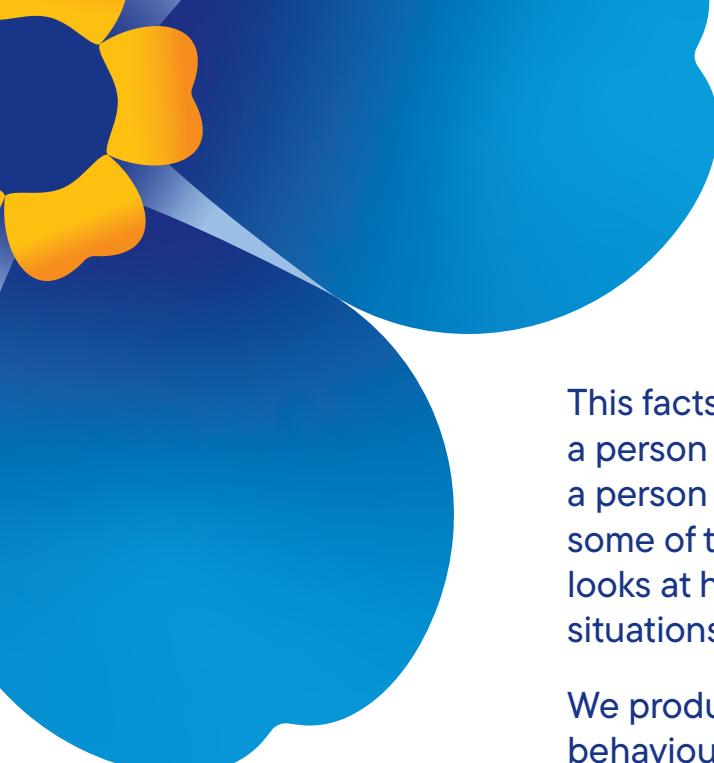


Changes in behaviour



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia



This factsheet is for anyone caring for or supporting a person with dementia. It tells you about behaviours a person with dementia might develop and explains some of the common causes. This factsheet also looks at how you can support the person and manage situations caused by these behaviours.

We produce more information on some of these behaviours, such as factsheets **501 Walking and dementia** and **509 Aggressive behaviour**.

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1 How does dementia change a person's behaviour?

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Changes in behaviour are sometimes the first sign that someone has dementia. For some people, the changes can come on gradually and can be hard to recognise at first. For others, they can be more sudden. As dementia progresses, you may see more changes in the person's behaviour and find this difficult to manage. Understanding how dementia can affect the person may help.

When a person with dementia starts to behave in ways that seem out of character, some people may assume this is a symptom of the condition itself, which isn't always the case. It's important to see beyond the behaviour and think about what may be causing it. There may be specific reasons why the person with dementia is behaving differently, such as:

- their frustration or fear about how dementia is affecting them (such as memory loss or language problems)
- their mental and physical health
- their problems with orientation – for example, not knowing which year, month or time of day it is, or not recognising familiar places
- the amount and quality of contact they have with other people
- their physical surroundings – for example, if the room is too dark, the person may become confused and distressed because they can't work out where they are
- a sense of being out of control, frustration with the way others are behaving, or a feeling that they're not being listened to or understood.

Dementia can affect a person's personality and habits, which may lead to changes in behaviour. For example, they may no longer be able to do things they enjoy or follow their interests without help, or they may experience symptoms of depression.

Knowing the person – how they react to and deal with things, their preferences, routines and history – can help when it comes to supporting them. For example, if the person has always been impatient or anxious, they may be even more so now that they have dementia.

When thinking about behaviour that challenges, it's important to remember that the person isn't trying to be difficult. The behaviour can be just as challenging for them as for those supporting them.

“

Grandad wasn't himself and he seemed bored. We thought maybe he was depressed because they were no longer able to get out and about.

Family member of a person with dementia

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What causes changes in behaviour?

As human beings, we all have the same basic needs. These include physical, psychological and social needs. We do things consciously and unconsciously to meet these needs. The symptoms of dementia can make it more difficult for someone to do this. They may also find it more difficult to communicate their needs or wishes. Changes in their behaviour may be:

- caused by them having needs that aren't being met (for example, if they are hungry or thirsty, they may seem more tired or less alert than usual)
- their attempt to meet a need (for example, if they feel too hot, they may remove clothing at inappropriate times)
- their attempt to communicate a specific need to others (for example, if they need to use the toilet, they may shout out).

This page and page 3 have examples of how different types of needs may affect someone's behaviour.

Physical needs

- The person may be in pain or discomfort. For example, they may be thirsty, need the toilet or generally feel unwell. They may have an infection or constipation. Or they may have been in one position for too long, or find the chair they are sitting in uncomfortable.
- The person may experience side effects from medication, such as drowsiness or confusion. This can also make it harder for them to communicate how they're feeling or what they need.
- The environment may not be comfortable for the person. For example, it could be too hot or too noisy, or they may not like the music or TV programme that is on.
- The person may have a condition such as sight loss or hearing loss. This can mean that they mistake something they see, hear, smell or touch for something else.
- The person may be sexually frustrated. For more information, see factsheet 514 **Sex, intimacy and dementia**.

Making changes to the environment can help meet a person's physical needs, for example, adjusting the temperature or turning down the volume on a radio. The person should have their eyesight and hearing tested, and glasses and hearing aids should be checked regularly.

Psychological needs

- The person may be frustrated by their situation – for example, not being able to do the things they used to. They may also be frustrated if other people assume they can't do things for themselves and take over.

- The person may feel depressed, anxious or have a mental health condition.
- The person may be having delusions (strongly believing things that aren't true) or hallucinations (seeing things that aren't there). These can be confusing and frightening, and may affect how the person behaves.
- The person may feel confused or unsettled by an environment that doesn't seem familiar. They may think they are in the wrong place.
- The person may seem to experience reality differently to you. For example, they may believe they have to go to work even though they no longer work.
- The person may misunderstand the intentions of those caring for them. For example, they may see personal care as threatening or an invasion of their personal space.

Often, psychological needs can be met in simple ways, such as listening to and talking with the person, or changing the subject and focusing on an activity they enjoy. However, some people may benefit from specialist support. Consider if the person may benefit from psychological therapies with professionals, such as cognitive stimulation therapy or reminiscence therapy. For more information, see factsheet 444 **Supporting a person with dementia who has depression, anxiety or apathy**.

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Social needs

- The person may be feeling lonely or isolated. They might not spend much time with others or feel included.
- The person may be bored or not feel stimulated.
- If the person has different visitors, such as multiple care workers, they may all have their own approaches. This can be confusing.
- The person may be trying to hide their condition from others or may not be aware of the difficulties they're having.

Support the person to have a daily routine and be as independent as possible. Their behaviour may be a response to feeling like they're not valued or able to contribute. It may be helpful to encourage the person to find the answer for themselves. For example, if the person keeps asking the time, consider buying a clock that is easy to read.

Staying connected can help someone feel comforted and stimulated. Help the person stay in touch with other people. You could help arrange visits, or phone or video calls.

Support the person and make adaptations if necessary, so they can continue doing the things they enjoy. They may also enjoy activities that engage their senses, such as aromatherapy, arts and crafts, or doll therapy. For more information, see booklet 77AC **The activities handbook**.

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2 Types of behaviour

The person's response to different needs means their behaviour may change in a number of ways. Some of the most common changes are listed in this section.

Repetitive behaviour

People with dementia often carry out the same activity, make the same gesture, say the same thing, make the same noise or ask the same question over and over.

Repetition may be because of memory loss. The person might not be able to remember what they've done or said, or the answer to a question. For example, they may keep checking they have their bag with them, or keep checking their fridge to make sure they have food.

Often, if someone is repeating the same question, they need an emotional rather than factual response. This may be because the person feels confused or anxious. They need comfort, security, or to feel included or reassured, rather than the repeated answer to their question. 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. For more information, see factsheet 526 **Supporting a person with memory loss**.

Trailing, following and checking

A person with dementia may follow you or someone close to them around, keep checking that they are nearby, or keep calling out or asking for people.

Living with dementia can make people feel insecure and anxious. This is why they may 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.

A person with dementia may ask for family members who have died, or ask to go home when they're already there. This can be due to 'time-shifting', which is when a person believes that they are living at an earlier time in their life. If this happens, try to understand and acknowledge their feelings. For example, wanting to go 'home' may be due to a need to feel safe and secure, so supporting them with this can help.

If the person is calling for someone from their past, try talking to them about this period in their life and respond to their feelings. For more information, see factsheet 527 **Changes in perception**.

Hiding, hoarding and losing things

A person with dementia may hide things, store them for a long time or lose them. This can be distressing for the person, as they may think someone is taking things from them. It can also be frustrating if you have to find things.

By hiding and hoarding things, the person may be trying to have some control of their situation. They may feel they need to stockpile items. They may also feel paranoid or have delusions that their things will get stolen, so they may be trying to protect them.

Losing things may be due to the person's memory loss. For example, the person may put an item away to keep it safe and then forget where it is, especially if they put it in an unusual place. For more information, see factsheet 526 **Supporting a person with memory loss**.

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Losing inhibitions

Sometimes, a person with dementia can lose their inhibitions and may behave in ways that others find embarrassing.

This can include:

- being rude
- saying things that aren't appropriate (for example, that someone is overweight)
- talking to strangers
- undressing in public
- apparent loss of sexual inhibition (for example, touching themselves inappropriately in public).

They may not understand that what they are doing is inappropriate. It's very unlikely that they are being inappropriate on purpose. Always respect the person and their dignity, and try not to cause them any distress.

Loss of inhibitions is more common in certain types of dementia, such as frontotemporal dementia (FTD), which causes damage to the frontal lobes in the brain. For more information, see factsheet 404 **What is frontotemporal dementia (FTD)?**

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Accusing

A person with dementia may make accusations against people around them, including their family, friends and carers. For example, they may believe that others are trying to steal from them or harm them. They may also become suspicious or paranoid, and feel that others are plotting against them.

It's important not to dismiss accusations without looking into them, as in some cases they may be true.

Sometimes, a person may not recognise a family member and may accuse them of being someone else. This can be due to time-shifting. For example, the person may feel they are thirty years younger and not recognise their partner, who they expect to be thirty years younger too. For more information, see factsheet 527 **Changes in perception**.

Agitation including restlessness

A person with dementia may become agitated suddenly because of a change or specific cause, such as noise or not being able to do something they previously could. Or they may feel a general sense of agitation but not know why.

Agitation can take many forms. For example, a person who is agitated may be irritable, restless and keep fidgeting. They may walk up and down, move objects, fixate on tasks such as tidying, or try to leave the house. For more information, see factsheet 501 **Walking and dementia**.

Aggressive behaviour

A person with dementia may behave in aggressive ways. Aggressive behaviour can be:

- **verbal** – for example, swearing, screaming, shouting or making threats
- **physical** – for example, hitting, pinching, scratching, hair-pulling or biting.

For more information, see factsheet 509 **Aggressive behaviour**.

Sundowning, sleep disturbance and waking up at night

Sometimes, a person with dementia may become confused or distressed towards the late afternoon or early evening. This is known as 'sundowning'.

Sundowning can be caused by a number of things including overstimulation during the day, tiredness, or disturbance to the person's 'body clock'. Some people feel agitated because they no longer do the things they used to do in the early evening, such as returning from work or picking up children from school. This can cause them to feel that something is wrong, even if they are not aware of why.

A person with dementia may also have problems with sleeping at night, and may sleep more in the day. They may find it difficult to get to sleep, or they may wake up in the night. For more information, see factsheet 534 **Understanding sleep problems, night-time disturbance and dementia**.

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Social withdrawal

Sometimes, a person with dementia will stop taking part in activities or conversation as much as they used to, or at all. This can happen when a person is aware that they are finding certain things more difficult to do. For example, they might keep losing the thread of conversations or have trouble expressing themselves.

They may also find too much stimulation distressing, such as being around lots of people. It's important that they have opportunities to take part in less stimulating activities that they enjoy.

People with dementia may also become more withdrawn over time as they lose practice in socialising or communicating.

Withdrawal can also be caused by depression or apathy. For more information, see factsheet 444 **Supporting a person with dementia who has depression, anxiety or apathy**.

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3 Reducing and managing behaviour that challenges

There are many possible reasons for behaviour that challenges – see ‘What causes changes in behaviour?’ on page 2. Sometimes, the behaviour happens in phases and stops over time. It can often be managed by recognising and responding to the person’s needs. However, there may be times when changes in behaviour happen suddenly, and you may need support from professionals.

Managing sudden changes in behaviour

Sudden changes in behaviour are often caused by a physical health problem such as constipation, pain or a urinary tract infection – especially when the person seems to be more agitated, confused or distressed.

If you notice a sudden change, it’s a good idea to ask the person’s GP to visit. They can check for any physical problems and arrange any necessary tests, such as blood or urine tests. Ask the doctor to review all medication the person is taking, including any non-prescription drugs. (See ‘Physical needs’ on page 2 for more on how this can affect a person’s behaviour.)

If the GP rules out health problems as a cause, they may refer the person to a mental health team. Mental health conditions such as depression may also contribute to changes in behaviour. These can often be managed with medication or with non-drug approaches. For more information, see factsheet **444 Supporting a person with dementia who has depression, anxiety or apathy**.

Think of the person’s point of view

Always try to see things from the person’s perspective. People with dementia can sometimes find it hard to understand what’s going on around them. This can be confusing and frightening for them. You might not understand their behaviour, and this can be frustrating for you. But the behaviour will often have meaning for the person with dementia.

Think about what you know about the person and their life. For example, if you know someone used to work night shifts, it might explain why they want to stay awake at night.

It's likely they're trying to stop feeling distressed. The behaviour may be the best way for them to communicate what they want or to help themselves feel better.

Be aware of the person's beliefs and thoughts, and try not to argue with them. For example, if they believe they need to collect their children from school, don't tell them they're wrong. Instead, ask them to tell you about their children, or move their focus onto an activity.

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Managing wellbeing

Always think about what you know about the person and what works best for them. The person is likely to respond to your behaviour and communication, so if you're frustrated or angry, it may make things worse. For example, if they are repeating questions, try to be patient and sensitive. They may not know that they have repeated themselves and may notice if you seem impatient, which might distress them.

If the person behaves rudely, don't attempt to argue or correct the behaviour. Offer them gentle reassurance, or try to distract their attention.

Other tips for managing the person's wellbeing include:

- **Spend time with the person.** This could be having a cup of tea and a chat. You could do an activity like playing a game or preparing food together, or keep close to them when you have tasks to carry out. For example, you could iron while they listen to the radio. Being with the person can help them feel reassured and comforted. If you're unable to meet, then phone or video calls can be a good way to spend time with them too.
- **Think about how the person has coped with situations in the past.** This may affect how they deal with things now. For example, a person who has always been anxious may become more anxious now they have dementia.
- **Think about how they are feeling, what they are trying to express and how you can support them emotionally.** Even though a person with dementia may have memory problems, they still feel and respond to emotions. If they forget an event that happened earlier in the day, they may still feel the emotions of it later. It can help to respond directly to how the person is feeling (for example, by saying, 'I can see that this is difficult for you').

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Antipsychotic drugs

Antipsychotic drugs often used to be prescribed to people with dementia if they showed behaviour that challenged. However, most of these drugs have limited or no benefits for people with dementia, may not treat the cause of changes in behaviour, and carry serious risks and side effects.

Antipsychotic drugs should only be prescribed by a doctor as a last resort if other treatments have not worked. They should only be used if the person's behaviour is persistently causing them severe distress, or putting them or others at risk of physical harm. Even then, they should be used alongside non-drug approaches based on the person's needs.

If antipsychotics are used, the doctor should monitor how they're affecting the person. Treatments should be reviewed after six or 12 weeks, or both. For more information, see factsheet 408 **Antipsychotic drugs and other approaches in dementia care**.

Steps for managing behaviour that challenges

It may be helpful to manage behaviours by looking at them in steps. A professional (such as a dementia specialist nurse or a dementia support worker) can help you to follow the steps on this page.

1 Identify the problem

- Is it the behaviour of the person that is causing the problem?
- Is the problem the reaction or attitudes of other people?
- Is the person's living situation or environment causing a problem?
- What are the other factors? Is the person trying to communicate a need, for example, that they are in pain, bored or thirsty?

2 Look at the situation

It can be helpful to keep a diary of the behaviour and the circumstances around it:

- When and where does the behaviour happen?
- Does the person always behave in the same way in the same place?
- Does it always happen with the same person or in similar circumstances?
- Who are the other people involved? For example, they may be visitors, a family member or a friend.
- Look for patterns in the behaviour. For example, is there a common theme to their questions?

- Look for triggers for the behaviour. Recognising these may help you prevent the behaviour from happening again. For example, if someone behaves in a sexually inappropriate way when you help them to get changed, they might be misinterpreting your actions. Changing how you approach this situation could help.

3 Consider how the person is feeling when they behave this way

Respond to the emotions the person with dementia is showing. Do they seem to be:

- tired, getting too much stimulation, scared, anxious or frustrated?
- embarrassed, ignored, misunderstood or feeling patronised?
- depressed, or having delusions or hallucinations?
- bored, under-stimulated or lacking in social contact?
- in an environment that makes them feel uncomfortable. For example, is it too hot or too cold?

4 Identify anything the person could be reacting to

Use what you know about the person to think about whether they could be reacting to:

- their awareness that they can no longer do something they used to enjoy
- something unpleasant happening
- something they dislike or are scared of
- change, for example, a new carer or living environment
- a memory
- being provoked, or a conflict with someone's personality.

5 Develop a strategy

Talk to the person with dementia and the people they spend time with to make a plan.

Start to make some changes and see whether they make a difference to the person's behaviour. You will likely need to try different things and find what works. For example, you could change the way you talk to the person when you're providing personal care. Also consider making changes to the environment. Focus on what is in the person's best interests, and what helps to support them as an individual.

It's important to be consistent. If possible, make sure that everybody supporting the person uses the same strategy, especially in care homes and hospital settings where the person may be supported by different carers at different times.

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6 Keep a record

The changes you make might not work every time. Try not to be disheartened if this happens. Sometimes, an approach needs to be tried several times to see if it is helpful. If not, another approach can be considered.

It can be useful to keep a record of what works, even if it doesn't work every time. You can then share this with others who look after the person, such as family members or friends, or health or social care professionals. It can be added to the person's care notes.

4 Looking after yourself

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Changes in the person's behaviour can be challenging, frustrating and upsetting. Over time, this can lead to you feeling exhausted. It can have a big impact on your physical and mental health, and general wellbeing. That's why it's important that you look after yourself – both for your sake and so you can continue to care for the person with dementia. Support is available – seek help if you need it.

Everyone is different, and finding your own ways to cope will be unique to you. The following suggestions may help, both when the behaviour is happening and over a longer period:

- Try to remember that the person is not behaving this way on purpose. It's important not to take it personally. They may be experiencing a different reality to you, and are responding to their needs. Look at the person's body language and try to understand what they might be feeling.
- Try to adapt to the situation as it is. Trying to get things back to the way they were before, or expecting too much of the person, can cause more problems.
- If you begin to feel frustrated or angry, try stepping away from the situation. Give yourself space to calm down. If you do lose your temper, try not to feel guilty. You are dealing with a stressful situation.
- If the behaviour is disrupting an activity, such as washing or dressing, ask yourself if this task needs to be done right now or if you could do it later. Sometimes, it's best to leave the person to do things how they want to, as long as this will not cause harm.
- Consider whether the behaviour is really a problem. For example, in some situations, talking to strangers may not be a problem. The person may be meeting a need to be sociable and the stranger may be happy to talk.
- It may help to explain to other people why the person is behaving in a certain way. They may be more understanding and may even have suggestions or solutions. It may also be useful for the person to carry one of our helpcards. For more information, go to alzheimers.org.uk/helpcards

Talk to someone about the situation and how you are feeling. This might be a friend, professional or another carer. Online discussion forums can be a good way of sharing your feelings and getting practical suggestions. For example, try our **Dementia Support Forum** – go to forum.alzheimers.org.uk

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Talking therapies can also be helpful. For more information, see factsheet 444 **Supporting a person with dementia who has depression, anxiety or apathy** as this includes information on therapies for carers.

It's important that you're able to have a break from time to time. For example, you could ask friends or family members to spend time with the person. You may want to find out about options such as local day centres, clubs or professional care. For more information, see our **Respite care** factsheets 462 (England), NI462 (Northern Ireland) and W462 (Wales).

For more information, see factsheet 523 **Carers – looking after yourself**.

“

It's important not to lose who you are – caring for yourself helps you to care for others.

Carer for a person with dementia

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Other useful organisations

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your notes

British Psychological Society (BPS)

0116 254 9568
info@bps.org.uk
www.bps.org.uk

The BPS provides access to a list of clinical and counselling psychologists offering private therapy services.

Carers Direct

0203 904 4520
info@carersdirect.org
www.carersdirect.org

Carers Direct provides advice for people who need help with their caring role.

Carers Trust

0300 772 9600 (9am–5pm Monday–Friday)
info@carers.org
www.carers.org

Carers Trust works to improve support, services and recognition for anyone caring for a family member or friend.

Carers UK

0808 808 7777 (helpline, 9am–6pm Monday–Friday)
advice@carersuk.org
www.carersuk.org

Carers UK provides information and advice about caring, alongside practical and emotional support for carers.

Counselling Directory

0333 325 2500 (10am–4pm Monday–Friday)
www.counselling-directory.org.uk

The Counselling Directory website includes a searchable database of counsellors and psychotherapists.

Dementia UK

0800 888 6678 (helpline, 9am–9pm Monday–Friday,
9am–5pm Saturday and Sunday)
helpline@dementiauk.org
www.dementiauk.org

Dementia UK provides specialist dementia support for families through its Admiral Nurse service.

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Refuge

0808 2000 247 (National Domestic Abuse Helpline, 24-hour)

www.refuge.org.uk

www.nationaldahelpline.org.uk/chat-to-us-online/ (chat service)

Refuge supports victims of violence and abuse, including sexual violence.

Relate (in England and Wales)

www.relate.org.uk

Relate NI (in Northern Ireland)

028 9032 3454 (appointment telephone line)

office@relateni.org

www.relateni.org

Relate and Relate NI offer relationship counselling for individuals, couples and families. They provide advice and support by phone, face-to-face and through their websites.

Samaritans

116 123 (helpline, 24-hour)

www.samaritans.org

Samaritans provides a 24-hour helpline listening service for people to talk with a trained volunteer about any problems they are having.



Factsheet 525

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This factsheet has been reviewed by people affected by dementia.

To give feedback on this factsheet, or for a list of sources, please email **publications@alzheimers.org.uk**

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We are reviewing this publication. If you would like to give us any feedback, you can email us at publications@alzheimers.org.uk or call us at **020 7423 7455**.

At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information on **Symptoms and treatments**.

For advice and support on this, or any other aspect of dementia, call us on **0333 150 3456** or visit alzheimers.org.uk

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit alzheimers.org.uk/donate



Together we are help & hope for everyone living with dementia

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