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# Respite Care for People Living with Dementia

“It’s more than just a short break”

Discussion Paper 17

**May 2009**

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with Anna Howe



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Warwick Bruen developed the draft of this paper in his role as Policy Advisor with Alzheimer's Australia and in consultation with the National Consumer Committee of Alzheimer's Australia. Anna Howe, a consultant gerontologist, revised the draft to incorporate recent statistics and developments in the field between 2007 and 2009.

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Alzheimer's Australia acknowledges the contribution made to this report by

- Members of the National Consumer Committee of Alzheimer's Australia
- Val Meredith and Wendy Hudson from Alzheimer's Australia WA
- Kaaren Sutcliffe in editing the report
- Glenn Rees, CEO Alzheimer's Australia

Alzheimer's Australia gratefully acknowledges the unconditional grant made by Novartis towards the cost of printing and distribution of this publication.

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## FOREWORD

The purpose of this paper is to put forward recommendations from the Alzheimer’s Australia National Consumer Committee on the provision of respite services for people with dementia and their families and carers. The Discussion Paper is a vehicle for presenting consumer views to the Australian Government, other levels of government, service providers and other agencies representing consumers of aged and community care services.

Respite care is a valued and much needed service. It is a complex policy area and while available evidence shows the effectiveness of a range of respite services, it also points to shortcomings and gaps. Respite care needs to be flexible because it must respond to greatly differing personal needs according to age, ethnicity, disease, frailty and geography. Access is also affected by the multiplicity of different kinds of services, whether based in the home or centre based or day/overnight respite.

This paper examines a range of quantitative data on use of respite services and more qualitative reviews of respite care carried out in Australia and overseas. We believe it can make a significant contribution to the debate on respite care in Australia, and to enhancing service delivery.

The Committee recommends that a change in direction is necessary at two levels.

First, the concept of respite care needs to embrace not just the notion of a short break for the carer, but the opportunity for both the carer and the person with dementia to continue their lives and engage socially. While respite needs to be part of an overall care plan, it is important in the process that the opportunity for social engagement is not lost. The dementia journey for people with dementia is long, and the particular need is for opportunities to continue life as normally as possible, including activities that have previously been part of everyday life.

Second, changes are needed in the provision of respite care to promote greater flexibility of response. The Committee believes strongly that while greater flexibility has been introduced through new forms of respite and brokerage, the greatest single problem for people living with dementia in accessing respite remains a lack of flexibility. Many of the recommendations made are directed at promoting flexibility as well as ensuring dementia friendly services. One means of achieving this is to adopt the principle of Consumer Directed Care in the use of brokerage funds so that the person with dementia and their carer can make choices in respect of the respite care that best meets their needs.

There is no one size fits all or any simple solution that would address the many concerns of people living with dementia about current access to respite care. But if the recommendations in this report are acted upon, it would achieve significant progress.



**Ron Sinclair**

Chairperson,  
Alzheimer’s Australia National Consumer Committee

## GLOSSARY

ACFI	Aged Care Funding Instrument, used for funding residential care since 2008
ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
ADL	Activities of daily living (e.g. dressing, bathing)
AIHW	Australian Institute of Health and Welfare
CACP	Community Aged Care Package, for community care
CALD	Culturally and linguistically diverse
CDC	Consumer directed care
CEWT	Carer Education Workforce Training Project, delivered by Alzheimer's Australia
COAG	Council of Australian Governments
DoHA	Department of Health and Ageing (Australian Government)
EACH	Extended Aged Care at Homes, high level package of community care services
EACH-D	As above, with special focus on dementia care
HACC	Home and Community Care Program
NDSP	National Dementia Support Program, delivered by Alzheimer's Australia
NRCP	National Respite for Carers Program
RACH	Residential Aged Care Homes
RCS	Residential Classification Scale, used for funding residential care to 2008
SDAC	Survey of Disability, Ageing and Carers, last conducted by ABS in 2003
VHC	Veterans' Home Care

## EXECUTIVE SUMMARY AND RECOMMENDATIONS

### Why a new approach to dementia respite is needed

Respite care is accepted as a crucial component of carer support that can assist people with dementia to stay living at home for as long as possible. But if this potential is to be fully realised, a new approach to respite care for people living with dementia is needed. This Discussion Paper identifies five sets of reasons that call for a new approach, and makes four sets of recommendations to set new directions for respite services for people living with dementia.

Part 1 sets out the most obvious reason why a new approach to dementia care is needed: as Australia’s population continues to age and an increasing number of people are diagnosed with dementia, the importance of flexible and quality respite care will increase proportionately. In the face of this rationale for a new approach, the first purpose of the Discussion Paper is to present the views of people living with dementia about what they want from respite care. The second purpose is to report on current patterns of use of respite services provided through different programs, and the third purpose is to present recommendations that would enhance respite care for people living with dementia.

Part 2 raises two sets of reasons for a new approach to dementia respite. People living with dementia believe that dementia respite is much more than “just a short break” and that a special approach is required. This special approach recognises that flexible responses are necessary because of the different stages of the disease process, that complex care is required to manage behavioural and psychological symptoms of dementia, and that the person with dementia and their carer both differing have differing social circumstances and care needs. In particular, the social isolation and stigma that may result from dementia necessitates an approach that supports early take-up of respite together with other services, and enables the person with dementia and their carer to engage socially and to continue activities that had previously been part of their everyday life.

Further reasons stem from the many additional challenges that people living with dementia face, over and above the process of ageing that is a journey for all. The concept of respite needs to be more than “just a short break” on this journey, and should embrace social engagement as well as integration with overall care planning. For some, admission to permanent residential care will occur at a late stage on the journey, and the role of respite care as stepping stones to this stage has to be recognised.

Part 3 turns to the programs that provide respite services and how they are currently used. It is recognised that a number of initiatives have been taken over the last decade to enhance respite care in Australia in general, and dementia respite in particular. However, the evidence assembled in this Discussion Paper from carers’ experience and from statistical sources indicates that take-up of existing forms of respite care by people with dementia and their carers is markedly less than optimal. Sub-optimal use arises both from shortcomings in the level and types of respite available, and from barriers that inhibit carers using respite. The Discussion Paper provides some insights into the reasons for this sub-optimal use and makes some constructive suggestions for delivering a level and range of respite services that are better matched to consumers’ needs.

Finally, a new direction is needed to address inadequacies that remain in the care system, notwithstanding increases in Government funding for respite services in recent years and more diverse services becoming available. The shortcomings most consistently flagged in the course of preparing this Discussion Paper were associated with a lack of flexibility in when and where carers could access respite, and lack of choice in the activities that respite offered. These inflexibilities often stemmed from rigidity in the structure of government programs through which respite services are delivered.

## Recommendations

The overall objective of the four sets of recommendations put forward in Part 4 of this Discussion Paper is to increase flexibility in the provision of respite care so that it is driven more by consumer needs and choice and is less by fixed program structures. The recommendations build on recent initiatives and especially aim to further the best practice demonstrated in flexible and responsive services that some providers have developed, so that consumers will have greater opportunities to integrate respite in community and residential settings in their overall care plan. The recommendations also call for a redirection of funding that is allocated to respite; as well as having to increase funding to meet growth in demand. Redirection of spending will make for more effective respite services and better outcomes for consumers.

### ***Enhancing access to flexible respite care***

A fundamental premise is that carers should be encouraged to use the respite care offered from an earlier stage, so that respite becomes an integral part of the care package for the person with dementia and use of different kinds of respite can increase or decrease as required during their journey with dementia. The first set of recommendations are thus aimed at expanding the supply of flexible respite services and enhancing access to make respite care a valued and integral part of the journey rather than a last resort.

**Recommendation 1:** In order to give particular attention to reducing the barriers to people living with dementia taking up respite as early as possible it is recommended that the Australian Government:

- expand carer education and training for dementia respite workers through the education and training component of the National Dementia Support Program delivered by Alzheimer's Associations, with specific attention to:
  - the development of joint sessions for family carers and respite workers;
  - ensuring that all family carers who receive support through these services have the option of having a contact worker assigned to them for follow-up contact and to assist in subsequently accessing respite services
- expand the support available through the National Respite for Carers Program to work with people living with dementia to plan future respite use, including respite in an emergency;
- conduct an audit of respite services to
  - identify preferred models of delivery for people with dementia and their carers, with particular attention to initiatives focused on special needs groups;
  - develop a Best Practice Guide based on the audit findings, and disseminate it to promote adoption of best practice in existing and new services; and
  - update training modules in the National Dementia Support Program and related TAFE courses and other training, in line with the Guide, and that standardised assessments of worker competency be promoted as a means of furthering best practice.

**Recommendation 2:** In order to address the greater unmet need for and shortfall in access to respite for people living with dementia compared to overall access, and to promote innovation in services, it is recommended that the Australian Government:

- give priority to dementia respite services in funding of all new respite services over a five year period to address unmet need, and that within this priority, particular attention be given to fostering dementia respite services for carers and people with dementia in special needs groups, and
- adopt a process for "designation" of residential respite services that incorporate links with community-based services and recognise these designated services through financial and other incentives.

**Recommendation 3:** As consumer directed care offers a means of maximising consumer choice and flexibility of care for people with dementia and their carers, it is recommended that a trial of consumer directed respite care be implemented and that an allocation of NRCP brokerage funds be committed to the trial. Given that carers of people with dementia in special needs groups often have particular needs that require more flexible responses, the trial should specifically include carers of people with dementia in these groups.

**Recommendation 4:** In order to encourage take-up of residential respite, it is recommended that the Australian Government reduce the costs to the consumer either by waiving the Basic Daily Care Fee paid by residents, for periods of up to 28 days or by reducing it by 50% for the allowable 63 days of respite a year.

**Recommendation 5:** To minimise confusion and inconvenience for consumers, it is recommended that Centrelink count permissible respite days for purposes of the Carer Allowance and Carer Payment on the same basis as the Department of Health and Ageing counts use of residential respite care, namely a financial year.

### ***Ensuring quality of respite care***

Concerns about quality of care pose barriers to using services. Our work found shortcomings in the quality assurance framework for ensuring the quality of respite care, particularly residential respite services, and insufficient attention to dementia-specific aspects of care in on-going care and respite care. Accordingly, a recommendation is made for an increased focus on respite care in general and dementia respite in particular within the established quality assurance frameworks, based on national standards and monitored by a single agency, to ensure a consistent approach to quality of respite care. Given that flexibility will be a specified criterion, action on this recommendation would go a long way towards ensuring the quality and flexibility of care required to support people with dementia and their carers, and maintain the dignity and quality of life through the transitions of their journey.

**Recommendation 6:** With the aim of ensuring consistent and sustained quality of services, it is recommended that the Australian Government work with the Aged Care Standards and Accreditation Agency to advance the quality of respite care by:

- reporting on outcomes across community care programs in a standard format, and giving specific attention to dementia care standards in this reporting;
- adding an expected outcome specifically for respite care to the relevant standards in the accreditation system for residential care; and
- funding respite care only in community and residential care services that meet standards and outcomes focused on respite care, including provision of training in respite and dementia care for their staff.

### ***Increasing flexibility of program structures***

A more adaptable program for provision of respite care would cater better for the transitions in the journey for persons with dementia and their carers and would result in greater uptake of services, in turn resulting in more effective and efficient use of the government resources and provider efforts. The recommendations focusing on resources propose adjustments to the current funding and planning arrangements rather than just seeking additional funding for more of the same services as already exist. These recommendations would see the National Respite for Carers Program become the vehicle for all respite funding over time.

**Recommendation 7:** It is recommended that funding for residential care respite be transferred from the Residential Aged Care Program to the National Respite for Carers Program to be used as brokerage funds that can be applied flexibly to meet consumer needs for different kinds of respite services. This transfer should be made in two steps:

1. an immediate initial allocation of funding equivalent to 1 respite bed per 1000 be made to take account of the under-use of the respite allocation,
2. pending the decision by the Council of Australian Governments on the future of aged care programs, transfer of all residential respite funding to a guaranteed stream of respite funding in a future aged care program.

**Recommendation 8:** In conjunction with this transfer of funding, and in order to meet unmet need for dementia respite care, it is recommended that:

- the planning target for residential respite places be reduced to 2 places per 1000 immediately and reviewed further as part of wider review of the planning process for residential aged care; and
- a planning system to cover all forms of respite be developed under the NRCP to ensure equitable allocation of funding and to promote diversity in provision, including through recognition and support of 'designated' respite services.

**Recommendation 9:** To ensure that funding for residential respite care is maintained in line with funding for permanent care, it is recommended that the level of funding for residential respite care for people with dementia be reviewed in relation to the Aged Care Funding Instrument (ACFI) to establish the appropriate level of funding for this service through the NRCP.

### **Monitoring implementation and evaluation**

The Australian Institute of Health and Welfare has made a significant contribution to monitoring and evaluating take-up and outcomes of service use by people living with dementia in its 2007 report *Dementia in Australia: National data analysis and development*.

That work was commissioned by the Australian Department of Health and Ageing to provide a guide to improving data on dementia in national data collections. Adoption of the strategies proposed by AIHW to improve data about dementia is a key step in measuring the effectiveness of changes in approaches to delivery of dementia care, including respite care, and providing better data on needs and service use to inform future government decisions. This data also needs to be made accessible to a wide audience on a regular basis through AIHW publications.

**Recommendation 10:** In order to monitor and evaluate the effectiveness of changes in delivery of respite care and related programs to people living with dementia, it is recommended that:

- the strategies proposed by the Australian Institute of Health and Welfare in 2007 for improving the reporting of all aspects of dementia in national data collections be adopted;
- a concise report on dementia care be included in the AIHW bi-annual report *Australia's Welfare* and a full account be presented by updating the 2007 report on *Dementia in Australia* every five years; and
- funding for research and development be included as a component of the National Respite for Carers Program.

## Timetable for action on recommendations

The timetable for action on the recommendations begins in the short term. A commitment to action on a number of recommendations that call for changes to arrangements for program administration could be made in the immediate future. These recommendations are concerned with developing a dementia respite strategy (Rec 1), establishing a trial of consumer directed respite care (Rec 3), harmonising the way respite days are counted for different purposes (Rec. 5), greater attention to respite in quality assurance (Rec 6), adjustments in the residential care planning process with regard to allocation of beds for respite care (Rec 8), review of respite funding in relation to the ACFI (Rec 9) and some elements of monitoring and evaluation of dementia care (Rec 10).

The timetable for recommendations that require changes to funding arrangements is set by the framing of the next federal budget. As all these recommendations are more concerned with setting new priorities and redirecting funding than with bidding for additional funding over annual increases already built into program funding arrangements, action should not be unduly delayed by resource constraints. Recommendations requiring budgetary measures are aimed at giving priority to dementia in future funding of respite services (Rec 2), funding a trial of consumer directed respite care (Rec 3), reducing the costs barriers to take-up of respite (Rec 4) and the first step of transferring resources for residential respite from the residential care program to the NRCP (Rec 7).

A longer term timetable is set in relation to transferring all residential respite funding to the NRCP (Rec 7), as such a move would be made in the context of decisions of the Council of Australian Governments about the structure of the whole aged care program. The recommendation for second edition of the AIHW report on Dementia in Australia 2012 (Rec 10) sets the final timeline.

## Postscript

The report of the House of Representatives Standing Committee on Family, Community, Housing and Youth *Who Cares...?* on better support for carers was released in late April 2009. Alzheimer’s Australia made a submission to this Review and appeared at hearings of the Committee. The Standing Committee Inquiry covered all means of supporting carers and so its scope was necessarily wider than the Discussion Paper focus on respite for people living with dementia. The Committee’s recommendations nonetheless take respite care and carer support in the same directions proposed in this Discussion Paper. Five specific recommendations made by the Standing Committee are of particular relevance to people living with dementia and accord closely with recommendations made in the Discussion Paper. These recommendations made by the Committee call for a national strategy to address training and skills development needs of carers (Rec 10), streamlining of Centrelink claiming processes (Rec. 21), for increased funding for respite care (Rec 33), for pilot studies of individualised funding programs, also known as consumer directed care (Rec. 35) and for expansion of the National Carers Counselling Program (Rec. 48)

## PART 1 Introduction and purpose of the Discussion Paper

### **Present and future needs for dementia respite care**

As Australia's population continues to age and an increasing number of people are diagnosed with dementia, the importance of flexible and quality respite care will increase proportionately. Respite care is a crucial component of carer support, and can enable people with dementia to stay living at home for as long as possible. At present, people with dementia and their carers are catered for in respite provided through the general aged care programs, and the capacity of these provisions to respond to consumer needs will have to be enhanced considerably if future needs are to be met.

Estimates of the number of people with dementia in Australia prepared for Alzheimer's Australia by Access Economics (2005) show an increase of just on 50% in the last nine years, from 171,220 in 2000 to 234,640 in 2009. Numbers are set to increase much more rapidly over the next 20 years due to the very rapid growth in the population aged 85 and over, among whom the prevalence of dementia is highest. From 2009 to 2030, the number is projected to double, to reach 465,460, and close to two out of every 100 people in the population will then have dementia.

This is a significant proportion of the population of Australia and it will be important that they are adequately catered for and that there is optimum use of available respite care and other services. According to the 2007-08 Alzheimer's Australia Research Annual Report, by 2013 the total cost to the health and aged care system of dementia is projected to rise to \$8.2 billion per annum, and this cost will rise steeply in future.

Much of the Discussion Paper focuses on respite care for older people as the majority of people with dementia are over 65 years of age. However, Access Economics estimates show that just over 10% of people with dementia are aged under 65, and particular issues arise around provision of respite care for these individuals, not least because they are the most likely to have family carers and other family members who are affected.

Dementia is a major factor precipitating admission to permanent residential care. Based on analysis of the ABS *Survey of Disability, Ageing and Carers 2003*, the AIHW (2007a) reports that 57% of people with dementia are living in households and 43% in cared accommodation. The impact of dementia is evident as these figures compare with 71% of all people aged 60 and over with moderate and severe activity limitations living in the community and only 29% in cared accommodation. AIHW also reports that people with dementia represent about a third of all older people who are receiving care in the community or in residential care. As well as benefiting the quality of life of people living with dementia, providing support to remain in the community, and thereby delaying admission to permanent care, is of great importance for public expenditure as permanent residential care is the most costly form of care. Addressing the respite needs of people with dementia is a key issue in the wider network of services.

While the process of ageing is a journey for all, there are many additional challenges for people with dementia and their carers. To meet these challenges, the concept of respite needs to be more than "just a short break", and has to embrace social engagement as well as integration in overall care planning. The social isolation and stigma that may result from dementia necessitates an approach to respite that, particularly in the mild and moderate phases of the disease, enables the person with dementia and their carer to engage socially and to continue activities that had previously been part of their everyday life. At later stages, there is a high probability of eventual admission to residential care, and respite can provide stepping stones to this point on the journey.

The research and literature review conducted in compiling this Discussion Paper show that use of existing respite care services by the carers of people with dementia appears to be sub-

optimal, alongside evidence of greater need for access to flexible respite care for these carers. Given the prediction of a doubling of persons with dementia in the next 20 years, there has to be concern about the welfare of these people and their carers, together with the need to ensure that government support that is provided is effective, efficient and of high quality and that services are well used by the consumers for whom they are intended.

## Purposes of this Discussion Paper

This Discussion Paper has three purposes. The first is to present the views of people living with dementia about what they want from respite care. These consumer views are reported in Part 1. People living with dementia believe that dementia respite requires a special approach and a recognition that flexible responses are necessary because of:

- the different stages of the disease process;
- the complexity of care in response to Behavioural and Psychological Symptoms of Dementia (BPSD);
- the differing social and care needs of both the person with dementia and their carer; and
- the need to support people with dementia in the community for as long as possible given the much higher likelihood that they will be admitted to permanent residential care compared to those who do not have the condition, and for support to continue through that transition if and when it becomes necessary.

This part of the Discussion Paper gives particular attention to the nature of additional requirements of five groups of people living with dementia who have special needs: those with Behavioural and Psychological Symptoms of Dementia (BPSD), those from culturally and linguistically diverse (CALD) backgrounds, Indigenous people, younger people with dementia and those living in rural and remote areas.

The Discussion Paper is not intended to provide a review of research on respite care for people living with dementia. A number of studies that are pertinent to particular issues are noted through the Discussion Papers, and two overview comments can be made. First, there is a considerable body of research from Australia and overseas that shows that respite is highly valued by carers. Access to effective respite has been shown to have significant benefits for the health of carers, enabling them to extend their caring role, and delaying or preventing the entry of the person with dementia to residential care. Second, studies generally highlight the complexity of delivering a quality respite service. For example, Stommel (1999) found that initial service encounters had a pronounced effect on both attitudes and service use throughout the caregiver career. Carers view their minimum respite requirement as services to extend to several hours or several times per week, and Cox (1997) found that carers reported significant improvement in their relative’s behaviour following inclusion in a multi-dimensional respite program.

The second purpose is to report on current patterns of use of respite care provided through different programs, and this picture is presented in Part 2. While several indicators show that a range of respite care services are quite widely used, others show that take-up of respite is sub-optimal: not all capacity is used and, at the same time, not all consumers are able to find the kind of respite they need, when and where they need it.

The third purpose is to put forward recommendations on what needs to be done to enhance respite care for people with dementia and their carers. Government funding for respite care has increased in recent years and services have grown, but inadequacies remain. It is when the

consumer views from Part 1 and the data in Part 2 are drawn together that some insights are gained into the reasons for the apparent sub-optimal use, and these insights provide the base for constructive suggestions for improvement.

This Discussion Paper draws on a variety of sources of quantitative and qualitative data. *Dementia in Australia: National Data Analysis and Development*, compiled by the AIHW (2007a), is a key document. This report is a major advance in consolidating available statistics to present a detailed profile of people with dementia and their carers, and their use of services. The AIHW report includes extensive further analysis of the ABS 2003 *Survey of Disability, Ageing and Carers* (SDAC). The consistency in the prevalence of dementia identified in the SDAC, the estimates developed by Access Economics and others developed by AIHW mean that the detailed picture in the AIHW report builds on a firm foundation. This Discussion Paper rounds out the statistical picture of respite care with qualitative reports from people living with dementia about their needs for respite, their experiences of using respite, and their views on what needs to be done to enhance respite.

The quantitative and qualitative data tell the same story from different perspectives and taken together, they provide a comprehensive evidence base for making recommendations for improving respite care for people living with dementia. Systematic and consistent identification of people with dementia and their carer in respite program data collections and other research studies are needed to inform further development of respite care.

The recommendations set out in Part 4 are directed to achieving improvements in four areas:

1. enhancing access to and flexibility of respite care;
2. ensuring quality of care;
3. rebalancing provision of care through changes to program structures and funding; and
4. monitoring implementation and evaluation.

## PART 2 What do people living with dementia want from respite care?

### **The importance of dementia respite: what people living with dementia say**

#### **The concept of respite care**

The needs of people with dementia and their carers are as many and varied as the journeys and transitions they experience. The rapid growth of the “old old” population in which the prevalence of dementia increases exponentially means that aged care services will increasingly be dealing with people with dementia and their carers. Further, the next wave of people diagnosed with dementia will include increasing proportions of baby boomers. To the extent that the baby boomers are better educated and better informed, they are likely to have higher expectations of services and more likely to be vocal if services fail to meet their needs and expectations.

The aim of respite care is to help maintain the caring relationship for as long as possible, thereby assisting the care recipient to stay living at home for as long as practicable. Ideally, those with dementia and their carers will be aware of and encouraged to use respite care services from early on so that respite care can become an integral and valued part of their journey. Such an approach is likely to enhance the welfare of all involved, all through the journey, but all too often using respite care is left to a last resort or occurs only in an emergency.

The focus of respite care has been on providing the carer and the care recipient with a short term break from their usual care arrangements. There are currently a number of government funded programs available that provide for respite care ranging from a few hours to several weeks, provided in the care recipient’s home, in someone else’s home, in a day care centre, during the day or overnight, in cottage style accommodation or in a residential aged care home or on rare occasions, in a hospital. Respite care can be provided by other family members or by paid staff. It is best planned in advance; planning for respite can reduce the likelihood of emergencies arising due to carer strain, but emergency respite will still be needed in other situations.

People living with dementia consider that seeing respite as “just a short break” devalues the concept in a number of ways. They say this limited view:

- neglects the need to integrate respite care with the overall care plan for the care recipient;
- undervalues the role respite can play in improving the quality of life of both the person with dementia and their carer;
- ignores the many different objectives of using respite care and the different responses needed to meet these objectives, including emergency respite and longer term planned respite; and
- casts eventual admission to permanent care as a failure to return to the community instead of a progression on the dementia journey.

Instead of been seen as “just a short break”, respite should be regarded as a way in which both the carer and the care recipient can continue their lives together or separately, depending on their particular care needs and social circumstances at particular times. Respite care is one of the key supports carers say they need to help them continue caring. This is particularly so for carers of people with dementia as the requirements of caring can be more physically, mentally and emotionally exhausting than for other carers. The needs of the person receiving respite care are equally important. Neither they nor their carers are helped if the person with dementia returns

from respite care depressed or more confused by the experience, and concerns about these possibilities as much as actual negative experiences can pose a barrier to using respite. Respite care should improve the quality of life for both the carer and the care recipient, and should, ideally, be an integral part of the transitions that occur as the journey of the person with dementia progresses.

### **Views from a focus group and consumer satisfaction survey: Alzheimer's Australia Western Australia, 2008**

Alzheimer's Australia WA (AAWA) provides dementia-specific respite services to people with dementia and their families. These services incorporate funding from both the Home and Community Care Program (HACC) and the National Respite for Carers Program (NRCP) and are provided in both metropolitan and regional areas of WA. AAWA also established a Consumer Advisory Group in 2000 and has developed a professional ethos of valuing consumer input and continually seeking advice and comment from the consumer group.

Before providing information and comment about dementia-specific respite services for this Discussion Paper, AAWA sought to ascertain the opinion of carers and people with dementia about respite services as a whole.

#### ***Focus group responses***

AAWA conducted a consumer focus group, attended by both carers and people with dementia in August 2008 to discuss the following four questions:

1. What does respite care for someone with dementia mean to you?
2. What constitutes "good" respite care for someone with dementia?
3. What is your experience (positive or negative) in receiving respite care services?
4. How could your experience with respite care be improved?

Responses to these four questions during the focus group session were as follows:

#### ***1. What does respite care for someone with dementia mean to you?***

Three main themes emerged clearly from consumers' answers to this question:

- Respite services should benefit both the carer and the person with dementia.
  - It should be a "break" for both – not just for the carer;
  - It should not be a static experience for the person with dementia, but should be positive, beneficial and enjoyable;
  - Respite services should also offer additional support to the carer; and
  - The term "respite" can be viewed in both positive and negative terms.
- Respite services should offer choice and flexibility to the consumer.
  - Respite workers of the same age, gender and interests as the person with dementia should be available;

- Consumers in regional areas should have respite programs that offer choice and flexibility;
- As not all carers and people with dementia want services between 9-5pm on weekdays, there should be flexibility in service hours, particularly for younger clients and employed carers; and
- Not all people with dementia are aged 65 and over, and younger people with dementia require specialised services.
- There should be quality in the respite services.
- Education and training for support workers in dementia-specific issues should be a priority;
- Any activities provided should be appropriate for the varying needs of people with dementia; and
- Respite services should change in line with the changing needs of people with dementia and their carers.

### **2. What constitutes ‘good’ respite care for someone with dementia?**

Consumers indicated that good quality respite services were those that:

- Benefit the carer;
- Provide opportunities for social and community engagement for the person with dementia;
- Focussed on meeting the individual needs of the person with dementia, noting the varying needs of client groups such as younger people living with dementia, clients from culturally and linguistically diverse backgrounds, Indigenous clients and clients living in rural and remote areas of WA;
- Used appropriately trained staff and provide respite within an appropriate environment;
- Were designed to meet the changing needs of people with dementia; and
- Had staff who could communicate appropriately with the carer and other supporting family members.

### **3. What is your experience (positive or negative) in receiving respite care services?**

- Consumers indicated some dissatisfaction with residential respite and their access to packaged care.
- They particularly raised the issue of requiring a continuum of care, that is, respite that is able to respond appropriately to the changing needs of the person with dementia.

The experience of a carer in Tasmania shows that respite can be a positive experience.

*I walked into my husband's nursing home for people with memory loss. Roy's unit houses 9 residents. John, one of my husband's fellow sufferers was a language expert; he spoke 3 languages, did his PhD in Germany in German and taught classical subjects at UTas. He is Dutch.*

*As I was talking to Roy, John was wheeled into the resident's living room and placed in front of the piano. John plays the piano by ear. He started to play something. Roy and I went into the living room where the carer was trying to encourage him to play something else. I played a C major arpeggio. He played one too. Then I played a minor arpeggio and he copied me and then played an A minor scale.*

*A carer came in from another one of the nursing home units with three dear old ladies following. One was Welsh.*

*I was asked if I knew Men of Harlech. I played the first line and John copied using both hands. Then I played The Ash Grove and again John copied. Then I played the melody of All Through the Night. John copied me and suddenly most of the residents and myself and Roy and the carers were all singing.*

*Now John had a recent brain scan and his brain is almost completely covered with protein plaques. He has no speech and has to be fed as he has trouble eating. He is also incontinent. But he has the ability to play once I played a tune.*

*What was so extraordinary was that the other residents in the room started to sing or tap their feet. The incident was like a ray of golden light streaming through the window on an otherwise rather dull day.*

*There is an ending. John, who plays the piano, once started, forgets how to stop! He got up in the middle of the night and started playing. Not a good time for the residents. Eventually the staff, at night, put some towels on the keyboard and the lid over the towels so John can't play at night.*

*'Well,' said the therapist, 'you would play 'All Through the Night!'.*

#### **4. How could your experience with respite care be improved?**

Consumers raised concerns about some of the unmet needs they experience. The main themes emerging from the discussion were:

- Suitable transport;
- Consumer Directed Care;
- The importance of considering respite services for the future;
- The value of access to appropriate information; and
- The importance of suitably trained staff in all aspects of respite services.

Another carer from Western Australia expressed her reservations about using respite:

*I often feel the need for respite. However, I am reluctant to send my husband to a service where he sits in front of television all day. Residential respite facilities should offer a range of stimulating activities, particularly suited for men (such as gardening, or wood work).*

#### **Client satisfaction in regional surveys**

Client satisfaction surveys are annually distributed from each of the four AAWA regional teams. 56 of the 115 survey forms sent from the Albany and Mandurah offices were returned, and the consistency of the answers indicates how highly carers value *dementia-specific* respite services. In response to the question “Which of the following reflects your level of satisfaction with the respite service you receive?” 50 carers said they were ‘highly satisfied’, four were ‘moderately satisfied’ and two gave no response.

Comments made by carers reflect the positive impact of dementia-specific respite services for the person with dementia and for the carer: many comments referred to ‘home-like’ or ‘family-like’ care in these comments. At the same time, carers and people with dementia appreciate services that are professional and appropriate, and that are person centred.

**Alzheimer's Australia Western Australia Client Satisfaction Survey**

Comments on benefits for the person with dementia:

- *I very much appreciate the time and effort the team at HH puts in, to care for mum when she is with them. They are like a second family. I know she is always safe, warm and well fed. They are a lovely group of genuine caring people. They all deserve our heartfelt thanks and commendation.*
- *We appreciated the care and sincere consideration given and the no fuss approach of all because it gave us the chance to have time for each other with a guilt free mind. And we knew his mother enjoyed her visits – was exceptionally well cared for and above all was treated as an individual person – they understood her. We can only say sincere thank you to every one of the wonderful folks from admin down for their wonderful care and love given to our "Grandma" who celebrated her 95th birthday with her friends at HH and was the happiest she had ever been because of them when she peacefully passed away in January 2008.*
- *She enjoys her visits and it has become very much a second home. She has always responded positively to staying at HH.*
- *I cannot speak highly enough of the care he has received. Just like being at home he tells me*
- *My husband always comes home having had a "most enjoyable time with lots of laughs" (his words)*
- *My husband has been kindly treated and the experience entirely positive.*
- *My spouse seems to have improved since he is going out in the bus with other men. Getting more feedback from him.*

Comments on benefits for the carer:

- *Every Wednesday morning I go to line dancing class and I am so happy to leave my husband with the respite carer, and do not have to worry about him being alone.*
- *I myself have just been on a weekend retreat with the group. It was the best.*
- *I enjoy my free time from caring to do my shopping and time to relax with a quiet cup of coffee.*
- *It feels more like family*
- *Always helpful and very patient. They are friendly and always care about my welfare as well as the dementia person. Nothing is too much trouble. They are like family. They patiently help and guide you when things get tough and you have to make big decisions. They also make me feel a worthwhile person.*

**Responsive respite: Alzheimer’s Australia Victoria, 2003**

A review carried out by Alzheimer’s Australia Victoria in 2003 found there was a great need for more ‘responsive respite’. Creating responsive respite meant ‘service providers working in partnership with their clients to identify a range of respite options’. This review concluded that there were three fundamental issues in improving respite services for people with dementia and their carers:

- reframing what respite is and developing a broader understanding of respite among service providers and staff;
- training and education for staff working with people with dementia, to develop a better understanding of dementia and appropriate dementia care; and
- facilitating the use of funding in flexible and innovative ways.

These findings are consistent with those of a number of other reviews: the key factors that are repeatedly identified are flexibility and innovation, together with consultation and participation of both the carer and the person with dementia in the planning process.

**Evaluation of the Carer Education Workforce Training Program (CEWT), 2004**

The findings of this evaluation provide strong support for the value of having respite workers with training in dementia care and the importance of carer education as a lead in to using respite care. The CEWT Program provides Commonwealth funding to the Alzheimer’s Association to conduct training programs for respite workers and family carers in conjunction with Carers Associations in each state.

One aim of the CEWT Program is to promote take up of respite services and the evaluation conducted in 2004 reported a wide range of positive outcomes for respite workers and for carers, and the carer education sessions were especially effective in overcoming barriers to using respite.

*Family carers participating in the evaluation of the CEWT program identified barriers to using respite associated with the nature of services and reluctance on the part of the person with dementia:*

*1. Respite Service Issues – lack of availability, little flexibility in the times provided, and lack of staff expertise with the local respite service were the most significant factors.*

*2. Issues around the person with dementia – these issues accounted for a significant number of reported barriers by carers. The high level of resistance to respite by the person with dementia was the single most important barrier to respite use. Carers often preferred ‘in home’ services because then the person with dementia may be more amenable to respite in a familiar surrounding or with familiar people. Families also feel they have more control over the specific service that is provided when it is delivered ‘in-home’.*

**Benefits for carers**

A total of 542 family carers participated in CEWT in the evaluation period. Assessment surveys were conducted at the beginning and end of the carer education courses, and 69 respondents were followed up four months later. The benefits of the sessions reported by carers at all stages show the important part that access to information and support play in promoting take up of respite:

- two out of three carers had not previously had contact with Alzheimer's Australia and presumably little if any contact with any other support agency or service;
- 9 out of 10 carers reported that the course improved their understanding of dementia and these benefits carried through at four months;
- at the end of the course, fully 95% felt they would be comfortable using respite compared to only 43% prior to doing the course;
- use of respite more than doubled from 25% of carers who were using respite at the beginning to 56% at the end; both informal respite from other family members and formal service use increased, and in-home respite with personal care particularly increased;
- the follow-up survey found that 90% of carers said they were much less or less stressed after using respite;
- carers also reported that they were assisted in understanding, planning for and coping with the future; and
- group sharing had a positive impact on their ability to cope.

The benefits of carer education were summed up by carers who said that the course had helped give them 'permission' to use respite services.

**Benefits for respite workers**

The 1,196 staff who participated in the CEWT program were either personal care workers or respite workers, and three out of four had more than 12 months experience in respite care and fully one third had five years or more experience. The modules that ran for 6 to 8 weeks were delivered through TAFE courses and other accredited training programs. The positive outcomes reported show that workers do not just learn about dementia on the job but that formal dementia-focused training is needed:

- overall ratings showed very high levels of satisfaction with the course, with around 80% saying they were very satisfied with several separate elements of the course;
- respite workers showed significant increases in knowledge about all aspects of dementia;
- improved understanding led to more positive attitudes to people with dementia and better communication with family members; and
- workers reported that they had acquired new skills for better practice in care.

A separate survey of managers of respite services whose staff had participated in CEWT found unanimous agreement that the course was highly relevant and effective. They also reported that

participants had transferred their gains in knowledge and skills to other staff and continuing use of course materials. Managers also commented that there were positive outcomes for the clients and families.

*After CEWT courses, respite workers had increased understanding of the needs the person receiving the respite and the associated family members and were more likely to:*

- *provide the client (person receiving respite) with choices,*
- *look for ways to improve the dignity of clients,*
- *encourage families to be more involved in care planning and discussions with staff,*
- *try and understand the perspective of the family and person receiving respite,*
- *pass on any knowledge they have to families to help them better manage,*
- *refer families to other specialist resources,*
- *be generally more supportive of families, and*
- *make attempts to improve communication with families.*

### **Consumer preferences: Access Economics choice modelling experiment, 2009**

Research commissioned by Alzheimer’s Australia and carried out by Access Economics in 2008-09 included a choice modelling experiment to investigate consumer preferences for eight dementia care scenarios – which had different mixes of services and levels of service. The web based survey was completed by 564 family carers who were currently caring for a relative with dementia, or who had been a caregiver. Half of these carers reported negative impacts on both their emotional and mental health, and on their lifestyle in terms of reduced time for other activities. Around a third also experienced negative effects on their physical health, increased costs and reduced ability to earn an income.

Carers expressed strong preferences for community care scenarios that included respite care compared to scenarios without respite, and the strength of preference increased with increased frequency of access to respite. Compared to scenarios with no respite (scored 0), demand increased:

- to 25% for scenarios that included only occasional respite (in emergencies or for special events)
- to 35% for scenarios that included respite available daily but for only part of the day, and
- to 48% when respite was available daily and for extended periods of time including holidays.

The scenarios included respite together with other services, and the service attribute that met with highest demand was home support such as shopping, transport and cleaning. The other attributes tested in the choice modelling experiment were a dementia care case worker, qualified staff providing periodic home support for specific care need, a community centre providing information, counselling, education and recreation, a helpline and emotional support for carers. None of these other services had as large an effect on demand for the care scenarios. These findings show that carers place a high value on respite, and that inclusion of respite together with other services in an integrated care plan has a very positive effect on carers’ choices.

## The importance of dementia respite: What the statistics say

It is generally agreed that most people want to stay living in their own homes for as long as possible, and that the extent to which people with dementia can do so depends very largely on the strength of family care. Data reported by AIHW (2007a) show that formal support for people with dementia is only effective when carer support is available and in turn, it is evident that carers of people with dementia have a greater need for formal services if they are to continue carrying on with their carer role.

Focusing on all those needing assistance in core activities (self care, mobility and communication), the AIHW analyses show:

- none of those with dementia were supported by formal services alone, compared to 7% of those without dementia;
- the same proportion of those with and without dementia, 86%, received support from informal carers;
- 57% of those with dementia received support only from informal carers compared to 65% of those without dementia;
- 29% received support from informal and formal care compared to 21% of those without dementia; it was evident that receiving formal services as well as informal support was especially important as the severity of dementia increased; and
- Compared to 7% of those without dementia, 20% of those with dementia did not receive needed help. This finding appears paradoxical, but can be resolved. It appears that the majority of those without help were people with mild dementia and who did not have a carer, and these individuals are unlikely to be able to remain in the community as their dementia increases in severity as formal services are ineffective without carer support. Respite care may however be a means to enabling these people to remain at home on their own for longer not only through giving them a break from having to manage on their own, by boosting their well-being, by increasing their capacity to care for themselves when they do return home and by linking them to other support services.

These findings make it clear that people with dementia are:

- less likely to be able to continue living at home on their own than other frail older people;
- that this likelihood decreases as the severity of their dementia increases;
- that formal services alone are inadequate, and
- carers of people with dementia are more likely to have to call on formal services than other carers.

The consistency between these findings and what carers say confirm that respite is even more crucial as an integral component of any community care strategy for people with dementia than for frail older people and carers in general.

AIHW (2007b) has aptly referred to different forms of respite care as stepping stones. It is evident that stepping stones of different shapes and sizes, and spaced close together, are traversed on the dementia journey. If there are too few respite services, and they are used too far apart, respite services may see carers and those they care for fall between the stepping stones on their journey.

## How are dementia needs different?

People with dementia and their families are emphatic that their experience is different from that of frail older people and carers who are not living with dementia. They are insistent that their care and support needs cannot be characterised simply as ‘aged care’. Their current experience of respite services in community and residential care settings is one of services that often fail to address their complex and multifaceted needs as adequately as they might.

The voices and opinions of these individuals have informed the writing of this section, and three key themes are identified as necessary to improving the effectiveness of respite services for people with dementia and their families and thereby enhancing the provision and take-up of these services.

### **1. Services should focus on the person with dementia and the carer**

Respite services have traditionally focused on providing a break for the carer. However, it is becoming increasingly apparent that respite is of equal importance for the person with dementia and for the carer, and that outcomes for both should receive equal consideration when respite services are developed, delivered and evaluated. Policies and planning to ensure that services focus on the person with dementia *and* the carer should be based on the following three principles:

- That respite is not a ‘stand-alone’ service, but is an essential component of a range of services required to meet the complex and multifaceted support needs of the person with dementia and their carer;
- That the needs of the person with dementia and the needs of their carer are unique, individual and often different; and
- That a comprehensive assessment of the needs of the person with dementia and their carer is essential to the effective development and delivery of effective respite.

Assessment for services requires information about the interests and abilities of the person with dementia and the level of carer stress so that individual care plans can be developed with clearly identified goals and strategies to achieve them. Rather than focusing only on providing a break from usual activities, these goals give more emphasis to continuity of personal and social relationships. The underlying goals that respite services should endeavour to address include:

- supporting the relationship between the person with dementia and the carer;
- reducing social isolation of both the person with dementia and carer by maintaining and promoting their health, well-being, independence, capacities, skills and interests;
- for the carer, providing opportunities to meet their social, emotional, family and occupational obligations and needs;
- for the person with dementia, providing opportunities for social engagement, companionship and stimulation and enabling them to remain living in the community and avoiding permanent admission to residential care for as long as possible;
- providing opportunities for social interaction with others who are on the dementia journey: sharing understanding of issues and experiences is an essential part of support that helps people living with dementia come to see what lies ahead and equip them to cope with future challenges, including coming to terms with the possibility of eventually relinquishing care at home for on-going residential care.

The mix of services that people living with dementia require changes over the course of the dementia journey. Access and eligibility for services should not be linked to assumptions about a person's needs according to their particular 'stage' of dementia. People with dementia can continue to participate in a range of community based respite services if provided with the appropriate level of support. However, many services are resourced according to service type rather than individual client need. Mechanisms to support and encourage consumer involvement, from the person with dementia and the carer, and consultation in the development and review of respite services are essential.

The significance of caregiver burden, particularly relating to dementia care, is well-known and influences the uptake and effectiveness of respite services. People with dementia also experience stress, anxiety and depression, associated with care-giving and these experiences influence their attitudes towards and acceptance of respite services. Information and counselling services that can facilitate take-up of respite and other direct support services play an important part on the dementia journey. Alzheimer's Australia is a key provider of these facilitating services. As well as delivering these services directly to people living with dementia, it has a key role to play in attuning other counselling services, case management and care coordination services to the special needs of people living with dementia, so that these services are aware of the need to promote early initial use of respite care and to provide advice and back up in the event of negative experience that may lead to withdrawal from respite or cessation of further use.

Some carers feel that there is a stigma attached to 'respite care', stemming from their direct experience or hearing about someone else's distressing experience, or because it means that they cannot cope on their own. Such stigma leads to a reluctance to use respite services. Younger people with dementia and their carers specially say that in the early stages of their journey they do not identify 'respite care' as a service that can meet their particular needs. Rather than taking a break, they are frequently seeking opportunities and support to remain as fully engaged as possible with their community.

## **2. Flexible and responsive services support consumer choice**

A more flexible and responsive range of services, funding and delivery options will increase opportunities for consumer choice as well as achieving a more efficient use of resources. Consumer choice can be increased by provision of services within a framework based on the following premises:

- Services should be sufficiently flexible in design and funding to better meet the needs of people with dementia and their carers rather than consumers having to modify their needs to fit into service resourcing and workforce constraints.
- Access to levels of service should be determined by individual need, not by program and funding types.
- Fragmentation of services across different jurisdictions should be reduced to encourage and enable smoother transition for consumers between services and service types as their needs change: having to change providers when consumers' needs change undermines the very continuity and familiarity of support that is so important to the well-being of people living with dementia and should be eliminated wherever possible.
- Service providers should be enabled to provide innovative respite options to meet individual needs, but current funding guidelines provide little by way of incentives or rewards for responsive service delivery.

- Early referral to services should be common practice, so that people with dementia who are newly diagnosed and their carers can be informed about and linked into services that best meet their needs. Early referral can be facilitated by improving awareness of dementia and services available to support families and people with dementia on the part of general practitioners, Memory Clinic staff, geriatricians and ACAT team members.

A succinct comment from a carer in South Australia who struggled for some time before finding help from a Carer Respite Centre sums up the importance of early referral:

*If only we had known the Carer Respite Centre was there.*

### 3. Desirability and quality of service practice and provision

The level of take-up of services is affected by many factors, including perceptions, past experience of using services, feeling that there is a stigma attached to dementia, and the guilt that is often present when carers ask for assistance with their caring role. Carers tend to indicate a higher satisfaction with respite services if the person with dementia’s experience is positive and meaningful and the service supports their well-being.

There is no single or standard approach to respite care for people with dementia, and no ‘one size fits all’ set of practices. From a consumer perspective, the key word is flexibility, in terms of the type, timing and frequency of respite on offer. Quality of respite care is more likely to be high when it:

- supports the relationship between the person with dementia and the family carer;
- assists in reconnecting the person with dementia to their community, their activities and their lifestyles;
- addresses the physical, emotional and social needs of the person living with dementia in a safe and caring environment;
- is set up within a network of other support services that respond to the complex needs of the individual;
- responds to the changing circumstances and needs of the person with dementia and the carer, including changes that lead to admission to permanent care;
- responds to the cultural diversity of the local population, and
- promotes a professionally-based care environment characterised by strong leadership.

Improving the desirability and quality of service provision will ensure consumer satisfaction and encourage optimal take-up of services. The factors that should be taken into account in developing strategies to support better quality outcomes for consumers include:

- adequate funding to enable the delivery of appropriate, high quality services;
- dementia specific input into the design of community-based and residential respite facilities to ensure that the environment can support the abilities, interests, cultural and spiritual needs of people with dementia;

- development of appropriate knowledge, skills and attitudes for all staff, through initial and on going dementia specific training, mentoring and monitoring of care practices and support;
- provision of care coordination, counselling, information and support as integral components of respite services, extending over the period of admission to and setline into permanent care;
- planning respite ahead, whether a few hours a week or a few weeks a year, to encourage take up and promote positive respite experiences, and to reduce the likelihood of a crisis, but at the same time, to have a plan in place should an emergency arise;
- recognition that people with dementia and their families may also require extra support when they are accessing health services, particularly hospitals and emergency departments, and when changing service providers; and
- recognition that support needs continue through the process of admission to permanent care and the period of adjustment that follows for the person with dementia and the carer.

## Additional needs of Special Needs Groups

### 1. Younger people with dementia

Respite care for people with younger onset dementia, that is under the age of 65, represents a particular challenge. Access Economics (2005) estimates that some 10,000 people under 65 have dementia in Australia. People with younger onset dementia and their families experience far more difficulty accessing services appropriate to their needs. Dementia is generally perceived as a disease of very old age, and therefore services are focussed on older people, resulting in a lack of suitable services. People with younger onset dementia are likely to leave the workforce because of their diagnosis, have different social interests, be more physically active and have different expectations of services.

The experience of one carer from Victoria shows that services are not likely to be prepared for caring for a younger person with dementia and that an individualised approach is needed.

*I cared for my 59 year old husband since he was diagnosed with dementia 8 years ago.*

*He requires constant care and can no longer be left alone. I work 3 days a week and sought residential respite care for my husband. After waiting 5 months for an ACAS assessment, and a further 5 months for the aged care facility to have a place available, I was taken aback to discover that the facility was totally unprepared for a person of my husband’s age. No one asked for a plan of care, what his normal routine was, did he have any interests, what job he had done, or who would visit.*

*The care he received was less than acceptable and my husband walked out of the facility. Only at this stage did the facility start to inquire about his needs.*

*I have since discovered that some other aged care facilities do ask relatives for information about the person’s previous occupation, special interests, hobbies and names of pets at the time of admission. Roll on person-centred care.*

The diagnosis of dementia has a dramatic effect on the whole family’s life plans and expectations. Carers of people with younger onset dementia are often still working and have younger families, and the more rapid deterioration often experienced by younger people can result in even greater behavioural and emotional challenges.

Ongoing training is required to equip service providers with the knowledge and skills to provide the level of support necessary to maintain the capacities and independence of younger people. There is also a higher prevalence of less common dementias in younger people, which requires workers to have particular skills to respond to the different needs associated with the range of dementias. Front-line staff also require support to deal with the emotional impact of caring for a younger person.

These issues have been well documented in report by Alzheimer’s Australia entitled *Exploring the Needs of Younger People with Dementia* in Australia that was funded by the Australian Government under the National Dementia Support Program in 2007. Recommendations were made to the Australian Government which included the need to increase the availability of services that are appropriate for people with younger onset dementia and to reduce barriers to using them.

The experience of another carer shows how services that could not respond to changing needs precipitated admission to permanent care.

*I cared for my husband Peter who at age 57 has frontal lobe dementia. I work one and a half days a week and accessed a range of respite care, including a Planned Activity Group 2-3 days a week, in-home respite one afternoon a month, day care 3 afternoons a month, and self-funded weekend respite. As Peter's condition deteriorated, these services were reduced by the providers.*

*An ACAT assessment determined Peter needed high care, so I investigated respite for high care. I found that there were no high care respite beds available as they were being used by permanent residents.*

*Peter is now in permanent residential care. I believe I could have kept him at home longer if adequate high care respite had been available.*

## 2. People with dementia from culturally and linguistically diverse backgrounds

The Access Economics 2006 report on people with dementia who speak a language other than English at home found that one in eight people with dementia were in this special needs group. Many of these people also speak English; loss of acquired English language ability is not a part of normal ageing, but it is a marker of the onset of dementia.

The report points out that those from ethnic communities continue to face barriers to accessing services, and Alzheimer's Australia's National Cross Cultural Network has identified a number of factors that affect the take-up of mainstream services by people who speak a language other than English, including:

- communication barriers;
- insensitivity to the needs of ethnic communities;
- family responsibilities;
- social isolation;
- access to transport, and
- cost.

Aspects of successful ethno-specific respite programs that make them more attractive to clients in this group include provision of:

- culturally and linguistically appropriate activities, with staff speaking the person's own language having a key role;
- culturally appropriate food;
- culturally sensitive surroundings;
- bilingual staff; and
- acknowledgement of the religious and spiritual needs of the individual.

An investigation of factors that make respite more responsive to clients and carers needs carried out by Alzheimer's Australia Victoria in 2003 found that because many CALD families believe in looking after their own, many in these communities were not familiar with the service system, or had a distrust of it, or they had little understanding of what respite meant. To address these barriers, providers need to expand the ways in which they adapt and promote their services to CALD groups.

Language and cultural barriers were reported to intensify difficulties when a person enters residential care. The scarcity of ethno-specific services, and particularly services that are also dementia-specific, means that poor communication in generic services can result in misunderstanding of the needs of CALD clients. Lack of understanding of the disease on the part of some carers in this client group can result in a tendency to refuse services until a crisis occurs. The capacity of service providers to respond to the respite needs of CALD clients and their carers can be enhanced by increasing their knowledge and experience of cultural issues, and provision of on-going dementia specific training for bilingual staff. Acknowledging that it will be difficult to find bilingual staff to cater for all CALD groups, the Victorian project recommended that all staff receive appropriate training to support responses to culturally specific needs and that the use of interpreters should become a more common practice.

### **3. People living with dementia in rural and remote areas**

People living with dementia in rural and remote areas can experience particular difficulties in accessing respite services that are suitable to their needs. Factors associated with these difficulties include:

- communities that are too small to support a range of viable services;
- distance to larger towns where residential respite may be available;
- disruption in moving the person with dementia further from their home;
- reluctance to use services due to perceptions of greater stigma attached to dementia or BPSD in small communities;
- lack of staff with dementia specific training and skills; and
- the diversity of communities in rural and remote Australia mean that it is impossible to generalise about availability of respite.

Data reported by AIHW (2008) indicates that there is considerable variability in use of residential respite between different geographic areas in each jurisdiction. By way of illustration:

- in NSW, bed provision per 1000 aged 70 and over and bed days used for respite were lower in all areas outside major cities compared to metropolitan areas;
- in Queensland, regional and remote areas had higher bed provision than the major cities and also had higher shares of bed days used for respite;
- in WA, a similar pattern as found for outer regional and very remote areas, but inner regional areas had lower bed provision and lower use of bed days for respite.

These variations can be related directly to the level of bed provision: where overall provision is low, pressure to use beds for permanent care means there is little scope for respite. The smaller size of homes in regional areas is also likely to reduce their capacity to offer respite places, but the development of Multi-Purpose Services in rural WA appears to have contributed to the delivery of more flexible respite and a high use of available beds for respite.

#### 4. Dementia respite services for Indigenous Australians

Alzheimer's Australia Northern Territory produced a report on services for indigenous people with dementia in 2002 which included the results of a survey of service providers. Key stakeholders were identified from a broad range of Northern Territory based organizations likely to be directly involved in the care and support of indigenous people living with dementia, or in the management and delivery of services within indigenous communities.

Some six out of ten respondents raised issues related to respite or residential care. The main comments were directed to the lack of services and facilities, inadequacies of facilities for indigenous people, and lack of support in homes and local communities. Respondents consistently mentioned that needed services and facilities were not available, particularly in remote indigenous communities. Comments mentioned:

- the lack of respite care and day centres;
- the need for purpose-built and appropriately staffed facilities to care for community members in communal or residential settings;
- centre-based respite was needed in all communities, and especially in remote communities, so that people with dementia can attend and their family carers are supported, contributing to the maintenance of caring relationships;
- such day care needs to provide diversional therapy and therapeutic activities;
- the need for services that can provide sleep-over staff to assist in the family home;
- the current emphasis in nursing homes is on permanent admission rather than places for respite; and
- residential and community respite facilities and services appropriate for younger people living with dementia are lacking.

Several respondents specifically mentioned a lack of emergency respite care. Often respite is being used as the last option when the family cannot cope. In addition, emergency needs cannot always be accommodated by existing respite services.

Indigenous people rarely use mainstream day care services, and to increase take-up of indigenous services, these services had to be more responsive to clients' and carers' needs. Areas for attention included:

- provision of appropriate activities, such as fishing;
- provision of indigenous foods as food is an important part of culture;
- recognising that the capacity for indigenous people to access structured respite is hampered by lifestyle where other issues take priority;
- built environments and surrounding of facilities;
- interpreters are not well used for residents or families, and
- increasing the number of indigenous volunteers and paid carers who were prepared to visit regularly, cook or do activities with people.

Respondents supported indigenous people being able to stay in their own communities: the main barrier was the difficulty in engaging reliable and appropriate carers in these communities.

Where staying on in their community was not possible, a range of supportive alternatives were identified, including:

- community contact visits, with individuals returning from residential care to visit families and communities in their homelands;
- groups from outlying communities being brought into town to visit people with dementia living in residential care, and
- sending recordings of community events to people who were in residential care, for respite or permanent care, to enable them to maintain their connections with their communities.

The Northern Territory report highlighted the need for culturally appropriate respite services for indigenous people with dementia, and underlined the need for all staff to be culturally sensitive when caring for these clients and their carers.

### PART 3 What respite care services are available now and how are they used?

The journey for people diagnosed with dementia, their families and carers is a long and arduous one. It progresses from the initial signs of memory loss to inevitable but often uneven deterioration of cognitive, physical and functional abilities. Integral to improving the individual experience of the dementia journey is the provision of appropriate respite services. From the consumer's perspective, all respite care, including residential respite care, is part of their care in the community and the distinction between community and residential respite care is artificial. In contrast, the boundaries between programs providing respite are very real.

The main programs through which respite care services are currently provided are:

- **HACC, the Home and Community Care Program**, the mainstay of community care, funds respite in the home, in day care centres and through social support. HACC also funds respite-related services of carer counselling, client care coordination and case management.
- **Veterans' Home Care** provides in-home and emergency respite to Veteran beneficiaries who can also use HACC community respite.
- **NRCP, the National Respite for Carers Program**, provides a range of specialised carer supports and funds respite services directly and through brokerage.
- **Package programs - Community Aged Care Packages (CACPs), Extended Aged Care at Home (EACH) packages and EACH-Dementia packages** - provide funding for in-home and community based respite, in some cases delivered by the package provider and sometimes through brokerage.
- **Residential respite** is part of the Residential Care Program. Clients are able to access residential respite following assessment by an Aged Care Assessment Team.
- **The Carer Payment and Carer Allowance** also assist carers to access respite care.

All these programs include some services targeted specifically to people living with dementia as a special needs group, but the availability of dementia focused services is uneven and the degree to which they are adapted to dementia care varies.

This section begins with brief accounts of take-up rate of different kinds of respite services overall, and take-up by people living with dementia where specific data are available. The conclusion that emerges from this range of evidence is that use of respite is sub-optimal: at the same time as there are shortfalls in take-up of available services, consumers cannot access the kind of respite they need, when they need it. This section ends with some estimates of unmet need compiled on the basis of this range of evidence.

## 1. Home and Community Care Program (HACC)

### What HACC provides

The Home and Community Care Program (HACC) is a joint Commonwealth/State and Territory Program which funds a wide range of community care services, including respite care.

Respite care in the HACC program is defined as:

*“Assistance provided to carers so they may have relief from their caring role and pursue other activities or interests. The motivation underlying the assistance to the carer is essential: a substitute carer is being provided so the carer gains time out”.*

HACC respite care is provided mainly in the home of the carer and/or client, although it may also include taking the client into the community for activities, and a number of other HACC service types also have a respite function. Social support is similar to respite, but is focused on maintaining the client’s social participation rather than on the carer. Centre-based day care also serves a respite function for clients with carers as well as providing support for clients who do not have a carer. Carer counselling support, client care coordination and case management can be seen as respite-related services to the extent that they facilitate access to and take-up of direct respite services.

HACC funding is by way of a grant to the service provider. It is the service provider who decides who will access the service and how much service will be provided, though national HACC guidelines shape these decisions. User fees vary from state to state and from region to region in some states, but again within program guidelines.

### What the statistics say: the HACC Minimum Data Set 2007-08 Annual Bulletin

This Bulletin reports several indicators of use of respite and related services. Table 1 presents data on use of these services by clients aged 70 and over; the 558,425 clients in this age group accounted for just on 70% of all clients.

Respite care is used by only a very small proportion of HACC clients and their carers, and for only about an hour a week on average. Many more use centre-based day care, for many more hours, and while more again use social support, they do so for few hours.

Use of respite-related services is also varied. Carer counselling is used by very few, but for a much greater number of hours than either client care coordination or case management which are used by more clients, but for few hours.

**Table 1: Use of respite and related services provided through the HACC Program, 2007-08, by clients aged 70 and over**

HACC service type	Number	% of clients aged 65+ receiving service	Average hours of service per client receiving service per year
<b>Direct respite services</b>			
Respite (in-home)	13,150	2.4	86
Centre-based day care	67,636	12.2	133
Social support 76,356	13.8	34	
<b>Respite-related services</b>			
Carer counselling support	7,394	1.3	35
Client care coordination	88,843	16.0	4
Case management	39,078	7.1	5

Trends in take-up of HACC respite over the last three years are varied.

- The number of older clients using HACC respite more than doubled from the 5,100 using the service in 2004-05, but average hours of respite used per client declined by some 10% from the 92 hours used in 2004-05.
- The number of clients using centre-based day care increased by 11%, and their average hours of use declined only marginally from 138 hours per year.
- The 2007-08 Bulletin did not report any data specifically on clients with dementia although the HACC Minimum Data Set now in use collects information on the client's functional status, and includes one item on memory loss or confusion, and one item on behavioural problems such as agitation. While not necessarily identifying all people with dementia, these two items will enable HACC data to be drawn out for people with one or both of these symptoms.

## 2. The National Respite for Carers Program (NRCP)

### What the National Respite for Carers Program provides

The National Respite for Carers Program (NRCP) is an Australian Government program which funds a wide range of respite services in the community. These include a network of 54 Commonwealth Respite and Carelink Centres (CRCCs) and 600 respite services across Australia. Of these services, 268 were dementia specific respite services, and the majority of the remaining NRCP services include people with dementia as a part of their target group.

CRCCs provide information on available respite services in a region, and in certain circumstances can purchase respite care, including residential respite, with brokerage funds. Centres also provide a 'one-stop shop' for a wide range of information on aged and community care services.

A number of initiatives have been taken over the last six years to expand the amount and range of respite delivered through the NRCP:

- The 2003-04 Federal Budget provided \$90.6 million over four years for the Enhanced Respite Care Services initiative to fund respite specifically for carers of people with dementia and BPSD.

- In 2005-06, initiatives amounting to some additional \$207 million over four years commenced, including:
  - respite care to assist employed carers (\$95 million over four years);
  - overnight cottage respite (\$61 million over four years);
  - incentives for residential respite providers (\$41 million over four years), and
  - increased rural and regional respite services (\$9.2 million over four years).
- In 2006-07, the NRCP budget was \$168 million, and in February 2007, an additional \$26.5 million was announced with the aim of providing 10,000 extra respite days in community settings over 5 years.
- In February 2009, \$12 million was made available for 35 projects to improve and support respite services in all states and territories, over two and a half years.
- These initiatives total \$503.5m from 2003-09, and it is timely for the outcomes to be reviewed to identify the outcomes for people with dementia.

Many of these initiatives have been rolled into the continuing NRCP and in 2008-09 the NRCP budget was some \$195 million. The types of respite services now funded include day respite in a community or residential setting, in-home respite, overnight respite in community cottages and residential aged care facilities, and respite for employed carers.

#### **What the statistics show: the NRCP Minimum Data Set 2007-08**

The NRCP Minimum Data Set (MDS) currently collects data from Commonwealth Respite and Carelink Centres (CRCCs) relevant to their carer respite support role. Respite support includes provision of respite information, referral to respite services, or use of brokerage funds to purchase direct respite or indirect respite (ie. supports that may have a respite effect for the carer). Data about the Centres information provision role is collected using the Commonwealth Carelink Centre Information System (CCCIS). The CCCIS database shows that in 2007-08, CRCCs reported 193,165 instances of assistance to carers for information provision.

The NRCP MDS shows that in 2007-08, CRCCs assisted 82,881 carers with respite support. Centres provided 58,733 instances of assistance to care recipients for direct respite; of these, 20,991 or 36% were for residential respite, and 26,418 or 45% were for in-home respite.

In 2007-08, CRCCs spent some \$50 million in brokerage funds; half of this was used for direct respite, of which 49% was spent on in-home respite and 22% on residential respite in community facilities. These direct respite brokerage funds purchased an average of 119 hours per person, in 2007-08. Carers using residential respite care received an average of 470 hours in 2007-08, while care recipients using residential respite care received an average of 476 hours in 2007-08. Carers receiving in-home respite received an average of 30 hours in 2007-08.

The very substantial increase in funding from the \$20 million spent on brokerage in 2003-04 has seen an increase of just on 60% in the number of carers receiving direct respite assistance. There has been little change in the balance between in-home and other forms of respite, or in the hours of respite received per client within this expanded provision

As well as arranging and purchasing direct respite care, CRCCs also arrange or purchase indirect respite care such as domestic help, social support and personal care, all of which enable the carer to benefit from a period of respite. No separate data on take-up of these services by people with dementia is currently available.

### 3. Veterans' Home Care

#### What Veterans' Home Care provides

Veteran's Home Care provides for in-home respite, residential respite and emergency respite that can include 24 hour in-home support. DVA pays for residential respite and meets the cost of the Basic Care Fee for up to 28 of the 63 days per year for which residential respite can be used. VHC also assists clients and carers access respite in the community provided through HACC and NRCP.

#### What the statistics say

In 2006-07, 9% of all VHC clients used in-home respite. The number of respite users was lower than in 2003-04, and greater growth in clients using other services contributed further to the decline in the proportion using respite, from 13% in 2003-04.

In 2006-07, VHC respite clients used an average of just on 70 hours, somewhat below the average use of HACC respite of 86 hours. No data are available on whether VHC clients used other services in conjunction with in-home respite, or specifically on clients with dementia.

VHC data is particularly useful in reporting use of emergency respite. Emergency respite was used by very few clients, one in 1000. This finding indicates that rather than holding respite services on stand-by for emergencies, the need is to provide counselling to carers and clients on the likelihood of needing emergency respite and assist them plan ahead for the eventuality should it arise. The very small number of episodes of emergency respite also indicates that it should not be impossible for these needs to be met by existing respite services.

### 4. Community Aged Care Packages

#### What CACPs provide

The mix of services provided to CACP clients and their carers can include respite in the home or in community settings, including day care centres. CACPs use a brokerage model, and there is a mix of service provision by the CACP provider and purchase of services from other providers, but where a CACP client uses residential respite, the cost is covered through the residential aged care program.

#### What the statistics say

While incomplete data limited the number of clients who could be included in a detailed analysis of data of the census of CACP clients in 2002 made by AIHW (2007a), the findings show clear contrasts between use of respite by people with dementia and their carers compared to other CACP clients. The data cover only in-home respite and do not include use of centre-based day care.

- Twice as many CACP clients with dementia and who had a carer used respite compared to those without dementia, but the proportion of both groups using respite was low, at 12% and 6% respectively.
- The average hours of respite received per week was higher for those with dementia, but again, the amount of respite was low, at 4 hours, compared to 3 hours for those without dementia.

## 5. The residential aged care program

### What the residential aged care program provides

Residential care homes are not required to provide respite care, and there are now no requirements for 'dedicated' respite beds. Instead, on application to the Department of Health and Ageing, homes are allocated a number of respite bed days per year for which the respite care subsidy can be paid, but which cannot be exceeded. Neither the allocation of respite bed days, nor the use of allocated bed days, has ever approached the Government's maximum possible provision. Providers who do offer respite care tend to operate a number of beds, sometimes in a respite unit, and not-for-profit providers are also likely to operate day centres funded through HACC and/or NRCP.

Care recipients seeking residential respite care must be assessed and approved by an ACAT for either low or high level respite care. Respite residents pay the Basic Daily Fee at the minimum rate, but do not pay an accommodation charge or bond. Respite use is limited to 63 days per person per financial year, though extensions can be approved by an ACAT.

From mid 2008, the Residential Aged Care Program implemented a new funding system for permanent care. One of the factors prompting this change was concern about the adequacy of funding for residents with dementia under the previous Resident Classification Scale. The new Aged Care Funding Instrument (ACFI) provides funding based on ADL care needs, a behaviour supplement and a complex health care supplement; each of these components is funded at a low, medium and high need level. The Behaviour Supplement in the ACFI is intended to cover care needs of residents with BPSD and behavioural problems due to other causes. Respite care however continues to be funded at two levels of the Resident Classification Scale with additional respite supplements.

- Respite in low care is funded at \$66.20 per day, made up of the respite subsidy of \$35.70 per day (set at RCS 3) as at March 2009, plus a respite supplement of \$30.50. The total amount approximates ACFI funding for a resident at the medium ADL level (\$63.65), and is above funding for a resident with a combination of low ADL care needs, a medium behaviour supplement and a low complex health care needs supplement ( $\$29.22 + \$13.85 + \$13.15 = \$56.22$ ). Low care respite funding is almost double the daily funding for a CACP (\$34.75).
- Respite in high care is funded at \$172.80 or \$142.82 per day, made up of the respite subsidy set at RCS 6, \$100.07 a day as at March 2009, plus respite supplements of \$72.73 or \$42.75 depending on whether or not the RACH uses 70% of its respite allocation. The lower rate for high care respite is more than the maximum ACFI rate of \$138.11 per day, and the higher respite rate is 25% above the maximum ACFI rate. Respite funding is also well above the daily funding of EACH packages (\$116.16) and EACH dementia packages (\$128.11).

### What the statistics say

#### AIHW Residential Aged Care Statistical Overview 2006-07

In 2006-07, 50,987 people were admitted at least once to residential care for respite, and these admissions accounted for 49% of total admissions. The average respite stay was 3.3 weeks, just over one third of the 63 days allowed for respite per year. The short stays of respite admissions meant that the 1.17 million respite days accounted for only 2% of all occupied beds days in residential aged care homes.

These bed days translate into 3,214 beds occupied by respite residents over a year (1.17m/365), or 1.6 beds per 1000 aged 70 and over. While this figure is little more than half the government planning target of 3 beds per 1000, there has been an increase of 25% in respite admissions over the 9 years to 2006-07, well ahead of the increase of 15% in permanent admissions.

Older people born in non-English speaking countries are less likely to use respite than those born in Australia or English speaking countries, especially at very old ages, and are even less likely to use permanent residential care. Indigenous people are however more likely to use respite than non-indigenous people, and more likely to use permanent residential care (AIHW 2007c). While no separate data are available on clients with dementia, these findings point to a need for different strategies for different special needs groups, with an emphasis on information and counselling to promote respite care among CALD communities, and action to expand provision to meet high demand in indigenous communities.

### **AIHW Bulletin: The ins and outs of residential respite care, 2006**

This detailed analysis (AIHW, 2006) provides several further insights into the use of respite care. The majority of residents, around two out of three, returned home in 2002-3; this proportion has remained steady to 2006-07. Only a few died or were transferred to hospital.

The outcome for a substantial minority was however admission to permanent care immediately or soon after the end of the respite stay: around 15% transferred directly to permanent care and this outcome had occurred for 40% in total within 6 months of their respite stay. The Statistical Overview for 2006-07 reports that on discharge from their respite stay, 13% of respite residents went to residential care and 16% were recorded as having 'other' outcomes. Further information provided by AIHW confirms that a high proportion of those with 'other' separations were in permanent care some time later within the year. This seemingly high level of admission to permanent care should not be taken as an indicator of "failure" of residential respite for several reasons:

- Admission to permanent care is the outcome for the minority of those who use residential respite.
- Admission to permanent care would likely have otherwise occurred earlier. Some of the 70% who had only one respite admission in a year may have used respite over previous years, and may continue to do so for some time before permanent admission. Increasing frequency of respite use may indicate permanent admission is imminent; 20% of clients had two respite admissions and 10% three or more in a year, but the total period over which they have used respite was not reported.
- A wider view of the potential effect of respite use on delaying admission is evident when all forms of respite are taken into account. Of all those admitted to permanent care in the period examined by AIHW, the first quarter of 2003, exactly half had used some form of respite: 24% had used community respite only, 14% had used community and residential respite and 12% had used residential respite only.
- AIHW found that those who used residential respite only were more likely to be admitted to permanent care a short time later compared to those who used residential respite in combination with community respite. This finding suggests that carers are most effectively supported when they can take up community respite early and later combine it with residential respite.

## 6. Carer Payment and Carer Allowance

The Carer Payment and Carer Allowance are both paid to carers through Centrelink. The Carer Payment is a means-tested benefit paid as income support to individuals who have left the workforce because of caring responsibilities. As of December 30, 2006, 111,419 people were receiving the Carer Payment, 39,474 or 35% of whom were caring for a person aged 65 or older.

The Carer Allowance is a non-means-tested payment to carers of severely disabled people, either a child or adult. As at December 30, 2006, 382,490 people received the Carer Allowance; 145,930 or 38% of these recipients were caring for someone aged 65 or older. Take-up of the Carer Allowance is estimated to be high, at close to 80%, among eligible carers.

Neither benefit is intended to pay for respite care, but both indirectly assist in respite. By supporting carers, the benefits enable carers to continue to support the person they care for rather than being admitted to permanent residential care. That continuing the care-giving role may involve use of respite care is specifically recognised as both payments continue to be paid to the carer for 63 days a calendar year when the person they care for is not receiving care from the carer. This provision is especially relevant to residential respite care. The time period of a *calendar* year is however reported to be annoying to clients because it is inconsistent with the residential care respite provisions which count respite use in a *financial* year.

### Indicators of sub-optimal use of respite services

A number of studies have been conducted over time in an endeavour to measure the take-up of various respite services, and to determine how well take-up reflects the level of need. These studies include a variety of qualitative research, including analysis of various client feedback exercises conducted by Alzheimer’s Australia, and analysis of quantitative data, mainly compiled by the ABS and AIHW. Reviews of respite that provided background material for the Discussion Paper are outlined in Appendix A and the research studies cited are listed in the References.

Most of the studies relate to general aged care services and separate data on clients with dementia and their carers is reported only in some data sets so it is necessary to extrapolate their patterns of service use in some areas. The statistical data provide considerable evidence to show that take-up of respite care, in its various forms, by persons with dementia and their carers is sub-optimal. Sub-optimal use is evident on the provider or supply side when use is below the level of provision, and on the user or demand side when consumers are unable to access the kinds of respite they need, when they need it, or are reluctant to use services that are available. The quantitative data provide estimates of the extent of unmet need for respite and the qualitative studies shed some light on some of the reasons for sub-optimal use. When the qualitative and quantitative data are taken together, a consistent picture emerges of a higher need for more access to flexible respite care.

### Estimates of unmet need based on the ABS Survey of Disability, Ageing and Carers 2003

A clear indication that carers of people with dementia are not accessing respite care as much as they feel they need to is seen in Box 1, which compares need and use of respite on the part of all carers and carers of people with dementia. The data on all carers is taken from the ABS Survey of Disability for Ageing and Carers 2003 and the data on dementia carers is taken from the AIHW further analysis of the same data.

The differences between need for and use of respite on the part of dementia carers and all carers are striking. Dementia carers are:

- about half as likely to say that they had no need and had not used respite;
- 50% more likely to need and have used respite; and
- more than 10 times more likely to say they need respite but had not used it.

Three factors mean that estimates of the level of unmet need based on the figures in Box 1 are likely to be under-estimates rather than over-estimates. AIHW notes that the method of identifying people with dementia in their analysis of the SDAC data may have missed out on some people with mild dementia, and was limited to people aged 65 and over. Further, the strict definition of dementia carers included only co-resident primary carers. Taking non-co-resident carers into account, AIHW estimated that there are 35,900 dementia carers in Australia.

**Box 1:** Need for and use of respite care by dementia carers compared to all carers, ABS Disability, Ageing and Carers Survey, 2003

Carer response		Needs respite care	
		No	Yes
Used respite care	No	<b>No need, not used</b> 76% of all primary carers 42% of dementia carers	<b>Need but not used</b> 2% of all primary carers 27% of all dementia carers
	Yes	Not applicable	<b>Need and used</b> 22% of all primary carers (incl. 4% who want more respite) 31% of dementia carers

Notwithstanding these limitations, two estimates point to the extent of unmet need for respite on the part of dementia carers:

- In absolute terms, of a total of 35,900 dementia carers, 27% who need respite but are not using it amounts to 10,000 carers with an unmet need for respite compared to just on 15,000 who have used respite.
- In relative terms, there are two dementia carers who need but have not used respite care for every three who have used it.

There is an associated need to develop respite-related services in conjunction with expansion of direct provision to overcome the barriers that carers face in taking up respite. In the 2003 SDAC,

dementia carers reported that the major reason for not using respite was that the care recipient did not want to use the service; far fewer carers said they themselves did not want to use the service. The negligible number of dementia carers who reported that available services were not suited to their needs may simply mean that the suitability or otherwise of available services was never put to the test. These findings indicate a substantial role for information and counselling services to support carers, and that respite in one form or another should be introduced at an early point in the dementia journey.

The estimates in Box 1 above are broadly consistent with findings of five recent Australian research studies cited by AIHW (2007a) and summarised in Box 2.

**Box 2: Findings of recent Australian research on use of respite care**

Study	Findings on take-up	Factors affecting take-up
Carers Australia 1999	<ul style="list-style-type: none"> <li>• around 27% of all carers commented on need for more respite care or substitute care,</li> <li>• 20% commented on need to increase range of respite care available.</li> <li>• respite care under-utilised because</li> <li>• carers do not know about available range of services</li> <li>• do not trust quality of care delivered;</li> <li>• have difficulty ‘letting go’ of the person they are caring for, even for short periods.</li> </ul>	Take up of respite limited by: <ul style="list-style-type: none"> <li>• demand side factors affect carers willingness to use respite</li> <li>• supply side factors to do with the type of respite care being offered, including lack of flexible responses.</li> </ul>
Leong et al. 2001	<ul style="list-style-type: none"> <li>• Family Needs Survey of 94 carers of people with dementia in Eastern Australia used Barrier Need Score to identify needs perceived as very important but which were poorly met or poorly satisfied.</li> <li>• Of 42 different needs, need for respite had third highest score, behind need to know that someone would provide care if the carer became ill and need for a telephone hotline.</li> </ul>	<ul style="list-style-type: none"> <li>• Respondents indicated that accessing in-home or institutional respite care at short notice was not usually possible.</li> </ul>
Brodaty et al. 2005	<ul style="list-style-type: none"> <li>• 84% of carers of people with dementia did not use respite (higher than total of 69% in Box 1 for dementia carers not using respite regardless of need)</li> <li>• 35% reported needing respite (comparable to 27% in Box 1)</li> </ul>	

Ward et al 2003	<ul style="list-style-type: none"> <li>• 36% of care recipients with dementia regularly attended day care</li> <li>• 28% used respite services (consistent with 31% reported as using respite care in Box 1)</li> </ul>	<ul style="list-style-type: none"> <li>• findings suggest take-up of respite has increased since 1998 study by Schofield et al. which found only 17% of carers of people with dementia used respite care.</li> </ul>
Luscombe et al. 1998	<ul style="list-style-type: none"> <li>• focused on carers of younger people with dementia</li> <li>• 33% of carers had used 1 type of respite</li> <li>• 35% had used 2 types of respite care.</li> </ul>	<ul style="list-style-type: none"> <li>• findings cannot be compared to figures in Box 1 which related to carers of older people with dementia</li> </ul>

### Underspending on residential respite care

As the take-up of residential respite care is below the planned level of 3 beds per 1000 aged 70 years and over, expenditure on residential respite is also well below the optimal level. One means of ensuring that more of the funds available for respite care were spent would be to make the shortfall of spending on residential respite available for other forms of respite by transferring the underspend to the NRCP, to be used as brokerage.

Details of use and expenditure on residential respite given in the *Report on the Aged Care Act 1997* for 2007-08 (Department of Health and Ageing, 2008) enables the shortfall in expenditure on residential respite care to be estimated, as set out in Box 3. In making these estimates, allowance is made for take-up of residential respite to reach 2 beds per 1000 aged 70 years and over, and funding for one bed per 1000 to be transferred to the NRCP.

The two estimates are broadly consistent and show that an allocation of funding for 1 respite bed per 1000 aged 70 and over would have involved spending in the order of \$75m a year in 2007-08. Transfer of funding of \$75m to the NRCP would have a significant effect on funding available for other forms of respite. Allocation of say \$75m to the NRCP would increase the program budget by over 40%, based on funding of \$179m in 2007-08.

Instead of continuing ad hoc additions to NRCP, funding on the basis of 1 bed per 1000 would have the advantage of indexing to growth of the older population, and also indexing to increases in benefits paid for residential respite. This step would pave the way for full transfer of all residential respite funding to the NRCP over time. Transfer of funding for 3 respite beds per 1000, some \$240m, would more than double NRCP funding of \$195m projected for 2008-09.

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**Box 3:** Estimates of shortfall of funding of residential respite care, 2007-08
 

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***Estimate based on share of current funding***

- The latest Report on the Aged Care Act 1997 reports expenditure of \$127.3m on residential respite for 2007-08.
  - This funding covered 1.6 beds per 1000 aged 70 and over used for respite.
  - Pro-rata funding for one bed per 1000 is thus estimated at \$79.6m ( $\$127.3\text{m}/1.6$ ), and funding for 3 beds per 1000 would be just on \$240m.
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***Estimate based on cost of 1 respite bed per 1000 70+***

- The Report on the Aged Care Act 1997 reports that in 2007-08, just over 41% of respite days were in high care and 59% were in low care.
  - Based on population of 1,953,744 aged 70 and over at June 2007, provision of one respite bed per 1000 would require 1,953 beds, say 2000.
  - In estimating the cost of one respite bed per 1000 aged 70 and over, it is assumed that these 2000 beds would be divided between:
    - 40% or 800 beds in high care RACH, divided between
      - 400 beds in RACH that reached 70% of their respite allocation and for which funding was the respite subsidy of \$100.07 per day + supplement of \$72.82 per day = \$172.8 per day = \$63,072 per year = \$20.9m.
      - 400 beds in RACH that did not meet the 70% benchmark for use of their respite allocation and for which funding was the respite subsidy of \$100.07 + supplement of \$42.75 per day = \$142.82 per day = \$52,129 per bed per year = \$25.2m.
    - 60% or 1,200 beds in low care RACH, funded at \$35.70 low care respite subsidy + \$30.50 low care respite supplement = \$66.20 per day = \$24,163 per year = \$29m.
  - Total annual cost of one bed per 1000 = \$75.1m
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A model for such a transfer of respite funds committed but not actually expended under the residential care program to the NRCP is seen in the establishment of the CACP program. The Government's response to a persisting shortfall in provision of hostel places through the late 1980s and early 1990s was to adjust the planning ratio for hostels downwards and to make funds equivalent to the difference available for CACPs. Transfer of funds allocated to residential respite to the NRCP would not only enable unmet need for respite care to be addressed through increased expenditure but would also achieve outcomes by way of greater flexibility and increased choice for consumers that CACPs have realised.

## PART 4 What needs to be done?

The views of carers, feedback from those working to support people with dementia and their carers, and the range of data presented in this Discussion Paper add up to a picture of a take-up of respite care services that is less than optimal. Imbalances are evident between the structure of respite care provision, the supply side of the equation, and the demand side, with carers needing respite but not being able to find it or being reluctant to use the services provided for one reason or another. The outcome of these imbalances is that while respite care is valued when it is used, overall use of available services is sub-optimal and hence resources are not being used as effectively as they could and should be.

These imbalances have to be addressed to achieve a supply of respite that is better attuned to the needs of people with dementia and their carers, and changes to supply of respite will result in increased take-up of respite and more effective use of services. The previous parts of the Discussion Paper have identified a need for a clearer focus on dementia in existing respite services and for additional provision of dementia respite services if unmet need is to be addressed. To these ends, four sets of recommendations are made in this Part. The cumulative effect of these changes would deliver better quality respite care that would make the dementia journey easier and contribute to the well-being of people with dementia and their carers.

### Enhancing access and flexibility of respite

#### What does flexibility mean?

The need for flexibility in respite services is the most consistent theme raised by consumers throughout this Discussion Paper. The many dimensions of flexibility raised by consumers are summarised in Box 4.

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#### Box 4: Dimensions of flexibility of respite care

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Flexibility in **when** respite is available:

- time of day, including overnight;
- days of the week, including weekends;
- frequency with which respite can be accessed, from occasionally to regularly;
- duration, from a few hours to a few days, to a few weeks; and
- planned ahead, including planning for how respite can be accessed in an emergency.

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Flexibility in **where** respite is available:

- in the home of the person with dementia and/or their carer;
- in community settings;
- in residential care settings;
- in settings that can provide both day and overnight respite; and
- providing environments designed for dementia care in all these settings.

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Flexibility in **what** is available by way of choice of activities:

- for the client to engage in activities suited to their individual interests and capacities;
  - for the carer to engage in activities that maintain their social networks;
  - that maintain engagement with the community rather than withdrawal from it; and
  - that give people living with dementia opportunities to share their experiences and knowledge.
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### Promoting early access

Lack of awareness or confusion about the range of services available inhibits early take-up of services, and in turn contributes to a sense that respite care will only be used as a last resort. A key to optimal use of respite therefore lies in encouraging carers to use more flexible, community-based services early in their journey and as part of the overall care package being put in place. Early take-up is the starting point for respite care becoming an integral part of the dementia journey and a valued part of the lives of people living with dementia rather than “just a short break”. Early take-up contributes to maintaining the well-being of the person with dementia and the carer as they become accustomed to using respite care and get to know services and staff; the stress that can accompany the use of residential respite for longer periods can be reduced and the overall outcome is that care in the home can be prolonged.

A critical element in a more holistic approach to the use of respite care that would achieve more effective and efficient use of the considerable resources that government allocates to respite services is education and training for family carers and respite workers. The importance of early access was demonstrated in the findings of the evaluation of the Carer Education Workforce Training Project outlined in Part 2. From 2005, CEWT was rolled out as the Information, Awareness, Education and Training component of the National Dementia Support Program delivered by Alzheimer’s Associations in all states and territories. It provides short courses to the broadest possible range of participant groups, including health professionals such as nurses and trainee psychiatrists to migrant resource centre workers and other service providers, with education sessions tailored to meet audience needs. A next step in advancing more holistic approaches is to bring together carer education and training of respite workers

The different programs through which respite is provided have differing eligibility and fee requirements, and these can be confusing for the carer and the person with dementia. This confusion can not only preclude early use but means that carers may not get information about available services or support in care planning, including how respite could be accessed in an emergency. These barriers can best be addressed by creating clear contact points that can streamline access to a range of respite services, and thereby give consumers greater choice. Respite-related support services provided through the NRCP combined with brokerage funding are means to this end.

A particular aspect of respite care that needs to be addressed early on is carer concern that poor care may lead to a decline in their relative’s functioning and that they will return home more confused and with more disturbed behaviour. This concern arises more in regard to residential respite which involves a greater change in routines and environment and a suspension of usual support networks. Reports of increased levels of confusion, escalation of behaviours of concern and deterioration in cognitive ability in the person with dementia all make carers reluctant to use on-going respite.

One family carer reported her experience:

*“For one week of respite, it took my mother three weeks to return to her pre-respite break state of well being.”*

To investigate these concerns, Alzheimer's Australia has funded a project on the impact of residential respite on people with dementia, being carried out by Ryburn, Doyle and Wells, researchers at La Trobe University's Lincoln Centre for Research on Ageing. A review of six recent studies carried out as part of the project found varied results: overall, while some respite clients did show declines in functioning, others showed improvements, and most importantly, there were no findings of lasting negative effects. This evidence points to a need for carers to be counselled prior to using respite about possible effects, and especially reassured that any negative effects are likely to be temporary, and to be provided with additional support in the event of such difficulties arising. Without such reassurance and support, carers who experience any difficulties may feel that admission to permanent care is the only way of managing.

### **Promoting flexible models of respite services**

A number of Australian Government initiatives to promote flexibility and an increased focus on dementia care in delivering respite services through community and residential care programs and the NRCP were noted in Part 3. It is likely that increases in take-up of some respite services that were also noted can be attributed in part to providers' responses to these initiatives that have resulted in more flexible services. At the same time, indicators of higher levels of unmet need for respite on the part of dementia carers compared to all primary carers reported in Part 3 point to considerable scope for further development of flexible services with a specific focus on dementia care.

Initiatives taken through the NRCP, especially increases in brokerage funds, have been intended to stimulate more variety in respite services, and innovative responses have included host family respite, overnight cottage respite, shopping respite, holiday respite, and work-based respite. Evaluations of two models of host family respite both found positive outcomes for carers and clients; one of these programs provided 24 hour respite in the home of a paid carer for up to three days and nights (Boldy, Davey, Crouchley & Lilly) and in the other, day respite was provided to small groups of people with dementia in the home of a paid care worker. The evaluations reported problems of small scale and sustainability and the need for on-going support from a larger organization was critical to success.

An audit of the outcomes of the NRCP initiatives is now timely as the models of flexible services with a dementia focus that are in operation provide a basis for identifying the features of best practice and promoting these approaches in other existing services and in new services. In turn, these best practices need to be disseminated through training courses for respite workers delivered through the NDSP, TAFE and other training services, and also in carer education so that carers know they can expect in best practice respite services.

The scope for widening the allocation of brokerage beyond the use of CRCCs as brokers and care managers also needs to be explored as other possible brokers could include dementia respite services, agencies involved in the Alzheimer's Association National Dementia Support Program and the Dementia Behaviour Management Advisory Services, and carers themselves in consumer directed brokerage. A key criterion for receipt of brokerage funding would be that agency staff had participated in training for respite workers and dementia care. Brokerage funding especially has the capacity for supporting on-going contact between family carers and support staff who not only facilitate access to initial respite but ensure services are adjusted in response to changing needs.

Additional funds were made available in the 2005 Budget for residential care providers to offer respite care, and outcomes of this measure also need to be audited. There is no ideal model of residential respite. Catering for just one or two respite residents may be the only option in small homes and in small communities; Multi-Purpose Services in rural and remote areas particularly provide for small numbers of respite residents as part of their mix of services. At a larger scale,

clustering respite residents in separate sections of homes appears to have advantages for providers and consumers. Cluster models are not distinguished just by having a number of respite beds, but by their capacity to create distinct environments and develop distinct cultures of dementia care so that the respite service is better suited to supporting a person who normally lives at home. Cooperation between residential care services and CRCCs can increase provision of residential respite by creating a ‘critical mass’ of respite places in homes that participate in respite booking systems that maintain a register of vacancies and refer consumers to the services that are most appropriate to their needs, particularly when these needs include dementia care. By way of example, the CRCC in the Southern Metropolitan Region of Melbourne supported the development of respite clusters in a number of residential care homes by managing a booking and referral system.

As residential respite has been found to be most effective when carers and the person with dementia are also using community respite and other services when living at home, formalised links between community-based and residential respite services emerge as a feature of best practice. These links are at present most evident where the same provider delivers community based respite, usually in a day centre, as well as residential respite and permanent care, but they can be developed through collaboration between different providers and a CRCC.

Further development of residential respite needs to move beyond simple allocation of places and waiting for providers to take up the allocation. Development by providers who are not only willing to operate respite units but who have the capacity to do so in a way that is closely linked to community respite and related carer support services provided through the NRCP could be actively fostered by a strategy for ‘designation’ of services. A two-way process could encourage providers to nominate their respite service for ‘designation’ if it met agreed operating criteria and standards, complemented by incentives that recognised ‘designated’ services in on-going funding and development initiatives.

Given that there is relatively more unmet need for dementia respite than for respite in general, an increased focus on dementia care should be promoted in existing and in new services. To address the priorities reported by consumers, priority has to be given to system-side increases in respite services for people with high dependency needs, those with BPSD and younger people with dementia, and more geographically focused attention to dementia respite services is needed for people living with dementia in rural and remote areas, in indigenous communities and local areas with culturally and linguistically diverse populations.

Taken together, these findings call for measures to consolidate recent initiatives to enhance access to and flexibility in provision of respite care and to expand preferred and effective models of respite.

**Recommendation 1:** In order to give particular attention to reducing the barriers to people living with dementia taking up respite as early as possible it is recommended that the Australian Government:

- expand carer education and training for dementia respite workers through the education and training component of the National Dementia Support Program delivered by Alzheimer’s Associations, with specific attention to:
  - the development of joint sessions for family carers and respite workers;
  - ensuring that all family carers who receive support through these services have the option of having a contact worker assigned to them for follow-up contact and to assist in subsequently accessing respite services
- expand the support available through the National Respite for Carers Program to work with people living with dementia to plan future respite use, including respite in an emergency;

- conduct an audit of respite services to
  - identify preferred models of delivery for people with dementia and their carers, with particular attention to initiatives focused on special needs groups;
  - develop a Best Practice Guide based on the audit findings, and disseminate it to promote adoption of best practice in existing and new services; and
  - update training modules in the National Dementia Support Program and related TAFE courses and other training, in line with the Guide, and that standardised assessments of worker competency be promoted as a means of furthering best practice.

**Recommendation 2:** In order to address the greater unmet need for and shortfall in access to respite for people living with dementia compared to overall access, and to promote innovation in services, it is recommended that the Australian Government:

- give priority to dementia respite services in funding of all new respite services over a five year period to address unmet need, and that within this priority, particular attention be given to fostering dementia respite services for carers and people with dementia in special needs groups, and
- adopt a process for "designation" of residential respite services that incorporate links with community-based services and recognise these designated services through financial and other incentives.

### ***Trial consumer direction in respite care***

A second means of promoting flexibility and access is to move away from approaches that fund providers to approaches that fund consumers. Funding for most respite services is channelled through providers, and it is the provider who determines what is available. Consumers report that some respite services are fairly inflexible in terms of what they offer, where they offer it, and when they offer it. In contrast, funding the carer and the care recipient, rather than the provider, gives more opportunities for consumers to receive what they need and want, and to stimulate provider responsiveness to meeting consumers' goals. Increasing the proportion of respite funded through brokerage, where the consumer has a greater say in what is purchased and the broker acts on behalf of the consumer, would drive providers to offer services in response to consumer preferences and needs rather than the other way around.

Brokerage and consumer directed models are easier to implement in community care where there is less concern about management of fixed capital facilities, but there is scope for extending the use of brokerage in residential care that has already begun through the NRCP. Brokerage enables greater consumer direction of care as it gives the consumer a greater say in choosing the type of care they want to receive and the provider they want to deliver the service, and so achieves a better fit between consumer needs and provision of care.

Alzheimer's Australia sees consumer directed care as a way of empowering consumers (Tilly & Rees, 2007), and proposes that part of the brokerage funds provided through CRCCs should be used to trial consumer directed respite care. Under this proposal, carers would be allocated a respite care budget which they could use to purchase the respite services they prefer. The budget could be held by the broker if the carer did not want to take on managing financial transactions and employer responsibilities. Such a proposal could involve family networks, neighbourhood networks and community organizations in the provision of respite. It has potential advantages particularly for people in remote areas, indigenous people, or people from culturally and linguistically diverse backgrounds. Though not an option that every carer would choose, consumer directed care has

been demonstrated in overseas studies to offer many benefits for people who choose that option. It certainly merits a trial in Australia, and a trial in respite care for people with dementia is seen as a good starting point.

**Recommendation 3:** As consumer directed care offers a means of maximising consumer choice and flexibility of care for people with dementia and their carers, it is recommended that a trial of consumer directed respite care be implemented and that an allocation of NRCP brokerage funds be committed to the trial. Given that carers of people with dementia in special needs groups often have particular needs that require more flexible responses, the trial should specifically include carers of people with dementia in these groups.

### ***Reducing cost barriers***

One of the barriers to using residential respite care is the cost to the client and their carer, and the anticipation of unaffordable costs can be as much a barrier as actual costs. While respite residents pay only the standard Daily Care Fee and no further means-tested care fees, nor an accommodation charge or bond, payment of this fee can be a significant impost for families who have to meet on-going costs from limited household incomes. The continuation of the Carer Allowance and Carer Payment for up to 63 days of respite a year and DVA coverage of the Basic Care Fee for 28 days of respite care all recognise that many household expenses continue even when the care recipient is using respite.

Cost barriers to respite could be reduced by the waiving the standard Basic Daily Fee for consumers and providing government funding for periods of respite up to 28 days, consistent with DVA. Alternatively, the Basic Daily Fee could be reduced by 50% for the full allowable 63 days a year.

**Recommendation 4:** In order to encourage take-up of residential respite, it is recommended that the Australian Government reduce the costs to the consumer either by waiving the Basic Daily Fee paid by residents for periods of up to 28 days a year or by reducing it by 50% for the allowable 63 days of respite a year.

Access would also be facilitated by resolving the difference between the way respite days are counted over a calendar year for the Carer Payment and Carer Allowance, and over a financial year in the Residential Aged Care Program. It would be far easier for carers to apply for and keep track of their entitlements if the payments were administered on the same time basis as the care provisions. As many carers may use residential respite over the Christmas-New Year holiday period, it would seem preferable to move to a financial year for both programs.

**Recommendation 5:** To minimise confusion and inconvenience for consumers, it is recommended that Centrelink count permissible respite days for purposes of the Carer Allowance and Carer Payment on the same basis as the Department of Health and Ageing counts use of residential respite care, namely a financial year.

## Ensuring quality of respite care

An important factor shaping take-up of respite services is carers' confidence in the quality of care that the person with dementia will receive. Just as a high level of confidence will increase take-up, a low level of confidence becomes a barrier. Special attention needs to be paid to quality issues in respite, as uncertainty about quality as well as actual experience of poor quality care will deter both the care recipient and the carer from using respite. The principles set out in the Quality Dementia Care Position Paper released by Alzheimer's Australia in 2003 apply equally to respite care in any setting as on-going care in the community and in residential care.

In community care, a major development in quality assurance came about through 2008 with the extension of the HACC standards to the NRCP and packaged care programs. Given the recency of this development, attention needs to be drawn to some features of the Quality Reporting process that are particularly pertinent to enhancing the quality of respite services for people living with dementia.

A central theme through this Discussion Paper has been the need for respite care to be an integral part of overall care for people with dementia and support for their carers. Several features of the Quality Reporting Process for the NRCP warrant note in relation to their potential to drive quality of respite care for people living with dementia:

- Providers are required to report on how they have addressed the needs of special needs groups, one of which is people living with dementia.
- Approaches to quality improvement include listening to what care recipients want and acting on what they say, and so should increase consumer direction.
- As a way of identifying best practice and innovations, providers are invited to identify what they have done particularly well that may benefit others.
- The standard and indicators for co-ordinated, planned and reliable service delivery, set out in Box 5, call attention to on-going assessment and the development of a service delivery/care plan, and offer a means of integrating respite into overall care plans and ensuring that carers' concerns about how respite can be provided in an emergency are addressed.

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**Box 5:** National Respite for Carers Program: Standard for Co-ordinated, Planned and Reliable Service Delivery

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**To ensure that each carer and the person(s) for whom they care receive coordinated services that are planned, reliable and meet his or her ongoing specific needs.**

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**Indicators:**

- 4.1 Each consumer receives ongoing assessment (formal and informal) that takes all support needs into account.
  - 4.2 Each consumer has a service delivery/care plan which is tailored to individual needs and outlines the service he or she can expect to receive.
    - Consumers' cultural needs are addressed.
    - The needs of consumers with intellectual difficulties, (including dementia, memory loss and similar disorders, and intellectual disabilities) are addressed.
  - 4.5 Consumers receive services which include appropriate coordination and referral processes.
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In residential care, more specific attention needs to be given to monitoring and reporting on quality of respite care for people with dementia and their carers. Tools to this end are provided by the two guides to Quality Dementia Care Standards in residential care released by Alzheimer's Australia in 2007. The guides were prepared with the objective of linking the principles and practice of good dementia care in residential care settings, for managers and for all staff, and enhancing dementia care within the framework of the residential care quality standards.

Residential respite is only a small part of all residential care provision in terms of occupied bed days, and the special needs of respite residents can easily be overlooked in the accreditation process. Most importantly, it needs to be recognised that respite care is different to permanent care. The fundamental way in which respite care is different is that it involves moves between the residential care setting and the consumer's usual home and support network in the community, and the way in which these moves are supported (or not supported) has a major impact on the experience of respite and the quality of the outcomes for the person receiving respite and their carer. Among the criteria that need to be covered in assessing the quality of residential respite distinct from permanent care are flexibility and responsiveness to consumer needs, consistency and continuity with care and support arrangements in the community, and consumer satisfaction.

Beyond monitoring the quality of respite care delivered by individual services and providers, whether in the community or in respite care, three steps need to be taken to ensure the quality of respite care:

1. As quality of HACC, NRCP and package programs is monitored through the Department of Health and the residential care program is monitored by the Aged Care Standards and Accreditation Agency, a collaborative effort will be needed to provide an account of progress in improving quality of respite services for people living with dementia across the service system as well as in individual services, and identify remaining shortcomings.
2. Notwithstanding the progress made in implementing Quality Reporting across the community care programs, the process remains focused on service outputs. The process does not measure the quality of the respite experience, and hence its value, for the person with dementia and their carer. A shift in focus to the outcomes of service use, not just service outputs, is essential to supporting quality service provision, and suitable outcome measures need to be developed and adopted in quality assurance systems.

3. An expected outcome specifically for respite care should be added to the residential care standard concerned with Resident Lifestyle (Standard 3) to ensure that providers and standards monitors give particular attention to assessing and reporting on the quality of residential respite care in the accreditation process. The expected outcome should extend to support provided in the immediate pre- and post respite periods. This addition would strengthen the accreditation process and ensure that funding for residential respite care is well spent and that the quality of care provided is of a nationally consistent high standard.

**Recommendation 6:** With the aim of ensuring consistent and sustained quality of respite services, it is recommended that the Australian Government work with the Standards and Accreditation Agency to advance quality of respite care by:

- reporting on outcomes across community care programs in a standard format, and giving specific attention to dementia care standards in this reporting;
- adding an expected outcome specifically for respite care to the Resident Lifestyle standard in the accreditation system for residential care; and
- funding respite care only in community and residential care services that meet standards and outcomes focused on respite care, including provision of training in respite and dementia care for their staff.

## Rebalancing provision

### Restructuring planning and funding of residential respite

The most conspicuous imbalance is between the need for more flexible respite, especially in the community, and the greater proportion of funding being allocated to residential respite that is usually available in fixed blocks of two weeks. At the same time, use of residential respite, which is the most costly form of respite both for the Government and the user, is persistently below the target of 3 beds per 1000 aged 70 and over set in the planning framework for the residential care program. Indexing planning to a flat rate of beds per 1000 population aged 70 years or over disadvantages people with dementia as prevalence increases exponentially with age and is much higher beyond 80 compared to the 70-79 age range.

Residential respite beds are allocated regionally, but take-up of the allocation is left to the discretion of providers, and with no requirement on providers to operate respite care, the outcome is very uneven provision geographically and inequitable access for consumers. Further, while some providers go to some lengths to develop a cluster or respite unit within the home, others provide no respite, and the remainder adopt an intermediate position of respite beds scattered through the home depending on vacancies. It is apparent that the current arrangements for providing respite through the residential care program have not been working effectively for some time and changes in the planning and allocation process are called for.

Two further factors that limit provision of residential respite also need to be addressed. First, many providers currently deliver respite as one of a number of services, with funds from more than one program: a large provider may be funded through the residential care program for residential respite, through HACC for community respite, and through the NRCP for both. Having to manage multiple program requirements in terms of eligibility, user fees, standards, user rights and reporting discourages efforts to provide respite and it is likely to be given a low priority as a result. These considerations appear to have a particularly pronounced impact in residential care when respite is seen as a very small but complicated 'add on' to the overwhelming provision of permanent care.

A second consideration that limits provider interest in admitting people with dementia to existing residential respite care beds, and that discourages further provision, is whether the respite care benefits give sufficient recognition to additional care needs associated with dementia. As the ACFI includes a three level behaviour supplement, the equity of respite funding could be readily established by comparing the current RCS based-respite funding with the level of ACFI funding received by respite residents who are subsequently admitted to permanent care, and a sample of those who return home, recognising that those who are admitted to permanent care may have higher care needs.

### **Transferring funds to NRCP brokerage**

The solution to these problems lies in funding all respite through the NRCP which currently covers all kinds of respite by direct funding and/or brokerage. A strategy similar to the establishment of CACPs by way of transferring unspent funds from the respite component of the residential aged care program to the NRCP is now in order, and it could be implemented in two steps:

In the short term, allocating funds equivalent to the shortfall in residential respite provision to the NRCP, and using these funds through brokerage, would increase the supply of respite and rebalance spending on residential and community respite in accord with consumer preferences and need in local areas. In the first instance, funding equivalent to 1 respite bed per 1000 aged 70 and over would still leave a margin for expansion up to 2 beds per 1000 to address unmet need for residential respite.

In the longer term, there is an argument for shifting all residential respite funding from the Residential Aged Care Program to the NRCP. This shift would enable CRCCs to purchase respite care directly from residential aged care providers, rather than leaving it to providers to take up an allocation. Further rebalancing of residential and community respite would come about in response to consumer demand rather than being fixed by government planning parameters. This move should be considered in the context of the Council of Australian Government’s deliberations on the future of aged care programs as it would achieve an integrated stream of respite care within a future single program.

A single arrangement with a substantial brokerage component would open up opportunities for residential care providers who wanted to ‘designate’ places for respite care to do so. In particular, it would offer scope for innovation for those seeking to develop a special focus on dementia care in both their community and residential respite services. Developing a close working relationship with a CRCC would not only provide a financial incentive for providers by way of maintaining high occupancy but would provide other incentives by way of support to clients and their carers. The proposed single funding arrangement would drive integration of respite funding at the program and provider level, and consumer direction for clients and their carers. Funding through NRCP would also ensure that designated respite services in residential care continued to provide respite care as funding would cease if the places slid into use for permanent care.

To ensure that residential respite provision continued to grow to meet need, funding through the NRCP could include an establishment grant as an incentive for providers approved to set up new services. Such a grant could cover short term costs arising due to initial low occupancy, administrative changes and adjustments in staffing, including training for dementia care. Approval of grants on the basis of an integrated plan developed by the provider in line with NRCP guidelines would ensure additional ‘designated’ respite places were provided in areas of need and would foster commitment to on-going operation with close links to community-based respite. Greater recognition of designated respite services is also consistent with enhancing quality of respite care as already discussed.

**Recommendation 7:** It is recommended that funding for residential care respite be transferred from the Residential Aged Care Program to the National Respite for Carers Program to be used as brokerage funds that can be applied flexibly to meet consumer needs for different kinds of respite services. This transfer should be made in two steps:

1. an immediate initial allocation of funding equivalent to 1 respite bed per 1000 aged 70 and over be made to take account of the under-use of the respite allocation; and
2. pending the decision by the Council of Australian Governments on the future of aged care programs, transfer of all residential respite funding to a guaranteed stream of respite funding in a future aged care program.

**Recommendation 8:** In conjunction with this transfer of funding, and in order to meet unmet need for dementia respite care, it is recommended that:

- the planning target for residential respite places be reduced to 2 places per 1000 aged 70 and over immediately and further adjustment be considered as part of wider review of the planning process for residential aged care; and
- a planning system to cover all forms of respite be developed under the NRCP to ensure equitable allocation of funding and to promote diversity in provision, including through recognition and support of 'designated' respite services.

**Recommendation 9:** To ensure that funding for residential respite care is maintained in line with funding for permanent care, it is recommended that the level of funding for residential respite care for people with dementia be reviewed in relation to the ACFI to establish the appropriate level of funding for this service through the NRCP.

## Monitoring implementation and evaluation

Monitoring and evaluating the effects of changes made in the delivery of respite care for people living with dementia will require systematic collection of data based on a standardised definition of dementia, and regular reporting in formats accessible to a wide audience. Routine reporting of this information needs to be complemented with on-going evaluation research that includes consumer input.

Assembling data for this Discussion Paper would have been a much more difficult task, and many more gaps would have remained, without the 2007 AIHW report, *Dementia in Australia: National data analysis and development*. This AIHW report was particularly valuable in linking population data from the 2003 SDAC with data on clients with dementia and their carers collected in various program Minimum Data Sets.

The 2007 report was commissioned by the Australian Department of Health and Ageing to provide a guide to improving data on dementia in national data collections, and AIHW proposed four strategies to this end:

- better and earlier diagnosis of dementia in Australia;
- improved consistency of identification of people diagnosed with dementia in all data collections, including through consistent use of agreed classifications and adherence to data standards;
- agreement about the extent of information to be collected; and

- a change in focus from services-focused data to person-focused data through support and encouragement of data linkage efforts and/or the collection and analysis of longitudinal data.

Adoption of these strategies is a key step in measuring the effectiveness of changes in approaches to delivery of dementia care, including respite care, and providing better data on needs and service use to inform future government decisions. Given that people living with dementia have greater need for respite care and other support services than other frail older people and their carers, and to inform consumers and providers about progress in meeting these needs, dementia care warrants a concise report in AIHW's bi-annual report, *Australia's Welfare*.

Fuller reporting is also required when new data become available. The next SDAC is to be conducted in late 2009 and updating of the AIHW 2007 report needs to be scheduled as soon as possible after the results of the 2009 SDAC become available, together with the most recent data on Australian government programs. Further full reports should be presented every five years thereafter.

The big picture of respite care for people living with dementia compiled from national data has to be complemented with a range of other research and evaluation to identify the distinctive features and outcomes of best practice models. Evaluations are best carried out by independent experts working in close collaboration with providers and with input from consumers. Evaluation of respite care lends itself particularly well to involving consumers at all three levels set out in the report on involving consumers in dementia care research commissioned by Alzheimer's Australia in 2008: at the level of individuals receiving respite services, at the level of those running services and at the broader systemic level through judgements about whether services are matching priorities and meeting the needs of people with dementia as a whole (Doyle, 2008). Ongoing research, evaluation and review of practices and approaches should be encouraged and adequately resourced to improve knowledge and understanding of the nature and quality of effective respite services. Funding for such research and development activities should be provided as a component of the NRCP.

**Recommendation 10:** In order to monitor and evaluate the effectiveness of changes in delivery of respite care and related programs to people living with dementia, it is recommended that:

- the strategies proposed by the Australian Institute of Health and Welfare in 2007 for improving the reporting of all aspects of dementia in national data collections be adopted;
- a concise report on dementia care be included in the AIHW bi-annual report *Australia's Welfare* and a full account be presented by updating the 2007 report every five years; and
- funding for research and development be included as a component of the National Respite for Carers Program.

## APPENDIX A Reviews of respite care programs

### 1. The Respite Care Review, 1996

The most comprehensive review of respite care in Australia was the Respite Care Review published by the then Department of Health and Family Services in 1996 (Department of Health and Family Services, December 1996). Though some eleven years old, many of the findings and recommendations of this review are still relevant. Two more recent reviews have yet to be released by the Australian Government. This review was based on several reports which analysed the provision of respite care in the community, in residential care and in the 'respite options' program.

This review reported that some 4% of principal carers had an unmet need for respite care, and a further 20% were "at risk" of needing respite care. However, the review warned that expressions of unmet need do not necessarily translate into use of services when they are made available. Those who did express an unmet need indicated that they wanted 'more of the same' in terms of respite and more choice from a wider range of options. The majority of carers were found to rely on informal support for their respite needs from family or friends.

Carers reported a high degree of satisfaction with the respite care services they received. Some 85% of carers using respite services in the community were happy with the respite care they received.

The Review also reported evidence of the effectiveness of respite care in helping frail aged or disabled people stay living in the community. The dependency level of people in the community receiving respite care was considerably higher than that of people not using respite care. This indicated that respite care helps carers maintain their caring role for longer.

The main deficiencies highlighted by the Review were the fragmented nature of respite arrangements and the rigidity and lack of flexibility in respite care arrangements. Since that review, the Government has established the National Respite for Carers Program which integrates various forms of Commonwealth funded respite care, and has expanded the respite options program into a brokerage program funded through Carer Respite Centres.

The Review presented six policy options for consideration by Government. These were:

1. A full cash out of respite services into the Carer Allowance.
2. Conversion of respite funds into vouchers for carers.
3. Conversion of respite funds into rebates for carers.
4. Conversion of respite funds to regional budgets with respite care management.
5. Partial conversion of respite funds into regional budgets with care management of higher need carers.
6. Status quo with improvements.

The list of improvements recommended in option 6 included:

- Conversion of unused residential respite provision into community respite provision.
- Single point of assessment for all types of respite care.
- Experimenting with 'cottage respite'.
- Integration of planning for HACC and NRCP respite.
- Widening of scope of respite options projects.
- Improved provision of information on respite.

The Government never formally responded to this review, but subsequent budget decisions indicated that a combination of options 5 and 6 was in fact pursued. The notion of partial regional budgets has been implemented through Carer Respite Centres, and most of the improvements recommended in option 6 are now in place, or are being implemented through 'The Way Forward' initiative which seeks to bring HACC and Commonwealth funded programs into closer alignment.

The most recent of these, funding for ‘cottage respite’ was announced in January 2006. Some \$59 million over four years has been given to 70 cottage respite providers across Australia to provide overnight respite.

## **2. Department of Health and Ageing Reviews of residential respite care, 2002-04**

The Department of Health and Ageing’s Annual Reports for both 2002-03 and 2003-04 list two consultancies to review overnight respite provision. The first was conducted by Marilyn Alt and Dianne Beatty and aimed to review current practice through extensive consultation with Carer Respite Centres and others. The second, conducted by Anna Howe and Colleen Doyle, reviewed all aspects of overnight respite in community and residential care settings with a view to developing best practice methodologies.

No reports from either of these consultancies have yet been publicly released.

## **3. Alzheimer’s Australia Victoria review, 2003**

Alzheimer’s Australia Vic reviewed respite services in Victoria in 2003 (Alzheimer’s Australia Vic 2003). They reported that people living in the early stages of dementia:

- would like to be supported to continue to participate in community activities;
- would like to be supported to undertake some activities as a couple;
- do not want to access traditional day care programs; and,
- certainly do not want to access residential respite in residential care facilities.

This review found there was a great need for “responsive respite”, by which is meant “service providers working in partnership with their clients to identify a range of respite options.” The main features of the small number of programs providing this form of respite are that they strive to provide:

- familiar and everyday practices and routines;
- continuity of lifestyle, leisure activities and interests;
- stimulation and participation;
- maintenance of independence; and,
- individualised support, based on knowledge, trust and continuity of relationships with a small number of service providers.

This review concluded that there were three fundamental issues in improving respite services for people with dementia and their carers, namely:

- reframing what respite is, and developing a broader understanding of respite among service providers and staff;
- training and education for services and staff working with people with dementia, to develop a better understanding of dementia, and appropriate dementia care; and,
- facilitating the use of funding in flexible and innovative ways.

## **4. Submission to Australian Government Pricing Review by Carers Australia, Alzheimer’s Australia and COTA National Seniors, 2003**

This submission pointed out some of the inadequacies of the current system including:

- inflexible respite delivery practices exist in aged care facilities;
- provider discretion in resident selection creates access barriers for people with high dependency needs or BPSD;

- providers prefer long stay residents to short stay;
- emergency respite difficult to access;
- not all providers use their respite allocations
- Carer Respite Centres have contributed to many improvements in in-home and community based respite services, but have not addressed the need for accessible, homelike facility based care;
- some innovative models responding to consumer needs have been developed by combining funding from various programs and these should be encouraged;
- funding of respite support services for carers of older people should be made separate from and additional to residential aged care; and,
- the feasibility of cashing out a further proportion of respite services tied up within the residential aged care program should be examined.

The submission recommended consideration be given to:

- mechanisms that link financing for respite places to provision of services and availability of places, and provide direct financial and other disincentives to providers who maintain unused places;
- financial modelling of respite service models, and,
- how aged care funding might encourage innovation in residential respite.

### **5. Aged and Community Services Australia (ACSA) Policy Position, 2004**

Though not technically a review, ACSA has released a National Policy Position on Respite (ACSA, 2004). This paper stresses the need for a range of different types of respite, including residential, in home, day care, host families, holiday options, emergency responses, banked hours models and carer education and support groups. ACSA has called on Governments to:

- fund all forms of respite as community care;
- amend community care guidelines to enable community care to continue while the person receives residential respite;
- fund innovative projects, including respite models for indigenous people, people from culturally and linguistically diverse backgrounds, people with dementia, people with a mental illness, and younger people with disabilities;
- increase funding in programs such as HACC to enable successful pilots to be extended;
- amend HACC Guidelines to enable overnight respite to be provided in community buildings (such as day care centres);
- adequately fund respite so that service providers are not financially disadvantaged; and,
- promote the role of Commonwealth Carer Respite Centres and evaluate their brokerage model.

### **6. UK review of dementia respite services**

In the United Kingdom, Arksey and colleagues from the University of York carried out a review of the effectiveness of respite services for carers for people with dementia through a comprehensive literature review and consultations (Arksey et al. 2005). They found that evidence of the effectiveness and cost-effectiveness of respite care and short term breaks is limited. In contrast, there was considerable qualitative evidence from carers and some care recipients of the perceived benefits of respite services.

In regard to day care they found that many carers place a high value on day care, and there was some evidence (though not reported in all studies) that some carers showed demonstrable improvements in physical health, stress and psychological wellbeing. The evidence on the impact

on people with dementia was unclear, with some studies reporting improvements or stabilisation, whereas others showed no positive effects. There was some evidence to suggest that day care attendance might have a preventative effect on entry to long term care.

In regard to in-home respite, carers reported high levels of satisfaction with in-home respite services, though they said they would have liked the service more often. No study was able to demonstrate significant positive effects of in home respite.

Host family respite similarly was highly valued by carers but no positive impact on outcome could be demonstrated.

Residential respite was seen as worthwhile in terms of physical and emotional benefits for the carer, including increased and better quality sleep, but there was mixed evidence on the impact of residential respite on activities of daily living, behaviour and dependency of the person with dementia. Some care recipients returned home in a worse state, though medical conditions could sometimes be diagnosed during respite breaks.

The study also reviewed packaged respite programs, combining different forms of respite, multidimensional care support packages and video respite (care recipients watched a tailor made video thus freeing up the carers time). Results from evaluations in these areas did not demonstrate clear results, but studies of multi-dimensional carer support packages showed a strong trend towards delayed entry to long term residential care.

## 7. Evaluation of the Carer Education Workforce Training Program, Applied Aged Care Solutions

The table below is taken from the CEWT evaluation report and summarises the outcomes of the program.

<b>Objective</b>	<b>Outcome</b> (exceeded, met, improvement needed, further research)	<b>Comment</b>
Participant Satisfaction	Exceeded	Format was very well received by both Respite Workers and Family Carers
Participant’s knowledge and attitudes to challenging behaviour	Exceeded	Knowledge quiz, vignettes and service provider feedback validates that the course achieved this outcome.
Understanding the needs of carers and the person with dementia	Exceeded	Vignettes and service provider feedback provides the evidence that this outcome has been met.
Understanding the needs of carers and the person with dementia	Exceeded	Vignettes and service provider feedback provides the evidence that this outcome has been met.
Understanding the needs of carers and the person with dementia	Exceeded	Vignettes and service provider feedback provides the evidence that this outcome has been met.
Understanding the needs of carers and the person with dementia	Exceeded	Vignettes and service provider feedback provides the evidence that this outcome has been met.
Program Outputs	Met	134 CEWT courses run in 2002/2003 period, unmet need for more courses.

Understanding the needs of carers and the person with dementia	Exceeded	Vignettes and service provider feedback provides the evidence that this outcome has been met.
Program Outputs	Met	134 CEWT courses run in 2002/2003 period, unmet need for more courses.
Nationally consistent training program implemented	Met	An accredited VET course provided National Standards that are accessible to the general public via other service providers. Process needs to be demonstrated to ensure that the content is regularly updated as required.
Participant's management of challenging behaviour	Met	For Respite Workers: assessment of this outcome would be strengthened by work place assessment of skills in practice. For Family Carers: issues are often changing (deterioration of health, new behaviours emerging etc), while the course assisted them they require ongoing support.
Identifying barriers to the use of respite	Met	Identified three major types, the information should be used in future planning of respite services 1. Respite Service Issues (lack of flexibility in times and types, availability in the area etc) 2. Person with dementia resistance is a determinant in type of respite used (e.g. home based is more comfortable for person with dementia) 3. Carer or Family Issues (e.g. knowledge and acceptance of respite) – the course directly addressed this issue
Uptake and Attitudes to Respite	Met	Reports by Family Carers indicated <ul style="list-style-type: none"> <li>• a better understanding of services available</li> <li>• more comfortable using respite</li> <li>• respite use was increased</li> <li>• respite helped to decrease stress levels</li> </ul>
National Assessment Guidelines	Improvement Needed	While National Assessment Guidelines were documented there were indications that their application may not be consistently applied. Commitment to multiple modes of assessment could be eroded if workplace assessments and indirect work based evidence are dropped in future.
Resource Allocation & Affordable fees for Respite Organisations & Workers	Improvement needed	Costs for Respite Worker participants varied significantly between states. Given the program is Commonwealth Government subsidised, the lowest possible fee should be nationally applied.
Program Reach - geographical & type of participant	Improvement needed	The geographical reach in some States and Territories was very limited. However, using an accredited VET course extends the future potential impact of the course beyond the current reach of the program – consideration should be given to 'master trainer' models for regional areas. The type of participants targeted varied considerably across CEWT sites. National guidance on the type of participant that should be targeted by the CEWT program would enable a more nationally consistent approach to be adopted and strengthen the intervention.
National Resources - Distance Education - Video 'Brain and Behaviour'	Further research	Distance Education package implemented late into the evaluation period, with limited uptake of this resource. The video 'Brain and Behaviour' was developed from an existing educational tool and was a well regarded training resource.

<p>Course Delivery Aspects</p>	<p>Further research</p>	<p>Now that the structure of the course is designed, review of the delivery format options is required (e.g. audio &amp; video conferencing, on-line internet courses). Rural and remote areas are disadvantaged if courses provided in a short time frame (over one or two weeks).</p>
<p>Identification of ‘Hidden Carers</p>	<p>Further research</p>	<p>In terms of hidden carers, 67% of Family Carer course participants had never had a contact with Alzheimer’s Australia. A mass media campaign may be required to access carers who have no contact with any formal services.</p>

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