Advancing practice in the care of people with dementia

4th Edition

Module 9:

The role of the carer

Dementia
Training
Australia

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Introduction

More than one in ten Australians are carers. It is estimated that 2.7 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 (AIHW, 2020).

Approximately one third of carers are the primary carer. Seven out of ten primary carers are women and their average age is 54 years. More than half of primary carers are providing at least 20 hours of care each week; while approximately one third are providing at least 40 hours of care each week (Carers Australia, 2020).

Dementia Australia (2020) estimate that 70% of people living with dementia live in the community. More than 90% of this population receive informal carer support. This equates to an estimated 1.2 million people are involved in the care of Australians living in the community with dementia of which many identify as informal carers.

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 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

Suggested readings for this module

Brooks, D. Ross, C. & Beattie, E. (2015). *Paper 42: The economic, social, and health impacts of caring and evidence based supports for carers*. Alzheimer's Australia. https://www.dementia.org.au/sites/default/files/NATIONAL/documents/Alzheimers-Australia-Numbered-Publication-42.pdf

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The role of the carer

What we know about carers

Caregiving has been described as:

> *"the provision of extraordinary care, exceeding the bounds of what is normative or usual in family relationships. Caregiving typically involves a significant expenditure of time, energy and money over potentially long periods of time; it involves tasks that may be unpleasant and uncomfortable and are psychologically stressful and physically exhausting" (Seeher & Brodaty, 2017, p 142).*

Carers are:

> *"people who provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged. Carers are an integral part of Australia's health system and are the foundation of our aged, disability, palliative and community care systems." (Carers Australia, 2020).*

People who care for a family member or friend say there are many rewards:

- The opportunity for personal growth and the development of new skills.
- Proving to yourself that you can meet new challenges.
- The satisfaction of knowing you have helped someone who needs you and done the best you could to improve their quality of life.
- Strengthening the relationship with the person you care for and knowing how much they appreciate your help.
- Receiving the acknowledgement of your family and friends

(Carers Victoria, 2020).

Challenges of caring

Caring can be very demanding and often restricts the lives of individual carers and their families.

- Financial hardship
    - There can be significant additional costs when providing care; e.g. laundry, specialist equipment, health care, and transport.
    - 50% of primary carers are already on a low income.
- Health and wellbeing
    - Carers are 40% more likely to have a chronic health condition compared to the general population. Some of these health problems are directly related to caring,

    e.g. back pain
  - Many carers experience chronic fatigue and sleep deprivation
  - Carers have the lowest wellbeing of any large group in Australia.
- Social isolation and relationships
  - Caring may leave little time for other family or social relationships
  - Carers may feel they miss opportunities with paid employment, recreation, and social activities
  - Carers often must deal with strong emotions. This can negatively impact on other relationships.
- Disadvantage
  - Loss of opportunities for paid employment, career advancement, and further education
  - Losses related to spontaneity and freedom.

(Carers Victoria, 2020).

Take care with labelling people as carers or caregivers. Not everyone will be comfortable with this term. Ensure the person is asked how they would prefer to be described (Guideline Adaptation Committee, 2016). Throughout this module the term carer will be used to describe unpaid carers as distinct from professional or paid carers.

Carers of people diagnosed with dementia

Caring for a person with dementia differs from other health issues due to the duration of the disease, the lack of treatment, the progressive nature of the disease, and the generally older age of the carers. The level of support required will increase as the disease progresses and the person living with dementia requires more assistance (WHO, 2015).

Carers for people living with dementia are usually partners/spouses or adult children (including daughters-in-law). They may also be friends and neighbours (Seeher & Brodaty, 2017). In Australia, approximately 42% of primary carers of a person living with dementia were the partner/spouse; while 44% were an adult child. Approximately half these carers were aged 65 years or older (Brooks et al, 2015).

Most people with dementia who are living at home rely on a carer for support; nearly a quarter of people living with dementia do not have any formal care arrangements in place. When the carer lives at the same address as the person with dementia, they are likely to be providing more than 40 hours of care each week. This care has enormous economic value, it has been estimated it would cost $A5.5 billion each year to replace family carers with paid carers (Brooks et al, 2015).

People may be motivated to provide care for many different reasons. Carers who are motivated by love or reciprocity, spiritual fulfillment, or feelings of mastery and accomplishment have been found to enjoy better health, more positive relationships, more social support, and less feelings of being burdened. However, carers who are motivated by family responsibility, sense of obligation, or ‘no choice’ are more likely to experience psychological distress, anxiety, and a sense of burden (Seeher & Brodaty, 2017).

Carers vary in their relationship and living arrangements, they may cohabit with the person living with dementia or may live separately. They also vary by the type of care provided. This may be defined as:

- Care providers
    - Facilitation of daily hands on care. This can be quite demanding in terms of both time and energy
- Care managers

Undertake responsibility to organise care delivered by others (Seeher & Brodaty, 2017; WHO, 2015).

Impact of caring

Providing care for a person living with dementia can have diverse effects on people. There are some adverse effects as well as positive aspects to this role.

Common negative effects:

- Psychological morbidity, especially depression and anxiety. Research indicates this is more common in people providing care for people living with dementia when compared to other carers or the general population. Sleep disturbances will also impact on this aspect of health. Carers will also report feelings of guilt, sadness, anger, worry, and a lack of control.
- Physical morbidity. Carers report higher rates of poor health and medication use. This may be due to a combination of factors:
    - Stress related to the caring role
    - Less time and ability to engage in preventive behaviours such as exercise
    - Using tobacco and/or alcohol as a coping strategy
- Social isolation. Approximately one third of people caring for a person living with dementia report feeling socially isolated. This can be exacerbated by distance from family and friends. One study showed 50% of carers had contact outside the house once a week or less. Social isolation is compounded by these factors:
    - Giving up leisure activities
    - Restricting social activities
    - Reducing or leaving employment
- Financial concerns. Up to a third of carers leave employment; the most common reason stated is due to a lack of alternative care arrangements. Carers who remain in the workforce report they turn down promotion opportunities and miss work more frequently. Expenses typically increase with more medical visits, home modifications, and assistive devices.

(Brooks et al, 2015; Lindeza, Rodrigues, Costa, Guerreiro & Rosa, 2020; Seeher & Brodaty, 2017; WHO, 2015).

Self-care for carers is essential to the person continuing in that role. Self-care considerations in the realm of dementia care include sleep, leisure, and social engagement and support. Carers are known to utilise activities with the person living with dementia and spiritual activities as self-care. It is also important for carers to be able to take breaks from caregiving.

Research indicates barriers to self-care include:

- female gender
- self-sacrificing behaviours
- being from an ethnic minority
- greater functional dependency of the person living with dementia.

Enablers to self-care are:

- insight to the impact of caregiving
- being able to balance self-care needs with the other person's needs
- recognising duality of roles; i.e. objective caregiving role as separate from previous relationship role

(Waligora, Bahouth, & Han, 2018).

Another group of carers who need consideration are those who have been impacted by their partner/spouse developing younger onset dementia. These carers may still have responsibilities for other dependents such as children. Financial issues related to employment changes may be exacerbated. Social isolation may be quite pronounced, especially with the view that dementia is an "old person's disease". The change in the relationship can have a profound impact on roles and relationships, intimacy, and sexuality. This is true of any relationship at any age but does seem to be felt more deeply in younger onset dementia (Holdsworth & McCabe, 2017). The other difference in this population is that support is provided by the National Disability Insurance Scheme (NDIS) as they are too young for aged care services: https://www.ndis.gov.au/

Supporting a carer

Assisting carers

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 undergo constant change. Carers 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, psychological support and financial assistance.

The Australian Government has developed a single website with access to a range of services and support for carers: https://www.carergateway.gov.au/

These services include:

- peer support
- self-guided coaching
- a phone-based counselling service
- practical skills courses

Knowledge

One of the best ways to support a person caring for a person 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.

Electronic Resources

WHO (2019) has developed a training and support manual for carers of people with dementia: https://apps.who.int/iris/bitstream/handle/10665/324794/9789241515863-eng.pdf?ua=1

Dementia Australia has developed help sheets providing advice about understanding dementia. These help sheets are available in multiple languages: https://www.dementia.org.au/resources/help-sheets#Dementia-Q&A

'*The Dementia Guide*' (2019) is produced by Dementia Australia. It may be downloaded as a digital copy or a hard copy may be ordered through the Dementia Australia website: https://www.dementia.org.au/resources/the-dementia-guide

Alzheimer's Society (UK) (2017) YouTube video about dementia: https://www.youtube.com/watch?v=fmaEql66gB0&feature=emb_logo

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 behaviour.

Electronic Resources

An education resource is provided by the Australian Government (2020): https://skills.carergateway.gov.au/

The Communication module (pdf) is here: https://skills.carergateway.gov.au/pdfs/CarerSkills-Module_2-Effective_communication_techniques-a.pdf

Dementia Support Australia can help via the Dementia Behaviour Management Advisory Service (DBMAS): https://dementia.com.au/services/dementia-behaviour-management-advisory-service-dbas

DBMAS is a support service for people with dementia who are experiencing changes in behaviour that impact their care or the carer. The service supports staff and carers in community, residential aged care, acute and primary care settings with expertise, advice and short-term case management interventions.

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 may be provided by different service providers.

Further information is available at My Aged Care: https://www.myagedcare.gov.au/caring-someone-living-dementia

When the person living with dementia is aged less than 65 years, services will need to be accessed via the NDIS: https://www.ndis.gov.au/

Self-care and stress management

Self-care for carers is essential to promote optimal health and quality of life, and to prevent negative health effects. Carers need to manage their personal needs and their caregiving needs (Waligora et al, 2019). The GP can create a mental health care plan to provide further support.

WHO (2020) have produced this video “Practical tips for carers of people with dementia”: https://www.youtube.com/watch?v=SAhEDIWbnSM&feature=emb_logo

WHO infographic posters covering topics of:

- Reaching out to others for help
- Caring for myself
- Ensuring that the person with dementia continues to receive care
- Responding to changes in the person with dementia
- Providing everyday care to the person with dementia
- Communicating information to the person with dementia can be found here: https://www.who.int/teams/mental-health-and-substance-use/brain-health/integrated-care-support/isupport-lite

Dementia Australia can assist in finding local support groups and also provides a counselling service: https://www.dementia.org.au/support/family-and-carers

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.

A phone based counselling service is available from the Australian Government Carer Gateway: https://www.carergateway.gov.au/

Transition to residential aged care

Moving to long-term care may be required as the disease progresses. This move may provide some relief and reduced stress, but the carer may still experience some psychological distress. Feelings of guilt, anger, anxiety, depression, loss of self, and financial difficulties may remain for several years (Seeher & Brodaty, 2017).

Dementia Australia provides help sheets to assist with this decision. The links below are for English versions, versions in multiple alternative languages are available here: https://www.dementia.org.au/resources/help-sheets#residential-care-and-dementia

- Residential aged care: https://www.dementia.org.au/sites/default/files/2020-06/Helpsheet-ResidentialCare01-ResidentialAgedCare_english.pdf
- Choosing a residential aged care home: https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-ResidentialCare02-Choosing-Residential-Aged-Care-Home_english.pdf
- Caring partnerships: https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-ResidentialCare03-CaringPartnerships_english.pdf
- Good care in a residential aged care home: https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-ResidentialCare04-Good-Care-In-Residential-Aged-Care-Home_english.pdf
- Coping with placement: https://www.dementia.org.au/sites/default/files/helpsheets/Helpsheet-ResidentialCare05-CopingWithPlacement_english.pdf

Assessing carer social and physical wellbeing

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 and it is important that health professionals are able to identify that a carer needs assistance.

Assessment of the care relationship needs to include:

- Other care responsibilities
- Family relationships
- Social connections
- Employment and/or education commitments
- Financial circumstances and eligibility for support
- Physical health
- Emotional health
- Quality of life
- Future goals

The care relationship also needs to be assessed for any risks:

- Lack of information and support
- Signs of distress: anxiety, depression
- High intensity care requirements in a cohabiting situation
- Multiple competing demands
- Conflict in relationships: either with other family members or service providers
- Changes in health of the carer or the person receiving care
- Limited support networks
- Significant changes in circumstances

(Victorian Government, 2012).

Maintaining the care relationship

Carers need to be supported to care for themselves. This will assist in maintaining the relationship between the carer and the person living with dementia.

Encourage carers and provide advice and/or referrals with:

- Health management
- Emotional and social wellbeing
- Building future capacity as dementia is a progressive disease and care needs will increase over time
- Emergency planning arrangements

(Victorian Government, 2012).

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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