

ADDRESSING CHALLENGES

This Help Sheet provides strategies to help deal with some of the everyday challenges that people with younger onset dementia face. It suggests strategies that may help individuals with younger onset dementia to overcome barriers and remain engaged in their family and community life.

A diagnosis of younger onset dementia is life changing for everyone, and adjusting to the diagnosis and the condition will involve enormous challenges: emotional, environmental and social among many others. Learning to identify the nature of these challenges can help people with younger onset dementia, their families and carers to develop effective strategies to apply when they occur. By focusing on strengths and developing individually tailored strategies, people with younger onset dementia may be empowered to remain active and independent for as long as possible.

Managing challenges

Below are some suggested strategies that people with dementia, their families and carers may want to try. It is important to recognise that dementia affects everyone differently, and that there is no 'right' way to deal with the challenges that dementia brings.

Tips for people with younger onset dementia

- Work together with family and or friends to address new challenges as they arise and don't forget to ask for help.
- Simplify the daily routine.
- Write step by step instructions for tasks.
- Draw on the services available to help you. Contact Alzheimer's Australia, join a support group, or make an appointment to see a counsellor or psychologist (and talk to your partner or spouse about coming along too). Not everything will be right for you, but there's no harm in trying.
- Continue to engage in well-learned, familiar tasks to help maintain self-esteem and a sense of purpose. The memories for completing many of these tasks are stored in an area of the brain that is not affected at the early stage of most types of dementia.
- Give feedback to those around you. Discuss what worked well for you and why.

- Use a diary calendar or checklist to help prompt and remind you about appointments and future plans.
- Use mobile phone reminders or the calendar on your computer to plan each day.
- Keep things in labelled boxes, trays or drawers and in set locations – labels need to be in large print.
- Use personal strengths to compensate for the challenges. For example, if spatial and visual skills are strong, use pictures or diagrams instead of written instructions. Or, if verbal skills are strong, use these to talk through issues and to maintain contact with others.
- Use a sense of humour to distract or lift your mood when you think this will help you.
- Recognise when you are tired and take a break.

Tips for families and carers

- Try not to schedule too many events or tasks in a day or a week.
- Try to focus on and acknowledge the strengths that the person with younger onset dementia has retained.
- Try to maintain a familiar and simple routine. Most people with dementia function better in familiar environments where things have been in the same place, or where the same routines have been followed for many years.
- Minimise change and inconsistency when possible.
- Try to identify any 'triggers' for changes in behaviour and work to minimise or avoid these triggers.
- Use a problem-solving approach to help come up with ways to manage challenging situations. Things that have helped in the past may be helpful again.
- Think about the challenging situation and write down observations.

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- When does the challenging situation occur?
For example, if late in the day, it may be when the person with dementia is tired, disoriented by strange surroundings or when there are a lot of distractions.
- Who was present?
- What emotion was expressed?
- How was the challenge responded to?
- Trial and error is a good way to carefully test out what you think might work and to learn from the person's response. Try one strategy at a time for at least a few days or a week to see if it works. If it does not work, consider why before trying another.
- Minimise distractions including clutter or background noise such as radio or TV.
- If a person with younger onset dementia's verbal communication skills are beginning to decline, try talking less and demonstrating more.

Managing visual information

An additional challenge some people with younger onset dementia can experience is difficulty processing visual information. This means they might 'miss' nonverbal information in the environment. They may find it more difficult to pick out an item amongst several others, for example finding milk in the fridge, or the person may begin to misunderstand information such as gestures, facial expressions or other nonverbal cues important for communication and understanding the environment. They could have difficulty identifying local landmarks in their neighbourhood, or even doorways and exits in their own homes.

As a general rule, if a person has difficulty with visual information, it's a good idea to try and reduce visual distraction, and to use systems such as labels, colour coding and verbal cues.

Tips for people with younger onset dementia

- Minimise clutter and mess.
- Store objects in shallow containers that prevent excessive overlap of items, or use separate labelled boxes or files.
- If you have a problem telling left from right, always wear your watch or bracelet on one side so you can use it as a cue.
- Keep objects consistently in their regular place. Create and keep lists or maps of these places.
- Put large print signs on doors and draws for example the bedroom, toilet, kitchen and back door/front door.

- Highlight protruding objects with a sign or bright ribbon.

Tips for families and carers

- Say exactly what you mean in clear simple language as you would if you were talking to the person on the phone. For example, rather than just looking pleased, also say "I am happy with this". If you are annoyed or frustrated say so, rather than just frowning or grumbling.
- Allow plenty of time for the person with younger onset dementia to look at things and take in the visual information.
- In the home, look out for difficulties with depth perception. For example, changed patterns on the floor surface such as striped carpet or tiles may appear to a person with dementia as a step up or drop down. People with dementia may also have decreased ability to see different colours, for example they may find it hard to distinguish between orange and red.
- In the home, try to minimise clutter, and remove items that may be tripped over. Mark or cordon off dangerous edges, or highlight steps that are difficult to see, with for example, masking tape.
- To get to places outside of the home, it may help to assist the person to practice taking frequently used routes to commonly visited destinations. Use noticeable and memorable landmarks to identify key points on the route. When providing directions, use words to describe the route as well as a map.
- Consider a GPS-enabled mobile phone or a personal alert device that the person with younger onset dementia can carry with them and which you or they could use to determine location if they become lost or disoriented. These devices can be very good at helping a person with younger onset dementia retain their independence in walking or visiting shops or friends.

For more information about how to make your home more dementia-friendly, see the website below and follow the links for practical suggestions for each room in your home: www.enablingenvironments.com.au

FURTHER INFORMATION

Alzheimer's Australia offers support, information, education and counselling. Contact the National Dementia Helpline on **1800 100 500**, or visit our website at fightdementia.org.au



For language assistance phone the Translating and Interpreting Service on **131 450**