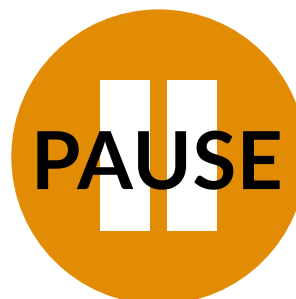


# Leaflet for relatives and/or carers of people with dementia



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There are often good reasons why someone with dementia is distressed or behaving unusually. However, they might not always be able to tell you what's troubling them.

The challenge is to work out what the cause is and what you can do to help, for the benefit of both of you. Sometimes we react to unusual behaviour without knowing what the person might need or be saying through their behaviour.

We have used the ideas of **"STOP"** and **"PAUSE"** to describe the key ways to help you listen and watch, in order to understand distress and unusual behaviour.

You may need to try some things for several weeks before you see improvement. If distress or behaviours do not resolve with the advice given on the following pages, consult your doctor or ask for a referral to your local specialist mental health services.

## Further advice

The Alzheimer's Society has more advice and information for people with different types of dementia, not just Alzheimer's dementia.

You can go to the Alzheimer's Society website at: [www.alzheimers.org.uk](http://www.alzheimers.org.uk) or call them on their helpline (freephone) on 0300 222 11 22.

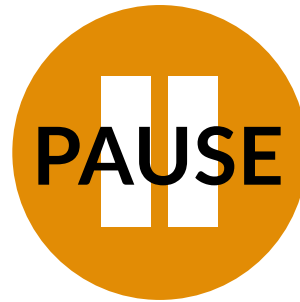
We have listed useful factsheets on particular behaviours at the end of this leaflet.

If you would like further help, please don't struggle on your own as there are many ways in which people in your situation can be helped. Please contact your local Alzheimer's Society or your doctor for advice. If you want information on how services can help you, see 'How health and social care professionals can help': <http://alzheimers.org.uk/factsheet/454>

## Before you respond



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<b>S</b>	See things from the point of view of person with dementia.
<b>T</b>	Think about your own thoughts and feelings.
<b>O</b>	Observe and ask what the person is trying to communicate and what is going on.
<b>P</b>	Patience and persistence.

<b>P</b>	Physical
<b>A</b>	Activity
<b>U</b>	You
<b>S</b>	Self-esteem
<b>E</b>	Emotion

## **P** is for **PHYSICAL**

### Are they in pain?

Pain can be a common cause of changes in behaviour and can result from many problems such as joint pain, dental problems or discomfort from skin problems or constipation.

#### What to do

- Ask the person if they are in pain.
- Watch out for signs of them being in pain.
- Change their position if they have been sitting in one place for a long time.
- If you think they are in pain get advice from their doctor. Note the activity they're doing when they are distressed or seem uncomfortable so you can give information to their doctor.
- Please seek advice from their doctor if the person is taking any medication for pain, either prescribed or purchased. It may be that prescribed pain-killers need adjusting or that those being self-medicated are unsuitable.

See factsheet 'Pain in dementia' on the Alzheimer Scotland: Action on Dementia website or <http://www.alzscot.org/downloads/IS38pain%20in%20dementia.pdf>

## Has their medication been reviewed or changed recently? Are they taking all their medication correctly?

New medicines might be causing side-effects. Older medicines may no longer be needed or may need adjusting. Incorrect use of medication may result in extra side-effects or result in limited or no expected benefits.

## Do they have an infection?

They might have an infection such as urinary tract or chest infection or cellulitis.

### What to do

Look out for things like smelly or cloudy urine (wee) or an unusually wheezy chest or redness, itchiness or soreness of the vagina (women) or penis (men) and report these to their GP.

## Are they hungry or thirsty?

Dementia can cause changes in taste and appetite. People may have difficulty managing or recognising food or cutlery. Dehydration (lack of liquid) can happen with changes between hot and cold weather. People may avoid drinking in order to avoid going to the toilet.

### What to do

- Note any problems with eating or drinking.
- People may need prompting to use cutlery, such as putting a fork in their hand and guiding their hand to the food.
- Meals may need to be little and often to ensure that blood sugar is maintained.
- Look for very yellow urine, which is a sign that they ought to be drinking more. Encourage drinking and provide support for going to the toilet if needed (see advice in Self-esteem below).
- Look for problems with denture pain or mouth ulcers.
- Let their GP know if you are concerned about how much they are eating or drinking.

See factsheet 'Eating and drinking': <http://alzheimers.org.uk/factsheet/511>

## Are they getting enough sleep at night?

Dementia can cause changes in people's sleep schedule so that they wake up more often and stay awake for longer at night. Confusion about time can lead them to think it is daytime at 4am and want to get dressed.

### What to do

- Note any signs of pain or discomfort upon waking.
- Keep bedtime routines and provide nightlights and comfort objects.
- Avoid watching TV in the bedroom or the person spending long periods in time in bed while awake; use bed only for sleep.
- Encourage outdoor exercise or activities to keep them alert during the day.
- Try to stop or reduce daytime napping.
- Avoid alcohol and caffeine before bedtime.
- See their GP if problems persist.

## Could they have hearing or eyesight problems?

People can become disinterested in a conversation or an activity just because they cannot see or hear easily.

## What to do

- Check how well they can see or hear things, even if they have glasses or a hearing aid.
- Improve the lighting.
- Make sure that you talk loudly and clearly into the good ear.
- Avoid competing noises or activities such as TV or radio.
- Try to move slowly and approach the person from the side where the eyesight and/or hearing are best.
- Get advice from an optician or hearing specialist if you think their sight or hearing could be improved.

## Could they be making 'visual mistakes'?

People with dementia might still have good vision but have problems with making sense of things correctly in front of them (called visuospatial difficulties). This might make it difficult for them to watch TV, use objects correctly or walk confidently. Other examples include misinterpreting reflections in mirrors or avoid stepping on shiny floor because it looks wet or slippery.

## What to do

- Improve the lighting.
- Make sure the rooms are free from clutter and there is space to move around with confidence.
- Cover-up or change busy patterns on walls and floors.

## Could they be experiencing hallucinations?

Hallucinations may occur with some types of dementia, especially dementia with Lewy bodies. Visual hallucinations are most common and involve seeing things that are not present, usually people and animals. This can be frightening and lead to changes in behaviour.

## What to do

- If they are not worried then don't dwell on it.
- Listen carefully and acknowledge what the person is saying.
- Talk calmly and try not to argue with them.
- Consult their GP if the hallucinations persist or worsen or are frightening.

## Could the room temperature be too hot or too cold?

### What to do

If very hot and the temperature cannot be reduced consider giving them more drinks, use fans or sit them outside in the shade. If cold, try the use of blankets and extra clothing.

## A is for ACTIVITIES

## Could they be bored or needing social contact?

### What to do

- Use simple activities to prompt conversation, such as looking at a vase of flowers, a picture on the wall or looking out of the window.
- Involve them in everyday activities like laying the table.
- Try and do activities they used to enjoy doing, e.g. gardening or visiting the seaside.
- Give the person regular opportunities to talk to someone.

- Visit your local dementia café where both of you can meet and chat with others in a similar situation (contact your local Alzheimer's Society for more information).
- Develop a "life story" together to support reminiscing and conversations. Find Life Story forms at: [http://www.dementiauk.org/assets/files/info\\_and\\_support/Dementia\\_UK\\_Life\\_Story\\_Template\\_final.doc](http://www.dementiauk.org/assets/files/info_and_support/Dementia_UK_Life_Story_Template_final.doc)

## Is there too much going on or is the person in unfamiliar surroundings with people they don't recognise?

### What to do

- Consider having more routine and structure in the day by doing the same things at the same time everyday.
- Have a quiet time or use calming activity or music, especially at times they are tired, such as after lunch.

## U is for YOU

### Are you looking after yourself?

Your situation may be extremely difficult to cope with and you may feel helpless and frustrated. It is important that you look after your physical health and have support. It's important that you do not take all the responsibility for managing very demanding situations.

See factsheet 'Carers: Looking after yourself' at: <http://alzheimers.org.uk/factsheet/523>

### What to do

Try to share the responsibilities with others and accept help from family, friends, neighbours or professionals.

### Do you understand why they are distressed or behaving badly?

You may struggle to understand someone's changing behaviour. How you understand the behaviour is crucial to how you will react. If you blame the person, you are more likely to get angry.

### What to do

- Try and find out as much as you can about dementia and what causes certain behaviours.
- Try to avoid taking things personally or having arguments over mistaken ideas or attempt to change their viewpoint. Your arguments will only end up frustrating you and probably upsetting them.
- Be mindful of your own tone and facial expressions and try to speak calmly.

## S is for SELF ESTEEM

### Are they frustrated because they are unable to communicate their needs or they can no longer do the things they used to do?

People with dementia can find it difficult to feel good about themselves. This can often be expressed through unusual behaviours.

### What to do

- Include people in conversations and be aware of how they might be feeling.
- Let the person finish their sentences unless they ask for your help.

- Don't point out their mistakes.
- Let them do jobs they are used to doing, e.g. putting some of the shopping away. Break the job down into smaller steps to help them. This will help them feel they are doing something useful.
- Explain what you plan to do or what you are doing.
- Ask them questions which require yes/no responses and give plenty of time to respond.
- Help the person recognise objects. Do this by showing them how to use the object, getting them to touch the object or using noise, e.g. flushing toilet.
- Use short simple statements rather than questions or gestures to indicate walking to the toilet, etc. For example, say "come to the toilet" rather than "would you like to go to the toilet"?

See factsheet 'Communicating' at <http://alzheimers.org.uk/factsheet/500>

## E is for EMOTIONS

### Are they sad, scared, depressed or anxious?

People with dementia still experience feelings and emotions even though they may not be able to explain to you their feelings or remember what caused them to feel that way.

#### What to do

- Note down what was going on to see if something triggers the change in feelings or mood. This might be due to certain music, noises or a visit from someone.
- Encourage distracting activities such as walking.
- Touching or holding their hand may help calm them and show them you care.
- Try to pick out key words or phrases and repeat these back as it may help the person focus on a particular topic.
- Respond to the person's feelings rather than correcting the accuracy of what they are saying. For example, if someone says they miss their mother, think about the meaning behind what they are saying. Are they sad or worried about something? You could encourage them to tell stories about their mother and what they miss about her to help them feel more secure. You might need to make try out different ways of responding to see what works best.

If someone's low or anxious feelings or mood persists, ask their doctor for a referral to specialist mental health services.

#### Other useful factsheets

Unusual behaviour	<a href="http://alzheimers.org.uk/factsheet/525">http://alzheimers.org.uk/factsheet/525</a>
Coping with incontinence	<a href="http://alzheimers.org.uk/factsheet/502">http://alzheimers.org.uk/factsheet/502</a>
Dressing	<a href="http://alzheimers.org.uk/factsheet/510">http://alzheimers.org.uk/factsheet/510</a>
Sex and dementia	<a href="http://alzheimers.org.uk/factsheet/514">http://alzheimers.org.uk/factsheet/514</a>
Moving and walking about	<a href="http://alzheimers.org.uk/factsheet/501">http://alzheimers.org.uk/factsheet/501</a>
Washing and bathing	<a href="http://alzheimers.org.uk/factsheet/504">http://alzheimers.org.uk/factsheet/504</a>
Dealing with aggressive behaviour	<a href="http://alzheimers.org.uk/factsheet/509">http://alzheimers.org.uk/factsheet/509</a>
Visuoperceptual difficulties	<a href="http://www.alzheimers.org.uk/factsheet/527">http://www.alzheimers.org.uk/factsheet/527</a>
Hallucinations	<a href="http://www.alzheimers.org.uk/factsheet/520">http://www.alzheimers.org.uk/factsheet/520</a>