

Considering a care home for a person with dementia

Caring for someone with dementia can be challenging. People living with the diagnosis often have complex needs, and as dementia is progressive, many family members find that caring becomes increasingly difficult as time goes on. There may come a time when you're 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 homes

Care homes are usually categorised into two main types – residential and nursing – although some offer both residential and nursing care in the same 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.

Residential homes with a dementia specialism can provide care for more specific needs related to a person's dementia.

Nursing homes also provide personal care, but they have

qualified nurse(s) on site as part of the care team. This means they can support people with more complex physical health, mental health or learning disability needs.

The needs of the person with dementia will help influence the type of care home you choose. People with dementia may live in either type of home, and some will move from a residential home to a nursing home as their needs become more complex.

When might you consider a care home?

If you're struggling to meet the needs of the person with dementia, or if caring for them is having a negative effect on your physical or mental health, a move into a care home may be the best decision for both them and you.

Some of the reasons for considering residential care include:

- sleep problems, including broken sleep throughout the night
- the person leaving the home alone and having difficulty finding their way back



- a breakdown or change in a home support arrangement
- incontinence and/or difficulties managing personal care such as washing and dressing
- increasing frailty of the person with dementia and/or the person caring for them
- difficulty managing multiple health conditions, for the person with dementia and/or the person caring for them
- fears over the person's personal 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 activities of daily living, eg neglecting their home and/or themselves
- the person becoming increasingly 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, if possible, and other family members, especially those who share the caring responsibilities.

If you are unsure whether residential care is right for your situation, it might help to request a local authority Social Services Needs Assessment – please see p6 for more details of these assessments and how to request them.

You can also call or email our free Helpline to speak to a dementia specialist Admiral Nurse about moving to a care home, or book a phone or video call appointment – please see Sources of support on p14 for information.

Capacity to make decisions

There may come a point when the person with dementia no longer has the mental capacity to make decisions for themselves about their care – including whether it is right for them to move into a care home.

To have capacity, the person 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, it's very important to establish the person's wishes for long-term care in advance, while they still have capacity. This will enable them to communicate their own opinions so you can respect them as far as possible if they lose capacity.

These are two ways of registering a person's wishes for their future care:

An Advance Care Plan (ACP) is a document in which the person sets out their wishes for their future medical and personal care, including residential care. ACPs are helpful as they enable you to plan ahead so you don't have to make unexpected and significant care decisions in a time of crisis.

Lasting power of attorney (LPA) is a legal process where a person appoints someone to be their 'attorney' and make decisions on their behalf if they lack capacity.

Your emotions

The decision to move a person with dementia into a care home can be very emotional. You may feel that you are letting them down by no longer being able to care for them, especially if – like many people – you promised yourself or them that they would never have to go into a home.

You may feel guilty for considering your own needs as well as those of the person with dementia. You may worry that you will be judged by other family members and friends for finding it difficult to continue with your caring responsibilities.

You may feel a sense of loss and grief – for example, if the move into a care home involves a change in your caring role, or if the person lived with you or you spent a lot of time with them, leaving you feeling lonely without them. However, supporting a person with dementia can be emotionally and physically exhausting, so it's important to recognise when you're beginning to struggle. Looking after yourself is important – you can't care for someone else if your own health is suffering.

Although it can be difficult, try not to feel guilty about considering residential care. Often, a move to a care home can be a very positive step, allowing the person with dementia to receive expert care that meets their needs. Also, when you are no longer absorbed in the daily duties of caring, you can focus on enjoying the time you spend together, which may improve your relationship.

Please see Sources of support on p14 for our information on grief, guilt and looking after yourself as a carer.

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 or not the person with dementia has an LPA and/or ACP, they should be consulted and involved in decisions about their future care wherever possible, and be given opportunities and support to do so.

If this is no longer possible, 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. You should always take into account the person's past and present wishes, values, beliefs and preferences.

For more information on mental capacity and decision-making, LPA

and ACPs, please see Sources of support on p14.

Assessments of care needs

There are certain assessments that you can request to help to establish the care needs of the person with dementia and whether they are eligible for any financial support.

Local authority Needs Assessments

If you're unsure whether residential care is right for the person with dementia, you can request a Social Services Needs Assessment by contacting your local authority (local council) – you can find their details at gov.uk/apply-needsassessment-social-services

An assessor – who may be a social worker or another person from the local authority – will assess what care needs you and the person with dementia have. 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 to you, but they can give you a list of the homes 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 are more accepting of advice that comes from a professional rather than a relative.

Financial assessment

The person with dementia may be eligible for some financial assistance with their care needs. If the Needs Assessment recommends the person receives support, which may include moving to a care home, Social Services will carry out an assessment of their finances.

If possible, this assessment should be completed before you make enquiries about care home places, as it might influence your decision – for example, some may be over your budget.

Financial assessments are routine but can be complicated. They take into account all of the person's assets. Any financial support that may be available is means-tested, so people who have savings and other assets (such as property) above a certain threshold will not qualify for assistance.

Don't hesitate to ask the social worker to clarify the process

and explain the outcome. You can also call or email the Admiral Nurse Dementia Helpline for advice – see Sources of support on p14 for details.

NHS continuing healthcare (CHC) funding

NHS continuing healthcare (CHC) is a package of care that is fully paid for 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 CHC covers other costs, such as home carers or care home fees.

There are two stages: 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 looks at each area in depth, with the assessor deciding if the person qualifies for CHC.

The process can be difficult and stressful, so it's highly recommended that you have the support of a dementia specialist such as an Admiral Nurse. You can call the Dementia Helpline to see if there is an Admiral Nurse service in your area or other local services that could help – please see Sources of support on p14 for details of the Helpline and our information on CHC.

Choosing the right care home for a person with dementia

Choosing the right care home can be challenging. Some might cost more than you can afford. Some might have limited bed availability or be unable to cater for the individual needs of the person with dementia.

In some cases, there may not be a local care home that can meet the person's specific needs. They might be offered a placement in a home that is some distance from you, which can be hard if you want to visit regularly.

Every care home is different, so it's important to research your options. You could start by visiting a selection of local care homes. Preparing some questions and a personal checklist of your requirements and wishes may be helpful when you're looking at potential care homes.



Alongside 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 in Northern Ireland
- the Care Inspectorate in Scotland

See Sources of support on p15 for contact details.

You can find care homes' inspection reports online or ask the home for a copy when you visit.

Sometimes, the most helpful way to find out about a care home is to talk to residents, relatives and staff. Ask friends, family, and other local people if they have any recommendations. Local carer support groups can also be a useful source of information.

What makes a good care home?

Every family will have their own needs and preferences when choosing a care home, but a warm welcome and residents and staff who seem content and involved with each other are good indications of a positive environment.

Other questions to consider are:

- What is the 'feel' of the home? Is it a homely environment?
- Use your senses: how does it smell? Is it warm enough? Is it noisy? Do the residents and the staff look happy?
- Are there opportunities for the person to continue with their hobbies and interests?
- Does the care home tailor activities to the person's individual interests?
- Are residents involved in the running of the home and garden, eg helping to prepare food, lay tables, do gardening?
- Is there access to books, board games, a radio, a television, puzzles etc?

- Does the quality of the food seem good?
- Is there secure access to outside space and fresh air?
- Is there a choice of social and communal areas – eg a quiet place for residents who like to sit peacefully, and a more lively space for activities and conversations?
- Are there places to sit and rest, other than the residents' own bedrooms?
- Is there regular access to healthcare and wellbeing support, including doctors, dentists, podiatrists and hairdressers?
- What specific dementia knowledge and training do staff have?
- What is the turnover rate of staff?
- What are the visiting times? Are they flexible?
- How accessible is the home for the people who are most likely to visit?

- How involved can families be? What residents' and visitors' groups are there?
- How are residents and their families offered choices and involved in care decisions?
- If the person has difficulty expressing themselves, how are they supported to communicate their wishes and preferences?
- What are the laundry facilities like? Ask other residents or visiting families about this if you're not sure how to tell
- Does the home arrange any special events such as trips out, parties, celebrations, film nights, themed activities etc?
- Are there links to the local community, for instance, can residents get their newspapers delivered? Go to church or other places of worship? Go to the Post Office?
- How easily can you communicate with staff if you have any questions, concerns or recommendations?
- How are residents and families supported as the person with dementia nears the end of life?

A compassionate, skilled team with supportive leaders is vital to a good home. Talk to the staff and home 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 and hopes for the future of the home.

The impact of moving into a care home

Moving into a care home can be a significant change for the person with dementia and for the people around them. The person with dementia may feel the loss of attachment to their main carer, as well as of their home and normal routines.

But although the move can be distressing, once you and the person with dementia have adapted to the change, 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 can be a great help during this transition. Involving the person with dementia and the wider family throughout the process will allow everyone to share their views and minimise disagreements.

There are some practical steps that can improve the process of moving into a care home, including:

- spending some time at the home prior to moving in – you could ask if it is possible for the person to have an overnight stay or even a short respite stay
- taking in personal items, such as photographs and paintings, cushions and favourite ornaments, so that the room looks comfortable and familiar
- taking in some of their own furniture, with the agreement of the care home
- ensuring comfort items are available, such as the person's slippers, duvet or pillow

How you can help

Once the person has moved into a care home, there are things you can do that may help them settle in and have a positive experience of living there, including:

Building positive relationships

- Get to know the staff by name and help them get to know you and the person with dementia too
- Be clear with staff about the person's needs and how their dementia affects them – everyone's experience is unique
- Get to know the wider team, including cleaners, gardeners and kitchen staff – everyone can contribute to making a positive difference
- Share your essential knowledge about the person with dementia. This will help staff deliver the best care possible. Even the smallest details are important: how they take their tea, what their favourite radio station is, what football team they support etc
- Develop and share the person's 'Life Story', for example through

a written record, photographs, music playlists and storyboards – these can be used by staff and visitors to understand what matters to the person, helping them communicate and interact better. Please see Sources of support on p14 for more information

- Ensure staff know how the person usually responds to being distressed. What gives them physical and emotional comfort? How can staff provide the best possible care if the person is upset?
- Keep the connection between you and the person with dementia by continuing with activities that you have enjoyed together, such as listening to music, dancing, sharing tea and cake, reading the newspaper, doing a jigsaw puzzle, watching a television programme
- If you are struggling to connect with the person, particularly if their ability to communicate changes, talk to staff about other ways of staying connected, eg looking at old photos or giving them a gentle hand massage

Working with staff

- Thank staff and tell them when you have seen care that is good

 you can also tell the manager, as this feedback can be useful in staff members' appraisals
- Look for solutions together when care is not as good as it should be

 keep conversations open and share your ideas
- Ask for regular review meetings to discuss any issues as they arise
- Develop your own knowledge about the patterns of work and routines of the home – for example, ask staff about the best time to visit, whether you could offer support at mealtimes, if you can be involved in group activities etc
- Offer to support staff with activities such as 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 p14
- Think about joining the home's Relatives' and Residents' Group to support the care home

Sources of support

If you would like to speak to a dementia specialist Admiral Nurse about transition to a care home or any other aspect of dementia, please contact our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email **helpline@dementiauk.org**

If you would prefer to pre-book a phone or video call with an Admiral Nurse, please visit **dementiauk.org/get-support/closer-to-home**

Dementia UK information Lasting power of attorney dementiauk.org/lasting-power

Advance Care Planning dementiauk.org/advance-care-planning

Grief, bereavement and loss dementiauk.org/bereavement

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

Life Story work dementiauk.org/life-story

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

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

Guide to applying for NHS continuing healthcare (CHC) funding dementiauk.org/guide-to-continuing-healthcare-funding

Other resources

Relatives and Residents Association relres.org

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

The Care Inspectorate (Wales) careinspectorate.wales

The Regulation and Quality Improvement Authority (Northern Ireland) rqia.org.uk

The Care Inspectorate (Scotland) careinspectorate.com

Make, register or amend a lasting power of attorney gov.uk/power-of-attorney

Getting a social care Needs Assessment

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

Financial assessments for social care nhs.uk/conditions/social-care-and-support-guide/helpfrom-social-services-and-charities/financial-assessmentmeans-test

carehome.co.uk - care home reviews carehome.co.uk

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

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org We receive no government funding and rely on voluntary donations, including gifts in Wills.

For more information on how to support Dementia UK, please visit **dementiauk.org/donate** or call **0300 365 5500**. **Publication date: June 2022 Review date: June 2024** © Dementia UK 2022



If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call 0800 888 6678 or email helpline@dementiauk.org

Open Monday-Friday, 9am-9pm Saturday and Sunday, 9am-5pm



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Dementia UK, 7th Floor, One Aldgate, London EC3N 1RE Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SCO47429).