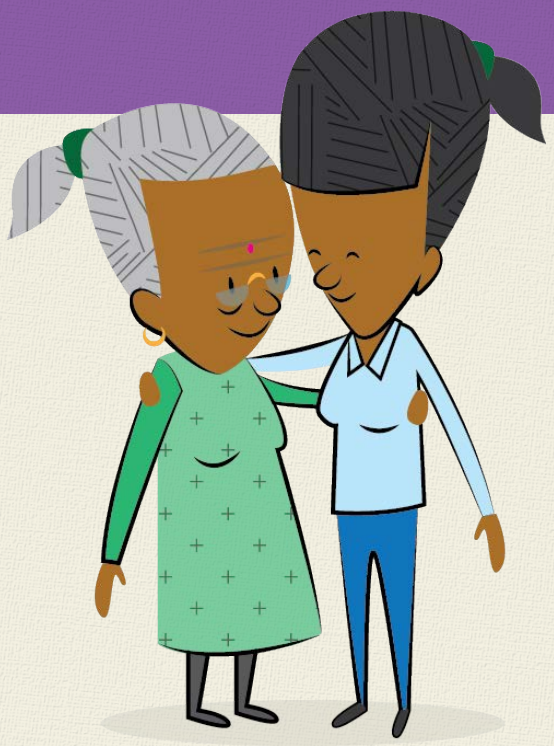
WHEN THEY GET OLDER .CO.UK

How to... Claim NHS Continuing Healthcare funding



One of a series of guides from When They Get Older

HELLO FROM US

Thank you for downloading this guide from WhenTheyGetOlder. We hope you find it useful.

NHS Continuing Healthcare (CHC) is designed to ensure that people with complex health needs have their care and nursing support fully funded by the NHS in England.

Making a claim for NHS CHC can be complex. Our regular contributor Roger D Burgess has been through this process himself and now offers independent and free support to others.

Roger has very generously prepared this guide to help you claim this full funding for people with specific complex and severe support requirements - known as "primary health needs".

Roger comments: "Continuing Healthcare funding is one of the NHS's best kept secrets; it is sometimes referred to as the 'Secret Fund'. Very few people are actually aware of the term or how to go about making an application. I hope this guide will help explain what you need to know and how to proceed. "

What is When they Get Older?

When They Get Older is an independent web service aimed at the families and friends of older people.

Our website and newsletter are packed full of valuable information, tips and tools to help you help your older family and friends as a caregiver, as well as offering advice from those who have been this way before and now share their experiences.

Visit our website to browse our extensive choice of articles and sign up for our regular newsletter to keep in touch with latest news around eldercare and hear about our latest articles and guides.

You can also tell us what you think about this guide, offer feedback on the service, and get in touch to tell your own story about caring for older people.

We look forward to your company.

IN THIS GUIDE

A guide to finding your way through the process of applying for NHS Continuing Healthcare (CHC) funding in England and Wales

For many it's surprising to discover that if a person has what is described as "primary health needs", the full cost of their care, including accommodation and food, is the responsibility of the **NHS** in England and Wales and **not** the local authorities.

This is **NHS Continuing Healthcare**. It covers 100% of the individual's care fees, including accommodation and food where appropriate, for people who require full-time care primarily for health reasons, and it is available in any setting - whether you are in a care home, in your own home, in a hospice or anywhere else.

NHS CHC is considered to be a duty, **not** a discretionary power.

The process for applying for NHS Continuing Healthcare is set out in The National Framework. This Framework and its associated tools are underpinned by legally binding Directions and Standing Rules (NHS England Guide for Health and Social Care Practitioners, September 2014 page 4 *Para 2.4*).

This process must be applied in all cases when

determining eligibility and there should be no deviation from its rules.

Providing false or misleading information is a now criminal offence under the 2014 Care Act. If you feel the information or reasoning being offered is inconsistent with the Framework, you may need to challenge it.

Who can apply for NHS Continuing Healthcare (CHC) funding?

Anyone over the age of 18 can ask for a NHS Continuing Healthcare assessment.

Tip. *There is no means testing and CHC is free from all budgetary constraints. Financial issues should not be considered as part of the decision on an individual's eligibility for NHS Continuing Healthcare.*

As the funding is not means-tested, there is no need for anyone to question you on finances or property assets when making an application for CHC.

It is important that the process of considering and deciding eligibility does not result in any delay to treatment or to appropriate care being put in place.

How do I access the NHS Continuing Healthcare service?

According to a Department of Health (DH) Equality Analysis, (revised 2012), the NHS has a duty to promote Continuing Healthcare at key locations. For example, you would perhaps expect to see this information freely available in your surgery waiting rooms, hospitals, health centre, care and nursing homes, etc. If you can't see it, ask for it.

Tip. In the majority of cases (but not all), when a person has been hospitalised, it is preferable for eligibility for NHS Continuing Healthcare to be considered after discharge, when the person's ongoing needs should be clearer.

To access the NHS CHC service, individuals need to be screened. You can ask a doctor, social worker or any NHS professional to help start the process. They may try to discourage you from making an application if they're not certain of a successful outcome, but if you believe someone may have the right level of need, don't be deterred.

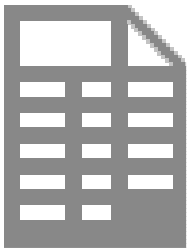
What is a “primary health need”?

Central to the application for funding is the definition of a primary health need.

This is determined through a **Check List** that looks at a combination of factors:

- Nature: the characteristics and type of the individual’s needs and the type of interventions required to manage those needs.
- Intensity: the extent and severity of the individual’s needs and the support needed to meet those needs, including sustained/ongoing care.
- Complexity: how the individual’s needs present and interact and the level of skill required to monitor the symptoms, treat the condition and/or manage the care).
- Unpredictability: how hard it is to predict changes in an individual’s needs that might create challenges in managing them, including risk to the individual’s health if adequate and timely care is not provided.

Each of the above characteristics may in combination or alone demonstrate a primary health need because of the quality and/or quantity of the care required to meet the individual’s needs.



Step 1 The Check List

The first step is the screening process, known as the Check List**,** available online or ask a member of NHS staff.

Everyone applying for funding will be required to take part in this stage unless there are special reasons for an individual to be fast tracked through to NHS CHC.

Tip. Always ensure that a family member, friend or someone acting for the patient is in attendance. They do have a right to be there and to be involved in the process, to ensure that a fair assessment is provided.

Needs score requirements for the Check List

You will need to have a copy of the Check List at hand to work through this section.

To be put forward for a full assessment for NHS Continuing Healthcare a person will require either:

- 2 or more needs in column A, or
- 5 or more needs selected in column B, or
- 1 in column A and 4 in column B, or
- 1 domain selected in column A in any box marked, with an asterisk (*) carrying a priority

If the individual meets these criteria and a positive recommendation has been agreed, then the next stage is a full Continuing Healthcare assessment for that person.

Step 2 The Multidisciplinary Team Meeting

The second step is a meeting of the **Multidisciplinary Team (MDT),** who will make a recommendation to the Clinical Commissioning Group on whether the application should be accepted or not.

What is the MDT meeting?

The MDT meeting brings together professionals from different NHS disciplines, eg doctor, nurse, social worker, occupational therapist etc. to discuss the application.

It must include a minimum of two (decision-making) professionals from different NHS disciplines.

This is when the very important **Decision Support Tool (DST)** is completed, and an informed decision taken as to whether or not a person does have a primary health need.

The MDT recommendation should be accepted by the Clinical Commissioning Group, as the MDT members are the key decision makers. *Page 45 Para 153* of the (revised) Framework explains that only in exceptional circumstances and for clearly articulated reasons should the MDT's recommendation not be followed.

The individual who is making the application and/or their representative do have a right to be involved in the decision-making process, and should always be encouraged to attend.

It is crucial that the views of the individual are

represented at the MDT meeting, or the whole process could be seen as unbalanced.

What is a Decision Support Tool (DST)?

A Decision Support Tool (DST) is a document on which decisions are supported.

It consists of 12 Health Needs Domains, which are systematically discussed in order to assist the Multidisciplinary Team come to a multilateral decision as to whether or not an individual has a primary health need.

Needs score requirements for the DST

To understand the score requirements, you will need a copy of the DST. Find it online, or ask an NHS member of staff.

To obtain eligibility at this point, the person will need:

- One "priority", or two or more "severe needs". Then eligibility would be expected.

- However, there are many factors to be considered, so several "highs" and a number of "moderate" needs combined, or any other combination, could still produce a qualifying result, but it could become less likely.

*Tip. It's important to make sure the right need levels are noted on the DST, or you may find that an individual's care needs have been given lowers needs scores, rather than the more appropriate higher scores. Awarding lower scores ignores the fact that the scoring system has been designed as an **upwards** scoring system.*

Note that the DST is not an assessment tool in its own right. It is a tool, which is why it should be completed at the MDT meeting and should not be altered once it is complete.

This point is very often misunderstood, and can be missed by NHS CHC staff, who may suggest they take the DST away on the basis that they require more information.

Not only is this procedure wrong, but it is also contrary to the National Framework, because the CCGs should not make decisions on eligibility in the absence of an MDT recommendation (Revised National Framework *Page 45 Para 155*).

Unless the correct procedures are followed, the result can be that eligible cases for NHS Continuing Healthcare are refused unnecessarily.

Tip. It is wise to ask immediately for a copy of the DST for your own records. (If the assessment is taking place in a care home or NHS office, there may be a photocopier nearby).

What is a Coordinator's role?

Prior to the meeting, the appropriate Clinical Commissioning Group should allocate a Coordinator who will be responsible for advising on all aspects of the CHC process and inform individuals and/or their representatives of the date, place and time of their MDT meeting, so that they can prepare their case.

The Coordinator should provide advice on access to advocates where necessary, and support the individual

and those representing them to play a full role in the eligibility process. Points for the Coordinator to remember can be found on *page 14* of the NHS England "Guide for Health and Social Care Practitioners 2014 edition".

In theory the Coordinator should be impartial. *Page 115 para 20.2* of the (revised) Framework explains how there should be an appropriate separation between the Coordinator's role and those making decisions.

Some have asked whether this means that the Coordinator cannot actually be a member of the MDT. However, *page 119 Para 25.1* of the revised Framework states that "It is recognised that in many situations this would raise significant practical difficulties in convening a properly constituted MDT".

This would then leave the individual with an un-constituted MDT**.** According to the Universal Dictionary the word "constitute" means to give legal form to an assembly. Unfortunately it seems the National Framework can be highly ambiguous, which serves to increase confusion.

What happens before the MDT meeting?

All the necessary assessments and investigations into the patient's medical history/condition, daily records etc. should be carried out and completed before the MDT meeting takes place.

There is normally a 28-day timetable from the Check List being received to allow for this (Revised National Framework *page 46 Para 162*).

This whole process has been designed to be robust, consistent and, above all, transparent from the outset.

You may ask the Clinical Commissioning Group for copies of any documentation that will be relied on during the course of the meeting and they are obliged to provide them.

If you do ask for any documents, ensure that you receive them in plenty of time prior to the meeting, so that the individual concerned and/or their representatives have time to read and fully understand their content.

It would always be advisable to prepare a copy of your own supporting evidence to take with you to the MDT meeting.

***Tip**. It is also a good idea to have someone at the MDT meeting taking minutes/notes, or use a good quality voice recorder if it can possibly be arranged.*

Expressing concerns at the meeting

You may want to observe the wording which is sometimes used in the assessment notes. For example a person with severe dementia or serious mobility problems may be described in the assessment notes as "needing assistance" with things like continence, eating etc. – because they cannot do anything for themselves.

However, using words like "needing assistance" implies that a person is able to manage, and just needs a bit of help here and there, when in fact the truth of the matter could be that the person is "entirely dependent", and "wholly vulnerable"**,** and needs **"**full intervention"**.**

If you feel that the assessment is not being discussed correctly, it is important not to be distracted from making your case at this time, even if it seems difficult to interrupt the conversation during the meeting.

Where an individual and/or their representative expresses concern about any aspect of the MDT or DST process, the CCG coordinator should discuss this matter with them and seek to resolve their concerns.

Where the concerns remain unresolved, these should be noted within the DST so that they can be brought to the attention of the CCG panel, if a panel is used.

Tip. If you have concerns about anything at the MDT meeting make sure they are written down – very clearly – in the DST.

Your concerns must at some point be noted. Don't wait until a local dispute resolution meeting for this to happen. Instead, get it done at the MDT assessment.

Before the MDT meeting ends, make sure you ask the lead assessor to include *all* your concerns – in writing – in the DST. (Better still - make sure the assessor does this throughout the meeting.) It would be wise to refuse to leave the meeting until this is done.

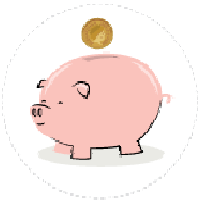
The completed DST

When you eventually receive your final draft of the Decision Support Tool (DST), usually through the post, read it carefully. It may be that some changes have taken place and this may mean the difference between

someone qualifying for CHC eligibility, or actually being refused it.

You may require some evidence in order to challenge a final DST draft. Asking MDT members to sign minutes/notes is one way. However, you may need to produce copies of any recordings - just something to consider.

Step 3 Ratification



The completed DST and your supporting evidence (where applicable) will now go before a Clinical Commissioning Group board or panel. Some CCGs could use as many as five core members, whilst others may have fewer.

However, no decision should be taken unilaterally by the CCG at this point. The purpose of the board or panel is to ratify a decision that has already been made by the Multidiscipline Team and recorded on the DST - especially when a case for eligibility has been clearly established - or perhaps to consider the case in more depth when there is a borderline situation.

When might an MDT decision not be ratified?

There are “exceptional circumstances” in which a CCG or panel might not accept an MDT recommendation regarding eligibility for NHS continuing healthcare.

In most cases, exceptional circumstances would only occur when the MDT team has not carried out its job function correctly.

The National Framework, page 130 Para’s 39.1 – 39.2 explains:

39.1 Eligibility recommendations must be led by the practitioners who have met and assessed the individual. Exceptional circumstances where these

recommendations may not be accepted by a CCG include:

- *where the DST is not completed fully (including where there is no recommendation)*
- *where there are significant gaps in evidence to support the recommendation*
- *where there is an obvious mismatch between evidence provided and the recommendation made*
- *where the recommendation would result in either authority acting unlawfully.*

39.2 In such cases the matter should be sent back to the MDT with a full explanation of the relevant matters to be addressed. Where there is an urgent need for care/support to be provided, the CCG (and local authority where relevant) should make appropriate interim arrangements without delay. Ultimately responsibility for the eligibility decision rests with the CCG.

There is a fairly narrow window for a CCG panel to overturn an MDT's recommendation. (Anyone involved in an individual funding request (IFR) process would fully understand.)

Even so, if the CCG panel has any concerns about the way in which the MDT has expressed its views, it is required to go back to the MDT to clarify the position.

A decision to refuse an individual CHC where a positive recommendation has been made by the MDT should only be made after a further dialogue with the MDT. The purpose of that dialogue is to enable the CCG panel to understand whether this is one of those rare cases with exceptional circumstances, where they would be entitled to depart from a positive recommendation.

It should be always be transparently clear that all needs,

even well-managed needs, are still needs. *DST page 7 Para 27* states:

Only where the successful management of a healthcare need has permanently reduced or removed an ongoing need will they have any bearing on CHC eligibility.

What happens if you fail to achieve eligibility?

If for whatever reason an individual fails to achieve eligibility for NHS Continuing Healthcare, they can appeal to the CCG and ask for the case to be reviewed. This is known as a "local review process at CCG level".

Always ensure that a family member or representative is in attendance. If you are unable to resolve the issue and all local dispute procedure has failed to provide a mutually acceptable resolution, the person can apply to their regional NHS England body and ask for their case to be reviewed.

The case will then go before an "Independent Review Panel" (IRP). Again the person and/or representative would expect to attend and provide own supporting evidence in much the same way as at the MDT meeting. Individuals may not automatically be invited, so always ask. You should find them very accommodating, and the person does have a right to have an involvement in these proceedings.

Remember this whole process is based on transparency.

If all the above options have failed, and you still feel that the applicant has been treated unfairly you can refer the case to the Parliamentary & Health Service Ombudsman. Telephone 0345 015 4033.

Losing funding

Unfortunately, achieving funding is not necessarily the end of the story.

More than 7000 people whose care and nursing fees had been covered by the NHS have had their funding cut, according to an investigation by the Daily Telegraph (May 2019 - register to read full article).

The findings come from just 71 of England's 119 Clinical Commissioning Groups, meaning the figures overall could be much higher.

NHS documents are reported to say that key to making savings is a reduction in the number of people eligible for NHS Continuing Healthcare and the average cost of the care package.

This is very surprising, given that an NHS Continuing Healthcare status can only be removed if an individual's care needs have either been permanently reduced or removed.

When someone living with dementia, for example, becomes eligible for NHS CHC, the chances of them recovering to the extent that they can manage with a reduced care package, or, no longer require their care package, are extremely remote – probably non-existent.

Conclusion

Many people have not heard about NHS Continuing Healthcare funding, whilst others have been put off applying because they do not have the necessary help needed to navigate the CHC system, which can sometimes be a daunting and complex issue, especially if procedures are not followed correctly.

I hope that the information provided here should help to give a clearer understanding of the process.

If the correct procedures are followed and an individual does have a “primary health need”, then they should become eligible for 100% NHS funding.

If you know of someone who may have a primary health need and they are currently paying for any part of their care including accommodation, help them to make an application for NHS Continuing Healthcare (CHC).

After all, it is part of their basic legal rights under current NHS policy.

Resources

NHS England information about NHS Continuing Healthcare
https://www.england.nhs.uk/healthcare/

National Framework
https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

Checklist
https://www.gov.uk/government/publications/nhs-continuing-healthcare-checklist

Decision support tool
https://www.events.england.nhs.uk/upload/entity/30215/nhs-continuing-healthcare-decision-support-tool-october-2018-revised-2.docx

Independent Review Panels
https://www.england.nhs.uk/wp-content/uploads/2014/05/irp-leaflet.pdf

NHS-funded advice site on NHS Continuing Healthcare
https://www.beaconchc.co.uk/

Reclaiming care fees

For more information about reclaiming care fees, refer to Refreshed NHS Redress Guidance, this document is available on-line Gateway Ref: 03261. Published 1 April 2015.

Note. Deadlines for NHS CHC were put in place in 2012 and

back-dated claims before 31st March 2013 will not be accepted.

About information available from When They Get Older

Please refer to our terms and conditions regarding information available on the When They Get Older website. We offer supportive guidance where we can but do not take responsibility for decisions and actions taken by anyone using that information. While we have checked downloads and links we cannot guarantee that these continue to remain safe, so do check them yourselves.

Need more help?

For further free advice contact the author of this guide, Roger D Burgess at rogerburgess262@btinternet.com.