

# Staying socially connected

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



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the dementia care experts

# Staying socially connected

This booklet includes tips and strategies for staying socially connected after your Mild Cognitive Impairment (MCI) or dementia diagnosis.

The information in this booklet is based on feedback from people with MCI and dementia.

Every person with MCI or dementia is different. This booklet provides general tips. Some tips may be very helpful for you. Other tips may not be as relevant to you. Please use the strategies and tips that are helpful to you and your loved ones.

## 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 <b>without any help</b> . 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. She gets confused and <b>needs other people to help</b> her with everyday tasks. In this scenario, Jane has dementia.

- There are many different kinds of MCI and dementia. This booklet is to help manage symptoms of all 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.

## Feelings of embarrassment, shame or frustration

- It is normal to experience strong emotions after you have been diagnosed with MCI or dementia.
- You may feel like other people think badly of you. It can make you feel like you have done something silly, stupid, or dumb.
- You might feel embarrassment, ashamed or frustration if you:
  - Forget someone's name.
  - Forget appointments.
  - Are not able to follow a conversation.
  - Unintentionally say or do something that upsets someone else.

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- Many people feel embarrassed, ashamed and/or frustrated. These feelings might make you want to stay home and avoid other people.
- You can reduce feelings of embarrassment, shame and frustration by:
  - Learning more about your diagnosis. You can ask your doctor questions about your diagnosis or symptoms. This can make you feel more comfortable.
  - Tell your friends and family how you feel. Trying to hide your feelings may make you feel worse.
  - Connect with other people who also have a MCI or dementia diagnosis. Sharing experiences with others can help you feel you are not alone.
  - Try and accept your symptoms as a new part of your life, and learn strategies to cope with them.
  - Only thinking negative thoughts about yourself may make you feel worse. Instead, be kind to yourself. For example:



Unhelpful thought	More helpful thought
"I cannot remember her name. I'm so stupid and I can't remember anything anymore."	"It's okay that I cannot remember her name right now. It will come back to me."

## Talking to friends and family

- It is important to talk with friends and family about your diagnosis so they can understand how to best support you.
- Friends and family may stop socialising with you because they do not know how to react to your diagnosis. They may feel unsure about what you need.
- You can talk with friends and family about how you want to socialise.
- Consider the below ideas for what you may share with friends and family:

Helpful information to share	How you can share information in conversation
<b>If they don't know, explain to them you have a diagnosis of MCI or dementia.</b> Share what you feel and think about your diagnosis. Share the changes you have noticed.	<i>I have been diagnosed with dementia. I am beginning to accept it. Sometimes it makes me worried. Sometimes I have trouble following fast conversations. Sometimes I forget what we have just been talking about. You can help me by:</i> <ul style="list-style-type: none"><li>• <i>Using short sentences</i></li><li>• <i>Repeating information when I need it</i></li></ul>

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Helpful information to share	How you can share information in conversation
	<ul style="list-style-type: none"> <li>• <i>If I forget, remind me of the topic we have been talking about</i></li> </ul>
<p><b>Share how you feel about socialising.</b> Share if you have noticed any problems. Share how you want to socialise.</p>	<p><i>Sometimes I feel nervous about attending social situations. Not everyone knows about my diagnosis. I feel especially nervous in bigger and noisier groups. Despite my anxiety, I want to stay as social as I can. You can help me by:</i></p> <ul style="list-style-type: none"> <li>• <i>Not telling other people about my diagnosis until I say I am comfortable to share</i></li> <li>• <i>Attending events with me</i></li> <li>• <i>Helping me find a quieter spot in noisy situations</i></li> </ul>

## Adjusting the way to you talk to friends and family

- MCI and dementia can cause changes in what and how you communicate with others.
- This can make you lose confidence when you talk with other people.
- Remember to try and stay calm. Becoming stressed will make things harder.
- Some strategies for managing common communication changes are:



Communication change	Strategy
<p>Finding it hard to follow fast or complicated conversations</p>	<ul style="list-style-type: none"> <li>• You can say <i>“I didn’t quite catch that, could you please slow down/speak a little clearer/re-explain that part”</i>.</li> <li>• Ask a trusted friend or family member to explain the conversation to you afterwards.</li> </ul>
<p>Finding it hard to think of the right word</p>	<ul style="list-style-type: none"> <li>• You can make finding the word into a game. You can usually remember details about the word to give clues. For example, if you were trying to remember the word ‘rose’. You can think to yourself <i>“it’s a flower with thorns. It smells nice. It is the flower of Valentine’s Day...”</i></li> </ul>

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Communication change	Strategy
Struggling to remember someone's name	<ul style="list-style-type: none"><li>• Say to the person, "sorry I am having trouble remembering your name, what is it again?"</li><li>• Ask a trusted friend or family member to quietly remind you of someone's name.</li></ul>
Forgetting what you meant to say in an important conversation	<ul style="list-style-type: none"><li>• Write down some dot points. This can give you structure and reminders if you lose your place. This is more helpful for conversations where you can plan ahead. For example, when discussing weekend plans with family.</li></ul>

## Staying socially connected

- It is important to stay in touch with family and friends who value you AND build new connections.
  - Regular high quality social connections are good for your mental and physical health.
  - Social activities may help prevent or delay further cognitive decline in people with MCI.
  - Social activities can also help people with early dementia. Social activities help you keep using your brain. This may help to slow cognitive decline.

For example, one person with dementia said:

*"I think it's more than just socialising because it's nice. It's actually socialising to keep your brain working and increase your longevity and capacity in those early stages."*

- You can:
  - Go back to social groups you enjoyed.
  - Reconnect with old friends.
  - Try new hobbies to share with new people.
  - Sign up to classes or social groups that meet regularly.
  - If you are not sure where to find social groups, ask family or friends. You can also contact your local Council.
- You may experience some challenges when socialising due to the symptoms of MCI and dementia. You can try:

Challenge	Strategy
Contacting a new group or going to a group for the first time	<ul style="list-style-type: none"><li>• 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"><li>○ Public transport or carpooling options.</li></ul></li></ul>

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Challenge	Strategy
	<ul style="list-style-type: none"><li>○ Which skill levels are welcome.</li><li>○ If they can accommodate any difficulties you may have. For example, if they provide handouts to support your memory</li><li>● Ask a friend if they can go with you.</li><li>● Remember you may need time to settle into a new activity. Attend at least three times before you decide whether to keep going.</li><li>● Remember that friendships take time to form. Be patient when meeting new people.</li></ul>
Keeping relationships going	<ul style="list-style-type: none"><li>● Reconnect with an old friend. In person catch ups are best. Video or telephone calls are second best.</li><li>● Reach out to friends. Do not wait for others to check in on you.</li><li>● Acknowledge your MCI or dementia diagnosis with your friends and family. It is important to tell friends and family you are grateful for their presence in your life.</li><li>● You may not be able to do as much for your friend as you used to. For example, you may not be able to take your turn hosting dinners anymore. Instead find new ways to socialise with them.</li></ul>
Not feeling motivated	<ul style="list-style-type: none"><li>● You may not feel motivated. This may be partly due to a feeling of grief or loss over activities you used to be able to do or used to have a different meaning to you. The more you do, the more motivated you will feel, and the easier it will get to do things.</li><li>● In person meetings may feel like too much effort. Start with phone calls or video calls.</li><li>● Plan recurring activities with a friend. This makes it easier to get into a routine.</li><li>● You may initially not want to go out or socialise. You will probably find it is okay once you get there.</li><li>● Some days you have more motivation to do it than others. Just keep trying.</li></ul>

Person with dementia experience:

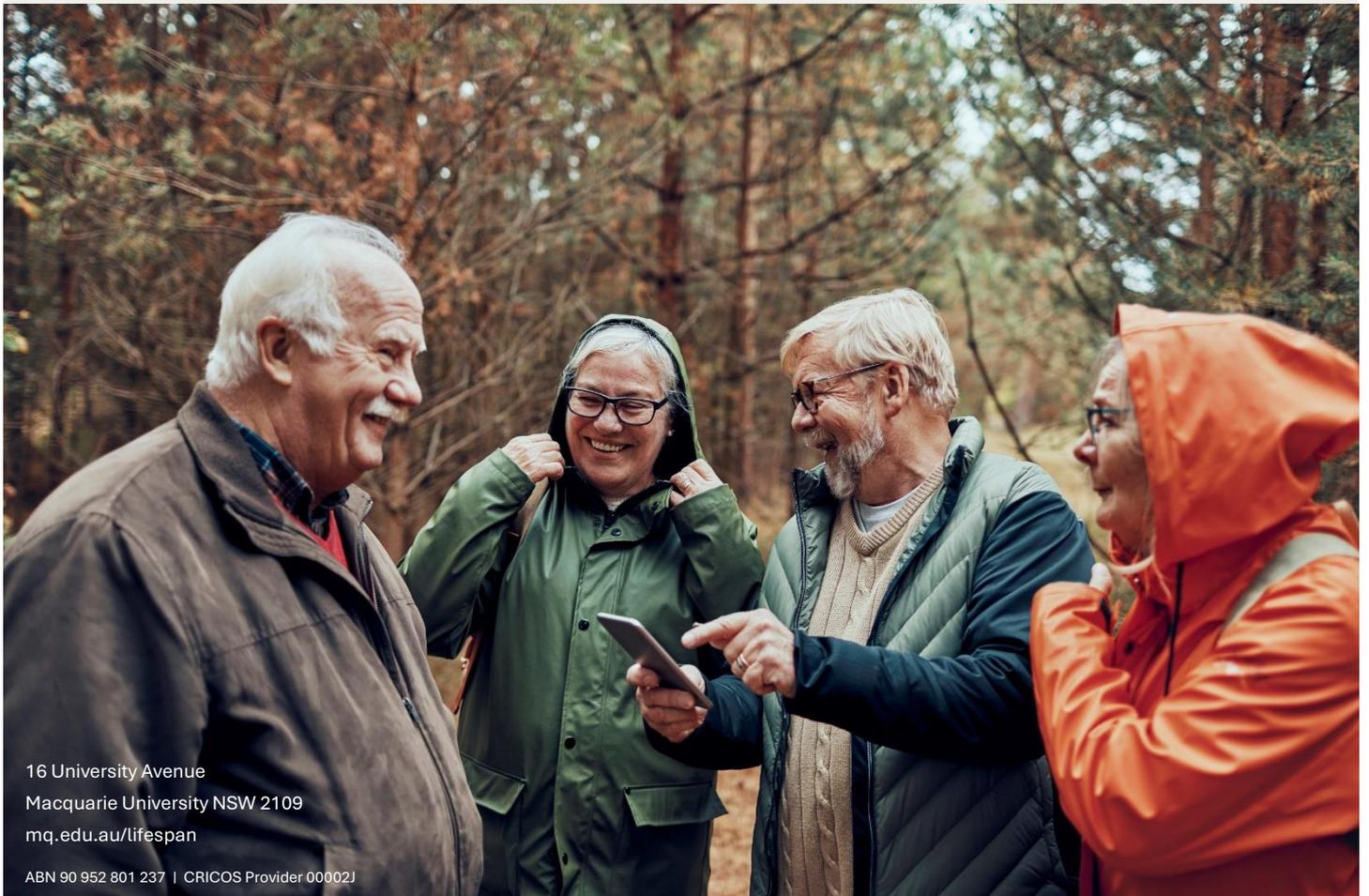
*“By starting new social activities, I made new friends. Volunteering also gave me many new and ongoing opportunities to engage socially with various people”.*



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