DementiaUK
Helping families face dementia

Guide to NHS continuing healthcare (CHC) funding

What is NHS continuing healthcare 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. 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' – in other words, a health need that requires more support than social services would usually provide.

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/

Wales: gov.wales/sites/default/files/publications/2019-04/continuing-nhs-healthcare-for-adults-in-wales.pdf

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

Northern Ireland: for more information on provision in your area, contact your local health and social care trust: nidirect.gov.uk/contacts/health-and-social-care-trusts

We have written this leaflet to guide you through applying for CHC, which is often a complex and stressful process. Our specialist dementia nurses, known as Admiral Nurses, are also here to help – please see Sources of support on p18.

For an at-a-glance guide to applying for CHC, please see our flowchart on p17.

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' in this leaflet). It can be carried out by a variety of health or social care professionals, as long as they are trained in its use. This includes GPs, social workers, district nurses and hospital nurses. It might take place face-to-face or by phone/video call.

The checklist is a brief assessment of the person's needs in 11 separate areas. These are:

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

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 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.

When is checklist screening not recommended?

There are some situations where it is not necessary to complete the checklist, for example if:

- It is clear that the person does not need CHC at this time (for example, if the health and social care they are currently receiving meets their needs)
- The person has short-term health needs or is recovering from a temporary condition that is expected to improve
- The local integrated care board (ICB) – which is responsible for managing health services in your area – has agreed that the person should have a full assessment for CHC without needing to complete the checklist first
- The person has a rapidly deteriorating condition and may be entering a terminal phase (approaching the end of life) – in this case, a 'fast-track application' should be used instead (see p8)

- The person was kept in hospital (sectioned) under the Mental Health Act, has been discharged and is now receiving a package of health and social care services known as section 117 aftercare
- The person has previously been unsuccessfully assessed for CHC using the checklist and there has been no change in their needs

If it is decided the checklist should not be completed, this should be recorded in the person's medical notes, along with the reasons.

However, if you disagree with the decision not to proceed with the checklist, do not be put off or feel that you are wasting your time. It is your right to ask for a checklist assessment, and you can request one directly from your local ICB. You can find its details at **nhs.uk/nhs-services/find-your-local-integrated-care-board** and ask to speak to the Continuing Healthcare Department.

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 it.

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 ICB in England, the local health board in Wales, or the health and social care board in Northern Ireland to remind them that you are waiting and ask for a clear timescale for the assessment.

If the person is being discharged from hospital, the full assessment should ideally take place once they have had some time to recover in a familiar setting (eg their home) or to settle into a new placement (eg a care home). However, in some circumstances assessments may be carried out in hospital.

The assessment is carried out by a multidisciplinary team of professionals (MDT) who provide information and evidence about the person's care needs. The MDT should include members of the person's health and social care team who are knowledgeable about their needs and have recently been involved in their care. It is helpful to keep a note of who is on the MDT and what their role is.

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 the checklist (see p3), plus 'other significant care needs to be taken into consideration' – ie needs that do not fit into any of the other domains. Each domain will be 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 individual health needs. For this reason, it is 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.

For our detailed guide to the DST assessment for a person with dementia, please see Sources of support on p19.

What are the assessors looking at?

When assessing the needs of the person with dementia, the coordinating assessor will look at the nature of their needs and whether they are complex, intense and/or unpredictable.

Nature: what specific needs the person has (which can include physical, mental health or psychological needs); how they are affected by those needs; and the type of support needed to manage them.

Intensity: the extent and severity of the person's needs.

Complexity: how their needs present, how they interact with each other, and the level of skill needed to manage these needs.

Unpredictability: how their needs fluctuate, which can make it challenging to manage them, including any risks if they do not receive the right care at the right time.

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 is 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 and for how long 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.

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.

Fast-track applications can be made for people who live in their own home or a care home and wish to remain there. They can also be made in other settings, such as hospices.

A fast-track application should be supported by a prognosis, where available – in other words, an estimate of how long the person may have to live. However, there

is no set time limit specifying how quickly their condition should be deteriorating or how soon they are expected to die to qualify for the fast-track process – it could be weeks, months, or even a year or more.

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 p11. Our specialist dementia nurses can also offer support, or you could contact Beacon – an organisation that provides free, independent advice on CHC. Please see Sources of support on p18-19 for contact details
- Contact the coordinating assessor to make sure you know when the assessment is happening and what they require from you

- Tell the assessor which professionals are involved in the person's care so they can consult them 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 p2). 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 are 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 walk off by themselves?
- 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 risk factors
- Seek the views of family and friends to support your case. They may have noticed examples of the person's needs that you have not
- 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

- Do not be afraid to ask for clarification at any stage if there is something you do not 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, CHC coordinating 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 is advisable that they are 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 is 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 dementia or a rarer dementia that has less common symptoms (see p14), it is 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 below.

What to do if you disagree with the CHC decision

If the person is not granted CHC funding, you can ask the local ICB 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 is 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 do not mean that the 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 (where dementia develops before the age of 65) 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 and active, and less frail than an older person. However, while their physical needs may be fewer, they may still have significant psychological/behavioural needs requiring specialist care and support.

For instance, they may lack insight into their condition and how it

affects them. This may mean they are reluctant to accept support from paid carers, which could lead to their family carers becoming physically and mentally overwhelmed. Or they may not remember that they have had to surrender their driving licence due to their dementia and attempt to drive their car.

Additionally, the person may have children at home who could be at risk, for example if they have lapses in concentration that affect their ability to carry out their parental responsibilities safely.

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 is strongly advised that you have an advocate who has specialist knowledge and experience of the condition. This could be a health or social care professional 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

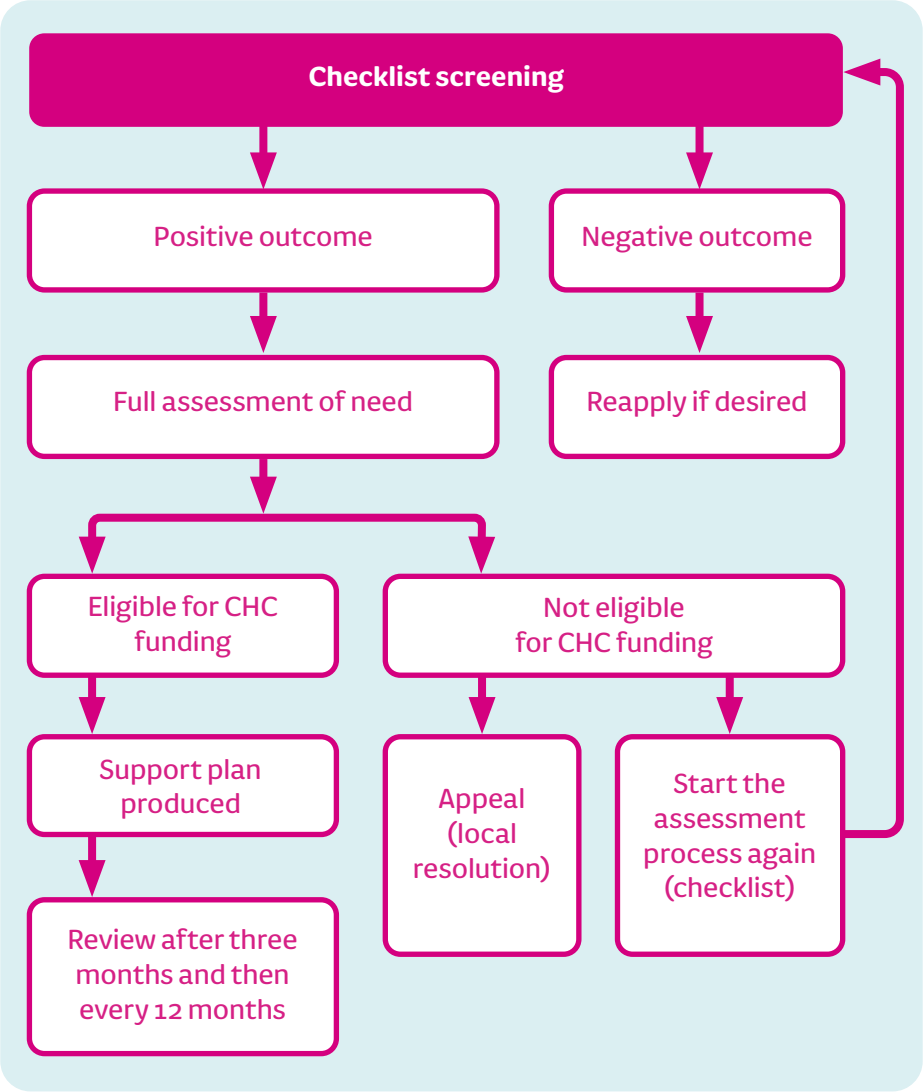
The CHC application process can be difficult emotionally. It can be upsetting to think in detail about the extent of the person's needs on their worst days, especially if caring for them has become routine and you do not often think about how challenging things can be. It might be hard to admit that you cannot always meet the person's needs yourself and you might worry 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.

You might also find that the person's health or social care professional tells you that they will not qualify for CHC and discourages you from applying; or that the coordinating assessor rejects the application despite your best efforts. Many people find the process frustrating and demoralising.

It is 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.

Our specialist dementia nurses can also offer support and guidance – please see Sources of support on p18 for more information.

The CHC process at a glance



Sources of support

To speak to a specialist dementia nurse about CHC 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**

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

Dementia UK resources

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

Changes in care: a stay in hospital
dementiauk.org/changes-in-care-a-stay-in-hospital

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

Considering a care home for a person with dementia
dementiauk.org/choosing-a-care-home

Financial and legal sources of support
dementiauk.org/sources-of-support-and-advice

Guide to completing the CHC decision support tool
dementiauk.org/CHC-decision-support-tool

Recognising the later stages of dementia and moving towards end of life care
dementiauk.org/end-of-life-care

Stages of dementia
dementiauk.org/stages-of-dementia

Other resources

Beacon – up to 90 minutes' free, independent advice on CHC
beaconchc.co.uk
Helpline: 0345 548 0300

NHS continuing healthcare checklist
gov.uk/government/publications/nhs-continuing-healthcare-checklist

NHS continuing healthcare decision support tool
gov.uk/government/publications/nhs-continuing-healthcare-decision-support-tool

Rare Dementia Support
raredementiasupport.org

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**

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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**
or scan the QR code.
Thank you.

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

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