

7. For carers

These pages may be helpful to people, including family members and partners, who provide paid or unpaid care and support to a person ageing with a brain injury.

What it might mean to care for someone ageing with a brain injury

As a carer and/or family member of someone growing older with a brain injury, you play an important and often undervalued role in helping them participate fully in life. As the person you are caring for gets older, you may notice that their health care and support needs are growing and you may start to provide more and more 'informal' (unpaid) care and support. You may also be ageing yourself so providing care is not as easy as it used to be.

It is important that you ask for help from health professionals and support organisations if things are getting to be too much. As well as accessing additional paid support in the home and/or respite care (see section on respite care), there are other strategies that may help you care for someone ageing with a brain injury.

Strategies to help you care for someone ageing with a brain injury

- **Try to encourage independence.** Although it may seem quicker and easier to do things for the person with a brain injury, letting them do what they can will help them maintain and improve their level of function and make them feel better about themselves too.
- **Stay informed about brain injuries and the potential effects.** This will help you understand different behaviours and issues that you observe, making you better able to manage them. Talk to their doctor, look online, or access support groups (see the next section).
- **Write things down.** It's easy to forget what doctors and other health professionals may tell you about the health of the person with a brain injury, so having everything recorded in one place is a great strategy, such as in a notebook, folder or in a computer file.
- **Record progress.** Recovery following a brain injury can be very slow, leading you both to feel discouraged at times. However, keep track of the goal attainment and progress that the person with a brain injury is making, as this can help you both stay motivated to stick with rehabilitation strategies.



- **To help you (and the person you are caring for) remember things at home**, it might be a good idea to write things down in a place where you can both see it easily, such as on sticky notes, a whiteboard or calendar. This can be helpful for remembering appointments and scheduled activities, as well as with “what to do” guideline actions around the home. This could help reduce your workload and help the person you are caring for be more independent
- **Be patient.** A brain injury can cause a range of personality and cognitive changes. You may find that the person you care for is different from before their brain injury and this may also change as they age. Try to stay calm and don't react. They might be in pain or very tired and just need some time alone. When you speak, do so slowly and clearly. If they don't understand, move on to another topic.
- **Take a break.** Caring for someone with a brain injury can be very tiring. Be good to yourself. Ask someone to take over for a while so you can rest and do something you enjoy (see the next section on caring for yourself on *page 39*).

Preparing for the future

If you are also experiencing the effects of ageing, you may be worried about what will happen if you are no longer able to continue providing care to the person with brain injury. It is important that you have mechanisms in place to ensure that both yourself and the person with a brain injury receive the care and support you each need. You might consider having an official:

- Enduring Power of Attorney
- Advance care directive
- Emergency care plan

To find out more about these options and others, please see the section on legal options on *page 33*, which may be relevant to both yourself and the person you care for.



Caring for yourself as a carer

Taking care of yourself while taking care of someone with a brain injury can feel like too much sometimes. Caring for someone can make you feel tired, stressed, and like you're in over your head, especially if you've been doing it for a long time. As the person you're caring for gets older and needs more help, you, as a carer (someone who helps without necessarily getting paid), might start feeling overwhelmed.

When you start feeling like this, it's important to ask for help from professionals. Going to see a supportive GP is a good first step. They can recommend other experts or organisations who can help make caring for your loved one easier. For example, these people can teach you ways to deal with difficult behaviours, and they can also help you take care of your own health.

A GP might also suggest you talk to a counsellor or psychologist if caring makes you feel down, overwhelmed, anxious or sad.

It's also important for you to have your own GP and health team, separate from the person you're caring for.

Sometimes, you might feel like your own needs aren't as important as the person you are caring for. But it's crucial for a carer to take care of themselves too. You can do this by finding your own separate and uninterrupted time every day, like going for a walk, doing something you enjoy, or spending time with friends on a regular basis.

Perhaps start by looking at your schedules for the week. For example, if the person you care for does a leisure activity in the community every week, that could be a good time for you to take a break. Even just a few hours away can make a big difference to your health and happiness.

Support groups

Support groups can also be really helpful for some people. These are places where people who are going through similar things can talk to each other about their challenges and share ideas. Being in a support group can help you feel less alone and give you a chance to make friends with people who understand what you're going through. Some support groups also run fun activities for carers, such as organised walks and movie days. There are even support groups specifically for people caring for someone with a brain injury. For example:

- Synapse is one organisation that runs support groups for carers of people with a brain injury. You can find both in-person and online groups here: <https://synapse.org.au/community-hub/carers-and-family>.
- You can also check out other brain injury organisations and services listed in the 'Organisations' section (see page 71), as many of them offer support groups too.

Where to get help

The Australian Government's Carer Gateway.

This is a program providing free services and support for carers: <https://carergateway.gov.au>

Carers Australia. This is the national peak body representing Australia's unpaid carers: <https://carersaustralia.com.au>

Young Carers Network (YCN). The YCN is an initiative of Carers Australia. It is a nationally coordinated resource to raise young carer awareness, provide information, and direct young carers to appropriate pathways for support: <https://youngcarersnetwork.com.au>

There are also Carers organisations in each state and territory:

- ACT <https://carersact.org.au> 02 6296 9900
- NSW <https://carersnsw.org.au> 02 9280 4744
- NT <https://carersnt.asn.au> 1800 422 737
- QLD <https://carersqld.com.au> 1300 747 636
- SA <https://carerssa.com.au> 08 8291 5600
- TAS <https://carerstas.org> 03 6144 3700
- VIC <https://carersvictoria.org.au> 1800 514 845
- WA <https://carerswa.asn.au> 1800 227 377



Respite care or short-term accommodation

What is respite care?

Respite care is when someone else temporarily takes care of the person with a brain injury for you for a little while. This could be a paid person or someone offering help for free. Respite care can happen at home, at community centres, or at places where they can stay overnight or for a few days. Sometimes, a friend or family member might help out, or there might be services available specifically for respite care, like short-term housing or organisations providing short term care in the community. The time for respite care can be as short as a few hours or as long as a week or more. It can be planned regularly, just once, or in an emergency, like when you get sick.



Why use respite care?

Taking care of someone with a brain injury can be a lot of work. That's why it's important for both the person with a brain injury and yourself to plan breaks from your caring duties. Even if you don't need respite care right now, it's smart to be proactive and learn about what options are out there that might be right for you. You never know when you might need it or how quickly you might need it, so it's good to be prepared. Although people's routines can be disrupted when they are away from home, respite care may still be worthwhile.

How do I access respite care?

First, it's crucial to know what options are available to you for funding respite care or short-term accommodation. Below are some funding schemes that may be available to you, providing you qualify:

The National Disability Insurance Scheme (NDIS)

NDIS can provide funding for short-term accommodation or respite care. Here is their guide for you to read: <https://ourguidelines.ndis.gov.au/supports-you-can-access-menu/home-and-living-supports/short-term-accommodation-or-respite/what-short-term-accommodation-including-respite>.

The following resource provides tips on how to access funding from the NDIS for respite care: <https://carersvictoria.org.au/media/2293/2078-give-us-a-break-tips-for-accessing-respite-ndis-flyer.pdf>

My Aged Care

My Aged Care may be able to provide respite care if you qualify. For how to access respite care through My Aged Care, go to: <https://myagedcare.gov.au/short-term-care/respite-care>

Other funders

Respite care may be funded by injury compensation schemes if you qualify (such as the Transport Accident Commission in Victoria or icare NSW), private health insurance companies, local councils, and the Department of Veterans' Affairs (DVA): <https://dva.gov.au/get-support/health-support/care-home-or-aged-care/services-support-you-home/respite-care>

Community programs or organisations

You can also check out what local disability organisations or local community programs might offer to support you and the person with a brain injury. They might have social events, support from peers who understand what you're going through, group therapy, or outings in the community. It's worth looking into this to see what's available near you. Your local council may be able to assist you in finding locally run programs.

If you cannot access any funding?

If you cannot get any funding for respite care, you may need to think about ways to plan and schedule it without spending too much money. One option could be to ask your family and friends and also perhaps local community groups to help you out. Or you might need to consider paying for some support at home yourself.

Emergency respite care

If you can't be there to care for someone due to illness or something else unexpected, you might need emergency respite care. If this happens you can start by checking out the Carer Gateway website: <https://carergateway.gov.au/what-respite>

You can also call them anytime at 1800 422 737. They can talk to you about your options and perhaps may be able to help you arrange emergency respite care if it's available.

It's also a good idea to have an emergency care plan ready just in case. This plan should have important information like emergency contacts, medications, any special equipment needed, the care needs of the person with a brain injury, and even completed hospital admission forms with the person's medical history filled in. You can use this template to make your own emergency care plan: <https://carergateway.gov.au/sites/default/files/documents/2019-04/emergency-care-plan.pdf>

