Tips No. 13

YOUNGER ONSET DEMENTIA

What is younger onset dementia?

Dementia is a term used to describe problems with progressive changes in memory and thinking. Dementia can happen to anyone, and although it is far more common over the age of 65, it can affect younger adults. Younger onset dementia comes in many forms, with the most common types being Alzheimer's disease, vascular dementia, frontotemporal dementia and dementia with Lewy bodies. There are also many rare forms of dementia that may occur in adults. Dementia is not a normal part of ageing.

Changed behaviours

People with dementia can experience behavioural problems due to changes in brain function, or just from not being able to function at the same level or in the same way as before the diagnosis of dementia.

Behavioural and psychological symptoms of dementia may include agitation, aggression, anxiety, wandering and disinhibition. Behavioural and psychological symptoms of dementia vary by individual, the cause and/or stage of dementia.

When working with emotional and behavioural changes you need to develop specific skills and strategies to problem-solve, change the environment, provide support, and deliver feedback and understanding.

Some key differences for younger people with dementia compared to older people include the following:

They may:

• be physically fitter and stronger and have the capacity to physically inflict hurt without intending to.



- be more active and more prone to wandering further distances or they may engage in more physical activities that could put themselves in danger.
- be part of a household with young children at home.
- still be working.
- wish to go out more, impact on more people, or feel the impact of social changes more acutely. Their social networks will often be larger than for an older person.
- find it harder to adjust because dementia is more unexpected at a younger age, similarly, family and friends may also have difficulty in adjusting.
- find it difficult to access appropriate respite or longer term accommodation.

While behavioural changes can be enormously challenging, it is important to understand that the behaviour is due to the condition and that strategies can be put in place that may address it.





Changed behaviours continued

Tips

Emotional reactions

Although some feelings and reactions may be caused by a normal response to the stress of change, some may be specifically caused by the disease process. If you are caring for a person with dementia, try not to take anger reactions personally.

- Talk to each other and try to determine what factors start emotional reactions, and how they may be avoided or minimised.
- Maintain health and fitness as this will facilitate both the strength and concentration capacity to manage.
- Practice relaxation and try to develop good sleep patterns. Fatigue can lead to increased vulnerability to emotions, as well as heightening learning difficulties.
- Keep to standard routines. Change in routine is a common cause of emotional reactivity, as is over-stimulation, or placing too many demands on oneself.
- Remember that difficulties are most likely to be highlighted when carrying out something new, or when in an unfamiliar setting. Be prepared for this and, if you are a carer, provide support where possible to minimise distress or frustration.
- Commence any new situation gradually, and break it down into manageable steps.
- Avoid overwhelming activities or placing unrealistic expectations on yourself.

Reduced Inhibition

The reduced capacity to inhibit responses, verbal output, or behaviour is a common symptom of younger onset dementia. It can, for example, cause a person to be over-friendly, suddenly aggressive, inappropriate, or to say things that they otherwise would keep to themselves. In general they have difficulty holding back on a behaviour or thought or ceasing a stream of conversation. A loss of inhibition especially if combined with impulsivity can lead a person to act in unintentionally harmful or dangerous ways. Consider these possibilities and set up the environment to reduce them.

- Seek feedback from others to learn about when reduced inhibition is happening and how you might address it. Look for nonverbal cues from others to gain a sense of whether they wish to interrupt conversational flow, or whether the person has spoken too long.
- In emotive situations encourage the person with dementia to use relaxation, or self-talk techniques to hold back on a response.
- Teach the person, through practice and example, that observation of other people's behaviour is helpful. They need to learn to consider the way your behaviour makes them feel, and then relate that back to their own behaviour.
- Identify the causes of inappropriate responses and put strategies in place to avoid them.
- Seek help from a professional if having difficulty in managing inhibitions.

Initiative problems

Lack of initiative is not the same thing as laziness. The person is not deliberately avoiding doing tasks or activities and as such it is important not to get angry or frustrated with them.

- Provide a written daily schedule, which sets out activities.
- Structure the day to suit the individual.
- Break tasks down into steps with a checklist to aid completion.
- Develop a checklist which can also act as a prompt, and start to work your way through each item on the list. Putting commencement times against a task may provide a more concrete means of getting the person started.



Changed behaviours continued

- Provide verbal reminders as a simple and useful prompt at certain time points in the day e.g ask the person to have a shower in the morning then ask them to make themselves breakfast etc. However, it is important to mix this up with other forms of prompting to avoid this being perceived as 'nagging'.
- Use an alarm clock to act as a prompt (e.g. for taking medication).
- Present options (two or three at most) to the person rather than waiting for them to generate an idea, for example, 'Would you prefer to have lunch now or go for a walk?'.
- In conversation, provide them with closed ended questions rather than open ones e.g. 'Do you like reading?' versus 'What hobbies do you have?'.
- Start a topic of conversation or direct a question to them in a group conversation, rather than waiting for them to spontaneously converse and engage.

Lack of Insight/Awareness

Sometimes a person with dementia may not be fully aware of the cognitive and behavioural difficulties that they are presenting with and how they are affecting them (and others). They may have lost complete insight, or they may have awareness of some changes but not the more subtle ones. This is thought to occur when the disease is affecting the parts of the brain usually involved in monitoring and criticising our thought processes and behaviour. As a result the person may deny their deficits entirely, or minimise their difficulties. This can lead to unreasonable expectations as to what they are able to achieve, and can impact on their willingness to utilise management strategies or listen to feedback from others. Lack of insight can be one of the most challenging issues to deal with and frequently results in frustration for both the person with dementia and their family.

- Provide the person with frequent, clear and simple explanations for treating an issue in a certain way, or why the person is unable to do something.
- If the person is unable to take on board the feedback, it is best to distract them by changing the subject or removing them from the situation.
- Avoid arguments. This will only exacerbate the problem.
- Understand and educate others also interacting with the person that this denial is not deliberate but due to the changes in their brain.
- Allow for failure within a safe context to aid insight and learning, but be careful to minimise the impact and exposure of a person's weaknesses where possible.



An Australian Government Initiative

You can learn more about dementia and ways to help by contacting Alzheimer's Australia in your State or Territory. National Dementia Helpline 1800 100 500

www.alzheimers.org.au