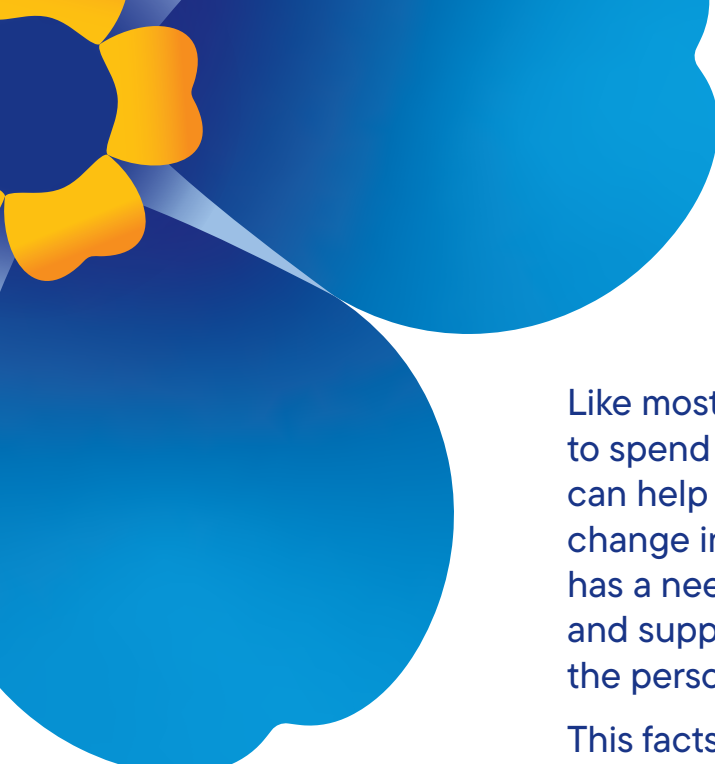


Walking and dementia



**Alzheimer's
Society**

Together we are help & hope
for everyone living with dementia



Like most people, a person with dementia may want to spend time walking. Walking is good exercise and can help relieve stress and boredom. However, a change in walking habits can be a sign that a person has a need that is not being met. By understanding and supporting them with their needs, you can help the person improve their wellbeing and safety.

This factsheet is for carers and anyone else supporting someone living with dementia. It explains why a person with dementia may want to spend time walking and suggests how to manage risks and help them walk safely.

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1 Walking about

A person with dementia may walk repeatedly around at home or leave the house during the day or night. This may become a problem, especially if they have difficulties with memory or can't find their way home.

It can be difficult to understand why the person you are caring for is walking about. By exploring the reasons, you can support them to remain independent and safe.

'Wandering' is a term that is sometimes used to describe a person with dementia walking about. 'Wandering' is unhelpful because it suggests that the person is walking with no reason or purpose. In fact, there will often be a reason or belief behind it. 'Walking with purpose' is also sometimes used, although it is less common.

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2 Why might someone spend time walking?

The reasons why a person with dementia might want to walk about may not be obvious. If you ask the person, they may not remember the reason or they may not be able to tell you. As the person's carer, friend or relative, you are likely to know them best. Trust your instincts and try to use your knowledge of the person to understand why they are walking. This may help you find ways to support them.

To help you, this section will focus on some of the possible reasons for walking about. It also contains tips on how to support the person.

Memory loss

A person with dementia might begin a journey with a particular goal in mind. However, due to short-term memory loss, they may then forget where they were going or the route they need to take, and become lost.

Some people with dementia may also forget where they have put an item and think that someone has taken it. The person might then start walking to try to find it. You can try to make this easier for them by keeping personal items where they can easily see them. You can also use notes or pictures on cupboards and drawers to show what is inside.

Confusion about the time

People with dementia often become confused about the time. They may wake up in the middle of the night and get dressed, ready to start the day. This confusion is easy to understand – in winter or summer in the UK, it is common to go to bed and wake up while it's either still dark or still light outside.

It can help if you place a large clock by the person's bedside that shows whether it is the morning or afternoon. Some clocks also show the day of the week and the date.

Clocks are available at shops selling independent living aids and equipment. They are also available from Alzheimer's Society's online shop – see shop.alzheimers.org.uk

The person you are caring for may walk a lot during the night if they have difficulty sleeping. This is common in older people and is particularly common in people with dementia. You can do simple things to try to help them sleep. For example, you can encourage them to develop a routine when going to bed at night. It may help if they avoid daytime naps, caffeinated drinks and alcohol.

See factsheet 534, **Understanding sleep problems, night-time disturbance and dementia** for more information.

Relieving pain and discomfort

People often walk when they are in pain because they are trying to ease their discomfort. Alternatively, a person may walk to try and 'escape' from their pain. The cause of a person's pain will not always be obvious – for example, if they have a headache or pain in their tooth. Sometimes, a person will feel distress or emotional pain due to a memory or a thought they have had. Speak to the person about what they are thinking or feeling to try and find out why they have a need to move around.

It might be that the person you are caring for is walking because they are uncomfortable. Check to see if any of the following may be causing them a problem:

- **They might need the toilet or be constipated.**
- **They may be wearing ill-fitting shoes, clothing or dentures.**
- **Their environment may be uncomfortable.** For example, it may be too hot or too cold, or there may be poor lighting or unfamiliar smells.
- **It may be too noisy for them.** People with dementia can find it difficult to cope with a lot of noise. Simple things like closing a door when you are vacuuming or lowering the television volume can help.
- **They may be overwhelmed.** If a person has had a busy day where a lot has happened, they may find it too much to process. Ask them what might help them feel more settled. It often takes trying different things to work out what the cause might be and how to offer support.
- **A person with dementia may walk about more when they are feeling unwell.** If you notice a sudden change in them – for example, if they become less able to focus or be still – ask whether they feel unwell.

If you think the person is walking about due to pain, discomfort or illness, talk to the GP. They can examine them for any physical causes or illnesses.

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Restlessness, agitation and anxiety

People with dementia who walk about may sometimes simply be feeling restless, like anybody else. They may appear agitated, fidget, tap their fingers or make other repetitive movements. These behaviours are known as 'restlessness'. They may be a symptom of the physical changes in the brain caused by dementia. It can be useful if you start by checking for any physical causes. Make sure they are wearing comfortable shoes and clothing. You can also try adjusting the heating to change the temperature.

There is also a medical condition called 'restless legs syndrome'. It gives people an overwhelming, irresistible urge to move their legs to stop unpleasant sensations. This condition causes people to get up and walk about during the night. If you think the person you are supporting might have restless legs syndrome, talk to their GP.

Some people may walk about because they feel anxious. A number of things can cause anxiety:

- A person with dementia might become more aware of the changes they are experiencing.
- They may be unable to continue with hobbies and tasks they enjoy.
- The person may have seen, heard or thought of something which has caused anxiety, but which they cannot remember or explain.
- They may be responding to hallucinations and how they interpret what they see – see factsheet 527, **Changes in perception**.

If the person feels anxious and needs to walk, go with them if possible. Try to encourage them to tell you why they are feeling this way. Reassure them, for example, by holding their hand if appropriate. Encourage them to breathe slowly and deeply, or to sing a song which you can gradually slow down. If they are walking too fast, try to keep pace with them and gradually go slower to encourage them to slow down too. If the person is feeling overwhelmed with anxiety, then they likely will not be able to explain what has triggered this until they feel calmer. This may not happen until they have walked for a while.

You may need to try different things to work out why the person is restless, agitated or anxious.

A person may feel the need to walk about as a side effect of certain medicines, such as some antipsychotic medicines. You could ask their GP whether their prescription could cause restlessness.

Relieving boredom

A person may walk or pace because they don't have enough things to do or have not been busy enough during the day. They may feel bored because they don't do as much as they used to – for example, seeing friends or going out. Having things to do gives everyone a sense of purpose and self-worth.

Try to find ways to help the person stay mentally engaged and physically active. For example, you could encourage them to play games or take part in hobbies that match their interests. Reminiscence and creative therapies can also help. Being involved in housework or daily tasks can help the person to stay active and engaged. Carrying out these tasks can also help the person's self-esteem and confidence.

Bear in mind that activities may need to be adapted, and the person may not want to do them for long periods of time. For more information and ideas, see booklet 77AC, **The activities handbook**.

Lack of physical activity

If the person you are caring for is constantly walking around, it may be because they have energy to spare. They may feel the need to do more regular exercise. If they are able, they could try exercise classes or activities such as walking or dancing groups. You can also help them to include more daily exercise without making big changes. Good examples include:

- doing seated exercises – see factsheet 529, **Physical activity, movement and exercise** for examples
- walking to the shops or around the garden if they have one
- walking up steps
- doing some housework or chores.

If they are able, the person could accompany someone to leave the house at least once a day to get some fresh air. It helps to see regular routines, such as the rubbish being collected, post being delivered or children going to school. It also helps to see the weather outside and the clothes that people are wearing. This can orientate them in terms of the time of day or year.

Continuing a habit or interest

As much as possible, people with dementia will often want to continue with habits or interests they had before their diagnosis. Walking may be an activity they have always enjoyed, or may be connected with another habit. You may find that the person you are caring for goes for a walk at times of the day when they used to be out and about.

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The care home staff would give my mum tea and toast and keep an eye on her, hopefully get her back to bed.

Family member of a person with dementia



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For example, this may be when they would have gone to work or walked the dog. Try to support their need to walk for as long as you can. If the person is mistaken about their need to walk, correcting them may cause distress and confusion. Try to change the subject or suggest another activity instead. Think about why they may be feeling the need to go to a particular place. It is much more important to focus on the person's feelings rather than whether what they are saying is true.

If you find that the person often wants to walk at the same time each day and you are unable to accompany them, it may help to go out with them slightly earlier in the day instead. Keeping to the same routes can give a sense of familiarity. It can also reduce the risk of the person feeling disoriented. If you can't go with them at all, you could ask family or friends if they can help.

In some areas, there are dementia-friendly walking groups. These groups help people with dementia to continue walking in a safe environment with other people. For more information see 'Other useful organisations' on page 16.

Searching for a person or something from the past

If the person is on their own, sometimes even for short periods, they may walk about to try to look for a specific person. This may make them feel extremely anxious. It can help to leave notes when you're going out to remind them about where you are and when you will return.

Try to put the notes where they will stay in place and where the person will see them. This could be near the kettle or on the inside of the front door. You may find it helpful to write key information on a whiteboard. Make sure the person's phone is nearby so that they can call instead of leaving home to try and find you.

As dementia progresses, the person you are caring for may try to find someone or something from their past. For example, they may not remember that someone has moved or died. Encourage them to talk about this so you can try to understand who or what they are searching for. Show them that you are listening and taking their feelings seriously. Try to avoid correcting what they say. It is much more important to focus on the person's feelings rather than whether what they are saying is true. For example, if they are looking for their mother, ask them about her and show them some photographs. This may meet their emotional needs, which might reduce their need to walk about and look for the person.

Feeling lost

A person with dementia might walk about because they feel lost. This can happen in unfamiliar surroundings, such as when moving house, attending a new day centre or moving into a care home. If the person's living environment has changed, make sure they keep familiar items. These might be photographs, ornaments or furniture. Try to reassure the person that they belong in the new place. If you can, match the layout of their new home with their previous one, using some of the same furniture if possible. The person may need extra help from family, friends or care home staff to find their way around. As the surroundings become more familiar, they may become less disorientated.

As dementia progresses, the person you are caring for may begin to feel lost in their own home. For example, they may forget where the bathroom is and walk around to try to find it. Leaving the bathroom door open and the light on could help. Signs on the doors can also be useful. For more information see booklet 819, **Making your home dementia friendly**. You can download it from alzheimers.org.uk/dementiafriendlyhome or call **0300 303 5933** to order a copy.

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[My mum] would go out at night (often inadequately dressed) and would have to be brought back. The trigger seemed to be that she no longer recognised her home, didnt know where she was and went out looking for it.

Family member
of a person with
dementia

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3 What can I do?

If someone you are caring for often walks about, it can be difficult to know how to respond. Take the time to try to understand why they are walking about and what they need. This can often help to manage the situation. Walking about may be a phase that the person is going through.

Try keeping notes for a couple of weeks about the person's behaviour and what is happening when they walk about. Write down any reasons they might give. This might help you to identify any triggers or patterns.

4 Staying independent

It is important for a person with dementia to stay independent for as long as possible. However, you may be worried about the person being at risk of harm or injury. If the person is walking about, try to balance their independence with keeping them safe.

In daily life, there will always be some degree of risk. You and any other people involved in the person's care need to decide what level of risk is acceptable. This helps maintain their quality of life and protect their independence and dignity. Remember that if the person has capacity (the ability to make decisions) then they can decide to do things even if they put themselves at risk. If the person does not have capacity, they should still be involved in discussions about their care as much as possible. All decisions must be made in their best interests. For more information on capacity, see factsheet 460, **Mental Capacity Act 2005**.

The steps you take to look after the person will depend on how well they are able to cope and the reasons why they spend time walking. Try to think about whether their environment is safe and whether anything can be done to make it safer. There is no such thing as a risk-free environment, but some places are safer than others. For example, a quiet area where the person is well known within the community is likely to have fewer risks. Looking at the person's environment can help you to see whether you can reduce any risks.

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5 If the person wants to leave the house

During a walk, a person with dementia may leave the home. This can be worrying for carers. It can be hard to know how to manage this situation without affecting the person's independence.

If you want to encourage the person not to leave the house, try to gently focus their attention onto something else. Suggest an activity – many carers find even everyday tasks like folding clothes or laying the table can help divert the person's attention. It can help if you suggest activities that involve moving around.

You can also try installing a door sensor. These can play a pre-recorded message asking the person not to leave the house. It may also help if you switch off any outside lights at night to minimise what they can see through the windows.

Smart home and telecare technology can help to keep the person safe. Devices such as movement monitors and pressure pads send an alert to a carer when they are stepped on. For instance, these could be placed at the front door so it is clear when the person has walked out of their home. You can also think about getting a specialist tracking device that uses GPS to locate where a person is. It is important to remember that for these technologies you will need to get the person's consent. A tracking device or smart home technology may or may not be suitable for them. For more information see factsheet 437, **Using technology to help with everyday life**.

Do not use medication, such as sleeping tablets, to prevent the person from getting up at night. Doses that are strong enough to stop someone from walking about can make them feel drowsy. In some instances, it may cause them to fall. It may also mean they are unable to respond quickly or at all in an emergency. Medication can also increase confusion, worsen memory problems and contribute to incontinence.

Locking doors when a person has dementia

Some carers may consider locking the doors when a person with dementia is home so that they cannot leave. However, a person with dementia should never be locked in when on their own. This can be very dangerous, for example, if there is a fire, or if they have an accident or fall. Locking the person in may also cause them to panic and injure themselves trying to get out.

If there is someone else in the house with the person, you may want to lock the doors to stop the person going outside. You might do this, for example, if they live near a busy road. If the person has capacity (the ability to make decisions) then you can lock the doors if they give consent. You should discuss whether to lock the doors with any other people who are involved in the person's care. Any decisions that you make should not place the person with dementia at any risk. Doors should only be locked for the shortest time necessary. Be aware of any fire risks and ensure that the locks are easy for you or another carer to operate.

If the person doesn't have capacity to agree to the doors being locked, it may be possible for this decision to be made on their behalf. Locking a door is depriving someone of their liberty, in this case their freedom of movement – so it's crucial that social services are consulted before this is done. They may wish to assess the situation to ensure that it is in the person's best interests to do this.

For more information see factsheet 483, **Deprivation of Liberty Safeguards (DoLS)**.

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6 Limiting the risk: tips for carers

- **Create a safe space to walk at home.** If the person's home has a garden, you could look for ways to make it safe for them to walk around. For example, you could make sure there are no obstacles on the ground and that the grass is not overgrown. You could create a flat, even path with a handrail. To make the experience more enjoyable, it could lead to points of interest, such as birdfeeders and garden ornaments.
- **Find a local service, group or organisation** that helps people with dementia take part in activities, including walking. Some organisations also specialise in structured leisure and wellbeing activities for people with dementia.
- **See if there are local volunteer schemes** in your area that help people with dementia to return home. For example, Neighbourhood Return notifies local volunteers who can help to look for someone. Contact your local council for more information about the scheme and to see whether it operates in your area.
- **Support the person's desire to walk where possible.** If the person you are caring for is determined to leave their home, try not to argue with them. This could be upsetting. Instead try to find out where they want to go. Help them take appropriate items, such as a mobile phone. You can also help them put on appropriate clothing if necessary, such as a coat. Accompany them if you can, and then try to divert their attention so that you both return home safely. If you are not able to go with them, ask for support from family and friends who may be able to help.
- **Make sure the person carries some identification** or the name and phone number of someone who can be contacted if they get lost. You could sew this information onto a jacket or handbag so that it is not easily removed. Or the person may find it useful to carry one of Alzheimer's Society's helpcards to show other people. For more information go to [alzheimers.org.uk/helpcards](https://www.alzheimers.org.uk/helpcards). You could also get them an identification bracelet, like those provided by MedicAlert® – see 'Other useful organisations' on page 16.
- **Save emergency contacts.** If the person uses a mobile phone, make sure some 'in case of emergency (ICE)' numbers are saved and easily accessible. This might be the phone number of their primary carer.

- **Consider using tracking technology.** If the person's mobile phone is switched on, it may be possible to trace them if they go missing. They would need to consent to this tracking before it is switched on.
- **Get support from the community.** If you trust local shopkeepers and neighbours, consider sensitively telling them that the person has dementia. You could also give them your contact details. Ask them to call you if they see the person walking about. You should get the person's consent to tell other people that they have dementia, if they are able to give it. If the person can't give their consent, only tell others about their diagnosis if you think it is in the person's best interests.
- **Inform the people involved in their care.** If the person is in day care, respite residential care or long-term care, tell the staff about their need to walk about. You can also ask about the policy on safe walking and care for residents who walk about. Some care homes have an 'open door' policy, which may not be best for someone who walks about.

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7 If the person you are caring for goes missing

- As difficult as it may be, try to stay calm and focus on finding the person safely.
- If you can't find the person, tell the local police. Keep a recent photograph of the person to help the police identify them. Consider taking part in the Herbert Protocol. This is a national scheme that encourages carers to complete a form of useful information. The form can be emailed or handed to the police if a vulnerable person goes missing. You can find more information at www.met.police.uk/herbertprotocol or contact your local police.
- If possible, make sure someone stays at the person's home while others go looking for them in case they return.
- Think of places the person likes or has visited a lot in the past as they may have gone there. For example, they might have gone to places they previously lived or worked, or somewhere they like to visit.
- Consider using the internet or social media to ask people in the local area to contact you if they see the person. You might find it useful to post to local area groups and missing persons groups. However, think very carefully about which groups you post to and how much information you decide to share online. For example, the person you are caring for may not want other people to know that they have dementia.

When the person returns

- Bear in mind that they may be feeling anxious if they were lost. Try not to react angrily or immediately question them too much about why they went out. Reassure them and try to get them back into a familiar routine.
- Once they are settled back home, it could be useful to gently ask them where they were going and why they went out. This could help you understand the reasons they went out, and help you stop them becoming lost again.
- After the situation is resolved, try to give yourself time and space to relax. You may find it helpful to talk to a family member, a friend or a professional.

8 Looking after yourself: tips for carers

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Caring for a person with dementia who walks about can be difficult. You might feel frustrated and disheartened if nothing seems to work to help them. As with much of caring for a person with dementia, there might be a lot of trial and error before you find what works. This can take some time, as you may need to use different approaches at different times.

You might feel overwhelmed or unable to manage at times. Try not to be hard on yourself. Remember that you are doing the best you can. It is very important that you look after your own wellbeing. Try to find ways to help yourself cope with the emotions you are feeling. For example, talk to friends and family members about any worries you have or how they can help and support you. You might also find it helpful to speak to your GP or a counsellor about how you are feeling and ways to cope.

See factsheet 523, **Carers – Looking after yourself** for more information and advice.

For emotional support, advice and information, call our Dementia Support Line on **0333 150 3456**.

You can also connect and share stories with other people who are caring for a person who walks about. You might want to do this through Alzheimer's Society's Dementia Support Forum (forum.alzheimers.org.uk). You can join discussions on walking about and share your own experiences. It is free and available 24 hours a day, every day of the year.

You or the person you are caring for may be able to get help through a care needs assessment. This is also called a community care assessment in Northern Ireland. It is the process that local authorities use to assess the care needs of a person with dementia. For more information see factsheet 418, **Assessment for care and support** (for England), NI418 (for Northern Ireland) and W418 (for Wales).

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Other useful organisations

AlzProducts

www.alzproducts.co.uk

Alzproducts is a UK Alzheimer's and dementia specialist shop.

British Gymnastics – Love to Move programme

<https://britishgymnasticsfoundation.org/lovetomove>

The Love to Move programme provides a downloadable guide to dementia-friendly seated gymnastics that can be done at home.

The British Psychological Society (BPS)

0116 254 9568

info@bps.org.uk

www.bps.org.uk

The BPS is an organisation that provides access to a list of clinical and counselling psychologists offering both NHS and private therapy services.

MedicAlert®

01908 951 045 (8am–3.30pm Monday–Friday,

9am–3pm Saturday)

info@medicalert.org.uk

www.medicalert.org.uk

MedicAlert® provides an identification system for people who have hidden medical conditions and allergies. You can buy jewellery engraved with details about the person's condition, an identification number and a 24-hour emergency phone number.

TechSilver

hello@techsilver.co.uk

www.techsilver.co.uk

TechSilver provides gadgets designed to make life easier, safer and happier.



Factsheet 501

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Reviewed by: Cath Burley, Consultant Clinical Psychologist (on behalf of The Faculty of the Psychology of Older People) and Jessica Peterson, Specialist Practitioner, Dementia Team, East Kent Hospitals University Foundation NHS Trust

This factsheet has also 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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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**



Patient Information Forum



**Alzheimer's
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Together we are help & hope
for everyone living with dementia

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