

Considering a care home for a person with dementia



Dementia is a progressive and complex condition, which means caring for someone with the diagnosis often becomes increasingly difficult as time passes. There may come a point when you are unable to look after the person at home anymore, or when moving into a care home is in their best interests, as well as your own and other family carers'.

Types of care home

There are two main types of care home:

- **Residential care homes** provide accommodation and personal care such as help with washing, dressing, giving medication, using the toilet and taking part in activities. Some specialise in caring for people with dementia
- Nursing homes also provide personal care, but with qualified nursing staff on site. This means they can support people with more complex physical or mental health needs or learning disabilities

Some homes offer both residential and nursing care.

The needs of the person with dementia will influence the type of care home you choose. Some people move from a residential care home to a nursing home as their needs become more complex.

When might you consider a care home?

If you are struggling to meet the needs of the person with dementia or keep them safe, or if caring for them is affecting your physical or mental health, moving into a care home may be the best decision for them and you. Reasons for considering residential care might include:

- sleep problems, including broken sleep throughout the night
- the person leaving the home alone and/or getting lost outside the home



- a breakdown or change in a home care arrangement
- difficulties managing personal care such as washing, dressing and continence
- frailty in the person with dementia and/or the person caring for them
- difficulty managing multiple health conditions in the person with dementia and/or the person caring for them
- worries about the person's safety, or the safety of yourself and others
- the person becoming reluctant to accept your help, or refusing help altogether

- the person finding it increasingly difficult to cope with daily living, eg neglecting their home and/or themselves
- the person feeling anxious and unsettled in their own home and/or not recognising that they are at home

When considering whether the time is right to move into a care home, try to involve the person with dementia and other family members, especially those who share the caring responsibilities. Our dementia specialist Admiral Nurses can also offer advice – please see Sources of support on p17 for information.

Capacity to make decisions

There may come a point where the person with dementia no longer has the mental capacity to make their own decisions about their care – including whether it is right for them to move into a care home. To have capacity, they must be able to:

- understand the information relevant to the decision
- retain the information
- use that information as part of their decision-making process
- communicate that decision to others

If possible, try to establish the person's wishes for long-term care in advance, while they still have capacity. This will help you respect their views as far as possible if they lose capacity. To ensure this happens, they should make:

An advance care plan (ACP): a document that sets out the person's wishes for their future medical and personal care, including residential care. An ACP will help you plan ahead and avoid having to make significant care decisions in a crisis situation.

Lasting power of attorney (LPA): a legal process where a person appoints someone they trust (known as their 'attorney') to make decisions on their behalf if they lack capacity. There are two types of LPA:

- health and welfare
- property and financial affairs

The health and welfare LPA allows the person's attorney to make decisions about them moving into a care home (as well as their medical care and whether they should receive life-sustaining treatment like resuscitation).

Regardless of whether the person with dementia has an LPA and/or ACP, they should be consulted and involved in decisions about their care wherever possible, and be given opportunities and support to do so.

If this is no longer possible and you need to decide if the person should move into a care home, a 'best interests' decision-making process should be followed, in consultation with the people who are involved with the person's care – for example, family members and health and social care professionals.

For more information on capacity and decision-making, LPA and ACPs, please see Sources of support on p18.

Assessments of care needs

There are certain assessments that can establish the care needs of the person with dementia and their eligibility for financial support.

Needs assessment: if you are unsure whether residential care is right for the person with dementia, you can request a social services needs assessment: please see Sources of support on p19.

An assessor – usually a social worker or occupational therapist – will assess what care needs the person has. This could be in person or by phone. They will then produce a report explaining their recommendations, which may advise that the person with dementia moves to a care home. They will not recommend a particular care home, but they can give you a list of options in your area for you to research.

It may be helpful for the assessor to introduce the idea of moving to a care home to the person with dementia and to other family members – sometimes, people find it easier to accept advice from a professional rather than a relative.

Financial assessment: if the needs assessment recommends the person receives care and support, which may include moving to a care home, they may qualify for financial assistance. Social services will need to carry out an assessment of their finances. If possible, this should take place before you start looking for care homes, as it might influence your decision – for example, some may be over your budget.

Financial assessments are routine but can be complicated, so do not hesitate to ask the social worker to clarify the process and explain the outcome. Our Admiral Nurses can also offer advice – please see Sources of support on p17.

Any financial support will be means-tested, so people who have savings and other assets (such as property) above a certain threshold will not qualify for assistance.

NHS continuing healthcare funding: this is a package of care that is fully funded by the NHS. It is for adults with long-term, complex health needs, which may include dementia. Normal NHS healthcare – for example, from a GP, district nurse or in hospital – is free, but



continuing healthcare covers other costs, such as home carers or care home fees.

There are two stages to the application process: the first is the 'checklist', which looks at certain criteria to see if the person is eligible for a full assessment. The full assessment then considers each area in depth, with the assessor deciding if the person qualifies for continuing healthcare.

The process can be difficult and stressful, so it is highly recommended that you have the support of a dementia specialist. You can call our Helpline to see if there is an Admiral Nurse in your area or other local services that could help – please see Sources of support on p17 for details of the Helpline and our information on continuing healthcare.

Choosing the right care home for a person with dementia

Choosing a care home can be challenging. Some might be too expensive. Some might be full, or be unable to cater for the person's individual needs. In some cases, there may not be a suitable care home in your area, and the person might be offered a placement in a home that is some distance from you, making it hard to visit regularly.

It can be particularly difficult to find a suitable care home for a person with young onset dementia (where symptoms develop before the age of 65). Many are tailored to older people and cannot support the different physical and mental health and social needs of a younger person.

Alongside the advice in this leaflet, we have also written a leaflet specifically to help you choose a care home for a person with young onset dementia – please see Sources of support on p17.

Every care home is different, so it is important to research and visit several options. Preparing some questions and a checklist of your requirements and wishes may be helpful during your visits. You can also ask friends, family, and other local people – such as members of carers' support groups – if they have any recommendations or insights.

As well as visiting homes, do some research into the quality of care. All care homes are inspected by independent regulators who rate them based on residents' quality of life and the care delivered. Care homes are inspected by:

- the Care Quality Commission (CQC) in England
- the Care Inspectorate in Wales



- the Regulation and Quality Improvement Authority (RQIA) in Northern Ireland
- the Care Inspectorate in Scotland

You can find care homes' inspection reports online (see Sources of support on p18) or ask the home for a copy when you visit.

What makes a good care home?

Every family has its own needs and preferences when choosing a care home, but a warm welcome, homely atmosphere, and residents and staff who seem content are good indications of a positive environment. You can find out a lot by talking to residents, relatives and staff. It is also important to use your senses: how does it smell? Is it warm enough? Is it noisy?

Other questions to consider are:

- Does the care home tailor activities to residents' individual interests?
- Are there opportunities for the person to continue with their current hobbies and interests?
- Are residents involved in the care home's daily activities and routines, eg helping to prepare food, lay tables, do gardening?
- Is there access to books, board games, radio, TV, puzzles, a piano etc?
- What is the food like? Can they cater for special diets?
- Is there secure access to outside space and fresh air?
- Is there a choice of social and communal areas eg a quiet space to sit and rest, and a livelier area for activities and conversations?
- Is there regular access to healthcare and wellbeing support, including doctors, dentists, podiatrists and hairdressers?
- Do staff have specific dementia knowledge and training?
- What is the staff turnover rate?
- What are the visiting times? Are they flexible?
- Can you have a meal with the person with dementia by prior arrangement?
- How accessible is the home for the people who are most likely to visit?
- What residents' and relatives' groups are there?
- How are residents and their families involved in care decisions?

- How are residents with communication difficulties supported?
- What are the laundry arrangements?
- Does the home arrange special events such as daytrips, visits from local nurseries, parties, film nights, themed activities etc?
- Are there links to the local community for instance, can residents get their newspapers delivered? Go to a place of worship? Go to the Post Office?
- Does the care home offer transport for visitors who cannot drive or use public transport?
- How easily can you communicate with staff if you have questions, concerns or recommendations?
- How will staff support you and the person with dementia as they approach the end of life?

A compassionate, skilled team with supportive leadership is vital to a good home. Talk to the staff and manager about how they provide care, what training the staff undertake, and how they make a difference to the residents. If the manager is new, you could ask about their vision for the future of the home.

The impact of moving into a care home

Moving into a care home is a major transition for the person with dementia. They may feel the loss of independence, and of their attachment to their main carer, home and normal routines. But although the move can be distressing, it will often lead to improvements in health and quality of life for you both, and more opportunities for socialising and meaningful activities for the person with dementia and those who care for them. The support of family, friends, professionals and the care home itself is essential during this transition. Involving the person with dementia and the wider family throughout will allow everyone to share their views and minimise disagreements.

To ease the process, you could ask if the person could have an overnight or short respite stay prior to moving in. Make sure they also have comforting and familiar items around them, such as their own bedding, photos and ornaments. They may even be able to take in their favourite chair or other small pieces of furniture.

How you can help

You can play an important part in helping the person settle into the care home and have a positive experience of living there.

Building positive relationships

- Try to think of the care home as an 'extended family' around you and the person with dementia this can frame the transition in a positive way for everyone
- Get to know the staff by name and help them get to know you too. This includes the wider team, eg cleaners, gardeners and kitchen staff – everyone can contribute to making a positive difference
- Share your essential knowledge about the person with dementia so staff can understand and support them better. You could do this by creating and sharing the person's life story – a record of their past and present life, likes, dislikes, values etc. Even the smallest details are important: how they take their tea, what their favourite radio station is, what sports team they support etc. Please see Sources of support on p17



- Be clear with staff about the person's needs and how their dementia affects them everyone's experience is unique
- Ensure staff know how the person usually responds to being distressed. What gives them physical and emotional comfort? How can staff support them if they are upset?
- Make sure you still spend quality time with the person, for example through meaningful activities that you both enjoy – like listening to music, dancing, sharing tea and cake, reading the newspaper, doing a jigsaw puzzle, watching a film
- If you are struggling to connect with the person, particularly if their ability to communicate changes, talk to staff about other ways to maintain your relationship, eg looking at photos or giving them a gentle hand massage

Working with staff

- Thank staff and tell them when you see good examples of care

 you can also tell the manager, as this feedback can be useful in
 staff members' appraisals
- Ask for regular review meetings and look for solutions together if issues arise keep conversations open and share your ideas
- Get to know the home's routines for example, find out about the best time to visit, whether you could offer support at mealtimes, if you can be involved in group activities etc
- Ask to be involved with the person's care planning (establishing and meeting the person's care needs in the present) and advance care planning (planning for the future) – see Sources of support on p17
- Consider if you could offer support with activities for example, if you play an instrument, could you lead a music session? If you enjoy gardening, could you start a residents' gardening group?
- Think about joining the home's relatives' and residents' group to support the care home more generally

Your emotions

Moving a person with dementia into a care home can be very emotional. You may feel that you are letting them down, especially if – like many people – you made a promise that they would never have to go into a home. You may feel a sense of loss and grief if your caring role changes or if you are now living alone.

You may feel guilty for considering your own needs when deciding to move the person into a care home, and worry that other family members and friends will judge you for not being able to continue in your caring role. However, supporting a person with dementia can



be emotionally and physically exhausting, so it is important to look after yourself. You cannot care for someone else if your own health is suffering.

While it is natural to feel guilty, moving a person with dementia into a care home is often a positive step, allowing them to receive expert care tailored to their needs. And when you are no longer absorbed in the daily duties of caring, you can focus on enjoying the time you spend together.

Please see Sources of support on p18 for our information on grief, guilt and looking after yourself as a carer.



Sources of support

To speak to a dementia specialist Admiral Nurse about transition to a care home or any other aspect of dementia, please call our Helpline on **o8oo 888 6678** (Monday to Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email **> helpline@dementiauk.org**

To book a phone or video call appointment with an Admiral Nurse, please visit **O dementiauk.org/book**

Dementia UK resources

Advance care planning • dementiauk.org/advance-care-planning

 Choosing a care home for a person with young onset dementia
 dementiauk.org/young-onset-dementia-choosing-acare-home

Creating a life storydementiauk.org/life-story

Coping with feelings of guiltdementiauk.org/coping-with-feelings-of-guilt

Grief, bereavement and lossdementiauk.org/bereavement

Guide to NHS continuing healthcare funding O dementiauk.org/guide-to-continuing-healthcare-funding

Lasting power of attorneydementiauk.org/lasting-power

Looking after yourself as a carer
 dementiauk.org/looking-after-yourself-when-you-care

Mental capacity and decision-making
dementiauk.org/capacity-decision-making

Care home inspectorates

The Care Quality Commission (England) • cqc.org.uk

The Care Inspectorate (Wales)
careinspectorate.wales

The Regulation and Quality Improvement Authority (Northern Ireland) relation or each of the second second

The Care Inspectorate (Scotland) • careinspectorate.com

Other resources

carehome.co.uk – care home reviewscarehome.co.uk

Care Rights UK – support for people having issues with care S carerightsuk.org

 Financial assessments for social care
 nhs.uk/conditions/social-care-and-support-guide/help-fromsocial-services-and-charities/financial-assessment-means-test

Make, register or amend a lasting power of attorney

gov.uk/power-of-attorney



My Home Life – supporting quality of life in care homes • myhomelife.org.uk

The needs assessment

• nhs.uk/conditions/social-care-and-support-guide/help-fromsocial-services-and-charities/getting-a-needs-assessment

Paying for your own care (self-funding)

• nhs.uk/conditions/social-care-and-support-guide/moneywork-and-benefits/paying-for-your-own-care-self-funding/

To speak to a dementia specialist Admiral Nurse about any aspect of dementia:

Contact our Helpline: **0800 888 6678** or **> helpline@dementiauk.org**

> Book a virtual appointment: • dementiauk.org/book

Our charity relies entirely on donations to fund our life-changing work. If you would like to donate to help us support more families:

- Call **0300 365 5500**
- Visit O dementiauk.org/donate
- Scan the QR code

Thank you.





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