Introduction

The structure and pattern of the day can be especially important to a person with dementia. The government’s messages to ‘stay at home as much as possible’ and ensure ‘social distancing’ have been consistent during this lockdown period and are likely to remain in place for some time. Additional details are applicable dependent on individual risk factors and circumstances (e.g. need to self-isolate or shield). For many people with dementia, full compliance with these protective measures can be challenging due to difficulties with memory, communication, understanding of the measures (and their importance), or a strong desire/need to walk.

A full explanation and specific guidance on measures we should adhere to in order to curb the spread of coronavirus (Covid-19) are detailed at NHS Inform. Ensuring you have the most up-to-date information can help to get the balance right between following current instructions and avoiding unnecessary restrictions or disruption of routines.

The impact of current measures and what might help

The impact of disruption to normal routines and connections, and the physical constraints of staying indoors, might have a profound effect on someone with dementia, possibly leading to feelings of loneliness, lethargy, stress, anxiety or depression. Walking is a healthy and therapeutic activity for most of us and may form an important part of a person’s usual routine. Unless specific measures indicate a person should not be leaving home at all, then going out for exercise is permissible and indeed encouraged, provided physical distancing is adhered to. Walking has many physical health benefits and contributes positively to our mood and sense of well-being. Getting out in the fresh air and daylight is likely to help maintain a regular sleep pattern.

New powers aiming to protect everyone mean police officers might speak to anyone who does not appear to be complying with the current safety measures. You may be concerned about what might happen if the person you care for who has dementia is approached by police officers about this issue. Police Scotland assure us that the focus is on a community-based policing approach and when they encounter anyone in the community who appears vulnerable, or who discloses a vulnerability, they will take the right steps to protect those people, engaging with relevant support agencies and carers to minimise any distress. The police have been given additional guidance to assist them when engaging with people who may feel anxious regarding being stopped by police.
Members of the same household can go for a walk together and now we can see people from one other household outdoors but must still remain two metres apart. Although we cannot be in close contact with others outside our own household, social interaction is still possible through a wave, a smile and a hello from the prescribed 2 metre distance. The healthy desire to be outdoors may be satisfied with time and activity in an area of garden if you have one available to you. Safe distance interaction might also then be possible with neighbours – a chat over the garden fence for example.

Current restrictions will, by their nature and intent, act to keep the person with dementia (and others) safe when out walking because there will be fewer people around, and many businesses remain closed. On the other hand, additional difficulties may present, for example, if a usual route has been altered, or a familiar area closed off. This could result in a person with dementia feeling lost or getting lost.

If you haven’t done so already, consider setting up a Purple Alert profile. This is a free app that helps to find a person with dementia if they go missing. Details of how to find and use the app can be found on the Alzheimer Scotland website here. An additional or alternative measure of security and reassurance can be provided by completing a ‘Herbert Protocol’ form. The Herbert Protocol form is completed with the consent of the person with dementia (or power of attorney) by the person who knows that individual best. In the event that a person with dementia goes missing, it provides information to assist the Police in tracing the individual concerned.

When compliance is especially difficult and what might help

If a person with dementia is unable to maintain physical distancing or is repeatedly going out, then further considerations are necessary. Think about the simplest and least restrictive options first, such as: “can I help with understanding or reminding the person about the current situation and need to stay at home as much as possible?”

Here are some suggestions to try:

- Have accessible information clearly visible at home (especially at the door), such as: Coronavirus: guidance for people with dementia and carers. This guidance has useful pictures as well as information which might aid understanding.
- A prompting reminder message at the front door about not going out just now – clear and simple.
- Have contact numbers handy if the person is living alone so that they can call for reassurance about what to do.
• If there is a pattern to going out, perhaps at a particular time of day, then maybe a phone call or activity around that time might help.

• Increase activities that involve being indoors or in a safe garden space to occupy the person’s time and interest. Some guidance on activities at home can be found here.

Technology may help, such as:

• Using video calling to reassure, seeing a friendly face, even on a screen has been shown to be very effective. There are lots of ways to set that up, using phones and tablets apps such as WhatsApp, Facebook Messenger and Apple FaceTime offer this option.

• Devices like My Home Helper, Echo Show and Google Home Hub can also be used.

• These devices can also be used to set prompts and reminders. These could be that it’s time for a favourite TV or radio show, or just as a reminder that it’s best to stay home for now, and that someone will call, or be around to see you soon.

• A music playlist or audiobook can offer some alternative activity. Have some ready to play when needed. Use Playlist for Life to help put together a personal play list which can be played on any device. The BBC Music Archives have great dementia friendly resources. Audible Stories is offering free audiobooks with a large selection available.

• A range of products which have been tested by families, and their reviews of these products, can be found here.

• A guide on technology enabled safer walking for someone with dementia can be found here.

Sometimes leaving the house is more than a simple desire to be out but driven by something else – perhaps you can explore other possibilities and try to reassure or meet that underlying need. Exploring possibilities shouldn’t involve too many questions of the person, which might distress, but aspects you might consider include:

Is the person:

• Bored?
• Looking for someone, somewhere, something?
• Trying to get away from something in their home environment (e.g. noise)?
• In any pain or discomfort?
• Feeling lonely, upset or anxious?
• Experiencing a sense of needing to be somewhere else (old routine)?
Greater understanding of such underlying needs may not provide any instant answers but can inform ideas you might try to alleviate the situation, such as:

- Ensuring the home environment is as comfortable as possible
- Making available supplies of favourite food and drinks.
- Maintaining contact in whatever way is possible so that reassurance can be given and gentle reminders of the current situation and why it is important to stay at home.
- Having conversations about the people the person is missing and where possible enabling the person to speak to them using technology or safe distancing.

If the person is experiencing more advanced dementia and is unable to understand or respond to communications about the risks, then other approaches that might be tried to reduce likelihood of the person leaving the house include:

- Hanging outdoor coat out of sight (seeing the coat may act as a trigger to put it on and go out).

Consider if the exit be made less obvious, with use of a curtain perhaps. Or a door sticker (these can be bought online – see example).

It’s also helpful to think about how the current constraints on movement may be perceived and experienced by the person with dementia – already possibly feeling they have lost so much control over their lives due to their illness. Freedom to go out and about is fundamental to most of us, so it’s worth considering how we can maximise choice and control and sense of purpose in other areas of the person’s daily life at this difficult time.

**When there are concerning changes**

If you find the person with dementia has become much more confused and especially if this occurs over a short period of time, it may indicate another health issue which requires medical attention. It’s important not to assume that sudden or marked changes in the person you support only relate to the coronavirus disruption to normal life. Contact your GP, NHS24 or emergency services as appropriate if you are concerned. Our Primary Health Care Teams and Hospitals are still there for concerns around other health issues.
It is useful to think about planning for the possibility of the person you support becoming ill, either with coronavirus or some other illness. Being prepared can reduce some of the stress around this possibility and ensure you have had an opportunity to think about what is important to you and the person you are supporting should this happen. GP’s are keen to support such planning and you may find your GP (or GP of person you are supporting) is in touch to have a conversation around this. In this short film GP Paul Baughan explains how and why he is contacting his patients to have these planning conversations. You can view it here.

You will find more information about planning for a possible hospital admission and other changes in your circumstances here.

Stay in touch with your support network

Although many support services and groups are unable to operate in the usual way, many are adapting and finding other ways to stay in touch with the people with dementia and families they usually support. More information about how Alzheimer Scotland staff are doing this can be found on our website: www.alzscot.org

Our Freephone Helpline is available to take your calls 24 hours a day.