

Dementia

A guide to person-centred dementia care



Living well with dementia

"It's normal to be worried when someone you love gets diagnosed with dementia. The fear of the unknown can be unsettling. Despite this, it's vital to understand that diagnosis does not mean the end of an active, happy and fulfilled life. Thanks to ongoing research, new techniques and assistive technology, it is possible to live well with dementia, and remain at home."

"With the appropriate level of care and support from a partner, family members and from professional care service providers, those with dementia can retain their independence and keep on doing the things they love. This guide will share techniques to help your loved one live well with dementia and remain in the comfort and familiarity of their own home for as long as possible. It will help you understand dementia from their point of view, in order to best provide the care and support they need."

- Dr Jane Pritchard
Consultant Admiral Nurse
The Good Care Group

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What is dementia?

Dementia is a collection of symptoms resulting from damage to the brain. There are many different types of dementia, the most common being Alzheimer's disease. Different types of dementia have different symptoms, as they all affect slightly different parts of the brain and can cause problems with a variety of issues relating to cognition.

Dementia causes problems with:

- Memory
- Thinking speed
- Mental agility
- Understanding
- Judgement

As a result, it can cause:

- Memory loss
- Confusion
- Difficulty finding the right words
- Difficulty with numbers
- Changes in mood and behaviour

Getting a diagnosis

If you are concerned about possible dementia, first we would suggest that you speak to your GP as signs of confusion can arise from different causes - many of which are easily resolved, such as dehydration, delirium and urinary tract infections. Therefore, obtaining an expert opinion is important. Dementia diagnosis is made through a range of cognitive tests and sometimes also requires brain scans or blood tests.



Different types of dementia

'Dementia' is an umbrella term, used to describe symptoms that occur when the brain is affected by certain diseases or conditions.

Each type of dementia has its own set of characteristics, and affects the brain in a different way. Learning about them is valuable, as it makes it easier to spot early signs and symptoms.

Common types of dementia include:

- Alzheimer's disease
- Vascular dementia
- Lewy body dementia (LBD)
- Frontotemporal dementia (FTD)
- Mixed dementia (one or more type combined)

Alzheimer's disease

The most common type of dementia, Alzheimer's, is caused by abnormal protein 'plaques' and 'tangles' building up in the brain. These plaques and tangles are thought to damage brain cells and disrupt chemical messages. Early signs and symptoms can include difficulty finding words, memory lapses (especially for recent events), low mood, and anxiety.

Vascular dementia

Vascular dementia, caused by reduced blood supply to the brain, occurs when damage happens to the vascular system, usually from small, repeated bleeds or blockages in blood vessels. Blood is unable to reach certain parts of the brain leading to cell death in those areas. Early signs and symptoms vary depending on what part of the brain is affected. They can be similar to those seen in people with Alzheimer's, but commonly include personality change, reduced brain processing speed, and an unusual gait when walking.

Lewy body dementia (LBD)

Dementia with Lewy bodies is a disease associated with abnormal deposits in the brain of a protein called alpha-synuclein, or 'Lewy bodies'. People with this type of dementia often have low mood, visual hallucinations and changes to alertness and attention. Some people also display symptoms similar to Parkinson's disease; including rigid muscles, slow movement, difficulty walking, and tremors.

Frontotemporal dementia (FTD)

FTD affects mainly the frontal and temporal lobes of the brain, causing shrinkage of these areas. It often affects people at a younger age, with 58 years being the average age that symptoms start. Its cause is unclear, although there is thought to be a genetic element. Symptoms can be mistaken for other conditions to begin with as people mainly experience personality and mood changes, apathy, and unusual behaviours rather than confusion.

Less common forms of dementia

There are many other rarer forms of dementia, which can be harder to diagnose. These include:

- Korsakoff syndrome
- Huntington's disease
- Posterior cortical atrophy (PCA)
- Corticobasal syndrome (CBS)
- Progressive supranuclear palsy (PSP)
- Creutzfeldt-Jakob disease (CJD)



What happens after diagnosis?

Obtaining a diagnosis is a positive step, as it means you know the type of dementia and will be able to understand symptoms and the steps required to best manage it. Early symptoms of dementia are often very mild and may progress only gradually. The rate of progression will vary from person to person, based on the type of dementia and their overall health and lifestyle.

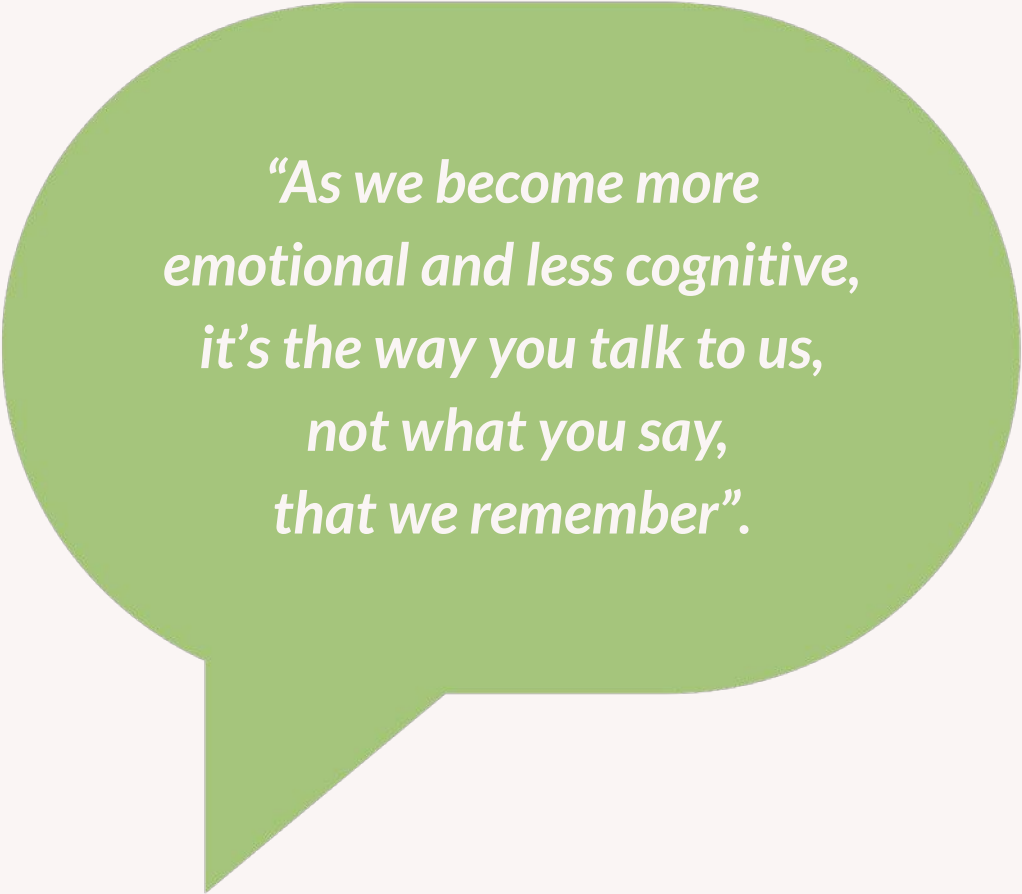
At present there is no cure for dementia. However, at The Good Care Group our team of carers will provide support in managing the symptoms and work closely with family and friends to help improve well-being and quality of life from the start of your loved ones' diagnosis throughout.

It is important to stress that a dementia diagnosis should not stop you or your loved ones from doing the activities that you enjoy - we support those to remain independent and to be active for as long as possible.



Feelings over facts: Relating and communicating

As dementia progresses, it becomes more difficult to store and process factual information. Consequently, feelings gain increased significance. Christine Bryden, who was diagnosed with Alzheimer's disease aged 46, illustrates the change:



“As we become more emotional and less cognitive, it’s the way you talk to us, not what you say, that we remember”.

Dementia can be best understood as the random, intermittent and increasingly frequent failure to store new factual memories, whilst continuing to store the feelings associated with those missing facts. People with dementia will always know how they are feeling, but not necessarily why. In the absence of recent factual information to provide a context for what is happening around them, they will seek out old factual memories stored long ago, perhaps from their youth, to help them make sense of their current situation.

If they are feeling relaxed and content as they search for old memories to map the ‘here and now’, they will match good and happy memories from the past. Conversely, if they are feeling anxious and scared now, they are likely to access more traumatic memories from the past.

Admiral Nurses

Admiral Nurses are highly skilled registered nurses with specialised dementia care training. Supported and developed by Dementia UK, a leading dementia charity, they provide life-changing support for families facing all forms of dementia.

At The Good Care Group, we have our very own Consultant Admiral Nurse, Dr Jane Pritchard. Jane provides support and insight into the care delivery for those living with complex care needs. Together with our occupational therapists, they run our Specialist Service at The Good Care Group.

The benefits of an Admiral Nurse in dementia care include:

1.

Expert guidance and advice: Helps families to understand the condition and what to expect as it progresses, as well as managing symptoms for the individual living with dementia.

2.

Emotional support: Dementia can be overwhelming for both the individual and families. Admiral Nurses offer emotional support to help manage the challenges associated with this diagnosis.

3.

Practical assistance: They can help with managing medications and coordinating with the caregiver.

4.

Identify potential issues: Admiral Nurses can identify issues early and intervene to prevent them. They offer strategies for managing challenging behaviours and provide support during crises.

5.

Improve quality of life: Admiral Nurses provide personalised support to enhance the independence and dignity of individuals living with dementia.



Dr Jane Pritchard

Support for every stage of dementia

Our very own model of dementia care has been developed by our Admiral Nurse, Dr Jane Pritchard. It articulates how we achieve the best care for those living with dementia and their families. The model is called 'EVER' and stands for:



E

Engagement - These are the different techniques we use to approach communication and build rapport.



V

Validation - This method is used to connect with people living with dementia emotionally through acknowledging their feelings.



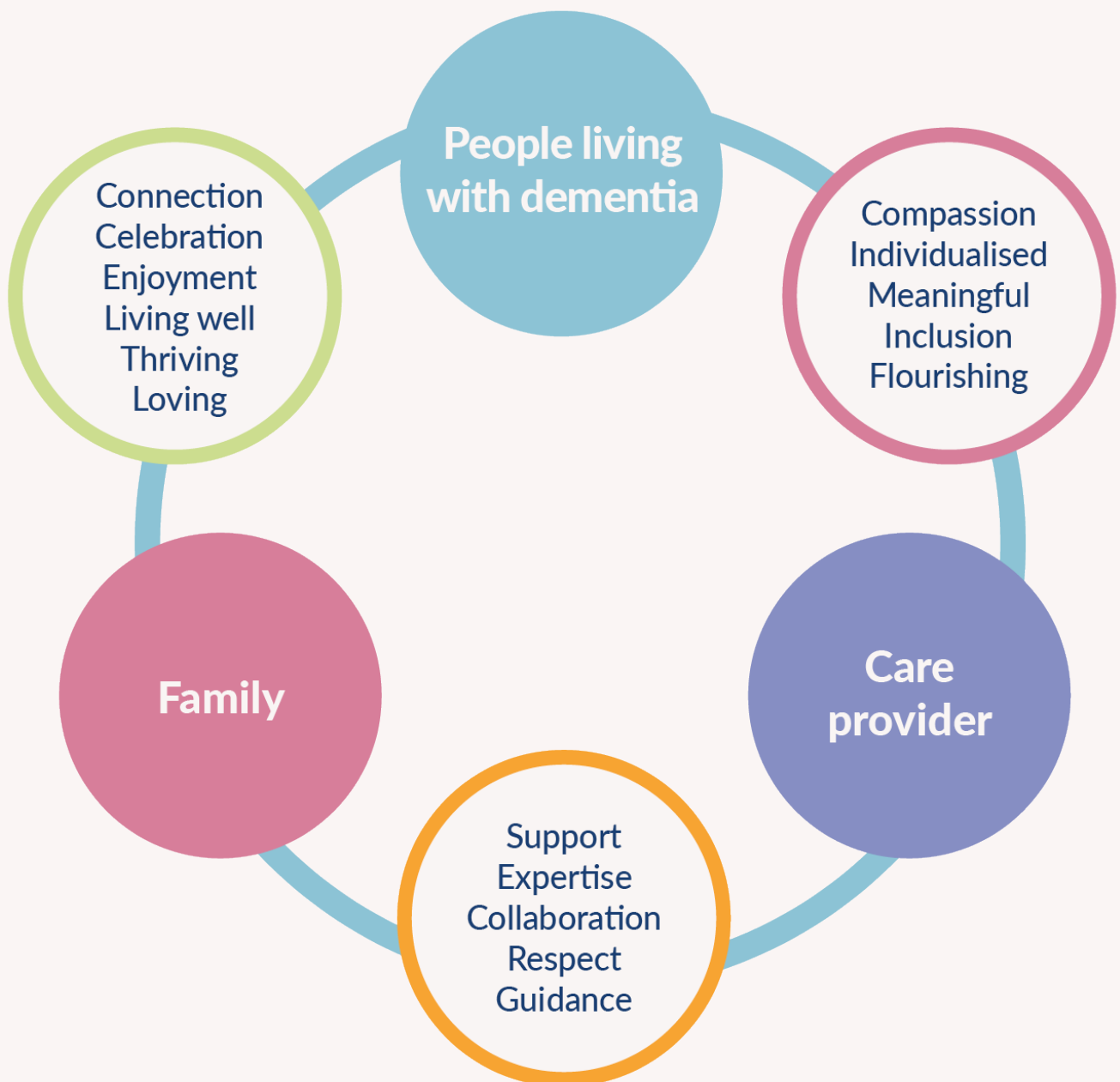
E

Enrichment - Enables people with dementia to live full, meaningful lives. This is achieved through a number of techniques such as reminiscence and music therapy.



R

Relationships - 'EVER' adopts what is called a 'Relationship-Centred' model. It acknowledges the importance of empathetic communication with others.



EVER has been curated and developed by our talented, in-house clinicians and is used throughout our dementia care training for our carers. Our personalised and fully managed dementia care services are designed to enable people with dementia to have the best possible quality of life, whilst receiving the care they need in the comfort of their own home.

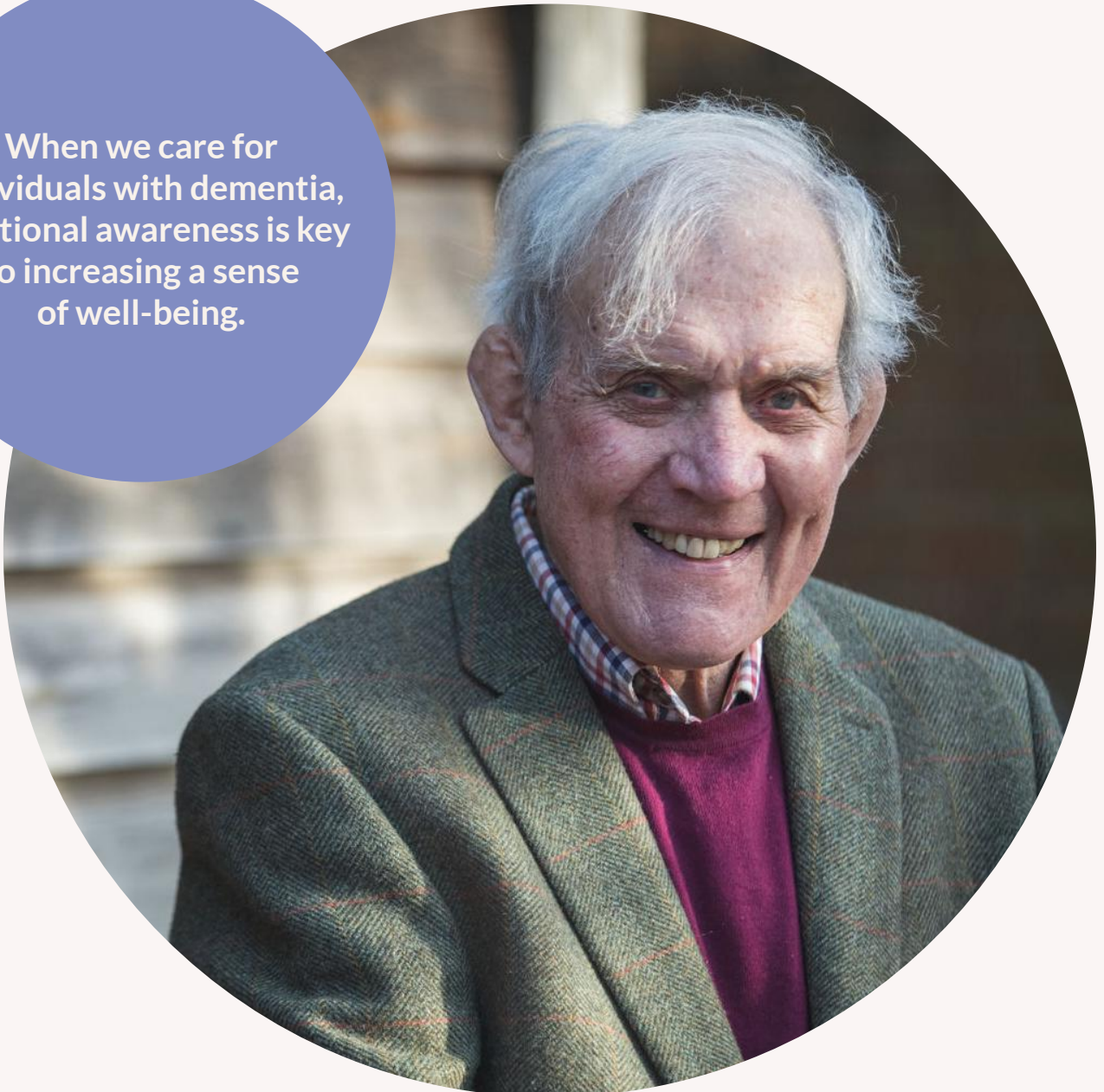
Useful tools for improving well-being

Adopt a person-first approach

The person-first view of dementia, developed by Tom Kitwood, proposes that dementia is not the problem; the problem is 'our' (individual, carer, professional, society) inability to accommodate 'their view of the world'. Our team of carers see that this is a **'person with dementia'**, not a 'person with **dementia**'.

People with dementia still have the same emotional needs as any other person, yet feelings are heightened and become increasingly important. For that reason, when we care for individuals with dementia, emotional awareness is key to increasing a sense of well-being. The tips in the next section will help put this person-first approach into practice.

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Validation therapy

Naomi Feil's (2002) approach of 'validation' recognises the value of a person's subjective experience. In recognising who the person is, we can offer individual and empathic care by properly acknowledging and understanding the various elements that make a person unique.

Reminiscing

Pam Schweitzer (1998) suggests that family carers might find revisiting the past improves their current relationship with the person they care for. Ideas for reminiscing include creating life history boxes or books, going out to visit memorable places, looking at family photo albums or listening to favourite music.

Assistive technology

A number of assistive technologies have been developed to help people with dementia retain some of their independence. Assistive technology can help manage potential risks around the home, and can reduce stress for carers, in addition to improving quality of life for the person with dementia.

Remaining in the comfort of your own home for as long as possible has many benefits for people with dementia. As the ability to store new memories deteriorates, familiarity, routine and older memories become increasingly important. Simple tasks such as making a cup of tea may be easy for a person with dementia when in their familiar home, but would become impossible to 'relearn' in a new environment. Even at home, as time goes on some practical help may be needed.



Examples of assistive technology



Location and tracking devices

Tracking devices can help give people with dementia a greater sense of independence. They can be attached to items the person normally keeps with them or taken on walks to allow safer walking.



Safety and security

Telecare sensors are monitoring devices that notify a nominated person, professional carer or call centre in the case of certain hazards, for example falls or leaving the home at night time. Other security devices include key safes to allow carers to enter the house or extra precautions to prevent unwanted callers.




Household appliances

Adapted versions of typical household devices, including doorbells, telephones, lighting, and home entry systems are available. These are designed with features such as larger buttons, bright colours and auto-functions, to make life easier to manage for people with dementia.

Introducing assistive technology

Assistive technology should be introduced gradually to reduce confusion. Generally, there is a higher chance of success if technology is introduced when dementia is still at an early stage. It's important to realise that not every tool will be useful for every person, and that assisted technology is more effective when combined with consistent, person-centred care at home.



“Engaging in arts activity
empowers people living
with dementia and enriches
life for them and those
around them”

Creative therapies: music and art

It is thought that people's aesthetic and imaginative responses remain strong for many years after the onset of dementia, so music and art can be a positive and energising experience.

Arts 4 Dementia work with arts venues to set up and facilitate art, music, dance, drama and poetry events around the country. *Arts 4 Dementia's* ambition is the establishment of widespread, continuing access to artistic stimulation that will enable people with dementia to live better and longer at home. They have found attendees to these events remain energised, happy and stress-free for some time afterwards, with 94% still benefiting overnight and 60% benefiting for a week or more. *"The creative part of the brain can remain undamaged for years, and we've found challenging arts activity elevates sufferers above memory loss, heightens brain function and restores self-esteem. We believe people with dementia have the right to enjoy life to the full, and engagement in inspirational arts activity can transform their lives, enabling them to live more enjoyably, and for longer, in the community".* - Veronica Franklin Gould, CEO of Arts 4 Dementia.

Simple ways to enjoy artistic stimulation:



Listening to music



Drawing, painting or doing arts and crafts



Dancing

Staying active and keeping healthy

Keeping as active as possible is extremely important for people with dementia. We ensure that our clients remain active by encouraging physical activities such as going for a walk, gardening and even household chores. These activities help keep a connection to normal life, retain skills and improve sleep, appetite, circulation and digestion.

We know from medical research that what is good for our heart is also good for our head, so keeping physically fit is important for everyone, particularly those with dementia. Regularity is key, so to continue doing the activities that you or your loved ones enjoy is important for maintaining that daily routine.

Staying mentally and socially active is important too, and it's vital to ensure that people with dementia see friends and family and enjoy their hobbies. They may require some adjustments as time goes on - such as seeing family in smaller groups. Engaging in consistent activity can help keep boredom and depression at bay, as well as help to preserve dignity and self-esteem. Doing activities together also helps to maintain an emotional connection, even during stages of confusion.

Choosing activities

Be mindful to choose activities that are likely to be successfully achieved. Some tasks, though they might seem simple to us, can be complex for people with dementia. Making a cup of tea, for example, involves approximately 38 separate steps! This might be achievable for people with early-stage dementia, but many people with advanced dementia will find single-step activities more enjoyable.

Activities such as sweeping, folding and sorting are achievable, as there is no sequencing involved. As dementia progresses people often become more sensory. At this point, creative therapies (music, art, dance) can be more successful. With advanced dementia, sensory therapy (stimulating the senses) becomes beneficial. Try hand massage, listening to music or stroking pets.





Eating well

Continuing to eat a healthy diet is important, but there are a number of reasons why people with dementia may not eat properly. Our carers can provide help with mealtimes to ensure that the individual with dementia is getting the nutrition they need.

Some of the reasons why people with dementia may not be eating include:

- No longer feeling hungry due to a sedentary lifestyle.
- Struggling to find the words to ask for food.
- Unable to recognise food or don't feel it looks appealing.
- May have forgotten they like certain foods, or have a preference for food from the past.
- Having trouble chewing or swallowing.
- Suffering from depression which can negatively affect appetite.
- In pain and cannot communicate what's wrong.
- A reduced appetite due to medication, lack of sleep or constipation.

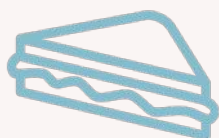


Tips for improving diet

At The Good Care Group, we have found that making diet changes can be beneficial for those living with dementia. Food can be made more appealing by offering the following:



Sweeter choices. A changing sense of taste means that people with dementia often develop a preference for sweeter foods. Trying roasting rather than boiling to caramelise vegetables, add fruits to stews and curries, and consider sweeter vegetables such as peppers and squash.



Finger foods. People with dementia may struggle with a knife and fork, or become unsettled when expected to sit for a meal. Foods that can be eaten in the hand, in an informal way, may work well.



Regular snacks rather than occasional large meals. Smaller portions are more appealing, easier to eat and ensure that blood sugar levels remain more stable during the day.



Their favourite food. Food they liked when they were younger may be more appealing than modern foods which they may not recognise. The focus should be on a nutritionally balanced meal. However, towards the later stages of dementia, ensuring a high calorie intake often becomes more important.

Bringing carers into the home

Dementia is a progressive disease, so there may come a time when you need extra help with care. Although the thought of arranging care can be distressing, planning for care provision will help ensure that your loved ones are able to stay where they are most comfortable and retain some of their independence.

As dementia affects recent recall, memories from many years ago are still accessible. For this reason, it is most beneficial for people with dementia to receive care in their own home. Bringing carers into the home allows continuity - they are still in a familiar environment, with their own belongings and routines, and access to family and pets as usual.



Staying at home makes it easier to introduce new carers with minimum disruption. Instead of a dramatic change of scenery, the carer can be introduced gradually, in a way that is acceptable to the person with dementia. Carers using a person-centred approach will deliver holistic care - taking into account personal and emotional needs - in addition to practical and medical tasks they may need help with.

Choosing well-matched carers with the skills and characteristics to manage dementia is very important. Once the best possible care team has been identified, ensuring that the care plan is sustainable is essential in avoiding exhaustion and regular changes in carers. Leaving one person to work alone for months at a time is a recipe for disaster and will compromise quality of care and carer continuity in the long run.

Introducing carers

- Avoid dramatic changes in routine and location.
- Retain as much familiarity as possible e.g. access to pets and belongings.
- Plan for future care to minimise disruption.
- Consider holistic care needs, not just practical tasks.
- Carer continuity is vital for truly person-centred care.



Conclusion

We hope this guide has helped allay some of your worries about dementia care, and you have taken away some practical steps that will help you support your loved one.

Although living with dementia will undoubtedly require some changes, it really is possible to live well, remain independent and stay in the familiar and comforting surroundings of home.

Taking on some of the suggestions in this guide - staying active, enjoying the arts and utilising a person-centred approach to care - will help ensure that loved ones with dementia continue to live a fulfilled and happy life.



For more information on home care options for dementia, please contact The Good Care Group:



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