

Getting the most out of Respite Care

A guide for carers of people with dementia





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Introduction

This guidebook is special

If you are supporting someone with dementia, *you are important*. You are helping that person to continue living in the community with dignity and love. However, to keep doing this, you need to look after yourself and sometimes that means taking a break.

Making the decision to use respite care is a hard one, but it is one that is shared by many carers like you. While there are many resources available to give you information about the care system, this resource is designed to help you in your decision-making about respite by providing you with information *from the carer's perspective*. In here you will find stories about carers and their experiences of respite care, as well as advice and tips to help you make the most of your respite experience.

At the back we have included contact details for organisations and services that can help you with information about accessing respite care when you are ready to make the decision to use it.

The idea for this guide began after reviewing the results of a national survey of over 300 carers of people with dementia¹. In that survey, they were asked about their experiences and opinions of respite care. The responses to this survey provided information of great potential use to other carers – and so this guide was begun. The original survey report can be found online at the following URL:
<http://www.dementiaresearch.org.au/respite>

Much of the information in this guide has been provided by the survey participants, but we have also received generous input from Alzheimer's Australia's Consumer Dementia Research Network (CDRN), which is a group of people living with dementia and carers of people with dementia who provide guidance and advice to research projects investigating issues related to dementia. The CDRN contributed largely to the "tips and advice" section².

We hope you that you enjoy reading this guide and that it gives you food for thought.

NOTE: This is not a "how to" guide; its purpose is to tell the stories and experiences of other carers, rather than to provide specific steps in the process of accessing respite care. Some service names and structures change over time or might differ between states. For more detailed information about how you can access respite care for yourself, please see the contacts section at the end of this guide.

¹ Fielding, E., Beattie, E., Readford, M., Neville, C. & Gresham, M. (2012). Respite Care in Dementia: Carer Perspectives. Report on Full Study. Brisbane: Dementia Collaborative Research Centre: Carers and Consumers.

² No real names or personal details are used in this guide.

Carers' Stories

The following stories are fictionalised accounts but they contain within them the words and experiences of carers, as told to the DCRC Respite Survey.

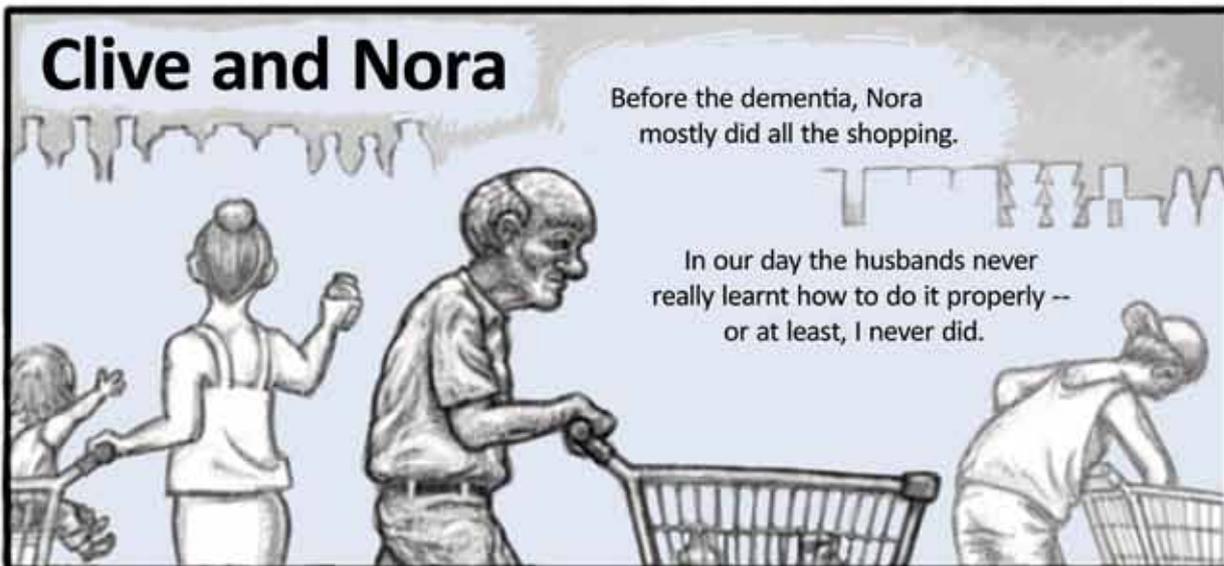
Each concerns a different form of respite care:

1. Day Centre

2. Residential Respite



Centre-based day respite



Clive and Nora

Before the dementia, Nora mostly did all the shopping.

In our day the husbands never really learnt how to do it properly -- or at least, I never did.



She was a marvel, she could shop for me and the four kids -- and the dog -- and still come home with change!



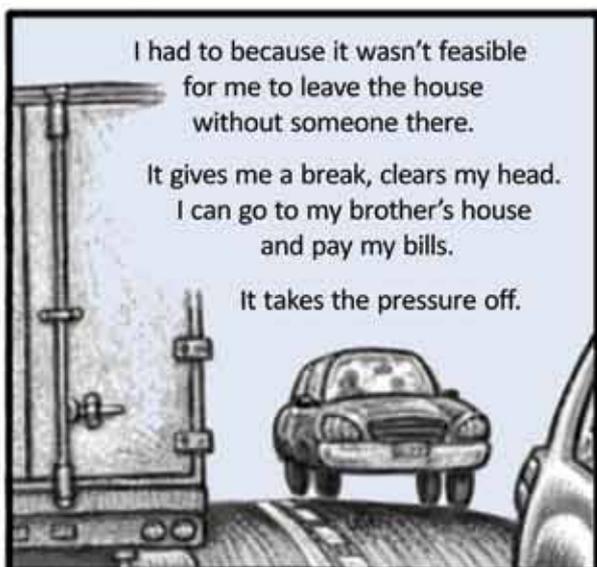
Well anyway, when she started getting forgetful, we'd both do it together.

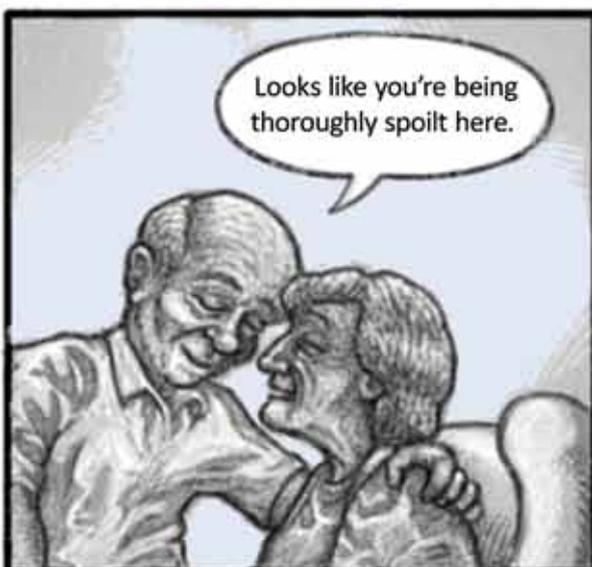


I enjoyed it actually -- a bit of an outing, really.



We'd always have a cuppa and cake together before we came home.





Residential respite

**Bernadette,
Doreen,
Sarah,
& Isabelle:
Mothers & Daughters**

My first grandchild...
isn't she beautiful.



I live in Perth, Sarah lives in Brisbane,
so I just HAD to come and stay
when Isabelle was born.
As much for my sake as for Sarah's.



Mum did the same for me
when Sarah was born.



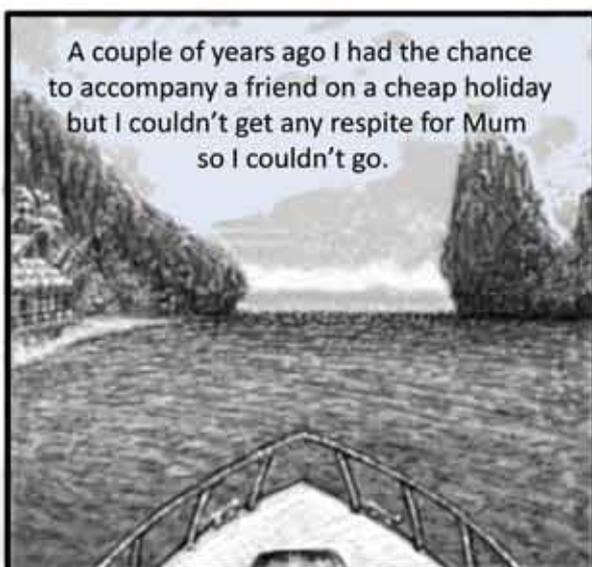
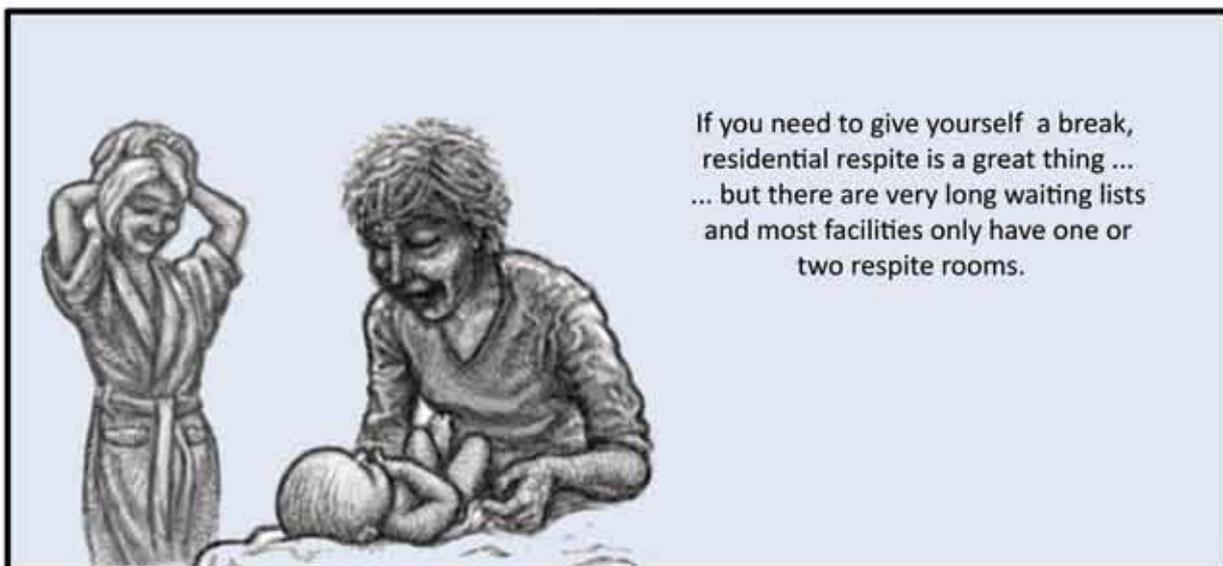
She would have loved to have come here
this time but she's really not up to
such a long journey anymore.

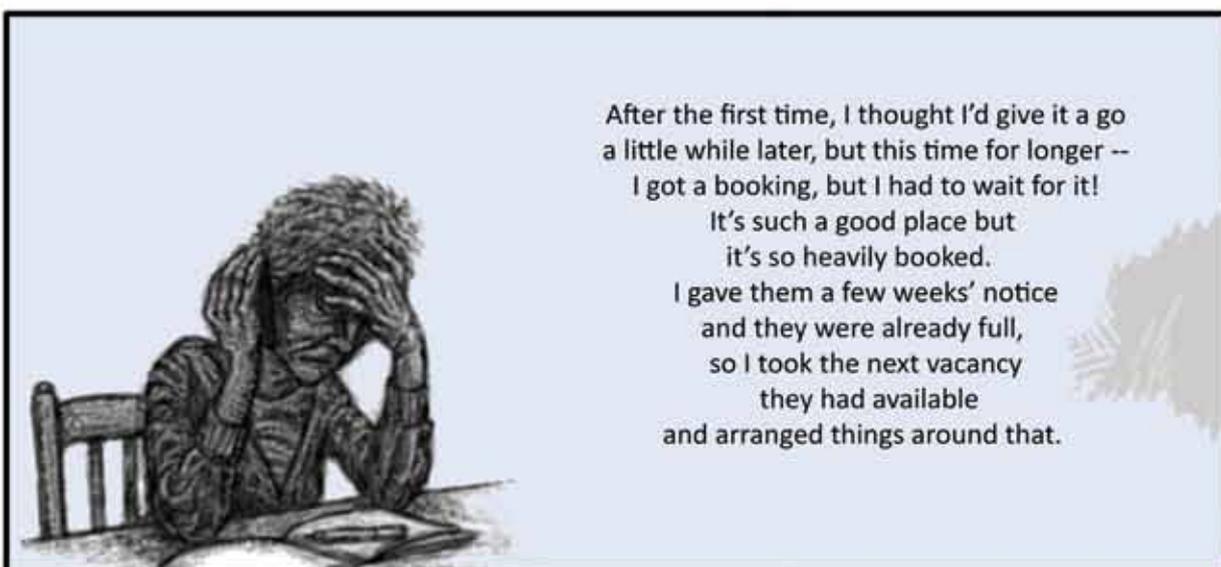
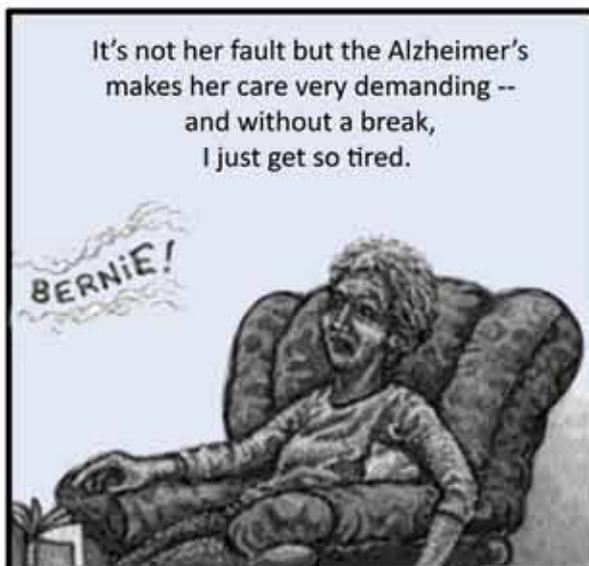


She's staying at a lovely place for
three weeks while I'm away.

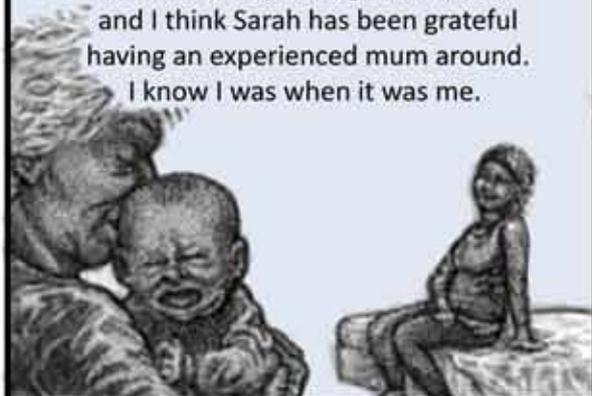


It's not home, but it's nice.





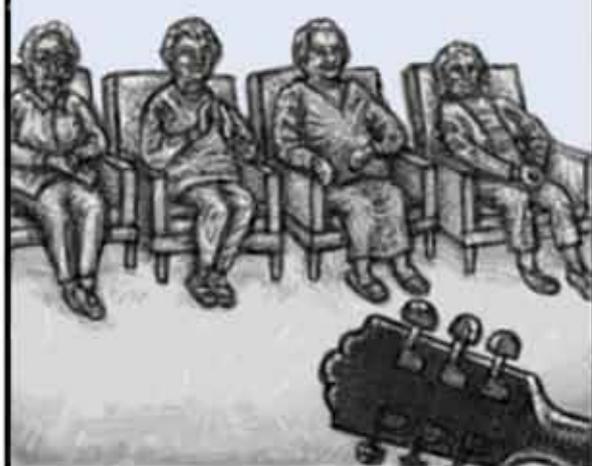
That's why this time I gave them
LOTS of notice.
I didn't want to miss this precious time.
It's been lovely seeing little Isabelle
and I think Sarah has been grateful
having an experienced mum around.
I know I was when it was me.



When I picked mum up after her last stay
one of the nurses told me about a
day centre nearby, so we had a look.



Mum goes there once a week now.



Respite services are very important to us.
Without these services I would have had to
place Mum into care which would not
have been in her best interest.
Or mine.



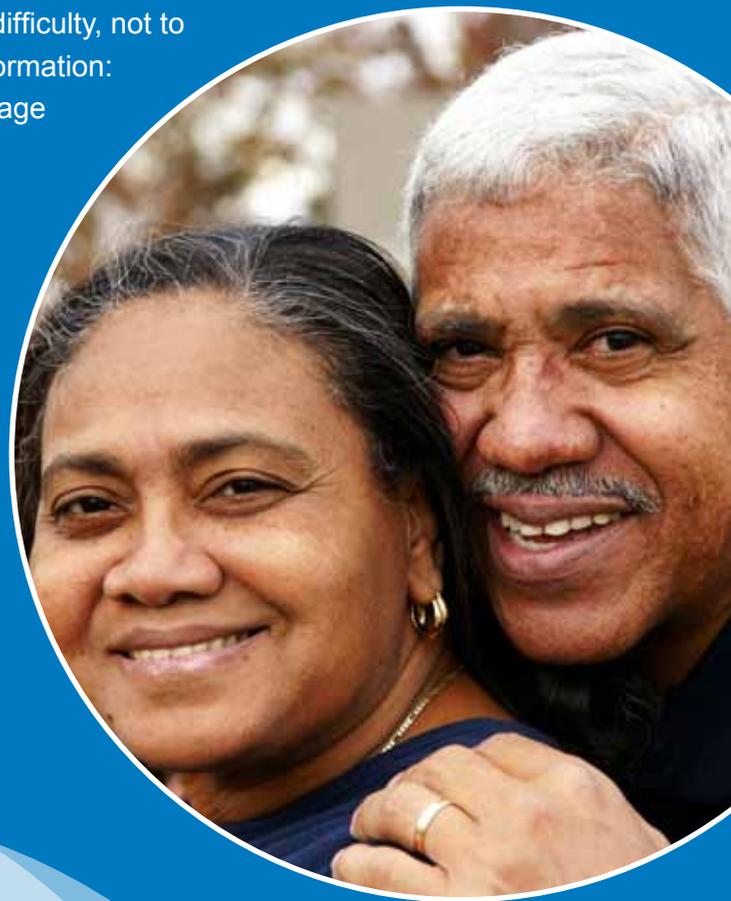
Sarah says she'll come to visit us
with Isabelle later this year.
I think mum would just love that.



Sometimes it doesn't quite work out the way you expected...

Good respite care can be of enormous benefit to the carer and the person with dementia. However, the path is not always a smooth one.

Here, based on information from the DCRC Respite Survey and the CDRN, we show where some people ran into difficulty, not to suggest giving up but to empower you with information: being prepared can help you prevent and manage difficult situations.



Case Studies

EFFIE

Effie cared for her mother at home. Her mum, Toula, had learnt English as an adult but had reverted to her first language over the course of the disease, even though she had previously been able to communicate effectively in English. Effie had found a culturally sensitive activity group for her mum; however, due to Toula's dementia, the program organisers requested that Effie stay at the respite group. As a result, an opportunity to have some respite turned into Effie volunteering her time to help run the activities.



In-home respite care was also used. While Effie experienced some excellent respite carers, who completed all the tasks and were able to communicate with her mum in her own language, she also experienced some unsatisfactory care workers who did not always do what was required of them or adequately stimulate her mother.

As a result of her experiences, ***Effie suggested more care workers with multicultural backgrounds would make respite care a more positive experience for her.***

JOSEPH

Joseph required close supervision; he had dementia, was doubly incontinent, experienced late afternoon anxiety, and had Parkinson's disease. He could sometimes do dangerous things such as leaving taps running or gas unignited, so he needed to be closely supervised for safety reasons. He and his carer, Bob, had an EACH³ package for respite care in place, but Bob had to report some care workers due to the poor care they were providing. He was most concerned about having a say in the care provided or who provided the care. The service they used had a "policy" that care workers were swapped around so they were never sure who would be attending and there were many new faces for Joseph to cope with. Bob considered a far better solution would have been consistency of care workers.



Their experience with residential respite was more positive. ***Despite Joseph not wanting respite, he enjoyed it once he was there and it gave Bob a good enough break to feel rejuvenated.***

JUNE

June used multiple services to help with her husband, including five hours per week from an EACH-D⁴ package; 12 hours per week at a day respite centre; and occasional use of a time-out program so she could go out in the evening. **June stated that these services had been a life saver, making it possible to keep caring for her husband (John) at home.**



June attempted to use another in-home respite service provided by another agency but found this very unsatisfactory. She had to stay to instruct new staff and different care workers were sent each day. This was very unsettling for John and June consequently did not get a proper break. She had also tried another day centre respite service which she found unsatisfactory, largely because there were too few staff for the number of clients and they did not appear to be adequately trained.

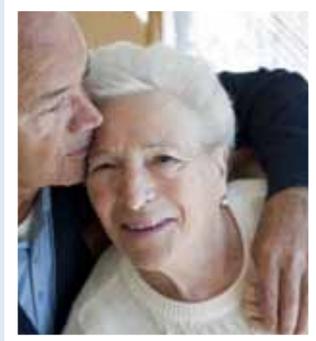
In contrast to these two experiences, June was always satisfied with her evening in-home respite provider because it consistently sent the same two staff with whom John felt comfortable. As a result, she was still able to do special things, which she believed were invaluable, reducing the feeling that life was “slipping away”. It also helped reduce the isolation she experienced after caring for so long. She felt that it gave her back some quality of life.

June’s overall conclusion about respite was that it was **wonderful but sometimes difficult to access.**

⁴ “EACH-D”: *Extended Aged Care at Home Dementia*, now replaced by Home Care Packages (Commonwealth Government)

DENNIS

Dennis thought respite was invaluable but in need of more flexibility. On accessing in-home respite, for his wife, Barb, he was dissatisfied with the inflexibility of times offered because it tied him to those specific hours. Initially Barb was not happy about having a stranger in the house, but as time went on she got used to the situation. However, Dennis worried that the respite staff sent to their home were not always well trained, with limited dementia-specific knowledge. Despite these problems, ***Dennis believed that the service was invaluable as it stopped him from becoming “burnt out” and prolonged the time when Barb would need long term care.***



It was his belief that caring for a person with dementia at home is preferable to residential care admission. In making suggestions about what would make respite better meet his needs, Dennis requested: more respite hours; respite over the weekend; consistency of staff even in an emergency; and a case manager to co-ordinate respite – a one stop shop.

MARY

Mary was working and studying while caring for her husband with dementia; she did not receive any regular help from family or friends. To manage these commitments, on occasions her husband (Jim) was left alone during the day. Mary also utilised centre-based respite and a drop in service, whereby a care worker visited throughout the day to check on Jim. However, while Mary thought the drop in service was a great idea, it didn't suit him:



“... It is great that care is available to people and I was amazed that it was free. It just did not work as required and my husband asked me not to provide the company. So I ring him up several times instead.

... For me it is important to remain to some extent a contributor to the workforce and society. ... I am fine looking after him. All I want is to remain able to work casually in my job ... “

Carers' Top Tips

Using respite care has many ups and downs and it can be hard working out how to get the best results for all concerned. Here is some ***advice from other carers and people with dementia*** to help you get the most out of respite care.



How do you decide when to use respite?

1 When it is needed

When it is considered to be *personally* beneficial to either the person with dementia and/or the person looking after them (family carer). No fixed time in the course of the condition.

When the *quality of care* within the caring arrangement, deserves/needs further support and consideration, for either party.

In my case, the GP and I decided I needed to use residential respite when my wife could no longer go to a local government/church day care centre.

2 Before you become too overwhelmed

Before you feel you are overwhelmed with your caring responsibilities.

It was definitely an adjustment for my mum-in-law as she was quite a shy person and didn't like 'strangers' coming into her home. Some of the carers proved to be wonderful and mum came to view them as her friends.

3 Trust your instincts

Trust your own judgement. If you are feeling like you need a break you probably do. Don't feel guilty. It is perfectly legitimate to have timeout/temporary relief from the hard work of caring for someone with dementia.

When the parties concerned know it is the right time for them, - it is ***not a decision which can be prescriptive*** - with a 'one size fits all' approach!



4 The earlier the better

From as early in the journey as you can, in order to familiarise the recipient and the carer.

Trying early.

In the initial stages I used respite to attend interstate Alzheimer's Australia meetings. That meant my wife understood the need and the periods were only a few days. So: a good introduction to respite.

Later as the care burden increased I took longer periods. **To fully wind down you probably need two weeks.**

I agree that to start early and with short respite may be good; but some tell us that **a short stay in a new place can be very distressing** because the person with dementia has no time to get familiar in a new place.

What worked for me was having a respite carer come into my home 3 days per month to take care of Mum while I went away (she spoke my mother's language). And then later it was 2 weeks in a residential facility and I stayed for a day and night to help mum settle in.

5 When it feels right

When respite suits the **personal relationship needs**, formerly and currently, for both parties.

When suitable, appropriate quality respite care is available - and there is **confidence in what will be provided** for the person with the condition.

Also give yourself time:

Remember the practical side: ACAT assessment must show the person qualifies for Respite, and then Carelink Centre will make a booking depending on vacancies in various facilities.



What are your tips about finding and booking into respite services?

1 Talk to other carers

The best source of reliable information can be directly from **other carers who are in a similar situation.**

This was not available for me, but I like the idea another carer talked about where she and her mother **both went into respite.** That enabled her to spend quality time with her mother whilst someone else managed looking after her.

If a carer can **talk to a carer who has been “through the hoop”** and or a GP who has had patients in respite that helps.

2 Talk to the experts

Ask your local Alzheimer’s Association or Carers Association, as well as other carers, about what is available locally.

Explore all options you think might be suitable. Don’t give up if it isn’t immediately successful. Try something else or persevere with your choice if you think it has potential.

The **Regional Dementia Advisory Service** - may have helpful information on respite choices available.

Local Community Services (Dementia specific) - may be of assistance.

Commonwealth Emergency Respite Service - will have useful information and guidance.

Use the Alzheimer’s body in your state or Dom Care [*South Australian Government Domiciliary Care Service*].

You will need to find them as the demand for their services is high and if you **don’t ask nobody will offer.**

3 Do your research

Check the service out personally and thoroughly before entering into any arrangement with them.

Ensure the contract and expectations of the respite service are clear and understood by all parties.

Accept responsibility for being the primary driver of what service you accept and how it will be provided. Do NOT accept compromises in a service which will not entirely suit the person with the condition (or the carer).

Ensure the cost of any services is clearly established and understood by all parties - including any entitlements to which the person with the condition or the carer may be entitled.

Finding and booking in for residential respite apparently **varies state to state**. **My husband's first respite was under emergency conditions and was a BAD experience for us both**. Organising it was confusing and frustrating which exacerbated the situation. **Now it's a matter of phoning the respite facility to check availability then phoning Commonwealth Care Link to apply for funding support**. For day centre services I rang the local support service when I learned from other carers of good services offered by them.

4 Know what you need

It is **important to find a service which will provide appropriate social activity and engagement** for the person with dementia so look carefully at what is being offered.

Also always think ahead and be planning for what might be needed in the future as both of your needs change.

Visit a few first; decide which ones you both like, and find a suitable one, then Carelink will liaise with you about vacancies.





6

Be prepared

Most of the carers I know prefer to have regular breaks booked ahead.

Timeframes vary between 2 monthly and 6 monthly and for a week to 3 weeks. We like a more flexible life BUT KNOWING that in [x] weeks I'll be having a break is always helpful.

When I was using respite you had to **book several months in advance** both to get into the place you wanted but also to make sure there was government money available.

I did find it very frustrating that **there is a government limit** and even if you were prepared to pay, the respite providers were not allowed to offer respite above the set limit.

Respite in residential care facilities has its uses but can be very confronting. I used it late on in my wife's journey, when she only had very limited understanding.

Using residential care facilities can be a very good way of finding out the quality of care and also how the person with dementia settles in. So if residential care becomes necessary then you know of a good place. That really worked for me as my wife is in an excellent home and I know she is very well cared for.

I would also mention for residential respite the need to **have all clothing named**; to check if any electrical items (toothbrush charger) need to be certified by the facility and don't forget to **advise Centrelink the recipient will not be in your care.**

It would be brilliant to have time to create a Memory Book for George to take with him. So far he can verbalise his history but as he loses his verbal skills (which is happening) that will be really important.

A gradual phasing in might be necessary. My husband was very reluctant to attend a day program for men so I went with him a few times, first just for lunch then gradually leaving him for longer.

How do you make the most of respite?

1 Trust that they are there to help

Remember that they are there to help you make sure that the services that you are offered 'fit' you and your situation. **Don't become one of those people that cleans the house before the house cleaner arrives.**

Some services may hinder more than help.

Remember the only people who know your situation and how you are coping with your situation are you.

My wife went into residential respite when it was necessary for me to travel for work.

It was a good introduction to eventually moving to full time high care.

I could not have held down my job without respite care.

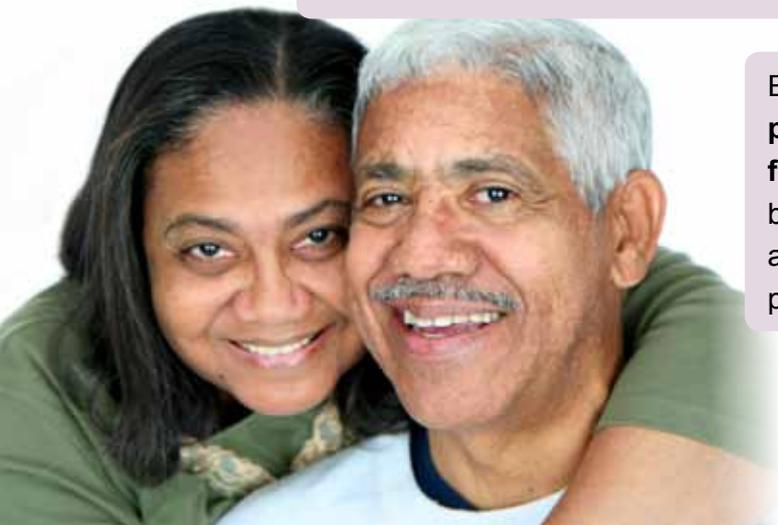
2 Communicate your needs

Any respite service should be provided in **full partnership and collaboration** with the carer and the person with the condition.

Ensure it is **tailored to the individual needs of the person with the condition**, both personally and in terms of their capacities.

Ensure it **supports and delivers normalisation and full participation** in the community for the person with the condition.

Ensure there is a **clearly established process and acceptance of responsibility for communication between all parties** before, during and after any respite, including any changes introduced by the service provider.



3 Keep in touch

Monitor the delivery and outcome(s) of any respite service you are receiving.

Review the service at very regular intervals together to ensure it is meeting the needs of both the person with the dementia and their carer.

Make a point of meeting the in-home care workers and determine if they will be a good 'fit' for your loved one.

Try to get these gems of people back every week so that your loved one isn't constantly having strangers around them at home.

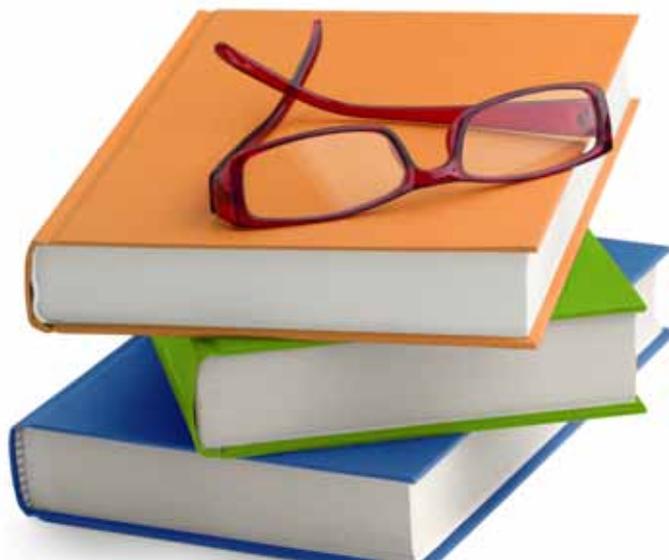
4 Allow yourself to enjoy your time

Do whatever relaxes you the most, from reading a book to going on holiday. Important thing is to recharge batteries.

Once you and the person you are caring for have a suitable respite arrangement in place, **make the most of the opportunity to do something you enjoy** and can't normally do in your caring role.

Do something which allows you to feel something other than a 'carer'.

Don't be too proud, use the support that is offered to support you both living as normal life as possible. **Use it to take some of the pressure off.**



Some other helpful hints

1 Don't forget to look after yourself

It's a long road, stay patient and **remember it is a lot harder for the person living with dementia than you.** Keep yourself well and together, it's a marathon not a 100m sprint.

Carers need counselling to know it's ok and to deal with the very strong issues of guilt, also a counsellor would have perhaps been able to tell me about services that I was unaware of.

It is hard not to feel guilty about using respite but think of it as a recharge which enables you to care for the person longer at home, which is what both parties want.

For the person with dementia in early stages, try to embrace respite as a positive challenge in every way, you will have to learn about new things and people and behaviours, which is good for the brain; and you will be helping your carer get recharged batteries.

For the Carer: make sure you have enough counselling beforehand because if you are going to feel guilty and ashamed that you are away from the person with dementia, the respite will be a total waste. You have a right to it and you have a duty of care to yourself. Even respite happens out of love and compassion for each other. Send postcards, don't phone all the time; send loving messages on pretty cards, a photo of the two of you, a bunch of flowers.

Looking after your own health and wellbeing is critical. Having appropriate respite care arrangements in place is likely to be one of the most important ways that you as a carer can remain physically and emotionally healthy.



2 Work with each other and give it time

Going into respite care does need family cooperation and mutual support:

When my mother had another stroke when visiting our family in Belgium, my sister needed to get her urgently into respite care in the UK, as my mother lived alone and about 3-4 hours drive away from my sister. My sister managed to get my mother a place in the village where she lived. ... I undertook to ring my mother each morning UK time, to try to get my mother to become more positive and accepting, and thankful to my sister.

Suggested improvements for respite

I would love to see more good quality day respite centres spread throughout the community, they seem to be as scarce as hen's teeth. Or even senior citizens centres catering for people with dementia. Likewise suitable centres for folks with younger onset dementia.

Where we lived in rural Victoria the only respite available locally was at the local hospital (a combination of acute beds and residential care beds). Because respite used one of the acute beds it could not be guaranteed i.e. it could be used only if the room was not needed for an acute patient. This made planning a time away very difficult because we didn't know until the day we wanted it, if there would be a bed available.

One time we took the person with dementia away on a short trip - when we returned in the evening his bed was no longer available as the hospital needed it for an urgent patient - even though his things were still in the room! This meant we had to make other plans on the spot. After that experience we ceased to use the respite!

In a nutshell there **needs to be a lot more information for both the carers and the care recipients** about the types, locations and costs of all forms of respite. It would be helpful if both the carer and recipient were able to visit facilities (both residential and day centres) before deciding what is needed. **Making informed decisions and choices is always better than flying blind** because you "heard" about this or that – as has been most of my experiences.

Summary

What carers told us

This guide provides the collective wisdom of carers throughout Australia. Their key messages were that **good respite care is available**, that it helps “recharge your batteries” and allows you to do the things you need to do like shopping, banking and working. Their advice about negotiating the system was to ask other carers, do your research, be prepared and maintain open communication with the respite service. Importantly, **don't be afraid to speak up** if you have concerns or if the service isn't meeting your needs.

A final piece of advice was not to feel guilty about using respite; remember, you need to maintain your own health and the ability to attend to life's necessary tasks in order to keep caring for your loved one.

Will you continue to use respite care? When asked this question, **over 90% of carers in the DCRC Respite Survey said “yes”.**

The reasons given for this were:

- It worked for them
- It helped keep the person with dementia at home longer
- It enabled the carer to keep caring
- The carer could see benefits for the person with dementia
- ... and if the need arose they would use more.



Some helpful contacts

If you want to explore the respite care options available to you, here are some contacts and resources that will help you get started.

Alzheimer's Australia

Online:

<https://fightdementia.org.au/support-and-services/families-and-friends/taking-care-of-yourself/using-respite-care>

National Dementia Helpline:

1800 100 500

My Aged Care

Online:

<http://www.myagedcare.gov.au/respite-care>

<http://www.myagedcare.gov.au/aged-care-services/national-respite-carers-program>

Free Call:

1800 200 422

Commonwealth Respite & Carelink Centre

Online:

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

Free Call:

1800 052 222

Health Direct Australia

Online:

<http://www.healthdirect.gov.au/#!/respite-care>

Free Call:

1800 022 222

Commonwealth Carer Resource Centre

Free Call:

1800 242 636

Home Care Packages

Online:

<http://www.myagedcare.gov.au/home-care-packages>

Please give us your feedback

Thank you for taking the time to read this guide, we hope that you have enjoyed reading stories from carers like you. In order to keep improving our products, we would greatly appreciate your feedback.

To provide us with your evaluation and suggestions, please go to the following link:
<http://www.dementiaresearch.org.au/>

Alternatively, you can send us an email at the following address: dcrc@qut.edu.au





Queensland University
of Technology