



Australian Government

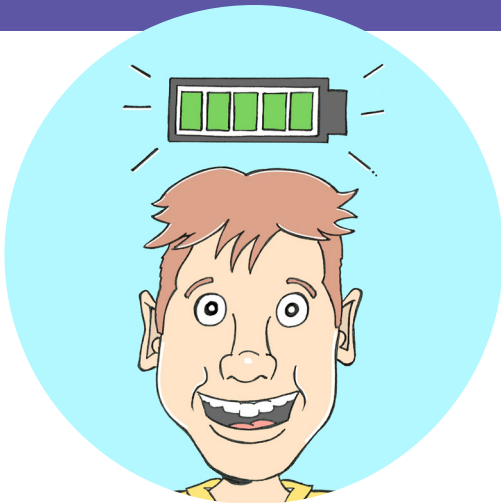


## Carer Skills 3

# Recharge and reconnect



How long will it take?  
20 to 40 minutes



### Learning outcomes

In doing this module you will:

- ✓ gain a better understanding of the importance of regularly recharging and reconnecting
- ✓ learn how to deal with negative feelings such as guilt
- ✓ create your care team
- ✓ develop a recharging and reconnecting plan
- ✓ commit to putting your plan into action

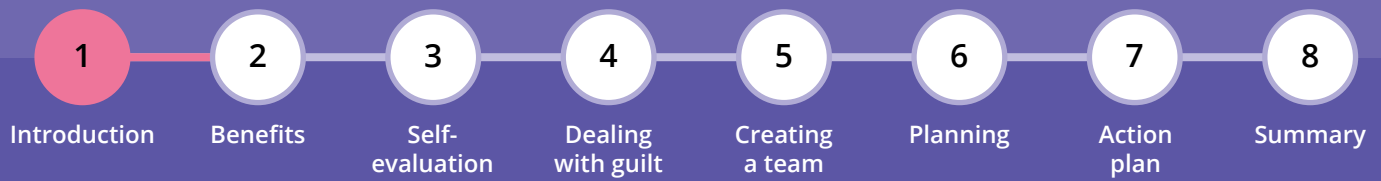


### Your wellbeing is important to us.

If you find talking about your experience as a carer upsetting, you may want to talk to someone.

Lifeline **13 11 14** and beyondblue **1300 22 4636** are two services that are both available 24 hours / 7 days a week if you need support.

# Introduction



*There is virtue in work and there is virtue in rest. Use both and overlook neither – Alan Cohen*

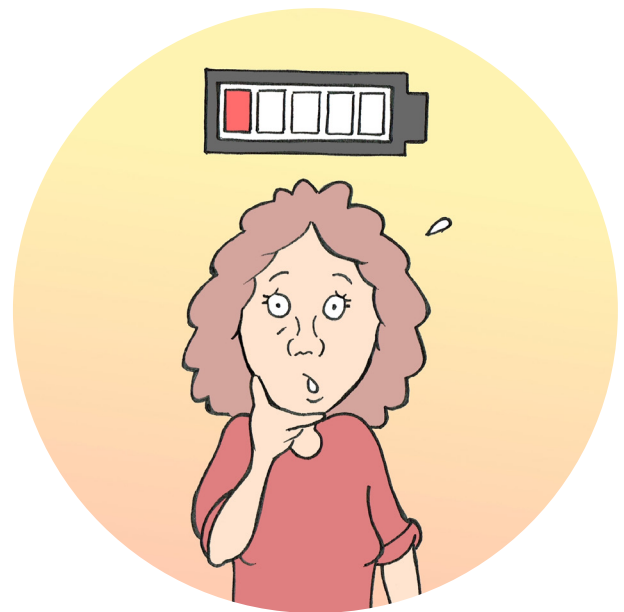
Carers lead busy lives with lots of responsibilities, and most find it difficult to find time to recharge and reconnect. For many carers, this busy life can, over time, become normalised. But it's important to make time to rest, reflect and do activities you enjoy because it will help you sustain your health, wellbeing and caring role.

Recharging is time you set aside for yourself to rest and relax so that you feel energised again.

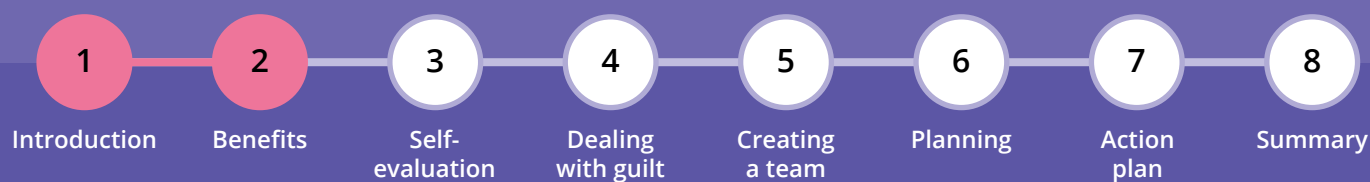
Reconnecting can mean reflecting on the relationships, talents, hobbies and interests you had prior to your caring role and could provide ideas for ways to take part in these activities and meet new people.

Recharging and reconnecting doesn't have to be about going away or involve a big expense. It could be as easy as spending 10 minutes sitting quietly in your garden, calling a family member or catching up with a friend.

This module will remind you how important it is to regularly take time to do this.



# Benefits of recharging and reconnecting



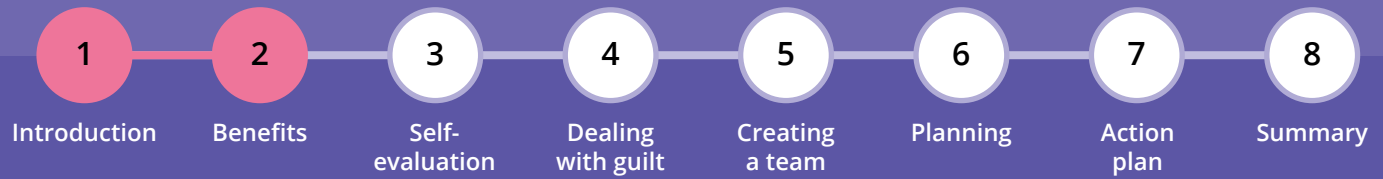
*Sometimes you have to take a break from the grind, clear your mind and enjoy some "me" time*  
– Merissa V Grayson

When you take a break from your normal responsibilities, where you may be constantly in a hurry, it is like pressing a reset button for both your mind and body. You feel rejuvenated, fresh and ready to tackle all that life has to offer again.

The table below lists the benefits of 'recharging your batteries' and the costs of neglecting to do this.

Benefits of recharging and reconnecting	Costs of not recharging and reconnecting
<ol style="list-style-type: none"><li>1. improved physical and emotional health and wellbeing for both you and the person you care for</li><li>2. stronger relationships with family, friends, your community and the person you care for</li><li>3. improved quality of life because you get the opportunity to do things you enjoy and find rewarding</li><li>4. rest and relaxation</li><li>5. improved sleep, clarity with daily planning and decision making</li></ol>	<ol style="list-style-type: none"><li>1. poor physical and emotional health</li><li>2. exhaustion</li><li>3. burnout</li><li>4. resentment and conflict</li><li>5. strained relationships</li><li>6. negative emotions such as anger, frustration, hopelessness and despair</li></ol>

# Benefits of recharging and reconnecting

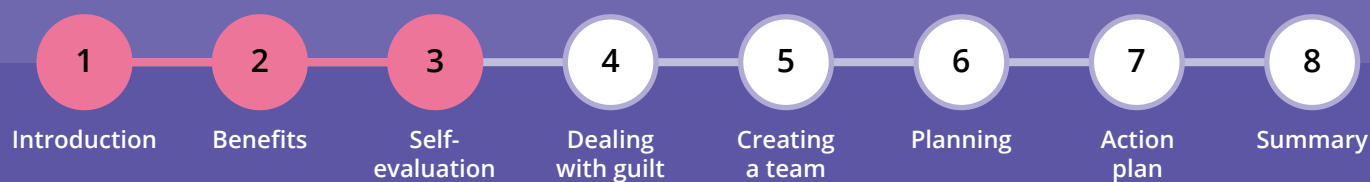


*I've only been a carer for a short time, but I can already see that I'm feeling the toll on my physical and emotional health. At the end of the day I have nothing left in the tank for me. I'm looking forward to learning more about how to recharge and reconnect.*

**Jessica (37)** lives in a remote community and is a carer to her friend, **Cathy (63)**, who lives with heart disease, retinopathy and an amputation.



# Do I need to recharge and reconnect?



**“ If you're running on fumes, you get to a point of diminishing results. Get some rest – Chuck Pagano**

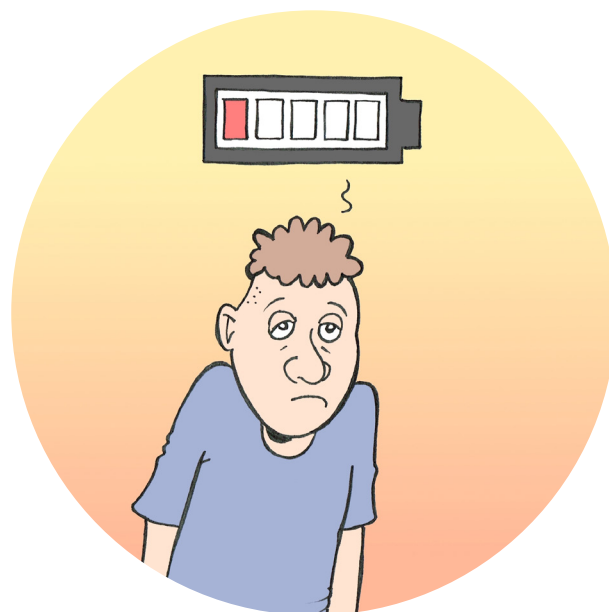
Many carers are stuck in a cycle of busy days and restless nights. The days and weeks speed by and before you realise it you can't remember the last time you got a full night's sleep, ate a relaxed meal or did something you enjoy. If this is your life, it can lead to stress and 'carer burnout'.

Answer the questions below to determine how useful you might find this module:

- Are you feeling run down, or experiencing frequent illness or other symptoms that you can't account for?
- Are you becoming more impatient with the person you care for and other family members?
- Are you feeling more sad, angry, exhausted or reactive than you used to be?
- Are you feeling stressed, anxious, worried or depressed?
- Do you feel trapped, resentful or that your situation seems hopeless?

- Are there activities you no longer do which you used to enjoy in your free time?
- Is it difficult, uncharacteristic or unlikely that you will ask for help?

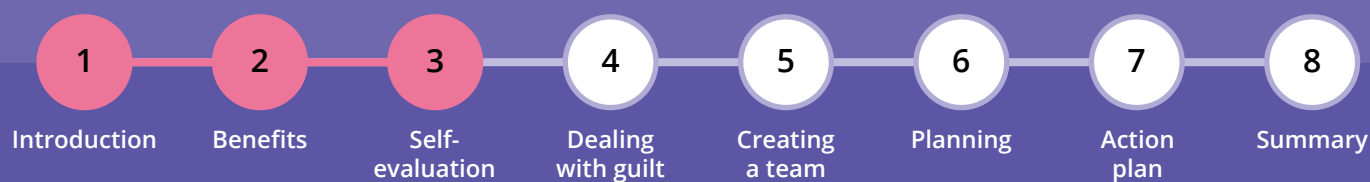
If you answered yes to one or more of these questions you could benefit from doing this module.



*The kids mentioned it some time ago ... but I'm only just seeing how stressed I am. I know that I am run down, and it's hard to find the time to do anything for me. I definitely need some help and tips on how to recharge...*

**Mary (57), carer to her husband with MS and her father-in-law with dementia.**

# Why don't I recharge and reconnect?



*Almost everything will work again if you unplug it for a few minutes... including you – Anne Lamott*

There are many reasons why carers find it difficult to recharge and reconnect, including that you:

- put your own health and wellbeing last
- feel recharging and reconnecting is not deserved
- are too tired to make the effort
- feel it's all too much trouble
- believe it's your responsibility to provide all the care, all the time
- feel guilty that you aren't coping
- are concerned people will think you aren't coping if you take time to recharge and reconnect

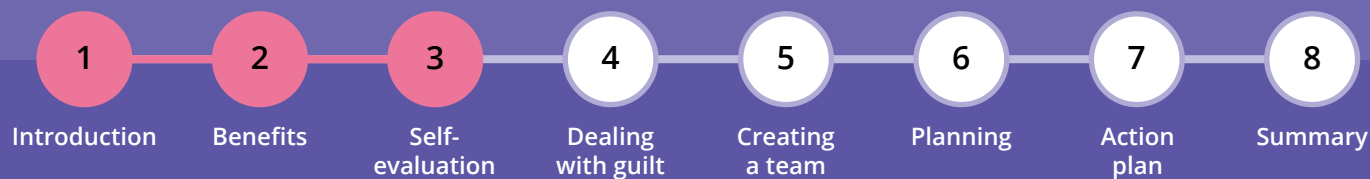
Regularly recharging and reconnecting can be difficult. For example, when:

- family and friends may not understand that you need support
- the person you care for doesn't want you to have time for yourself or want outside support
- the demands of other family members make it difficult for you to have any time for yourself

Finding alternate care services can be challenging. For example:

- you do not know which services are available, or how to get help organising them
- there is a lack of respite services in your area
- the costs of some types of respite could be outside your budget
- you have concerns about the quality of some types of care

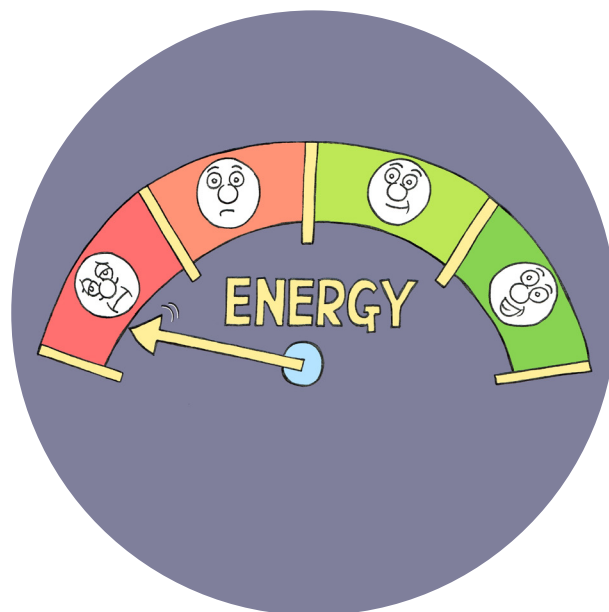
# Why don't I recharge and reconnect?



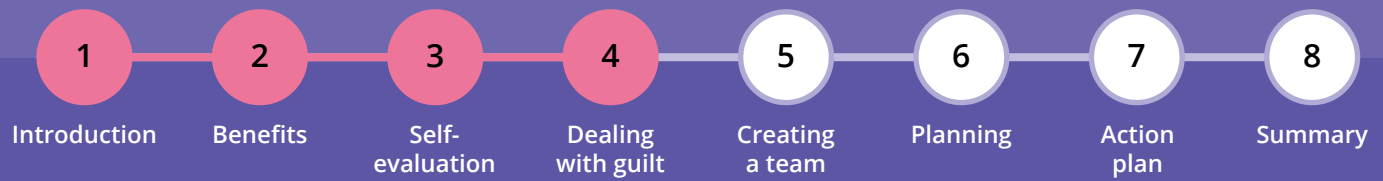
*When I took over Liz's care, we lost most of the services that were involved with helping her. Every service had the same story – they were only funded to support my parents as aged carers. Trouble was that Liz had built a routine she was comfortable with and it was hard to transition her because she didn't want anything to change.*

*I felt like I had no choice but to do as much as I could for Liz to make up for all that she was losing. As a result, life is just extra busy these days – between working for my children and caring for Liz, I just don't find the time for me anymore.*

**Megan (44), mother of two, working full-time and as a carer to her sister Liz (43) who has Down Syndrome.**



# Dealing with guilt and other negative feelings



*To deliver your best you need some rest – Ragavendra Vignesh*

Caring for someone is rewarding but doing it by yourself can be tiring.

Many carers struggle to ask for support or to accept it when it's offered.

Getting support with caregiving can feel uncomfortable and some carers say they feel:

- **guilty** for not doing everything themselves
- **fear** that something could go wrong when someone else cares for their loved one – as well as a lack of trust
- **undeserving** – feeling they don't deserve support and that they're supposed to do it all themselves

The first step is to recognise you're having these feelings. The second step is to work through your feelings rather than continuing to be overworked and stressed.

- Ease your guilt by reminding yourself that:
  - while feeling guilty is normal, it is not helpful so practice letting go of these feelings
  - having time for yourself is not only good for you, but it is good for the person you care for since it gives them a break and opportunities to socialise and have new experiences

- Deal with your fear and lack of trust by:
  - developing a **care plan** to help your paid carer, or family, care for your loved one in your absence
  - carefully choosing the respite arrangements
  - starting small by having short breaks until the respite arrangements are well bedded down
- Overcome your negative feelings by talking to a friend, another carer or counsellor.

If you want to continue caring for your loved one it is essential that you:

- prioritise your own health and wellbeing, not just the health and wellbeing of the person you care for
- make the effort to regularly recharge and reconnect.

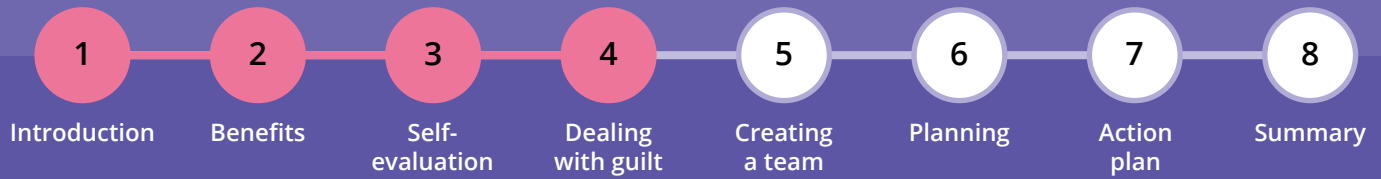
Recharging and reconnecting will help you:

- keep in perspective your needs and the needs of the person you care for
- remain healthy
- feel more rewarded by your caring role

It will also make your caring more sustainable in the long term.



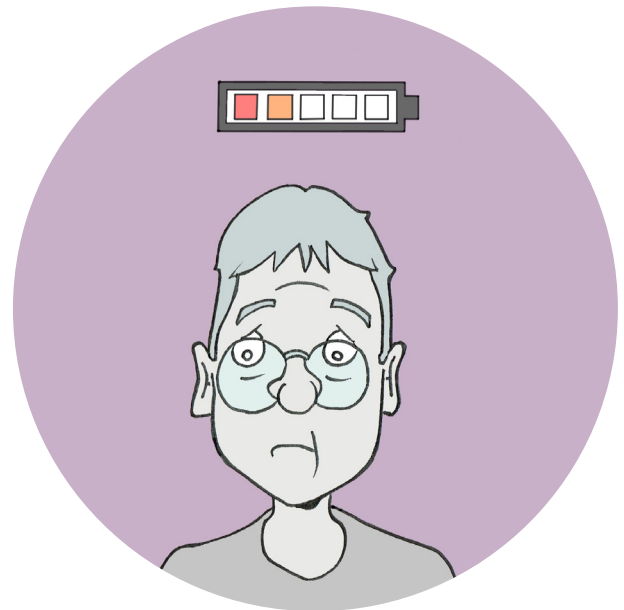
# Dealing with guilt and other negative feelings



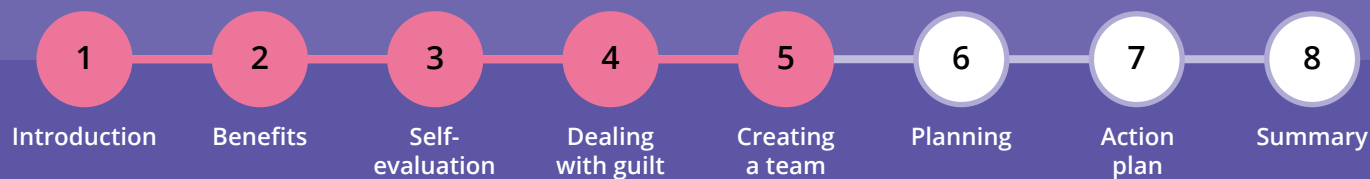
*Before the accident, Nancy did everything ... she raised the kids, she took care of the house and she worked full-time. I'm trying my best to do what she would do, which is put her head down and get on with it without any complaints.*

*Sometimes I can't help but think that retirement was meant to be my time. Reading this module has helped me see that I shouldn't get caught up feeling guilty about wanting to recharge and reconnect.*

**Tom (67), carer to his wife, Nancy (60), who lives with a spinal cord injury.**



# Creating your care team



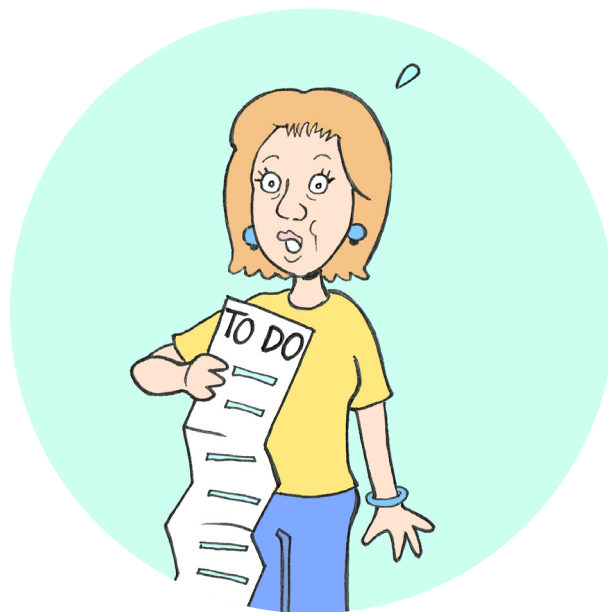
**“ Alone we can do so little, together we can do so much – Helen Keller**

Caring shouldn't be a one-person show. Creating a care team for you and the person you care for will benefit you both as well as be a rewarding experience for all members of your team.

Often people don't offer support because:

- from the outside, it looks like you've got everything under control
- they don't know how to help
- they may be scared of doing a bad job

The first step is to develop a 'job list' of tasks and activities which other people can do, and to keep the list up to date. Then use the template below to build your care team. You might be surprised by how much potential support there is around you and the person you care for.



**i** *It's a work in progress, but I've made a list of things that dad needs help with and have tried to organise more people to help.*

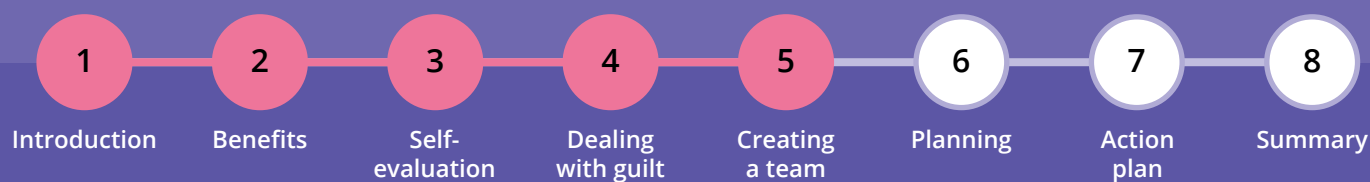
*I've built an online calendar for us all to use so we can see when dad needs help. Being an online calendar, everyone can see where they can help and, most importantly, dad knows who and what to expect every day.*

*I've also set up a transport service to help get dad out and about, and "Meals on Wheels" to deliver meals to his home.*

*I'm hoping that with all of this set up, dad might be able to continue living independently and I get some time back to get on with my life – fingers crossed!*

**Renee (22), carer to her father (48), who has schizophrenia.**

# Creating your care team



## Family members

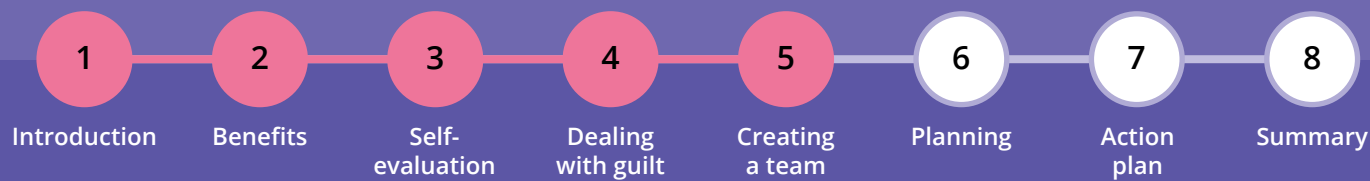
Family members can be a great back-up. Think about which members of your extended family could help. You could ask them to do a specific task on your job list. For example, spending time with your loved one while you have coffee with a friend or taking your loved one on an outing while you have some time to yourself.

Even family members who live a long way away can contribute, for example by making medical appointments, regularly contacting your loved one (via telephone or video conferencing), paying bills electronically etc.

*List the family members you will ask for support along with a task or activity.*

Family member	Task/activity	Frequency

# Creating your care team



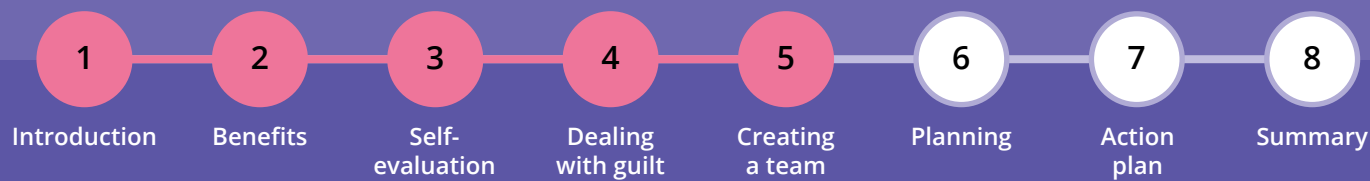
## Friends

Your friends and the friends of the person you care for may be able to help. You could ask a friend to do a task and see how the request is received.

*List the friends that you can approach together with a suggested task or activity.*

Friend	Task/activity	Frequency

# Creating your care team



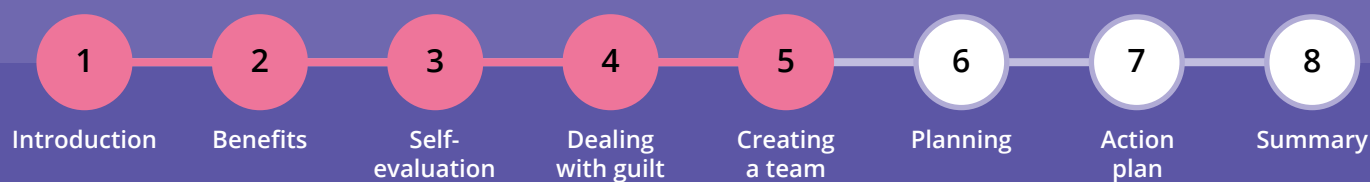
## Neighbours

Neighbours can be a good source of support. Perhaps you can do something for a neighbour in return for some help with caring.

*List the neighbours you think have capacity together with a suggested task or activity for each person.*

Neighbour	Task/activity	Frequency

# Creating your care team



## Other options

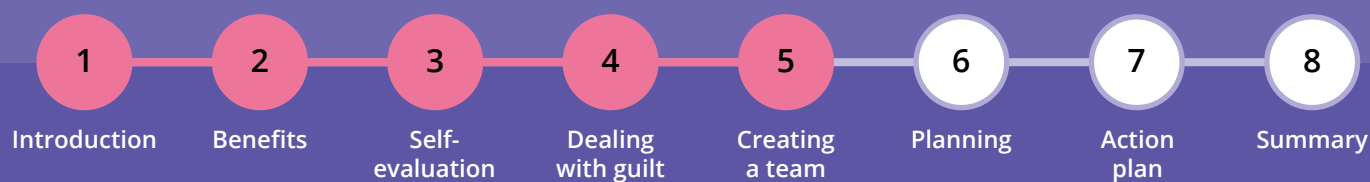
Other carers and peer support groups can be a great source of support because they are in a similar situation to you. Depending on the circumstances, you could swap care or do odd jobs for each other. List the other carers you know who might be in a position to help.

Faith-based or social groups and clubs are another potential source of support.

*Think about the various groups of people that you and the person you care for are involved with who might be able to help and list them below.*

Person/organisation	Task/activity	Frequency

# Creating your care team



## Paid in-home and out-of-home care

The following types of respite services are available:

- in-home respite
- centre-based respite
- community access respite
- residential respite care

Respite care can be flexible, based on individual needs, and is also available in an emergency through the Commonwealth Respite and Carelink Centres.

The costs of these services will depend on your circumstances and those of the person you care for. Further information about these types of care is available under **"Additional resources" on page 28.**

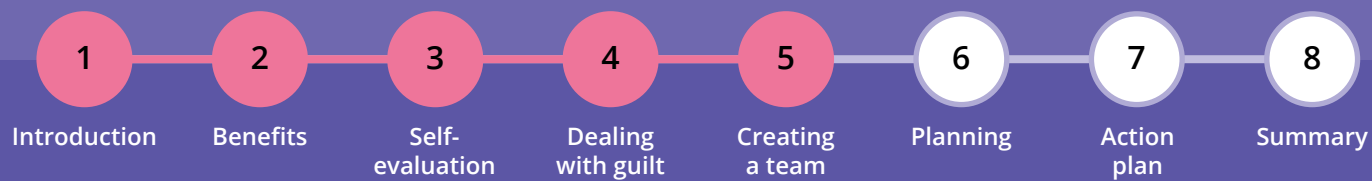
Depending on your circumstances and those of the person you care for, you could be eligible for:

- transport – taking the person you care for to and from appointments or on social outings
- domestic support – housework, personal care, gardening, odd jobs or repairs
- food services – shopping, food preparation or providing pre-cooked meals

Further information about these types of care is available under **"Additional resources" on page 28.**



# Creating your care team

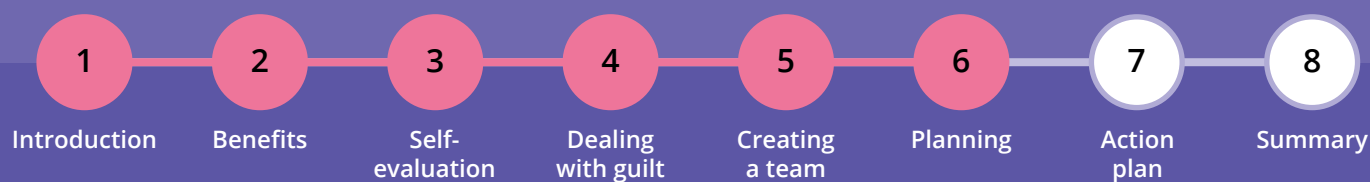


*Once you have worked out which options apply to your circumstances, list them below.*

Person/organisation	Task/activity	Frequency



# Planning for emergencies



**Take rest. A field that has rested gives a bountiful crop – Ovid**

Most carers fret about what will happen to their loved one if they get sick, or they are injured or unexpectedly called away. Things have a habit of happening when you least expect.

Having a pre-prepared emergency care plan will give you peace of mind.

The Carer Gateway website has the following resources for emergency care:

- [emergency respite](#)
- [planning for an emergency situation](#)
- [planning for an emergency \(video\)](#)



You can order an [emergency care kit](#) from Carer Gateway. Once you have completed your emergency care plan give copies of it to:

- at least one other member of your family or to a close friend
- your doctor (GP)
- support workers
- anyone else who should know what to do if you are suddenly unable to continue caring

It may be useful to upload a copy of the plan to your own, and the person you care for's eHealth record.

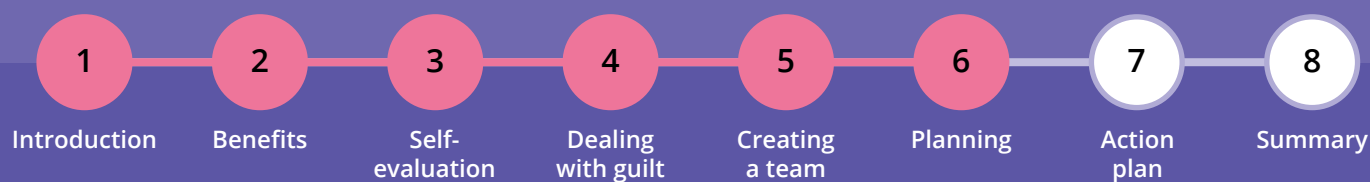
When you and the person you care for travel, make sure you take a copy of your emergency care plan with you.

The emergency care kit includes a Carer Emergency Card which you can complete and keep in your wallet so people know you care for someone. The card contains the contact details of people who have your emergency care plan.

*I know neither of us is getting any younger and I think it's a good idea to have a plan for emergencies. So ... with Sue's help I've made a list of people she is comfortable with who could help out in an emergency.*

**James (70) lives in a rural area and is a carer to his wife, Sue (68), who experienced a stroke last year.**

# Recharge and reconnect throughout the day



*Taking time out each day to relax and renew is essential to living well – Judith Hanson Lasater*

Research shows that regularly recharging throughout the day not only improves your health and wellbeing but also your productivity. The recharge doesn't need to be long, even a 5-minute recharge can work wonders.

Regular recharging can:

- improve focus and increase motivation
- boost creativity and decision making
- provide the opportunity to step back and see things from a different perspective, which can lead to better choices
- reduce stress
- help maintain interest and energy levels
- provide a chance to refuel
- help you be more efficient after you recharge

Recharging can also:

- be used to avoid burnout and feeling like you are at the end of your tether
- reduce the “boring factor” of mundane tasks
- be used to break down big tasks into smaller, shorter tasks
- decrease your risk of injury

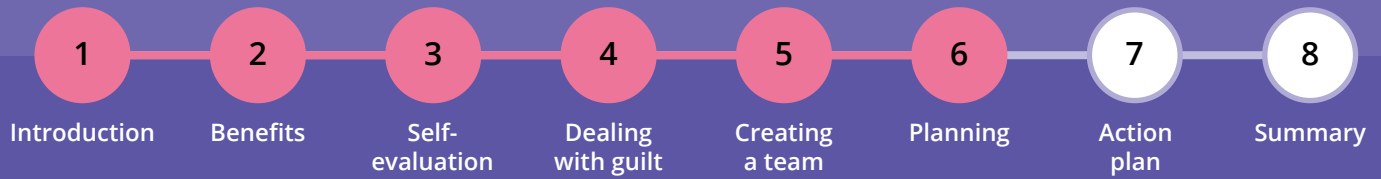
Including recharging into your busy life can be difficult. To make it easier to remember, you can:

- use an automatic reminder on your smartphone or watch
- use a time-tracking app
- schedule regular reminders in your diary or calendar

During your recharge you can:

- have a snack or take a coffee/tea break
- go outside and spend 5 minutes in the sunshine
- stretch, do some yoga or breathing exercises (to relax or energise, depending on how you want to feel)
- listen to a podcast, read an interesting article or watch something funny
- call a family member or friend
- play with your pet or go for a walk

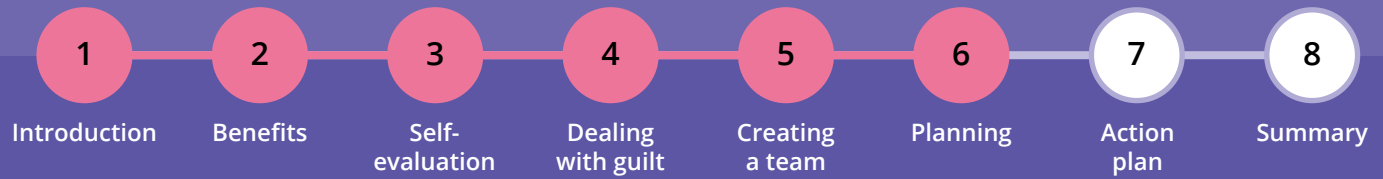
# Recharge and reconnect throughout the day



*Use the template to plan your recharges throughout the day. Decide how long each recharge will be, how often you will recharge, when you will recharge and what you will do during your recharge.*

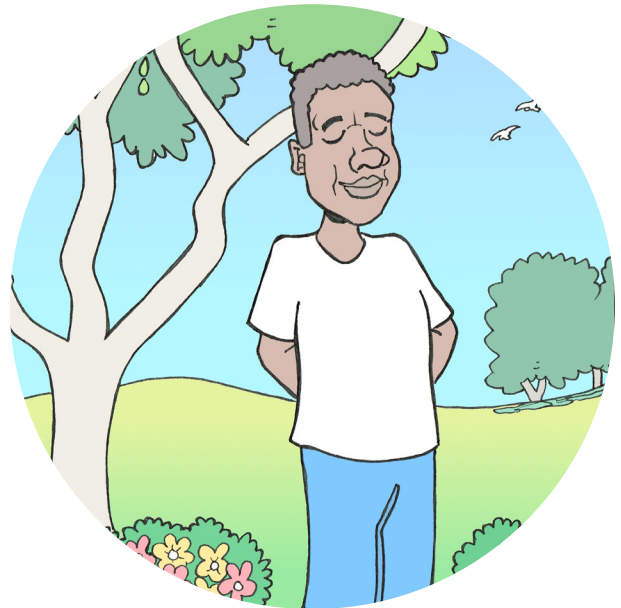
Morning time	Morning activity	Afternoon /evening time	Afternoon/ evening activity

# Recharge and reconnect throughout the day

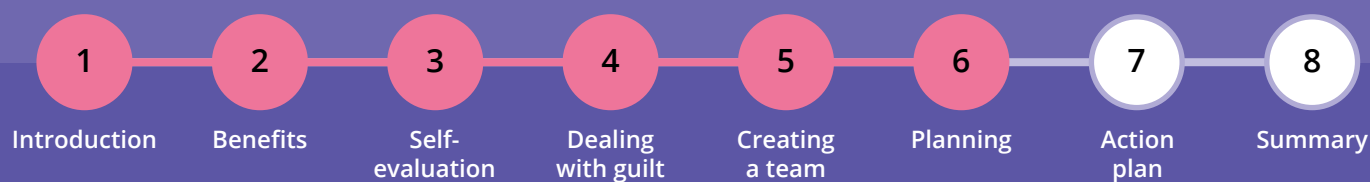


*Lily helped me set up reminders on my phone. Now I have automatic reminders to schedule regular exercise, catch ups with friends and time to read over these modules to make sure I am practising the skills.*

**Cheryl (56), carer and parent to both her son, Daniel (33), who abuses substances, and daughter Lily (29), who has generalised anxiety disorder.**



# Recharging and reconnecting for the long term



*The greatest gift that you can give yourself is a little bit of your own attention*  
– Anthony J D'Angelo

If you continue providing care without regularly having longer recharges, over time you run the risk of becoming increasingly ineffective, frustrated and stressed.

There is never a perfect time to recharge because there is always something to do, instead of taking care of yourself and accepting that well-deserved time for yourself. It is important to get into the habit of scheduling recharging before you need it.

No two caring situations are alike so only you will know what type of recharge is best for you and how often you need it. Try to have a range of breaks including:

- a couple of hours each week
- a day here and there
- occasional weekends
- a week or two for a holiday

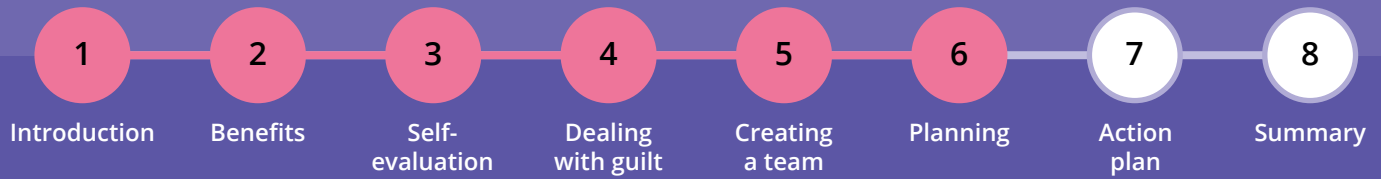
While you are thinking about what might work best for you and the person you care for, have a think about what you might want to do with the time. You could:

- join the patchworking, cooking or chocolate making class you've been interested in
- become a member of a social club – for example fishing or a Men's Shed
- attend a special family event
- visit family or friends interstate
- go on a holiday or have a holiday at home

If possible, involve the person you care for in the planning. If they feel anxious, angry or confused about why you need to recharge and reconnect, reassure them that it will be good for them too. It will give them:

- an opportunity to meet new people
- opportunities to experience new activities
- memories to look back on
- something to look forward to
- a change of scenery
- a good feeling because you are happier and have more energy

# Recharging and reconnecting for the long term



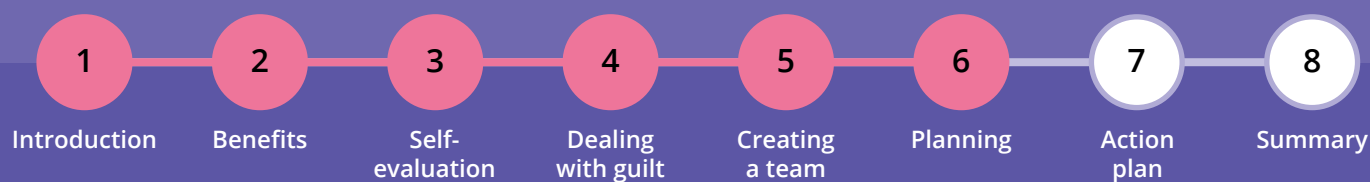
*Use the template below to plan your **weekly** recharging. You may find regular commitments can be easier to organise.*

Day/time	Activity	Replacement care

*Use the template below to plan your **whole day and weekend** recharging*

Day/time	Activity	Replacement care

# Recharging and reconnecting for the long term



Use the template below to plan your *one or two week* recharging.

Day/time	Activity	Replacement care



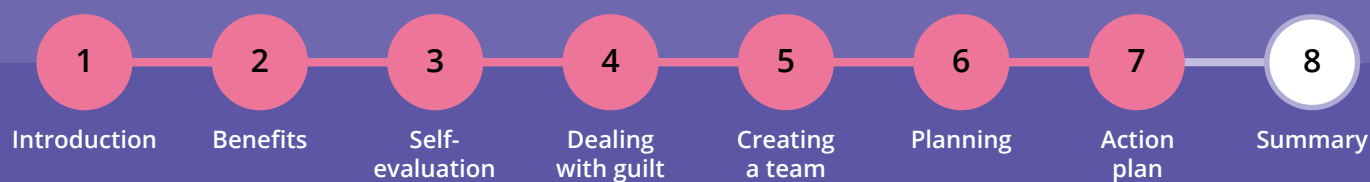
*Irene and I used the templates to help us make plans for how we can both recharge and reconnect with Alice, our other kids and with each other. At first, I was sceptical ... I wasn't convinced that doing this would be worth our time ... but I was wrong.*

*We now have confirmation of our respite arrangements for the next 6 months ... just knowing that we have some planned breaks coming up is a big relief.*

**Jack (42) and Irene (40), parents to 3 children, including Alice (7) who lives with autism.**



# Building your recharge and reconnect plan



**“ The key is not to prioritise what’s on your schedule, but to schedule your priorities – Stephen Covey**

You have identified your care team and planned your regular short recharges throughout the day and longer recharges throughout the year.

*Use the template below to develop your recharge and reconnect plan.*

## Step 1 – Talk to the family, friends neighbours and others you have identified as having the capacity to support you.

You may want to get some tips from the [“Effective communication techniques” module](#) before you do this. A resource has been developed for how family and friends can help.

## Step 2 – Arrange the paid in-home and out-of-home care you identified in other options.

These services, especially respite in residential aged care facilities, can sometimes have waiting lists so it is best to book early.

## Step 3 – Put together a care plan, including a daily activity sheet for your loved one.

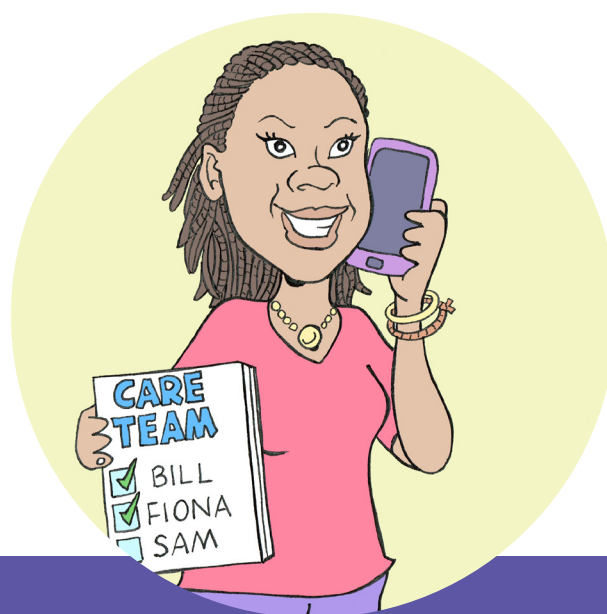
A template is included in the [resources](#) – if possible, do this with the person you care for.

## Step 4 – Prepare the person you care for.

It is best to include the person you care for at each stage but this is not always possible. Talk about the arrangements together. Try to be calm and cheerful. Be understanding if they are anxious or reluctant.

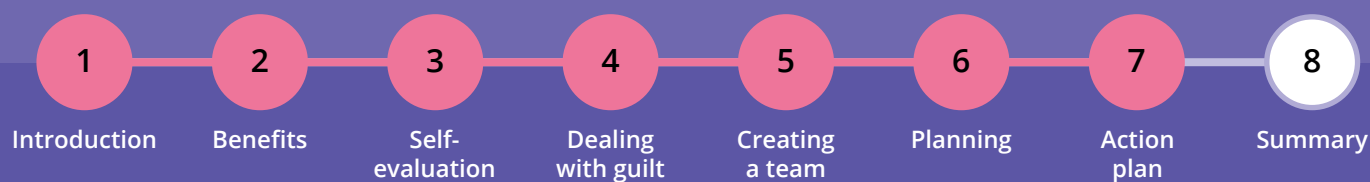
It may be difficult for the person you care for to adjust to receiving care from someone they don’t know. Give lots of reassurance and encouragement.

Involve other family members if you can. Explain that you have put together a care plan for the person you care for which includes their routines, medications etc.





# Building your recharge and reconnect plan



## Impact on Centrelink carer payments

You can have up to 63 days of respite from your caring role each calendar year without affecting your carer payment or carer allowance from Centrelink. If you exceed 63 days, contact Centrelink to discuss your particular circumstances.

## Enjoy your recharge

To begin with, you may find it hard to leave the person you care for. Stay calm and try not to draw out the goodbyes. Remind yourself about the benefits for you and the person you care for.

While you're away, try to switch off, recharge and reconnect.

## Review your plan

After your recharge, review your plan. Have a think about how the arrangements worked, for you and the person you care for. You may need to refine your plan for next time. Involve the person you care for in the review and deal with any problems together.

Remember that other people may do things differently. This doesn't mean their way is wrong, it could be good for the person you care for to experience different ways of caring.

If the care arrangements didn't work out, look for an alternative. Don't give up.



*The last two years with Ivy have been really challenging. I love her like family and want to do everything I can to help her ... but as her health deteriorates, I have been finding it more and more challenging to care for her in my home.*

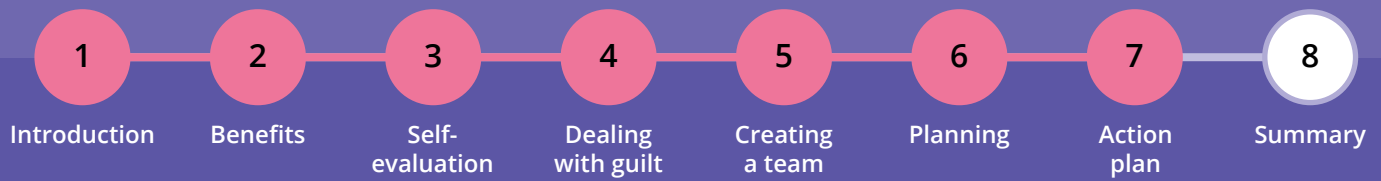
*My husband, Rob, is supportive, but he thinks that I'm burning the candle at too many ends and he's worried I'm starting to burn out. Using this module I have made a plan and everything is feeling much more manageable. Just last week I got approval for a two-week respite stay for Ivy at the local nursing home. Rob is delighted and is already planning a two-week holiday for us.*

*Thankfully the nursing home has also organised some daytime respite in the lead up to the two-week stay.*

*At first I felt guilty putting Ivy into respite for me to have a holiday, but I know I need to recharge to be the best I can be for Ivy so now I need to keep working on the guilt in the lead-up to the holiday.*

**Joanna (57), carer for her friend, Ivy (79), who has heart disease, breast cancer and suspected cognitive impairment. Joanna lives with her husband Rob (66).**

# Putting your plan into action



*Sometimes the most productive thing you can do is relax – Mark Black*

The most common tips experienced carers have for new carers are to:

- prioritise their own health and wellbeing
- take the time to regularly recharge and reconnect

In the beginning it may take a bit, or even a lot of effort on your part to organise regular time for yourself. Dig deep and remind yourself that it will be worthwhile in the end.

When you're putting your plan into action, you should:

- spend time with positive people who will encourage you to regularly recharge and reconnect
- learn to say yes to offers to socialise
- **learn to say no** if your days become overloaded
- think twice before taking on extra commitments – you are already doing enough, if not too much
- start small and build up to longer recharges
- let others help

Make “me” time a priority. Remind yourself that:

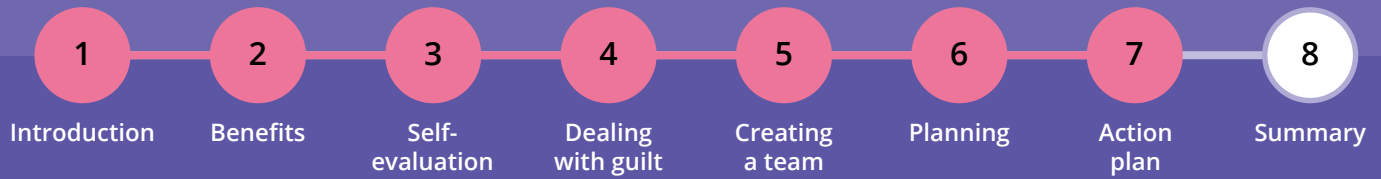
- the person you care for will soon get used to the new routine of regular recharges
- you are a team and you both have needs that require attention

Be prepared for little things to go wrong. Whatever happens, you or the alternate carer will manage.

Celebrate your successes – even the small successes – and be kind to yourself if the plan didn't go quite as you had hoped. Sometimes plans need refining.

Don't forget to review your plan. You can redo the module as often as you want.

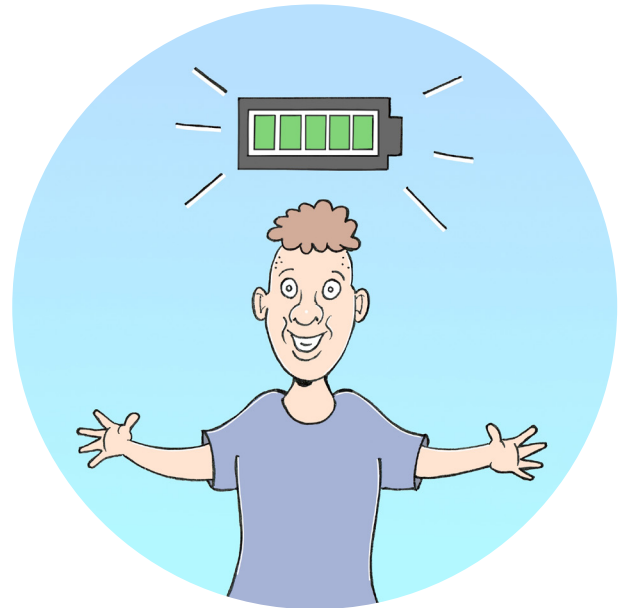
# Putting your plan into action



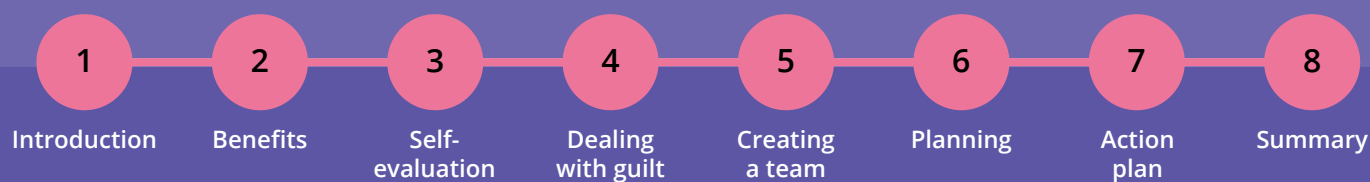
*Mum is finding it hard to adjust to the changes, which made me question whether I should be making these changes. I noticed I was feeling guilty, but I re-read the module and reminded myself of how important it is for my health and sanity to make "me time". I'm also lucky that my best friend is dropping in regularly to make sure that I'm having "me time".*

*As a first step, I reached out to my brother and he is now visiting mum twice a week, which means I get two nights off per week. I know I need to work on building more supports into the plan, but I'm really proud of myself, and I'm already physically and mentally stronger.*

**Sally (34), carer to her mother Joan (62), who has pancreatic cancer.**



# Additional resources



## More resources for carers



*If we keep doing what we're doing, we're going to keep getting what we're getting – Stephen Covey*

The following resources have been developed:

- How family and friends can help
- Care plan template
- Daily routine template
- Learning to say 'no'

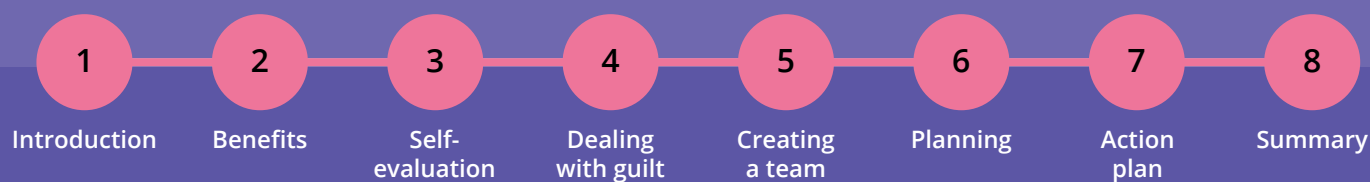
Carer Gateway has the following resources:

- **Emergency care kit**
- General respite information:
  - **What is respite care?**
  - **Who can get respite?**
  - **Respite at home**

For help with respite:

- **If you are caring for someone over the age of 65**
- If you are caring for someone in the NDIS you may be able to get short-term accommodation for the person you care for away from home or replacement care in the home.
- For respite, including emergency respite (during business hours or outside standard business hours), please contact the Carer Gateway on **1800 422 737**, which will direct you to your nearest service provider, who will help organise respite options in your area.

# Additional resources



“

*No matter how strong or strong-willed you are, you cannot live a stressful, maxed-out life without that pace eventually biting you in the butt. It is necessary to take breaks, set parameters, and be kind to yourself if you want to continue making an impact in your little corner of the world – Cynthia Mendenhall*



**Congratulations,  
you've completed  
the *recharge and  
reconnect* module.  
Well done!**



Having completed the *recharge and reconnect* module you should now:

- ✓ have a better understanding of the importance of recharging and reconnecting
- ✓ know how to deal with guilt and other negative feelings
- ✓ have created your care team
- ✓ have developed your taking a break plan
- ✓ have committed to putting your plan into action

Please see the following pages for more resources on:

- [How family and friends can help](#)
- [Learning to say no](#)
- [John's Care Plan](#)

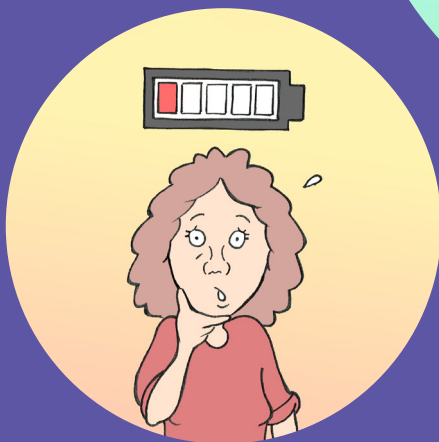
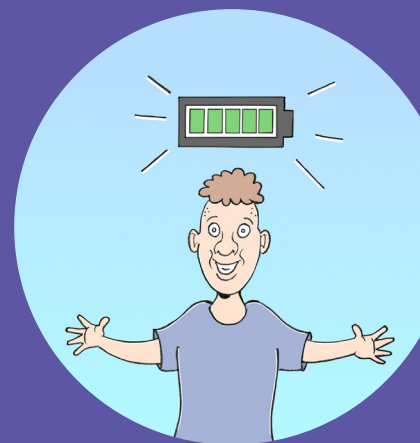
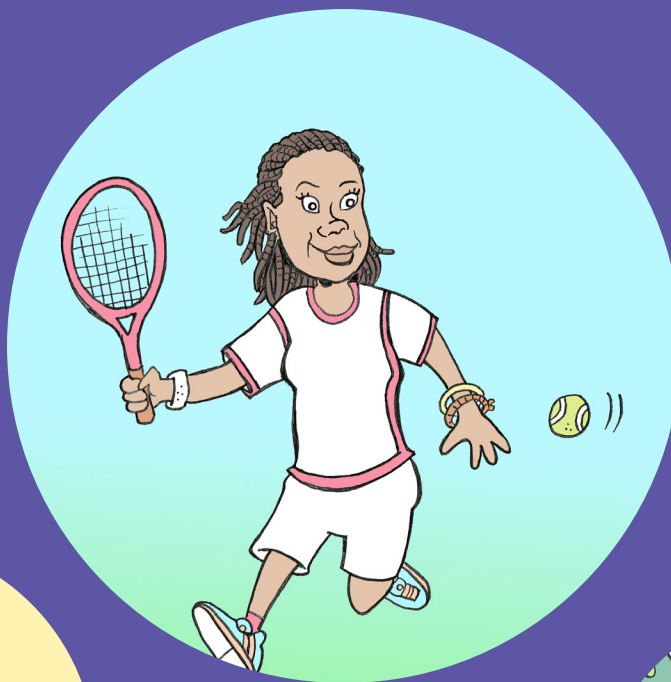


Australian Government



## Resources

You can find further resources on the following pages on How family and friends can help, Learning to say no, John's Care Plan and John's Daily Routine



# How family and friends can help



*You are never strong enough that you don't need help – Cesar Chavez*

The main reasons why some family and friends may be reluctant to help in providing care include:

- they don't realise you need help
- they don't know how to help
- they're scared of doing a bad job
- they live a long way from the person needing care

## **Maybe they think you don't need help**

Family and friends are often reluctant to offer to help because:

- from the outside looking in, carers often look as if they have everything under control and don't need help
- they aren't involved in the day-to-day care so they are unaware of how much time and energy is needed to care for your loved one

One way to let your family and friends know about the extent of your caring role is to arrange a meeting with them to explain it. Family and friends are often shocked to learn just how much carers do.

Other ways to involve family and friends is to let them see first-hand. You can do this by:

- asking your relative or friend to attend a medical or therapy appointment with you and your loved one
- asking your relative or friend to help with a specific task – for example, they could:
  - pick up prescription refills
  - collect your online grocery shopping from the supermarket or do the grocery shopping for you
  - help with meal preparation
  - help with housework
  - pay bills, either online or in person
  - arrange regular social events such as family visits, lunches and picnics
- having them visit when you would normally be putting the person you care for to bed and asking them to do some of the things you would normally do
- if the person you care for agrees, taking a video on your mobile phone showing the care you provide
- creating a family and friends care group using a private messenger app or Facebook page

Having regular meetings; keeping family and friends up to date with your loved one's health, wellbeing and care needs; and involving family and friends in aspects of your loved one's care are all good ways of involving them. This exposure will help your family and friends realise how much time and energy caregiving involves.



# How family and friends can help

## They don't know how to help

Some family members and friends do not know how they can help. If this is the case, it is better to ask the person to do specific tasks.

You could write up a list of tasks or activities and your family and friends could nominate which ones they would like to do. If you do this, make sure you include the day and time by which they need to be completed.

The other option is to ask for help with specific tasks or activities as suggested above.

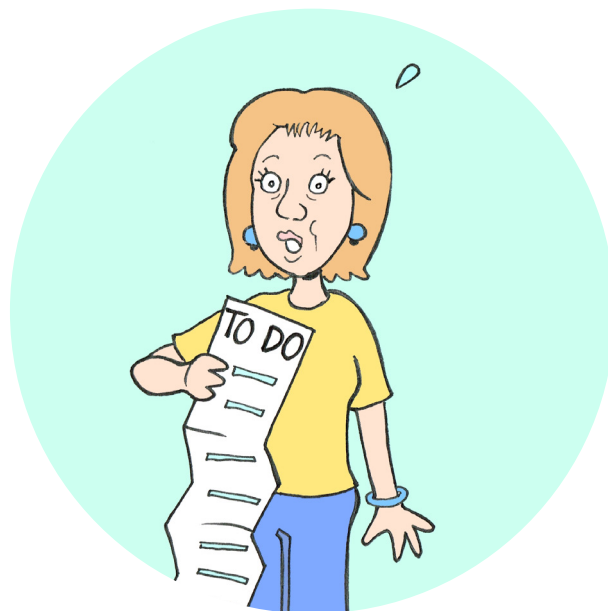
## They're scared of doing a bad job

Some people are reluctant to offer to help because they are afraid they will not do a very good job. They see you as a "professional" carer who knows what you're doing and they may feel inexperienced and clumsy by comparison.

These people might be prepared to help if you slowly ease them into the role and train them in caregiving.

Start out by having them watch you while you care for your loved one, which helps them overcome their fear and become familiar with the routine. The more first-hand exposure they have the more comfortable they'll become.

For example, you could invite them over for a meal. While they're there, explain the ways you help your loved one – "I'm cutting up the meat to make it easier to chew", "Let's encourage John to drink his tea so he won't get dehydrated" or "Mum needs a straw with fluids".





# How family and friends can help

## Other tips

Other things to remember when sharing the care with family and friends:

- No one is a mind reader – that's why it's important to ask for help when you need it.
- When family members get out of touch, it helps to share information with them in a formal, regular way via email, telephone call or family meeting. Make sure you share doctor's notes, diagnoses, test results etc.
- Acknowledge each other's strengths – some people are suited to hands-on care, some are good at running errands and fixing things around the house, others might be great with financial and legal paperwork and some might be good at navigating the healthcare system. Match tasks with those most suited to do them.
- Understand and accept that some family members either won't or can't help.
- When the family member or friend lives elsewhere, they can still contribute – for example, by helping with research or paperwork, coming to visit and taking over the care while you have a break, paying bills online etc.
- Don't expect equality in caring, especially amongst siblings caring for parents since typically one or two siblings will often take on the bulk of the care.
- Be specific when you ask for help – don't assume people will understand what you are asking them to do.
- Share your loved one's respite care plan and any current problems or worries – when someone doesn't know what's going on, they can feel excluded, which makes them less likely to help.

- If family members do not realise, or are in denial about your loved one's declining health:
  - give them information about the condition, such as typical symptoms and the type of care they will need
  - together, meet with an expert such as a GP, medical specialist or specialist nurse
- Other people do things differently from you:
  - this doesn't mean their way is wrong
  - it could be good for the person you care for to experience different ways of caring



*It was a huge step to move dad into a nursing home – it isn't what we would normally do in our culture ... but it was no longer safe to keep him at home. At first, I was at the nursing home every day – but it was getting too much for me alone.*

*This resource got me thinking ... I had thought no one else wanted to help, but it turns out they didn't know how they could help. So, while I still visit regularly, my sister is now taking him home cooked meals, his older sister calls him daily, and his brothers are taking him out on weekly walks.*

*Every little bit helps ... dad feels more comfortable and I finally have time to recharge between visits.*

**George (49), carer to father, Rafael (75), who lives with depression, diabetes and vascular dementia.**

# Learning to say no



*You can be a good person with a kind heart and still say no – Lori Deschene*

Do you sometimes wish you could say no? You are not alone. Many people struggle to say 'no'.

You might feel that saying no is uncaring or selfish, or you might fear being disliked or criticised, or that you risk a friendship if you say no.

Many carers have busy lives with little time for themselves. One way to reduce the overload and find some time for yourself is to learn when and how to say no.

Sometimes saying no may be the only way to achieve the best outcome.

Learning to say 'no' is a powerful skill and it takes practice to become comfortable in saying it.

## Tips for saying no

**Keep your refusal simple.** Be firm, polite and brief. You're not asking permission to say no. You don't need to give a reason unless you want to. Use phrases such as "I can't ... my plate is overloaded as it is" or simply "No, thank you."

**Practise saying no** in front of a mirror or in front of a friend. Practising saying no will help you become more comfortable and confident in saying the word.

**Start by saying no to little things** – this could be telemarketers or something minor. The more you practise saying no, the better equipped you'll be to decline the bigger propositions in life.

**Give yourself some time** by saying "I'll get back to you". When you've had time to think about it, you'll be able to say no more confidently.

**Think about a compromise**, but only if you want to. Suggest an alternative to suit both of you.

**Separate refusal from rejection.** You're saying no to a request, not rejecting the person! People usually understand that it's your right to say no, just as it is their right to ask the favour.

**Don't feel guilty.** It's important for the people around you to hear you say no because it reminds them that you are in charge of setting your boundaries. True friends will respect your boundaries.

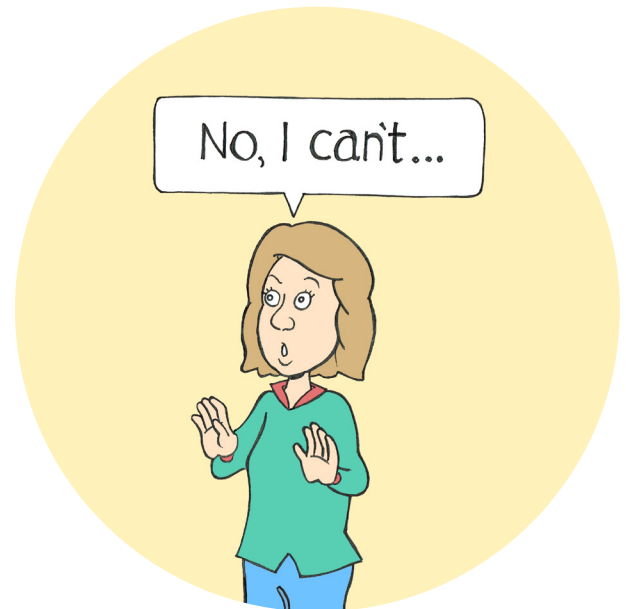
# Learning to say no



*I was so glad to read this information. I have always struggled with saying no, because I really don't want to upset anyone. But I am exhausted ... I know I've been burning the candle at all ends lately.*

*My son, John (36), called me at the last minute to babysit the grandkids – and while I would usually drop everything, this time I said a simple “No, sorry John – it's been a crazy week – I need some time out”. I felt bad, but I know it was the best decision for me. I told John that if he gives me more notice next time, I will try to help out ... he was fine with that.*

**Mary, 57, carer to her husband with MS, and her father-in-law with dementia.**



# John's Care Plan

*Note: The template can be modified to suit personal circumstances.*



## John

- Date of birth:
- Age:
- Medicare number:
- Private health insurance:
- Ambulance:
- Registered with my eHealth record
- Has health information in phone or medi-alert item:
- Has health summary for quick translation with healthcare providers (could add a brief history)

### Diagnosis

- (add in the condition here)

### Medications

- Webster-pak – kept in the kitchen
- Requires reminders and needs assistance to take medication
- A list of John's current medications, including dosages, is attached
- John also takes one Vitamin D in the morning with breakfast
- John can have Panadol if he is in pain or has a temperature

### Immunisations

- Flu – 7 July 2018
- Tetanus – 5 March 2015

### Allergies

- Medications:
- Foods:
- Other:

### Important people in John's life

- (For example, family, relatives, friends, neighbours, teacher, carer or others)

### Mobility and safety

- Assist to sit and stand
- Uses walker
- Keep living space tidy
- Keep night light on
- Environmental controls
- Specialist clothing or footwear

### Communication

- Needs specialised skills such as sign or use of augmentative system
- Able to speak/write/gesture/indicate needs – how?
- Interpreting and translating?

### Behaviour

- Description of behaviour
- Triggers for behaviour
- Strategies to overcome behaviour

# John's Care Plan

## Personal care – any equipment and type of assistance needed for:

- Showering (for example, shower chair and some assistance needed to wash and dry off)
- Shaving
- Dressing
- Brushing teeth
- Nail care
- Toileting

## Meal time

- Assistance with preparing food
- Assistance with eating food
- Assistance with drinking
- Supervision during meal time
- Assistance with tube feeding
- Supervision of meal and snack choices
- Other

## Special dietary requirements

- Vegetarian
- Needs food chopped – can't use a knife.

## Aids/Equipment

- Walker
- Glasses – need to be cleaned daily
- Hearing aid – check batteries and clean daily
- Dentures – clean daily
- Assistance dog
- Service provider for maintenance:
  - Wheelchair
  - Electric bed
  - Hoist

## Safety

- Line of sight supervision in the home or outside in the community so they do not wander off.

## John's interests and hobbies

- (add in interests and hobbies here)

## John's routine

- See attached table.

## John's likes and dislikes

- (add in likes and dislikes here)

## John's goals

- Take medications as scheduled
- Healthy and nutritious eating
- Exercise – follow prescribed physical therapy routine

## Carer's household tasks

- Meal preparation
- Cleaning
- Laundry
- Take out garbage
- Recycling
- Drive John to and from his activities/ medical appointments
- Grocery shopping

# John's Care Plan

## Household supply list

- Disposable gloves
- Paper towels
- Cleaning products, such as dish and laundry detergent, counter-top cleaner, disinfecting wipes and/or bathroom spray cleaner
- Garbage bags – large and small
- Skin care products, especially personal hygiene wipes and barrier creams
- Absorbent under-pads for bedding, if needed (disposable or cloth)

## Carer Details

Name:

Relationship with John:

Telephone number:

Address:

## Emergency contact details

Name:

Relationship with John:

Telephone number:

Address:

Name:

Relationship with John:

Telephone number:

Address:

## GP details

Name:

Telephone number:

Address:

## Pharmacy details

Name:

Telephone number:

Address:

## Nearest hospital with an emergency department – details

Name:

Telephone number:

Address:

## Other specialists/professionals – details

Name:

Health discipline:

Telephone number:

Address:

Name:

Health discipline:

Telephone number:

Address:

Name:

Health discipline:

Telephone number:

Address:

# John's Daily Routine

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	Sunday
Morning						
Afternoon						
Evening						

**Wake-up routine**

**Bedtime routine**

**Night-time wake-ups**

**Transport** (public transport such as buses, trams and trains, taxis, school bus, modified vehicle etc)

**Meal times and medications**

**Breakfast:** 8.00 am – 1 x cereal, piece of fruit and cup of tea (milk – no sugar); tablets from Webster-pak

**Lunch:** 12.30 pm – salad sandwich (please vary the bread/rolls and meat daily), piece of fruit and cup of tea (milk – no sugar).

**Dinner:** 6.30 pm – tablets from Webster-pak

**1 hour before bed** – tablets from Webster-pak