

Coping with distress



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It is quite common for people with dementia to become distressed at times. This is often because they are trying to communicate something that they are unable to express verbally or in a more logical way, as they might have been able to do before their diagnosis. They might show their distress by:

- crying
- groaning
- shouting
- swearing or using other offensive language
- calling out for someone
- asking to go home (sometimes even if they are at home)
- behaving aggressively
- appearing agitated, for example pacing, fidgeting or trying to leave the house
- becoming withdrawn or uncommunicative
- swaying or rocking
- pulling or tearing at items like clothes or bed covers

Causes of distress

Confusion, fear or anxiety

A person with dementia who is distressed may be feeling disorientated, frightened or anxious. They might be trying to make sense of the world around them and might see things quite differently from you – for instance, they may not recognise the place they are currently in as their home, or they may believe someone is trying to harm them.



It is often thought that people with dementia cannot experience depression or anxiety, but this is not the case. They may, however, be unable to vocalise how they are feeling, leading to greater distress which shows itself in their behaviour.

Unmet needs

A person with dementia may have an unmet need that they cannot tell you about, like being hungry or thirsty, or too hot or cold. They may be in discomfort or pain, for example from an existing health condition; a problem like constipation or an infection; or sitting or lying in the same position for too long. They may need the toilet, or may be tired, bored or want to stretch their legs.

Changes in routine

Changes in routine can be distressing for a person with dementia.

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This can include doing things at a different time than usual, or going somewhere they do not usually go to, such as a hospital appointment, a family gathering, a work function or a school play. These places can be noisy as well as unfamiliar.

Having visitors can also be unsettling due to the different faces, sounds and activity. If the person is not used to seeing people, they may lack confidence and struggle to interact with others without feeling distressed. They may also be upset if they do not recognise the person who has come to see them.

Sundowning

Some people with dementia feel more confused and distressed in the evening. This is known as sundowning. Please see Sources of support on p11 for more information.

Past life events

Occasionally, people with dementia who have experienced past traumatic events, such as a close bereavement, domestic or sexual abuse, a work-related accident or being involved in combat as a member of the armed forces, may relive this trauma as their condition deteriorates. This can cause distress which may be as intense as when the incident occurred.

Techniques to prevent distress in a person with dementia

Try to maintain a daily routine where things happen at a predictable time. If there will be a change to the person's routine, give them information in easy to digest nuggets, and in a timely manner. For example, if you are going out, give them some advance notice – perhaps a few hours – so they are prepared, but not so much that they then forget what is planned, or worry they will miss the event. But be guided by your knowledge of the person; some feel more anxious if they are told in advance of a change to their routine.



Make sure family members and friends know that the person with dementia may become distressed in unexpected situations so they know not to drop in or take them out without prior notice.

If you are going out, allow plenty of time to leave the house so the person does not feel rushed, and factor in extra time to get to your destination. For example, ensure there is plenty of time to park and go to the toilet before an appointment. You could also look at providing adaptations or aids to reduce overstimulation in busy, noisy or bright places, such as headphones, earplugs or ear defenders; a hat with a visor, like a baseball cap; and tinted or ‘transition’ glasses that darken in bright light.

Try to pre-empt the person’s needs. You might want to offer a drink and snack at regular intervals; help them choose their clothes for the day to make sure they are comfortable and appropriate for the weather; or plan a toilet break every couple of hours when you are out.

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If you suspect the person might be unwell or in pain, make an appointment with their GP or talk to a pharmacist about what may help.

Find out about the person's life history to identify any possible trauma triggers, like a specific place, person or occurrence. You can then try to avoid those triggers or offer more support if they occur. Compiling a life story – a record of their past and present life – may help; for more details and a link to our template, please see Sources of support on p10.

What to do if the person becomes distressed

It is important to try to identify the cause of the person's distress so you can take steps to support them. As a family member or close friend of the person with dementia, you may be the best person to reassure and comfort them.

If the person does become distressed, these methods may help them feel calmer.

- Try to remain calm yourself. The person might say something upsetting to you when they are distressed. Take 10 seconds to think about what you are going to say before you reply
- Use a soothing and steady tone of voice
- Try to maintain eye contact
- If the person is confused or disorientated by a situation or a change in routine, calmly explain what is happening
- Ask them what is upsetting them, and if they are able to explain, listen carefully to what they say, even if they are confused
- Empathise with the feelings they may be trying to express, such

as fear: you might say, “You seem frightened, but it’s okay – you are safe here with me”

- Sit beside the person and hold their hand or offer a comforting touch on the arm
- Give the person a hug, if they usually enjoy this and are not too agitated
- Maintain a calm, low stimulus environment if possible. This may include leaving a public place if necessary, or if you are at home, going into a bedroom or other quiet space away from other people
- Look for signs that they have an unmet need. Groaning or rubbing a body part may indicate that they have pain in that area, for example
- Play some music they love or a favourite film
- Look at photos together and talk about happy family events
- Offer them a warm drink and something to eat
- Encourage them to go with you into a different room or outside for a change of scene
- If there are children or teenagers in the home, encourage them to give the person some space by going into another room and doing a quiet activity – for example, they could wear headphones if they are playing video games to reduce background noise
- Offer the person something to stroke, hold, squeeze or feel to reduce agitation, such as a stress ball, cushion, fidget toy, soft toy animal or lifelike doll. Please see Sources of support on p11 for details of our information on using dolls in dementia care

Sometimes, none of these tips will work, and it might seem like the more you try to calm the person down, the more upset they become. It can help to acknowledge that they are upset and then give them some space by going into a different room or outside for a few minutes if it is safe and appropriate to do so. If the person is very distressed it could take some time minutes for them to recentre.

Make sure you have a plan in case a situation escalates and you feel unsafe, for example going into a safe room like the bathroom and phoning a family member or friend for help. Bear in mind that people with young onset dementia (where symptoms develop before the age of 65) may be physically stronger than an older person, meaning there may be a greater risk of them harming themselves or other people if they become distressed. Stress hormones in the body can also make people seem stronger at a time of distress. Please see Sources of support on p11 for more information on keeping yourself safe when caring for someone with dementia.

Calming techniques for you

It can be very difficult to remain calm when a person with dementia is distressed. You might like to try this calming breathing technique which is designed to give you a moment to distance yourself from the stressful situation before helping you come back to the here and now.

1. Take a deep breath in and tense your jaw, shoulders and arms.
2. Hold the breath for two or three seconds.
3. Let the breath go, relaxing your jaw, shoulders and arms. As you exhale, mentally say a soothing word to yourself, such as 'relax' or 'calm'.
4. Let your arms, shoulders and jaw go limp and loose.



Repeat this a few times until you feel it helping.

The person with dementia might also find this calming. You could try talking them through it.

If necessary, there is nothing wrong with taking five minutes away from the situation – it might help both you and the person return to a less distressed state. Remind yourself that you are doing your best in challenging circumstances and try to be kind to yourself.

Sources of support

If you are living with dementia or caring for someone with the condition, register for our free online sessions, ‘Dementia: what next?’ at [▶ dementiauk.org/dementia-what-next](https://dementiauk.org/dementia-what-next)

To speak to a dementia specialist Admiral Nurse, call our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit [▶ dementiauk.org/book](https://dementiauk.org/book)

Dementia UK resources

Anxiety in a person with dementia

[▶ dementiauk.org/managing-anxiety](https://dementiauk.org/managing-anxiety)

Changes in perception and hallucinations

[▶ dementiauk.org/changes-in-perception](https://dementiauk.org/changes-in-perception)

Creating a life story

[▶ dementiauk.org/life-story](https://dementiauk.org/life-story)

Life story template

[▶ dementiauk.org/life-story-template](https://dementiauk.org/life-story-template)

Delirium (sudden confusion)

[▶ dementiauk.org/delirium](https://dementiauk.org/delirium)

Depression in a person with dementia

[▶ dementiauk.org/managing-depression](https://dementiauk.org/managing-depression)

False beliefs and delusions

[▶ dementiauk.org/false-beliefs-and-delusions](https://dementiauk.org/false-beliefs-and-delusions)



Keeping yourself safe when you care for someone with dementia

➤ dementiauk.org/keeping-safe

Music and dementia

➤ dementiauk.org/music

Pain and dementia

➤ dementiauk.org/pain-and-dementia

Restlessness and agitation

➤ dementiauk.org/dealing-with-restlessness

Sundowning

➤ dementiauk.org/sundowning

Tips for better communication

➤ dementiauk.org/tips-for-communication

Using dolls in dementia care

➤ dementiauk.org/doll-therapy

**To speak to a dementia specialist Admiral Nurse
about any aspect of dementia:**

Contact our Helpline:

0800 888 6678 or [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Book a virtual appointment:

[▶ dementiauk.org/book](https://dementiauk.org/book)

**Our charity relies entirely on donations to fund our
life-changing work. If you would like to donate to help us
support more families:**

- Call **0300 365 5500**
- Visit [▶ dementiauk.org/donate](https://dementiauk.org/donate)
- Scan the QR code



Thank you.



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Helping families face dementia



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