

Keeping safe when you care for someone with dementia



Dementia can affect a person's ability to manage their reactions to difficult thoughts and feelings. This could lead to them experiencing such intense states of distress that they may become verbally or physically aggressive, putting them and those around them at risk of harm.

This could be in the form of:

- Threats and intimidation (eg making threats to harm you or themselves; invading your personal space; breaking things that belong to you)
- Verbal aggression (eg shouting; swearing; name-calling)
- Physical aggression (eg pushing; slapping; kicking; throwing things)

There are many reasons why this might happen. For example, sometimes the person with dementia might believe they are under threat, and this can cause a 'fight or flight response'. This triggers the part of their brain that is responsible for regulating emotions such as fear and anger. It can lead to behaviours that sometimes seem illogical, irrational and an overreaction, which may include verbal and physical aggression.

You can ask a health professional for help with understanding these in more detail.

What might cause a risk to personal safety?

Every person with dementia will experience the condition in their own way. However, factors that may trigger distress and lead to aggressive behaviour include:

• Feeling unwell or in pain



- Difficulty communicating, including difficulty being understood and understanding other people, causing frustration
- Having unmet needs that they cannot express, eg being hungry, thirsty, hot or cold; needing the toilet; being bored
- Changes in routine, eg going on holiday; family gatherings; new processes at work; visiting other people's homes
- Difficulty empathising with other people and understanding their emotions
- Changes in or side effects of medication
- Factors in their environment that cause distress, discomfort and/ or overstimulation, eg loud noises, busy places
- Changes in perception, false beliefs and hallucinations, eg believing that someone close to them is stealing from them – please see Sources of support on p15 for more information

- Sundowning a state of confusion or anxiety that typically occurs in the evening and often makes people believe they are in the wrong place and that they need to 'go home', even if they are already at home. Please see Sources of support on p16 for more information
- Other mental health issues or learning disabilities that cause difficulty regulating emotions please see Sources of support on p15 for information on dementia and learning disabilities
- Hormonal/mood changes associated with menopause please see Sources of support on p15
- Their own life experiences, including previous life trauma eg if they have been a victim of violence themselves in the past
- The effects of alcohol lowering a person's inhibitions

Identifying risks when caring

We naturally assess risk in our own lives all the time, from things like crossing the road to deciding what is safe to eat in the fridge. These risk assessments are often so routine that we do not have to think about them.

Learning to assess factors that may put you or the person with dementia at risk can be more difficult, but it is an important skill to develop. It is helpful to follow these steps:

- Try to identify what is causing the person distress. For example, are they uncomfortable or experiencing pain? Do they seem upset about something in their environment? Do they want to leave the house, or are they misidentifying you as someone else?
- 2. Consider who this might put at risk. This could be the person with dementia themselves, you, or other people around them such as family members in the home, including children. For example, if

the person wants to leave the house, attempting to stop them could lead to them pushing you out of the way.

- 3. Make a plan to reduce the risk of harm. For example, in the case of sundowning, you could close the curtains before dusk to ease the transition from day to night or try distracting the person with a calming activity that they enjoy before they become distressed.
- 4. If necessary, seek help from others for example, the person's GP may be able to carry out a health and medication review to see if changes could be made to ease their distress, or refer them to a specialist team for a review.
- 5. Keep reassessing the risk. Reflect regularly on any changes

 for example, a new carer or a change in the person's
 dementia symptoms.

Strategies for keeping safe

Sometimes you, the person with dementia and/or those around them may end up in an unsafe situation, no matter how well you try to manage the risks. It is a good idea to have some strategies in place to keep everyone safe and help you feel assured and more in control.

Reducing risk in your environment

- Check the person's home environment to make sure it is as low-risk and manageable as possible
- Where possible, remove anything that might trigger aggressive behaviour, such as mirrors or reflective surfaces – the person may see their own reflection and believe it is an intruder
- Keep the home as clear and clutter-free as you can, especially around exits and entrances this will provide both you and the person you care for with space to move and adapt in difficult situations

- Try to reduce trip hazards like rugs; fit sturdy stair rails; use fire guards; and consider fitting safety glass in doors
- Remove objects that might be used aggressively in the heat of the moment for example, put knives and scissors away in a drawer rather than leaving them on the kitchen worktop
- Try to maintain a calming, low stimulus atmosphere, especially if the person with dementia is feeling anxious. For example, you could play quiet music or relaxing nature sounds rather than loud television programmes or high energy music. If there are children at home who are triggering the person's stress, you could take them into another room and encourage them to take part in a quiet activity; or take them for a walk outside the house

Please see Sources of support on p15 for our information on making the home safe and comfortable for a person with dementia.

Considering the person's needs

Anger, anxiety and fear may result from the person having unmet needs, leading to verbal or physical aggression.

- Be aware of any physical health issues that may be causing distress, such as pain; constipation; infections such as chest or urinary tract infections (UTIs); pre-existing health conditions like diabetes or chronic obstructive pulmonary disease (COPD)
- Consider whether the person is hungry or thirsty; tired; too hot or cold; needs the toilet; is in discomfort from tight or irritating clothing; needs physical contact or intimacy
- Think about whether the person could be feeling bored or under-stimulated and try to address this, eg by going for a walk; playing a board game; watching a film; doing a jigsaw



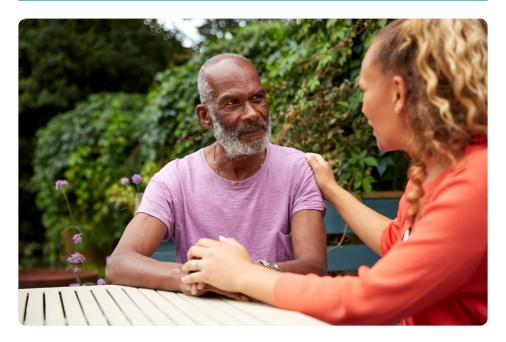
- Check whether the person is taking any medication as prescribed; whether the type or dose has changed; and whether they could be experiencing side effects. If you are unsure, book a review with their GP or pharmacist
- If the person has difficulty communicating, look for ways to work around this, eg using pictures to show what you are talking about. Please see Sources of support on p16 for tips for better communication
- If the person works, encourage them to tell their employer about their diagnosis so support can be put in place to help prevent situations that might cause frustration – please see Sources of support on p15 for information on dementia and employment
- Be aware of other aspects of the person's life that might cause distress, eg sensitive topics of conversation; anniversaries of upsetting life events; seeing family members or other people who they have a difficult relationship with

What to do in a crisis

Putting preventative strategies in place may help to reduce distressed and aggressive behaviour, but at times, risky situations may still occur. Try to keep in mind that it is likely that the person's behaviour is being caused by their dementia, and if you can respond in a controlled manner, it will pass.

In a situation where you, the person with dementia or people around you are at risk:

- Aim to remain calm when met with heightened emotions. Try not to mirror the person's emotions or behaviour: for example, try to speak in a low and steady tone even if they are shouting
- Repeating a phrase like, "I'm sorry if I've upset you, but I am here to help" may help to calm the person
- Avoid confronting, correcting or arguing with the person
- If you are standing, move an arm's length away and turn your body slightly sideways to seem less threatening to the person. This will also minimise how much of your body they can reach and protect vulnerable areas
- Keep your body language calm and non-confrontational; keep hand gestures to a minimum, and arms loose and 'open'
- Create a natural barrier between you, for example standing behind a table or on the opposite side of a bed but try to keep a clear path between you and any exits
- If the person is in an environment that is causing distress, such as a noisy supermarket or a busy family gathering, support them to move to a calmer place if possible



- Put yourself on the person's level if you can for example, if they sit down, you could sit down too. Avoid standing over them
- If it is safe to do so, give the person some space to calm down and feel less anxious. Move to another room and come back after 10 to 15 minutes to see how they are
- If the person's distress is triggered by not recognising someone, it may help if the person they perceive as a 'stranger' leaves the room
- Experiment with things that may help to calm the person in advance of events that may be unsettling for example, playing their favourite music, going for a walk, or spending some time in the garden or another outdoor space
- If they are in distress, avoid travelling in the car with them until they are calm

- If the person wants to leave the house, it is often best to let them go rather than preventing them leaving in case you or they are hurt in the process. If they usually need accompanying outside the home, you can follow them at a safe distance or call for help from a neighbour, relative or friend or the emergency services
- If possible, and if it will not increase the person's distress, call another person, such as a family member, for help and support
- It is also useful to complete a Herbert Protocol form this is a scheme that involves collecting important information about a vulnerable person to help police locate them if they are missing. Please see Sources of support on p16

Making a personal safety plan

It is a good idea to put together a personal safety plan to use in situations where you feel at risk, for example if the person with dementia is being physically aggressive or making threats.

- Make sure you know where the exits from the building are; keep routes to the exits clear; and stand so you are closest to the door
- If you feel very uncomfortable or unsafe, go into a room away from the person where you can phone a family member, friend or the emergency services for support. The bathroom is often the most convenient place, and you can lock the door if you need extra protection. You can also conceal a phone in there for emergencies but remember to keep it charged
- Have a code word to use with family and friends if you are in danger, such as 'pineapple'. This can save time explaining that you need help in a crisis. You can agree this in advance so they understand what is happening if you call and what they should do next

- Keep a 'go bag' of useful items in an easily accessible place in case you need to leave in a hurry. Include a spare house key, phone charger, change of clothes, snacks and a drink, and a list of important contact numbers and medications
- If you or anyone else feel unsafe or in danger, please call 999 to speak to the emergency services

What to do after an episode of risk

Once the immediate crisis has passed, these tips may help:

- Ensure that if anyone has been injured, they receive medical attention if required. Out of hours, you can call 111 for advice and to book an appointment with a local NHS provider if necessary. You can also request mental health support for the person with dementia
- Keep the environment calm and quiet
- Give the person time and space to stabilise (this may take over 20 to 30 minutes due to the levels of the stress hormone adrenaline in their body)
- Keep your voice low, soothing and reassuring, and your body language relaxed
- Be aware that the person's emotions may still be heightened, and that even minor triggers in the next few hours may inflame the situation again
- Be reassuring there is unlikely to be a benefit in reminding the person what happened or criticising their behaviour
- Revisit your risk assessment to see if you can put steps in place to prevent further episodes of risk

• Talk to your GP or other health or social care professionals involved in the person's care. You can also speak to your local authority's Safeguarding Team (or ask the professional to contact them on your behalf). They will be able to advise and support you, your family and the person with dementia when incidents occur and monitor any safety concerns. They can also put plans in place to support vulnerable adults and their families (including children) who are affected by the change in behaviour

Keeping children safe

It is very important that any children around the person with dementia are kept safe. If a parent is living with young onset dementia, for example, it may have an impact on how they care for their children. Normal childhood behaviour such as shouting or boisterous play may trigger episodes of distress in a person with dementia, which may lead to aggression.

Older adults with dementia may also find interacting with children difficult at times and react in what seems to be an inappropriate way.

To protect children from risk:

- Consider whether the person's caring abilities might put the child at risk – are they safe to be alone with the child at home; babysit them; drive them to school; go to the park; cook them a meal? Is there a risk of physical discipline or using inappropriate language?
- If you believe the person with dementia could pose a risk to the child, make sure there is another adult nearby, even if in another room
- Support the child to be open with you about things they find difficult or uncomfortable – such as a parent's lack of patience, or having to help them with personal care – so you can address them



- Speak to the child's school about what is happening they can look for signs that they are struggling and may be able to put support in place like seeing a school counsellor
- Ensure the child knows some basic, age-appropriate safety tips, like moving away from the person with dementia if they are worried or frightened and going into a safe room
- Be alert to signs of abuse or harm these may be physical (eg bruises, grazes) or behavioural (eg tearfulness, anger, bedwetting). Speak to your GP, a social worker or the child's teacher for advice and support

When risk becomes abuse or harm

Everyone has the right to feel safe in their own home, but occasionally, the reactions of a person with dementia or another family member could tip over into domestic abuse or violence. This can take many forms, including:

- physical violence
- emotional abuse
- controlling or coercive behaviour

Children who see, hear or experience domestic abuse are 'victims' in their own right.

Domestic abuse can be very difficult to talk about, but it is essential to get help, for example from Dementia UK's Helpline, your GP and/or domestic violence charities – please see Sources of support on p15-17.

If you or anyone else feel at immediate risk, please call 999. The emergency services are there to help both you and the person with dementia and will only resort to removing the person to a place of safety if the situation becomes too difficult and dangerous to manage.

Your local authority Adult Social Services Team can also put plans in place to support vulnerable adults and children and advise you about remaining safe yourself. This is referred to as 'safeguarding'.

For advice and support from a specialist dementia nurse, please contact our Helpline or book a virtual clinic appointment – see Sources of support on p15.

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 **O dementiauk.org/dementia-what-next**

To contact our free Dementia Helpline, call **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email **> 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 **O dementiauk.org/book**

Dementia UK resources

Changes in perception and hallucinations
 dementiauk.org/changes-in-perception

Difficulty with sounds

Odementiauk.org/dementia-and-difficulty-with-sounds

Employment and dementia • dementiauk.org/employment

False beliefs and delusions • dementiauk.org/false-beliefs

Learning disabilities and dementiadementiauk.org/learning-disabilities

Making the home safe and comfortable for a person with dementia

Odementiauk.org/safe-comfortable-home

Menopause and dementia

Odementiauk.org/perimenopause-and-menopause

Sundowning Odementiauk.org/sundowning

Tips for better communication • dementiauk.org/tips-for-communication

Other resources

Carers TrustCarers.org

Childline - support for children and young people

childline.org.uk 0800 1111

Find local Adult Social Care Services

nhs.uk/service-search/other-health-services/local-authorityadult-social-care

Galop - the anti LGBT+ abuse charity

♥ galop.org.uk 0800 999 5428

Herbert Protocolherbertprotocol.com

Men's Advice Line
mensadviceline.org.uk
0808 8010 327

National Domestic Abuse Helpline

0808 2000 247

NHS: getting help for domestic violence and abuse

nhs.uk/live-well/getting-help-for-domestic-violence

NSPCC – preventing child abuse nspcc.org.uk

Refuge – against domestic violence
refuge.org.uk
0808 2000 247

Women's Aid womensaid.org.uk



Your pull-out guide to staying safe in a crisis

- Speak calmly and quietly do not shout or argue
- Think about what might have triggered the person's behaviour (eg noise, pain, frustration) and try to remove the trigger
- Keep yourself at arm's length from the person and turn sideways to protect your body and seem less threatening
- Stand on the opposite side of a table or bed to create a natural barrier
- Keep your route to the exit clear
- Try calming activities like playing gentle music or suggesting a walk
- If it is safe, leave the person alone for 10-15 minutes to calm down
- Do not try to stop the person leaving the house if they wish to do so you can follow at a safe distance or call for help from a family member, friend, neighbour or the emergency services
- If you feel in danger, go into another room that feels safe, eg a bathroom where you can lock the door
- Call a family member or friend for support agree a code word like 'pineapple' in advance to save time explaining what is happening
- If you need to leave the house to keep yourself safe, take your 'go bag' see p11 for information

Useful numbers

Family/friends to call if you need help

GP

Non-emergency medical advice: call 111

In an emergency: call 999

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

Contact our Helpline: **0800 888 6678** or **> helpline@dementiauk.org**

> Book a virtual appointment: • 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 O dementiauk.org/donate
- Scan the QR code

Thank you.





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