

Introduction to Booklet

This booklet is designed to offer you insights into what dementia is, how it can affect an individual and simple steps which can be taken to help. It is aimed at individuals suffering from Dementia and their families/carers.

This booklet has been developed using resources from Age UK, Dementia UK, Alzheimer's UK, Local Authorities and the expertise of experienced carers. This booklet is solely for informational purposes; please reach out to us, your GP or any of the charities and support groups mentioned if you feel you may need help or any further information.

What is dementia?

Dementia is a progressive disorder that affects how your brain works and in particular the ability to remember, think and reason. Dementia is an umbrella term used to describe a range of progressive neurological disorders, that is, conditions affecting the brain. There are many different types of dementia, of which Alzheimer's disease is the most common. Some people may have a combination of types of dementia. Regardless of which type is diagnosed, each person will experience their dementia in their own unique way

Dementia is not a consequence of growing old but the risk of having dementia increases with age. Most people who are affected by dementia are over 65, but there are many people younger than this.

Understanding a little about the type of dementia you have will help you come up with strategies for both coping with memory loss, and maintaining emotional well-being. Good sources for finding out more about dementia are your local carers' groups, the library and the NHS Choices website.

Additional Support

Support is accessible for people suffering from dementia, their carers and family.

For example, try contacting:

- Your GP
- The Alzheimer's Society
- Dementia UK
- Age UK
- Carers UK

Common consequences of dementia

Dementia can affect each individual differently. However, there are some common consequences of dementia:

Memory problems

People with dementia might have problems retaining new information. They might get lost in previously familiar places and may struggle with names. Relatives might notice the person seems increasingly forgetful, misplacing things regularly.

Cognitive ability, i.e. processing information

People with dementia may have difficulty with time and place, for example, getting up in the middle of the night to go to work, even though they're retired. Also their concentration could be affected. There may be a difficulty when shopping with choosing the items and then paying for them. For some people with dementia the ability to reason and make decisions may also be affected. Some people with dementia get a sense of restlessness and prefer to keep moving than sit still; others may be reluctant to take part in activities they used to enjoy.

Communication

People with dementia may repeat themselves often or have difficulty finding the right words. Reading and writing might become challenging. They might experience changes in personality and behaviour, mood swings, anxiety and depression. People with dementia can lose interest in seeing others socially. Following and engaging in conversation can be difficult and tiring, and so a formerly outgoing person might become quieter and more introverted.

Losing Independence

A person with dementia may gradually lose their independence and become more reliant on the care and support of others around them. This can be a hard change to make and can be distressing for everyone involved.

Confidence and self-esteem

Dementia may cause people to feel insecure and lose confidence in themselves and their abilities. They may feel they are no longer in control and may not trust their own judgment. They may also experience the effects of stigma and social 'demotion' - not being treated the same way by people - as a result of their diagnosis. All of this can have a negative impact on the person's self-esteem.

Dementia may also have an indirect effect on someone's self-esteem by affecting other areas of a person's life. Health issues, financial circumstances, employment status and, importantly, relationships with those around them may suffer.

Things that may help:

There are plenty of things that can be done throughout the home to stay independent as long as possible.

Things you can do around the house

- Let in as much natural light as possible;
- Keep a list of important contacts by the phone;
- Leave clearly written notes and reminders in prominent places;
- Use clocks that display the time, date and day of the week;
- Mark hot appliances, such as radiators;
- Avoid patterned curtains and carpets where possible;
- Think about colour coding keys and locks;
- Remove clutter where possible;
- Display photos of loved ones or happy memories. It may be helpful to label photos with names and relationships;
- Listening to music and the radio rather than watching television. It can be a welcomed change and bring back memories.

In the kitchen

- Labelling cupboards and drawers can help with staying as independent as possible and can be particularly helpful with items that are used often;
- Fit an automatic shut-off mechanism on the cooker to avoid accidentally leaving the cooker on after using it. Newer cookers have these mechanism built in. A gas detector can be fitted if leaving the gas hob on is the problem;
- Store items away safely, helping to minimise clutter. It can also avoid confusion. Harmful substances such as cleaning products should be stored away, remove artificial fruits and store pet food in a separate cupboard;
- Avoid scalds and burns by trying not to use stainless steel appliances such as toasters and kettles, as they get very hot;
- A drain tap in the kitchen sink may help catch any items that are dropped down the sink accidentally, such as teaspoons;

In the bedroom

- Install a night light near the bed to make sure if you wake up in the night. You can install a motion-activated light that comes on as needed;
- Make it easier to get dressed by not keeping all clothes, shoes and cosmetics on shelves and in wardrobes. Too much choice can be overwhelming and make decisions difficult. Laying out clothes in the order you put them on can help make the process easier;
- Try bedclothes and linens that contrast in colour to the rest of the room so the bed is easier to see, especially if the bed is placed in the middle of the room;
- Pressure sensors in or beside the bed can detect someone getting out of bed and not returning within a certain time. An alert can be sent directly to an emergency response or chosen contact, such as your neighbour or carer;

In the bathroom

A flood prevention plug will let water out of the bath automatically when it becomes too full. Some of them also change colour when the water gets too hot.

Contrasting tones can be extremely helpful in the bathroom. Towels, grab rails, soap and even a toilet seat in a different colour to the surface can help you recognise them.

Keep medicines stored away safely. Make sure any out-of-date or unwanted medications are disposed of - this can be arranged with your local chemist.

Make sure taps are easy to use as some modern mixer taps can be confusing. Traditional, separate hot and cold taps can make things much easier.

Consider bigger adaptations to the bathrooms such as a walk-in shower or getting a bath seat installed. These adaptations may be more expensive but could prove very beneficial to remaining independent and living well with dementia.

Memory cafes

Memory cafes also offer information and support in an informal setting where people with dementia and their carers can attend together. There are often professional carers available to talk to in confidence.

To find out about local memory cafes, ask your dementia adviser, local Age UK or Alzheimer's Society.

Day centres

Some people feel mixed emotions about day centres, but a variation in routine can benefit people with dementia and their family/carers. There are some specialist dementia day care centres, while others may cater for people with mild dementia.

Day care can be difficult at first for the person with dementia to get used to. Talk to the staff if they seem upset or unhappy about going. Different day centres offer different activities and environments – you may find the person's social and cultural needs are better met by a different one.

Life Histories

Note: IHCT can provide a "Reminiscence Workbook"

Memory Box

Creating a Memory Box for your loved one is a great way for them to take a stroll down memory lane. It can also be a great comfort to have familiar items from home and items that remind them of happy days.

Below are some suggestions of items you could put in your loved ones Memory Box.

- Photos
- Newspaper Cuttings
- Books
- Ornaments
- Keepsakes
- Small Toys
- Jewellery
- Tickets/programmes from cinema/theatre/sport
- Tools that were used for hobbies (examples: gardening gloves, paint brushes)
- Tools that were used for professional life
- Items associated with family members (baby shoes, stuffed animals)
- Items associated with favourite pets

You know your loved one best, what do you think would bring to mind happy memories for them?

Communication

- Make sure you're in a good place to talk - quiet, with good lighting and without too many distractions
- Get the person's full attention before you start.
- Position yourself where the person can see you as clearly as possible and try to be on the same level as the person
- Sit close to the person (although not so close you are in their personal space) and make eye contact.
- Make sure your body language is open and relaxed.
- Have enough time to spend with the person. If you feel rushed or stressed, take some time to calm down.

How to speak

- Speak clearly and calmly.
- Speak at a slightly slower pace, and allow time between sentences for the person to process the information and respond. This might seem like an uncomfortable pause to you, but it is important for helping the person to communicate.
- Use short, simple sentences.
- Try to laugh together about misunderstandings and mistakes - it can help. Humour can help to bring you closer together, and may relieve the pressure. However, be sensitive to the person and don't laugh at them.

What to say

- Try to avoid asking too many questions, or complicated questions. People with dementia can become frustrated or withdrawn if they can't find the answer.
- Try to stick to one idea at a time. Giving someone a choice is important, but too many options can be confusing and frustrating.
- If the person is finding it hard to understand, consider breaking down what you're saying into smaller chunks so that it is more manageable.
- Ask questions one at a time, and phrase them in a way that allows for a 'yes' or 'no' or in a way that gives the person a choice
- Rephrase rather than repeat, if the person doesn't understand what you're saying. Use non-verbal communication to help

- As dementia progresses, the person may become confused about what is true and not true. If the person says something you know is not true, try to find ways of steering the conversation around the subject and look for the meaning behind what they are saying, rather than contradicting them directly. For example, if they are saying they need to go to work is it because they want to feel useful, or find a way of being involved and contributing? Could it be that they are not stimulated enough?

Listening

- Listen carefully to what the person is saying, and offer encouragement.
- If you haven't understood fully, rephrase what you have understood and check to see if you are right. The person's reaction and body language can be a good indicator of what they've understood and how they feel.
- Allow the person plenty of time to respond - it may take them longer to process the information and work out their response. Don't interrupt the person as it can break the pattern of communication.

Body language and physical contact

- Non-verbal communication is very important for people with dementia, and as their condition progresses it will become one of the main ways the person communicates. You should learn to recognise what a person is communicating through their body language and support them to remain engaged and contribute to their quality of life.
- A person with dementia will be able to read your body language. Sudden movements or a tense facial expression may cause upset or distress, and can make communication more difficult.
- Make sure that your body language and facial expression match what you are saying.
- Never stand too close to someone or stand over them to communicate - it can feel intimidating. Instead, respect the person's personal space and drop to or below their eye level. This will help the person to feel more in control of the situation.