



DementiaUK
Helping families face dementia

Guide to NHS continuing healthcare (CHC) funding



What is NHS continuing healthcare?

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. These needs may be the result of illness, disability or an accident.

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.

CHC may be awarded if the person is assessed as having a ‘primary health need’ – that is, if dealing with health issues is the most important part of their care.

CHC is available in England, Wales and Northern Ireland. In Scotland, there is a similar provision called Hospital-Based Complex Clinical Care, but this only covers care in hospital settings.

To find out more about CHC and its equivalents throughout the UK, visit:

England: [nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/](https://www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/nhs-continuing-healthcare/)

Wales: [gov.wales/continuing-nhs-healthcare](https://www.gov.wales/continuing-nhs-healthcare)

Scotland: careinfoscotland.scot/topics/how-to-get-care-services/hospital-based-complex-clinical-care/

Northern Ireland: continuing healthcare funding in Northern Ireland is currently being developed. In the meantime, contact your local Health and Social Care Trust for information: nidirect.gov.uk/contacts/health-and-social-care-trusts

Applying for CHC can be a complex and stressful process, so we have put together this leaflet to help guide you through. Our dementia specialist Admiral Nurses are also here to help – please see Support for you on page 12.

For an at-a-glance guide to applying for CHC, please see our flowchart on p13.

Applying for CHC funding – the checklist

The first stage of being assessed for CHC involves a screening checklist, which determines whether the person qualifies for a full assessment of need (which we refer to as full assessment.)

It can be carried out by a GP, Social Worker, District Nurse, care home nurse or other health or social care professional. It might happen face-to-face (including in a person's own home or care home – not just in a hospital or GP practice), or by phone/video call.

The checklist is a brief assessment of the person's needs in 11 separate areas. In each area, the assessor will decide if the person's needs are high (A), moderate (B), or low/no needs (C.)

A full assessment will be triggered if:

- two or more areas are rated A
- five or more areas are rated B, or one A and four Bs
- there is an A rating in any of: behaviour, breathing, drug

What does the checklist cover?

- breathing
- nutrition
- continence
- skin integrity
- mobility
- communication
- psychological/emotional
- cognition
- behaviour
- drug therapies and medication
- altered states of consciousness

therapies and medication, or altered states of consciousness

Checklist outcomes

Once the checklist has been completed, there are two possible outcomes:

- the person IS put forward for a full assessment
- the person IS NOT put forward for a full assessment

Bear in mind that the threshold for receiving a full assessment is low, so even if the person qualifies for assessment, there is no guarantee that they will be awarded CHC.

The full assessment of need

If a person qualifies for a full assessment of need, it will be carried out by a coordinating assessor. They should contact you soon after the checklist result to arrange the full assessment.

Ideally, the assessment should include members of the person's health and social care team. These people form part of the multidisciplinary team (MDT) which provides information and evidence about the person's care needs. It is helpful to keep a note of who is involved, and what their role is.

The full assessment should be done within 28 days of the checklist being completed, but many families face much longer waits.

If 28 days have passed, you can contact the coordinating assessor or your local NHS body (the local Clinical Commissioning Group in England, the Local Health Board in Wales, or the Health and Social Care Board in Northern Ireland) to remind them that you are still waiting, and ask for a clear timescale for the assessment.

The full assessment involves the coordinating assessor and other members of the MDT completing a Decision Support Tool (DST.) This contains 12 separate 'domains' in which the person's needs are recorded. These are the same as in the checklist (see page 3), plus 'other significant care needs to be taken into consideration' – ie needs that don't fit into any of the other domains. Each domain will be

Fast-track applications

If a person's health is deteriorating rapidly and it is thought that they are approaching the end of their life, they may be eligible for a fast-track application. This is completed by an appropriate clinician who has a good knowledge of their health and care needs. It allows them to bypass the assessment process so CHC funding can be paid sooner.

assessed in much more detail than at the checklist stage.

It is important to understand that having a particular diagnosis, such as a dementia diagnosis, does not automatically mean the person is eligible for CHC funding – it

depends on their own individual health needs. For this reason, it's vital that any evidence you give accurately reflects their needs on a bad day – not on a good or average day, or the day on which the assessment takes place.

Example

As an example, in the behaviour domain – in which a person with dementia might have significant needs – the MDT might consider:

- Does the person display challenging verbal behaviours like shouting, swearing or screaming?
- Are they physically aggressive or destructive, for example slapping, kicking, punching or destroying property?
- Does their behaviour put them at risk of harm – for example, do they leave home alone when it's not safe for them, display inappropriate sexual behaviour, head-bang, try to eat raw food etc?
- Are there particular triggers for their challenging behaviour, such as a certain environment or carer?
- How is their behaviour currently being managed – for example, can they be distracted, or do they need to be restrained or given sedative medication?
- How frequently do carers need to intervene in their behaviour?

This is not an exhaustive list, and every single category will require the MDT to look at many different areas and their impact on the person's health.

Tips for the CHC process

These tips may be helpful in preparing for the CHC assessment and ensuring the person's needs are fully explained and understood.

- Consider getting specialist, professional help and advice, eg from a health or social care professional who understands both the nature of dementia and the CHC process. See Appointing an advocate on page 8
- Contact the coordinating assessor to make sure you know when the assessment is happening and what they require from you
- Tell the assessor who is involved in the person's care so they can consult these professionals during the assessment process
- Familiarise yourself with the DST forms – you can download these from the website of the local NHS body responsible for CHC funding (see links on page 2.) The more you understand about what the assessors are looking for, the more able you will be to contribute evidence and build a strong case
- Record as much as you can about the person's needs and how they are changing. Written evidence holds more weight than oral evidence, so you could keep notes. Recording short video clips that illustrate their needs may also be useful
- Make sure your evidence is aligned to the domains in the DST – think of specific examples in each area
- Focus on describing the person's needs on a bad day – family carers often underplay how difficult and complex the person's needs can be
- Be specific. For example, rather than saying, "They get very difficult if I try to take them out," give examples of what that looks like – do they push or hit you, become tearful, shout and swear, or throw things?
- Use powerful language like 'danger' and 'risk' to communicate the extent of the person's needs
- Ask others involved in the person's care to provide an accurate, up-to-date



assessment of their needs. If they live in a care home, you could ask the staff to keep a log of their needs, behaviours, clinical issues and risks

- Seek views of family and friends to support your case. They may have noticed examples of the person's needs that you haven't
- Ensure your view of the person's health and care needs is represented, and that it is understood by the coordinating assessor and any other professionals involved
- Don't be afraid to ask for clarification at any stage if there is something you don't understand
- If you think of anything you forgot to mention during the assessment, follow it up afterwards with the coordinating assessor

Appointing an advocate

Often, coordinating CHC assessors have little understanding of dementia and how it affects the person, leading to them underestimating their needs. An advocate can speak up for you and the person you care for, and make sure their needs and rights are properly expressed. They can also help you remember and understand what is said in conversations.

Anyone can be an advocate, but it's advisable that it's someone who is a specialist in dementia care. If there is an Admiral Nurse in your area, they may be able to act as an advocate – but it's best if they already know the person and their needs. Other options include:

- a family member or friend
- an independent advocacy service
- a non-practising solicitor – they can help ensure the correct legal processes are followed, but may not have specialist knowledge of dementia

A paid carer cannot act as an advocate.

If the person has young onset or a rarer dementia that has atypical symptoms (see page 11), it's especially important to use an advocate who has expertise in their particular type of dementia. Many assessors lack understanding of rarer dementias and how the person's condition affects their needs.



What happens if the person qualifies for CHC?

Once the DST has been completed, a recommendation is made to the local NHS body responsible for awarding CHC funding as to whether the person is eligible for CHC. Only in very rare circumstances can the local NHS body overrule this recommendation.

You will receive a letter explaining whether or not the person you care for is eligible for CHC. If they are, a CHC nurse will usually work with you to make a Support Plan. This will include:

- the person's health and wellbeing goals
- the day-to-day care and support they need
- how their needs and care will be managed
- where their care will be provided, eg in their own home or a care home
- who will be responsible for providing their care

CHC funding can either be paid directly to the person's care service provider, or as a personal health

budget – where a designated person (such as a health or social care professional, a care organisation or a family member) manages the budget and decides how it is spent. This option gives you more control and flexibility over how the funding is used, so you can change how it is spent if the person's needs change.

What happens if the person does not qualify for CHC?

If the person's CHC application is rejected, they may qualify for joint funding instead, where the cost of their care is shared between the NHS, which provides the health funding, and the local authority, which provides social care funding. The social care element is means tested, so the person may need to contribute towards the cost of this care, depending on their financial circumstances.

Some people will not qualify for any funding at all. This can be a worry for many families, so you may want to appeal the decision or restart the application process – see overleaf.



What to do if you disagree with the CHC decision

If the person isn't granted CHC funding, you can ask the local NHS body to reconsider the decision.

This is called local resolution.

However, local resolution is usually only successful if there was an error in the assessment process – not just because you disagree with the outcome.

For this reason, it's often better to start a new application. This provides another opportunity for the person's health needs to be assessed in detail. Often, their

needs will have changed since the first assessment, which may mean they are now considered eligible for CHC funding. You can restart the process immediately after receiving a negative outcome.

CHC reviews

Because people's needs can change over time, the local NHS body will review the person's entitlement to CHC after three months, and then usually every 12 months. These reviews look at:

- whether the person's needs are the same
- whether their care package still

- meets their needs
- if they are still eligible for CHC

These reviews are standard practice and don't mean that a person's CHC will be taken away – in fact, if their needs have increased, they may be entitled to more support. A full reassessment should only be necessary if there have been significant changes to the person's needs.

Young onset dementia and rarer dementias

People with young onset dementia (dementia in someone aged 65 or under) often find it harder to prove that they qualify for CHC. The assessment is often weighted towards physical health needs, and coordinating assessors may not understand how dementia presents in younger people.

For example, a younger person may be physically fit – they may be able to dress and feed themselves independently, move around without help, and go to the toilet alone. However, while their physical needs may be fewer than in older people, they may still have significant psychological/

behavioural needs requiring specialist care and support.

For instance, they may not remember that they have had to surrender their driving licence due to their dementia, and get into their car and drive off. Or they may be prone to aggression and anger – and because they may be much stronger than an older, frailer person, these behaviours may put them, their carers or others at risk of injury.

It can also be difficult for people with rarer types of dementia to successfully apply for CHC funding. Their symptoms and needs may be different from more common types of dementia, and the assessor may not understand how their condition presents and how it affects their life. For example, they may not display significant memory loss, but instead have problems with concentration, problem-solving, spatial awareness and hallucinations.

If a person with young onset dementia or a rarer dementia is being assessed for CHC, it's strongly advised that you have an advocate who has specialist

knowledge and experience of the condition. This could be someone who is involved with the person's care, an Admiral Nurse who is already working with the person and their family, or an independent advocate.

Support for you

The CHC application process can be difficult emotionally. It can be upsetting to think in detail about the extent of the person's needs on their worst days, especially if caring for them has become routine and you don't often think about how challenging things can be.

It might be hard to admit that you can't always meet the person's needs yourself, and feel that your caring abilities will be judged. Or you might be worried about upsetting the person you care for by talking about their difficulties, especially if they are attending the assessment in person.

Some people find that the person's regular health or social care professional tries to tell them that they won't qualify for CHC; that there is no point applying; that they are wasting their time; or that

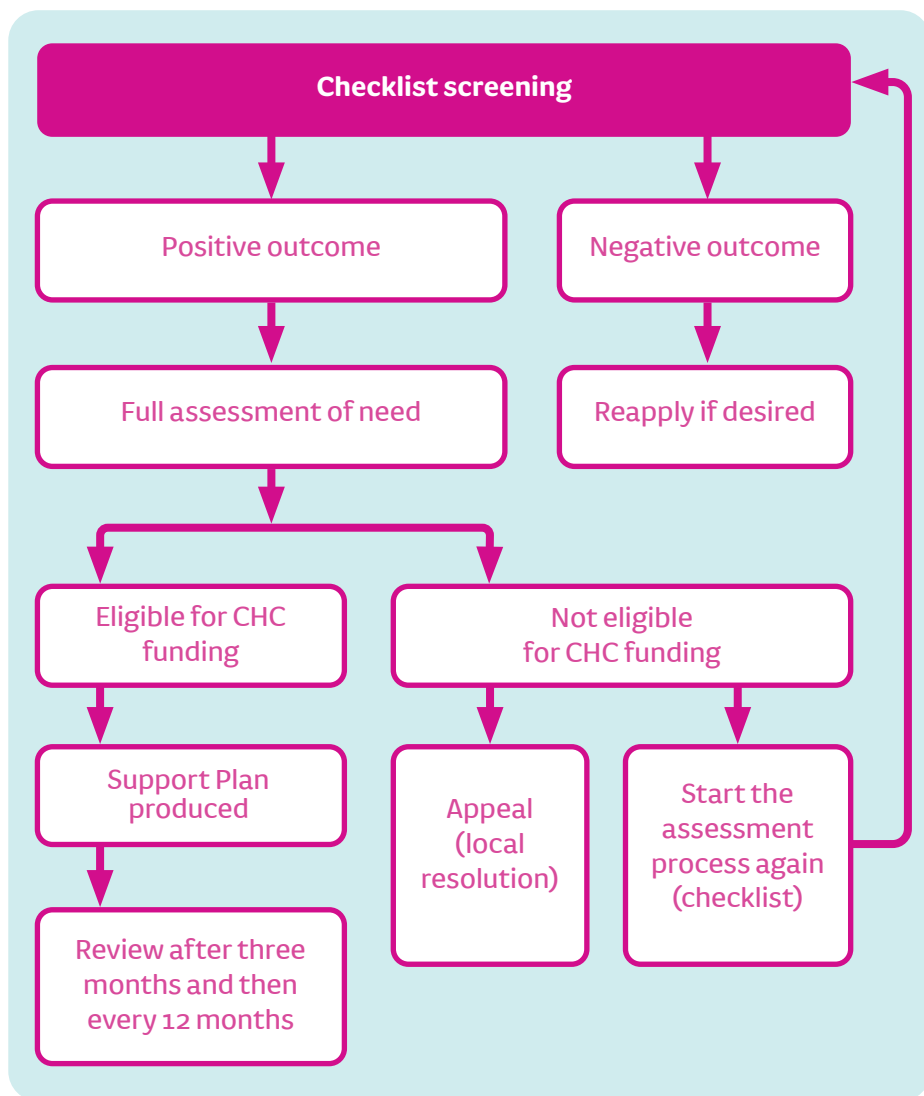
it is not their responsibility. But everyone is entitled to checklist screening, so try not to be put off.

It's important that you feel well supported both practically and emotionally throughout the CHC assessment process, so try to involve people who can support you when things feel difficult. You could talk to a friend or family member, your GP, the person's Social Worker, or someone from a carers' support group.

Dementia specialist Admiral Nurses can also offer support and guidance. To find out if there is a nurse in your area (for example, in a hospital or GP practice), visit dementiauk.org/get-support/find-an-admiral-nurse/

You can also speak to an Admiral Nurse about CHC or any other aspect of dementia on our free Helpline: call 0800 888 6678 (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email helpline@dementiauk.org. If you prefer, you can book a phone or video appointment in our virtual clinic at dementiauk.org/get-support/closer-to-home/

The CHC process at a glance





Glossary

Advocate

Someone who can offer knowledge, expertise and/or support, ensuring the person's needs are represented and their rights respected

Checklist

A brief evaluation of the person's needs, carried out by a health or social care professional, to see if they qualify for a full assessment of need

Coordinating assessor

The person who leads the full assessment of need

Decision Support Tool (DST)

The document that the assessor

uses to record information about the person's health needs during the full assessment

Domains

The 12 areas of need in the DST that the assessors look at

Fast-track assessment

A CHC assessment for people who may be approaching the end of life. This bypasses the checklist and full assessment of need

Full assessment of need

A detailed assessment of the person's health and care needs to decide whether they are eligible for CHC funding

Hospital-based Complex Clinical Care

The equivalent of CHC in Scotland – this only covers care in a hospital or a specialist NHS unit

Joint funding

Where the NHS and local authority jointly fund the person's care if they don't qualify for CHC

Local resolution

The first stage of appealing a CHC decision, where you can explain why you think the assessment was flawed

Multidisciplinary Team (MDT)

The team of health and social

care professionals who conduct the full assessment of need

Personal health budget

A budget that allows a person to decide how their CHC funding is spent

Primary health need

A need that means the majority of the person's care relates to their health, rather than social care

Social care

Practical support that helps people with daily living, such as home adaptations, home carers, access to day centres, and meals on wheels. This does not include their healthcare needs

Our Admiral Nurses can help

If you have any questions or concerns about dementia, you can call the dementia specialist Admiral Nurses on our Helpline for free.

Call **0800 888 6678** or email helpline@dementiauk.org

Opening hours:

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

If you would prefer to pre-book a phone or video call appointment in our virtual clinic, please visit

dementiauk.org/get-support/closer-to-home/

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: Nov 2021

Review date: Nov 2023

© Dementia UK 2021



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



dementiauk.org • info@dementiauk.org

Dementia UK, 7th Floor, One Aldgate, London EC3N 1RE
Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC047429.)