



Supporting carers and people with dementia
to use respite in the Illawarra Shoalhaven



A Respite Decision Guide for Carers of People Living with Dementia

This 'Decision Guide' has been adapted for the local needs of carers in the Illawarra and Shoalhaven as part of the Rethink Respite project.

The design and development of the original guide was conducted by Stirling, C., Lloyd, B., Vickers, J., Robinson, A., Croft, T., Scott, J., Abbey, J. The GOLD Book for Carers: Guiding Options for Life with Dementia Hobart: The Print Centre.

We appreciate the authors allowing us to use and adapt their work for the benefit of carers of people living with dementia in the Illawarra and Shoalhaven region.

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What is the Decision Guide?

The Decision Guide is for you if you are caring for a person 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 still a person living with dementia.

What is the Decision Guide about?

The decision aid will help you:

- make decisions about respite services,
- realise the right time for you to use respite services,
- choose between respite services, and
- make 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 Decision Guide can make it easier for you to decide about services.

How to use the Decision Guide

Part One: Use the ReThink Respite website (www.rethinkrespite.com) or printed resources to find out why respite services can be good for you and the person for whom you provide care.

- Find information about different levels of service help.
- Find information about the 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: See how others have felt about respite by watching or reading the respite stories on the ReThink Respite website (www.rethinkrespite.com)

- 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.
- To help with this, you can also access the local Dementia Illawarra Shoalhaven website (www.dementiais.com) or Alzheimer's Australia website (www.alzheimers.org.au) or phone the National Dementia Helpline on 1800 100 500. See page 3 for Contacts for Further Information.
- You could also try talking to your doctor or the practice nurse at your local medical centre.

PART ONE: Information

To access information about respite, you can use the 'ReThink Respite' website (www.rethinkrespite.com) to find out how respite could be of benefit to you and the person with dementia you support.

Types of planned respite services

The resources provide you with basic information about both planned and emergency respite services and suggest some advantages and disadvantages for each one. This is provided 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 there may be limits to your 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.

Contacts for Further Information

Visit the ReThink Respite website (www.rethinkrespite.com) or look for local services in the Rethink Respite printed directory.

More detailed information about each service, including how to find out about costs and eligibility, can be obtained through the My Aged Care website (www.myagedcare.gov.au) or call My Aged Care on 1800 200 422.

For dementia specific advice contact the Illawarra or Shoalhaven Dementia Advisory Service:

- Illawarra: 4296 6747
- Shoalhaven: 4422 9583

For general advice call the Dementia Helpline: 1800 100 500

For practical information and resources to support carers, call the Carer Gateway: 1800 422 737

For short term respite in the case of an emergency call Commonwealth Respite and Carelink Centre 1800 052 222

In-home or flexible respite

What happens with this kind of service?

In-home respite includes services offered to carers and people with dementia within their home. Support for the person with dementia can be provided with or without the carer being present. In-home respite can provide direct support for the person with dementia including:

- In-home Day Respite
- In-home Overnight Respite
- Social Support including companionship and assistance to pursue an activity of interest (e.g. gardening, woodwork, board games)
- Domestic assistance
- Personal care
- Home modifications
- Other flexible respite options.

In-home respite is available during the day or overnight, occasionally or on a regular basis depending on the needs of the carer and individual with dementia. Individuals with dementia who are reluctant to attend day centres and/or residential centres may feel more comfortable accepting in-home respite services.

What are some of 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.
- List any other possible advantages you can think of in your own situation.

What may be some disadvantages that could arise 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.
- List any other possible disadvantages you can think of in your own situation.

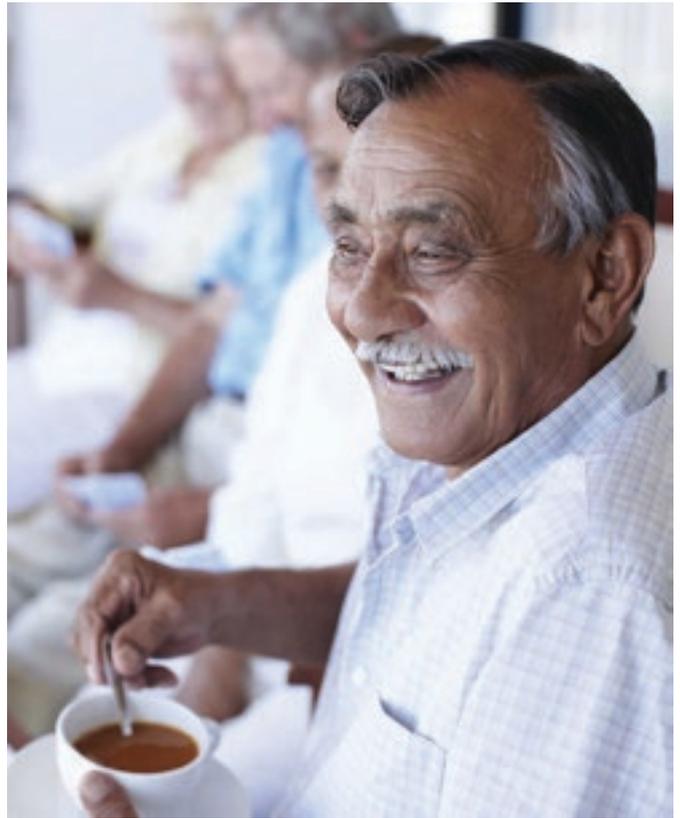
Centre based respite

What happens with this kind of service?

People with dementia can attend centre-based facilities to participate in enjoyable activities and socialise with peers. Some centres cater for a range of individuals (e.g., aged, individuals with disability), while others are exclusively for people with dementia.

Some services include transport to and from the facility, while private transport is necessary for other services. Typical activities at centre-based respite include:

- Arts and crafts (e.g., painting)
- Gardening
- Story/poetry reading and writing
- Cooking
- Quizzes
- Listening to and playing music
- Singing and dancing
- Physical activity classes and outdoor games
- Movies
- Some centres have 'specialised' activities, such as a 'Men's Shed' which are workshops allowing clients to engage in woodworking and handicrafts.



What are some of 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.
- List any other possible advantages you can think of in your own situation.

What may be some disadvantages that could arise from this kind of service?

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

Short-term residential respite

What happens with this kind of service?

Residential respite involves the person with dementia staying overnight in a residential centre/ aged care home. Residential respite can be arranged on a planned or emergency basis. In emergency/short notice situations, carers use residential respite when they themselves are unwell or unable to provide care for another reason.

Residential respite usually takes place in a residential aged care facility or can also be offered within a specially designed 'home' or 'cottage'. Most facilities have:

- communal 'living' or activity rooms, gardens and/or courtyards
- a staff kitchen
- sleeping areas – single or twin share rooms with suitably modified bathrooms (e.g., handrails and wheelchair access).

Residents can take part in activities similar to those offered at day-centres, such as music, arts and craft, cooking, and games.

Some residential respite services organise outings which residents can take part in. Some services include transport to and from the facility, while private transport is necessary for others.

What are some of 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.
- List any other possible advantages you can think of in your own situation.

What may be some disadvantages that could arise 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.
- List any other possible disadvantages you can think of in your own situation.

Cottage respite

What happens with this type of service?

Overnight or weekend care can be provided for a person living with dementia in a respite house or cottage-style facility. It can also be provided in the home of a host family.

In the Illawarra/Shoalhaven region, Cottage Respite is offered via the Southern Council Group at Sanctuary Point and Fairy Meadow.

For more information visit Southern Council Group (SCG) SCG Community Care Programs or download the Cottage Respite Services Directory.

Wollongong City Council also offers the Dementia Respite Options Program which provides up to 52 hours of respite in a home-like environment which is safe and secure. Contact: 4227 7248

What are some 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 which is a more homely environment than residential care.
- List any other possible advantages in your own situation that you can think of.

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What may be some disadvantages that could arise from using this kind of service?

- Carers may not feel comfortable leaving the person they care for.
- 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 the cottage.
- List any other possible disadvantages in your own situation.

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Informal care

What is informal respite?

Respite does not always involve formal or organised services. Examples of informal respite include:

- a friend or family member accompanying the person with dementia to an activity they enjoy (e.g., watching bowls, going fishing, playing golf)
- a friend or family member staying overnight with the person with dementia while you go away for a holiday or short break.
- a friend or family member staying at home with the person with dementia and allowing you time to relax, go shopping, or undertake other tasks or activities.
- a friend or family member helping with domestic duties around the home.

Organising informal respite

Consider the following when asking someone to provide informal respite:

- What you would like the informal respite to involve (e.g., frequency and duration of respite, activities involved).
- Why you are asking this particular person to provide support (e.g., what characteristics do they have that would make them a good informal support person?).
- Are there any potential barriers which may interfere with organising informal respite this with person. Consider and discuss ways to overcome these barriers.

What are some of the advantages of this kind of respite strategy?

- Often able to provide support beyond or different to that offered by formal respite services.
 - Can be more flexible than formal respite arrangements.
 - Informal supports often know you well and are able to provide the support you need most.
 - Other possible advantages in your own situation.
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What disadvantages could come from this kind of strategy?

- Informal support people may have little knowledge or experience in supporting someone with dementia.
 - You may feel reluctant to ask family members or friends to give the amount of support you feel you need.
 - Other possible disadvantages in your own situation.
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PART TWO: Thinking Through Your Respite Decisions

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 decision aid 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.



Five steps to decision making ¹

This guide will take you through five 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 A. Getting clear about your decision

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

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Think about when you might make this decision.

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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

Are you leaning towards any particular type of service or option?

- Yes No

If Yes, which one?

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Step B. 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

¹ Adapted from O'Connor, Jacobsen and Stacey (2006) Ottawa Personal Decision Guide, Ottawa Health Research Institute, Canada.

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. Make some notes about which considerations may need some more thinking or talking about to help you get closer to making a decision

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

Step C. Exploring your need for decision support

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

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2. Which options do these people prefer?

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3. Are any of these people pressuring you?

- Yes No

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

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How do their preferences differ from yours?

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In what ways could these people support you?

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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?

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Make some notes about which considerations may need some more thinking or talking about to help you get closer to making a decision.

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Step D. 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 or flexible respite
- Centre-based respite
- Short-term residential respite
- Cottage respite
- Other (please specify)

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

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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
..... ★★★★★ ★★★★★
..... ★★★★★ ★★★★★
..... ★★★★★ ★★★★★
..... ★★★★★ ★★★★★
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..... ★★★★★ ★★★★★
..... ★★★★★ ★★★★★

Step E. 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 request more information from the contacts provided on page 5 or ask your family doctor or another health professional. For dementia specific advice contact the Illawarra or Shoalhaven Dementia Advisory Service:

- Illawarra: 4296 6747
- Shoalhaven: 4422 9583

For general advice call the Dementia Helpline: 1800 100 500

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)
- a free carer counselling and support service:
 - **Alzheimer's Australia NSW** on 1800 100 500 or email helpline.nsw@alzheimers.org.au
 - **Your Time Counselling/Support/Advocacy**
 1. Helensburgh to Gerroa: CatholicCare: 4254 9330 or 4227 1122 enquires@catholiccare.woll.catholic.org.au
 2. South of Gerroa to South Durras: Anglicare 4423 1018
- **ReThink Respite Coaching, visit www.rethinkrespite.com**



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 the ReThink Respite website (www.rethinkrespite.com) or resources to watch or read some stories about others experiences.



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 D of this guide, to remind yourself of what matters to you.
- 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: How Others Have Felt

See how others have felt about respite by watching or reading the respite stories on the ReThink Respite website (www.rethinkrespite.com)

- Read some short stories about other carers' use of respite services. You can download the original GOLD BOOK for examples: <http://eprints.utas.edu.au/22429/>
- Ask other carers you know about their experiences

This may help you to 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. To help with this, you can access the local Dementia Illawarra Shoalhaven website (www.dementiais.com) or Alzheimer's Australia website (www.alzheimers.org.au) or phone the National Dementia Helpline on 1800 100 500. For dementia specific advice contact the Illawarra or Shoalhaven Dementia Advisory Service:

- Illawarra: 4296 6747
- Shoalhaven: 4422 9583

See page 3 for Contacts for Further Information. You could also try talking to your doctor.

