## What is **Dementia?**



Dementia is progressive and is caused when the brain is damaged by illnesses such as Alzheimer's disease or strokes. Everyone is unique and will experience dementia in their own way. Different types of dementia will affect people in different ways. How people respond to the person with dementia and their environment are other factors that will impact on how well someone lives with dementia.

For someone living with dementia, the world can seem a confusing place at the best of times. During an event such as is happening now in Ukraine, an experience where the world is changing at pace, such huge disruption can cause additional trauma and distress. Being uprooted from familiar surroundings and routines and a lack of usual access to family and friends can seriously exacerbate the symptoms of dementia.

It is with this in mind that we have produced this guide for anyone who finds themselves caring for a person with dementia in the home.

#### Six key areas

We care for thousands of people across the world who live with dementia, and work with leading experts to develop training for those who deliver care. We'd like to share our insights with families and those stepping in to help with care for someone, to help minimise distress as best possible.

The following information centres around six key areas where carers can help to understand the condition and how it affects behaviour and provides some tips and advice for those who are able to assist in caring for someone with dementia.

#### Reality



People living with dementia may experience a different idea of reality or sense of what is going on from our own. This is because of the changes in the brain caused by the disease. It can be unhelpful to confront the person with the truth when their reality is different to yours. We must remember to step into their reality and not expect them to come into our reality.

For example, if we remind a person that their partner, who they have been asking for, has passed away, they may start to grieve all over again, although this is not always the case.

It may be beneficial to advise them that their partner is at work at the moment. They may then accept this and and carry on with their day.

If a person is seeing something that is not there we must remember that to them it is real. As we cannot see what the person is seeing we will need to ask where it is and take their concerns seriously. One way of dealing with this is by redirecting, which may include changing the topic or focus or influencing the mood to a more pleasurable and enjoyable one for the individual.

With your knowledge of the person you will begin to recognise some needs are related to certain things they say, or a question they ask. If they asked for their mother they may want comfort or reassurance. This could be a simple cuddle, holding hands or just being close to them to satisfy that need for comfort.

## Non-verbal communication



One of the difficulties often faced by those with dementia is difficulty with the verbal communication of their wishes or needs. An individual with dementia may not be able to tell you they are upset or angry about something, so you need to be on the lookout for non-verbal communication cues that provide clues to how the person is feeling or what they are thinking.

For example, a person with dementia may still be able to smile to show happiness, frown to show frustration, pace if they need to use the bathroom or grimace if they are in pain. The tone, pace, speed and volume of the voice also need to be considered.

# Understanding behaviours and needs



It is important to understand how individuals with dementia may express themselves through behaviours. This is usually a means of them communicating a need.

For example, a person with normal (cognitive) brain function, who is in pain, would be able to tell someone they are in pain. Living with dementia may mean that a person cannot comprehend the pain and may be unable to vocalise that they are in pain. They may display behaviour such as crying, shouting, fidgeting in their seat, walking around or declining to eat or drink.

The challenge is to try and understand that this is how the person with dementia is communicating and that they are trying to communicate a need. Initially we may try and comfort somebody by listening and talking to them, holding their hand or just being with them.

# We can then start to try and understand what they are trying to communicate to us. Sometimes, this is trial and error and it may take us a while to understand that they are trying to tell us, for example, that they are in pain.

We can then take appropriate steps. For example, this may be a change of position, talking to them and acknowledging that they are in pain, the use of medication as advised by a health care professional or relaxation methods such as listening to music the individual enjoys.

Redirecting may also be beneficial in this scenario, and could include changing the topic or focus or influencing the mood to a more pleasurable and enjoyable one for the individual.

### Offer simple choices



Often, offering a reduced choice enables the person to more easily work out the options and make a choice, helping them to retain some control.

For example, instead of offering a list of many choices for a meal, offer two or three items of food that you know the person likes.

If the individual is resistant to doing something, the choices should not be to "do this" or "do that". These are directions, not choices.

If a person is upset or distressed they may be unable to make choices at that time. We must always allow time for them to make choices and not rush them, speak clearly, use picture prompts or point to the items to aid communication.

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## Benefits of activities



Activities play an important role in helping the individual with dementia feel safe, secure and valued. Whether the activity is going for a walk or simply brushing somebody's hair, it can help that person reconnect to daily life.

A person with advancing dementia may not be able to participate in the same activities as a healthier person. They may not initiate an activity or even want to do an activity, but is it important that they remain active as long as they can.

## Nutrition



Good nutrition can promote overall health, improve the person's ability to cope, help prevent some physical and psychological effects of dementia, improve sleep, and most importantly, contribute to a better quality of life.

Maintaining adequate levels of nutrition can also prevent hospitalisation by helping to avoid health problems such as constipation and infections. These are commonly reasons a person with dementia may be admitted to hospital. Changes in taste may also be part of the progress of dementia. Sweet, salty or more highly seasoned foods may be needed to help maintain nutrition and hydration. The person with dementia may not remember to eat and drink, they may not get the feeling of being hungry anymore or they may be unable to prepare and cook food or use cutlery any longer. A person with dementia may also overeat, drink too much or consume unhealthy options in excess. The colour, texture and taste of food and drink is important as these add to the sensory pleasure of eating.

#### Encourage the person with dementia to eat and drink, as far as you are able to, by:

- Making food available whenever they want to eat
- Encouraging them to help prepare the food, set the table, wash or put dishes away
- If you need to cut the cooked food into bite-size pieces, do so before you place the plate in front of them
- Using boldly coloured plates with large rims or bowls that are a different colour than the food, and use non-slip placemats
- Cups with lids, wide bases and using flexible straws with

- the persons agreement, can all help them to eat and drink independently
- It may assist them to make a choice if there is a reduced selection
- Serving smaller portions may assist them to eat more as they will not feel over faced by the portion size. More can always be offered
- Trying to ensure dentures fit correctly and the dentures/ teeth/mouth are kept clean and in good condition/health

#### More help

The <u>Polish Alzheimer's Association</u> can provide you with more help, including factsheets, materials and training for people supporting someone living with dementia. Find out more by visiting www.alzint.org/member/polish-alzheimers-association/



www.homeinstead.co.uk

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