



When people with dementia walk

– guidance for carers

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Introduction

"He's just home from the care centre, and he goes for a walk between 4:30 and 5, then we have our tea. Then he goes for a walk. He will not sit still unless I give him something to do. TV won't hold him. He's always been that type of man, he never sat very much. It's not till you're retired that you notice, and it's only got worse." (Carer, talking about her husband)

Sometimes people with dementia walk – this is often referred to as 'wandering'. They may walk around the house, or they may leave their homes, sometimes at odd hours of the day or night. Perhaps they can't explain where they want to go, or their explanation doesn't seem to make sense. Often the person's walking can be frightening for the carer, who worries about him or her getting lost or hurt. Or the carer may be frustrated because of restless walking.

"In Inverness, he had the roads, and he would come back. But on the island, it was so empty, and I wouldn't know where he'd gone. He could have gone along the cliff path, where the rocks were crumbling. ... You're waiting for the worst. You're just waiting to hear what might have happened. You can't sit, you can't eat, you're just waiting for the terrible news. ... So far the Lord has spared him. But there's a busy road not a mile from where we lived, and if he'd tried to cross it, well, I don't know what might have happened." (Carer, talking about her husband)

Walking can be one of the most stressful issues that a carer of a person with dementia can face. But it may be possible to improve the situation both for you and for the person with dementia.

What do we mean by walking?

A person with dementia may wander away from home, or walk restlessly about the house, apparently unable or unwilling to stay still. In the past this has been called

'wandering'. We now call this behaviour 'walking', as often it's inappropriate to describe what the person with dementia is doing as wandering: he or she may have a very definite purpose, even if it isn't immediately obvious.

"One time we saw a lot of cars parked outside, and my son said 'Oh, there must be a football match on.' And my husband said 'Oh, there's a match, I must go.' And we said 'Wait a minute, you don't have a ticket!' But he said 'What do you mean, don't be stupid, I don't need a ticket, I'm one of the directors, I've got my box.' And he just went off, we couldn't stop him. My son phoned up the football ground and told them: there's a man coming along, he thinks he's one of the directors, here's my number to call if there's any trouble. I died a thousand deaths, waiting for him. We asked where have you been, and he said 'I've been to the football, I had tea and pies'." (Carer)

Walking may be just a phase. Eventually the person with dementia may stop trying to get up and go places. Often in the later stages of dementia, the person becomes calmer and less likely to roam about.

Why do people with dementia go walking?

Walking may appear aimless, but almost certainly has a purpose behind it, even if the person with dementia cannot explain the reasons very clearly.

- The person may be feeling lost or uncertain in a new environment. Sometimes people may not recognise their own home, or may believe they still live in a house they moved away from years or decades ago.
- It is common for a person with dementia to become confused about the time. Someone may wake in the middle of the night and get ready for the next day. This may occur especially in winter, getting up and going to bed in the dark, and in summer, when the first light comes very early. Someone

used to shift work may be getting up at what he or she thinks is the right time to go to work.

- The person may have a specific purpose – to go somewhere, to find something or someone, to complete a necessary task. He or she may set out to accomplish a goal and forget what it was. He or she may forget that you have said that you are going out and set out to look for you.
- It is common for people with dementia to believe that they are younger than they are. They may try to carry out old routines: going shopping, going to work.
- Walking can relieve tension or physical discomfort. If a person has toothache or constipation, sitting still with nothing to do can make mild discomfort feel worse. If the person with dementia is suddenly restless, unusually unable to sit still, it may be that he or she is trying to get away from some new discomfort.
- Walking may be a sign that the person isn't burning off enough energy during the day – he or she needs exercise and stimulation.
- For many people, walking is a lifelong habit, and they go on long walks for pure enjoyment.

"I went out with him, and we walked for two and a half hours, and we were just in the house, when he said 'I think I'll go for a dander.' Never see him tired. But then by 9pm I'll say to him 'I think it's time for bed,' and he'll say 'yes' and then he'll go." (Carer)

What can carers do?

If you can let the person walk freely in a safe area, do so. In order to best deal with the situation of a person with dementia who is walking, consider the reasons why the person is walking. You might find another Alzheimer Scotland information sheet useful: *Understanding and Dealing with Challenging Behaviour* – call the Dementia Helpline on 0808 808 3000 or see our website www.alzscot.org for a copy. If you know why the person is walking, you may be able to help

him or her do it safely, or find another way to help.

Safety at home

Carers often worry that a person with dementia walking around at home may accidentally come to harm.

You can:

- make the house safer (see also Alzheimer Scotland *Safety in the home* – call the Dementia Helpline on 0808 808 3000 or see our website www.alzscot.org for a copy.).
- set up simple alarms so that the person you are caring for cannot go out without your knowledge. This could be a simple string of bells on the door, or an electronic alarm sounded by a pressure pad under the doormat such as you sometimes find in shop entrances. (But a loud noise might be distressing to the person with dementia.) Door alarms are available that simply attach to the door frame without wiring, and cause a pager to silently vibrate. The pager can be carried in a pocket and picks up the alarm signal. These are designed for people who live alone: the alarms can activate a bell or light in a neighbour's house.

You can get help in safety-proofing your home from an occupational therapist (OT). You can contact an OT through the social work department, your GP or your local hospital.

There is no such thing as a completely risk-free environment. However, you can minimise risk.

Using technology

Every so often the newspapers carry stories about some new gadget that can be used to track someone with dementia who goes missing; or the use of tagging devices similar to those assigned by the courts to ensure that convicted criminals comply with curfew arrangements.

Safer walking technology can be divided into two categories:

- alarm systems to alert carers to the fact that an individual has moved outside a set boundary. These devices may trigger a sensor (door, bed, chair, floor) and notify another person (perhaps a carer in the same house or living elsewhere, or a monitoring centre) should the person open a door where a sensor is located or leave a designated area. This can't help locate the person though.
- electronic tracking devices used to locate a person. These systems are now becoming more available but they vary in price and some can involve paying a subscription on top of the cost of buying the equipment. Tracking devices use GPS (global positioning satellite) technology to enable devices, including mobile phones, to pinpoint the position of the person if they go missing. Once the person is tracked down, a carer, family member, friend or care professional can then collect them and bring them back home.

If you are thinking about buying any "safer walking" equipment, it is important to consider the full cost (including any subscription and maintenance costs) and how easy it is to operate, as well as whether the person with dementia is able and willing to use it or wear it. Having a mobile phone with GPS capability is no use if the person leaves it at home, or if the battery runs out, for example. You also need to think about the range or distance covered by the equipment. A physically fit person with dementia could cover quite a distance in a short time.

at dementia is a very useful website giving details of all kinds of assistive technology, including alarms and locating devices. www.atdementia.org.uk/ or contact the Dementia Helpline on 0808 808 3000 for more information about technology.

Ethical issues

On the positive side, tracking technologies can be said to give people with dementia greater freedom and independence, enabling them to walk more freely; carers may feel greater peace of mind knowing that the person can be tracked should he or she wander from home. This type of technology could be said to be less restrictive than, for example, a constantly locked door.

On the negative side, there are issues of loss of privacy and the negative associations with the word tagging. Information would need to be stored about the person and carer contacts – who would have access to that information? Could the use of a tag lead to a carer having a sense of false security? What if the person with dementia will not, or cannot, give consent to wearing a tagging device?

“I think a way around this dilemma would be to discuss the issue of electronic tagging as soon as possible after dementia is diagnosed. Permission could be obtained in the same way that Power of Attorney has to be by law i.e. while the person is still able to make rational, informed decisions.” (Daughter).

Walking with company

Many people walk for pleasure. Walking, or other forms of regular gentle exercise, may actually help someone with dementia keep his or her mind in better shape.

You may not always be able or willing to walk with the person with dementia, but feel safer if the person is not going out alone. Ask friends and relatives for help. Perhaps a neighbour with a dog might like company on their daily walks. Some carer support groups offer group walks: it's worth asking if there is one in your area.

If the person with dementia is walking because he or she is bored, it might help to arrange outings.

“On Tuesdays, when I have him all day, we sometimes just jump on the bus to Inverness,

because that takes an hour, and then we just wander around, and then we come home, and then that's one day taken care of. If we go on a bus it's not so bad, because I might see someone, and he's looking out of the window.”
(Carer)

Too much energy

If a person with dementia is walking because he or she has too much energy, it may help to join an exercise class. Regular physical exercise is good for people with dementia: consider dancing, yoga, tai-chi, or even a marching band. Some local councils offer special exercise programmes for older people. Talk to the person running the class and find out what's needed for the person with dementia to attend: safety requirements may mean that someone else must attend too.

For a younger person with dementia, who has been used to regular exercise in a gym, (and if you can afford it and have space), you might consider buying a walking machine or treadmill, of the sort used in gyms. In this way the person with dementia can get daily exercise without the fear of getting lost. This would probably be unsuitable for a person who has never used a walking machine before. Experiment in the local gym first.

You may find that asking the person to help with household tasks that are still within his or her ability is a diversion from walking, as well as good exercise. For example, using the vacuum cleaner, sweeping a path, or cleaning the car. It doesn't matter how frequently the task is done, if the person with dementia still wants to do it.

Diversion

You may be able to divert the person with dementia from wanting to walk. Sometimes a person with dementia will forget having just come back from a walk and want to go out again, or want to go out at an inappropriate time (when it's night, or it's raining hard). Or he or she may want to carry out old routines: going shopping in his or her old

neighbourhood, returning to a workplace, preparing a meal.

Giving the person a clear task to perform may distract him or her from wanting to go out. For example, you could ask the person to sort objects – tidy out the cutlery drawer or one of the kitchen cupboards. Some carers have found that they can suggest a bath as a distraction.

One carer gave her husband a box of garden tools. He would spend hours outside in the garden. The carer resigned herself to the damage he did because he was safe and active and she could watch him from the window while she did something else in the house.

Walking alone

Is the person really at risk?

It can be especially worrying for carers if the person goes for walks alone. If this concerns you, consider carefully whether the person is really at risk. For example, perhaps the person has never yet failed to come home, and is careful on the roads. In this case, perhaps the person's independence is worth the low level of risk. However, if the person tends to get lost or is not safe on roads, the situation is quite different.

Arrange safer routes

If the person with dementia is walking outside alone, you can minimise the risk of getting lost. Arrange consistent outside walks – walk a well-defined route that ideally does not entail crossing major roads (though people with dementia often retain basic road skills). Go with the person until you are confident that he or she has learned the route. Stand outside the house with the person with dementia and work out together how to recognise his or her home at the end of the route.

Tell people in advance

Make sure that local shopkeepers and your neighbours know that the person with dementia may have difficulty finding the way home, and ask them to help. Inform the local

police station. You could also speak to the local taxi company, especially if there is one you regularly use, and the local bus company, if there is a risk that the person with dementia may catch a bus. (Obviously this will only be practical if there are regular drivers and only a few buses that the person might catch.)

Stay in touch

Make sure that the person with dementia has a contact phone number on him or her at all times when outside the house. You can get a Helpcard from Alzheimer Scotland that the person with dementia can carry: it's a small, single-folded, credit-card size, with space to include a contact name and phone numbers.

You can also get jewellery – a bracelet or a wrist pendant – from MedicAlert, a registered charity that provides emergency identification for people with hidden conditions such as dementia. The MedicAlert jewellery is engraved metal (options run from stainless steel to solid gold) and includes a 24-hour helpline number as well as the person's medical needs.

If the person with dementia is reluctant to wear the jewellery, you could try one or more of the following strategies; have it presented as a gift, especially as a gift from a grandchild or a nephew or niece; ask the person's GP to present it as a medical requirement; place the bracelet on the person's wrist next to their wristwatch or another bracelet he or she often wears, so that it is associated with something that he or she is already accustomed to. Make sure that the bracelet is sized accurately to the person's wrist measurements, so that it can't slip off easily.

If the person with dementia does not live alone, and has only mild dementia, it may be a useful reminder for him or her to carry their address in an accessible form such as a card in the wallet. But people who might be vulnerable should only carry a contact phone number.

Staying visible

It is a good idea to make sure that each day the person with dementia wears one or two items of brightly-coloured clothing. If he or she goes out at night, a jacket with a reflective stripe helps, or you could sew bicycle reflector strips onto jacket sleeves. Bright clothing may make it easier too if the person should get lost and you need to describe what he or she is wearing.

Finding the way home

Make sure the person's home is easily identifiable. Is the street number freshly painted and visible? What can the person with dementia see, standing on the street, that would remind him or her that this is home? If the person lives in a block of flats, can you mark the door of the flat in a very distinct way, perhaps with a photograph or a poster? Think about this both in terms of helping the person with dementia to return home alone, and also to make it easy for someone who wants to help to get him or her home safely.

Discouraging walking alone

You can discourage a person with dementia from leaving home without locking him or her in the house. Try a mirror on the door or a bead curtain over the door. However, some people with dementia may find these distressing, and this will work for some and not for others.

If the person is at risk if he or she goes out alone, for example at night, it may be necessary at times to restrict him or her from leaving (deadbolts on doors, new locks), but this is not recommended as a general tactic. There are legal issues involved in restricting someone from leaving his or her own home. There are also safety issues if someone cannot leave the house in case of fire or other danger.

But what if the person does get lost?

Precautions

Always have a recent photograph of the person with dementia to hand, and if possible, a recent video. Make a list of useful information to pass on to the police: better to do it in advance even if you never need it, than try to think of things when you are panicking because the person has gone missing. Information such as date of birth, identifying marks, jewellery, hair colour, medical condition, allergies, blood type, medication, complexion, eye colour, and dental work may all be helpful to the police. Don't forget to include any other names the person used in the past – for example, a woman's maiden name.

You could also have notes of places where the police might find the person, such as old neighbourhoods, former workplaces, or favourite places.

Keep an item of recently-worn clothing in a plastic bag – you could simply keep a blouse or a pair of trousers or socks out of the wash each time, and put it into the next wash, replacing it with a more recently-worn item. This is, of course, for the kind of emergency that you hope will never happen, but bear in mind that you do not make an emergency more likely to happen by preparing for it in case it does.

What to do?

Don't panic. Check the person's usual route for walking, and ask your neighbours and local shopkeepers if they have seen him or her. Remember that someone who does not know where he or she is going will often follow the direction of the dominant hand – a right-handed person will often turn right, a left-handed person will often turn left. Think about where else the person might have decided to go to: where did he or she live in the last clearly-remembered period of his or her life? Is the person trying to return to the home he or she remembers? Has the person been

thinking about going to work, or to a social club, or some other familiar place, and started out in that direction?

“He went into long-term care but he got out of the home. He went missing. The care home rang the police, but he had walked over a mile in a very little while. Someone spoke to him, and asked him his name and where he lived. He gave the address he had when he was a young boy.” (Carer)

If you can, ask a friend or a relative to help you search. Keep a list of neighbours and their phone numbers. Don't forget that someone must be available at all times at the contact number that the missing person is carrying.

If you cannot find the person yourself or with help, notify the local police. Give them the person's photograph or video and the other information you have ready.

Afterwards

When the person with dementia returns, do not scold him or her for getting lost or show that you are upset and worried: he or she may already be anxious with the experience of getting lost. The person needs to be reassured and to return to a familiar routine.

Once the person is safe and calm, call a friend or a relative or the Dementia Helpline (0808 808 3000) – talk to someone to whom you can vent your feelings of anxiety or anger.

Don't forget to contact all the people you asked to help when the person with dementia was missing, and let them know the outcome.

Summary

- Walking may be just a phase: eventually the person with dementia may stop trying to get up and go places.
- Walking may appear aimless, but almost certainly has a purpose behind it, even if the person with dementia cannot explain his or her reasoning very clearly.

- In order to best deal with the situation of a person with dementia who is walking, consider the reasons why the person is walking.
- There is no such thing as a completely risk-free environment: but you can minimise risks.
- If you can let the person walk freely in a safe area, do so.
- You can make the house safer for a person with dementia walking around at home
- You can set up simple alarms so that the person you are caring for cannot go out without your knowledge.
- Remember that walking, or other forms of regular gentle exercise, may actually help someone with dementia keep her or his mind in better shape.
- If a person with dementia is walking because of too much energy, it may help if he or she can join an exercise class.
- You may be able to divert the person with dementia from wanting to walk by giving her or him a clear task to perform.
- Make sure that the person has a contact phone number on him or her at all times when outside the house.
- Tell neighbours and other people in advance that the person has dementia and may get lost or confused.
- Make sure the person's home is easily identifiable from the street to help both the person with dementia and someone trying to help her or him find the house or flat.
- Always have a recent photograph of the person with dementia to hand, and a list of useful information to help identify or find the person.

References

Further useful information and sources used in writing this information sheet:

MedicAlert®, 1 Bridge Wharf, 156 Caledonian Road, London, N1 9UU.
0800 581420 (freephone)
Phone 020 7833 3034
Email: info@medicalert.org.uk
www.medicalert.org.uk

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www.alz.org/living_with_alzheimers_wandering_behaviors.asp

UK Wandering Network.
www.wanderingnetwork.co.uk/

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