

Advancing practice in the care of people with dementia

3rd edition

Module 10:

Carer Health and Support



**Dementia
Training
Australia**

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Module 10: Carer Health

Introduction

It is estimated that 2.6 million Australians provide care to a family member or friend who may be frail aged, have a disability, mental illness or a chronic medical condition. Of those in a caring role, 771,400 are primary carers; that is, they provide the main source of unpaid informal care (AIHW, 2013, p. 332). We know that the number of people needing care is growing (Carers Victoria, 2008). Currently it is estimated there are 322,000 Australians living with dementia (AIHW, 2014), which will increase to 942,624 by 2050 (Deloitte Access Economics, 2011). “On 10 August 2012, the Australian Health Ministers recognised dementia as the ninth National Health Priority Area” (AIHW, 2014).

Estimates suggest that around 200,000 Australians are carers of a person with dementia living in the community, with 57% of these being the spouse/partner, and 36% being the son or daughter (AIHW, 2012, p. 117). Health professionals will therefore be treating increasing numbers of people who are juggling their caregiving responsibilities together with their own health care needs.

This module explores the caregiving role and provides some insight into the caring experience as it relates to caring for someone with dementia. The module also discusses what the health professional can do to support people in carer roles and what resources are available to both carers and health professionals.

Objectives

On successful completion of this module you will be able to:

- Explain what a caring role may involve
- Identify the possible impacts of caring
- Develop some strategies to support a carer
- Find resources to assist carers

Module

Topics

The role of the carer

The impact of caring

Assessing carer wellbeing

Supporting a carer

Resources for carers

Professional carers

References

Suggested
readings for
this module

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What we know about carers generally

The role of the carer

“The 2009 Survey of Disability, Ageing and Carers (SDAC) defines a carer as a person of any age who provides any informal assistance, in terms of help or supervision to people with disability or long-term conditions of people who are aged 60 and over. The assistance has to be ongoing, or likely to be ongoing, for at least 6 months” (AIHW, 2013 p 326).

Based on the 2009 SDAC, 92% of care-recipients received informal help with various activities (AIHW, 2013).

These informal carers provided the greater part of assistance to people living in the community, with the majority being female (61%). The Australian Bureau of Statistics 2011 Census identified an increase in the number of carers from 2006 data in males aged 60–69 and carers aged 85 and over (AIHW 2013 p. 327).

Around one-third (32%) of primary carers reported feeling weary or lacking energy due to their caring role, with 30% reporting frequently feeling worried or depressed. Carers who spent an average of 40 hours or more per week providing care were more likely to report these adverse effects (AIHW, 2013).

Carers Victoria data about carers indicates:

- They are generally female
- They are often caring for more than one person
- Carers are equivalent to 62.2 % of health and community sector budget
- While they are of working age they are not able to undertake paid work due to caring responsibilities
- Carers who also work in paid roles work below skill levels
- Carers have the lowest level of health and wellbeing of any group in Australia and higher rates of mental health problems.

(Carers Victoria, 2008)

The needs of carers will differ depending on their particular situation. Factors that will increase the risk of social disadvantage for people providing care are: the duration of the caring period; the number of hours of caring per week; and the perceived level of support available (Carers Victoria, 2008 p. 10).

Carers of people with dementia

The vast majority of care for people with dementia is provided in the home by a relative. For those living in the community, 92% had one or more carers (AIHW, 2013). The demographics of carers of people with dementia reflect those of carers generally (AIHW, 2012). Carers often help with personal care, transport, housework, communication and other activities, as well as managing behavioural changes, providing supervision and liaising with external service providers. For people living with dementia, “access to such assistance can improve their quality of life, and may also help them delay or avoid entry into residential aged care services” (AIHW, 2012 p.117).

Dementia is predominantly associated with people over the age of 65 (Deloitte Access Economics, 2011), and nearly half of the care-recipients accessing care packages from services have primary carers at home, who are aged 65 and over (AIHW, 2012, p. 179). As discussed above, the majority of carers are co-residents, partners/spouses and caring for a partner/spouse with dementia can create strenuous demands on an older person. The progression and changes associated with dementia also place changing demands on the caring role as the level of dependency increases over time. Caring for someone with dementia is associated with greater difficulties and higher levels of carer stress than caring for a person who is not cognitively impaired (Selwood, Johnston, Katona, Lyketsos, & Livingston, 2007).

About 60% of carers of people with dementia may provide care for more than five years (AIHW, 2012, p. 130) and therefore need to cope with the role changes over time as the needs of the person with dementia change. Carers are required to adapt to an ever-changing situation. Each care situation will be different and factors that may influence that situation are the type and strength of the relationship between care-recipient and the carer(s), the physical, social and cultural environment, socioeconomic circumstances and spiritual and religious beliefs.

The carer's journey

Of great importance to both care-recipient and caregiver is that carers often provide the bulk of emotional support to a person with dementia. This support can understandably cause tremendous strain for carers and is one of the major reasons for carers seeking help.



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For many people in the earlier stages of dementia, carers may need to provide supervision rather than assistance; however, at this stage many people with dementia begin to need assistance in areas like organising their time (where they need to be), managing their finances and organising/using transport. As dementia progresses and the person becomes more dependant carers will need to assist the care-recipient with activities of daily living, including continence, dental care, dressing, hygiene, meals and nutrition, pain, sleep and intimacy and sexual issues.

Carers of people with dementia are likely at some stage to have to deal with their relative being transferred to residential care. Throughout this journey carers of people with dementia are required to cope with changed emotional and behavioural patterns of the care-recipient. Caring for someone with dementia can become a twenty-four hour a day role as the person may experience sleep disturbance, nocturnal increased confusion and nocturnal wandering. The person may also not be able to be left alone in the home during the day due to concerns regarding their safety.

Alzheimer's Australia has developed Help Sheets providing advice to carers regarding these activities of daily living. These Help Sheets are available from:

<http://www.fightdementia.org.au/understanding-dementia/help-sheets-and-update-sheets.aspx>

Impact of caring

Many carers who accept the role of caring for a family member indicate that it can be a rewarding experience; however, that does not appear to be the case for most carers. Data from the 2009 SDAC Survey (AIHW, 2012) indicates that 73% of primary carers of people with dementia do not feel satisfied with their caring role, with more than thirty per cent experiencing frequent interrupted sleep, and indicating the caring has placed a strain on their relationship, and with over 14% frequently feeling angry or resentful. Perhaps the biggest impact of caring is the emotional aspect of the role. Carers face having to adapt to a changed relationship with the person being cared for. This may be particularly difficult for adult children adapting to caring for a parent, especially once assistance is needed with personal activities of daily living.

Carers of people with dementia are also faced with the emotional stress associated with declining cognition in the person being cared for. The nature of dementia means that each person will experience dementia in a different way. This means pressure on carers to become skilled on an “as needs basis”. While people with dementia do retain certain personal and interpersonal values and remain capable of having meaningful relationships, the way in which they may express themselves will change. Often the physical disabilities associated with dementia become the least onerous aspect of care and it is the change in mental health, and the associated behavioural changes, that often cause the greatest distress and caregiver burden.

The carer’s role can hugely impact on the general health and wellbeing of the carer and has ramifications in areas such as:

- Health – both physical and mental
- Social activity
- Personal relationships
- Finances both in short and long term

(Carers Victoria, 2008)

Carers of people with dementia may themselves be older and subject to age-related health problems or disabilities. Carers may neglect their own health in favour of their caregiving responsibilities. Health issues such as depression, physical and emotional exhaustion and injuries sustained from care tasks such as lifting may also arise as a direct result of being a carer. Carers may also experience alterations in their personal relationships with other family members, friends, and, in the case of non-spousal carers, their own spouse/partner and children.

Opportunities to participate in normal activities outside the home or caring responsibilities may become limited as the needs of the person with dementia increase and carers are at risk of becoming socially isolated. The financial impact of caring can be significant as opportunities to earn an income may be limited and carers often may experience an increase in general living costs related to caring.

<http://www.fightdementia.org.au/understanding-dementia/section-3-looking-after-families-and-carers.aspx>

(Alzheimer’s Australia; 2013; Carers Victoria, 2008)



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Resource

Assisting carers

Supporting a carer

At various stages carers of people with dementia will require different types of assistance and support. The skill base of the carers and the physical and social environment required to best support a person with dementia will therefore undergo constant change. Carers will therefore require ongoing assistance and information to keep abreast of the needs of the person being cared for. Assistance required through the course of dementia includes information and knowledge, practical support with physical care needs and psychological support.

- Knowledge

One of the best ways to support a person caring for an individual diagnosed with dementia is to provide them with knowledge about dementia. Providing information enables carers to develop an understanding of how dementia might impact on the person concerned and the sorts of things carers can expect. Each person in a caring role is unique; it is therefore important that health professionals find out from the carer what information is most needed at this point of time. As learning about dementia and the changes is quite complex, information may need to be provided several times in different formats over time. These formats could be verbal information provided by the health professional, written or internet-based information, or information from other carers. Essentially, information should be tailored to the individual. Providing information to the person with dementia in the early stages can also assist them to understand the condition and what to expect. Information given to carers includes understanding the changing nature of dementia and helping them to understand that future needs will vary depending on individual experience and early intervention strategies employed by the carer and health professional team.

Alzheimer's Australia has developed Help Sheets providing advice to carers regarding understanding dementia:

<http://www.fightdementia.org.au/understanding-dementia/section-1-about-dementia.aspx> (Alzheimer's Australia, 2013)

Alzheimer's Society (UK) 2014 has developed several You Tube Clips about how the workings of the brain are affected by dementia:

<http://www.alzheimers.org.uk/braintour>



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- Communication and behavioural changes

Carers require knowledge of how best to communicate with the person with dementia as cognition deteriorates, and how to understand the changes in behaviour and what factors may trigger these sometimes unusual or out-of-character behaviours.

<http://www.fightdementia.org.au/understanding-dementia/section-5-changed-behaviours-and-dementia.aspx> (Alzheimer's Australia, 2013)

- The aged care service system

If carers have had no prior experience of the aged care system, information about what services are provided and how to access them can be overwhelming. Different services may be needed at different stages as the dementia progresses; these services may be provided by local councils, community health centres, through an aged care package and Commonwealth Respite and Carelink Centres.

<http://www.myagedcare.gov.au/>

- Self-care and stress management

- a. How to take a break and make the most out of respite services
- b. Recognising and preventing your potential for elder abuse
- c. How to work with doctors
- d. Going to hospital.

- Relationships, families and conflict

When caring for a family member with dementia, family relationships can be put under severe stress. Encouraging family members to talk openly with each other about the changes and using an independent person, such as a counsellor, to facilitate these conversations may be beneficial.

- Coping with RACF admission

Moving to long-term care is said by family to be 'the hardest thing' they ever experience. Although it provides some physical and emotional relief from the 36-hour day, it is also associated with enormous guilt, grief, fear as to whether they have made the right decision, a need to protect the person in care, a loss of control over care and a sense that all of their experience is not valued by staff who have taken control of care and a million other emotions.



Electronic Resource

Practical support

- How to cope after death of the person with dementia

http://www.fightdementia.org.au/common/files/NAT/20130912_NAT_HS_LookingAfterFamiliesHelpSheet_5.pdf

(Alzheimer's Australia, 2012)

Practical support provides assistance with the tasks of caring such as meals, home care, personal care, and respite services.

Ultimately the type of assistance provided to carers will depend on the needs of the individual carer and situation. In line with the person-centred approach health professionals must seek to meet these needs.

Psychological support

At various stages through the course of living with dementia carers may need emotional and psychological support. This may be from their personal family and support networks but there may be times at which professional counselling is required.

There are many milestones through the journey of caring for a person with dementia, and, as stated above, the needs of the carer will vary at each milestone.

The table below provides a summary of a few possible milestones and the possible needs of carers.

Possible milestone	Possible needs
Diagnosis	<ul style="list-style-type: none"> Information Counselling Referral to Alzheimer's Australia Assistance with forward planning
Having to seek assistance from external support services	<ul style="list-style-type: none"> Assistance with identifying appropriate services and learning about the aged care system of services Financial advice
Having to give up employment to take on full-time caring	<ul style="list-style-type: none"> Financial advice Assistance with applications to Centrelink Advice as to maintaining social contacts
The decision to, and process of moving the person with dementia into residential care	<ul style="list-style-type: none"> Information and advice about the process of transfer to residential care Support in dealing with emotions which may include guilt, grief and fear Advice on: <ul style="list-style-type: none"> choosing an appropriate facility maintaining a relationship with the person with dementia after admission developing relationships with facility staff
Death of the person with dementia	<ul style="list-style-type: none"> Support to come to terms with the situation Advice as to returning to social participation Financial advice

Assessing carer social and physical wellbeing

Assessing carer burden

As can be seen from the information given above the role of caring for a person with dementia, whilst rewarding in many ways, can place enormous stress on the carer. Carers may not report stress or that they are experiencing 'carer burden' and it is important that health professionals are able to identify that a carer is in need of assistance.

Numerous tools are available to assess 'carer burden'; these aim to identify the presence and degree of stress being experienced by the carer.

Examples of such tools are the:

- Carer Burden Index
- Family Carer Assessment Tool.

Assessment tools such as the Carers' Needs Assessment for Dementia (CNA-D) (Wancata et al., 2005) can assist health professionals to identify the specific needs of a carer and to determine whether the identified needs are being met.

Nolan, Grant and Keady (1998) presented a practice guide outlining the use of three psychometrically tested assessment tools:

- Carers' Assessment of Difficulties Index (CADI)
- Carers' Assessment of Satisfaction Index (CASI)
- Carers' Assessment of Managing Index (CAMI).

The primary role of respite care services are to enable the carer to 'take a break' from their caring responsibilities. Respite services are provided either in the community setting or in the form of respite care in residential aged care facilities. Community respite usually provides short-term respite either in the person's home or in day centres. Short-term respite allows carers to participate in hobbies, to go shopping, or attend social functions.

Residential respite provides care in residential aged care facilities.

Government-funded residential respite is limited to 60 days per year. An assessment by an Aged Care Assessment Service (ACAS) is required to be eligible for residential respite in a government-funded aged care facility. Commonwealth Carelink Centres provide information on all types of respite care. Telephone: 1800 052 222 or:

<https://www.dss.gov.au/disability-and-carers/programmes-services/for-carers/commonwealth-respite-and-carelink-centres>



Paper based resource

Role of respite care

Summary

This module has explored the role of caring for a person with dementia. The module has demonstrated that caring for someone with dementia, whilst rewarding in many ways, can be extremely difficult, frustrating and stressful. The need for health professionals to be aware of the issues faced by carers and of how to support carers has also been highlighted. The module has also identified that the health and wellbeing of carers is at risk and should be monitored by all health professionals having contact with the carer.

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Resources for carers

Alzheimer's Australia provides a comprehensive range of support services for people with dementia and their carers. Services include early intervention programs, counselling, and family information sessions. Alzheimer's Australia has also prepared a series of Help Sheets aimed at providing information for carers. These Help Sheets cover all aspects of living with dementia and are easily accessible in a printer-friendly format at: <http://www.fightdementia.org.au/understanding-dementia/help-sheets-and-update-sheets.aspx>

Information relating to **carers support services** can be found on the Alzheimer's Australia website. Links to state-specific services are also provided. <http://www.fightdementia.org.au/services/>

Carers Australia advocates on behalf of carers to influence policies and services at a national level. It works with state and territory Carers Associations, to deliver essential national carer services. To find your state / territory website click on the link below:

<http://www.carersaustralia.com.au/>

<http://www.carersaustralia.com.au/publications/>



Electronic
Resources

Commonwealth Carelink Centres provide free information about the services available to both informal carers and those working with people with a disability.

<http://www9.health.gov.au/ccsd/index.cfm>

Telephone: 1800 052 222

Dementia Behaviour Management and Advisory Services. A free service providing advice and support to carers and health professionals regarding management of behavioural symptoms of dementia

<http://dbmas.org.au/>

Telephone: 1800 699 799

National Dementia Helpline

A 24-hour telephone information and support service available across Australia. **Telephone: 1800 100 500**

Professional carers

Health professionals working with people with dementia can also be considered as carers. Caring for people with dementia can be both rewarding and challenging. As with informal carers, providing professional care to people with dementia can be made easier if the health professional has the knowledge necessary to assess and manage the key aspects of dementia. Knowledge and understanding of dementia can also enhance the ability of health professionals to provide person-centred care (*Zimmerman, Williams, Reed et al., 2005*). *Zimmerman, Williams, Reed et al. further state that* knowledge about dementia can also increase work satisfaction among health professionals caring for people with dementia.

Health professionals caring for people with dementia must also acknowledge that it can be stressful and challenging, particularly where the person with dementia exhibits behavioural symptoms. It is therefore important that mechanisms are in place to support health professionals in caring for people with dementia.

Resources for health professionals

Alzheimer's Australia: source of information useful to both health professionals and carers

<http://www.fightdementia.org.au>

Carers Australia: advocates on behalf of carers to influence policies and services at the national level

<http://www.carersaustralia.com.au/>

Commonwealth Carelink Centres provide free information about the services available to both informal carers and those working with people with a disability.

<http://www9.health.gov.au/ccsd/index.cfm>

Telephone: 1800 052 222

Dementia Behaviour Management and Advisory Services. A free service providing advice and support to carers and health professionals regarding management of behavioural symptoms of dementia: <http://dbmas.org.au/>

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