at <http://www.alzheimers.org.au/upload/EpidemicFullReportMarch2003.pdf>

¹¹ Knapp M et al, ‘Dementia: International Comparisons’, PSSRU Discussion Paper 2418, Page 20, available at <http://www.pssru.ac.uk/pdf/dp2418.pdf>

'Because of the severity of the condition, people with dementia are heavy users of health and aged care services including GP consultations, pharmaceuticals, aged care assessments, community care programs, hospitals and residential aged care. They also require much time and help from their carers and their behavioural and psychological symptoms are also distressing to many of their carers.'¹²

The costs of entering residential care can be particularly problematic.

As a self funded retiree it feels as if I am being "punished" for carefully managing my finances over the last 40 years and I have heard that complaint from many others. (Carer WA)

. . . the residential hostel bond is frightening and I am sure the residential costs worry many carers. (Carer NSW)

*In 2003 Peg got too much for me to look after and went into a nursing home...because of the cost of the nursing home I had to sell our house and I moved into an apartment and invested the difference in price to pay for Peg's care. I visited Peg every day...
(Former carer, Victoria)*

Negotiating entry arrangements can be difficult. Legislative arrangements such as 'Relationship ceased as a result of ill health'¹³ and 'Illness Separated Couple'¹⁴ can be confronting as well as complex to understand.

Entering residential care is a transition point which can cause great stress for both people with dementia and family carers. While entry may be planned, frequently it is the result of carer ill health or another trigger event. Regardless of the circumstances, extreme grief is a common response. At the same time, Centrelink arrangements might require a person on Carer Payment to be transferred to NewStart with its attendant obligations. There is little recognition of the physical, mental and time demands that continue after entry to residential care.

'Having to suddenly place a loved one with dementia into residential care due to the carer's ill health places an enormous additional feeling of guilt on the carer. You feel you have let them down and this is really a time that the carer needs greater compassion and understanding. Firstly, the carer will still be involved as much as possible with their loved one and carers should in any event not have the carers allowance stopped when the person with dementia moves into residential care but rather only when the patient passes on. At the point when the carer too is ill, this is certainly not the time to stop the carer's payment – they need it now possibly more than ever.' (Family carer, NSW)

¹² Australian Institute of Health and Welfare, Australia's Health 2008, p 217 available at <http://www.aihw.gov.au/publications/index.cfm/title/10585>

¹³ More information is at http://www.facsia.gov.au/guides_acts/ssg/ssguide-2/ssguide-2.2/ssguide-2.2.5/ssguide-2.2.5.20.html

¹⁴ More information is available at http://www.facsia.gov.au/guides_acts/ssg/ssguide-2/ssguide-2.2/ssguide-2.2.5/ssguide-2.2.5.60.html

Moving to a different State/Territory to support an older parent with dementia may have unexpected financial consequences for younger family carers if employment is difficult to obtain. The taking on of a caring role may not be seen as a sufficient reason to obtain access to superannuation contributions in such circumstances.

Full-time caring may have an impact on retirement income. Family carers who wish to continue to contribute to their superannuation after 65 may feel obliged to place the person with dementia in respite care while they pursue the 'gainful' activity necessary to make contributions. Such inappropriate use of available respite care may result in excessive stress for both parties. Being a full-time carer is not regarded as meeting the gainful employment test. This reinforces the view of many family carers that their contribution is under-valued.

Family carers frequently report problems in accessing existing government benefits through Centrelink. While bonuses are welcome additions to the family budget, uncertainty is difficult. Strengthening the capacity of the income support system would provide the income needed by family carers to meet the costs of caring as well as help to overcome a general perception of the limited value that the Government places on the task of caring.

Supporting carers to remain employed

'To enable carers to remain in the workforce, the best solution is to place the person receiving care into a "Long Day Centre". These centres are open 7am to 7pm and give the carer "peace of mind" about the care of their loved one.'
(Carer NSW)

'Many respite care programs within communities may not, or even will not, provide care for a household where the primary carer is still at work. Frequently this means the carer has no choice but to give up work because the cost of 'private care' is prohibitive. Somewhat discriminatory at times...'
(Former carer, Victoria)

Any caring may lead to exclusion from the labour market, and the loss of income is significant. As caring responsibility intensifies, the rate of full-time employment falls. Only 10 to 15 per cent of carers who have intensive care responsibilities work full-time.¹⁵

As dementia is a progressive degenerative disease, where constant 24 hour supervision will eventually be required, very few co-resident primary carers are able to maintain paid employment. The physical, psychological and time demands on the carer prohibit employment unless there is a significant level of assistance.

The demands of the caring role have direct and indirect implications on employment opportunities such as having to take jobs with less responsibility, miss promotions or training opportunities, reduce working hours or use leave entitlements for care purposes.

¹⁵ Centre for Health Service Development "Effective Caring: a synthesis of the international evidence on carer needs and interventions", December 2007

Family carers of people with dementia need:

- Specific long day care for those who need to work for a living to support the household;
- Access to day care or at-home respite and emergency respite care for those who would like to maintain at least part-time employment;
- Support to return to the workforce once the person with dementia has died or entered residential care.

Supporting carers in caring

'if (the) person being cared for is happy then (the) Carer is also much happier and that is especially true of someone with dementia' (Family carer, WA)

Caring for someone with dementia is physically and emotionally draining. Carers can become socially isolated and often their own health deteriorates. Significant numbers of carers are forced to stop caring because of illness or injury. This heightens the importance of community support including on-going access to both planned and emergency respite services.

Early and accurate diagnosis is essential if family carers are to be well supported in their role. Accurate diagnosis is required so that people affected by dementia can access appropriate services, supportive professionals, available medications and relevant information and advice.

Family carers need to have information about how to care for the person with dementia and where to get assistance from, if needed. This information can be difficult to locate and obtain.

'I want to care for my partner in my own home but need information readily available. Some suggestions are: Could local papers be asked to have one page available set apart each week for this information? Could more use be made of Centrelink as an information vehicle? The Senior Newspaper is a good resource but not readily available and people do not know of its existence.'
(Carer Victoria)

Carers value the assistance of the aged care assessment teams in supporting planning for current and future care. However the usefulness of the program is constrained by a current mismatch between the demand for their services and the resources available resulting in reduced access and unacceptable waiting periods.

Support group research¹⁶ conducted in 2006 yielded strong evidence around the needs of family carers of people with dementia:

- the ongoing value of support groups for family carers of people with dementia to ensure their ongoing physical and emotional well being;
- Family carers of people with dementia were stressed – particularly emotionally stressed;

¹⁶ Brown, Jo-Ann. Quality Support Groups Research Project. *A Report on Dementia Support Groups in NSW*. Alzheimer's Australia NSW. 2007.

- Carers of people with dementia were more emotionally stressed than physically stressed, and most of the stress was based around issues of grief and loss which were not always recognized, acknowledged or dealt with appropriately;
- The mutual aid that carers received from each other in ongoing support groups was found to relieve stress and attendance at support groups provided good ongoing socio-emotional support for carers.

'Support group attendance is invaluable. So much can be learned by sharing concerns with other carers, many of whom have or are dealing with the same/similar problems.' (Carer NSW)

Regular and appropriate respite can help both people with dementia and their family carers to continue with their lives after a diagnosis, while also improving quality of life and avoiding excessive carer burden and premature entry to residential care. The lack of respite services for carers of people with dementia often stops carers of people with dementia from attending support groups which have been shown to ease social isolation and emotional stress.¹⁷

'Regular (best is 5 days a week) attendance at a day centre of quality and sensitivity to clients with dementia is:-

- a) Good for the client receiving stimulation, interaction with others etc*
- b) Excellent for the carer who can pursue interests, meet with friends and attend to household and financial responsibilities without pressure of caring concerns.'* (Carer NSW)

'... we would like ... a holiday where AA staff take us away for a break and leave our husbands/wives to relax at home. It overcomes the lack of suitable respite for younger onset and gives activities to keep us active. The fact that I am in respite at the present may be colouring my outlook as there are 4 of 8 in 90's , 2 in 80's 1 younger onset who is non verbal and me!!' (Person with younger onset dementia, WA)

Research by Leong et al¹⁸ indicates that:

- Respite was one of the most frequently mentioned needs.
- Carers wanted services to be more flexible, responsive and available when needed, rather than involving delays or lengthy periods on a waiting list.
- Health care professionals (GPs, community nurses, members of ACATs) could help by arranging and facilitating family conferences.

Continuity of care is of crucial importance for people with dementia and their families and carers who require consistency and reliability in care provision as their condition deteriorates and cognitive impairment gets worse.

¹⁷ Brown, Jo-Ann. Quality Support Groups Research Project. *A Report on Dementia Support Groups in NSW*. Alzheimer's Australia NSW. 2007

¹⁸ Leong J, Madjar I and Fiveash B (2001) *Needs of family carers of elderly people with dementia living in the community*. Australasian Journal on Ageing, Vol.20, No.3, pp.133-138

Caring demands can change with the unpredictability of dementia. Unlike a physical disability, dementia can mean a person's behaviour can change from day to day, week to week - so there is often no consistency for the family carer. It requires family carers of people with dementia to be super flexible and to be able to adapt to changing circumstances. This can cause added stress and often makes it difficult to plan ahead.

Challenging behaviours related to dementia may limit respite and care options and create added stress for families and carers. People living with dementia, particularly those with dementia with psychological and behavioural symptoms of dementia need priority access to specialty respite. While the Extended Aged Care at Home – Dementia packages are helpful for those who can access them, the funded places are currently very limited in number and coverage.

The issue of wandering or 'walking' can create added stress for family carers of people with dementia, as they need to be constantly vigilant about keeping track of individuals. Family carers can be supported by

- Programs such as *Safely Home*;
- access to home modification and maintenance benefits to ensure that a carer's home is secure;
- information about preventative approaches; and
- the appropriate use of assistive technology.

Many family carers do not drive and have relied on their partners for transport. They consequently "allow" the individual to continue driving longer than they should. Even where carers do drive, it may become difficult and often dangerous when carers have to deposit their person on a footpath and then drive off to park the car. Public transport becomes difficult to use as the dementia journey proceeds. Some family carers need help with public transport which can be very difficult to manage i.e. getting to that transport and getting on and off it. All family carers of people with dementia need access to community transport options, taxi subsidy vouchers and disabled parking as the condition progresses.

Family carers need dementia-friendly facilities in the community which support them in taking the person with dementia on an outing. e.g. wheelchair friendly lifts, footpaths, buildings and easy access to medical appointments/facilities. They also need help in making the home user friendly for the person with dementia eg wheelchair access and appropriate toilet and shower arrangements so the person can be assisted to use these.

Many family carers need help with the domestic tasks that the person with dementia previously did such as shopping, housework, meal preparation, cutting lawns, gardening, changing light globes and tap washers, financial decisions and management. Carers also need guidance in helping the person with dementia with walking, getting into or out of a car and using a wheelchair, as movements become more difficult.

Enhancing family carer skills

As dementia progresses individuals lose their capacity to undertake routine daily tasks and many family carers find that they need to develop new skills beyond those involved in disease management and care. Unlike other conditions, dementia involves loss of capacity which may mean that individuals lose the ability to communicate effectively and are unable to provide guidance or pass on skills. Building practical knowledge and skills in areas that family carers value helps to reduce burden and maintain them in a caring role for longer.

In 2006, the Department of Health and Ageing funded the *Dementia Caring Project*. Alzheimer's Australia partnered with 52 Commonwealth Carer Respite Centres who contacted carers and families of persons with dementia to develop a menu of skills enhancement activities that consumers desired.

"Many carers indicated that it was a first for them to be asked what they would like for themselves – and many couldn't believe what we were offering them." (Victoria)

"It was found that the session content had a direct and immediate effect on carers. The sessions made carers feel more prepared to handle changes with their loved ones in the future." (Tasmania)

"Consumers felt empowered to start a consumer group to work together for positive change in dementia care." (Tasmania)

The project enabled over 900 individuals to take part in various learning and skills enhancement sessions. The most popular and commonly sought after skills areas included:

- Knowing how to obtain information about legal issues;
- Understanding dementia;
- Advocacy;
- Self care strategies;
- Managing behaviours of concern;
- Continence management;
- Health and well being;
- Communication;
- Knowing how to access information to support decision making e.g. in choosing residential care, dealing with Centrelink, accessing support services;
- Home maintenance;
- Personal care;
- Home making skills and other role reversal related practical tasks such as car maintenance, cooking; and
- Use of computers and the internet for practical tasks such as internet banking, online shopping, sending e-mails.

Feedback from both family carers and the participating organisations was very positive. The Project identified an ongoing need for non-disease related skills education and training for carers, in addition to dementia-related knowledge and care skills.

Consumer Directed Care

Consumer Directed Care will give more hours of care and gives the primary carer greater choice of the type of care service.(Carer NSW)

Alzheimer's Australia supports a Consumer Directed Care approach to community care. People with dementia and their family carers should have the option of making their own choices in respect of the care services they need to meet their own individual circumstances. Equally, people who wish to let services make the choice for them should be free to exercise that option.

Arguably, the best way of maintaining a person's independence is to allow them the option to decide what services will enable them to live as independently as possible for as long as possible in the setting of their choosing.

A number of European countries, including the Netherlands and the United Kingdom have introduced this principle in their community care programs. So too have a number of states in the USA. Evaluations of CDC have shown that it provides better outcomes than those that rely on mainstream agency delivered programs.

Despite increased Government funding of respite, access to flexible quality respite care continues to be a problem for family carers. This is particularly the case for people from Aboriginal and Torres Strait Islander communities or culturally and linguistically diverse backgrounds, and people in rural and remote areas.

People with dementia progressively lose many of the relationships on which their lives have been built as well as the capacity to engage in normal activities. Respite services should promote social engagement in activities that have been part of individual lives before diagnosis. Flexible respite care services embracing the principle of CDC would make this possible.

Consumer Directed Care gives people the option to hire a family friend or neighbour. This could be a valuable option in rural and remote regions of Australia where there are fewer service providers and high costs for staff travel including transport and time to travel long distances. The option would also be likely to be attractive to people from culturally and linguistically diverse backgrounds as they could recruit people from their own communities.

Younger people with dementia

Younger people who are physically active (and even more significant in my case, who have very low cognitive capability) are not catered for in day centres and to some extent respite care, as they really need one on one care as they can't entertain themselves. That is not catered for in the current regime which sets limits of a few hours a week of one on one care. That is very constraining to a carer. (Carer, WA)

There are some 10,000 people with dementia in Australia under 65 years of age. In a report prepared by Alzheimer's Australia to the Australian Government *Exploring the needs of younger people with dementia*¹⁹, it was concluded that as their condition progresses, younger people, like older people, want timely quality and accessible services that meet their individual and holistic needs. However, there are unique and complex issues faced by younger people with dementia and their family members. These are well reported in literature in Australia and overseas.

The issues younger people may face include:

- Difficulty and/or delays in getting an accurate diagnosis;
- Family responsibilities including still actively raising a family;
- Currently working or being only recently retired;
- Having significant financial commitments based on previous earnings;
- Needing to revise their expectations of everyday life, such as work, finances, living arrangements, social and sexual relationships, and independence and responsibilities for others;
- Future plans that are affected at an earlier stage in life;
- Being more likely to have a rare form of dementia than Alzheimer's disease or a genetically based cause; and
- Experiencing difficulties in accessing appropriate services, particularly as younger people with dementia are often otherwise physically strong and healthy.

Carers of people with younger onset dementia often have dual caring responsibilities. They may be caring for a partner with younger onset dementia and for older parents as well. In addition, teenagers of parents with younger onset dementia are often dealing with a person with both mental and physical challenges and inconsistent behaviour and needs. The unique needs and stress on carers of people with younger onset dementia needs to be recognized.

There are few appropriate services for this group. This gap in services could be addressed through targeted funding to develop services for people with younger onset dementia including appropriate day care and respite care and cluster accommodation in residential care facilities services through existing dementia care networks and services.

There is also a great need to improve the understanding of younger onset dementia among health professionals and the general community through targeted education and information.

¹⁹ Available at <http://www.alzheimers.org.au/upload/YoungerOnset.pdf>

Advance Planning

Advance care planning plays an important role in supporting family carers by allowing people with dementia to plan for their future health care and financial capacities against the time when they lose their capacity to make those decisions. The law not only has the potential of offering people with dementia the ability to make decisions about the future, but of protecting their financial, and medical choices. Unfortunately current legal provisions relating to enduring powers of attorney and advance care directives are complex and vary across the jurisdictions; terminologies are confusing and inconsistent and all too often the wishes of the person with dementia are not appropriately followed. Currently the opportunity of advance decision making is underutilised.

Most people are unaware of their legal right to appoint a decision maker, particularly with enduring powers. Barriers that have been identified include a reluctance to think about death and disability, lack of confidence, and a perception that the law is disempowering. Structural factors such as lower income, cultural background, disability and gender can limit the capacity to make informed choices.

Community education on these legal matters appears to be limited and ad hoc. Currently there is little assistance to help people to complete the necessary legal documents and to decide whom they can trust and appoint as their substitute decision maker. The subject is complex, involving the law, medicine and family values. It is about relationships, not just about completing legal documents. The law and practice varies across jurisdictions and the terminology is confusing and inconsistent. Planning completed in one State is not always recognised in another, which can create additional difficulties for family carers.

Research has demonstrated that not all health professionals, including general practitioners are well informed about the enduring powers and advance directives and may lack the time or skills to assist people with this process. Lawyers also vary in their knowledge of the issues confronting people with a recent diagnosis of dementia. There is no formal training in capacity assessment and no consistent method currently used in legal practice.

While informal arrangements can often work well in families, many individuals with dementia and their family carers encounter significant problems when wishes for future care and decision-making are unknown. End-of-life care can also become more difficult in the absence of advance directives. If powers are not in place the guardianship law may have to be utilised.

An increasing number of people with dementia who have not put enduring powers in place are referred to Guardianship Tribunals across Australia. Approximately 50% of all referrals relate to people with dementia.

The House of Representatives Inquiry Report on *Older People and the Law* states that advance planning would reduce the demand for publicly funded guardianship tribunals and that “enduring powers of attorney are valuable instruments and older people, in particular, should be encouraged to make them”²⁰ but that at this present time “the complexity of instruments within and between States can also confuse and deter people from making an enduring power.”²¹ Advance planning could reduce not only this economic cost but also the social cost for people with dementia and their family carers.

The National Consumer Committee of Alzheimer's Australia advocates for:

- Achieving national consistency in advanced care planning legislation and regulations across all jurisdictions including clear guidelines on the status of these documents and their impact on the provision of appropriate care.
- Implementing education and support programs for consumers, care providers and health professionals about how to develop and use an advanced care plan, including enduring power of attorney documents.
- Providing training for professionals who will be advising people on legal, medical and social implications of the relevant documents.
- Establishing a national registry to ensure that the status and content of an advanced care plan is known and accessible in all health care settings in each jurisdiction.

An increased focus on early planning for people with dementia may also help to reduce discrimination and stigma.²²

Overcoming discrimination experienced by carers

‘Greater community education about dementia is vital for people in the community to begin to understand and appreciate the emotional and physical stress of carers and their families.’ (NSW carer)

A NSW research study²³ into carer support groups found that stigma was a major factor that prevented carers from accessing support and assistance from service providers and support groups. The research found that community attitudes needed to change. If the community were more aware and accepting of dementia, then family carers of people with dementia would be readily acknowledged and supported.

Recent research indicates that “just over one in two Australians feel that people who have Alzheimer’s disease or another form of dementia are ‘unfairly treated’ or ‘discriminated against’ because of their condition.”²⁴ This discrimination also directly and indirectly affects the families and carers who support those people with dementia who may be denied access to necessary services and treatment.

²⁰ Standing Committee on Legal and Constitutional Affairs, House of Representatives, *Older People and the Law* (2007) 3.16

²¹ *Ibid* 3.14

²² Pfizer Australia Health Report Issue 40, ‘Looking at dementia’, available at www.healthreport.com.au

²³ Brown, Jo-Ann. (2008) Quality Support Groups Research Project. *A Report on Dementia Support Groups in NSW*. Alzheimer’s Australia NSW. 2007.

²⁴ Pfizer Australia Health Report Issue 40, ‘Looking at dementia’, available at www.healthreport.com.au

A public education program could address both aspects of dementia and the plight of family carers including their isolation and the huge and varied emotional stresses that they experience.

Improving quality of life for carers

'My interaction with a fairly large number of carers is that their overriding emotion is grief.'

'They all need to understand the enormous emotional and often physical stress that carers are subjected to. Caring brings constant anxieties and it is very difficult to "switch off" even when working or pursuing other activities within the community. Carers are lonely and appreciate interest, a kind word or a phone call from time to time.' (Carer NSW)

Recent research by Frank²⁵ suggests that grief and loss issues are the main barrier to effective care giving, not the hands on day-to-day physically exhausting work.

For a carer to try to maintain some quality of life, it is very important to pursue some outside interest on a regular basis. However this can only be possible if the person with dementia is attending a quality day centre or has a carer with them.

Whilst still in the caring role, family carers need to be encouraged to join and participate in a few activities thereby establishing a pattern of regularity and interaction with other people. Carers need time to look after their own health, to do household shopping, to have social outings. They need to have things to look forward to themselves.

All carers experience loneliness largely due to friends (and sometimes family) "walking away", fewer and fewer phone calls expressing friendship and concern for their situation etc. (Carer NSW)

²⁵ Frank, Jacquelyn (2008), Evidence for Grief as the Major Barrier Faced by Alzheimer Caregivers: a qualitative analysis, *American Journal of Alzheimer's Disease & Other Dementias*, Vol 22 Number 6 516-526