



MACQUARIE
University
SYDNEY • AUSTRALIA

**LIFESPAN HEALTH
AND WELLBEING
RESEARCH CENTRE**

Staying socially connected

INFORMATION BOOKLET FOR CARERS OF PEOPLE LIVING
WITH DEMENTIA OR MILD COGNITIVE IMPAIRMENT (MCI)



Authors:

Matovic, D.^a, Picard, G. K.^a, Chen, J.T.-H.^a, Neelakandan, A.^a, & Wuthrich, V. M.^a

^a Lifespan Health and Wellbeing Research Centre, Macquarie University.

Acknowledgements:

Thanks to consumer representatives Hannah Loon, Cathy Roth, and Paul Turner, stakeholders, carers, and people living with mild cognitive impairment and dementia for their feedback.

This project was funded by:

The Australian Association of Gerontology RM Gibson grant in partnership with the Dementia Australia Research Foundation

Suggested citation:

Matovic, D., Picard, G. K., Chen, J.T.-H., Neelakandan, A., & Wuthrich, V. M. (2024). *Staying socially connected: Information booklet for carers of people living with dementia or Mild Cognitive Impairment (MCI)*. Lifespan Health and Wellbeing Research Centre, Macquarie University.

© Lifespan Health and Wellbeing Research Centre, Macquarie University, May, 2024

Images: Shutterstock

Project funded by



Dementia
Australia™
**Research
Foundation**



AAG | Research
Australian
Association of
Gerontology | Trust

Staying socially connected

Carers can become isolated and disconnected from their social network due to the demands of caring for a person with dementia or Mild Cognitive Impairment (MCI). This also happens to people living with dementia or MCI.

This booklet includes tips and strategies for staying socially connected with friends and family after starting to care for or support someone with dementia or MCI.

There is a separate booklet written for people living with MCI or dementia to help them to maintain social connections.

The information in this booklet is based on survey responses and interviews with carers and supporters of people living with dementia or MCI. The booklet also contains cognitive and behavioural strategies relevant for carers' needs, with a focus on:

- Helping you explain to friends and family how they can assist you to maintain social connections in your carer role
- Strengthening your social network
- Managing barriers to engaging in social activities.

Every carer's experience is unique. The challenges and needs of carers change along the course of dementia. Strategies that are helpful in the beginning of the diagnosis may not be as helpful later. In addition, different carers will have different challenges and needs as the experience of dementia is not the same for everyone. As such this booklet provides general tips that might help you to stay socially connected to others during this period. Some tips may be very helpful for you. Other tips may not be as relevant to you. You can pick and choose which strategies to apply to your circumstances.

MCI and dementia

- MCI and dementia are two different diagnoses:
 - MCI is cognitive impairment without impacting your everyday life. Memory or thinking changes are noticeable by friends and family. Some people who have MCI will develop dementia later.
 - Dementia is more severe cognitive impairment that does impact your everyday life.
- Here is an example to show the difference between MCI and dementia:

MCI	Dementia
Jane has some memory problems. But Jane can still look after herself without any help . She can use memory aids to function independently. In this scenario, Jane has MCI.	Jane has memory problems. Because of her memory problems, Jane forgets to pay her bills, forgets appointments and gets muddled and confused. She needs other people to help her with everyday tasks. In this scenario, Jane has dementia.

Staying socially connected

There are many different kinds of MCI and dementia. No two people will experience MCI or dementia the same way. [Learn more about](#) the difference between MCI and dementia.

This booklet is designed to help manage symptoms of all kinds of MCI and dementia. It does not matter what type of dementia or MCI the person you are assisting has.

Dealing with embarrassment, shame or frustration

Some people feel embarrassed, ashamed or frustrated about a family member's diagnosis of MCI or dementia. Carers can also experience embarrassment, shame or frustration when the person with MCI or dementia acts in a way that seems odd or is embarrassing. It can be hard to know how to manage these behaviours when they occur, especially when they occur in public.

Here are some strategies that might help you deal with these behaviours:

Ignore the behaviour

Let the behaviour pass without giving it too much attention, especially if it is not impacting anyone negatively.

Use distraction

Ask them a question or talk about something you know that interests them; gently move them to a different area in the room; play some music; or get them to talk to another person for a few minutes.

Redirect the conversation

Adapt to the changes in the conversation by provide the linking statement so other people can follow along with the conversation. Gently remind the person with MCI/dementia what the topic of conversation was.

Apologise if needed

If the person with MCI/dementia has said or done something others find inappropriate, apologise on their behalf. You can decide whether or not you want to explain their diagnosis of MCI or dementia.

Ask a friend or family member to look after you

Asking your friend to visit you for a cup of coffee, or drop off some groceries can alleviate stress and make you feel better.

Practice relaxation strategies

Both you and the person with MCI/dementia might benefit from taking a few deep breaths, doing some stretches or putting on some relaxing music.

Look for common triggers

These may include changes in the person's energy levels, emotional state or environmental factors. Plan activities at times of the day when they are most rested. Avoid noisy environments.

Talk to friends, family and other carers about your carer experience

Talking about your feelings of embarrassment or frustration can help other people to support you.

Staying socially connected

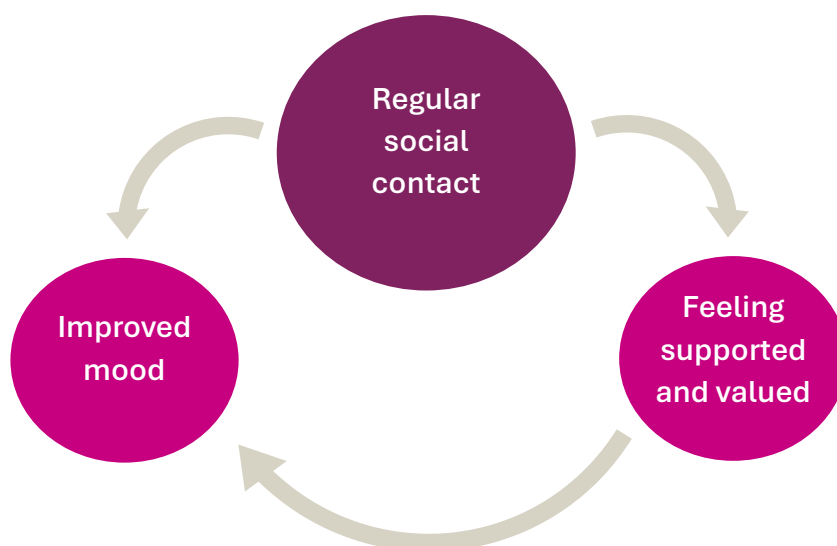
It can also be helpful to be mindful of how you are thinking about the situation. Thinking unhelpful thoughts about yourself and your situation can make you feel worse. For example:

Unhelpful thought	More helpful thought
"This is so embarrassing. I feel so out of place at this dinner...they probably don't want to us to be here".	"It's okay, the awkwardness will pass. Jane has dementia and everyone here understands that. They want to support us and spend time together".

Maintaining your social support networks

Maintaining regular high quality social connections is good for your mental and physical health. We usually feel the happiest when we engage in meaningful social activities such as spending quality time with family and friends, or participating in group activities. Social isolation is one of the biggest risk factors for developing dementia in older adults, so maintaining social activities can also help you to prevent developing dementia yourself.

When you are caring for a person living with dementia, it can be challenging to have regular social contact due to caring commitments. The less you engage in social activities, the less motivated you feel, and you gradually withdraw from your social network. It is important to find solutions to overcome barriers so that you can still maintain social support while caring for a person living with dementia.



Staying socially connected

Strategies to maintain your social network	
Reach out to people in your existing social network for EMOTIONAL support	<p>These may be people in your life that:</p> <ul style="list-style-type: none">• you would feel comfortable sharing your thoughts and feelings with (both positive and negative)• you most enjoy spending your time with• you feel truly care about you and would be supportive of you under almost any circumstance
Reach out to people in your existing social network for PRACTICAL support.	<p>These may be people in your life that:</p> <ul style="list-style-type: none">• You can count on to provide practical help you when you need it (e.g., getting a ride somewhere, doing chores, moving furniture, making a meal for you etc.).• You could get advice, assistance with administrative tasks, and making practical decisions

It can be much easier to maintain social networks as a carer if the person that you're supporting is actively engaged as well. You could consider doing activities together to keep the person with MCI/dementia active, adapting the activity if needed. You may want to check whether your state provides a companion card which allows you free entry into participating venues and events when accompanying someone you care for (e.g., [NSW companion card](#)). At the same time, it can also be helpful to also have independent social activities. This can help you both speak freely about any issues you may need support with.

You may also find it helpful to arrange formal caregiving to engage the person with MCI/early dementia and free your time for social activities. It can be good to do this early on, so it becomes a routine before dementia gets worse and then a person becomes more resistant to change.

Carer experience:

“Arranging a formal caregiving, if and when you do get it organised, and we have now, it's such a relief. We've got a lovely young man who comes and does stuff – goes bike riding and swimming, and all sorts of things. And it's someone that you trust – it can make a huge difference.”

Staying socially connected

Friends and family want to stay socially connected with you, but sometimes they do not know how to best do this.

You can help your friends and family by educating them about changes in your circumstances and roles. This would help them learn what they could do to assist.

Family and friends can be very supportive if they know how to respond and what actions they can take.

For example, one carer said:

“Initially friends were inclined to stay away. However, by explaining that we were the same people we always were and that my partner needed to continue to have social interaction with friends, close friends have maintained contact.”

How can **friends and family** help you stay connected?

Strategy	Examples
Ask them to check in on you regularly and provide emotional support.	<ul style="list-style-type: none">• Be dedicated to staying in touch. You could plan a weekly phone call.• Visit you at your house.• Encourage you to get out of the house or engage in a self-care activity.
Ask them to have a flexible attitude. Remind yourself to have to be flexible as well.	<ul style="list-style-type: none">• A social interaction with a friend or family member may not go as planned, and that is OK. You can try doing something else or just “do nothing” together and enjoy each other’s company.• Be understanding as to why you cannot always attend activities and events. Ask you how they can keep in touch in meaningful ways. Perhaps you cannot make it out for coffee, but you could schedule a chat on the phone instead. Do what fits with your schedule at the time.• Ask you what strategies work best for you and check in from time to time about any changes to your circumstances.

Staying socially connected

Strategy	Examples
Ask friends to attend social groups with you and help you maintain your hobbies and interests.	<ul style="list-style-type: none">• Ask you what interests you can continue to enjoy together. You can continue to engage in shared social groups such as a book club, Probus (https://probussouthpacific.org/) or knitting club.• Brainstorm ideas for helping you keep up hobbies or interests.• Join new social groups together (e.g., walking group, gardening group, volunteering) or try new one-on-one activities together. Try to give things a go and see what works for you.
Ask them to give practical support.	<ul style="list-style-type: none">• Carers often report having less time and energy. It can be helpful to ask others to provide transport or picking up groceries for you.• Friends and family can organise an activity with the person with MCI or dementia while you have some time to yourself.• Help and advice with administrative tasks (e.g., organising respite) and making decisions around care.
Suggest resources for them to read up on MCI or dementia.	<ul style="list-style-type: none">• Look at resources from organisations like Dementia Australia. They provide information on how to support people with MCI or dementia, and their carers or supporters.

Another carer said:

What we did right at the outset was I prepared friends. I included in that a short blurb on dementia. I said, "Hope you will continue walking with us on this journey". We reassured our friends that it was still okay to go out and have dinner and to do some fun things together. And for friends when they're informed, it's quite frightening. They don't know what to expect and what to do. It reassured them that we had normality it and we expected them to be part of that normality. It works really well. We've maintained a wide social network, even now we're nearly 11 years down the track, and those friends are still part of our life.

Staying socially connected



Develop a wider social network

It is important that you have regular social contact with a wide variety of people, not just with one person (e.g., a relative). It may take some time to build up or re-build social contact or friendships. The key to maintaining quality social connections is consistency.

Some things to consider when building and maintaining your social connections are:

PRIORITISE the activities that maximise enjoyment and a sense of wellbeing

REVISIT activities or interests that you used to love. For example, go back to hand crafts, swimming, or a walking group.

SCHEDULE regular activities with other people. For example, an exercise class or weekly coffee catch up.

MEET new people who are in a similar carer role. You can learn from each other and share your experiences.

RECONNECT with old friends you have lost touch with.

Try **NEW** activities (e.g., a choir, photography, advocacy, walking group). You can meet different people and bring new joy and connection to your life.

Staying socially connected

You could talk to your existing friends and family to help you come up with **ideas** and to broaden your social networks. You could also ask friends and family to **attend** new social groups with you to help you broaden your hobbies and interests.

It can also be helpful to join carer support groups for emotional and practical support.

Carer experience:

"I'd strongly recommend carer support groups. They're such a good resource. And it's just so good talking to other people and realising that, you know, people go through the same things, and you don't have to reinvent the wheel. It's not just the support, but people know things."

Overcome obstacles to increasing social activities

As a carer, sometimes it can be challenging to spend quality time with other people. This can be due to feeling like you do not have people you can turn to, being nervous about meeting new people, or lacking the motivation to socialise. Below are some strategies for overcoming these common challenges.

Challenge	Strategy
Worry about contacting a new group or going for the first time. You may have concerns about transport and parking, limited availability due to care commitments, meeting new people, or not having the skills required for the activity.	<ul style="list-style-type: none">• Write down what you want to ask the group organiser before calling. You could email instead if this is more comfortable. You can ask about:<ul style="list-style-type: none">○ Public transport or carpooling options.○ Which skill levels are recommended.• Ask a friend if they can go with you.• Remember you may need time to settle in. Try a new activity at least three times before you decide whether to keep going.• Ask a friend or family member if they could spend time with the person with dementia or MCI while you are at your activity.
Not having friends or family to spend quality time with. This might be because of: <ul style="list-style-type: none">• Loss of friendships (due to increased carer responsibility, changes in living arrangements)• Conflict with others about carer responsibilities	<ul style="list-style-type: none">• Reconnect with an old friend. In person catch-ups are best. Video or telephone calls are second best.• Reach out to friends, rather than waiting for others to check in on you.• Spend time nurturing social relationships with people who value you. You may need to let some people know that you are caring for a person with dementia or MCI, and how this may affect your social life (e.g., needing to cancel with short notice), so they can better understand

Staying socially connected

Challenge	Strategy
<ul style="list-style-type: none">• Difficulties forming new friendships• Anxiety about meeting new people	<p>your needs.</p> <ul style="list-style-type: none">• Friendships take time to form. Be patient when meeting new people.• It is never too late to repair damaged relationships. It may take some time and might involve some difficult conversations.
<p>Dealing with low motivation</p> <p>You may not feel motivated. This may be partly from a feeling of grief or loss over activities you used to be able to do or used to have a different meaning to you. Everyone feels unmotivated sometimes. It can become a problem if we do not find motivation again. The more you do, the more motivated you will feel, and the easier it will get to do things.</p>	<ul style="list-style-type: none">• If in-person meetings feel like too much effort on some days, use phone calls or video calls instead.• Plan recurring activities with a friend. This makes it harder to just not go.• Remind yourself that people usually enjoy themselves when they get over initial hesitation to socialise.• Just keep trying, even though some days you have more motivation to socialise than other days.• Remind yourself that your carer responsibilities will change over time.• Reframe unhelpful thoughts. For example, instead of thinking “<i>It is too hard, I cannot be bothered. It is not worth it</i>”, think “<i>It may be hard to start, but when I get going it will be easier. I value this activity and I usually enjoy myself.</i>”

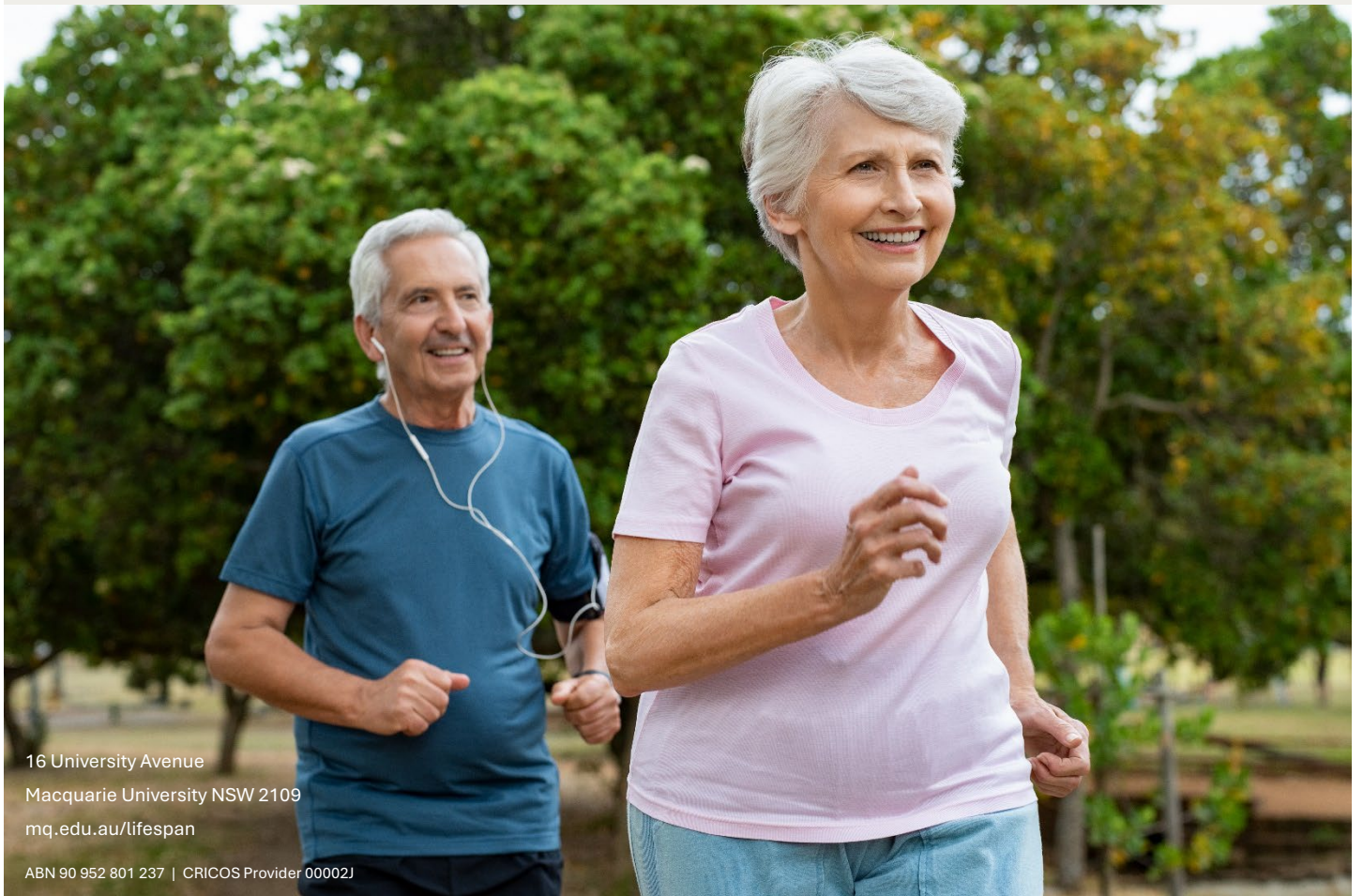
Carer experience:

“It’s important to maintain social networks and talk to other people even when you feel that you can’t be bothered or it’s not worth getting dressed and going out because it makes a difference to get up and move and go out and meet people.”



MACQUARIE
University
SYDNEY • AUSTRALIA

**LIFESPAN HEALTH
AND WELLBEING
RESEARCH CENTRE**



16 University Avenue
Macquarie University NSW 2109
mq.edu.au/lifespan

ABN 90 952 801 237 | CRICOS Provider 00002J