



The GOLD Book for Carers: Guiding Options for Life with Dementia

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Institute, University of Tasmania
ISBN: 9780-646-51659-2

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Suggested citation: Stirling, C., Lloyd, B.,
Vickers, J., Robinson, A., Croft, T., Scott, J.,
Abbey, J. (2009). The GOLD Book for Carers:
Guiding Options for Life with Dementia
Hobart: The Print Centre

Acknowledgements: The development of
the GOLD book was guided by an expert
advisory group, including representatives
from Alzheimers Australia, Carers Tasmania,
the Commonwealth Carelink and Respite
Centre and the Home and Community
Care Program in Tasmania. Research and
development of the Gold Book was made
possible by funding from the JO and
JR Wicking Trust, University of Tasmania
(including the School of Nursing and
Midwifery), Menzies Research Institute,
and Department of Health and Human
Services Tasmania.

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What is the GOLD book?

The GOLD Book is for you if you are caring for a person with dementia. GOLD stands for Guiding Options for Living with Dementia. Even though you don't have dementia yourself, the experience of caring for a person with dementia will affect your life. In this sense, you are a person living with dementia.

What is the Gold book about?

- helping you to make decisions about services,
- realising the right time for you to use services,
- choosing between respite services,
- making your life easier as you care for a person with dementia.

Why might I need help thinking about services?

Services are there to help you care for your relative or friend with dementia. Yet many people only use services as a 'last resort'. One reason for this is that there are so many different things to balance when making service decisions:

- You may not know enough about what the services do.
- You may have other people with ideas different from yours involved in the decision.
- You may not be able to decide which services would be most helpful in your own situation.
- You may be worried about making a 'wrong' decision.

The different sections of the GOLD book can make it easier for you to decide about services.

We focus on **respite** services in particular because they:

- allow carers to take a break from care giving.
- let someone else look after the person with dementia for varying amounts of time.
- protect the health and wellbeing of carers of people with dementia.
- If you suspect that your stress levels are too high, you could benefit from doing the Carer Stress Test ➡ page 30.

How to use the GOLD Book

Part One – Find out why services are a great help

- Find information about different levels of service help.
- Find information about three kinds of respite services.
- Find suggestions about possible advantages or disadvantages of each kind of service.

Part Two – Think through the decision

- Do step-by-step thinking about the things that may affect your choices about using respite services.
- Be guided to become clearer and more confident about the choices you make.

Part Three – Read how others have felt about respite

- Read some short stories about other carers' use of respite services.
- Gain reassurance about any concerns that you may have about using respite care.

Part Four – Get more information

- Find some information about dementia and the changes it is likely to cause in the person you are caring for.
- Find a test to help you recognise when your own stress levels could be too high ➡ page 30.



PART ONE:

Services are helpful, especially respite

What are services?

Services are helpful activities provided by people other than family or friends. They may be free, wholly or partly paid for by governments or other organisations, or you may need to pay for them yourself.

You might think ***'We are doing fine at the moment. Why should I be thinking about respite services now?'***

The truth is that getting help from services at an early stage makes it easier for you to gradually increase the support you need as the work of caring increases. On the other hand, waiting too long means that often a crisis will trigger service use. This might lead to carers being too tired, stressed or sick to continue. By planning ahead to use services, and by using them early, you can reduce your chances of being in a crisis situation in the future.

You don't need to worry about making a wrong choice, because no decision you make about service use has to be final. If one kind of service doesn't work well for you, then you can choose to stop using it and try a different one.



Grouping services according to how they help you

Many kinds of services can make carers' lives easier and more enjoyable, but sometimes the variety can be confusing. We have grouped services into the service types that you might use as a carer, and provided basic information about why you might use these services. You can find more information about a range of services in the 'Community Care' section of your Carelink Aged Care Guide. You can request one by calling the Commonwealth Respite and Carelink centre on **1800 052 222**.*

Ways to learn more about your situation and what has happened to others in a similar situation

You could try:

- talking to your doctor or another health professional.
- asking for an Aged Care Assessment. Your doctor or local hospital can refer you to an Aged Care Assessment Team (ACAT), who will assess the needs of the person you are caring for. For further information, call the Commonwealth Carelink Centre **1800 052 222*** or the Aged Care Information Line: **1800 500 853***
- using telephone or Internet information and support services (Telephone counsellors, Internet Blogs and Chat rooms, Internet information pages).
- contacting a support organisation, such as Alzheimer's Australia **1800 100 500**,* or Carers Australia **1800 242 636***
- joining dementia support groups (people getting together, either formally or informally, to discuss shared issues and experiences).

* **All numbers listed are free from a land line, but may be charged at a timed rate if called from mobile phones.**

Getting help with particular problems

You could try:

- personal or family counselling (discussing problems and issues with a qualified counsellor, on your own or as part of a group),
- calling the Dementia Behaviour Management Advisory Service **1800 699 799*** for help with managing psychological and behavioural symptoms of dementia.
- talking to a health care professional, or a support organisation.
- home modifications – such as a picture of a toilet on the toilet door and radiators mounted high on the wall.
- getting help with transport.
- getting some new ‘carer’ skills through a training course.

Getting help if you have too much to do

You could try:

- using regular cleaners - help with household tasks, such as vacuuming and bathroom cleaning
- getting occasional help with maintenance tasks, such as cleaning windows, gutters and gardening.
- getting help with food supply and preparation, such as shopping assistance and delivered or bought meals
- getting help with the health care of the person with dementia – such as walking, medications, wound care or other health needs of the person with dementia (this might include nurses,
- using therapists, occupational therapists, podiatrists and trained helpers).
- using services that help with the personal care of the person with dementia – (e.g. trained helpers who help with showering and dressing the person with dementia).

To determine the availability of any these services and your eligibility for them, call the Commonwealth Respite and Carelink Centre:

1800 052 222*. Since there is a waiting list for many services, it is very important that you **plan early** for services you may need in the future.

Getting time to recharge your batteries and attend to everyday business

You could use:

- *In-home respite*
- *Day respite*
- *Short-term residential respite*

Respite is an important service for carers.

Please read on!



Three types of respite services

We provide basic information about three kinds of respite services and suggest some advantages and disadvantages for each one. We do this to help you to think about how each service might fit your own situation. As you read through, think about these questions:

- What changes in your life might cause you to consider using each service?
- How might you feel about using each service?
- What do you think the reaction would be from the person you are caring for?
- Would anyone else involved in that person's care have any opinions about you using the service?
- How important are the opinions of each of these people to you?

As with most things, as well as advantages, there may be some disadvantages for your situation. Weighing these up in your mind can help you move towards making a decision. You don't need to worry about making a wrong choice, because no decision you make about service use has to be final. If one kind of respite service doesn't work well for you, you can choose to stop using it and try a different one.

It is important to know that you may have a limited entitlement to respite services. This could mean that your respite hours will run out when you need them the most. Find out about your entitlement as early as possible, so you can plan to use the services available to you at times when you need them the most.

More detailed information about each service, including how to find out about costs and eligibility, can be obtained through health care professionals, such as doctors and community nurses, or a Carelink guide ➞ page 4.

1. In-home respite

What happens with this kind of service?

Trained helpers come into your home at a pre-arranged time to look after the person with dementia for a temporary period. All helpers will have had a security check from the police before coming into your home.

What are the advantages of this kind of service?

- During this time, carers are free to do other things, including recreational activities, which might be difficult or impossible to do when they are with the person they are caring for.
 - The person with dementia has an opportunity to chat to a different person.
 - The person with dementia is reassured by being at home while being cared for by an unfamiliar person.
 - Other possible advantages in your own situation.
-

What disadvantages could come from this kind of service?

- You or the person you care for may not be comfortable with other people coming into your home.
 - The service may not be available at times when carers need or want it.
 - Other possible disadvantages in your own situation.
-



2. Day respite

What happens with this kind of service?

The person with dementia spends some time away from home at a respite centre. Transport is often provided to and from these centres. Social activities are provided in a group setting.

What are the advantages of this kind of service?

- Carers have a longer time to do other things, including recreational activities, which might be difficult or impossible to do when they are with the person they are caring for.
 - The person with dementia may feel more accepted and relaxed in the company of other people who have dementia.
 - Some difficult behaviours in the person with dementia may be improved through this experience.
 - Other possible advantages in your own situation.
-

What disadvantages could come from this kind of service?

- The person with dementia cannot come and go exactly when he or she wants to.
 - The person with dementia may not want to go or not enjoy the activities.
 - If this happens, carers may feel worried or guilty.
 - Other possible disadvantages in your own situation.
-

3. Short-term residential respite

What happens with this kind of service?

People with dementia are admitted to a residential facility and live there for a short period of time. Residential respite may be planned or used in the case of an emergency.

What are the advantages of this kind of service?

- Carers can use this longer break to relax or go away for a holiday.
 - Carers can enjoy undisturbed sleep.
 - The person with dementia is in a safe and secure environment.
 - Other possible advantages in your own situation.
-

What disadvantages could come from this kind of service?

- Carers may not feel comfortable leaving the person they care for in residential care.
 - The person with dementia may not want to go or not enjoy the experience.
 - The person with dementia may have difficulty readjusting to life at home after returning from residential care.
 - Other possible disadvantages in your own situation.
-





PART TWO:

Thinking through a decision about respite services

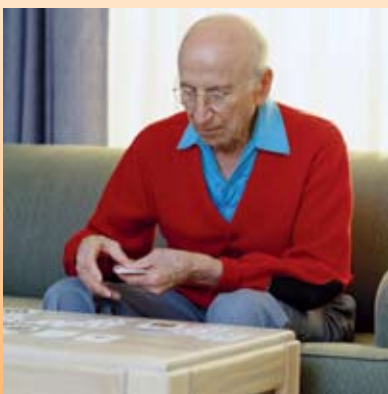
There are many reasons why you might need help with making a decision about respite services. It can be difficult to imagine how services might improve your own situation. You may have to consider the different preferences of several people, such as the person with dementia, other family members, or trusted friends. You might have some concerns about allowing people you don't know well to look after the person you care for, even for a short time. The GOLD book will guide you through these and other issues, to help you to arrive at decisions that can work well for you as a carer.

How a decision guide about respite services can help

Now that you have thought about how respite services could work in your own situation, you will need to consider:

- what kinds of issues might be making it difficult for you to decide about using respite services, and
- what kinds of information or resources you need to help you arrive at a decision.

Working through these issues and needs using a decision guide can help you to become more confident about the decisions you make and to explain your decisions to others if necessary. The next few pages contain a guide to help you be clearer about the issues and needs that will affect your decisions.



Four steps to decision making⁴

This guide will take you through four steps for making respite service decisions, based on your own needs and requirements. You can write down your responses if you like, or just read through and think about each step.

Step 1.

Getting clear about your decision

1. Think about **why** you need to make a decision about using respite services.

.....

2. Think about **when** you should make this decision.

.....

3. Think about **how close** you are to making a decision about respite services.

- ☐ I have not yet thought about options
- ☐ I am thinking about the options
- ☐ I am close to making a choice
- ☐ I have already made a choice

4. Are you **leaning** towards any particular option?

- ☐ Yes ☐ No

If Yes, which one?

.....

⁴ Adapted from O'Connor, Jacobsen and Stacey (2006) Ottawa Personal Decision Guide
Ottawa Health Research Institute, Canada

Step 2.

Identifying what you need to make a decision

Below are some things that we know can help people make decisions. By answering these questions you can find out what support you need to make your decision.

1. Do you have enough support from others in making your decision?

☐ Yes ☐ No

2. Are you choosing **without** pressure from others?

☐ Yes ☐ No

3. Do you understand the options that are available to you?

☐ Yes ☐ No

4. Are you aware of both the potential advantages and disadvantages of each option?

☐ Yes ☐ No

5. Are you clear about which potential advantages and disadvantages matter most to you?

☐ Yes ☐ No

6. Do you feel sure about the best choices for you and the person you are caring for?

☐ Yes ☐ No

Now go over your answers to these questions.

People who answer 'No' to one or several of these questions are more likely to delay their decisions, change their minds or feel regret about their choices.

Now work through steps three and four, which focus on meeting your needs so that you can feel comfortable and sure about your decision.

Step 3.

Exploring your need for decision support

1. Who else is involved in the decision about using respite services?

.....

2. Which options do these people prefer?

.....

3. Are any of these people pressuring you?

☐ Yes ☐ No

If so, who is pressuring you, and in what way(s)?

.....

How do their preferences differ from yours?

.....

In what ways could these people support you?

.....

What role do you prefer in making decisions about care for the person with dementia?

☐ I prefer to share the decision making with others

☐ I prefer to make these decisions myself, after hearing the views of others

☐ I prefer that someone else decides. Who is this?

.....

Step 3.

Exploring your need for more knowledge and certainty

Think about the following questions for the respite option you are considering. You can write down the respite option you are considering and your answers to the questions or just think about them.











1. What respite option are you considering?

- ☐ **In-home respite**
- ☐ **Day respite**
- ☐ **Short-term residential respite**

2. What kinds of changes might cause you to think about this option?

.....

3. What advantages and disadvantages does this option have? (put your answers in the boxes below, then circle 1 to 5 stars to show how much the advantages and disadvantages mean to you)

Advantages of the respite option	Disadvantages of the respite option
<div></div>	<div></div>

Step 4.

Planning the next step based on your decision needs

This step is about overcoming things that might be making it hard for you to make a decision about services or resources.

1. Do you need more information about dementia to help you think about what changes are likely to happen?

☐ Yes ☐ No

If you answered Yes, you could try

- reading Part Four of the GOLD book ➡ page 25.
- finding information from a dementia support service ➡ page 4.
- asking your family doctor or another health professional.

2. Do you feel that you have enough support to make a decision?

☐ Yes ☐ No

If you answered No, you could try

- discussing your options with a trusted person (e.g. health professional, counsellor, family, friends).
- finding out what help is available to you to carry out your choice (e.g. funding, services in your area) ➡ page 4.



3. Do you feel pressure from others to make a particular choice?

☐ Yes ☐ No

If you answered Yes, you could try

- focusing on the opinions of others who matter most.
- sharing and discussing this guide with other people involved in the care of the person you are caring for.
- asking these other people to complete their own copy of this guide.
- looking for areas of agreement. When you disagree on facts, agree to get more information. When you disagree on what matters most, respect the other's opinion.
- finding a neutral person to help you and the other people involved to come to a decision.
- looking at what other people have done – Go to Part Three of the GOLD book to read some stories about others ➡ *page 21*.

4. Are you still unsure about which advantages and disadvantages matter most to you?

☐ Yes ☐ No

If you answered Yes, you could try

- going over your responses in Step 3 of this guide, to remind yourself of what matters to you ➡ *page 17*.
- finding people who know what it is like to experience the advantages or disadvantages of the options you are considering (e.g. from support groups).
- talking to others who have made similar decisions.
- reading stories about what matters most to others (support groups often recommend particular books and articles).
- discussing with others what matters most to you.



PART THREE:

Carer stories

Here are some short stories about other carers' use of respite services. These stories are based on the experiences of real carers. They may help to reassure you about any concerns that you have about using respite services.

Ruby's Story: Doing the housework

Ruby and Norm have been married for fifty-three years. Ruby has always stayed at home to do the housework and to look after Norm, who now has dementia. She enjoys doing housework and takes great pride in her domestic skills. A few months ago, Ruby was finding many household tasks too difficult. She has health problems of her own, and it was hard for her to attend to Norm's almost constant need for companionship when she was so tired. She didn't want anyone to come into her home to help, because she thought they would judge her when they saw piles of unwashed clothes and mould building up in the bathroom. She also worried that no-one else would keep her home as clean as she did.

What happened next?

Ruby arranged in-home respite care for Norm, after talking to a telephone counsellor from a dementia support group about her worries and concerns. She was reassured that dementia service workers are trained and fully aware of the difficulties experienced by carers of people with dementia, and would never judge her by the condition of her house. She was also pleased to learn that she could arrange to have someone to sit with Norm and talk to him while she did her housework herself. Yesterday, when her housework was finished, she went next door for a quick chat and a cup of tea with her neighbour, Moira. Norm was still happily looking through a photo album with his respite carer when she returned. He hadn't noticed that she had been gone at all.

Sarah's Story: Time for everyone

Sarah is the primary carer for her mother Dorothy, who has dementia. She is also married, with two teenage children, Tom and Kelly. One night, Tom told Sarah how disappointed he was that she no longer had time to watch him play football. He understood that Sarah needed to spend a lot of time with Dorothy, to prevent her from having accidents or wandering away from home and getting lost, but he needed his mother's attention too. Kelly added that she felt the same way. When Sarah's husband Jim made a joke about hardly seeing her any more, Sarah felt that it was the last straw.

What happened next?

Sarah arranged for several services to help her care for her mother. Dorothy now has meals delivered every day and her house cleaned on two afternoons a week. She also goes to day respite every Wednesday and Friday. Her favourite part is going on group bus excursions with the new people she has met at the respite centre. On Fridays, Sarah can now spend time with her family. Sometimes she watches Tom play football, has lunch with Jim or goes shopping with Kelly. On Wednesdays, she goes swimming on her own and catches up with her friends. Sarah is much more relaxed now and she notices that Dorothy is also more settled.



Bob's Story: A promise made

Bob has been caring for his mother, Kath, full-time for six years. She is now in the late stages of dementia. Kath needs constant care, as she forgets to eat and has difficulty swallowing. She also wakes several times every night, needing Bob's attention. A few months ago, Bob was physically, mentally and emotionally worn out from attending to Kath's every need, and Kath's doctor suggested he consider full-time residential care for her. Bob couldn't bring himself to take up this option because, long before his mother had dementia, he had promised her that he would never put her in a nursing home.

What happened next?

Bob knew that if he didn't take a break from care giving soon, he would be unable to continue looking after his mother at all. He arranged for Kath to be cared for in a short-term residential facility. Feeling secure that she was in safe hands, he spent eight days bike riding with his friend Barry. When Bob returned from his holiday, his health had improved and he felt able to resume his carer role. He realised that, when he made his promise to Kath, neither of them could have imagined how hard their future situation would be. He decided to make some enquiries about the availability of permanent residential care for Kath, in case he became unable to manage on his own.



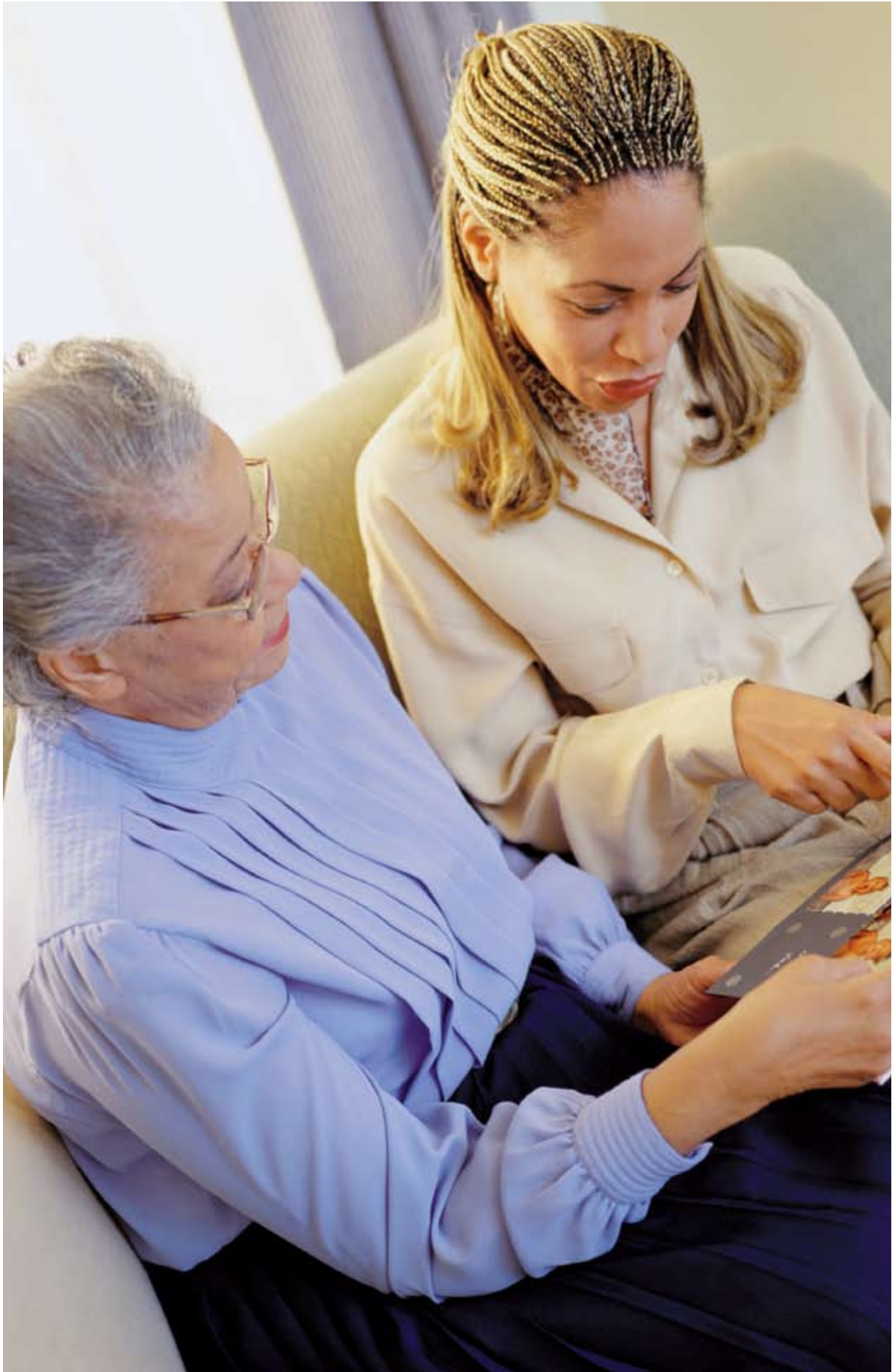


Pam's Story: A troubled marriage

Pam has been caring for her husband George since he was diagnosed with dementia three years ago. Looking after George has been particularly difficult for Pam, because their marriage has never been happy. Although he has not been violent, George has said a lot of hurtful things to her and their children over the years, and these are hard for them to forget. Now she is the only family member willing to take responsibility for his care. Lately, George has been suspecting her of poisoning his food. He follows her around the house, asking again and again what she has put in his dinner. Pam is angry, distressed and exhausted. One night, during one of these episodes, she raised her fist at George and only just stopped herself from hitting him. She was shocked by the possibility that she might seriously harm her husband. She desperately needed to talk to someone who would understand how she felt without judging her, and who could give her some helpful advice.

What happened next?

Pam called the National Dementia Helpline on **1800 100 500**. She explained her situation to a counsellor, who provided her with information about the possible causes of her husband's behaviour and reassurance that she was not to blame for the way she was feeling. On the advice of the counsellor, Pam then called her son and asked if he could stay with his father for a few hours while she got out of the house. When she returned, she felt calmer and ready to make plans for the future that included her own wellbeing as well as her responsibilities to George. Pam arranged for George to go into full-time residential care. He didn't want to go at first, but he soon got used to his new home. Pam realised that she had not entirely given up her carer role, as she was visiting her husband twice a week and helping him with his personal care. After a few weeks, she began to notice that her health had improved. When her grandson Tim came to mow her lawn yesterday, he told her how pleased he was that she was looking so much happier.



PART FOUR:

About dementia

Some facts about dementia

Being knowledgeable about dementia will help you to plan ahead. Here are some basic facts that you may like to know:

- Dementia is not a normal part of aging. It is a progressive disorder of the brain.
- There is at present no cure for dementia, but medical scientists around the world are trying to find one.
- There are several types of dementia, but the most common are Alzheimer's Disease, Vascular Dementia, Mixed Dementia, Parkinson's Disease, Dementia with Lewy Bodies, and Frontotemporal Dementia.
- Because it has a range of causes and people are all different, dementia can show in different ways. There are, however, some broad guides as to what is likely to happen. Dementia for most people involves a progression from mild to severe symptoms. On average, people spend around half of their time with milder symptoms and the other half with increasingly severe symptoms.
- The survival time for someone with dementia varies depending on the type of dementia they have and the age at which they first have symptoms. Average survival times of between 4 and 8 years are often reported by researchers, but some people can live for 20 years after diagnosis.
- Because of the changes happening in their brains, people with dementia gradually lose their ability to perform normal tasks, such as hobbies, chores, and the everyday things they need to do to look after themselves. By the final stages of the disease, they will need to be cared for and supervised at all times.

Diagnosing dementia

Dementia can be difficult to diagnose. There are different causes of dementia, and different symptoms, such as unusual forgetfulness and personality changes. Some symptoms that are similar to those of dementia may turn out to have other causes. It is therefore important to have any diagnosis confirmed by a doctor.

To be diagnosed with dementia a person must have:

- 1) a decline in at least two of the following areas:
 - a. memory
 - b. talking, or understanding written or spoken speech
 - c. planning, solving problems, doing complex tasks
 - d. understanding what is seen

PLUS

- 2) the decline must cause problems with everyday living

Different kinds of tests are used to diagnose dementia. The Mini Mental State Exam (often called the MMSE) is one test that is commonly used by doctors and other health professionals to quickly check for a decline in mental abilities. If problems show up with this test, then further assessment is needed to diagnose the cause of the problem. A high score of between 24 and 30 is normal, but a score lower than this means there is some loss of mental ability.

The MMSE can also be used to see whether any diagnosed dementia is getting worse. If you know the score of the person you are caring for, you may like to write it down in this space, to keep as a record over time and to discuss with your doctor.

Date: MMSE Score:

Date: MMSE Score:

Date: MMSE Score:

What the MMSE score means

30-24	is normal
23-20	shows mild impairment and may mean an early stage of dementia
19-10	middle stage of dementia
9-0	severe dementia

The stages of dementia

The type of dementia has a big impact on how the disease affects people, particularly in earlier stages of the disorder.

Here are two lists that show what often happens in the earlier and later stages of dementia. Because particular symptoms will vary from person to person, the list can only be used as a general guide. The symptoms listed will not affect everyone with dementia. However by the late stages of the disease, most people with dementia will have similar problems. Expert advice should be sought from people who know about the particular type of dementia that has been diagnosed in the person you are caring for.

THE EARLY STAGE OF DEMENTIA

In the early stages of dementia people may

- have some memory loss, which will interfere with everyday activities.
- show some changes in personality or behaviour.
- have some difficulties with remembering times and dates and with knowing where they are.
- have some difficulty in handling problems.
- have some problems with functioning at home and need help. They will give up more difficult chores and hobbies.
- need to be reminded about personal care.
- still be able to undertake most activities, but much less well than before they had dementia.

THE LATER STAGE OF DEMENTIA

In the later stages of dementia people may

- have more memory loss.
- have difficulty talking or eating.
- be incontinent.
- be unable to do any significant activities in the home.
- need a lot of help with all aspects of personal care.
- need permanent supervision and help.

The final part of the GOLD book is a test for you to do to see if you are becoming too stressed. This is important, as too much stress can make you sick. If your stress levels are too high, you would benefit very much from seeking support from available services.

Carer Stress Test⁵

Here is a checklist to help you to recognise when you are under stress and need support. It can also help you to identify problem areas that might be improved by using services. Tick the boxes that apply to you.

- | | | |
|---|------------------------------|-----------------------------|
| ⇒ My sleep is disturbed. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| ⇒ I have to spend a lot of my time being a carer. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| ⇒ I get physically tired or injured from being a carer. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| ⇒ I don't have time for things I want or need to do. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| ⇒ There are too many demands on my time. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| ⇒ I have family problems from being a carer. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| ⇒ My work has been affected by my carer role. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| ⇒ I have had to change my plans for the future. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| ⇒ I feel under emotional strain. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| ⇒ I am upset by the behaviour of the person I care for. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| ⇒ I am distressed that the person I care for has changed so much. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| ⇒ I have financial difficulties because of my carer role. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |
| ⇒ I feel completely overwhelmed. | <input type="checkbox"/> Yes | <input type="checkbox"/> No |

Give yourself a score of 1 for each Yes answer. Then add them up.

Write your score here

A total of more than 7 indicates that you have a high level of stress. You should therefore seek immediate support ⇒ *page 4*.

⁵ Adapted from Robinson BC. Validation of a caregiver strain index. J Gerontol. 1983; 38: 344-348.

Things to remember

Emergency numbers

General emergencies (Life threatening)..... **000**
Dementia related emergencies National Dementia Helpline: **1800 100 500**

Important telephone numbers

Aged Care Information Line:..... **1800 500 853**
Alzheimers Australia:..... **1800 100 500**
Carers Australia:..... **1800 242 636**
Commonwealth Respite and Carelink Centre:..... **1800 052 222**
Dementia Behaviour Management Service:..... **1800 699 799**

Other numbers important to me

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My notes

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This decision aid used the following key resources for information.

1. Australian Institute of Health and Welfare. Dementia in Australia: National data analysis and development. Canberra: AIHW; 2007.
2. Alzheimer's Association. 2009 Alzheimer's disease facts and figures. *Alzheimer's & Dementia*. 2009;5(3):234-70.
3. Bartlett H, Gray L, Byrne G, Travers C, Lui C-W. Dementia Research Mapping Project Final Report. Canberra: Australian Government; 2009.
4. Eagar K, Owen A, Williams K, Westera A, Marosszeky N, England R, et al. Effective Caring: a synthesis of the international evidence on carer needs and interventions. Wollongong: Centre for Health Service Development, University of Wollongong; 2007.