

Dementia: through their eyes

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 a 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 home care and support they need.

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The Good Care Group

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Getting a diagnosis

What is dementia?

Dementia is a syndrome, 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.

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, speak to your GP who can refer you to a specialist clinic. 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.

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, the government is investing in ongoing research, and drugs are available to manage the symptoms of certain types of dementia, such as Alzheimer's disease. There is also much that partners, family, friends and carers can do – as this guide will demonstrate. By understanding the psychology of dementia, you can help manage symptoms, minimise distress, and ensure your loved one has a good quality of life from diagnosis and throughout the journey of dementia.

It's important to stress that a diagnosis of dementia should not stop people doing the activities they enjoy – those with dementia should be supported to remain independent, involved in their decisions and active for as long as they can.



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. This way of understanding dementia was first described by Oliver James in the book *Contented Dementia* (2008).

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"*. Loved ones and carers must 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 caring for people with dementia, emotional awareness is key to increasing their sense of wellbeing. The tips in the next section will help put this person-first approach into practice.

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.

Communicating well

Changes in relationships can make relating to someone with dementia a challenging and emotional time for partners, family and friends, but it's vital to continue spending time together - companionship can significantly boost quality of life.

The SPECAL® Three Golden Rules are simple yet highly effective person-first communication techniques. Using these will not only promote the wellbeing of a person with dementia but can help improve your relationship with them and make the time you spend together more positive.

1. Avoid asking direct questions

Avoid asking any direct question that requires the person with dementia to search for factual information. Asking them to search for facts which they may not have access to will increase their awareness of their disability, causing them unnecessary distress and potential trauma. It is surprising how much information you can gather without asking direct questions!

2. Listen to the expert

Listen to the questions the person with dementia is asking, and consider very carefully what the best answer might be from their perspective rather than your own. It is crucial that the information they receive generates good feelings for them. We owe it to the person with dementia to avoid leaving them with anxieties that they cannot, only moments later, explain.

Everything they say and do has a meaning, even if they cannot express their feelings in words. Although you may not understand what they are saying, you can still empathise and demonstrate that you are listening carefully. Dementia does not change people's needs for companionship, reassurance and comfort.

3. Do not contradict

Do not argue with the person with dementia. They are increasingly likely to use intact memories from their pre-dementia past, in order to understand what is happening around them in the present. The rest of us need to avoid disturbing the sense they are making, and start where they are at.



Assistive technology

Staying at home for as long as possible is beneficial 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. 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.

Examples of Assistive technology

1. Location and tracking devices

Tracking devices can help give people with dementia a greater sense of independence. They can be attached to items that are commonly mislaid or taken on walks to allow safer walking.

2. Safety and security

Telecare sensors are monitoring devices that notify a nominated person or call centre in the case of certain hazards, for example extreme weather, 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 against unwanted callers.

3. 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 the 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.



Creative therapies: Music and art

“Engaging in arts activity empowers people living with dementia, and enriches life for them and those around them” - **Dr Natalie Ryan**, Dementia Research Centre, University College London.

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

Physical, mental and social activity

Keeping as active as possible is extremely important for people with dementia. Physical activities such as walking the dog, gardening and even household chores 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 look for activities that they enjoy and are easy to fit into their 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 confused stages.

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 the creative therapies described above (music, art, dance) can be more successful. With advanced dementia, sensory therapy becomes simple and intimate. 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, so help may be needed at mealtimes to ensure they are 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

It may be helpful to adapt the diet of people with dementia, to make food as appealing to them as possible. Try offering:

- **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 caramelize 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.

Serving food

When serving food, leave drinks and snacks in accessible places, ensuring that food is visible. Remember that a clear glass of water or a glass of milk on a white table could be hard to see. Try coloured juice or cups which are highly visible.

Colour perception can be a problem for people with dementia and similar colours are sometimes not distinguishable. Aid recognition by carefully arranging food on the plate in distinct colours.

Meal times

You could try to involve people with dementia in meal preparation – peeling potatoes, shelling peas and washing vegetables are all simple one-step tasks that can help a person feel involved. It will also psychologically prepare them for the impending meal.

Meal times should be social, relaxed and pressure free. Use the opportunity for conversation and companionship, and do not outwardly focus on how much is being eaten.

Problems with chewing and swallowing

It's important to consult a speech and language therapist when someone is having problems with chewing and swallowing. Softer options like scrambled egg can be helpful as well as nutritious soups.

Seek advice before pureeing food as this is not always the right thing to do. If you have to offer pureed food be careful to maintain the nutritional content (adding water can dilute the nutritional value) and try to make it look and taste as appealing as possible – keep the ingredients distinct on the plate, rather mixing it all together.

Dehydration

Dehydration is a big risk for people with dementia and can result in increased confusion, delirium, urinary tract infections, health problems and even hospitalisation. Dehydration occurs when people don't drink enough fluids and this can happen to people with dementia for a number of reasons, including:

- Inability to recognise drinks
- No sense of thirst
- Medications (particularly diuretics)
- Lack of physical and coordination skills to drink.

Tips to promote fluid intake:

- Have a drink on hand during meals
- Use a clear glass so they can see what's inside, or a brightly coloured cup to draw attention
- If possible, offer them the cup or put it in their line of sight
- Describe what the drink is and where it is, so that if they have a problem with their sight they can still find the drink
- Offer different types of drink (both hot and cold) throughout the day
- Make sure the cup or glass is not too heavy or a difficult shape
- Offer foods with high liquid content like gravy, jelly and ice cream.

Getting enough rest

Dementia can affect the body clock, causing disruption to normal day and night rhythms. Not getting enough sleep at night can cause a wide range of problems for people with dementia including:

- Decreased health (our immune system works harder for us when we are rested)
- Increased confusion, exhaustion and inability to concentrate
- Risky behaviours such as wandering at night.

How to help promote a healthy sleep pattern

During the day:

- Establish a daily routine – routine and regularity are very important for people with dementia
- Avoid long naps
- Promote physical activity – being sedentary makes us feel lethargic in the day and does not help with sleep at night
- Increase access to natural sunlight – our internal body clock works off daylight
- Provide lots of cues and prompts about the time of day. Try drawing back the curtains and playing upbeat music in the morning.

At night:

- Dim the lights, draw the curtains, and play quieter and more soothing music towards the end of the day
- Make time to wind down and relax – if you are busy doing chores at 8pm, the energy you give off will stimulate the person with dementia who is less likely to feel ready for bed
- Avoid caffeinated drinks after 6pm
- Make sure medication side-effects are not interfering with sleep patterns: ask a doctor about the best times to take medications.

Medical support

There are drugs available which can help manage the symptoms of dementia and help the brain to continue to function in spite of the progressing damage.

Treatment options for Alzheimer's disease include acetylcholinesterase inhibitors. These increase the amount of neurotransmitter available by inhibiting the action of the enzyme responsible for its deterioration. NICE provide practice guidance related to the use of this medication (NICE 2006).

Treatment for other forms of dementia requires a careful balance to manage symptoms of the dementia and the side effects of the prescribed medication (NICE/SCIE 2006).

A note on antipsychotics

It is very common for people with dementia to experience behavioural and psychological symptoms such as aggression and agitation.

In some cases people may be prescribed antipsychotic drugs. While antipsychotic drugs do help some people, they can cause side-effects, particularly when used over a long period of time. It is now felt that two thirds of prescriptions for antipsychotics are unnecessary or inappropriate.

Instead, there are a number of simple treatment and therapy options that can dramatically improve these symptoms without the need for medication. This is called person-centred care and is described above in 'Feelings over facts: relating and communicating'.

Providing one-to-one care which is truly person-centred is vital for supporting people with dementia, allowing them to live well without the anxiety and distress that can cause behavioural problems.



Funding care

Working out the costs involved in home care and in particular who pays for care can be a difficult and worrying time for partners and families, in addition to the emotional strain of finding care for your loved one. This leaflet provides helpful information, but if you need further advice, you can contact The Good Care Group and we will be happy to assist you.

Financial help available very much depends on individual circumstances, but we have summarised some of the main options below.

Council funding

Local Authority Funding is limited to those who have assets worth less than £23,250 in England (Scotland £25,250, Wales £23,750) including savings and property, and is subject to an assessment. Those who qualify get help depending on their assessment.

Attendance Allowance is provided by the Government to anyone over the age of 65 who requires personal care due to a disability. The payments of either £55.10 or £82.30 per week are dependent on the level of care required and are non-means tested, tax free and usually added to pension payments.

Those under 65 with long term health conditions or disabilities can apply for Personal Independence Payments (PIP) payments ranging from £21.55 and £138.05 a week.

Carers allowance

This is a non means tested but taxable benefit paid at a rate of £62.10 per week to people who regularly care for someone who is severely disabled and living at home. Carers allowance is only paid if you spend at least 35 hours per week caring and do not receive other benefits of £62.10 or more per week.

Continuing Healthcare Funding

Those with complex medical conditions and ongoing care needs may be able to apply for NHS Continuing Healthcare funding, which if accepted covers 100% of care fees. The conditions covered by NHS Continuing Healthcare are quite specific, and are subject to a strict assessment.

Financing care at home

Funding care privately can be a daunting prospect, and getting expert financial advice is very important before making any decisions. Options such as equity release or care fees annuities can be helpful for some people.



Getting more information

There are a number of resources available to support those affected by dementia. Here's a selection of organisations who provide information, support and services to help people with dementia and their families, friends and carers.

Contented Dementia Trust

www.contenteddementiastrust.org

Charitable organisation focused on providing a person-centred approach to the care of people with dementia.

Dementia UK

www.dementiauk.org

UK Charity whose 'Admiral Nurses' provide specialist dementia care

Alzheimers Society

www.alzheimers.org.uk

A membership organisation working to improve the quality of life of people affected by dementia.

Re-Cognition Health

www.re-cognitionhealth.com

A private company providing diagnostic support.

Young Dementia UK

www.youngdementiauk.org

Support for younger people diagnosed with Dementia.

Age UK

www.ageuk.org.uk

UK charity dedicated to helping people make the most of later life.

Society of Later Life Advisers

www.societyoflaterlifeadvisers.co.uk

A not for profit organisation providing access to financial advisors for later life.

Solicitors for the elderly

www.solicitorsfortheelderly.com

An independent, national organisation of lawyers who provide specialist legal advice for older people, their families and carers.

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 them. 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 fears 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.

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

Phone: 0800 023 4220

Online enquiry form:


www.thegoodcaregroup.com/enquire-now/

Or there is more information on our website:

www.thegoodcaregroup.com

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.



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