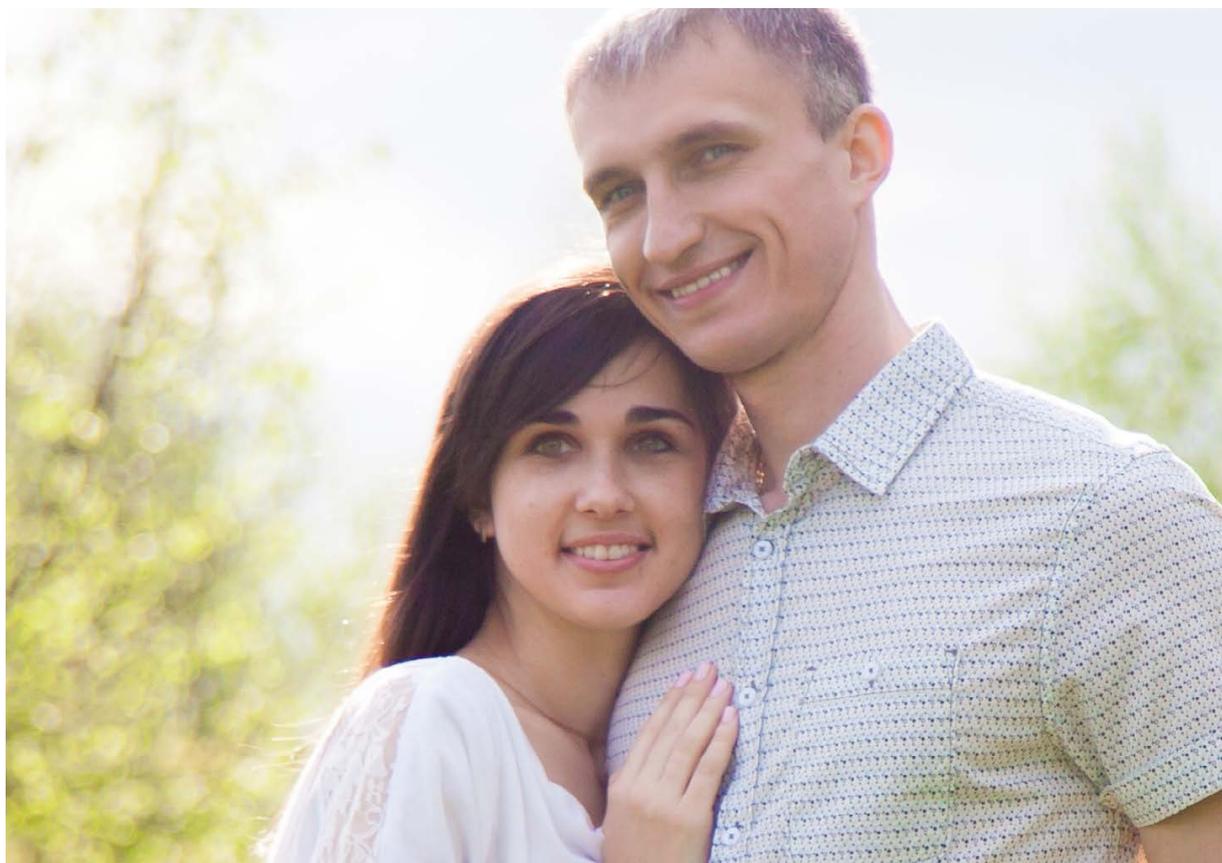


CARING FOR SOMEONE WITH DEMENTIA: THE ECONOMIC, SOCIAL, AND HEALTH IMPACTS OF CARING AND EVIDENCE BASED SUPPORTS FOR CARERS

PAPER 42 OCTOBER 2015

A Report prepared for Alzheimer's Australia by Deborah Brooks, Project Officer; Catherine Ross, Research Assistant; & Elizabeth Beattie, Professor, Aged and Dementia Care School of Nursing, Queensland University of Technology.



**TALKING ABOUT ALZHEIMER'S
ACROSS AUSTRALIA**
FIGHTDEMENTIA.ORG.AU

CONTENTS

Executive Summary	4
Key facts on informal carers and dementia	5
Overview	5
Future projections	5
Impact of caring	5
Evidenced based supports	5
Introduction	6
Background: the Australian picture	7
Numbers of informal carers in Australia	7
Care provided by informal carers	7
Carer involvement in the future	8
The impact of caring	9
Psychological health and emotional well-being	9
Physical health	10
Social isolation	11
Economic impact of caring	12
Evidence-based supports for carers	13
Information, education and training	13
Psychosocial therapies	14
Case management	14
Multi-component interventions	14
Social support groups	14
Respite care services	15
Conclusions	17
References	18

EXECUTIVE SUMMARY

There are approximately 200,000 Australians providing unpaid care to a person with dementia. These carers are often the spouse or child of the person and provide wide-ranging support, including helping the person with dementia with activities of daily living, personal care, and managing behavioural and psychological symptoms of dementia, as well as making difficult decisions about treatment options, use of services, finances, and long-term care. Some carers have work, children and other family commitments to cope with as well.

Providing this type of intensive support can have substantial impacts on the wellbeing of the carer. Many carers experience negative effects on their emotional, psychological and physical health, social activities and support networks, ability to work and finances. Influencing factors include carer age, co-residency, previous health, personality, coping style, the severity and type of dementia, and the availability of social support.

There are a range of supports and services available for carers in Australia including information, education and training, psychosocial therapies, case management approaches, social support groups, respite care, and multi-component programs that combine these. Research to date suggests that structured multi-component and individualised psychoeducational¹ and psychosocial interventions² led by qualified professionals tend to show the most positive improvements in carer outcomes. However, even with the supports currently available, many carers find difficulty in accessing the supports they need when and where they need them.

If we are to achieve an aged care system that supports people to live in the community for as long as possible, then carers are an essential part of the equation. Most people with dementia rely on informal carers to supplement formal care; as often the hours available even at the highest level of home care package are simply not sufficient to support a person with dementia to stay at home. In order to provide people with choice over where they receive care, there is a need for not only a good system of home care but also a comprehensive, evidenced-based approach to supporting informal carers.

1 Psychoeducational interventions refer to interventions that include elements of education, skills training, information and advice about available services and resources, and require active participation by carers.

2 Psychosocial interventions refer to interventions that focus on identifying and modifying carer's beliefs and developing new strategies to help cope with caring demands.

KEY FACTS ON INFORMAL CARERS AND DEMENTIA

Overview

- There are more than 200,000 Australians providing informal unpaid assistance to people with dementia
- The vast majority of people with dementia living in the community (91%) rely on an informal carer to support them
- Most informal carers are either the spouse or adult child of the person with dementia
- Nearly a quarter of people with dementia living in the community (22%) rely solely on informal care and do not access any formal care services.
- 81% of co-resident informal carers provide more than 40 hours of care per week.

Future projections

- Access Economics projects that by 2029 there will be a shortage of 94,266 full time equivalent (FTE) family carers.
- It is estimated the current cost of replacing family carers with paid carers is \$5.5 billion per year

Impact of caring

- Caring for a person with dementia can lead to increased rates of depression, stress and anxiety compared to non-carers
- In Australian surveys of carers, 31% of respondents reported that caring for the person with dementia had a negative impact on their physical health (3), and 34% reported feeling weary or lacking in energy. The stress of caring may result in impaired immunity, high levels of stress hormones, hypertension (high blood pressure) and an increased risk of cardio-vascular disease

- The demands of caring for someone with dementia have been shown to put carers at risk of social isolation. A National Carer Survey in the United States found that carers of people with dementia were more likely to report giving up their holidays or hobbies, having less time for family, having more family conflicts and work related problems
- Caring can also have significant financial impacts. According to the Dementia in Australia report, 54% of carers of people with dementia (and 45% of primary carers) are of working age (1). However, only 56% of these (and 38% of primary carers) were employed at the time of the survey.

Evidenced based supports

- Interventions to support carers include information, education and training, psychosocial therapies, case management approaches, social support groups, respite care, and multi-component programs that combine these. Research to date suggests that structured multi-component and individualised psychoeducational and psychosocial interventions tend to show the most positive improvements in carer outcomes.
- Despite reports of high satisfaction by carers, research evidence to support the effectiveness of case management approaches, informal support groups and respite care is inconclusive, and further high quality studies are needed in these areas

INTRODUCTION

When a person begins to experience the symptoms of dementia, their families and friends begin a new and difficult journey of their own. They have to try and cope with the emotional impact and implications of a diagnosis, come to terms with and manage the changes they see in their relative/friend, provide emotional and practical help on a daily basis, and make difficult decisions about treatment options, use of services, finances, and long-term care. Some may have work, children and other family commitments to cope with as well.

These family members or friends are usually called informal 'carers' or 'caregivers'. Definitions of informal carers vary, but they can be described as "someone such as a family member, friend or neighbour, excluding paid or volunteer carers organised by formal services, who have been identified as providing regular and sustained care and assistance to the client without payment other than possibly a pension or benefit" (1, p.119).

This care can be wide-ranging, all-encompassing and will change with time. Initially carers may have to help the person with dementia with instrumental activities of daily living (IADLs) such as household chores, shopping, preparing meals, managing finances, arranging appointments and taking medications. They may also have to support changed behaviours and associated psychological symptoms. As the condition progresses, carers need to help with more fundamental activities of daily living (ADLs), such as getting in and out of bed, eating meals, and personal care such as going to the toilet, bathing and dressing. As such, carers of people with dementia tend to provide more intensive and extensive care than carers of people with other conditions (2).

So what impacts does this caring role have on family members and friends? What services and resources are the most effective in terms of supporting them in their caring role? The purpose of this paper is to provide policymakers and consumers with information and evidence on the impact of the caring role on informal carers who are providing support for someone with dementia living in the community and the evidence base for effective supports for carers.

BACKGROUND:

THE AUSTRALIAN PICTURE

Over the past decade the Australian Government and a range of organisations have grappled with understanding, measuring and managing the national challenge posed by dementia. Often these discussions have been part of broader analyses of the aged care system and how it might fare in the future, with numbers of older people forecast to grow significantly.

The role played by informal carers of people living with dementia has been acknowledged – to greater and lesser extents – as integral to these analyses. As a result, a fair amount is known about the profile of informal carers and the effects of taking on the caring role.

Numbers of informal carers in Australia

The Department of Health and Ageing funded the AIHW's Dementia in Australia (2012) report, which set out the most comprehensive detail about dementia in Australia to date (1). Key findings included:

- There were 298,000 people living with dementia in Australia in 2011, with a projected increase to 342,800 in 2015
- The majority of people with dementia (70%) were living in the community
- There were around 200,000 informal carers of people with dementia living in the community
- About 9 in 10 people with dementia living in the community were receiving care from one or more carers, and about two-thirds of these carers were women
- Half of carers of people with dementia were 65 and over

- Around 42% of main carers of a person with dementia were the spouse/partner and 44% were the son or daughter.

Care provided by informal carers

The AIHW 2012 report drew on analysis of data from the 2009 Survey of Disability, Ageing and Carers. This revealed that over a fifth of people with dementia living in the community (22%) relied solely on informal carer support. It also set out the sorts of assistance provided by co-resident primary carers to the person with dementia:

- 92% provided assistance with mobility
- 85% provided assistance with self-care
- 79% provided assistance with communication.

The survey asked about carers' participation in a range of other activities: health care, cognitive or emotional tasks, household chores, property maintenance, meal preparation, reading or writing tasks and transport. For each of these activities, more than 90% of primary carers provided this assistance (excluding maintenance with 69% providing assistance with this).

The same survey data also revealed the scale of contribution by co-resident family carers: 81% were providing 40 or more hours of care per week on average, and 94% of co-resident primary carers provided continuous (rather than episodic) care.

The 2009 Access Economics publication, Making Choices, also reports on the scale of support provided by carers based on findings from their survey of 564 informal carers of people with dementia (3). It found that on average, informal carers provided 24 hours per week of care, although

the distribution was split with nearly 20% of carers providing 0-4 hours and a similar percentage providing over 55 hours per week (3).

The AIHW report (2012) stated that co-resident primary carers of people with dementia were almost twice as likely as all co-resident primary carers to provide 40 or more hours of care per week (81% versus 42%).

Carer involvement in the future

Some analysts have attempted to forecast the likely number of people who will be living with dementia in 10, 20 and 40 years' time – and, related to this, to establish whether there will be enough informal carers to meet required needs. The concern is that, while the number of people with dementia increases, the future availability of carers is under threat for a range of reasons, such as the effect of an aging population, workforce constraints and a reluctance of individuals to provide informal care (4).

The AIHW's estimates are that the number of people with dementia will reach almost 400,000 by 2020 and 900,000 by 2050 (1). Access Economics presented similar forecasts (4), even while using different approaches for their calculations.

Based on its projections of the number of people living with dementia and carers in the future, Access Economics' Making Choices report suggests that by 2029 there will be a shortage of 94,266 full-time equivalent (FTE) family carers. It also estimated the current cost of replacing family carers with paid carers is \$5.5 billion per year (3).

THE IMPACT OF CARING

In 2012, Alzheimer's Australia investigated 'The cost of dementia in South Australia' (5). In this study, carers reported a wide range of impacts of caring, including lack of time for self, social isolation, responsibility, exhaustion, a sense that dementia was taking over, and needing more support. They regarded these personal costs as more stressful than the financial pressures related to living with dementia. This section will examine the evidence regarding the impact of the caring role on informal carers who are providing support for someone with dementia living in the community.

Psychological health and emotional well-being

Research has shown that caring for a person with dementia may have both positive and negative impacts on informal carers. Some carers have reported positive feelings such as family togetherness, companionship, increased self-awareness and resilience, personal and spiritual growth, and the satisfaction of helping others (6-9).

However, many family carers of people with dementia experience significant strain, stress and psychological illness such as clinical depression. Compared to non-carers and carers of people with other health conditions, those caring for a family member with dementia tend to experience more strain, and have higher levels of stress and depression (10-14). Depression has been reported in 15-30% of carers of people with dementia (11) compared with 17% in non-carers (13).

The term '*carer burden*' is often used by researchers to describe the effects of caring for a family member or friend with dementia (15). This term, however, is considered offensive by some carers and people with dementia (see Alzheimer's Australia's Language

guide: <https://fightdementia.org.au/sites/default/files/language-guidelines.pdf>). For this reason, this paper will refer to the "*impact of caring*" when discussing research that measured "carer burden". *Objective impact* describes the stressors that result from the dependence and needs for assistance of the person with dementia, such as demands on carer time. *Subjective impact* refers to stressors that result from the mental impact of caring, such as distress, depression, anxiety or feelings of exhaustion. A recent European study (2014) confirmed that increasing severity of Alzheimer's disease was associated with greater subjective and objective impact of caring (16). The behavioural and psychological symptoms of dementia (often referred to as BPSD), such as aggression, wandering, hallucinations, delusions, are also closely related to greater impact of caring, due to the need for increased support (16, 17).

The impact of caring tends to be greater for those who live with the person with dementia, as these carers tend to provide more hours of care on a day-to-day basis, and may experience disruption of sleep due to night-time disturbances (12). Indeed, the AIHW report found that 66% of carers had their sleep interrupted frequently or occasionally due to their caring role (1). Co-resident husbands and wives tend to be older than other informal carers and are more likely to have co-existing health problems themselves, such as reduced mobility, frailty, impaired vision and hearing, and chronic disease, making caring more difficult and demanding (12). Adult child carers and younger spouse carers (for example of people with early onset dementia) may experience different stressors however, with competing work, family and social demands (18). Adult daughter carers report higher levels of impact of caring and negative emotions than adult son carers (18).

Caring for a relative or friend with dementia can have a profound emotional impact, with carers reporting feelings of guilt, sadness, anger, lack of control and worry (18). Carers may also experience grief whilst caring, both for themselves in terms of loss of companionship, personal freedom and control, and for the person living with dementia in terms of loss of personhood. Anticipation and ambiguity about the future, anger, frustration and guilt have been found to be common and may occur at any stage; from diagnosis to admission to residential care and beyond (19).

"I was unable to cope with the workload which included meals, supervision, housekeeping, visits to medical facilities etc." (20)

"Grief at the prospect of losing [relative] to a residential care facility. Not much depression. Some anger occasionally that life should turn out this way. These emotions have not been that severe, but will probably become more so when I have to make the decision to move her in. For the moment though, I just want to enjoy the life we have together." (21)

"Look after yourself. Do what you need to do, to keep the stress levels down. Try to be firm with your loved one while helping them understand that you know this is very difficult for them and that you love them." (21)

Physical health

The demands of caring may have physical impacts on some carers. In Australian surveys of carers, 31% of respondents reported that caring for the person with dementia had a negative impact on their physical health (3), and 34% reported feeling weary or lacking in energy (1). A recent study by the American Alzheimer's Association (2014) reported that 74% of carers of people with dementia were 'somewhat' to 'very concerned' about maintaining their own health; they were more likely than non-carers to report their health as 'fair or poor' and say that caring made their health worse (2).

There is some evidence to suggest that caring for a relative with dementia can have detrimental physiological health consequences. For example, there are indications that the stresses and strains of caring may result in impaired immunity, high levels of stress hormones, hypertension (high blood pressure) and an increased risk of cardio-vascular disease (2, 10, 22, 23). High stress levels have been associated with higher mortality rates in both carers and non-carers, suggesting high levels of stress to be a risk factor and not caring per se (24).

It is important to note that the mental and physical health impacts of caring for someone with dementia are influenced by a number of factors, such as carer age, previous health, personality, coping style, the severity and type of the dementia and the availability of social support (1).

"The realisation that I could not continue to care for her long-term because of the effect on my health, which was deteriorating through lack of time to take care of me as I coped with onset of arthritis." (21)

“They seem to think that the children (who are nearly all over 60 years) can look after them forever but we can’t. I can barely look after myself and I need them to accept services from outsiders because it’s destroying my health looking after them.” (20)

Social isolation

The many demands of caring for someone with dementia have been shown to put carers at risk of social isolation (17, 23). A National Carer Survey in the United States found that carers of people with dementia were more likely to report giving up their holidays or hobbies, having less time for family, having more family conflicts and work related problems (25, 26). Providing assistance with everyday activities (such as bathing, dressing, making meals, and so on) and providing supervision for family members with BPSD, are both related to a reduction in carers’ social and recreational activities (17). As maintaining an active life through leisure and social activities is related to increased well-being (27), a reduction in these activities can be seen as a further negative impact of the caring role.

Carers in general tend to have smaller social networks than non-carers, and social support can decrease over time (28). In a large-scale study of carers in Victoria, Schofield et al. (1998) reported that female carers had lower levels of social support than those who did not have caring responsibilities. Furthermore, people caring for someone with dementia reported that they had less support than those caring for a person with a physical disability (28). Primary carers of people with dementia are more likely than other primary carers

to say they have lost touch or were losing touch with existing friends due to the caring role (1). Carers may also experience feelings of social isolation due to the stigma associated with dementia and behavioural symptoms and negative social reaction in the wider community. In the EURO CARE study, 22% of carers felt that people were rejecting them or avoiding contact because of the illness; 9% said that others showed fear and 2% reported laughter or ridicule (12).

Conflict with other family members can further reduce opportunities for informal social support. Lack of support from family and friends (perceived or otherwise) has been associated with higher impact of caring and depression. Conversely, carers who receive informal support from family or friends report lower levels of stress and depression (29).

“A couple of years ago I had the chance to accompany a friend on a cheap holiday but as I was unable to get any respite for mum I was unable to go. I did not have a break for almost 18 months at that time and I was beginning to get sick from the strain.” (20)

“Also my ability to care for grandchildren when needed and my social life.” (21)

Economic impact of caring

In 2003, the Access Economics report estimated the total cost of dementia in Australia to be \$5.6 billion; \$3.2 billion in direct health sector costs (mainly residential care), around \$1.7 billion in family and carer costs, and the remainder in productivity losses, home and community care, modifications and aids (30). The disability burden from dementia in Australia was reported to be the second highest of any disease, and set to overtake depression by 2016. According to the World Alzheimer Report (2010), the costs of informal care have been estimated to be 55% of the total costs of care (31).

The costs of caring for someone with dementia include the time given to provide assistance as well as any costs associated with care, such as travel to appointments and payment for services. Other costs include loss of earnings, inability to continue working or early retirement of both the carer and the person with dementia. The economic impact of caring for someone with dementia therefore varies between families. Informal carers provide assistance with many different activities of daily living, and some also provide supervision of behavioural symptoms. The time spent giving care varies from person to person but has been estimated as between 4 and 55 hours per week, increasing as the condition progresses (3).

According to the Dementia in Australia report, 54% of carers of people with dementia (and 45% of primary carers) are of working age (1). However, only 56% of these (and 38% of primary carers) were employed at the time of the survey. Of those who had left work in order to provide care, the most common reason was that no alternative care arrangements were available (74%). A report by the American Alzheimer's Association found that 54% of carers said they had to go in to work late, leave early or take time off work because of their caring

responsibilities (2). The Australian Making Choices survey, found that 20% of respondents had to take leave of absence from work to provide care, 13% had to permanently reduce their work load, and 8% had to stop work altogether in order to provide care (3). In general, a higher proportion of families of carers suffer from financial hardship (e.g. difficulty paying bills on time) than non-caring families in Australia (32).

"My great concern at the moment is still trying to balance out, I mean I still have financial commitments, I still have a mortgage. My primary concern is how to ever return to a life of earning proper money again and of resuming a career." (20)

"Our provider does not trust the government to pay the bill despite having a government order so they debit our bank account for everything within five days of going into the care and I understand they will refund the funds at some time after the government pay. OK if you have a substantial bank balance but if you do not?" (20)

SUPPORTS FOR CARERS

There are many types of interventions provided to support carers of people with dementia who are living in the community. Some aim to provide carers with strategies and resources to cope with and manage the symptoms of dementia; others aim to provide respite from the demands of everyday caring. All aim to reduce the negative impacts of caring, such as depression, stress etc., and/or increase self-efficacy, resilience and well-being.

For the most part carers report high levels of satisfaction with the services which are provided in Australia. At the same time, however, national consultations completed by Alzheimer's Australia in 2012 revealed that many carers find the aged care system confusing and that it is often difficult to know what services are available or to access flexible services when and where they need them. Access to appropriate respite has been particularly problematic for some carers. In addition, carers from groups such as Aboriginal and Torres Strait Islander, culturally and linguistically diverse, and those from regional areas find accessing appropriate services particularly difficult.

Many of the supports available to carers have been evaluated formally using randomised controlled trials, non-randomised controlled trials, case control studies and observational studies. This section will review the current evidence-base for such supports in order to gain an understanding of those that may be most helpful for carers.

Information, education and training

Information, education and skills training are a key part of many support services provided for carers of people with dementia, and are recommended in national dementia strategies where these exist. Interventions usually include structured programs led by qualified professionals that provide carers with:

- Education about dementia, its symptoms, progression and changing care needs
- Skills training to support the carer in this role
- Information and advice about available resources and services.

A review of information services for people with dementia and their carers found no clear evidence of the provision of information alone on the impact of caring, but indicated that a combination of information, skills training and telephone support may have positive benefits (33). Telephone support or counselling can be seen as a more accessible option for some people, due to time or location constraints, however its impact on carer health is inconclusive. There is some evidence to suggest that telephone counselling can reduce depressive symptoms for carers of people with dementia and that it meets important needs of the carer, however more research is needed in this area due to the small number of studies and their moderate quality (34).

A recent review of educational interventions found a moderate effect on the impact of caring and a small effect on depression (35). Others have found that 'psychoeducational' interventions (where all of the above elements are present and requiring active participation by carers) may have positive effects on outcomes such as carer depression and subjective well-being, but evidence is mixed as to effects on carer health or burden (36, 37). As most of these studies only reported findings at the completion of the intervention, evidence is limited as to a more sustained impact over time. Parker et al (2008) recommended the following factors as positively contributing to the effectiveness of educational interventions: encouraging active participation in educational interventions for carers; offering individualised programs rather than group sessions; providing information on an ongoing basis, with

specific information about services and coaching regarding their new role (36).

“...there’s just so much out they’re offering, there’s so much information that comes in and I get totally confused with it.” (20)

Psychosocial therapies

Psychosocial therapies are provided by qualified professionals and tend to focus on identifying and modifying carers’ beliefs and developing new strategies to help cope with caring demands. Cognitive behaviour therapy (CBT) is a type of psychotherapy that helps people to change unhelpful thoughts, feelings and behaviours, such as ascribing a negative meaning to their relative’s behaviour and blaming the person rather than the disease (38). There is some evidence to suggest that CBT can improve carer burden and depression (37). Similarly, research indicates that ‘Cognitive Reframing’, a component of CBT which focuses on family carers’ negative thoughts about their relatives’ behaviours and about their own performance in the caring role, may have a beneficial effect on carer anxiety, depression, and subjective stress (38).

Case management

Case management (also known as care management) refers to interventions delivered in the community (i.e. not in hospital or residential care settings) which focus on the planning and co-ordination of care required to meet the identified needs of the person with dementia (39). It usually involves a professional (typically a nurse or social worker) who arranges and monitors a package of

long-term care services. How case management is organised and implemented varies widely. A recent review of studies suggests that case management may be effective in reducing impact of caring and depression and improving carer subjective well-being, but these findings must be treated with caution due to the variation in interventions, outcome measures and reporting (39).

Multi-component interventions

Multi-component interventions, i.e. programs that combine a number of interventions such as information, education, skills training, psychosocial therapies etc., usually over an extended period of time, tend to show positive improvements in carer outcomes. In Parker et al’s (2008) systematic review of interventions to assist carers to support people with dementia living in the community, ten out of twelve studies using this approach reported significant outcomes, such as reduced depression, increased subjective well-being and self-efficacy (36). Multi-component, individualised psychosocial interventions are considered to be particularly promising.

Social support groups

Social support groups tend to be more informal and less structured than other interventions, and can be led by professionals, volunteers or carers themselves. They are often organised by organisations such as Alzheimer’s Australia, and provide carers with the opportunity to share and discuss their experiences and feelings with others who are caring for someone with dementia in their local area. The type of and rationale for these groups varies; they can be open or closed, provide opportunities for information giving or exchange, problem-solving, emotional support and friendship (40).

Research into the effectiveness of support groups is limited. Some studies suggest that support groups may have a beneficial effect for carers, for example in terms of carer satisfaction (40) and subjective wellbeing (37). Qualitative research has indicated that support groups can help empower carers, in terms of helping them construct an identity as a carer; promote a sense of competence in the role; foster the use of formal support services; and build a context in which carers feel understood (41). However, there is no conclusive evidence that they reduce the negative impacts of caring, such as carer depression and more studies are needed in this area (36, 42).

“Some sort of carers’ support would be helpful. Whilst there are activities provided at ACT Carers, I have not heard of one-on-one counselling to help me with the decision making processes with knowledge of financial aspects, power of attorney issues, dealing with family members, etc.” (21)

Respite care services

Respite care has been defined as “planned temporary relief for the caregiver through the provision of substitute care” (2, p.40). It may be used to give the carer a break from their caring responsibilities, for mental or physical relief, to allow carers to engage in social or recreational activities or in response to a crisis (43), and to allow the person with dementia to continue to remain living at home for as long as is appropriate (44). From the perspective of the person with dementia, respite should allow ‘participation in an enjoyable activity (or activities) that is meaningful and appropriate, which provides opportunities for social engagement,

companionship and stimulation and which supports them to live in the community for as long as possible’ (44, p.16). Formal respite care services vary, but may include in-home help, time spent in adult day care centres, or time spent in residential care facilities for the person with dementia (43). The type of respite used will depend on the needs of the carer, the person with dementia and the availability of services in the area. Use of respite care also varies in terms of the hours required, ranging from a few hours to a few weeks depending on individual needs (43).

Not all carers will need or choose to use formal respite care services, but research indicates that use of respite services by carers of people with dementia is lower than would be expected (43), although that uptake is increasing (44). According to the *Dementia in Australia* Report, 39% of primary co-resident carers of people with dementia had used respite services – compared with just 11% of all primary carers (1). The report drew on data from the 2008 Community Care Census which explored use of the National Respite for Carers Program. It asked primary carers of people with dementia for their main reason for first accessing respite and found the reasons varied: emotional stress and strain (49%); increasing needs of the care recipient (22%); carer employment issues (9%); and carer’s need for time to maintain regular activities (7%). Over half of co-resident primary carers of people with dementia (52%) said they needed additional support. The greatest single area of unmet demand was for more respite care: 48% said this was the main area in which they needed more help.

Evidence of the effectiveness of respite care services in terms of improving carer outcomes, such as mental and physical health, and stress, is mixed with some studies reporting positive impacts and others reporting no impact at all (43, 45). Those who

do use respite care tend to report high levels of satisfaction with the services they received (20, 43, 44). This includes allowing carers time for self-care, maintaining family and social relationships, catching up on rest, and providing relief from the caring role (43, 45). However, negative experiences have also been identified, in particular the poor quality and inflexibility of care provided by some in-home, day care and residential respite services (20, 46). In a recent review of the literature, Neville et al (2015), concluded that the difficulties in predicting whether and how carers will benefit from respite care services are due to the many differences between carers, people with dementia, services delivered and types of research carried out to date (43).

"It has given me peace of mind to know that they are in a safe environment whilst I am away and that they are being properly cared for." (20)

"Needed a rest and time to myself. There are things you can't do around home when you've got a person with dementia because they want to be with you all the time." (20)

"It is such a good place but it is so heavily booked. I gave them a few weeks' notice and they were already fully booked." (20)

"Respite services are very important to us [person with dementia and carer]. Without these services we would have had to place [the person with dementia] into care which would not have been in her or society's best interest." (20)

"I feel not enough options are available for carers or the clients. There should be more flexibility, less complex organisation, and different options to meet the various needs of clients e.g. not all are over 80 and in advanced stages." (20)

CONCLUSIONS

Australia is facing a massive increase in the number of people with dementia and this in turn will lead to an increase in the number of people providing informal care. Already over 200,000 Australians are supporting people with dementia. 91% of people living with dementia in the community have the support of an informal carer.

Most people with dementia and their families prefer that the person with dementia remain living at home for as long as possible. However, the impacts of caring are substantial and wide-ranging, and whilst positive impacts have been reported by some, many carers experience negative effects on their emotional, psychological and physical health, social activities and support networks, ability to work and finances. If we are to support people with dementia to live at home for as long as possible, there is a great need for effective community interventions and services to support carers in their role; to help reduce negative impacts such as isolation and illness, and to help increase self-efficacy, resilience and well-being. This need to support informal carers will only increase as the numbers of people living with dementia rises in the future.

Interventions to support carers include information, education and training, psychosocial therapies, case management approaches, social support groups, respite care, and multi-component programs that combine a number of these. Research to date suggests that structured multi-component and individualised psychoeducational and psychosocial interventions (i.e. interventions that combine information, education, skills training, and psychosocial therapies) led by qualified professionals over a period of time and with active participation by carers, tend to show the most positive improvements in carer outcomes. More research is needed to further examine the effectiveness of case management approaches, informal support groups and respite care.

REFERENCES

1. Australian Institute of Health and Welfare. Dementia in Australia. Canberra: AIHW, 2012 Cat. no. AGE 70.
2. Fargo K. Alzheimer's Association Report: 2014 Alzheimers disease facts and figures. *Alzheimer's and Dementia*. 2014;10(2):e47-e92.
3. Access Economics. Making choices. Future dementia care: projections, problems and preferences. Report by Access Economics Pty Limited for Alzheimer's Australia. 2009.
4. Access Economics. Dementia across Australia: 2011-2050. A report for Alzheimer's Australia. 2011.
5. Alzheimer's Australia. The cost of dementia in South Australia. Adelaide: AASA, 2012.
6. Netto NR, Jenny GYN, Philip YLK. Growing and gaining through caring for a loved one with dementia. *Dementia*. 2009;8(2):245-61.
7. Sanders S. Is the Glass Half Empty or Half Full?: Reflections on Strain and Gain in Caregivers of Individuals with Alzheimer's Disease. *Social Work in Health Care*. 2005;40(3):57-73.
8. Zarit S. Positive aspects of caregiving: More than looking on the bright side. *Aging & Mental Health*. 2012;16(6):673-4.
9. Cohen CA, Colantonio A, Vernich L. Positive aspects of caregiving: Rounding out the caregiver experience. *International Journal of Geriatric Psychiatry*. 2002;17(2):184-8.
10. Burns A, Rabins P. Carer burden in dementia. *International Journal of Geriatric Psychiatry*. 2000;15 Suppl 1:S9.
11. Cuijpers P. Depressive disorders in caregivers of dementia patients: A systematic review. *Aging & Mental Health*. 2005;9(4):325-30.
12. Schneider J, Murray J, Banerjee S, Mann A. EURO CARE: A cross national study of co resident spouse carers for people with Alzheimer's disease: I—factors associated with carer burden. *International Journal of Geriatric Psychiatry*. 1999;14(8):651-61.
13. Schulz R, O'Brien AT, Bookwala J, Fleissner K. Psychiatric and physical morbidity effects of dementia caregiving: Prevalence, correlates, and causes. *Gerontologist*. 1995;35(6):771-91.
14. Pinquart M, Sörensen S. Differences between caregivers and noncaregivers in psychological health and physical health: A meta-analysis. *Psychology and Aging*. 2003;18(2):250-67.
15. Pearlin LI, Mullan JT, Semple SJ, Skaff MM. Caregiving and the stress process: An overview of concepts and their measures. *Gerontologist*. 1990;30(5):583-94.
16. Haro JM, Kahle-Wroblewski K, Bruno G, Belger M, Dell'Agnello G, Dodel R, et al. Analysis of burden in caregivers of people with Alzheimer's disease using self-report and supervision hours. *The Journal of Nutrition, Health & Aging*. 2014;3:1-8.
17. Donaldson C, Tarrier N, Burns A. The impact of the symptoms of dementia on caregivers. *The British Journal of Psychiatry*. 1997;170(1):62-8.
18. Cherry MG, Salmon P, Dickson JM, Powell D, Sikdar S, Ablett J. Factors influencing the resilience of carers of individuals with dementia. *Reviews in Clinical Gerontology*. 2013;23(4):251-66.
19. Chan D, Livingston G, Jones L, Sampson EL. Grief reactions in dementia carers: a systematic review. *International Journal of Geriatric Psychiatry*. 2013;28(1):1-17.
20. Fielding E, Beattie E, Readford M, Neville C. Respite Care in Dementia: Carer Perspectives. Dementia Collaborative Research Centre: Carers and Consumers.: 2012.
21. Doan H. Stress levels among Australian family carers of people with dementia in transition to residential aged care placement. Unpublished thesis: Queensland University of Technology; 2014.
22. Brodaty H, Green A. Who cares for the carer? The often forgotten patient. *Australian Family Physician*. 2002;31(9):833-6.
23. Schulz R, Martire LM. Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry*. 2004;12(3):240-9.
24. Fredman L. Mortality associated with caregiving, general stress, and caregiving-related stress in elderly women: results of caregiver-study of osteoporotic fractures. *Journal of the American Geriatric Society*. 2010;58(5):937-43.

25. Alzheimer's Disease International. World Alzheimer Report 2009. 2009.
26. Ory MG, Hoffman Iii RR, Yee JL, Tennstedt S, Schulz R. Prevalence and impact of caregiving: A detailed comparison between dementia and nondementia caregivers. *Gerontologist*. 1999;39(2):177-85.
27. Adams KB, Leibbrandt S, Moon H. A critical review of the literature on social and leisure activity and wellbeing in later life. *Ageing and Society*. 2011;31(4):683-712.
28. Schofield H. Family caregivers: disability, illness and ageing. St Leonards, N.S.W: Allen & Unwin in association with the Victorian Health Promotion Foundation (VicHealth); 1998.
29. Moon H, Dilworth-Anderson P. Baby boomer caregiver and dementia caregiving: findings from the National Study of Caregiving. *Age and Ageing*. 2015;44(2):300-6.
30. Access Economics. Delaying the onset of Alzheimer's disease: Projections and issues. Report to Alzheimer's Australia. 2004.
31. Wimo A, Prince M. World Alzheimer Report 2010: The Global Economic Impact of Dementia. 2010.
32. Edwards B, Higgins DJ, Gray M, Zmijewski N, Kingston M. The nature and impact of caring for family members with a disability in Australia. Australian Institute of Family Studies: 2008.
33. Corbett A, Stevens J, Aarsland D, Day S, Moniz Cook E, Woods R, et al. Systematic review of services providing information and/or advice to people with dementia and/or their caregivers. *International Journal of Geriatric Psychiatry*. 2012;27(6):628-36.
34. Lins S, Hayder-Beichel D, Rücker G, Motschall E, Antes G, Meyer G, et al. Efficacy and experiences of telephone counselling for informal carers of people with dementia. *The Cochrane Database of Systematic Reviews*. 2014;9:CD009126.
35. Jensen M, Agbata IN, Canavan M, McCarthy G. Effectiveness of educational interventions for informal caregivers of individuals with dementia residing in the community: systematic review and meta analysis of randomised controlled trials. *International Journal of Geriatric Psychiatry*. 2015;30(2):130-43.
36. Parker D, Mills S, Abbey J. Effectiveness of interventions that assist caregivers to support people with dementia living in the community: a systematic review. *International Journal of Evidence-based Healthcare*. 2008;6(2):137-72.
37. Pinquart M, Sörensen S. Helping caregivers of persons with dementia: which interventions work and how large are their effects? *International Psychogeriatrics*. 2006;18(4):577-95.
38. Vernooij-Dassen M, Draskovic I, McCleery J, Downs M. Cognitive reframing for carers of people with dementia. 2011.
39. Reilly S, Miranda-Castillo C, Malouf R, Hoe J, Toot S, Challis D, et al. Case management approaches to home support for people with dementia. *The Cochrane database of systematic reviews* 2015;1:CD008345.
40. Hornillos C, Crespo M. Support groups for caregivers of Alzheimer patients: A historical review. *Dementia*. 2012;11(2):155-69.
41. O'Connor D. Toward empowerment: ReVisioning family support groups. *Social Work with Groups*. 2003;25(4):37-56.
42. Lauritzen J, Pedersen PU, Bjerrum MB. The meaningfulness of participating in support groups for informal caregivers of older adults with dementia: A systematic review protocol. *The JBI Database of Systematic Reviews and Implementation Reports*. 2013;11(11):33.
43. Neville C, Beattie E, Fielding E, MacAndrew M. Literature review: Use of respite by carers of people with dementia. *Health & Social Care in the Community*. 2015;23(1):51-63.
44. Howe A. Alzheimer's Australia Respite Review Policy Paper. 2013.
45. Tretteteig S, Vatne S, Rokstad AMM. The influence of day care centres for people with dementia on family caregivers: An integrative review of the literature. *Aging & Mental Health*. 2015:1-13.
46. Singh P, Hussain R, Khan A, Irwin L, Foskey R. Dementia care: Intersecting informal family care and formal care systems. *Journal of Aging Research*. 2014;2014:486521.

FIGHTDEMENTIA.ORG.AU

Visit the Alzheimer's Australia website
for comprehensive information about
dementia, care information, education, training
and other services offered by member organisations.

Or for information and advice contact the
National Dementia Helpline on

1800 100 500

The National Dementia Helpline is an Australian Government funded initiative

**TALKING ABOUT ALZHEIMER'S
ACROSS AUSTRALIA**
FIGHTDEMENTIA.ORG.AU