



Belfast Health
and Social Care Trust

Dementia and Behaviour: Walking and Wandering



Information for carers

Community Mental Health Team for Older People

We hope this information helps you understand changes in your relative's behaviour due to dementia, and that you find some tips that work well for you both.

Share the tips that worked with family, friends and others who spend time with your relative, it will reassure them that they are doing all they can for both of you - give them this booklet to read or go through it together.

We have booklets on many other changes in behaviour that may occur due to dementia and would be very happy to share them with you.

Please call us on: 02895040346

Community Mental Health Team for Older People



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Understanding Walking in Dementia

Most of us will spend quite a bit of our day walking, whether to get from one room to another, to go to the shops or just because we like to get out and about. We benefit from the exercise, the changes in scenery and from being able to choose to do so.

Dementia does not usually change this natural desire to walk. However, it can sometimes be difficult to see why a person with dementia may be walking at a given time. Where others struggle to make sense of the reasons for walking it can often be thought of as 'wandering', but this term can be misleading as it suggests the person with dementia is walking aimlessly when actually they can have their own reasons for doing so. Difficulties with memory, thinking or communication due to dementia can make it difficult for them, or others, to see that reason.



As well as being puzzling there may also be times when your relative's walking can become a more of a problem, both for them and for you. Walking may be more of an issue for the following reasons:

- Your relative walks too far, or for too long, or they walk at night
- Your relative may get frustrated because they cannot remember what they were doing or where they were going.
- They may become more frustrated if they are restricted from walking around.
- There may be other concerns about your relative's safety if their thinking and memory difficulties mean you would be worried about them outside alone, perhaps due to road safety, falls or other reasons.

This booklet will look at some of the most common reasons for walking and give tips that others who are caring for someone with dementia have found useful, including what you might do if there are safety concerns.

Reasons your relative may walk

Continuing a habit

Did your relative always go for walks just because they liked the outdoors? Maybe they always walked the dog at a certain time? Someone who used to walk as a hobby may want to continue doing this.

What can help

- If your relative is able to and still wants to continue walking for fun, keep up those routines.
- Make space for regular walks in your relative's daily schedule.
- Encourage your relative to walk around their garden if they have one, or to join you in walking.

Relieving Boredom

While we all like to have quiet time, we also enjoy doing things and keeping ourselves occupied. This is true for your relative with dementia and like everyone else, when bored they may want to do something active - walking may be a way for your relative to do something, rather than nothing.

What can help

- Create a daily plan that includes chores, hobbies and activities your relative enjoys and keep it in sight.
- If your relative has access to a garden, encourage them to walk in it.

Getting Comfortable

We all like to be comfortable. If any one of us were in a room that was too dark, bright, warm, cold or noisy, we would probably get up and move to somewhere more comfortable. Many people with dementia can be more, or less, sensitive to light, temperature, noise and busy places than they used to be. So they may feel uncomfortable even when others feel fine. This can be another reason for your relative walking.

What can help

- Ask if your relative would they like the lights turned on/off.
- Check that your relative is neither too cold nor too warm.
- Check that the volume of the TV or radio is suitable for them.
- Try and keep visitors to one or two people at a time.



Relieving pain or discomfort

Sitting for long periods can cause stiffness, and some people may walk to ease this. Others may walk to relieve pain or discomfort.

If you notice your relative walking much more than usual consult your GP as it may suggest they have an infection or they are unwell.

What can help

- Look at how your relative is holding themselves, notice if they are limping or if there are any other signs of pain.
- Walking quickly whilst bent over can sometimes be a sign of constipation. If your relative is constipated you can get medicine from the chemists.
- If you notice your relative stops walking when usually they would, check for problems with toenails, bunions, corns or calluses. Check their footwear to see if it fits properly and isn't too big or too tight on them. Many problems with feet can be treated by a chiropodist, and your G.P. can organise this.

Changes in surroundings

Most of us are creatures of habit, and we find comfort in what we are used to. Your relative is no different, however, dementia may mean that changes to their surroundings are more unsettling and take longer to adapt to. They may not understand, or remember, where they are or why things have changed.

What can help

- Reassure your relative and let them know you are there for them.
- It can help to create a routine that resembles their old routine such as continuing to get up at the same time, or getting involved in similar morning activities.
- Keep personal objects such as photos and so on where your relative can see them.
- Be patient. You might have to show your relative around many times before they get used to any new surroundings.

Feeling lost

Memory problems caused by dementia can sometimes mean that the person doesn't understand where they are and why they are there. Walking can be a sign that your relative does not recognise their surroundings, and this can be the case even when they are in their own home. For example you might find them walking from room to room and not settling anywhere.

What can help

- Reassure your relative that everything is ok and that you will stay with them.
- If your relative doesn't realise they are in their own home, correcting them can cause them to become upset or confused. Reassure them that they are safe with you and see if you can distract them with another activity.
- It can be a good idea to put familiar items such as pictures, ornaments and so on where your relative can easily see them.

Getting lost whilst out walking

Problems with memory are common in dementia and there may be times when your relative is out walking and they forget where they are going, where they have been or why they were going out in the first place. They may also forget how to get home again. If your relative gets lost this will be worrying for both of you.

What can help

- Encourage your relative to carry some form of identification such as a passport. You could try making a card with your relative's name, address, and details of a person to contact. You may even want to try stitching their name and contact details to the inside of their coat or jacket.
- You could also speak to your local shopkeepers and neighbours about your relative's dementia so they can help if they see your relative looking confused or lost.

Searching for something

Sometimes walking could mean that your relative is looking for something and has forgotten what it is they are looking for or where it might be. Whilst this happens occasionally for all of us, it can happen much more frequently for people with memory difficulties.

What can help

- Make sure your relative has plenty to eat and drink, and that they are not too warm or cold. They may be looking for something to eat, an extra jumper etc.
- If your relative has problems finding the bathroom then accompany them to the bathroom every few hours.
- You will be the best person to know your relative's likes and needs, have a think about what they may be searching for and see if you can help them find it.
- Try offering an alternative activity your relative enjoys to help distract and settle them for example a cup of tea and a chat, looking through some pictures or a walk in the garden.

To cope with anxiety or stress

Your relative might be feeling anxious. If they would have gone for a walk to 'clear their head' before they had dementia they may still want to do this.

What can help

- Make sure your relative can still go for a walk, if you are worried about them walking outside alone, perhaps someone can go with them or they can be encouraged to walk in the garden.
- Reassure your relative that you are there for them.
- A relaxing activity such as a hand massage, listening to music they like, etc. can help to put your relative at ease.
- Involving your relative in daily chores and activities can help to distract them, and prevent or reduce distress.



Because they can...

Many people with dementia feel they are losing control over their own lives and just like any of us, doing something independently can help them feel good about themselves and provide a sense of independence and control. Your relative may walk because they can and it makes them feel good.

What can help

- Ask if you can come along - doing this in a way that your relative feels you want to accompany them rather than that you feel you need to accompany them will increase good feelings for them. For example:
 - ◆ *“I could do with a walk, are you going out?”*
 - or
 - ◆ *“We need some milk; will we walk to the shop?”*
- Look at the weather forecast and then make sure your relative has the right clothes and footwear.
- If your relative is trying to leave the house when it is raining heavily, snowing, very icy or late at night it will be better if you can distract them with another activity. Try to remain calm and avoid arguing with your relative as this is unlikely to be helpful.

Walking at Night

You may find your relative walks at night. For some people this will be because they need to use the bathroom. For others it can be that they get night and day mixed up due to the way that dementia changes the brain.

What can help

- If your relative still understands time you could keep a luminous clock on their bedside table so that if they wake they can see what time it is and settle again.
- It may be helpful if your relative does not drink too much before bed and encourage your relative to go to the bathroom just before bedtime.
- Use nightlights throughout the home and leave the bathroom door open - this will make it easier for your relative to find the toilet.
- You may want to use devices that signal when a door has been opened so you will know if your relative is walking about inside the house or perhaps wanting to go outside.

If there are other problems with your relatives' night time routine, or you are struggling to get enough rest, please contact your GP or Community Mental Health Team for Older People.

Searching for, or reliving the past

As well as affecting thinking and memory abilities, dementia can also mean that understanding the passage of time becomes more difficult.

Because of this, people with dementia may make sense of the world from a mixture of past and present memories. Your relative may want to see familiar people from a time in their past, or to carry out routines they would have done previously, and they may spend time walking in search of these; they may be searching for someone they once knew, or they could be trying to go home to an earlier or childhood home.

Walking can also be linked to wanting to carry out a task or job they did at an earlier time in their life, such as collecting the children from school, or going to work.



What can help

- If your relative believes they need to go 'home', or to see their parents, or to go to work etc, trying to correct this can be very difficult for them to accept - take a minute, think how you feel when you are **sure** you are right, but someone insists that you're not.... frustrated? bewildered? anxious?
- Try to get a good understanding of your relative's need to walk or their reasons for wanting to leave the house. You can then reassure them from their sense of the world and encourage them to a different activity such as having a cup of tea, eating dinner etc. For example:

"I know you want to go to pick the children up from school, but your sister is picking them up today so we can chat and have a cup of tea. You will see them later, we can relax."

Or

"Work is closed today, it's a holiday so everyone has the day off, will we tidy the garden today?"

Whilst you may need to reassure your relative in the same way several times, usually the sense of urgency they feel will pass.

- If your relative becomes more anxious, frustrated and insistent in their need to walk and it is safe to do so, it can be helpful to go out walking with them. When any sense of urgency has passed and they are more settled you can then suggest going to your house for a cup of tea etc.

- If these suggestions do not work, if you feel it may be difficult to encourage your relative home following a walk, or if you feel it is unsafe for them or for you, a review with your GP, the Community Mental Health Team for Older People or psychogeriatrician will be helpful. Contact them and arrange an appointment.



Safety when out walking alone

Would you be concerned for your relative if they left the house alone?

There are many reasons that your relative may not be as safe outside alone as they used to be. Perhaps they cannot judge distances and speed of traffic as well as they once did. Perhaps they may get lost. Maybe their mobility has reduced and they are likely to fall. Or perhaps they are much more vulnerable now and would be at risk from others who may not care as much as you do about your relative's well-being.

If any of these are concerns, take some time to think about what would be helpful if that happened - it's much harder to think clearly when you are worried or concerned. So, even though it is very unlikely to happen, planning for the 'just in case' can be useful. On the next couple of pages are suggestions others have found helpful in this situation. **We have also included a pull out sheet to guide you. Please fill in useful names and numbers and keep it somewhere easy to find so you can use it if needed.**

Think and Plan

Complete the guide sheet (in this booklet) to note names and numbers. Keep it somewhere easy to find, for example you might stick it onto the fridge or pin it to your wardrobe door.

1. **Who lives near you?** Thinking ahead, who may be able to give you a call if they see your relative out alone? Talk to neighbours, give them your number and ask them to phone you if they think your relative is out walking alone. This might feel a little difficult, but most people

will be happy to help if they can. It also means you will not have to explain at a time when you may be anxious and more focused on your relative's wellbeing.

2. **Who would be able to come over and help you** either by going out to look for your relative or by staying at home in case your relative comes back while you are out? Talk to family and friends who would be able to do this. It can be good to have a few people, just in case someone is not available at the time.
3. **Where is your relative likely to go?** The local shop? Social Club? Church/Chapel? A friend's house? Previous employment? Again, talk with them, give them your number and ask them to phone you if your relative goes there alone. Also, let them know that you might phone them to check if your relative is there or to keep an eye out for them.
4. **On their return:** Everyone is likely to be quite emotional when your relative returns – relief usually comes along with anxiety, anger, and perhaps tears. It can be very difficult to keep a calm atmosphere when you have been worried, however, your relative may be confused and upset and they will probably not understand why they feel this way. Remember their behavior happened because of their dementia - they felt they were doing the right thing; it was not their intention to worry anyone.

Caring for yourself

All of the information in this booklet may make caring for your relative easier, but your well-being is just as important. You will find it easier to look after your relative the way you want to if you can get regular breaks. Ask friends and family to keep your relative company whilst you look after yourself, they will want to help. If you have been caring for a while it might be hard to think of what you would do if you had a break!

What can help:

- Catch up with some friends
- Go shopping for yourself
- Go for a walk
- Go for a relaxing bath



USEFUL CONTACTS

Age NI Advice Line

0808 808 7575

www.ageuk.org.uk

Alzheimer's Society

(028) 9066 4100

www.alzheimers.org.uk/northernireland

CAUSE

(families, partners, friends caring for mental health)

0845 6030 291

www.cause.org.uk

Lifeline

0808 808 8000

www.lifelinehelpline.info

MindWise

(028) 9040 2323

www.mindwisenv.org

How to contact us:



Community Mental Health Team for Older People Tel: (028) 9504 0346

operates from Monday to Friday
9am to 5pm

We also offer an extended telephone advice
and support service for people living with
DEMENTIA and their carers operating:
Monday to Friday until 8pm
Saturday to Sunday 10am to 2pm

If you need to speak to someone
outside these hours please contact:
Regional Emergency Social Work Service
(028) 9504 9999

[www.belfasttrust.hscni.net/services/
CommunityMentalHealthTeams](http://www.belfasttrust.hscni.net/services/CommunityMentalHealthTeams)

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