



An Australian Government Initiative

Dementia - a National Health Priority



Dementia: Carers and Families Facilitator's Guide

Produced by:

**RURAL
HEALTH**
EDUCATION FOUNDATION

Helping Australians with dementia and their carers

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Dementia – a National Health Priority

The Dementia Series, produced by the Rural Health Education Foundation and funded by the Australian Government Department of Health and Ageing, is a series of educational television broadcasts now available on DVD, to assist GP's, geriatricians, aged care workers and other primary health care professionals across all settings to better understand and deliver quality care and support to people living with dementia, their carers and families.

Dementia: Families Carers

Carers and families of people with dementia provide fundamental care in the home and other settings and they need to be well supported in their role.

This program helps to equip carers with the tools to deal with medical and psychosocial issues relating to care management, and helps them to understand their role in working with health professionals and other providers in delivering care.



Australian Government

Department of Health and Ageing

Part 1

Introduction - How to use this learning guide

The **Facilitator Learning Guide** has been designed with a number of activities that can be used to facilitate group discussion and engage with the material covered in the DVD.

The **Facilitator Learning Guide** has been designed to provide a framework for facilitating discussion of the key issues raised in the program.

A Guide to Facilitating Adult Learning is a booklet developed by the Rural Health Education Foundation (the Foundation) to support the facilitation of discussion with small groups. It covers the basic aspects of how people think and learn, running groups and facilitating learning in face-to-face settings. It is designed to provide some basic instructional information to assist people facilitating face to face learning. We encourage you to read this booklet before you work with groups as a guide to facilitate the learning guide discussion.

The Participant Learning Guide has been designed to support the learning of participants and to provide a record of the information presented in the broadcast and the activities covered in the group facilitation.

Session Planning

The following table overviews the activities within this learning guide. Activity time is based on numbers of 5-6 per group. Larger groups will take up to twice as long.

DVD Chapter	Activity Time	Activity	Page
1 (14 minutes)	25 - 30 minutes	1. Dementia, Carers and Families	4
2 (12 minutes)	20 minutes	2. GPs and carers involvement in care planning	6
3 (23 minutes)	25 – 30 minutes	3. Discussing issues with families and carers	7
3	15 minutes	4. Case Study 1 Geoff and Maria – Where are they now?	7
4 (9 minutes)	25 – 30 minutes	5. An indigenous model of dementia care	8
5 (12 minutes)	15 – 20 minutes	6. Caring for the carer	9
	15 minutes	7. Review	10

The table above gives approximate timings for the activities included in this guide. Session planning should include time for viewing the particular DVD chapter as the prompt to the activity and delivering the background material provided in each section. As a guide each session could be delivered in a 2 – 4 hr workshop.

The activities contained within the Learning Guides are short and not designed to tell a full story. Rather they provide a stimulus for participants to think about the information and the issues arising from it. The case studies and activities provide the opportunity to relate information to real life situations and to use the content to build skills in reflective practice.

Part 2

Program 5 Dementia: Carers and Families

Dementia is a broad term used to describe a large range of illnesses that cause progressive decline in a person's functioning, including loss of memory and the ability to think and learnⁱ

Health professionals, carers and families make the difference for people with dementia.

Key Issues from the program

- GP's play an important role in the lives of people with dementia
- we need to be proactive, ensure early diagnosis and early intervention with services to optimise outcomes
- we need to educate families early about the dementia journey, and stay positive
- person centred care is vital – there is no one size fits all
- there are a range of support services, the earlier they are accessed the better
- management of people with dementia requires team work
- the GP is the fulcrum in the care of people with dementia
- people come with “baggage” or life experiences which can influence their behaviours, so ask about their history
- Alzheimer's Australia provides an enormous amount of information, support services and provides education for people with dementia, their carers and families
- with early intervention we can provide better care for a longer amount of time
- we need to be prepared, and provide timely information to the patient and their family
- we need to support families through the process
- rural GP's have enormous time constraints
- the time taken initially will pay dividends later as it sets the groundwork for a long lasting relationship and improves resilience of the family
- GP's become more of a support than a resource over time
- as a carer we often feel powerless and fearful, and can have difficulty coping
- carers need to take time to establish a relationship with GP
- the person with dementia and their family are living with a changing set of issues and need to learn how to adjust, to allow for the maximum comfort and happiness of the person with dementia
- families need support to give them confidence to provide the care the person needs

The good, the bad, the ugly... A question

- it is good to see people reaching for support and getting it
- respite is truly valued
- there are gaps in service provision
- we need to get smart about how the money is spent and not take carers for granted
- we need to reduce stigma attached to cognitive degeneration and preserve dignity
- in rural communities the person with dementia has often been looked up to and respected.

Once a person is diagnosed with dementia and they display increasing behaviours of dementia, families are worried about how they will be perceived. There is often there is an undercurrent stigma – which needs more education

Section 1

Dementia: Carers and Families

View DVD
Chapter 1

Approx 14
minutes

This section will discuss:

- dementia as terminal illness
- life altering for the patient and their family / carer
- the carers role
- role reversal / changes to roles and responsibilities
- feelings of grief and loss of expectation for the future
- feelings of guilt
- involving carers in care planning
- the stress – social, financial, emotional and physical
- caring for people who live alone with dementia

Activity 1

Dementia: Carers and Families

Part 1

Imagine...

You live in small rural community.

Your parents live on a farm about 30 km from town.

One of your parents has had dementia for 3 years. They have marked cognitive decline and a high level of dependence on their spouse, who is aging and getting frail. They have just started getting aggressive at times when you help them shower and they seem quite agitated.

In small groups, discuss some of the changing issues that have occurred to your family over the past three years and the issues that you can see may occur in the foreseeable future.

Part 2

Discuss the role the GP should play in working with the family to manage the person with dementia. Discussion should include:

- dementia is a terminal illness
- physical changes with aging and cognitive decline
- cognitive changes based on the trajectory of dementia progression
- emotional challenges for the patient and their family including feeling of grief and loss of expectations for the future
- the potential stigma of dementia in a small community
- role reversal / changes to roles and responsibilities
- stress – social, financial, emotional and physical
- support requirements and available facilities in a small rural setting including need for respite
- education for family, carers and the broader community
- caring for people who live alone with dementia

Section 2 GPs and Carers involvement in care planning

View DVD
Chapter 2

Approx. 12
minutes

This section will discuss:

- engaging the carer in care planning
- the informant role
- monitoring treatment outcomes
- facilitating quality of life
- monitoring nutrition and eating
- making “home dementia” friendly
- reinforcing the importance of maintaining involvement in hobbies etc
- deal with confidentiality and the dementia patient not wanting the carer or family involved

Activity 2 GPs and Carers involvement in care planning

Discuss the role of the GP, particularly in a rural setting, in care planning with carers for a person with dementia.

How will you, as a GP or health professional

- be the informant for the family
- monitor treatment outcomes
- facilitate quality of life
- monitor nutrition and eating
- make “home dementia” friendly
- reinforce the importance of maintaining involvement in hobbies etc
- deal with a situation such as the dementia patient not wanting the carer or family involved

Section 3 **Discussing Issues with Families and Carers**

*View DVD
Chapter 3*

*Approx. 23
minutes*

This section will discuss:

- raising issues with families
- breaking the diagnosis news to families
- legal matters
- driving
- enduring power of attorney
- organising a will
- starting drug treatment
- challenging behaviours
- intimacy and sexual issues

Activity 3

*Review DVD
Chapter 3*

Discussing Issues with Families and Carers

Have the group review DVD chapter 3

In small groups have the participants discuss the following issues

- breaking the diagnosis news to families and letting the family know what to expect without overwhelming them initially
- legal matters
- driving
- enduring power of attorney
- organising a will
- starting drug treatment
- challenging behaviours
- intimacy and sexual issues
- as the disease progresses, discussing advanced care plan (Program 2)

Discussing issues with families and carers – key considerations

- encourage the carer and family to work out what is essential to worry about and what not to worry about
- lay out path ahead
- discuss issues of driving and loss of control, isolation etc
- discuss need for enduring power of attorney and wills to be sorted out early (issue of cognitive competence and sense of control and input for the patient)
- raise possibilities of range of symptoms and disease progression
- recommend Alzheimer's Australia as resource

Activity 4

Case Study 1 Geoff and Maria – Where are they now?

(extended version available on the DVD)

This case involves an interview with Geoff Maria about where they are now and how they are coping 3_ years down the track.

Discuss the case the difficulties, challenges adjustments Geoff and Maria have had to make over the last 3_ years.

Section 4 Accessing Respite and Cultural Issues

View DVD
Chapter 4

Approx. 9
minutes

This section will discuss:

- respite options
- culturally appropriate ways of providing care, support and respite for Indigenous patients and carers

Activity 5

Case Study 2 An Indigenous Model of Dementia Care

(extended version available on the DVD)

Discuss the case study on the “Troopy Model” of providing culturally appropriate respite for Indigenous patients’ carers in remote communities.

Identify strategies that can be implemented in your own communities to address the culturally specific needs of Indigenous people any other culturally specific groups that are in your community.

Accessing Respite and Cultural Issues – key issues

- getting prepared early for respite or residential care is ideal but often not easy for the carer to face
- understand source of behaviours
- identify threshold for specific behaviours / conditions for the patient and their care / family
- identify the level of resilience and how to support the family to develop resilience
- ensure carer has permission to let go and get respite care
- culturally sensitive respite makes an enormous difference to the patient and their families within their communities
- provide opportunities for the person with dementia to contribute to their community

Section 5 Transition and Ensuring the Carer is Coping

View DVD
Chapter 5

Approx.12
minutes

This section will discuss:

- education about the disease and practical coping strategies
- how carers can monitor their own mental and physical health
- support that is available, where and how to access services
- when and how to go about considering residential care
- palliative care
- end of life decision making
- helping carers and families deal with grief and loss

Activity 6 Caring for the Carer

Discuss how you will provide the following information to carers, when and how you will monitor their progress

- education about the disease and practical coping strategies
- respite options in your community
- how carers can monitor their own mental physical health
- the support that is available, where how to access services

As the disease progress to the late stage, we need to consider end of life matters. Ideally, an advance care plan has been discussed with the patient while their cognitive function was still competent.

- when and how to go about considering residential care
- palliative care
- end of life decision making
- helping carers and families deal with grief and loss

Key issues

- support carers through transition to supervised care
- determine permission requirements and resilience of carer and family
- let the carer and family know that it is OK and it is often better than they imagine it will be
- monitor the carer – they get sick too
- caring is very stressful
- monitor specific crisis point such as:
 - when diagnosis is made
 - end of life decisions are made
 - transition from home to residential care
- ensure the carer and family access a good support network
- end of life decisions need to be faced and talked through
- need to discuss palliative care verses life prolonging care
- caring for a loved one with dementia is “brutal” - we need to reach for any good as it happens

Review

Review

Have the participants think about having to share the learning from this program with a group of colleagues. In small groups or pairs have them identify the key learnings from the session and document them in the space provided below.

Consider:

- the impact of dementia on families and carers
- engaging the carers in care planning
- how and when to discuss issues with families
- caring for the carer
- respite options including culturally appropriate options
- managing late stage dementia and end of life matters



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Rural Health Education Foundation
Unit 17, 2 King Street DEAKIN ACT 2600
PO Box 324 CURTIN ACT 2605
Phone: 02 6232 5480
Fax: 02 6232 5484
Email: rhef@rhef.com.au
Web Site: www.rhef.com.au