

A guide to understanding dementia



IndependentPeople

Homecare Services



Welcome

A diagnosis of dementia for you or a loved one can come as a shock. Even if you have been half expecting it, having to adjust to a life with dementia can be a worrying and upsetting time, and it can be especially hard for those close to you.

This guide draws on our wide experience of caring for hundreds of people with dementia and our understanding of the sadness and stress it can cause family and friends. At Independent People Homecare, we recognise every person living with dementia is unique and will experience dementia in their own way. We hope this guide will provide some useful information about dementia and how to care and support a loved one.

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What is dementia?

The word 'dementia' describes a set of symptoms that may include memory loss and difficulties with thinking, problem-solving or language. These changes are often small to start with, but for someone with dementia they have become severe enough to affect daily life. A person with dementia may also experience changes in their mood or behaviour.

Dementia is caused when the brain is damaged by diseases, such as Alzheimer's disease or a series of strokes. Alzheimer's disease is the most common cause of dementia, but not the only one. The specific symptoms that someone with dementia experiences will depend on the parts of the brain that are damaged and the disease that is causing the dementia.

Did you know...

...the word dementia comes from the Latin *de* meaning "apart" and *mens* from the genitive *mentis* meaning "mind"? Dementia literally means "deprived of mind".

Alzheimer's versus dementia

What's the difference?

Many times we are asked what is the difference, or are there any differences? So, let's help clarify the differences for you in a simple way.

Dementia is an umbrella term for anything that can cause issues with brain functioning such as confusion, memory loss, or loss of problem solving ability. While Alzheimer's disease is the most common form of dementia in older people.

In a nutshell...

...dementia is a symptom, and Alzheimer's disease is the cause of the symptom.



Did you know...

Did you know there are over 100 types of Dementia?

Types of dementia

Alzheimer's is the leading cause of dementia in the UK; responsible for up to 70% of all dementia cases. A slowly progressive brain disease that actually begins well before the individual starts to show any symptoms.

Vascular dementia is the second most common cause of dementia. Otherwise known as vascular cognitive impairment, those who are diagnosed with vascular dementia may not suffer memory loss in the early stages of the condition, but will instead have an inability to plan or make decisions, combined in many cases with poor or impaired judgement.

The most common forms of dementia



How can I tell if someone has dementia?

Each person is unique and will experience dementia in their own way. The different types of dementia also tend to affect people differently, especially in the early stages. Other factors that will affect how well someone can live with dementia include how other people respond to them and the environment around them.



They will often have problems with some of the following:

- day-to-day memory – for example, difficulty recalling events or conversations that happened recently
- concentrating, planning or organising – for example, difficulties making decisions, solving problems or carrying out a sequence of tasks (such as cooking a meal)
- language – for example, difficulties following a conversation or finding the right word for something
- visuospatial skills – for example, problems judging distances (such as on stairs) and seeing objects in three dimensions
- orientation – for example, losing track of the day or date, or becoming confused about where they are.

A person with dementia will also often have changes in their mood. For example, they may become frustrated or irritable, apathetic or withdrawn, anxious, easily upset or unusually sad. With some types of dementia, the person may see things that are not really there (visual hallucinations) or strongly believe things that are not true (delusions).

Dementia is progressive, which means the symptoms gradually get worse over time. How quickly this happens varies greatly from person to person. As dementia progresses, the person may develop behaviours that seem unusual or out of character. These behaviours may include asking the same question over and over, pacing, restlessness or agitation. They can be distressing or challenging for the person and those close to them.

A person with dementia, especially in the later stages, may have physical symptoms such as muscle weakness or weight loss. Changes in sleep pattern and appetite are also common.

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The 7 stages of dementia

1 Normal behaviour

No symptoms are apparent, though changes in the brain might already be occurring – these can happen several years before symptoms emerge.

2 Forgetfulness

They forget things easily and constantly lose things around the house, although not to the point where the memory loss can easily be distinguished from normal age related memory.

3 Mild Decline

Loved ones may begin to notice subtle changes and signs that something 'isn't quite right.' They might be frequently losing their purse, or keys or forgetting appointments. Experts believe this stage can last up to seven years.

4 Moderate Decline

Symptoms become clearer to everyone. They find it difficult to manage money or pay bills, or remember what they had for breakfast. If they visit their doctor at this point, and undergo a Mini Mental State Examination (MMSE) it's likely they will be diagnosed with dementia. The average length of this stage is around two years.

5 Moderately Severe Decline

Loved ones may need more help with day-to-day living during this stage. Whilst they can probably still take care of other personal needs on their own (such as using the toilet), they could find it difficult to dress appropriately or be unable to remember simple facts about themselves, such as their address or phone number. However, they usually recognise family and friends and can recall events from decades ago (especially their childhood) with great clarity. On average this stage can last around 1.5 years.

6 Severe Decline

This is the stage when constant supervision is needed at home. They may need help with washing and dressing and may also become incontinent. You could notice changes in their personality and behaviour – such as anger and aggression – which can be upsetting and difficult to cope with. However, although they might be very confused, they often still know and recognise the people closest to them – which can be some comfort. Experts believe this stage can last, on average 2.5 years.

7 Very Severe Decline

Many of those with dementia pass away before they reach this stage, often as a result of other health conditions. At this stage, they'll experience severe loss of speech, need assistance with day-to-day living, feeding, need round-the-clock care and the support of professional Carers (if they haven't already got this). It's important to remember that the person with dementia no longer really understands what's happening.

Caring for someone at home with dementia

There is no 'right' or 'wrong' way to care for someone with dementia – every person has their own unique needs.

However, certain behaviours that are commonly displayed by those living with dementia can be handled using tried and tested techniques. The main thing to remember in all circumstances is that direct confrontation is best avoided, as this can distress the patient and lead to more extreme behaviour.

“83% of people with dementia said being able to live in their own home was very important”

Alzheimer's Society



Frequently asked questions

Here, we have explored many of the questions that are commonly asked by those caring for someone with dementia.

Q How can I keep them in their routine?

Those living with dementia often respond well to routines, which can help them give a sense of meaning and security. A weekly planner* displaying a daily routine prompts the person to eat, shower, dress and includes events or appointments for each day.

*Please call for your free Dementia weekly Activity planner

Q How can I make their home safe?

- Call their gas/electric and water companies as they can install safety devised or adapted controls
- Remove locks from bathrooms door in case of an emergency
- Install smoke and carbon monoxide detectors
- Replace the telephone with larger numbers and ensure you keep a large typed list of important numbers.

Q Should I make any adjustments to the interior décor?

It is recommended that any patterned carpets and wallpapers are removed from the home. These can often be confusing to those with dementia – they may try to interact with the detail. Mirrors can be a source of confusion, as the patient can misinterpret what they are seeing in their reflection, so for this reason, we would suggest covering up all mirrors and reflective surfaces where possible.

Try displaying photos of family members and pictures that show happy images from your loved one's previous life. These evoke positive feelings and help them recognise those closest to them.

A large clock which includes am/pm, date and day of the week can be useful so they can easily see the time as those living with dementia are often confused about the time of day.

Q How can I develop a sleep routine for a loved one?

Dementia can severely disrupt an individual's sleep cycle. The easiest way to ensure a good night's sleep is to make sure the patient is active and stimulated throughout the day – this will ensure they feel tired and ready for bed in the evening.

Avoid naps where possible. If your loved one does need a rest, make sure they sleep at the same time every day, for the same amount of time.

Q Is it safe for the person to leave the house?

If a person with dementia wants to leave the house, you should try to find a solution that lets them do so safely. With a visiting or Live-in Carer from Independent People Homecare, they can help a loved one take a walk safely. You may be able to get help through a local service, group or organisation that helps people with dementia to take part in leisure activities, including walking.

Q How can I prevent the person from running away from me in public?

It's not unusual for those living with dementia to want to retain their independence – and this may cause them to want to physically run away from you (and, indirectly, the constraints that are being placed on them). If this happens, don't visibly chase them, as this will make them feel as though they are being treated like a child. Follow them calmly, and remain as far away as you can. Remember that they may not recognise you, so they may react with distress if they feel they are being followed by someone they don't know.

There is no 'right' or 'wrong' way to care for someone with dementia – every person has their own unique needs.

Q What do I do if they don't want to eat the food I have prepared for them?

Many people struggle to eat and drink properly when suffering from dementia – and many will refuse the meal that is being presented to them. Wherever possible, cook food that you know they like. Explain what the food is and, if necessary, how to prepare or eat it. Try different flavours and preparation methods to stimulate their appetite, and choose colourful food that is easily identifiable. If they refuse food in the first instance, don't be afraid to try again later in the day.

Q He/she won't let me take care of their personal needs – what do I do?

Understandably, many people will feel uncomfortable or embarrassed when they are being cared for. This can lead to distress when addressing many aspects of personal care, including washing and bathing. They should be encouraged to do as much for themselves as they can, as this will help them feel capable and independent. The key to managing their personal needs is to try various approaches until you find one that suits their needs. Perhaps you could wash at the same time to make them feel less self-conscious? Or maybe you could introduce wet wipes in the first instance to help them feel more at ease?



Q How can I encourage them to use the toilet?

Many people with dementia are not inclined to use the toilet. They may simply not be able to locate it, or they make struggle to decipher the cistern from the rest of their surroundings. Ensure that the toilet seat is bold, bright and easily identifiable; if needs be, place a visual sign on the toilet door to make it clear where the bathroom is. Always enter the bathroom first, as this will encourage them to follow.

Q How can I reduce their anxiety and agitation?

As a rule, dementia is a largely disorientating condition. Losing their identity and independence can be extremely distressing. The best way to cope when they become agitated or angry is to try to identify the source of the problem. If the person is becoming frustrated that you are helping them, give them some space for a couple of minutes to allow them to calm down, then try again. You will soon begin to notice what triggers anxiety – from there, you can take steps to reduce exposure to the things that are causing negative reactions.

With the support of one of our dementia Carers, a care plan is tailored entirely around the needs of the individual.

A dementia homecare Service

There are many care options, all of which can help improve their quality of life – but none are as flexible and as accommodating as home care. Live-in care or visiting care for those living with dementia will enable them to continue to remain at home, both in the early stages and late stages of the condition.

With the support of one of our dementia Carers, a care plan is tailored entirely around the needs of the individual by a health care professional, ensuring they can continue to make your own lifestyle choices whilst remaining in the comfort of your own home. By being given the option to stay in your own home, you or a loved one will be free to welcome visitors, free to continue with your own routine, and free to live as independently as possible; the only difference is that you will be supported around the clock by an experienced, professionally dementia trained Carer.

To find out how we can help you or a loved one,
then call our care team an informal chat on
0808 278 8807

Why choose dementia care at home?

- Care is provided 24 hours a day, 7 days a week.
- When in their own homes, people feel safe in the familiar environment.
- Care homes can have dedicated suites for dementia care. Although this is a good idea in theory, in practice, they make for confusing and noisy environments.
- Life in your own home can be more stimulating with a Live-in Carer or visiting Carer and friends and family can still visit as easily as before.
- On better days, the customer is not confused as to why they are in a care home. Instead, they are in the familiar, secure and warm environment of their own home.
- Customers' own homes are filled with happy memories, which can be both stimulating and comforting to those with dementia.
- Customers in their own home are less likely to be awake during the nights. If they do struggle to sleep, there is someone there just to look after them, on a one to one basis.
- Daily routines can be established or maintained, bed time is the same as is meal times.
- Being adequately stimulated in the day often means that sleep patterns are often improved.
- 1:1 support ensures better safety and stimulation.

Case study

Living at home with the support of a Carer

Meet Kathy

For over 50 years, Kathy and her husband ran a day centre for Age Concern for local people to participate in social activities and were recognised and awarded a lifetime membership for the dedication and support they had given to so many.

Unfortunately, Kathy had to retire from her work as her health started to fail her; after being diagnosed with dementia, this was when Kathy needed care herself. After contacting a few care companies, Kathy's family finally settled with Independent People Homecare 'as they have done a wonderful job in building the company to an excellent standard and employing such wonderful Carers in their community'.

Initially, Kathy just had visits a couple of times per day helping her with day-to-day living. As her condition deteriorated, Kathy's family increased her visits and now has Carers visiting her four times a day, seven days a week and they even help her attend a day centre herself twice per week.

Kathy is happy with her life and loves to reminisce about her past with the Carers who visit, she enjoys talking about her daughter, her grandchildren and great grandchildren. She loves all the Carers that visit her and says she would not be able to cope without them. As a people person, Kathy always looks forward to her Carers visiting and having a 'good ole chat'.

We're proud to care for people like Kathy. At Independent People Homecare, our Carers not only help with day-to-day living but are also trained in helping families cope with a loved one living with dementia. As Kathy's condition deteriorates, families also have peace of mind knowing Kathy will continue to stay at home with a professionally trained Live in Carer who will provide 1-2-1 care all in the comfort of her own home, 24 hours per day/7 days per week.



Useful contacts

Alzheimer's Society

www.alzheimers.org.uk

T: 0300 222 11 22

Age UK

www.ageuk.org.uk

T: 0800 678 1174

Admiral Nursing Direct

T: 0800 888 6678

E: helpline@dementiauk.org

To find out more or to arrange a FREE assessment

Call us on **0808 278 8807**

or email: **hello@iphomecare.co.uk**

or visit: **www.iphomecare.co.uk**



IndependentPeople

Homecare Services

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