

## CONFUSION AND DEMENTIA IN OLDER PEOPLE

**Confusion and dementia can occur in adults of any age, but are much more likely in older people. However, they are not a normal part of ageing.**

Topics covered:

- Signs of dementia
- What to do if you are concerned that a person may be developing dementia
- Supporting the person with dementia
- Communicating with the confused person
- Discussing sensitive issues
- Discussions and decisions about driving
- Discussions and decisions about care
- Behaviours that you may find challenging
- Assisting the confused person who is wandering
- Delirium.

### What is confusion?

'Confusion' is a broad term that refers to a decline in normal cognitive ability, which may vary from mild to severe. The cognitive changes may be associated with dementia, delirium or other medical conditions. It may include a number of the following signs and symptoms: lack of alertness, poor attention span, disorientation to time and place, trouble following a conversation, unclear or illogical speech, impaired short-term memory, difficulty in planning and carrying out tasks, inappropriate behaviour, disconnection from reality or delusional beliefs.

### What is dementia?

'Dementia' is a condition involving progressive decline of cognitive abilities such as short-term memory, language and the ability to plan and carry out tasks. Dementia is an umbrella term for a large group of illnesses that cause this progressive decline. The early signs of dementia are subtle and can differ from person to person. However, the symptoms appear over months and years and tend to get worse over time.

*Because of the progressive nature of dementia you may find that some of the strategies suggested in these guidelines are more applicable at the earlier stages, while others will be applicable at later stages.*



## SIGNS OF DEMENTIA

The following signs may indicate a person is developing dementia:

### Cognitive signs

- **Memory loss, e.g.:**
  - Forgetting things more often, and not remembering them later
  - Repeatedly misplacing items by putting them in inappropriate places
  - Forgetting the first part of an explanation by the time the explanation finishes
  - Difficulty remembering much, or any, new information.
- **Difficulty communicating or finding words, e.g.:**
  - Forgetting simple words
  - Substituting inappropriate words.
- **Difficulty with complex tasks or abstract thinking, e.g. forgetting completely what numbers are and what needs to be done with them**
- **Difficulty with planning and organizing, e.g.:**
  - Trouble following a familiar recipe or keeping track of monthly bills
  - Difficulty concentrating and taking much longer to do things than before.
- **Poor or decreased judgement, e.g.:**
  - Giving large amounts to telemarketers
  - Paying less attention to grooming or not keeping clean.
- **Inability to reason**
- **Difficulty with coordination and motor function**
- **Problems with disorientation, e.g.:**
  - Becoming lost on a familiar street
  - Not knowing where they are, how they got there or how to get back home
  - Losing track of dates, seasons and the passage of time.
- **Loss of ability to do everyday tasks**
- **Hallucinations and delusions. Emotional signs**

### Emotional signs

- **Apathy, withdrawal and loss of initiative, e.g.:**
  - Uncommunicative
  - Passive and requiring prompts to become involved.
- **Personality changes, e.g.:**
  - Suspicious, fearful, paranoid
  - Disinhibited or behaving inappropriately
  - Agitated.
- **Mood swings, e.g. rapid changes from calm to tears to anger, for no apparent reason.**

It is important to note that changes in memory or other signs above do not necessarily indicate that the person has dementia, but may be related to other health problems.

*This list is adapted from lists from Alzheimer's Australia ([fightdementia.org.au](http://fightdementia.org.au)), Alzheimer's Association USA ([alz.org](http://alz.org)), and the Mayo Clinic ([mayoclinic.org](http://mayoclinic.org))*



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## WHAT TO DO IF YOU ARE CONCERNED THAT A PERSON MAY BE DEVELOPING DEMENTIA

Early detection of dementia may have benefits for the person, their family's acceptance and the long-term management of the condition.

### Talking to the person about your concerns

If you are talking to the person about your concerns about their memory and functioning, you should:

- Ask the person how they are feeling about their memory.
- Try to keep the conversation positive by focusing on the benefits of early treatment for retaining skills and strengths.
- Explain that you are concerned because you care.
- Try to make the person feel at ease and reassure them that their memory problems are not their fault.
- Reassure them that you care for or love them regardless of their memory and functioning, as this will provide a sense of security for the person.
- Try not to be upset if the person refuses to accept what you are saying.

### Seeking professional help

You should encourage the person to see a doctor if:

- The person shows signs of dementia.
- Others in the person's life are worried about changes in the person's memory and functioning.
- The person is worried that there have been changes in their memory and functioning.

Note that if there is a sudden cognitive deterioration in the person, **immediate** medical attention is required. In some cases, it may be a result of a reversible illness. (See the section entitled 'Delirium'.)

Before the person attends an initial appointment with a doctor, you can help them to prepare for the appointment by thinking about and recording what information would be useful at the appointment, e.g. medical and family history, a list of behavioural or memory changes you have noticed in the person, questions for the doctor. Consider going to the doctor's appointment with the person, so that you can act as an advocate for them. If you attend the doctor's appointment, ask the person's permission to be given confidential information from the doctor.

### If the person is reluctant to get help

The person may be reluctant to visit a doctor because they may not have the insight to realise something is wrong or, if they do, they may be afraid of having their fears confirmed. They may also be embarrassed or upset about their memory loss.

If the person is reluctant to get help, you should:

- Discuss the matter with them and try to identify the reason behind their reluctance.
- Acknowledge any fears or worries the person expresses and help them overcome these by providing care and reassurance.
- Tell them that a doctor's visit will help to rule out any physical or temporary conditions causing their signs or symptoms.



- Suggest that the person go for a general medical check-up.

If the person remains reluctant to get help, identify another individual who has a good relationship with the person to support them to seek help. If the person refuses to seek help and their health or safety is at risk, get aged care assessment services involved.

## **SUPPORTING THE PERSON WITH DEMENTIA**

### **Seeing the person behind the dementia**

You should think of the person as a 'person with dementia' and not a 'demented person'. Even though the person has failing memory or reduced understanding, it does not mean that they do not have a sense of self, personality, or thoughts and feelings. Do not assume that the person cannot learn and enjoy new things. In the earlier stages, the person may still retain much of their intellectual capacity and may still have the desire to be a contributing member of society.

### **Helping the person with their memory problems**

If the person complains about memory loss, acknowledge it rather than dismiss it, e.g. say 'It must be frustrating.' Let them talk about it, unless it seems to upset them more than help them.

You should also be aware of a range of memory strategies that you can use to assist the person. If the person has forgotten that they have done something and keeps asking to do it (e.g. attending a doctor's appointment), consider using the following strategies:

- Repeat the answer, in a kind and reassuring tone of voice.
- Acknowledge the emotions behind the person's concerns.
- Patiently accept the repetition, if the above strategies do not help.

If the person does not recognise what an object is for, consider using the following strategies:

- Explain what it is for in a sensitive manner to avoid the person feeling a sense of failure.
- Demonstrate the use of the item.
- Use step-by-step prompts.
- Acknowledge any frustration the person may be experiencing.

Help the person's memory by providing appropriate information for a situation, e.g. when introducing people, you might say, 'Here's your nephew John and his wife Sharon.' Avoid quizzing the person, e.g. asking 'Do you remember everyone's name?' Also avoid asking questions such as, 'Do you remember?', 'Don't you remember?' and 'Have you forgotten?', because it may upset the person and is unlikely to be helpful. It is best to avoid pointing out any errors the person makes, as this can be discouraging for someone with memory loss.

### **Helping the person to complete tasks**

Use strategies that will help the person maintain as much of their independence as possible and reduce the possibility that the person feels they are being treated like a child or as incapable. You should not blame the person for mistakes that arise from their lack of ability or their misunderstanding of what is needed of them.

If the person is struggling with a task (e.g. dressing), consider using the following strategies:



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- Acknowledge the person's frustration.
- Offer help, or do the task with them, rather than just doing the task for them.
- Explain how to do the task in a sensitive manner to avoid the person feeling a sense of failure.
- Explain to them each step of the way what you are doing in a soft, reassuring way, e.g. 'I am going to help you sit down now. Then we can tie your shoes.'
- Allow plenty of time for the person to complete a task, because they may take longer than they used to.
- Break down tasks into small, simple, concrete steps.
- Use step-by-step prompts.
- Help the person at the point at which they have become stuck.
- Avoid interrupting the person in the middle of a task unless necessary.
- Do not give the person too many things to do at once, as this may increase their level of anxiety.
- Attempt to reduce any stress on the person because stress can increase confusion.

## Helping the person who is disoriented

Do not assume the person knows who you are. It may take time for the person to sense that you are friendly or to recognise you as someone they already know and trust. You may need to introduce yourself to the person each time you talk to them. You should use orienting names whenever possible, e.g. 'Your son, Jack.'

If the person is not oriented to time, adjust your communication to refer to daily events rather than dates or times, e.g. instead of saying, 'John will be here at two o'clock', say 'John will be here after lunch.'

If the person is going to be in an unfamiliar place, try to ensure that they have some familiar people with them.

## Helping the person who has regressed into the past

As the person's memory fails, they may be more likely to live in the moment. However, they may also regress into the past. Regressions into the past are felt as actual current experiences for the person. If the person has regressed into the past, do not dismiss their resultant feelings and thoughts.

If the person talks about deceased people as though they are alive (e.g. a parent who has died long ago), try to understand why they are talking about the person, in case it references a need that can be addressed.

## COMMUNICATING WITH THE CONFUSED PERSON

Try to connect with the person by drawing upon their remaining social skills, e.g. 'Hello, how are you?' and 'Pleased to see you today.' Continue sharing your day-to-day thoughts and feelings with the person, using a warm, easy going and pleasant manner, as it lets them know that they are valued. Encourage the person to continue to express themselves, even if they are having trouble making themselves understood. When assisting the person, treat them with respect by trying to be patient and not talking down to them.

If the person does not talk much, this does not mean that their thoughts and feelings are absent. Pauses in the conversation do not need to be filled with words. Silence is not



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necessarily a negative thing – it can be a way to connect with the person. Be aware that you may have more of a problem with silence than the person does. Do not automatically interpret the person's silence as anger or depression.

## **Gaining and keeping the person's attention**

Your best chance of getting and maintaining the person's attention is to have a one-on-one conversation with the person in a quiet setting. Eliminate or reduce distracting noises, such as television, music or other people's voices. Avoid startling the person by approaching them slowly and from the front, without sudden movements, so that they have time to focus.

If the person does not respond, or if it looks like they are not paying attention, try again after a break when the person may be more focused. Be aware that the person may not be able to attend to a discussion or task for very long. Therefore, look for signs of frustration. If the person does not want to talk, turns away, or says or gestures 'No!', do not force them to talk.

## **Being understood during a conversation**

Look for signs of understanding, e.g. the person's body language and facial expression. However, do not assume that the person understands you because they are nodding or giving a superficial response. In order to increase the likelihood that the person will understand you when talking to them, you should:

- Be prepared to give the person your full attention.
- Establish friendly eye contact when speaking to the person to assure them that they have your full attention.
- Position yourself so that you are at the same eye level as the person, or lower.
- Stay still and ensure that the person can see your face and gestures. This may make it easier for them to follow the conversation and stay attentive.
- Use concrete words (words you can picture), rather than abstract words, idioms, metaphors or slang.
- Avoid expressions that can be taken too literally, e.g. 'shake a leg'.
- Avoid using pronouns, including third person pronouns, e.g. instead of saying, 'Here it is,' say, 'Here is your hat.' Or instead of saying 'he' or 'she', identify people by their actual name.
- Focus on one main idea at a time and avoid discussing too many things at once.
- Use short sentences and pause between them to allow time for the information to be understood.
- Try to use positively framed instructions, and limit the number of negative words, such as 'don't'. For example, say 'Stay here', rather than, 'Don't go away.'
- Adjust the pace of your speech depending on how well the person appears to be understanding you.
- If you have repeated a sentence or question using exactly the same words and the person still does not seem to understand or does not respond, try repeating it in a different way.



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It is also important for you to understand the person. Keep in mind that the person's words and answers to questions may not reflect what they meant to say. Let the person know if you have understood them by providing validation and acknowledgement to the person. You can do this by:

- Listening with interest
- Nodding your head appropriately
- Reflecting back what they have said.

## Communicating in a group situation

If others are present in the conversation, you can include the person by:

- Addressing the person directly
- Using appropriate body language, e.g. facing the person
- Trying to ensure that only one person speaks at a time
- Avoiding interrupting the person in the middle of a conversation, unless necessary
- Letting the person respond for themselves and not answering questions for them.

The person's feelings and behaviours may be affected by the negative actions of others (e.g. patronising or angry behaviour). Even though the person has failing memory or reduced understanding of a conversation, the person still has resultant feelings and emotions, which may last for many hours. Help others communicate with the person by modelling appropriate communication and letting them know what to expect when talking with the person. If you observe someone using baby-talk with the person, take them aside and tell them they need to talk with the person in an adult manner.

## Asking the person questions

Adjust the way you ask questions using either open- or closed-ended questions depending on the purpose of the conversation with the person, e.g. closed-ended questions may be useful for helping the person in an everyday task, whereas open-ended questions may encourage conversation with the person about feelings. Questions that call for short answers may make the person feel successful instead of embarrassed and frustrated over their inability to form and keep in mind a lengthy answer.

Ask one question at a time and avoid questions that require a lot of thought or memory, e.g. don't ask 'What did you do today?' Instead, shape the question to address current feelings, e.g. 'Are you having a good day?'

## Offering the person options

Offer options instead of commands, in order to give the person a greater sense of control over their life. However, be aware that the person may become more confused if they are offered too many options at once. When offering the person a choice, list the available options so that the person can use the information to answer, e.g. 'Would you like tea or coffee?' rather than 'What would you like to drink?'

## Non-verbal communication

Non-verbal communication, including body language and tone of voice, may be more effective than spoken words when communicating with the person. Gestures, facial expressions, props, and non-verbal and visual cues may be helpful in reinforcing your verbal messages. Be aware of your non-verbal cues, such as behaviour, facial expressions, tone of voice and eye contact,



making sure they match what you are saying. Your behaviour may send a message to the person, e.g. non-threatening tone of voice and body language may help to gain the person's confidence in your ability to assist. Conversely, your tone of voice may indicate frustration, and talking loudly or looming over the person may indicate hostility or a threat. Also, your tone of voice or display of emotion may be mirrored by the person, e.g. an anxious tone may trigger anxiety in the person.

A gentle touch of the arm or hand can communicate to the person that you are interested and really care. If you have a close relationship with the person, touch can be a powerful way of connecting with the person and can show you are interested in them and care. However, pay attention to non-verbal cues that may indicate that the person does not want to be touched. Look for and respond to the physical and non-verbal cues that may indicate the person's needs or feelings, e.g. the person who appears anxious or agitated may be in pain, need to go to the toilet or be troubled by something going on around them.

## Challenges experienced during communication

When communication is difficult, try to be patient and do not give up trying to understand the person. There are some things you can do to help overcome communication difficulties. To encourage the person to continue communicating you can show them you are listening by maintaining eye contact, smiling and talking in a gentle tone.

If the person is having trouble expressing themselves, or their words are mixed up and seem nonsensical:

- Listen to the person, because these may have meaning for them.
- Avoid expressing annoyance.
- Let the person know it is all right and encourage them to continue to explain their thoughts without interrupting, speaking for them or 'filling in the blanks' too quickly.
- Smile and say, 'I am having a problem understanding.' This implies that the person is not the problem.
- Focus on and acknowledge the emotion that the person is trying to convey, because this will help the person feel understood even if they cannot find the appropriate words.
- If you think you understand what they are trying to say, clarify this them.

If the person repeats questions or statements over and over again:

- Listen to the person and try to guess what their underlying concern is and reassure them about this, e.g. a repeated question about the time might be because they are worried they will miss an event.
- Avoid expressing annoyance.

If the person begins rambling:

- Avoid looking away or acting distracted because the person will sense the lack of interest and this may close down communication.

If you suspect the person is in pain:

- Point to or touch the area you think might be hurting and ask the person to nod if it hurts there.

Sometimes, the best thing to do is remain silent and let the person find their own way to cope with difficulties in conversation, e.g. 'talk around the topic' before finding the right word or phrase.





Factors in the person's environment may make communication more difficult. A busy, cluttered, noisy or unfamiliar environment may cause distress or confusion for the person. Furthermore, the person may misunderstand aspects of their environment, which may increase confusion or frustration, e.g. mirrors might make the person think there is somebody else in the room. If the person is having communication problems, check that they are not being affected by something unrelated, e.g. their hearing aid may not be working or they are wearing the wrong glasses.

Talking with a confused person may require skilled communication and you may make mistakes. If you feel you have done something wrong when communicating with the person (e.g. acted impatiently), apologise to demonstrate your respect.

## DISCUSSING SENSITIVE ISSUES

*Please note that the guidelines in this section are likely to be most helpful and appropriate for a family caregiver.*

Because dementia is progressive, there will be times when discussions will be needed about major changes in the person's life. If possible, wait until the person is relaxed and focused before trying to discuss a sensitive issue with them, e.g. the person may be more tired or confused in the evening and more responsive after they have rested. When discussing a sensitive issue, such as diagnosis, planning for the future, stopping driving or deciding when to move to a higher level of care, you can use the communication strategies above. In addition, you should:

- Choose a place familiar to the person as a setting for such a conversation, because this is likely to help facilitate communication and minimise anxiety.
- Approach the person in a calm, gentle, non-judgemental manner, because this sets the mood for the subsequent conversation.
- Begin the conversation with neutral topics to help build trust and help the person feel relaxed, e.g. talking about the weather or family.
- Consider enlisting the help of another person who can remain calm and objective.

When discussing topics that evoke a strong emotional response from the person, do not reject or dismiss what the person says about their feelings, e.g. 'Oh, you don't need to worry about that.' Rather, validate and acknowledge how the person is feeling, e.g. 'I can see this is upsetting, that's very understandable.' If the person shows negative emotions (e.g. tearful, angry), take them somewhere private where they can express this without feeling embarrassed.

### Discussing the diagnosis

In preparing to talk with the person about their diagnosis, learn as much as possible about their particular type of dementia. Find out about organisations that provide resources or services to people with dementia and their carers.

Keep in mind that discussions at diagnosis can provide a basis for more detailed discussions later on, e.g. discussions about dementia progression or advice on topics that may be discussed later. When discussing the person's diagnosis:

- Choose how you explain to the person what is happening based on their ability to understand, e.g. a straightforward explanation ('You have dementia') versus a more gentle approach ('You have a memory problem').
- Reassure the person and let them know that they will be supported and helped.



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- Let them know that there are things they can do themselves that can support their memory and maintain their independence.
- Remain open to the person's need to talk about their diagnosis, increased limitations and negative feelings as their dementia progresses.
- Give the person the opportunity to talk about their experiences and how they see themselves as they lose some of their functioning and capabilities.

The person may not acknowledge their diagnosis. This could be due to an inability to understand or a self-protective mechanism to help them cope. If the person does not acknowledge their diagnosis, do not try to force them to recognise it. If needed, get advice from the person's healthcare professionals on how to talk to the person about their diagnosis.

## **Making decisions and planning for the future**

Arrange times to meet with the person to discuss their wishes, concerns and any preferences for the future. Allow the person to make whatever decisions they are capable of making, as long as these do not involve danger to the person or to others. Let the person know that any decisions made about the future can be revisited if they wish to do so.

If the person has concerns about facing the future, reassure the person about the advantages of planning, e.g. 'Don't be scared of planning ahead. It will make life much easier in the future.' It may be helpful for both you and the person to share any sadness and concern about the future.

If the person does not have a Power of Attorney or an Advance Care Directive on relevant topics (e.g. care preferences, management of finances and arrangements after death), encourage or assist them to make an appointment with an appropriate professional to develop these. (See below for more information on Advance Care Directives and Power of Attorney.)

## **WHAT IS AN ADVANCE CARE DIRECTIVE? WHAT IS A POWER OF ATTORNEY?**

### **What is an Advance Care Directive?**

An Advance Care Directive is a document describing how the person wants to be treated when they are unable to make their own decisions due to their present state of illness. In most countries, this is not a legal document; it is an agreement made between the person, their family, and hopefully their usual healthcare professional.

### **What is a Power of Attorney?**

A Power of Attorney is a legal document where the person appoints someone of their choice to manage their legal and financial affairs. In some countries this includes making decisions about health care.

## **Discussions and decisions about driving**

A diagnosis of dementia is not automatically a reason to take away the right to drive. However, while the person might be driving safely early on, their progressive decline in cognitive abilities means a time will come when they will be at high risk of causing an accident.



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While the person may appear to be driving safely, they may:

- Be relying entirely on the habits of driving and may be unable to respond appropriately to a new situation
- Not be capable of reacting quickly to an unexpected problem or making a decision needed to avoid an accident
- Forget unsafe driving incidents and therefore have a false sense of confidence about their driving ability.

Even if the person is currently safe to drive, they can become disoriented and lost, even on familiar roads. Discuss ways that they can communicate with someone should they become lost. Make sure they have appropriate identification in case they need to ask someone for help.

Do not try to keep the person driving longer by acting as a 'co-pilot' (e.g. by giving instruction and directions to the person when they drive), because in an emergency situation there is rarely enough time for instructions to be given and acted upon to avoid an accident.

You should be aware that no examination or single indicator exists to determine when the person poses a danger to themselves or others by driving. However, the following may indicate that the person should stop driving:

- You would not want a child or grandchild to be driven by the person.
- The person has been involved in recent accidents while driving.
- The person is more frequently becoming lost while driving.
- The person modifies their driving behaviour to accommodate changes in skill, e.g. driving shorter distances, driving only on familiar roads, avoiding night driving.

## Talking with the person about driving

It is important to talk to the person about driving issues (e.g. safety and liability), being aware that stopping driving can be a sensitive issue because it may be linked to independence for the person. You should communicate with the person about their driving early, because this can help the person decide on a course of action before an accident occurs. Find out about relevant local laws regarding driving after a diagnosis of dementia. Encourage the person to begin to plan for when they stop driving, e.g. what transport they will use, setting up automatic bill payment online and delivery services.

If the person has had an increase in frequency of unsafe driving incidents, have a discussion with them about restricting their driving. Initiate the discussion about driving in a way that is less likely to lead the person to be defensive about their abilities, e.g. rather than saying, 'Your driving is terrible, you are getting lost, and you're just not safe', you can say 'I am concerned about your safety, how are you feeling about your driving?' Include the person, as far as possible, in decision-making regarding any driving restrictions.

If you are going to have a frank discussion with the person about concerns over their driving ability, be prepared for a wide range of reactions, e.g. sadness, relief, anger, defensiveness.

When discussing driving restrictions, you should:

- Acknowledge how difficult it may be for the person to give up driving.
- Look for ways to help the person save face and maintain their self-esteem, because giving up driving can mean the person admitting their increasing limitations.
- Listen to the concerns of the person, because it will be helpful for them to feel as if their concerns and feelings are being recognised and heard.



## **If the person refuses to talk about driving or is not convinced they should stop**

If the discussion with the person does not go well, do not blame yourself. Remember that the person's impaired insight may be making it difficult to understand that their driving is no longer safe. Try to remain patient, firm and empathetic.

Share observations of the person's unsafe driving with family members and healthcare professionals. Ask the person's healthcare professionals to raise questions about driving safety with the person. A healthcare professional may recommend a driving assessment, e.g. by an occupational therapist. If there has been a driving assessment, you should both agree to abide by the results.

If it is clear that the person can no longer drive safely, do not delay in taking the necessary steps to stop the person driving. If the person is insistent on driving, and you decide to find ways to make driving impossible for the person (e.g. disabling the car in some way or hiding the keys), be prepared for angry or aggressive behaviour from the person and take steps to minimise any possible risk to safety.

## **Once the decision is made to stop driving**

Once the decision is made that the person should stop driving, stand by the decision and be consistent and vigilant in ensuring that the person adheres to any driving restrictions. You may need to remind the person that they should not be driving, because they may forget or decide to continue.

You can help minimise the impact of giving up driving by:

- Being available to drive the person, if possible
- Arranging for home deliveries of medication and groceries, and automatic bill payment
- Asking the person's family members, friends and neighbours to support the person emotionally, socially and practically, e.g. by visiting the person and helping with transportation
- If the person is able, encouraging them to take charge of their new transport arrangements, e.g. by getting details of local transport services and arranging transport with friends or family
- If the person uses their driver's licence as a form of identification, arrange for them to get an alternative form.

If you require further assistance in dealing with the person's driving, call a dementia or Alzheimer's helpline for assistance.

## **DISCUSSIONS AND DECISIONS ABOUT CARE**

A diagnosis of dementia does not automatically mean the person's level of care must change, e.g. they can no longer live alone or that they must leave the family home and move into residential care. However, you should encourage the person who has received a diagnosis of dementia to make decisions in advance about their future care, e.g. what they want to happen if their current living arrangements become too difficult. In planning for future care decisions with the person, consider and discuss with them the range of factors that may impact upon care and living arrangements during the course of the disease, e.g. the health of family members, financial matters and the different stages of the illness.

Find out about the range of care services offered in the person's community that may be useful at different stages of the person's dementia, e.g. respite, day centres and supported

residential care. You can do this by making early contact with any local aged care assessment services to learn about what levels of care may be available to the person in the future.

As the dementia progresses, monitor the person's living situation carefully for risks to safety. Identify any risks in the person's living arrangement and work with the person's health care professionals to lessen them where possible, e.g. using meal delivery services if cooking becomes unsafe. Be aware that the person needs to live in an environment that best supports both their safety and quality of life, and this may mean living at home with support services, even if there is some risk.

There may be times when, because of your own health or the needs of other family members, you are temporarily unable to provide the person with the care they need. Find out about what respite options are available in the event that the person needs to temporarily get care elsewhere.

You should also have a plan in case the time comes when the person's illness advances to the point where it is no longer possible for you to provide the level of care they need, or something happens to you which prevents you from being able to provide adequate care.

## **Deciding whether to change to a higher level of care**

There is no single indicator to determine when a person should move to a higher level of care and it varies between individuals and families. Remember that your physical and emotional health is as important as that of the person.

Include other key people (e.g. the person's family and healthcare professional) in open and honest discussions concerning the person's care and living arrangements, so they can help and support the decision to make a change, when the time comes. A health care professional can give advice on the type of care that the person needs.

A move to a higher level of care may improve your relationship with the person, because time together may be less stressful and free from the worries of practical care. See the box below for considerations for when deciding whether it is time to change the level of care. Keep in mind that it is best practice to move the person's place of living as infrequently as possible.

## **If you are considering a move to residential care**

A move to residential care may not mean less time devoted to caring for the person or that you must completely give up any caring role you have. You may still need to be involved in their care, e.g. checking medications are correct and that daily needs are being met. Remember that moving the person to residential care is not a failure on anyone's part, nor are you betraying the person. It is necessitated by a need for greater care due to the disease.

## **Reactions to the decision to move to a higher level of care**

If you find it difficult to tell the person that they need to change their current living situation, enlist someone to help you, e.g. the person's healthcare professional or someone else they respect.

Be prepared for a range of reactions to the decision, e.g. anger, bitterness, sadness and accusations. The person may not realise the impact that their care needs have on others, or they may be concerned that a move away from home would mean a loss of independence and control in their daily lives.

If the person attempts to get out of newly made arrangements, validate any distress they are feeling, but reinforce the non-negotiable nature of the decision, e.g. 'I realise it is upsetting that you can't live at home, but it is no longer safe for you to do so'.

If you are distressed about having made the decision to change the person's living situation, seek counselling support.

## CONSIDERATIONS FOR WHEN DECIDING WHETHER IT IS TIME TO CHANGE TO A HIGHER LEVEL OF CARE OR A MORE SUPPORTED LIVING ARRANGEMENT\*

- There are signs in the person's house that show they are not managing, e.g. unclean clothing lying around, electrical appliances left on.
- There are changes in the person's appearance, e.g. unexplained weight change, altered grooming standards or poor hygiene.
- The person is not getting an adequate diet.
- The person cannot manage their medication.
- There have been particular incidents or problems, e.g. robbery because a stranger was let in or a door was left unlocked.
- There is risk to the safety of the person or others, e.g. because the person is forgetting to turn off the stove, falling on stairs or unresponsive to emergencies.
- There are challenging behaviours that require greater supervision, e.g. wandering or aggression.
- The person is no longer able to recognise or interact with their environment.
- The risks of the current living arrangement (e.g. safety issues) outweigh the benefits e.g. independence and familiar location.
- There are suitable alternative forms of care available for the person.
- There are others who can help with caregiving in the person's current living situation.
- The strain on caregivers or family has become too great, e.g. night time restlessness is keeping others from getting a good night's sleep, or around-the-clock care is too stressful or overwhelming.
- The person's values, views, history or preferences would be consistent with the proposed change.

*\* Some of the items in this list may only be appropriate when considering a move into residential care, while others may apply when considering any change to the level of support a person is receiving.*

## BEHAVIOURS THAT YOU MAY FIND CHALLENGING

If the person shows challenging behaviours, remember that it is no one's fault and that they are not behaving this way on purpose to annoy or irritate. It is likely that their illness is causing the behaviour. They may also be frustrated by a loss of skills and an increasing dependence on others.

Challenging behaviour may not be meaningless or random. The person may have a need that they cannot communicate, or there may be an underlying psychological issue, such as anxiety or depression. Try to identify any needs underlying the behaviour and help the person to meet those needs.



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When you are feeling challenged by the person's behaviour, do not argue or try to reason with them if they no longer have the ability to do so. In an emotionally charged situation, where you think you might lose control, remove yourself, if possible, and return when you feel calmer.

## Resistance

Rather than asking questions that are likely to trigger immediate resistance (e.g. 'Do you want to take a shower?'), break the task down into steps and use statements rather than questions, e.g. 1. 'I will walk you to the bathroom', 2. 'Put your hand under the water and tell me if it is the right temperature', etc.

## Arguments

Arguments may develop from the person's frustration and are not necessarily a reflection on you. Avoid arguing with the person, because this is likely to cause the person to become angry, anxious, frustrated or more confused. If an argument develops, acknowledge the person's feelings and frustrations, and change the topic of conversation or begin a new activity.

## Agitation

Agitation can occur every day at around the same time for some people (e.g. around sunset) and will eventually pass. Loud noises, an over-stimulating environment, or physical clutter may also cause agitated behaviour.

If the person becomes agitated, you should react calmly and reassure the person that they are safe and that everything is under control. If the person is pacing and it is safe to do so, let them pace. Be careful about touching the person who is agitated or

## Anger and aggression

There are some common reasons for anger or aggression in a person with dementia, e.g. situations where the person feels trapped, controlled, fearful, humiliated or helpless, or where there are changes in surroundings or routine. If the person is angry or upset, do not argue with them, try to explain away the anger, or restrain them, as this might make things worse. Remain calm and, if possible, move the person elsewhere in a quiet, unhurried way.

If you are concerned about the person becoming aggressive, remove potentially dangerous objects from the environment. If the person becomes aggressive, leave the room, if it is safe to do so, and give the person the time and space to calm down. If anyone is at risk of harm, contact emergency help.

Avoid physically restraining the person, as this may make them feel fenced in and they may become more aggressive. However, if nothing else works, and there is risk of harm to the person or others, physical restraint may be necessary.



## Disinhibited and inappropriate sexual behaviour

If the person engages in disinhibited or inappropriate sexual behaviour, do not show shock or disapproval, or make fun of the behaviour. React with patience and gentleness, even though the behaviour may be embarrassing, and guide the person to a private place.

Consider ways to modify the environment to reduce the triggers for this behaviour, e.g. not going out in public or having visitors at times of the day when the problem behaviour is more likely to occur, or having a different person help with showering.

## Delusions and hallucinations

**Delusions** are false beliefs, for example of persecution, guilt, having a special mission or being under outside control. Although the delusions may seem bizarre to others, they are very real to the person experiencing them. Be aware that the person may appear to have a delusion because they misidentify people or misinterpret situations and feel threatened. Similarly, they may have gaps in their memory, which they compensate for by creating a false story, which they believe to be true.

**Hallucinations** are false perceptions. Hallucinations most commonly are auditory, such as hearing voices, but can also involve seeing, feeling, tasting or smelling things. These are perceived as very real by the person, but are not actually there.

If you think the person is experiencing delusions or hallucinations, you should:

- Approach them cautiously, trying not to startle or frighten them.
- Acknowledge any fear they may have.
- Comfort the person in the same way you would if their experience was real, by responding to the person's emotional tone, e.g. remind the person that you are with them, tell them they are safe, or say something like 'I didn't hear anything, but I know you are frightened. I'll look around to make sure everything is okay'.
- Respond in a calm, supportive manner and offer reassurance.
- Try to reduce factors that may be contributing to the delusions or hallucinations, e.g. unclear background noises, darkness or being alone.
- Check if the person has had enough to eat and drink, and had enough sleep.

Do not:

- Try to reason with the person about
- their delusions or hallucinations
- Agree with the delusions or hallucinations
- Argue or confront the person about whether the delusions or hallucinations are real.

Delusions and hallucinations can be a sign of delirium, which is a medical emergency. (See section on Delirium.)



## ASSISTING THE CONFUSED PERSON WHO IS WANDERING

**Wandering** is a dementia-related behaviour that sees a disoriented individual move about, sometimes with repetitive pacing or lapping in one area, and at other times leaving their usual environment. A wandering person may become lost, leave a safe environment or intrude in inappropriate places.

### How to tell if a person is wandering

A person who wanders may do so for a variety of reasons, e.g. they have set off to go somewhere and forgotten where it was they were going, are searching for a place from their past, believe that they have a job to do, or are bored. There are signs that can help you recognise that a person is wandering and needs help, these include:

- Wearing inappropriate clothing
- Having an unsteady gait
- Behaving in an unsafe or inappropriate way
- Appearing restless
- Pacing
- Displaying repetitive movements.

*This list is adapted from a list from Alzheimer's Association USA (alz.org)*

Do not assume that a person who appears to be wandering is necessarily confused, e.g. the person may want exercise.

### What to do if you encounter someone who is wandering

If you encounter a person who is wandering, be aware that they may have impaired judgement regarding their own safety and that they may have health problems affecting their movement and orientation, e.g. moving is painful or their eyesight is poor. You should:

- Introduce yourself to the person and offer help.
- Adopt a caring attitude and an approach that communicates warmth and respect, because this will confirm that you are not a threat and that you have the person's best interests at heart.
- Try to understand the person's perspective about why they are wandering, because this may assist you to respond in an appropriate way.
- Ask the person if you can contact a family member or friend.
- See if the person has any needs that you could help them meet, e.g. they may be thirsty, hungry or need to go to the toilet.
- Check whether the person is injured because they may be unable to communicate that information effectively.
- Try any approach that may help you connect with the person and gain their trust.
- The person who is wandering may become frightened, which could further reduce their ability to cope. If you encounter a person who is wandering and they look scared or anxious, engage them in conversation and attempt to calm them down and gain their trust.

If you know the person who is wandering and know where they live, quietly join the person and, in a friendly calm manner, engage in light conversation, e.g. asking the person, 'Where are you going?' or 'How is your day going?' After a short while, suggest something to change the direction of the walk, either sitting down for a moment or making a turn.



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Don't leave the person who is wandering alone, especially if they are distressed, and even if they decline your help. However, only attempt to provide assistance if you can do so without putting yourself in danger.

## **Ways of identifying people who wander**

There may be a local ID system for identifying and helping people who are confused and lost, or there may be a local organisation that provides identification cards or bracelets for people who wander. Check if the person has any identification or a tracking device on them that will provide you with useful information to be able to contact the person's home or carer.

## **Contacting emergency services**

If you cannot find out any of the person's emergency contact information, suggest that they sit and have a chat with you, while you quietly call emergency services. You should also call emergency services if you are very worried about the person's health or safety. When emergency services arrive, sit down with them and talk quietly with the person to see how you can help.

## DELIRIUM

**Delirium** is a condition where a sudden and obvious worsening of a person's usual level of functioning appears over hours or days. Delirium can involve problems with attention, awareness, orientation to environment and other areas of cognitive functioning. It is caused by an underlying disease or environmental factors, such as medication or infection. Delirium more commonly occurs in an older person, however, it can occur in a younger person as well. People with dementia are also more likely to develop delirium.

### Delirium is a medical emergency

Delirium is a medical emergency requiring immediate medical help. If you suspect the person is experiencing delirium, contact a doctor immediately and inform them of the sudden changes in the person, and arrange an appointment. Be prepared to provide information about the person's changes in behaviour or physical function, past medical history and current medications, noting any new medications or changes in dosage. You can do this by writing down your observations about the sudden changes in behaviour and physical function, e.g. when the confusion or other problems began.

### If you are caring for a person with delirium

It can be comforting for the person experiencing delirium to see familiar faces and friends, especially if the person is in hospital. However, you should inform any visitors of what to expect of the person.

Being in a delirious state may reawaken past distressing or frightening experiences for the person, and these may be experienced as reality or as part of a dreamlike state. If you know that the person experiencing delirium has had previous experiences of trauma that may be affecting their current emotional state (e.g. being trapped, frightened or very ill), tell the health professional caring for the person. Let staff know if there is anything they could say or do that will make the person feel more at ease or reassured.

If you are caring for a person with delirium, you should:

- Talk clearly and slowly.
- Ensure the person gets adequate food and fluids.
- Orientate the person to their environment, i.e. remind them where they are, what time of day it is and who you are.
- Reduce distracting noises, such as radio and television.
- Ensure there is adequate lighting.
- Ensure the person has their comfort items, e.g. familiar blankets, photos, favourite music or clothing.
- Check that the person is wearing their hearing aids or glasses.
- Monitor the person to protect them from falls and dangerous objects.
- Introduce yourself each time you see the person, if necessary, and do not take it personally if they fail to recognise you.
- Use nicknames or other familiar phrases that are likely to be reassuring.
- Avoid sudden movements that may frighten the person.
- Try not to over-excite the person with too much activity.



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## **PURPOSE OF THESE GUIDELINES**

These guidelines are designed to help a family member, friend, neighbour, concerned community member or a paid carer without specialist qualifications to provide assistance to an older person experiencing confusion or cognitive changes associated with dementia, delirium or another condition. The role of the helper is to assist a person who may be developing dementia or delirium, is experiencing a worsening of existing dementia symptoms or is in a crisis due to their confusion. Older person refers to those aged 65 or older. However, it is expected that the resulting guidelines may also be relevant to assisting adults with confusion who are younger.

## **DEVELOPMENT OF THESE GUIDELINES**

These guidelines were developed using the Delphi research method, which involves systematically determining the expert consensus of panels of people with expertise in dementia and delirium, either as a carer or professional. The experts were from Australia, New Zealand, Ireland, the UK, and the USA.

Details of the methodology can be found in: Bond KS, Jorm AF, Kitchener BA, Kelly CM, Chalmers KJ. Development of guidelines for family and non-professional helpers on assisting an older person who is developing cognitive impairment or has dementia: a Delphi expert consensus study. *BMC Geriatrics* 2016; 16:129.

## **HOW TO USE THESE GUIDELINES**

It is important to tailor your support to the needs of the person you are helping. These guidelines are a general set of recommendations only, and most suitable for providing mental health first aid in high-income countries with developed health systems.

These guidelines have been developed as part of a suite of guidelines about how to best assist a person with mental health problems. These other guidelines can be downloaded from:

[mhfa.com.au/resources/mental-health-first-aid-guidelines](http://mhfa.com.au/resources/mental-health-first-aid-guidelines)

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Mental Health First Aid Australia. Confusion in older people: MHFA Guidelines. Melbourne: Mental Health First Aid Australia; 2015.

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