



Social
Futures

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Carers sharing with Carers

Coping strategies for family and friends caring
for someone living with dementia.

About this booklet

The idea for this booklet came from sessions that Social Futures held with Carers who are caring for someone living with dementia. We found that it was so empowering and supportive for Carers to share their thoughts and coping strategies and we were impressed with the valuable and practical ideas.

We were planning more sessions in the following months but had to cancel due to the COVID-19 isolation restrictions. We decided to support Carers by putting together this booklet, in collaboration with the Northern NSW Local Health District Dementia Outreach Service, to share ideas from the sessions.

We want to extend our heartfelt thanks to all the wonderful Carers who participated in sharing their thoughts and experiences with others.

Acknowledgements

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We acknowledge the Traditional Owners of the land where we live and work and their continuing connection to land, water, sea and community. We pay respects to Australia's First Peoples, to their unique and diverse cultures, and to Elders past, present and future.

Dementia Friendly Communities

24 hour helpline for Carers (including Dementia Behaviour Management Advisory Service).

Call **1800 699 799** or visit dementia.com.au

Forget Me Nots

A singing group that meets regularly in Grafton and Maclean.

Contact **Leigh Robertson 0431 355 797** or visit facebook.com/forgetmenotchoir

If you don't have a computer or printer and want any of the listed online resources mailed to you or need help connecting with support services call or text Social Futures Project Coordinator **Linda Wirf on 0406 409 747** or email linda.wirf@socialfutures.org.au

Resources

Carer Gateway

Phone counselling, Carer Forums, self-guided coaching and courses for Carers wanting to upskill or connect with other Carers.

Visit carergateway.gov.au or call 1800 422 737

Dementia Australia

Resources for people living with dementia and their Carers including tips for people living with Dementia during COVID-19.

Visit dementia.org.au or contact the Dementia Australia National Dementia Helpline on 1800 100 500.

Dementia Friendly Communities

Information about dementia friendly communities in Northern NSW.

Visit dementiafriendly.org.au or call DAISI Services on 1800 800 340.

Dementia Alliance International

For people with a medically confirmed diagnosis of any type of a dementia from all around the world. Represent, support, and educate others living with the disease, and the wider dementia community.

Visit dementiaallianceinternational.org

From one Carer
to all Carers

'Acknowledge the amazingness of being a Carer and the value of the work you do every day.'



Day to day coping strategies

Be flexible

One of the key things to remember is that things will keep changing and what worked last week may not work this week. We need to keep finding new strategies. Be flexible and understand that no one strategy will work all the time – every day is different. It can help to look at each problem one by one and find solutions as you need to. Find the motivator that works for each situation and build on that, even if it's different to what worked in the past.

Communication

Finding ways to communicate and making communication as pleasant as possible is important. Talk about issues openly and set boundaries to help enable clear communication. Try limiting choices and being very specific in the information you are communicating.

One Carer noted that sometimes agreeing with the story that the person you are caring for is telling can avoid upsetting or confusing them. Going along with their version of events rather than arguing can help things to flow more smoothly – if it's not important, you don't need to stress or correct errors in their story.

Therapeutic stories can help to keep things calm. Validating that what the person you are caring for is experiencing is really happening for them and sharing in their story without judgment can often help to resolve the situation and avoid conflict.

Try thinking 'how can we do this together?'

Try using subtle suggestions to encourage the person you are caring for to make positive decisions rather than telling them what to do. Sometimes modelling the desired behaviour or task can work better than words.

Remember that acceptance of new ideas or situations may take time, so go slowly and avoid conflict.

Patience is the key.

Take time to look after yourself and reflect on your strengths.



'Too often we underestimate the power of a touch, a smile, a kind word, a listening ear, an honest compliment or the smallest act of caring, all of which have the potential to turn a life around.' Leo Buscaglia

My Aged Care

Arrange an assessment for respite care, Home Care Packages and other assistance.

Visit myagedcare.gov.au or call **1800 200 422** to arrange an assessment.

Need help accessing My Aged care?

For one on one assistance with getting registered on My Aged Care contact Seniors Rights Service.

Visit seniorsrightsservice.org.au or call **1800 424 079**.

Make connections

Talk to other Carers who are further along in the journey and ask what support is available and how to access it. Carers support groups can also help you to realise that you are not the only one in this situation. Sharing experiences can be a positive way of supporting each other. Find out about Carer support groups in your area by contacting **Carer Gateway** on **1800 422 737**.

There is value in talking with someone who is not part of your family. Try to talk to someone else every day and maintain your own social connections. Seek counselling if you need it. You can contact **Carer Gateway** to find out about free counselling and peer support available in your area on **1800 422 737**.



When you need to communicate something important to the person you are caring for make sure you have their attention first, ensure they are focussed and don't rush. It may help if you take the time to establish a connection. Making eye contact and saying something like 'can you please listen' or a gentle touch may help the person you are caring for to focus. Combining mime and visual cues with the words you are saying provides different pathways for understanding. Try remaining calm, talking in a gentle but matter of fact way and focusing on one idea at a time. Check that hearing aids are functioning correctly and glasses are cleaned regularly.

Avoid arguments

We may need to be adaptive and flexible about how and when things happen. Don't try to engage or make things happen when the mood isn't right. Plan ahead for the times of day that may be problematic. For example some Carers have noticed that sundown can be a time of escalation in mood for the person they are caring for. Perhaps use this time to reminisce, listen to music, go for a drive or an afternoon walk.

Remember, you can choose not to respond rather than respond negatively. If it's not important, try distraction or walking away. As one Carer says 'removing myself from the situation for 20 minutes or so really helps sometimes'. Refocus by changing the subject or doing something else for a while.

Sometimes however you may need to say 'that's just the way it is, this is what's happening' and be prepared to walk away from any negative reactions. Arguing will often make the situation worse.

Create a dementia friendly environment

Simple things like thinking about ways to make the house safer and easier to navigate can make life easier for everyone and help the person you are caring for maintain some independence.



Looking after yourself and finding support

Don't do it all alone

It can be easy as a Carer to be so focussed on your caring role that you forget the importance of looking after yourself. It really helps with wellbeing to do something for yourself, like study or another interest outside of the house. Reflect on what you need to do to stay positive. Don't be afraid to ask for family support when you need some time out.

Organise regular respite care at home if the person you are caring for doesn't want to go out to a social respite group. It is good for you and good for the person you are caring for to have your own space and time. You need at least four hours a week to be able to fully relax and do something you enjoy. Try to find a respite carer that the person you are caring for actively likes. Someone whose company they enjoy. You may need to try a few different respite carers until you find a good match. It will make it so much easier if there is a positive relationship and the person you are caring for looks forward to the time spent with their respite carer.

Think about how a Home Care Package can make your life easier, for example having someone to mow the lawn may free up some of your time to do something you enjoy.

The government Home Care Packages Program provides support to older people with complex needs to help them stay at home. Home support, as well as providing physical assistance, brings someone else into the house and can provide social interaction, respite and help with transport.



Be kind to yourself

Facing the situation honestly - 'it is what it is' - can be helpful but it is also important to be able to 'let it go' and not dwell on negatives. Actively working on finding solutions can help keep up the positivity.

Try to find time for reflection. Stepping back occasionally and taking stock of what is working or how you could make it work better will help keep the bigger picture in focus. Expressing our feelings in safe supportive environments is better than holding things inside. Remember to tell yourself that you are doing the best that you can.

Dementia Australia

Information about creating a dementia friendly home environment. Visit dementia.org.au/resources and click on help sheets.

The website also has information and ideas about staying connected while staying at home. You can also contact the **National COVID-19 Older Persons Information Line** on **1800 171 866**.

Dementia Outreach Service

Is a free service that provides education, support and advice to carers of people living with Dementia. Call **My Aged Care** for a referral on **1800 200 422** or contact the **Dementia Outreach Service** (Far North Coast) directly to arrange a referral on **02 6620 6274**.



Coping strategies out and about

These strategies from Carers were shared before the introduction of isolation restrictions. They are included as they may be helpful when we are able to go out and about again.

Find activities that work

Try to go out somewhere together regularly to break up the day and vary the routine. Finding outings and social activities that work for both of you are the key to enjoying time spent outside the home. These might be different to what the person you're caring for used to enjoy doing or what you used to enjoy doing together.

Many Carers have found that singing and dancing groups have worked well for them and there are many that are dementia friendly. Dementia Cafés can be a good option as well.

Contact the **Dementia Outreach Service** (Far North Coast) on **02 6620 6274** to find a local Dementia Café Connections group near you.

The person you are caring for may need more rest or sleep than they used to so try and schedule activities for times when they feel most active and alert. Think about only doing one activity and keeping it short.

Small changes can really help

Using the accessible toilet when you are in public spaces can make it easier for the person you are caring for to find their way out. They don't need to lock the door if they find it difficult, you can just stand outside the door.

If alcohol is an issue, try non-alcoholic wine or adding part soda water so that the person you are caring for can still feel included in social gatherings.

Personal strengths you can draw on

Develop your resilience

Carers agree that resilience and a relaxed and positive attitude helps them to cope. Our attitude towards change can shape the way we perceive our situation. Accepting that change will happen rather than fighting it, embracing change and surrendering to changes are strategies that work for some Carers.

One Carer described how life became more positive for them when, instead of worrying about what lay ahead, they started anticipating the future as the next adventure in their shared life journey with their partner. Being in the moment can really help to lessen worry and stress.

Grow your understanding

Understanding that the person you are caring for is often experiencing, or is motivated by, fear or confusion can help you to step back and not take things personally. Patience is so important. The key message is to calmly persist and remember that it may take a very long time for the person you are caring for to accept something new.

Knowledge about the condition helps understanding so seek out opportunities to inform yourself from trusted sources of information. The Dementia Australia website has a wealth of information, fact sheets and resources that will increase your understanding about many aspects of dementia.

Find time to laugh

Keep your sense of humour and don't forget to laugh together. Find joy in the giving when you can and be aware that you are playing a key role in creating a happy life for the person you love. Sharing humour can be a positive time of connection.