

Walking about

Many people with dementia feel the urge to walk about and in some cases leave their homes. Walking is not a problem in itself – it can help to relieve stress and boredom and is a good form of exercise. As with all behaviour, walking about can indicate a specific underlying need that the person with dementia has. Understanding what this is and finding a solution could help to maintain the person's wellbeing. This factsheet explains some of the reasons why someone with dementia may walk about and outlines the ways in which you can help.

When a person with dementia often walks about, it can be worrying for those around them and may at times put the person in danger. It may not be clear why the person is walking about and this is often referred to as 'wandering'. However, this term is unhelpful because it suggests aimlessness, whereas the walking often does have a purpose. Rather than dismissing it, it is important to think about how the person's independence, safety and dignity can be preserved.

The person might walk repeatedly around the house, or get up and leave the house at any time of day or night. People with dementia can often experience problems with orientation, which may cause difficulties in finding their way home. This can make those closest to them feel very anxious and concerned for the person's safety.

Why might people walk about?

There could be a number of reasons why a person with dementia walks about. Once you understand these and can identify the person's

needs, you can start to find ways to help meet them. Keeping a journal for a couple of weeks may help identify any triggers.

Possible reasons for walking about include:

- continuing a habit or interest
- relieving boredom
- lack of physical activity
- relieving pain and discomfort
- responding to anxiety and relieving stress
- feeling lost (especially in a new environment)
- restlessness (as a symptom of dementia or a side effect of medication)
- memory loss
- searching for the past or seeking a sense of fulfilment
- confusion about the time.

Continuing a habit or interest

As much as possible after diagnosis, people with dementia will want to continue with habits or interests that were part of their regular routine. Walking is one such example. You may find that a person wants to take more walks at times of the day when they used to be out and about. For example, at times when they might have gone to work, walked a dog or collected children from school. Try to accommodate this for as long as you can. If you are unable to accompany the person yourself, you could ask whether relatives or friends can help.

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Relieving boredom

Many people with dementia do not have enough to do and often walk about to relieve boredom. They may also have previously done activities but now no longer feel fulfilled. Being occupied gives us a sense of purpose and self-worth, and people with dementia are no exception. Try to find ways to keep the person mentally engaged and physically active. This might be through playing games or taking part in hobbies. Involving a person with dementia in your daily chores and household tasks can give them a sense of fulfilment (see factsheet 521, **Staying involved and active**).

Lack of physical activity

Constant walking about may also indicate that the person with dementia has energy to spare and feels the need for more regular exercise. There are many simple ways to incorporate more exercise into a daily routine without making big lifestyle changes. Good examples include:

- using a rocking chair or exercise bike
- walking to the shops rather than driving
- walking up steps rather than using the escalator
- doing some gardening or brisk housework.

Encouraging the person to leave the house at least once a day for some fresh air may help address the issue. Seeing regular routines such as the rubbish being collected, postmen delivering the mail or schoolchildren going to school can also help to orientate people. For more information see factsheet 529, **Exercise and physical activity**.

Relieving pain and discomfort

People often walk about when they are in pain, in an attempt to ease their discomfort. In the case of arthritic or rheumatic pain, walking can actually help. Alternatively, some people may be trying to 'escape' from the pain. If you think this might be the case, raise your concerns with the person's GP.

People may also start to walk about more when they are physically unwell – see 'Restlessness and agitation' below. If you notice a sudden change in a person's walking habits and restlessness, contact the GP who can examine them for any underlying physical illness.

Other sources of possible discomfort include needing the toilet, and ill-fitting shoes, clothing or dentures. The person may also be responding to an uncomfortable environment. For example, it may be too hot or too cold, or there may be unpleasant lighting, noises or smells. You may need to go through a process of trial and error to work out a cause of restlessness. For example, if the reason was not connected with the person needing to go to the toilet, try adjusting the heating or ventilation to change the temperature.

Responding to anxiety

Some people walk about if they are agitated, stressed or anxious. This may be a response to the issues noted above. A less common reason is that the person may be responding to hallucinations or issues with visual perception. This is a more common symptom of some types of dementia (see factsheet 527, **Sight, perception and hallucinations in dementia**). Try to encourage the person to tell you about their anxieties, and reassure them in whatever way you can.

Feeling lost

New surroundings can trigger feelings of uncertainty in people with dementia. Common examples include when respite (replacement) or residential care has been arranged, when the person moves to a new house or when they are attending a new day centre. If the person's

living environment has changed, showing them familiar items, such as photographs or clothing, may help to assure them that they belong in a new place.

The person may need extra help in finding their way about. They may also be more confused about the layout of their own home if and when they return. This disorientation might disappear once they become familiar with their new environment. However, as the dementia progresses, the person may fail to recognise familiar surroundings, and may even come to consider their own home as unfamiliar. It may be helpful to provide signs, for example for the toilet, even in the person's own home.

Alzheimer's Society's free publication, **Making your home dementia friendly**, contains useful information on this subject. The booklet is also available to download from **alzheimers.org.uk/dementiafriendlyhome**

Restlessness and agitation

People who walk about may also feel agitated, fidget, tap their fingers or make other repetitive movements. Collectively these behaviours are known as 'restlessness' and may be a symptom of the physical changes in the brain caused by dementia. For more information see factsheet 525, **Changes in behaviour**.

The need to walk about may also be a side-effect of certain medication (such as some antipsychotic medications). Again, ask the person's GP to check whether their prescription could be causing them to feel restless.

There is also a medical condition called 'restless leg syndrome' which causes an overwhelming, irresistible urge to move the legs to prevent unpleasant sensations — mostly at night. This condition can lead to people getting up and walking about during the night. If restless leg syndrome is suspected, arrange for the person to visit their GP.

Memory loss

Short-term memory loss can lead a person with dementia to walk about and become confused. They might embark on a journey for a specific purpose, with a particular goal in mind, and then forget where they were going and find themselves lost. This can be a distressing experience. The person could also be searching for something that they have lost or think is lost. Keeping personal possessions on view may help prevent this.

Alternatively, they may have forgotten that their carer has told them they are going out, and will try to look for them. This may lead to the person feeling extremely anxious, and they will need plenty of reassurance in return. In the earlier stages, it can help if the carer writes notes reminding the person where they have gone and when they will return. These should be securely placed in a location where the person will see them, such as near the kettle or on the inside of the front door.

Searching for the past or seeking a sense of fulfilment

As the person's dementia progresses, they may try to seek out someone or something related to their past. Encourage them to talk about this, and show them that you take their feelings seriously. Try to avoid 'correcting' things that the person may say. It is important to focus on what the person is feeling rather than the factual accuracy. For example, if the person is looking for their mother, ask them what they miss about her and maybe bring out some old photographs. This may help address their emotional needs.

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 for the next day. This confusion is easy to understand, especially in winter when it is common to go to sleep, and wake up, when it's dark.

Having a large clock that shows am and pm, and keeping it by the person's bedside can help. Some clocks also show the day of the week and the date (see factsheet 437, **Assistive technology – devices to help with everyday living**). However, if the person's body clock is seriously out of sync, you may need to seek professional help.

If night time walking is a particular issue, the person may be having sleeping difficulties — something common in older people and particularly common in people with dementia. Simple measures that may help include avoiding daytime napping and not consuming caffeinated drinks such as tea, coffee or energy drinks in the evening or late at night. Drinking alcohol, smoking or eating a large meal should also be avoided near bedtime. Taking dementia medication in the morning may be helpful if nightmares or vivid dreams are a problem at night-time, but check with the GP. Exercise and some complementary therapies may also be helpful in addressing this — see factsheets 529, Exercise and physical activity, and 434, Complementary and alternative therapies.

Staying independent

It is very important that people with dementia are encouraged to stay independent for as long as possible. Some degree of risk is inevitable, regardless of the choices made. Those caring for the person need to decide what level of risk is acceptable in order to maintain the person's quality of life and protect their independence and dignity. Family and carers should support the person to be involved in these discussions as much as possible.

Steps to safeguarding the person will depend on how well they are able to cope, and the possible reasons for their behaviour. The safety of the person's environment should also be taken into account. There is no such thing as a risk-free environment, but some places are safer than others. Things to consider include:

- does the person live on a busy main road or in an urban area where people don't know their neighbours, or
- do they live in a peaceful rural area where they are well known within the local community?

What can I do?

Should I stop the person from leaving the house?

If a person with dementia wants to walk about, you should try to find a solution that lets them do so safely. You may be able to get help through a care needs assessment (also called a community care assessment) or through a local service, group or organisation that helps people with dementia to take part in leisure activities, including walking.

Alzheimer's Society provides leisure and wellbeing services in some areas, visit **alzheimers.org.uk/dementiaconnect**. There are also organisations that specialise in structured activities of this kind for people with dementia (for details see factsheet 529, **Exercise and physical activity**).

Some family carers decide to lock or bolt doors to prevent the person with dementia from leaving the house. You should never lock a person with dementia in the home if they are alone as this could be very dangerous in the event of a fire, accident or fall.

A situation may arise where you feel the person — even if they're not alone — should be locked in to prevent them from leaving. For example, if you live near a busy main road, you will want to stop the person from leaving the house and potentially endangering themselves. This can be done but only if you feel that the person is unable to make a decision on their own about the dangers of leaving the house. The decision must also be in the best interests of the person and not to make things easier for you or anyone else. It must also be the least restrictive option available for keeping the person safe.

If you do decide upon this option, make sure you have a plan to help them if they become upset and want to leave. Be aware of any fire risks and ensure that any locks or bolts are easy for you to operate. You should discuss this issue with any other people who are involved in their care, such as a community nurse or other family members. Any decisions taken should not place the person with dementia at any kind of risk. For more information on making decisions on behalf of

someone else, see factsheets 460, **Mental Capacity Act 2005**, and 484, **Making decisions and managing difficult situations**.

There are less restrictive options to consider than locking doors. They include distracting the person and trying to engage them with a different activity, such as folding laundry. You can also try deterring them from leaving by fixing a bead curtain across the front door or painting the door the same colour as the surrounding walls. If there are outside lights it may be helpful to switch them off at night. These approaches do not suit everyone and may be confusing or distressing for the person.

Do not use medication, such as sleeping tablets, to prevent the person from getting up at night or walking about. Doses that are sufficiently powerful to stop someone from walking about can cause drowsiness and, in some instances, falls. It can also increase confusion, worsen memory problems and possibly cause incontinence.

Limiting the risk: tips for carers

- If the residence has a garden, consider making it secure so that the person can walk outside safely. Having a circular path with points of interest, such as birdfeeders and garden ornaments, can make the experience more enjoyable.
- Ask whether there are any local volunteer schemes, such as Neighbourhood Return, in your area that help return home people with dementia.
- If the person is determined to leave, try not to confront them, as this could be upsetting. Instead try to get them to put on appropriate clothing (eg outdoor shoes and a coat) and accompany them a little of the way. You can then divert their attention so that you can both return safely to the residence.
- Make sure the person carries some form of identification or the name and phone number of someone who can be contacted if they get lost. You could sew this into a jacket or a handbag so that it is not easily removed. Consider identification bracelets like those provided by MedicAlert (see 'Other useful organisations').

- If the person uses a mobile phone, ensure that the phone number of the primary carer is stored and is easily accessible. If the mobile phone is switched on it may be possible to trace the person if they go missing. Specialist tracking devices are also available (see factsheets 437, Assistive technology devices to help with everyday living, and 484, Making decisions and managing difficult situations).
- Consider sensitively telling local shopkeepers and neighbours whom you know and trust about the person's dementia and give them your contact details they may be able to keep a look out.
- If the person is in day care, respite residential care or long-term care, tell the staff about their tendency to walk about. You can also ask about the home's policy on safe walking and care for residents who are prone to walk about.

If the person disappears: tips for carers

- Try not to panic.
- If you are unable to find the person, tell the local police. Keep a recent photograph to help the police identify them. Think of places that the person likes or used to visit a lot they may have gone there.
- When the person returns, try not to tell them off, criticise them or show them that you are worried. If they were lost, they may be feeling anxious themselves. Reassure them, and quickly get them back into a familiar routine.
- Once the situation is resolved, try to relax. Phone a family member or friend if you need to talk about it.
- Remember that this type of behaviour may simply be a phase. Taking the time to understand what the person's needs are can often help to resolve the problem.

Other useful organisations

MedicAlert

The MedicAlert Foundation 327–329 Witan Court Upper Fourth Street Milton Keynes MK9 1EH

T 01908 951045 E info@medicalert.org.uk W www.medicalert.org.uk

Provides an identification system for individuals with hidden medical conditions and allergies. Jewellery is engraved with details of the person's condition, an ID number and a 24-hour emergency phone number.

Walk 4 Life

W www.walk4life.info

Part of the NHS's Change 4 Life initiative, the website offers information on walks, events and walking groups in your area.

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Reviewed by: Dr Gwyn Grout, Consultant Nurse, Hampshire Partnership NHS Foundation Trust.

This factsheet has also been reviewed by people affected by dementia.

A list of sources is available on request.

Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland: 0300 222 11 22

9am-8pm Monday-Wednesday 9am-5pm Thursday-Friday 10am-4pm Saturday-Sunday

alzheimers.org.uk

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