

## Living with dementia

Living with dementia can be a challenge, but there are services available to help.

Local community services can help people living with dementia in the early stages, while respite and residential dementia care might be required later on.

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### Where do I go for dementia information?

Usually the initial point of contact to access care services for those living with dementia or Alzheimer's disease is either their GP (for healthcare solutions) or Adult Social Care services (for most other services).

If you are concerned about your persistent forgetfulness – or the memory difficulties of a friend or family member, it is important to consult a GP. He or she can undertake an initial examination and can then refer you to a memory clinic for further dementia tests.

The types of dementia support available are likely to involve the NHS, Adult Social Care and voluntary agencies. Some examples of dementia services and support for people with dementia include:

- Specialist day centres;
- Memory cafes;
- Respite or short breaks;
- Assistive technology and community alarms;
- Home care;
- Community equipment;
- Extra care, sheltered housing; and
- Carers' support groups.

## Supporting someone living with dementia

If you know someone who is worried about their memory, encourage them to visit their GP. The more support you can give someone, the better life with dementia can be, especially in the early years.

Too often people fear dementia, and this causes them to avoid people with the condition, making them feel isolated and stigmatised. With the right support, people can live well with dementia and continue to do the things they enjoy for a number of years following diagnosis. Focus on the person's abilities not their disabilities. Encourage them to continue with hobbies or interests whenever possible; a good understanding of dementia will enable you to communicate and support the person better.

When someone is living with dementia, they need:

- Reassurance that they are still valued, and that their feelings matter;
- Freedom from as much external stress as possible; and
- Appropriate activities and stimulation to help them to remain alert and motivated for as long as possible.

A person living with dementia is not being deliberately difficult; often their behaviour is an attempt to communicate. If you can establish what this is, you can resolve their concerns more quickly. Try to put yourself in their place and understand what they are trying to express and how they might be feeling. Understanding someone's life history can also help to understand what they may be expressing.

## Activities for people with dementia

Keeping people living with dementia occupied and engaged can help them to manage their symptoms. Finding activities that they enjoy and can complete is important to help them feel a

sense of purpose, accomplishment and self-worth. Try these as a starting point for dementia activities at home.

## Crafts

Crafts like drawing, painting or cutting and sticking can be a great pastime for anyone living with dementia, no matter how advanced their symptoms. Adult colouring books are widely available, but you can also get simpler books that might have more familiar images.

Depending on the stage of the person's dementia, you might want to consider 'painting with water' sets. These are sheets of paper which you paint water onto to reveal a colourful image. Some are reusable as, when they dry, the image disappears.

There are many other craft activities for people with dementia, including making collages, activities that use different textures, and modelling using playdough or modelling clay.

## Games

Games can be a perfect way to avoid boredom when someone is living with dementia. Specialist dementia games available can include simplified versions of family favourites, like snakes and ladders or scrabble; reminiscence activities that might spark memories or conversations; and easy wordsearch books.

## Jigsaws

There are puzzles designed especially for people with dementia. These usually have between 10 and 70 large pieces that form a traditional puzzle image. If your relative enjoys jigsaws, this activity could stimulate them without being too complex to complete. The completed pictures are appropriate for adults and cover many themes.

## Sensory

Sensory activities can be an extremely calming pastime for people with dementia. You can buy games that use smells to trigger memories, or you can buy or make a 'fiddle muff' if the person struggles with restless hands or fidgeting.

## Music

Music is widely recognised as a great way to engage people living with all stages of dementia. Any music can help, from playing a favourite CD to creating a personalised playlist of songs that are associated with happy memories. If the person with dementia lives alone, consider a simple radio with very few buttons for ease of use. Even just singing a favourite song can be an opportunity to connect.

## Household tasks

If the person with dementia shows an interest, let them carry out tasks around the house. Anything like folding towels to laying the table or washing up can help them to feel a sense of accomplishment and purpose. Be prepared that, depending on the level of their symptoms, the tasks may not be completed perfectly, so try not to see it as them 'helping' you with chores, just support them to enjoy the experience.

Ultimately, when introducing activities, be led by the person with dementia. Whatever they choose to do should be enjoyable and engaging. What is of interest one day, may not be the next. Consider how the person with dementia feels about certain activities and what they may have enjoyed in the past and bear in mind that some people can become frustrated by tasks that require completion if they are unable to complete them.

## Dementia day centres

In the earlier stages of dementia, day care support can offer vital help. A good day opportunity will be able to offer a range of activities and support that will enable the person with dementia to retain skills and remain part of their local community.

Specialist day care for people with dementia should be organised and run with the needs of people with dementia in mind, aiming to build on their strengths and abilities. Activities will vary but may include outings, entertainment, personal care, meals, hairdressing and support for carers.

Attendance at day centres can be offered from a just a few hours a week to a number of days.

## Respite care for dementia

Spouses, partners and relatives who care for a person with dementia can have an assessment and may need a break from caring. This is known as 'respite care' and may be a regular short break of a few hours a week or a period of a few weeks. It may be planned or be required in an emergency.

Regular respite care might involve the person with dementia attending a day centre or a care worker visiting the person's home to give the carer a break. If the relative caring for a person wishes to go on holiday or is unable to care because of illness or an emergency, a period of respite care may be provided in a care home or a care worker may provide care in the person's own home.

## Dementia home care

People with dementia may struggle in new environments and may function better and be more content in the familiar surroundings of their own home.

If homecare is an option, Adult Social Care or the homecare provider can assess the person's needs and a support plan can be drawn up. The person with dementia should participate as fully as possible in the assessment and planning. If they are unable to participate, family members can assist, or an advocate may be required.

The person with dementia will respond best to stable care staff who know them well. Continuity of care can be provided by either care agencies or carers employed directly by the person or his or her family. Staff can be employed if the person pays privately or receives a direct payment from Adult Social Care to contribute towards the cost of care.

## Dementia care homes

According to the Alzheimer's Society, one third of people with dementia live in a care home and more than two thirds of care home residents have dementia or memory problems.

Having dementia doesn't change who the person is, each person with dementia is a unique individual with their own emotional, physical and social needs and a set of hopes, aspirations and values. Meeting these needs with an individually tailored care plan enables the person to experience the best possible quality of life. Subsequently, a good care home will offer a person-centred approach to dementia care. This means that the unique qualities and interests of each individual will be identified, understood and accounted for in any care planning.

The person with dementia will have an assessment and an ongoing personalised care plan, agreed across health and social care that identifies a named care co-ordinator and addresses their individual needs.

They must also have the opportunity to discuss and make decisions, together with their carers, about the use of advance statements, advance decisions to refuse treatment, Lasting Power of Attorney and Preferred Priorities of Care.

It is important that care and support options are tailored as one size does not fit all. Some options can work well for one individual but prove to be stressful and unsuitable for another person. Make sure staff know the person with dementia by providing life-story books, telling staff about their likes and dislikes and providing belongings that bring comfort and have meaning for the person with dementia.

Within the home, much is down to the attitude and skills of the manager and the staff. Do they provide an environment that enables a person with dementia to exercise choice and personal preferences even in the later stages of the condition? Who is the person in charge of championing dementia care best practice in the home?

Dementia-specific training is needed to ensure that care home staff have an understanding of how best to support and care for people with dementia.

The design of a care home specialising in dementia should be based on small group living, preferably with accommodation on one level and opportunities to go in and out of the building within a safe and accessible environment. Plenty of natural light and an easy way of finding one's way around the building and grounds are essential for minimising disorientation.

## **Dementia Friends**

People with dementia sometimes need a helping hand to go about their daily lives and feel included in their community. Dementia Friends is an initiative to change people's perception of dementia. It gives people an understanding of dementia and the small things they can do that can make a difference to people living with dementia – from helping someone find the right bus to spreading the word about dementia. Visit [www.dementiafriends.org.uk](http://www.dementiafriends.org.uk) for further information.

