

Supplementary Information: Dementia



Please, read this information in conjunction with the Supporting Individuals in Distress - Adults course booklet which has a section on supporting Older Adults.

What is dementia?

The term 'dementia' describes a set of symptoms which include loss of memory, mood changes and problems with communication and reasoning. It affects over 850,000 people in the UK, with numbers set to rise to over 1 million by 2025. This will soar to 2 million by 2051.

Dementia is progressive, which means the symptoms will gradually get worse. How fast dementia will progress depends on the individual person and what type of dementia they have. Each person is unique and will experience dementia in their own way. It is often the case that the person's family and friends are more concerned about the symptoms than the person may be themselves.

Symptoms of dementia may include the following:

- Loss of memory - this particularly affects short-term memory, for example forgetting what happened earlier in the day, not being able to recall conversations, being repetitive or forgetting the way home from the shops. Long-term memory is usually still quite good.
- Mood changes - people with dementia may be withdrawn, sad, frightened or angry about what is happening to them.
- Communication problems - including problems finding the right words for things, for example describing the function of an item instead of naming it.

In the later stages of dementia, the person affected will have problems carrying out everyday tasks and will become increasingly dependent on other people.

More information about dementia is available on the Alzheimer's Society website: <https://www.alzheimers.org.uk/>

Dementia affects more than a person's memory, it can also affect the following:

- What people see, or how they interpret what they see
- What people hear, or how they interpret what they hear
- The language and words people use (we may think they are using the right word for something when we are not)
- How people react to things and their emotions
- How people relate to others

- Individual's coordination skills in tasks/ actions e.g. walking, eating, swallowing, dressing, etc.
- Physical ability / habits – knowing when they are hungry, knowing when they need the toilet, knowing when to sleep etc.

Dementia care and distress

As carers working with older people with dementia, you will be involved in looking for the reason for, or the triggers of behaviours. Many of the individuals you work with may not be able to verbally express how they are feeling, what they want or need. You will need to know about the individual's history and be observant to help them when they become distressed. Know how to distract an individual because some may think that they need to pick up children from school, cook tea, go shopping, go to work; activities or routines that in their adult life they would have done. Reassuring them is very important so that they won't worry.

As the disease progresses and an individual becomes more dependent, it is still important that we encourage them to maintain their independence and give them a sense of purpose. Encouraging people to complete tasks that they are able to do is essential e.g. folding napkins or cooking. Finding out the music and films that they like and playing it for them, reminiscing using their family photos or objects can be especially important as their mobility decreases. Place objects of interest where they can be seen and reached, and encourage any conversation where possible. This could be as simple as sorting through a handbag or showing a DVD about a place that is significant to them; use any triggers to stimulate a memory.

Behaviours of Distress

This information is taken from, 'Behavioural Challenges When Supporting a Person with Dementia,' from the Social Care Institute for Excellence. Read in full here:

<https://www.scie.org.uk/dementia/living-with-dementia/difficult-situations/>

Aggressive Behaviour

Aggressive behaviour is by no means a common response from people with dementia. Only rarely is it actually a symptom of dementia. If aggression does occur, the most likely reason is that the person is reacting to a distressing situation.

Some reasons why a person with dementia might be aggressive include:

- The person might be feeling unheard or misunderstood.
- The person might be feeling threatened or frightened.
- The person might be feeling embarrassed, frustrated or annoyed because they need help to do things they used to do independently.
- The person might be asserting their own wishes when others are trying to make them do something they don't want to do.
- The person might be in pain.

A Different Reality

Some reasons why a person with dementia may have a 'different reality':

- Asking for a close relative who has died can indicate, for example, a need for closeness, acceptance, affection, or something specific that the relative used to do (for example, a favourite meal that the relative used to cook).
- A person's belief that they still work or have young children can indicate, for example, a need for being involved in an activity that has value or purpose, or the need to feel needed.
- A person who sees or hears something that isn't there may be experiencing a hallucination, which could be a symptom of their dementia or might indicate an infection or side effects from medication. Alternatively, the person might be confused by something that they can see or hear. For example, flowery wallpaper could be mistaken for insects on the wall, or a person coughing in the next room could be mistaken for a dog barking.

A person with dementia may believe that things from the past are happening now or may see things that aren't there: this is their reality. The person's 'reality' will often be just as real to them as our 'reality' is to us. Both telling the truth and lying can cause distress. It's better to respond to the person's feelings and try to address their needs.

Problems Related to Using the Toilet

People with dementia may experience difficulties with their continence for a number of reasons. These problems can often produce strong feelings in the person, such as embarrassment and anxiety.

Repetition

Memory problems in dementia often cause people to repeat themselves. This may test our patience, but there are various things we can do to help. Memories that are shared frequently are often very significant for the person.

Walking

People with dementia might walk for a variety of reasons. Once we understand the reason, we know whether there's anything we need to do. If we are concerned that the person is at risk, we need to give full consideration to the person's abilities and difficulties to come up with a plan that meets their needs.

Refusing Help

There are many reasons why a person with dementia may not be prepared to do exactly what we would like them to do. A person with dementia should not be expected to follow our wishes or conform to our standards, in fact, we should be doing our best to cooperate with them. We need to consider our approach and to gain as much knowledge as we can about the person, their standards and preferences.

Sexual Expression

It is perfectly natural and normal for people with dementia to have sexual needs. 'Inappropriate sexual behaviour' may be labelled as such because of other people's prejudices or preconceptions. Staff can give sensitive support to help people to express

their sexuality appropriately. Behaviour that seems sexual may actually be prompted by other needs. Having dementia does not automatically mean that a person lacks capacity to consent to sex. We need to uphold people's rights to privacy.

Being Withdrawn

People with dementia do not inevitably become withdrawn. Often, becoming withdrawn is a response to isolation, boredom or low self-esteem and indicates unmet physical or psychological needs. People with advanced dementia may not be able to interact much, but they may still be very alert to what is going on around them. When a person is withdrawn, never treat them as if they're not there. It is important to try to find ways of making contact with people who are withdrawn.

The following is sourced from - [alzheimers.org.uk](https://www.alzheimers.org.uk)

Ways to support a person with dementia

When someone's behaviour changes in a way that causes difficulties for them or you, there are a number of ways to support them. Many of these don't involve drugs and should be considered <https://www.alzheimers.org.uk/> first, including:

- supporting them to take part in activities they enjoy or find useful (for example making music or exercising)
- spending time with them – having a cup of tea and a chat with them, or doing something together - being present
- helping them to have a daily routine
- psychological therapies with professionals, such as cognitive stimulation therapy or reminiscence therapy
- adapting the environment if this is affecting the person (for example if it's too hot, cold, loud or bright).
- being aware of their beliefs and thoughts and trying not to argue with them. For example, if they believe they need to go and collect their children from school, don't tell them they're wrong -instead ask them to tell you more about their children.

Repetition

Often if someone is repeating the same question, they need reassurance rather than information. For example, if they keep asking what day it is they may need reassuring they haven't forgotten something rather than needing to know that it's Monday.

Repetition can be exhausting and frustrating, especially if you haven't been able to take a break. Try to remember that the person isn't being difficult on purpose. It can also be frustrating for people with dementia, especially if their questions are unanswered and they are left feeling anxious and insecure.

Shouting and screaming

- Don't ignore or talk over the person. Involve them in what is happening and explain what is going on.
- The behaviour may be a response to them not understanding your intentions. For example, if you're helping them get dressed or undressed they may not understand why. Providing clear directions about what you're doing and why. Always give people time.
- Try to make sure the person spends time with others and has things to engage their senses (such as smells that prompt memories or objects they can play with). Think about whether the environment could be causing the person distress or not meeting their needs. For example they may not be able to find the toilet, or bad lighting may be causing shadows, which can be confusing.

Sleep Disturbances

A person with dementia may keep getting up during the night and may become disoriented when they wake up. They may get dressed or try to leave the house. This might make the person tired during the day and they may sleep for long periods, which might be very stressful for you. The person may have problems during the night but not realise they've had them - telling them so the next day may just add to their distress.

Dementia can affect a person's sleep patterns. This is separate and different from normal sleep difficulties that come with getting older. It can cause problems with the sleep-wake cycle and also interfere with the person's 'body clock'. Disturbed sleep can have a negative impact on a person's wellbeing (and those living with them). The tips below may help.

- Make sure the person has plenty of daylight and things to do during the day.
- Think about improving the sleeping environment. Make sure the room is a comfortable temperature with the right amount of light. If it's too light, consider blackout blinds.
- Avoid drinks containing caffeine (such as tea, coffee and cola) after 2pm.
- Avoid alcohol in the evening.
- Consider a clock next to the bed that shows whether it's day or night.
- If the person likes to have something to cuddle, consider a soft toy.
- Going for a walk, having a warm milky drink, or having a bath or shower before bed may help the person relax.
- Gentle exercise may help someone to sleep - but they should try to avoid exercise too close to bedtime.

- Make sure the person's home is safe – leave a light on in the hall and toilet; consider a nightlight in the bedroom and remove any trip hazards (for example loose rugs or furniture in the way).
- If the person wakes up at night, try gently reminding them that it's night-time.
- Having a low mood can contribute to poor sleep. If you think the person may be depressed see the GP.

Hoarding and Hiding

This can be very frustrating if you have to spend time finding things or trying to find out from the person where they are. It can be frustrating and distressing for the person as well, as they may think someone is taking things from them. Hiding and hoarding may be an attempt by the person to have some control of their situation. The person may also feel paranoid or have delusions and believe their things will get stolen, so they may try to hide or protect them.

A person with behavioural variant frontotemporal dementia (FTD) may be more likely to hoard.

- Consider a hoarding box or drawer where the person can put objects they want to keep safe.
- Try to work out where the person seems to hide things, then show the person you're helping them to find them.
- If the person becomes anxious about lost items, try to reassure them and help them feel better.
- Don't leave important documents or items lying around - the person may move them to keep them safe for you.
- Keep a spare set of things that are often lost, such as keys or glasses.
- Consider assistive technology (such as a locator device) to help people find objects.
- If the person hides food or other perishable things, check their 'hiding places' regularly, and throw out things that have gone bad.

The most common accusations are that others are trying to steal from them or harm them. They may also accuse their partner of being unfaithful, or of being an impostor. Being falsely accused can obviously be distressing. Often the person's accusations are based on a delusion or hallucination.

Trailing and Checking

They might ask to go home when they're already there. This can be frustrating, tiring and upsetting for you and the person.

Living with dementia can make people feel insecure and anxious. They may feel a constant need to be reassured, because the world around them no longer makes sense.

This is why they may follow you around and look for reassurance that they are not alone. They may also have forgotten where you are and follow you to check you're still there.

Trailing and checking may also show the person has other unmet needs. For example, if they are asking for parents who have died, or asking to go home when they are actually in their home, it may show they need to feel secure and safe.

Always try to find out the underlying need behind what the person is asking for, including how they're feeling. This will help you think about how to meet that need. Just telling them the truth (for instance, that the person they're asking for has died) might not help, and may make the person feel more upset and distressed.

Document a plan for the individual on how to manage the behaviours specific to them.

- Being with the person may reassure them. Keep close to them when you have tasks to carry out. For example, you could do the ironing in the living room while the person listens to the radio.
- If the person is [asking to go 'home'](#), try to understand and acknowledge their feelings and reassure them that they are safe. Their need may be more related to a feeling of 'home' as a place of safety and security than an actual place.
- If the person is calling for someone from their past, try talking to them about this period in their life and respond to the feelings the person is showing.
- Think carefully about whether to tell the person things that may cause them distress, even if they're true. For example, if the person is asking for their partner after they've died, it may be better to comfort them and talk to the person about their partner.

Loss of Inhibitions

Losing inhibitions can include being rude, saying things that aren't appropriate (for example that someone is overweight), talking to strangers, undressing in public, and apparent sexual disinhibition (for example touching themselves inappropriately in public).

This can be embarrassing and distressing for both the person with dementia and those around them. They may not understand that what they are doing is inappropriate. It is unlikely that they are being inappropriate on purpose. Always respect the person and their dignity, and try not to cause them any distress.

Some common causes of a person losing their inhibitions include:

- certain causes of dementia and the area of the brain that is affected. For example, some people with frontotemporal dementia (FTD) lose inhibitions because of damage to the frontal lobes in the brain
- needing the toilet (which may explain why they're touching themselves) or being too hot (which may explain why they're undressing)
- boredom or wanting to talk to someone

- sexual frustration.
- Try to stay calm and remember the person is not behaving like this on purpose.
- In some situations it may help to think about whether the behaviour really matters. For example, in some situations talking to strangers may not be a problem. The person may be meeting a need to be social and the stranger may be happy to talk to them.
- Try gently distracting the person.
- Be aware of possible triggers for certain behaviours. If you know what these are you may be able to prevent the behaviour from happening in the first place. For example, if someone behaves in a sexually inappropriate way when you help them to get changed, they might be misinterpreting your actions. Try to change how you approach the situation and see if this helps.
- If the person is undressing, take them somewhere private, and check whether they are too hot, uncomfortable, or want to use the toilet.
- If the person behaves rudely, don't attempt to argue or correct the behaviour. Try to distract their attention.
- It may help to explain to other people why the person is behaving in that way. They may be more understanding if they know why something happens and they may have some suggestions to help find solutions.

Sundowning

Sundowning is a term used for the changes in behaviour that occur in the evening, around dusk. Some people who have been diagnosed with dementia experience a growing sense of agitation or anxiety at this time.

Sundowning symptoms might include a compelling sense that they are in the wrong place. The person with dementia might say they need to go home, even if they are home; or that they need to pick the children up, even if that is not the case. Other symptoms might include shouting or arguing, pacing, or becoming confused about who people are or what's going on.

As the day goes on, the person with dementia becomes more tired, and this can lead to their symptoms worsening. Hunger, thirst and physical pain can also play a part. As darkness falls, street lights come on and people settle in for the evening and some people with dementia become increasingly concerned that they are in the wrong place.

<https://www.dementiauk.org/get-support/understanding-changes-in-behaviour/sundowning/#:~:text=Sundowning%20is%20a%20term%20used,are%20in%20the%20wrong%20place.>

It is important that any behaviour is not just dismissed as 'sundowning' when it is in fact trying to meet a need. An individual may be trying to communicate with you, rather than behaving a certain way just because daylight is beginning to fade. Always consider what other reasons there may be for a person's behaviour.

This pattern of behaviour may continue for several months and often happens in the middle and later stages of dementia.

The causes of Sundowning are not well understood.

- disturbance to the 24-hour 'body clock' that tells our bodies when to sleep, caused by the physical changes to the brain
- loss of routine at a previously busy time of day
- too little or disturbed sleep
- too little or too much light
- prescribed medication wearing off
- medications that worsen confusion and agitation
- lots of noise
- other conditions such as sight or hearing loss.

<https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/sundowning>

What can be done to help?

Be aware of sundowning in the late afternoon and early evening and look for early signs. These signs may include increased confusion or anxiety and behaviors such as pacing, [wandering](#), or yelling. If you can, try to find the cause of the person's behavior.

- If the person becomes [agitated](#), listen calmly to his or her concerns and frustrations. Try to reassure the person that everything is OK and distract him or her from stressful or upsetting events.
 - Try to support the person to do things they find relaxing and enjoyable at this time of day.
- It might help for the person to avoid daytime naps, although some people find a rest after lunch helps if they get tired during the day. You will need to know the individual you care for and what is in their behaviour / care plan.
- Natural daylight during the hours of light can help the person – try to support them to get as much as possible by getting outside or sitting by a window.
 - make sure curtains are open and other objects aren't covering windows.
 - Light boxes can be of use to increase exposure in the winter months.
- Try to distract the person with a favorite snack, object, or activity.
 - offer a drink, suggest a simple task like folding towels, or turn on a familiar TV show (but not the news or things that might be upsetting or too exciting).
- Make early evening a quiet time of day.

- You might play soothing music, read, or go for a walk. You could also have a family member or friend call during this time.
- Reduce noise, clutter and the number of people in the room.
- Think about the environment -
 - Close the curtains or blinds at dusk to minimize shadows and the confusion they may cause.
 - Turn on lights to help minimize shadows, but make sure that they are not too bright.
- Make sure people get enough rest at night; being too tired can increase late-afternoon and early-evening restlessness

<https://www.nia.nih.gov/health/tips-coping-sundowning>

What can make Sundowning worse?

- coffee, cola, or other drinks with caffeine late in the day.
- [alcoholic drinks](#); they may add to confusion and anxiety.
- too many activities during the day; a full schedule can be tiring.

Document the things that work for individuals and things that can make things worse.

If Sundowning Problems Persist

If sundowning continues to be a problem, seek [medical advice](#). A medical exam may identify the cause of sundowning, such as pain, a sleep disorder or other illness, or a [medication side effect](#).

NICE GUIDELINES - ng97

Read in full here - <https://www.nice.org.uk/guidance/ng97>

1.7 Managing non-cognitive symptoms - Agitation, aggression, distress and psychosis

1.7.1 Before starting non-pharmacological or pharmacological treatment for distress in people living with dementia, conduct a structured assessment to:

- explore possible reasons for their distress and
- check for and address clinical or environmental causes (for example pain, delirium or inappropriate care).

1.7.2 As initial and ongoing management, offer psychosocial and environmental interventions to reduce distress in people living with dementia.

1.7.3 Only offer antipsychotics for people living with dementia who are either:

- at risk of harming themselves or others or
- experiencing agitation, hallucinations or delusions that are causing them severe distress.

1.7.4 Be aware that for people with dementia with Lewy bodies or Parkinson's disease dementia, antipsychotics can worsen the motor features of the condition, and in some cases cause severe antipsychotic sensitivity reactions.

1.7.8 Ensure that people living with dementia can continue to access psychosocial and environmental interventions for distress while they are taking antipsychotics and after they have stopped taking them.

1.7.9 For people living with dementia who experience agitation or aggression, offer personalised activities to promote engagement, pleasure and interest.

1.7.14 For people living with dementia who have sleep problems, consider a personalised multicomponent sleep management approach that includes sleep hygiene education, exposure to daylight, exercise and personalised activities.

Suggested Further Reading

The Alzheimer's Society has a guide for those with dementia and those who care for a person with dementia.

<https://www.alzheimers.org.uk/publications-about-dementia/the-dementia-guide>

<https://www.alzheimers.org.uk/get-support/publications-factsheets/caring-person-dementia-practical-guide>

Explore The Alzheimer's Society website: <https://www.alzheimers.org.uk/>

The relationship between pre-morbid personality and challenging behaviour in people with dementia: a systematic review. Osborne et al (2010). Social Care Institute for Excellence.

<https://www.scie-socialcareonline.org.uk/the-relationship-between-pre-morbid-personality-and-challenging-behaviour-in-people-with-dementia-a-systematic-review/r/a1CG000000GLvsMAG>

NHS Dementia Guide <https://www.nhs.uk/conditions/dementia/>

Restraint Reduction Network Training Standards (2019)

Appendix 8 Specific considerations and adaptations to the training standards for services supporting older people and people who are living with dementia.

- People with dementia can benefit from a high level of input from family carers or family members. They can both help the individual make sense of what is happening around them and provide insight and information that can be invaluable to the care team. The individual can have a complete lack of comprehension and therefore find it impossible to understand and follow instructions from staff. They are in a different reality and the use of restrictive practices including physical or mechanical restraint is likely to be terrifying and dangerous.
- Any behaviour management strategies are likely to be supplemented/supported by personalised programmes/plans of care which should reflect the needs and wishes of the individual, as well as considering any advance directives which may have been agreed. Physical restraint will need to be contextualised and positioned within any overall plan and all individualised behaviour management strategies.
- Where a person is experiencing cognitive decline related to their mental health or potential dementia, the impact can be significant. The development of multiple higher cortical deficits, including those associated with perceiving, understanding, problem solving, remembering, learning and making judgements can be both frightening and disorientating. This may be considered a risk factor in respect to the presentation of behaviours of concern, as well as within the context of any physical restraint technique
- A higher incidence of personal neglect may be evidenced in patterns of personal care, taking of fluids/ drinking, poor diet or the refusal of food. This can increase the likelihood of poorer general health and increase the risk of infection and malnutrition.
- The potential for a higher incidence of psychological impairment amongst the population with dementia could be manifested in a perceived unwillingness to co-operate with staff. This may lead to staff considering decisions that might need to be made based on best interests. This in turn may be linked to staff decisions to use restrictive practices.