

Young onset dementia: choosing a care home



Dementia is often associated with old age, but it can also occur in younger people. When symptoms develop in people under the age of 65, it is known as ‘young onset dementia’.

Each person with young onset dementia experiences it in their own way, but during the later stages, people may become increasingly dependent on others. Over time, living at home may no longer be safe, manageable or accessible, or their family may be unable to provide the level of care and support they need. At this stage, you may need to consider a move into a care home.

‘Care home’ is a term used to cover residential care settings. These may be:

- **Residential care homes:** these provide general everyday living support, for example with washing and dressing, eating, mild to moderate mobility needs, taking medication and recreational activities. They do not normally have Registered Nurses or other medical professionals on site
- **Nursing homes/care homes with nursing:** these provide a higher level of care for people who have complex needs, disabilities or medical conditions, and have Registered Nurses on site

Difficulties in finding a suitable care home

People with young onset dementia may have unique and complex care needs, which can make finding a suitable care home challenging. Many homes do not accept people under 65 due to their age, physical fitness and/or behavioural support needs. Others have little or no experience in caring for a person with young onset dementia.

A small number of residential care homes provide accommodation specifically for younger people with dementia, but they are the exception, not the norm. You may find that there are no care homes



that are suitable for a younger person in your area, so you may need to compromise on location and convenience. Or you may have to opt for a home that cares primarily for older people but is willing to be adaptable for a younger person. Bear in mind that many homes have waiting lists.

The person's abilities and interests may change and decline as their dementia progresses. When looking for care homes, try to think about what needs the person might have in the future as well as what they need now, and how the care home might be able to support them.

Choosing a care home

If the needs of the person with young onset dementia are increasing, start looking at care options early so you do not have to make a decision in a crisis.

It is a good idea to look at a care home's inspection reports from:

- The Care Quality Commission (CQC) in England: ➡ [cqc.org.uk](https://www.cqc.org.uk)
- The Care Inspectorate in Scotland: ➡ [careinspectorate.scot](https://www.careinspectorate.scot)
- Care Inspectorate Wales: ➡ [careinspectorate.wales](https://www.careinspectorate.wales)
- The Regulation and Quality Improvement Authority in Northern Ireland: ➡ [rqia.org.uk](https://www.rqia.org.uk)

Your local council website can provide information on care homes in your area (or the local Health and Social Care Trust in Northern Ireland) – please see Sources of support on p15. You can also search for information and reviews online, for example at

➡ [carehome.co.uk](https://www.carehome.co.uk), and ask the person's health and care professionals if they have recommendations.

Most care homes hold open days or coffee mornings, which are great opportunities to see what they are like. You can also make appointments to visit. All care homes are different, so visit as many as you like; this will help you decide what is most important. When you visit, talk to the manager, staff, residents and visitors, ask lots of questions and have a good look around.

Ask other families living with dementia about their experiences with care homes in your area, especially if their relative has young onset dementia. If there is a local young onset dementia support group or service, speak to the staff and group members to see if they have personal knowledge of care homes that may be suitable. Please see



Sources of support on p14 for details of our database of young onset dementia groups and services.

When you are looking for a care home, it can be hard to think of all the things you might want to know, particularly when it is for a younger person. Our leaflet on choosing a care home (see Sources of support on p13) contains lots of helpful suggestions and information, but here are some additional points to consider, specific to people with young onset dementia:

- Are staff experienced in looking after people with young onset dementia, including helping them maintain as much independence as possible?
- Are there any other younger residents in the home?
- Can it provide a stimulating, age-appropriate environment?
- What activities are provided? Are they of interest to a younger person, or can they be tailored to meet their needs?

6 Dementia UK

- Does the home have arrangements with venues like leisure centres, coffee shops and pubs to enable residents to visit?
- Will the care home work closely with other professionals involved in the person's care, for example their GP, Community Mental Health Team, physiotherapist and occupational therapist?
- Can they cater for the person's food and drink preferences and appetite, including special requirements such as religious diets/ food from the person's culture?
- Are there opportunities to socialise, access indoor and outdoor open space and be active?
- Can staff support residents to leave the home, for example to go for walks, go shopping, go to the gym, go swimming, see friends etc?
- Is there internet access?
- Does the home play music, films and TV programmes that appeal to younger people, and provide entertainment from a range of eras?
- How can they support the person's religious and cultural needs?
- Can they accommodate personal preferences for room décor, furnishings, routines and activities?
- Can the care home support a couple's privacy and sexual needs if required, such as by providing a double bed or do not disturb signs; or allowing the person's spouse or partner to help them have a shower or bath?
- If you have children, would they feel welcome and comfortable visiting their parent or relative in the home?
- Does the home provide care until the end of life?



A member of staff should meet you and the person with dementia for an assessment before the care home accepts them as a resident. This helps to ensure they can meet their needs and will avoid the person having to move to a different care home within a short space of time if it proves unsuitable.

You will need to work with the staff to assess the level of support needed and develop strategies together to ease the transition. Short respite stays can be helpful to determine whether a home is suitable before full-time care is required, although not all homes offer respite breaks.

Residential care for people with learning disabilities

People with a learning disability such as Down's syndrome have a higher chance of developing dementia at a younger age. If the person has a learning disability as well as dementia, care home staff will need specialist knowledge and skills in order to support their needs.

Some care homes will accept a person with mild to moderate needs, but a specialist home for people with learning disabilities may be more suitable for a person with complex needs. Please see Sources of support on p14 for information on dementia and learning disabilities.

Paying care home fees

When a younger person develops dementia, it can have a significant impact on the family's finances. They often need to leave work earlier than they expected and may have other financial commitments like a mortgage and dependent children. Having to pay for care at this stage of life is an additional financial worry that most people have not planned for.

When you are looking for care homes, find out about the cost of care and any financial assistance you may be entitled to as this may influence your choice. You can ask Social Services for a needs assessment to identify the person's care needs; this will be followed by a financial assessment (means test) to establish whether any financial support is available. Most people will need to contribute at least some of the costs of care.

If the person has complex long-term health needs, they may be eligible for NHS continuing healthcare (CHC) funding to cover the cost of nursing home care. This is a non-means-tested benefit available in England, Wales and Northern Ireland for people who have health needs that require care beyond what a local council could reasonably be expected to provide. It is not specific to the person's diagnosis. You can discuss whether it is an appropriate time to apply for CHC with the person's health and social care professionals.

If the person's condition is deteriorating rapidly and it is thought that they are nearing the end of life, they may be assessed for 'fast-track CHC' so that care and support can be put in place as soon as possible. CHC is not available in Scotland.



Please see Sources of support on p13-15 for information on the needs assessment, disability benefits and CHC.

Some people in England, Wales and Northern Ireland who have been detained (‘sectioned’) in a mental health ward/hospital under the Mental Health Act 1983 qualify for free aftercare, known as ‘section 117 aftercare’, when they leave. This is arranged by Social Services and the NHS and provides ongoing support for the person’s mental health needs, which might include residential care.

The person’s care team should start planning their section 117 aftercare before they are discharged from hospital. If you are not sure whether the person with young onset dementia is eligible for section 117 aftercare, ask their Mental Health Team as soon as possible. Please see Sources of support on p15 for information on section 117 aftercare.

There is no direct equivalent to section 117 aftercare in Scotland, but some people may be given a Compulsory Treatment Order. This might, in some cases, specify that they are cared for in a care home, although the focus is on care in the community.

Making the transition into a care home

Before the person moves in, give the care home a clear description of their needs, preferences, routine, likes and dislikes. Let them know about anything that might trigger distressed behaviour and what usually helps calm them.

If the person has a care needs plan and/or advance care plan, you can share these with the care home to help guide their care and support. If the person does not have these, you can start working on them, together with the care home staff and the person's GP. Our advance care plan template may be helpful: please see Sources of support on p13.

It is also helpful to create a life story for the person. This is a record of their personal information, past and present life, likes and dislikes and values, and will help staff get to know them. You could use Dementia UK's life story template: see Sources of support on p14.

To help the person settle in, bring in items that will provide comfort and familiarity – for example their own bedding, pictures and photos, ornaments, cushions, books and small pieces of furniture. Be aware, however, that items sometimes get misplaced or broken in care homes. It is a good idea to label the person's possessions, including clothing, with their name, and avoid taking in valuable items.

Encourage family and friends to visit the person regularly and try to involve them in activities and family life. Find out about how children can be supported to visit – for example if they feel uncomfortable around the other residents, could they see the person in a quieter



space or in the garden? Can you bring in games or other activities that the child can do with their family member?

When a person with dementia moves into a care home, it is important that you and other family members take the time to build a good relationship with the manager and care staff. This will help them support the person well.

The emotional impact of moving into a care home

Moving into a care home is a life-changing event for the whole family, especially when it happens at an age where it would not usually be expected. The person with dementia may be upset and angry about the decision, and want to stay in their own home where things feel safe and familiar. Roles and relationships may change, and the person's partner and/or relatives may feel guilt at having to move them into a home. Children may need additional support to come to terms with a parent moving out on a permanent basis.

Some care homes provide support groups for relatives. If there are other younger residents, the home may be able to connect you

with their family members to share experiences and support. You may also be able to access support for the person with dementia, yourself and other family members through the GP or Community Mental Health Team.

While finding a suitable care home and making the transition can be difficult, moving into the home may offer many benefits, including supporting the person's care needs, relieving family members of some of their caring responsibilities, and providing the person with company and meaningful activities. Once everyone adjusts to the move, it can improve everyone's health and quality of life.

If you need support around choosing a care home for a person with young onset dementia and moving them in, our specialist Admiral Nurses can help – please see Sources of support on p13.



Sources of support

If you are living with dementia or caring for someone with the condition, register for our free online sessions, ‘Dementia: what next?’ at [▶ dementiauk.org/dementia-what-next](https://dementiauk.org/dementia-what-next)

To speak to a dementia specialist Admiral Nurse, call 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](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit [▶ dementiauk.org/book](https://dementiauk.org/book)

Dementia UK resources

Young onset dementia section

[▶ dementiauk.org/young-onset-dementia](https://dementiauk.org/young-onset-dementia)

Advance care planning

[▶ dementiauk.org/advance-care-planning](https://dementiauk.org/advance-care-planning)

Advance care plan template

[▶ dementiauk.org/advance-care-plan-template](https://dementiauk.org/advance-care-plan-template)

Care needs assessments and financial means tests

[▶ dementiauk.org/the-care-needs-assessment](https://dementiauk.org/the-care-needs-assessment)

Considering a care home for a person with dementia

[▶ dementiauk.org/choosing-a-care-home](https://dementiauk.org/choosing-a-care-home)

Coping with feelings of guilt

[▶ dementiauk.org/coping-with-feelings-of-guilt](https://dementiauk.org/coping-with-feelings-of-guilt)

Find support: searchable database of young onset dementia support groups and services

➤ dementiauk.org/find-support

Guide to NHS continuing healthcare funding

➤ dementiauk.org/guide-to-continuing-healthcare-funding

Learning disabilities and dementia

➤ dementiauk.org/learning-disabilities

Life story work

➤ dementiauk.org/life-story

Mental capacity and decision-making

➤ dementiauk.org/capacity-decision-making

What is young onset dementia?

➤ dementiauk.org/about-young-onset-dementia

Young Dementia Network

An online community for everyone living with, working with or interested in young onset dementia, hosted by Dementia UK

➤ youngdementianetwork.org



Other resources

carehome.co.uk: directory of UK care homes

➤ carehome.co.uk

Disability benefits

➤ gov.uk/browse/benefits/disability

Find your local council

➤ gov.uk/find-local-council

Find your local Health and Social Care Trust (Northern Ireland)

➤ nidirect.gov.uk/contacts/health-and-social-care-trusts

Section 117 aftercare

➤ rethink.org/advice-and-information/rights-laws-and-criminal-justice/mental-health-laws/section-117-aftercare-under-the-mental-health-act-1983

**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 ➔ **dementiauk.org/donate**
- Scan the QR code



Thank you.



dementiauk.org • info@dementiauk.org

Publication date: July 2026 Review date: July 2029. © Dementia UK 2026

Dementia UK, 7th Floor, One Aldgate, London EC3N 1RE
Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC 047429).