



**DementiaUK**  
Helping families face dementia

## Young onset dementia: choosing a care home



Dementia is often associated with old age, but it can also occur in younger people. When it develops in people under the age of 65, it is known as ‘young onset dementia’. Around 70,800 people in the UK are estimated to be living with the condition.

Each person with young onset dementia experiences it in their own individual way, but during the later stages most people will become increasingly frail and dependent on others.

For some people, the disabilities and changes resulting from young onset dementia mean that eventually, living at home is no longer an option. The physical home environment may no longer be manageable or accessible, or other people who share the home may be unable to provide the level of care and support needed. At this stage, you may need to consider a move into a residential care home.

It is a good idea to think about what you would ideally want to happen if this situation arises, so that a plan can be put in place that follows your preferences as much as possible.

### **The difficulties of finding a suitable care home**

If the time comes when a care home becomes the best option for the person with young onset dementia, it can be a shock to discover that many homes do not accept people who are under 65. This may be due to their age, physical fitness and/or behavioural support needs.

People with young onset dementia may have unique and complex care needs and finding a home that is suitable for them can be challenging. It is advisable to start looking early so you do not have to make a decision in a sudden crisis situation. Bear in mind that many homes have waiting lists and the person’s abilities and interests will change and decline over time. It is therefore important to think about what needs they might have in the future, rather than how they are now.

You may find that care homes have had little or no experience in caring for a person with young onset dementia so 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 a helpful way of determining whether a home is suitable before full-time care is required, although respite breaks are not offered by all homes.

## Choosing a care home

A small number of residential care homes provide accommodation specifically for younger people or have young onset dementia-specific households or units, but they are the exception not the norm. You may find that a home offering age-appropriate care is some distance from where you live, so you may need to compromise on distance 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.

Your local authority and the Care Quality Commission website will have information on homes in your local area. Searching online or using a care home website such as [carehome.co.uk](https://www.carehome.co.uk) can also be useful.



If there is a young onset dementia support group or service near you, contact the staff or speak to group members to see if they have personal knowledge of local care homes that may be suitable (see Sources of support on p6 for details of our database where you can search for young onset dementia groups and services). The professionals who are supporting you may also have suggestions.

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. The Dementia UK leaflet on Choosing a care home for a person with dementia (see Sources of support on p6) contains lots of helpful suggestions and information, but here are a few additional points to consider:

- Are staff experienced in looking after people with young onset dementia?
- Are there any other younger residents at the home?
- Can it provide a stimulating, age-appropriate environment?
- What activities are provided? Are they of interest, or can they be tailored, for a younger person?
- Can they accommodate the person's appetite and tastes?
- Are there opportunities to socialise, access outdoor space and be active?
- Do the staff support residents to leave the home to go walking, shopping, to church etc?
- Does it provide access to telephones, the internet and a range of music and TV channels?
- Do they play music, films and provide entertainment from a range of eras?
- Can they accommodate the person's religious and cultural needs and interests?
- Can they accommodate personal preferences for room décor, furnishings, routines, activities and remaining as independent as possible
- Can they support a couple's privacy and sexual needs if required, such as a double bed or do not disturb signs?
- If you have children, would they feel welcome and comfortable visiting a parent in the home?
- Does the home provide care until the end of life?

It is a good idea to visit a number of different homes as this can help you to decide what is and is not important. You may need to book an appointment to visit. Talk to the manager, staff, residents and visitors, ask lots of questions and have a good look around. Find out about the cost of care and any financial assistance you may be entitled to as this may influence your choice of home. See Sources of support on p7 for details of our Guide to NHS continuing healthcare (CHC) funding or visit: [which.co.uk/money/pensions-and-retirement/financing-later-life-care](https://www.which.co.uk/money/pensions-and-retirement/financing-later-life-care)



A member of staff should meet you and the person with dementia for an assessment before they accept 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 if it proves unsuitable. Give a clear description of the person's needs, routine and anything that might trigger distressed behaviour as well as things that calm them.

It is helpful to share a copy of the person's care plan with the home and, if possible, their life story – a record of their past and present life that will help staff get to know them. You could use Dementia UK's life story template: see sources of support on p7.

People with a learning disability such as Down's syndrome are at greater risk 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 a mild to moderate learning disability, but a specialist home may be more suitable for a person with complex needs.

Once found, the right home may offer many benefits in terms of company and sharing the responsibility for care and support. Once everyone adjusts to the move, there can be improvements in health and quality of life for all.

## Emotional impact

Moving into a care home is a life-changing event in any person's life but even more so when this happens at an age when it would not usually be expected. It is important that the chosen home can provide ongoing care that meets the person's needs now and in the future.

Moving into a home will impact the person with dementia and the whole family. The person may want to stay in their own home

where they feel safe and things are 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.

Encourage family and friends to visit the person regularly and try to involve them in activities and family life as much as they are able.

Some care homes provide support groups for relatives. If there are other younger residents, they may be able to connect you with their family members.

## Sources of support

To speak to a dementia specialist Admiral Nurse about choosing a care home for a person with young onset dementia or any other aspect of dementia, please call our Helpline on **0800 888 6678** (Monday to Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email [helpline@dementiauk.org](mailto:helpline@dementiauk.org)

If you prefer, you can book a phone or video appointment at a time to suit you at [dementiauk.org/book-an-appointment](https://dementiauk.org/book-an-appointment)

### Dementia UK information

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

### Find support

Searchable database of young onset dementia support groups and services  
[dementiauk.org/find-support](https://dementiauk.org/find-support)

Considering a care home for a person with dementia  
[dementiauk.org/choosing-a-care-home](https://dementiauk.org/choosing-a-care-home)

About young onset dementia leaflet  
[dementiauk.org/about-young-onset-dementia](https://dementiauk.org/about-young-onset-dementia)

Advance Care Planning  
[dementiauk.org/advance-care-planning](https://dementiauk.org/advance-care-planning)

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

**Guide to NHS continuing healthcare funding**  
[dementiauk.org/guide-to-continuing-healthcare-funding](https://dementiauk.org/guide-to-continuing-healthcare-funding)

**Learning disability**  
[dementiauk.org/learning-disability](https://dementiauk.org/learning-disability)

**Life story work**  
[dementiauk.org/life-story](https://dementiauk.org/life-story)

**Mental capacity and decision-making**  
[dementiauk.org/capacity-decision-making](https://dementiauk.org/capacity-decision-making)

**Young Dementia Network**  
An online community of people living with young onset dementia, their family and friends, and professionals  
[youngdementianetwork.org](https://youngdementianetwork.org)

### **Other resources**

**Care Inspectorate**  
Independent regulator of health and social care  
[careinspectorate.com](https://careinspectorate.com)  
(Scotland)  
[careinspectorate.wales](https://careinspectorate.wales)  
(Wales)

**Care Quality Commission**  
Independent regulator of health and social care in England  
[cqc.org.uk](https://cqc.org.uk)

**Financial assessments for social care**  
[nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/financial-assessment-means-test/](https://nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/financial-assessment-means-test/)

**Getting a social care Needs Assessment**  
[nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/getting-a-needs-assessment](https://nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/getting-a-needs-assessment)

**My Home Life – supporting quality of life in care homes**  
[myhomelife.org.uk](https://myhomelife.org.uk)

**Relatives and Residents Association**  
[relres.org](https://relres.org)

**The Regulation and Quality Improvement Authority**  
Independent regulator of health and social care services in Northern Ireland  
[rqia.org.uk](https://rqia.org.uk)

The information in this leaflet is written and reviewed by dementia specialist Admiral Nurses. We hope you find it useful. If you have feedback, please email [feedback@dementiauk.org](mailto:feedback@dementiauk.org)

**Publication date: May 2023**

**Review date: May 2025**

**© Dementia UK 2023**

**We want to ensure no one has to face dementia alone – and we can only do this because of our generous supporters. If you would like to help, please consider making a kind gift.**



To donate: call **0300 365 5500**,  
visit [dementiauk.org/donate-to-support](https://dementiauk.org/donate-to-support)  
or scan the QR code.  
Thank you.



If you have questions or concerns about any aspect of dementia, please contact our Admiral Nurses.  
Helpline: **0800 888 6678** or [helpline@dementiauk.org](mailto:helpline@dementiauk.org)  
Virtual clinics: [dementiauk.org/book-an-appointment](https://dementiauk.org/book-an-appointment)



**[dementiauk.org](https://dementiauk.org) • [info@dementiauk.org](mailto:info@dementiauk.org)**

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