Dealing with Restlessness
Looking after someone with dementia

Caring for someone with dementia can be really difficult at times. That’s why we provide specialist dementia nurses - Admiral Nurses - who work with families during the toughest times, advising them on the specialist techniques and approaches they could use to prevent and manage potentially distressing situations.

Restlessness and dementia

Restlessness can present as someone pacing, fidgeting, or trying to leave the house. When someone with dementia is restless, it might be that they have an unmet need that they are trying to communicate. They might:

- Be in pain. Do they have arthritis, or joint pain?
- Have an infection or constipation. Are they in discomfort when using the toilet? Have they become incontinent? Are they going to the toilet more frequently?
- Be bored. Do they want or need stimulation? Have they been inside all day?
- Be anxious. People with dementia may experience anxiety if they feel they are in unfamiliar surroundings – even if they are not
- Need to go to the toilet

Pacing

Often, if someone with dementia gets up and starts pacing, there is a reason for it – but they might not remember or be able to communicate what that reason is. You could ask them if they need the toilet, or if they would like to go for a walk.

Spending a lot of time inside, sitting down, can be unsettling for anyone. So if they want to walk about, it is fine to let them do so, as long as they are not in any danger and it is not causing them distress.
Wanting to leave the house

Some people with dementia might struggle to recognise where they are as ‘home’. This might be because they have become disorientated. This confusion can become worse at dusk, known as ‘Sundowning’*. This can also be because they are thinking about somewhere they lived in the past.

The carers we work with have had some success with the following methods. These can help the person with dementia feel more at ease, which might make them less inclined to want to leave the house.

*Please click on Sundowning to view the leaflet

These include:

- Putting coats and shopping bags away in cupboards, rather than keeping them near the front door. Some people with dementia find these items trigger their desire to leave; seeing them makes them feel as though they were about to go out.
- Hanging a curtain rail above the front door and pulling the curtain when appropriate. Hiding the door can stop someone with dementia wanting to open it.
- Involving the person in household tasks. What did
they like to do before their diagnosis? Asking them to help you with jobs such as folding washing or laying a table can help them feel included. Thanking the person for their help can help them feel appreciated and needed, which might help them to feel calmer and reduce their desire to leave.

• Asking the person about the place they want to go to and listening carefully to what they say. Speaking to them about previous homes and the memories they made there can help them to feel reassured.

Assistive technology such as tracking devices, alarms and monitors can be very useful to help you know where the person is around the house. This means that you do not need to follow them to see what they are doing, as this can sometimes cause the person more anxiety.

Your local social services can provide you with information about what assistive technology is available in your area, and any funding you might be eligible for.

You can put locks on the doors and the windows, but do carefully consider this, as trying to open locked doors and windows can be distressing for a person with dementia.

**What to do if the person leaves the house**

Occasionally, the person might leave the house, and it’s important that you have a plan in place for if and when this happens:

• Talk to your neighbours; explain the situation and make sure you have their contact details and they have yours.

• Make sure the person with dementia always has their name and your contact details on them. Sew these details into their clothes, or encourage them to wear identification jewellery, such as a bracelet or necklace.

• Phone the police. A national scheme called the Herbert Protocol is in place to help the police find missing, vulnerable people. There is a form to fill in (in advance) with details about you and the person with dementia, which you can find here:

  https://www.met.police.uk/herbertprotocol
Sources of support

If you have any further questions about helping a person with dementia who is restless, or the Herbert Protocol, or any other aspect of caring for someone with dementia, please call the specialist dementia nurses on the Admiral Nurse Dementia Helpline, open Monday to Friday, 9am-9pm, and 9am-5pm at weekends, on 0800 888 6678 or helpline@dementiauk.org

The Herbert Protocol
Dementia UK leaflet on Sundowning
The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support Dementia UK, please visit www.dementiauk.org/donate or call 0300 365 5500.

Publication date: January 2019
Review date: January 2021
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If you’re caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call 0800 888 6678 or email helpline@dementiauk.org

Open Monday – Friday, 9am – 9pm
Saturday and Sunday, 9am – 5pm

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