Factsheet 20

NHS continuing healthcare and NHS-funded nursing care

November 2017

About this factsheet

This factsheet explains what NHS continuing healthcare is; how the NHS decides whether you are eligible for it and what to do if unhappy with an eligibility decision.

It explains NHS-funded nursing care – a weekly payment made to nursing homes by the NHS, towards their costs of providing residents with nursing care.

The following factsheets may also be of interest:

6 *Finding care at home*

10 *Paying for permanent residential care*

22 *Arranging for others to make decisions on your behalf*

37 *Hospital discharge*

39 *Paying for care in a care home if you have a partner*

41 *Getting care and support*

76 *Intermediate care and reablement*

The information in this factsheet is applicable in England. If you are in Scotland, Wales or Northern Ireland, please contact Age Scotland, Age Cymru or Age NI for their version of this factsheet. Contact details can be found at the back of this factsheet.

Contact details for any organisations mentioned in this factsheet can be found in the Useful Organisations section.

Contents

1 Recent developments

- NHS-funded nursing care single band rate, for year starting 1 April 2017, is £155.05 a week. If you moved into a nursing home before 1 October 2007 and were on the high band at that time, it is £213.32 a week.

2 Continuing care terminology

Health and social care professionals use these terms to describe support from the NHS and local authority (LA) social services department.

Continuing care describes on-going care that meets physical, mental health and personal care needs arising from a disability, accident or illness.

Continuing NHS and social care is on-going care involving free NHS and means-tested social care services. It may be called a '*joint package of care*'.

NHS continuing healthcare – a complete package of on-going NHS and social care support, arranged and funded by the NHS.

Note

Residential home refers to a residential care home, **nursing home** to a care home providing nursing care and **care home** refers to both as appropriate.

NHS continuing healthcare is referred to as **NHS CHC, PG** refers to Practice Guidance and **LA** to local authority.

3 NHS continuing healthcare

Background

If you have complex needs, the boundary between NHS and social care responsibilities is not always clear. Services provided by the NHS are free whereas those arranged by social services are means-tested. Decisions about who has overall responsibility for your care can have significant financial consequences.

In the early 1990s, the Parliamentary and Health Service Ombudsman received complaints about local criteria and processes used in making NHS CHC eligibility decisions. The legality of some eligibility decisions was challenged in the courts. In October 2007, the Department of Health introduced a *National Framework for NHS continuing healthcare and NHS-funded nursing care* to standardise how decisions are reached.

3.1 What is NHS continuing healthcare?

NHS CHC is a package of care arranged and funded solely by the NHS in England if you are aged 18 or over, to meet physical or mental health needs arising because of a disability, accident or illness.

You can receive NHS CHC in any setting. Whether you live at home or a residential setting such as a care home, the NHS funds a health and social care package, or a care home place to meet your assessed health and personal care needs.

3.2 How is NHS CHC eligibility decided?

NHS CHC eligibility decisions are '*needs based'* and rest on whether your need for long term care is primarily health related because of complicated, intense or unpredictable healthcare needs. This is called having a **'primary health need'.**

Having a particular diagnosis does not determine eligibility - people with the same health condition can have very different needs. However staff responsible for making an eligibility recommendation should indicate they have information about, or an understanding of, your underlying condition(s) and their fluctuating nature.

The term '*primary health need*' comes from a 1999 Court of Appeal case known as *Coughlan*. The decision stated there was a legal limit on nursing care assistance a LA could provide. It is limited to nursing care which is:

- merely incidental or ancillary to the provision of the accommodation which a LA is under a duty to provide (the **quantity test**), and
- of a nature that a social services authority can be expected to provide (the **quality test**).

Assessors consider if four key indicators of your needs, in combination or alone, demonstrate a '*primary health need*' because of the quantity and/or quality of care required to manage them. The indicators are:

Nature - the type and features of your needs, be they physical, mental or psychological, and the kind (quality) of interventions required to manage them.

Intensity - this relates to both the extent (quantity) and severity (degree) of your needs and support required to meet them on an on-going basis.

Complexity - how different needs present and interact to increase the knowledge and skills staff need to a) monitor your symptoms b) treat any multiple conditions you have, along with the interaction between them, and how this affects management of your care.

Unpredictability - the degree to which unexpected changes in your condition mean your needs fluctuate and create challenges because of the timeliness and skill mix required to manage them. It affects the level of monitoring required to ensure you and others are safe and the level of risk to you or others, unless you receive adequate and timely care. Someone with unpredictable healthcare needs is likely to have either a fluctuating, unstable or rapidly deteriorating condition.

Tools used to inform an eligibility decision seek to identify these characteristics.

3.3 What is the National Framework?

The *National Framework for NHS continuing healthcare and NHS-funded nursing care* aims to minimise local interpretation and improve transparency and consistency when deciding eligibility for NHS CHC by:

- setting out clear principles and processes staff *must follow* to establish NHS CHC eligibility. See sections 4, 5, 7 and 8.
- providing a *national* process, guidance and tools *staff must use* to support decision-making – the **Checklist, DST** and **Fast Track Tool**
- *p*roviding *common* paperwork staff *must use* to record evidence that informs decision-making
- clarifying the interaction between assessment for NHS CHC and for NHS-funded nursing care in nursing homes.

The Framework includes **general guidance,** numbered **Practice Guidance (PG)** explaining what staff are looking for and must record to support an eligibility recommendation and copies of the **Tools.** There are **appendices,** including one describing procedures for running an Independent Review Panel if you wish to challenge an eligibility decision.

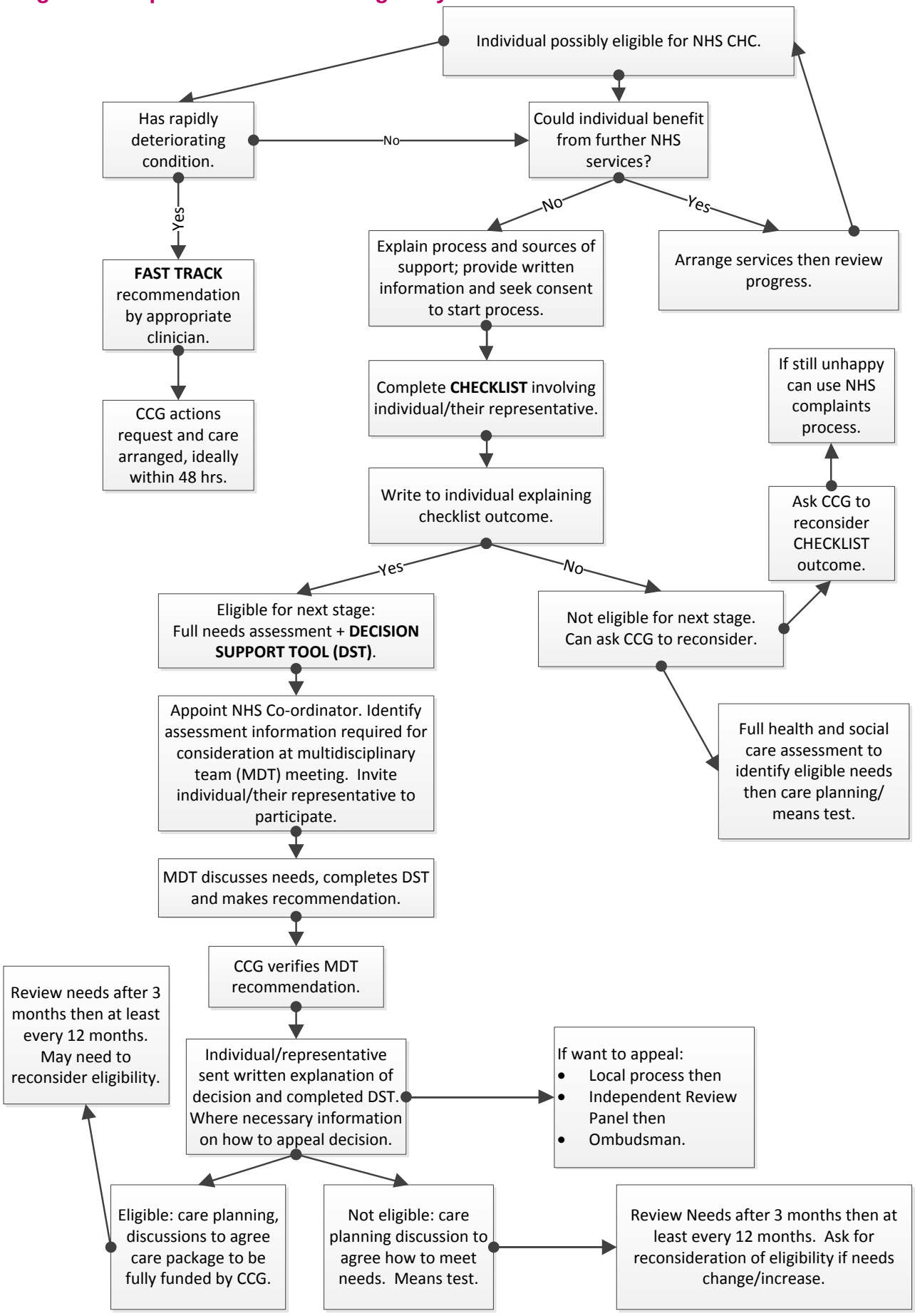
The guidance, appendices and tools are at www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

Understanding the decision making process

The chart on page 7 outlines the process. To help you, your family or representatives navigate and understand the decision-making and appeals process, you can contact Beacon. They provide up to 90 minutes free independent advice funded by NHS England.

For a basic guide for the public see www.gov.uk/government/publications/nhs-continuing-healthcare-and-nhs-funded-nursing-care-public-information-leaflet

Stages in the process to decide eligibility for NHS CHC



3.4 Who decides NHS CHC eligibility and funds your care?

Your local Clinical Commissioning Group (CCG), made up of local GP practices, manages the NHS CHC process for patients registered with its member practices. It makes eligibility decisions and arranges and funds your care package, unless you choose a personal health budget (see section 9.6). A CCG's budget constraints must not influence eligibility decisions. Each CCG has a manager responsible for NHS CHC.

To identify your CCG, enter your GP practice postcode at www.nhs.uk/Service-Search/Clinical-Commissioning-Group/LocationSearch/1

3.5 Routes to reaching an NHS CHC decision

In most cases, staff follow these steps:

- the type and level of your needs prompt them to apply the **Checklist**
- a **positive Checklist** triggers a full assessment of your needs
- a multi-disciplinary team (MDT) uses assessment information to complete the **DST**, informing their eligibility r*ecommendation* to the CCG
- CCG makes the final eligibility *decision* and only in exceptional circumstances should it not follow the MDT recommendation.

If there is a clear need, staff can recommend a full assessment without completing the Checklist. You have a right to challenge a decision:

- if a full assessment is not offered after completing the Checklist, or
- after a full assessment and receiving a final eligibility decision.

If you have a rapidly deteriorating condition and appear to be reaching the end of your life, staff can use the '**Fast Track Tool'** to recommend you move quickly onto NHS CHC (see section 7).

3.6 When should eligibility be considered?

A CCG must take reasonable steps to ensure it conducts an NHS CHC assessment where it appears there may be a need for such care. Not everyone with on-going health needs is likely to be eligible. Ask NHS or social care staff if they have *considered if you may be eligible* when:

- your condition is rapidly deteriorating and you may be approaching the end of your life. You may be eligible for 'fast tracking'
- staff are planning your hospital discharge and your long term needs are clear. If possible, a full assessment should take place away from a busy acute hospital ward
- intermediate care, rehabilitation or other NHS services are ending and no further improvement in your condition is likely

- your physical or mental health deteriorates significantly and your current level of care, at home or in a care home, seems inadequate
- you live in a nursing home and staff review your nursing care needs. This should happen at least annually and include consideration of NHS CHC eligibility.

Note
If staff propose a permanent place in a *nursing* home, they must have considered your NHS CHC eligibility before deciding NHS-funded nursing care needs. If you need a full assessment and completion of the DST, it should take place away from a busy hospital ward and ideally before you move into the nursing home.

4 National Framework principles

4.1 Person-centred approach involving you and your carers

Staff should say if they think you may be eligible for NHS CHC and make arrangements to start the process. They should ensure you, your family or representative understand how they decide eligibility and receive information and advice about the process in a format you can understand. This includes asking about hearing or visual difficulties or language preferences and ensuring you have support to participate. Staff should take account of how you see your needs, how they affect you and might be managed.

You should know about key milestones and timeframes they are working to and be alerted to delays as they occur.

You can, if you wish, ask a family member or representative to support you throughout the assessment process. Staff should give reasonable notice of key events, such as dates to complete the Checklist or DST, so your representative can arrange to be there.

The Framework PG 4 fully explores key elements of a person-centred approach to NHS CHC.

Note
A note to para 44 of the Framework states the term '*representative*' is intended to include any friend, unpaid carer or family member who is supporting you in the process as well as anyone acting in a more formal capacity (for example, a welfare deputy, an attorney or an organisation representing you).

4.2 Deciding if you have mental capacity to give consent

Staff must ask at the outset if you agree to be considered for NHS CHC and be clear whether this applies to a particular stage or the whole process. They must ask if you agree to staff sharing necessary personal information about you with individuals or organisations likely to be involved in your care and explain who this could be.

You can refuse to give or withdraw consent to be considered for NHS CHC at any stage. If you do, staff should try to find out why and address your concerns. They must explain a LA cannot take responsibility for meeting needs found to be an NHS responsibility.

If staff are concerned about your ability to consent to an assessment or sharing of personal information, they must apply a two stage test to decide if you have capacity to make such decisions:

Stage 1 Is there an impairment of, or disturbance in, the functioning of your mind or brain? If so,

Stage 2 Is the impairment or disturbance sufficient that you lack the capacity to make the *particular* decision that is required?

You are considered unable to make the decision if the answer to these questions is '*yes*' and you are unable to do one or more of the following:

- understand information given to you
- retain that information long enough to be able to make the decision
- weigh up the information and make a decision
- communicate your decision – talking, sign language or muscle movements such as blinking or squeezing a hand are acceptable.

Staff must take all practical steps at all stages to help you make a decision yourself. If staff agree you lack capacity to give consent, they must check if there is an attorney able to act on your behalf on health and care matters under a Lasting Power of Attorney (LPA) or a court appointed personal welfare deputy. A partner, family member or 'third party' can only give consent on your behalf if appointed to do so.

If there is no one, the person leading your assessment is responsible for making a '*best interests*' decision on your behalf. When doing this, they must consult you and those with a genuine interest in your welfare, usually including family and friends. They should record their decision with reasons in your notes. If there is no one to consult, they must arrange an Independent Mental Capacity Advocate to represent you.

Note
An attorney or deputy for property and financial affairs does not have the authority to give consent or make health and welfare decisions. See Framework PG 7.3.

4.3 Confidentiality and sharing information

Staff must share information with an attorney under a registered LPA (health and care) or a Court Appointed Deputy (personal welfare). Family members or carers should have information relevant to their caring role.

Sharing information in the absence of formal authority

There are circumstances where it is acceptable for a third party, who assumes responsibility for acting in a person's *'best interests'* but does not have formal authority of an LPA or Deputyship on health and care matters, to legitimately request and receive information.

When deciding whether to share personal/clinical information with a family member or someone chosen to represent you, the information holder must act within the following principles:

- any decision to share information must be in your '*best interests*'
- only share information necessary to act in your '*best interests'*.

Subject to these principles, staff should not unreasonably withhold information and you can expect them to share information with:

- someone making care arrangements who requires information about your needs to arrange appropriate support
- someone with a LPA (Finance), Deputyship (Finance), or registered Enduring Power of Attorney seeking to challenge an eligibility decision, or other person acting in your *'best interests'* to challenge a decision.

5 Process for reaching an eligibility decision

5.1 Apply the Checklist

The Checklist helps staff identify who should have a full assessment to determine NHS CHC eligibility. The threshold is set deliberately low, so all who require full assessment have this opportunity.

The assessor should ask if you want to be involved when they complete the Checklist and to have a family member, advocate or other representative with you.

Note
A decision to apply the Checklist does not imply you should or will be eligible for either a full assessment or NHS CHC. Seeing the Checklist beforehand helps you and your family prepare for, and contribute, when staff complete it.

Who can apply the Checklist?

As far as possible, the assessor should be someone who assesses or reviews care needs as part of their day-to-day work (doctor, nurse, other health professional or social worker) and is familiar with the guidance and detailed DST. The CCG or LA decides who can apply the Checklist in a hospital or non-hospital setting.

Applying the Checklist as part of hospital discharge

If you are about to be discharged from an acute hospital and have significant health and care needs, before applying the Checklist, staff should consider, if you have the potential to improve if they offer short term NHS-funded services such as rehabilitation or intermediate care in a community hospital or other setting. If they offer additional services, staff should apply the Checklist at the end of this period, when your needs are clearer.

Being on a busy hospital ward can cause disorientation or atypical behaviour if you have dementia. Considering if you might benefit from intermediate care, before applying the Checklist, may be more appropriate and better reflect your long term needs.

If staff complete a Checklist on an acute hospital ward and it indicates a need for a full assessment, they may propose intermediate care services before moving to this stage. Doing this can show if further improvement is possible and enable staff to make a reasonable judgement about your long term needs away from the hospital setting.

Should staff need to refer you to social services for ongoing support following an appropriate assessment, the paperwork should say if you have been considered for NHS CHC and the outcome.

For information about intermediate care see factsheet 76, *Intermediate care and reablement*.

Applying the Checklist if you live in a care home

The CCG may have a protocol for completing the Checklist for care home residents. If it does not and your care needs change or increase significantly, the home can ask the CCG CHC team to complete one.

Applying the Checklist if you live in your own home

If NHS or social care staff think you may be eligible for NHS CHC, they may be trained to complete the Checklist. If they are not, they should contact the CCG CHC team.

Can a family member complete the Checklist?

A family member cannot complete Checklist but they can contact the CCG CHC team to explain why they think someone should visit you to complete one.

Completing the Checklist Tool

The Checklist Tool and DST use the same **12 '*domains*' or '*areas of need*'** (see section 5.3). The Checklist tool has three columns for each domain. Each column has a description representing a level of need: Column A represents **'high' needs.** Column B represents **'moderate' needs**. Column C represents **'no and low' needs**.

The assessor completes the Checklist by choosing the description most closely matching your needs. They must take account of well-managed needs and any needs expected to increase over the next three months. The Checklist aims to be relatively quick and straightforward to complete but staff must have evidence to back up their choices.

Checklist outcome

You require a full assessment if the Checklist shows:

- two or more domains rated as **high** or
- five or more domains rated as **moderate or**
- one domain rated as **high** and four rated as **moderate** or
- **high** in one of four priority DST domains and any level of need in other domains.

Staff should share the outcome with you and your representative as soon as they can and forward a copy of the completed Checklist. You should have enough information to understand the reasons for their decision. It is good practice for staff to record the decision in your notes.

A positive Checklist

A positive Checklist means the CCG should undertake a full assessment. In most cases, it should take no more than 28 days between the CCG receiving the Checklist and reaching an eligibility and funding decision. CCG staff should tell you, and as appropriate your family, the timescales they are working to and if it is likely to take longer.

While awaiting a decision, your care remains an NHS responsibility but you may have to pay for support. If the CCG unnecessarily takes longer than 28 days and you are found eligible and have funded your care beyond 28 days, you can apply for a refund.

A negative Checklist

A negative Checklist indicates no need for a full assessment. The CCG must send a written explanation of the decision, explaining your right to ask them to reconsider it. In doing so, they must take account of additional information you or your representative provide. You should receive a written response of their findings, telling you of your right to use the NHS complaints procedure, if unhappy with their decision.

If the CCG does not revise its decision

You should have an assessment of your health and social care needs to identify your needs and eligibility for further NHS and social care support.

5.2 Undertake a full multi-disciplinary needs assessment

On receiving a positive Checklist, the CCG appoints a case co-ordinator. They must ensure you and your representative understand the process, participate as much as you can and wish to, and keep you informed until there is an eligibility decision. As with the Checklist, completing this stage away from an acute ward is likely to better reflect your needs.

The co-ordinator must gather up-to-date information about your physical, mental health and social care needs, inviting contributions from relevant health and social care professionals, including staff caring for you at the time and those with direct knowledge of your needs but not currently caring for you. This can be a consultant, specialist nurse or community mental health team. Each should consider your views, assess your needs where appropriate and prepare a report including reasons for their statements and observations, and findings from risk assessments.

5.3 Completion of Decision Support Tool (DST)

The DST has 12 '*domains*' or areas of need that must be considered:

1. Behaviour ►►
2. Cognition ►
3. Psychological and emotional needs
4. Communication
5. Mobility ►
6. Nutrition – Food and Drink ►
7. Continence
8. Skin including tissue viability ►
9. Breathing ►►
10. Drug therapies and medication: symptom control ►►
11. Altered states of consciousness ►►
12. Other significant care needs to be taken into consideration ►

Each domain has descriptions of between four and six levels of need:

'No need' 'low' 'moderate' 'high' 'severe' 'priority'

The different levels reflect changes in the nature, intensity, complexity or unpredictability of the need.

►► indicates this domain goes up to priority level of need

► indicates this domain goes up to severe level of need

The co-ordinator selects a multi-disciplinary team (MDT) to complete the DST, arranges a meeting to complete it and invites you or a representative to attend. They should give reasonable notice of the date so your representative can arrange to attend if they want.

At the meeting, the MDT discuss assessment reports, evidence submitted by you or your representative and use their professional judgement to complete the DST, which informs their *recommendation* to the CCG.

Multidisciplinary team (MDT)

A MDT is defined as:

- two professionals from different health professions, or
- one professional from a healthcare profession and one responsible for assessing individuals for community care services.

As a minimum, an MDT can be two professionals from different healthcare professions, but the Framework makes clear it should usually include both health and social care professionals, knowledgeable about your health and social care needs. The DST should record names, job titles and signatures of MDT members.

Your and your representative's role at a MDT meeting

The co-ordinator should identify any support you or your representative need to participate, explain the meeting format and how you can contribute to the discussion. If you and a representative are present, you should have copies of assessments circulated to MDT members. If no one can attend, the co-ordinator should obtain your evidence and views.

The DST should record whether and how you and your representative contributed. If you were not involved, it should record whether it was because you were not invited or declined to participate.

Completing the DST

When completing the DST, an MDT should:

- complete all care domains
- use assessment evidence and professional judgement to select the level most closely describing your needs
- choose the higher level and record any evidence or disagreements if they cannot decide or agree the level
- consider interactions between needs and not marginalise needs because they are successfully managed. Well-managed needs are still needs and should be recorded appropriately
- consider needs recorded in domain 12.

If the MDT is confident it has all information required, it can discuss and agree the recommendation without you or your representative present. The DST lets you and your representative give views on the completion of the DST not recorded elsewhere, including if you agree with domain levels selected and why. You should be allowed to give your views on the completed domain levels before leaving the meeting.

If you have concerns about the MDT meeting or DST process that are not resolved, staff should record them, with reasons, in the DST. This ensures the CCG is aware of them when making its final decision.

The completed tool should give an overall picture of your needs. If your condition is anticipated to deteriorate and your needs in certain domains increase in the near future, they should record and take this into account in their final recommendation. Your likely condition over the next few months can influence the timing of your next review.

If you are not present when the MDT agrees its recommendation, they should let you know the outcome as soon as possible.

Alzheimer's Society produces information to help evaluate emotional and psychological needs of people in later stages of dementia. www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2565

MDT recommendation to the CCG

The DST has a summary sheet to record chosen levels for each domain and a summary of your needs. Having considered what this signifies in terms of the key indicators - nature, intensity, complexity and unpredictability of your needs - in combination or alone, the MDT agrees and provides reasons for its recommendation.

You could expect a **clear recommendation of eligibility** if you have:

- **priority** level of need in any of the four domains with a priority level
- **two or more instances of severe** needs across all domains.

Depending on the combination of needs, it may indicate a primary health need if there is:

- one domain recorded as **severe** together with needs in a number of other domains, or
- a number of domains with **high and/or moderate** needs.

Staff should consider interaction between needs in various domains, evidence from risk assessments and base their judgement on what evidence indicates about any combination of the nature, complexity, intensity and unpredictability of your needs.

If all domains have low needs, this is unlikely to indicate eligibility. If all domains show no needs, this indicates ineligibility.

The CCG's decision

Only in exceptional circumstances should the CCG go against the MDT's recommendation. These might be: DST not completed fully, gaps in evidence, or obvious mismatch between evidence and recommendation.

The CCG may share its decision with you verbally but should always confirm in writing, giving clear reasons for the decision and a copy of the completed DST. It should tell you who to contact for clarification and how to request a review, if they decide you are not eligible.

Note
An eligibility decision is not permanent. It can be overturned if a review shows your needs have changed and no longer meet the primary health need threshold.

If you are not eligible for NHS CHC but have specific health needs

The CCG may decide they are responsible for some of your health related needs because they need support beyond what a LA can legally provide, even if you are not eligible for NHS CHC.

If so, the LA and CCG agree their respective responsibilities for a joint package of care and tell you if the CCG contribution affects how much you pay following a mean-test.

Use of a panel

Panels are not required as part of the decision-making process. CCGs can use them to ensure consistency and quality of decision-making but they should not play a financial gate-keeper role.

If the CCG and LA disagree about your eligibility, they may use a panel as part of their local dispute resolution process.

If a person dies while waiting for an eligibility decision

If you die while waiting for an eligibility decision and were receiving means-tested services that could have been funded through NHS CHC, the CCG must complete the decision-making process and where necessary, arrange appropriate reimbursement.

If you were not receiving such services, there is no need to continue the decision-making process.

6 Challenging an eligibility decision

Submitting a request for a review of the decision

If you want to challenge a decision following a full assessment and completion of DST, you or your representative **must write to the CCG no later than 6 months from the date you received written notification of the decision**. You can contact Beacon for advice if considering whether to appeal. The CCG should acknowledge your letter in writing within 5 working days and explain the appeal process.

The 6 month deadline does not apply if you satisfy the CCG you had good reasons for missing it and the CCG believes it can access relevant information and records that informed the original decision.

Composing your letter

Explain why you are challenging the decision, providing as much evidence as you can. Where possible, it should relate to DST domains. If you believe you should have been placed at a higher level for a particular domain, give examples from your experience or a report you believe the DST did not capture. Highlight gaps in evidence supporting the overall decision or failures to follow the Framework.

This is particularly important if the person making the request is a close relative or representative but is not a court deputy or attorney with a LPA. If the person who the decision relates to does not have capacity to instruct their relative to request a review, the CCG must adopt a '*best interests*' process when considering whether to accept their request. This is discussed in Framework PG 68.2.

Funding your care once you challenge the CCG decision

The CCG decision remains valid and in place unless, or until, either stage of the review process recommends you should be eligible.

You should receive appropriate care while awaiting the outcome of the review. You may have to contribute towards the cost of your care package during this time. Your financial circumstances affect who is responsible for arranging and paying for your care. If you are responsible for funding some, or all, of your care and your appeal is successful, you can claim costs incurred on provision of receipts (See section 13).

6.1 Review process

The Review process after a full assessment only helps if you are dissatisfied with:

- the procedure the CCG followed to reach the eligibility decision, including how eligibility criteria were applied, or
- the CCG's '*primary health need*' decision.

There are two stages in the review process:

- a **Local Review** managed by the CCG, and
- if unhappy with the outcome, you can request an **independent review** managed by NHS England (NHSE) who may decide to appoint an Independent Review Panel (IRP). If going to local review would cause undue delay, NHSE has discretion to put your case straight to independent review.

Note
If after discussion you are unhappy with issues such as the type, location or content of your NHS CHC care package, the CCG should tell you how to use the NHS complaints process. For more information, see factsheet 66, *Resolving problems and making a complaint about NHS care.*

Local Review stage and timescales

Each CCG should agree and make its local review process publically available, with agreed timescales for its various stages. The process usually involves a review meeting where you can ask questions and try to gain a better understanding of the decision and resolve the matter. It can include referring your case to a neighbouring CCG for their consideration or advice. You can ask to be present when they meet.

The CCG is **expected to investigate and make a decision in relation to a local review within 3 months of receiving your request**, unless there are good reasons for extending it. These may include difficulty accessing relevant information or availability of MDT members.

The CCG should write to you with local review outcome as soon as possible but no more than 3 months from the date of your request. This should explain how to request an independent review if you are unhappy with the reasons for its response. If it cannot meet this time period, it should explain why in writing and commit to a written response as soon as it reasonably can.

Independent Review Panel stage and timescales

You must ask for an independent review, in writing, no more than 6 months after hearing the final outcome of the local review. It should be arranged and completed within 3 months of your request being received**,** unless there is good reason for a delay.

NHSE, via regional teams, is responsible for arranging IRPs and can decide, on the advice of an independent individual who can chair a panel, not to convene one. If it decides not to convene a panel, it should send you a full written explanation of the reasons and tell you of your rights to use the NHS complaints procedure.

Role of the Independent Review Panel and your contribution

The IRP has a scrutiny and reviewing role. There is no need for you or the CCG to be legally represented when a panel meets, although you may wish a family member, advocate or advice worker to represent you. If you want advocacy support, your CCG has details of local services.

The panel has a chair, independent of the NHS, and experienced health and social care professionals, independent of the CCG making the eligibility decision.

At the meeting, you can explain why you are appealing, based on points raised in your letter, and answer the panel's questions. You can speak to Beacon to discuss how to prepare your case for the meeting.

IRP and local procedures should follow key principles for dispute resolution found in annex E of the Framework. They include:

- gather and scrutinise available and appropriate oral or written evidence from relevant health and social care professionals, and from you or your representative, and the completed DST and MDT deliberations
- compilation of a robust and accurate identification of care needs
- access to independent clinical advice to advise on clinical judgements
- audit of any attempts to gather records said not to be available
- involving you or your representative as far as possible, giving you an opportunity to contribute to, and comment on, information at all stages
- recording deliberations and making them available to all parties
- clear, evidenced written conclusions on the process followed and your eligibility.

The IRP makes a recommendation to NHSE. The panel's role is advisory but in all but exceptional circumstances, the CCG should accept its recommendations.

Independent Review Panel recommendation

NHSE should **tell you the IRP findings as soon as practicably possible and no later than 6 weeks after the panel decision**. If the CCG decision is overturned because of the IRP recommendation, the CCG should refund the cost of services you paid for since their '*not eligible*' decision.

If the CCG decision is upheld and you still disagree with the decision, their letter should explain how to ask for your case to be referred to the *Parliamentary and Health Service Ombudsman* (PHSO).

You or your representative are entitled to contact the PHSO within 12 months of receiving written notification of the outcome of the IR.

7 Using the Fast Track Tool

If you are approaching the end of your life, you may be eligible for '*fast tracking*'. This means receiving prompt NHS funding for end of life care and by-passing the full assessment process. To be eligible for fast tracking, you must have:

- a rapidly deteriorating condition
- that may be entering a terminal phase.

If staff caring for you in any location observe such changes, they should contact an '*appropriate clinician*' and ask them to consider completing the Fast Track tool, explaining why they believe you meet the conditions. An '*appropriate clinician*' is a doctor or nurse responsible for your diagnosis, treatment or care, or with a specialist role in end-of-life needs and an appropriate level of knowledge or experience.

CCGs should make fast track decisions on a case by case basis. They should not impose strict limits that base eligibility on a specified, expected length of life remaining. They should accept and promptly action a Fast Track tool recommendation and be able to put a suitable care package in place, preferably within 48 hours.

When developing your care package, staff should ask if you have an advance care plan and take account of your expressed care preferences and wishes. For example, if you live in a residential home and want to remain there, staff should make every effort to enable this to happen, if it is clinically safe and within the home's terms of registration.

Once appropriate care is in place, it is important for the CCG to monitor your needs and review effectiveness of the care package. In doing this it may find your needs indicate it is appropriate to reconsider your eligibility. If eligible for fast track your funding should not be removed without an MDT completing a DST and making a recommendation. The CCG should tell you the outcome in writing and if proposing a change in funding, explain your right to request a review of its decision.

8 Regular reviews of eligibility decisions

Regular reviews are part of the NHS CHC process and you have the right to be represented by a person of your choice. If you are eligible, or were considered, for NHS CHC and the NHS subsequently provides or funds *any* part of your care package, **your case review should take place no later than three months after the initial eligibility decision and then at least annually**. The MDT making the original recommendation may have specified different timing for your first review.

The focus should be on whether your needs have changed and consequently whether your care plan needs revising, not on whether you remain eligible for NHS CHC.

The CCG and LA should support a decision to remove eligibility and it must involve completion of the DST. If they disagree about your eligibility, they should resolve it using the local disputes procedure. During that time, the CCG must continue to fully fund your care.

If the CCG and LA agree you are no longer eligible, the CCG should inform you in writing, with their reasoning, and explain your right to request a review of their decision. One month's notice of a change of funding responsibility is reasonable.

9 Care planning when eligible for NHS CHC

9.1 Your care package

The CCG deciding your eligibility is responsible for funding your care package. In deciding where you live and your care package, staff should take account of your views and preferences and risks associated with different options. The care package must be one the CCG believes is appropriate to meet eligible health and social care needs, taking account of goals or outcomes you want to achieve. The budget must be sufficient to pay for services or a care home, wherever it agrees you may live.

You should know who to contact with concerns and who is responsible for monitoring your care and arranging regular reviews. If the CCG agrees you can live outside its area, they remain responsible for funding and monitoring care associated with your NHS CHC.

If you are to live outside the CCG area, you must register with a GP. Any NHS community, dental, optical or hospital services unrelated to your eligibility for NHS CHC are the responsibility of your new GP practice's CCG. Your care can be provided in a range of settings.

9.2 Care home

If you are to live in a care home, the CCG is responsible for meeting the cost of your assessed care needs and accommodation. Issues to be aware of, if a care home is the preferred or best option, include:

- **CCG has block contracts with several care homes in an area.** It is your assessed needs that determine whether any of these homes are suitable. There may be '*needs based reasons*' for a CCG to consider more expensive homes or accommodation than usual. Examples include if there is a recognised link between feeling confined in a small room and displaying behaviour that challenges those caring for you or where there could be identified benefits of a specialist rather than generic care provider.
- **It may be appropriate to move to a home closer to relatives who live in a different CCG area.** You can give reasons but cannot assume they will be accepted. A CCG agreeing you can live in a care home in another CCG area remains responsible for your care home fees.

- **Your current care home cannot meet your assessed needs.** You need to discuss your options with the CCG.
- **Your current care home can meet your NHS CHC needs but is more expensive than the CCG normally pays to meet similar needs.** This can arise if you self-funded your care home place before being eligible for NHS CHC or if social services contributed to the cost but to meet your preferred home's higher costs, a friend or relative paid a '*top up"* fee. Top ups are allowed for social care, but not under NHS legislation.

  The Framework Practice Guidance **PG 99** says: '*Funding should be sufficient to meet needs identified in the care plan in the locality they are to be provided. It is also important that the models of support and the provider used are appropriate to the individual's needs and have the confidence of the person receiving services. Unless it is possible to separately identify and deliver the NHS-funded elements of the service, it will not usually be permissible for you to pay for higher-cost services and/or accommodation.'*

  In reviewing your current accommodation, the CCG should explore why you want to stay in your current home or in the same room and consider if there are clinical or over-riding needs-based reasons for doing this.

  If you live in a more expensive home, the CCG may propose you move to a different home. **PG 99.4** says: '*In such situations, CCGs should consider whether there are reasons why they should meet the full cost of the care package, notwithstanding that it is a higher rate, such as frailty, mental health needs or other relevant needs of the individual mean that a move to other accommodation could involve significant risk to their health and wellbeing*.'

9.3 Hospice

Hospice care may be appropriate if you are reaching the end of your life. Staff should take account of your wishes and preferences when deciding the setting and location of your care.

9.4 Own home

Your CCG must fund, and if asked arrange, a package to meet your identified health and personal care support needs but not rent, mortgage, food and normal utility bills. If running specialist equipment adds substantially to utility bills, an NHS contribution may be appropriate.

If you lived at home before becoming eligible for NHS CHC, you may have had Direct Payments from the LA. The CCG should aim to arrange services to maintain a similar package of care and replicate as far as possible, the personalisation and control of Direct Payments.

You can ask for, and the CCG should offer, a Personal Health Budget unless there are clinical reasons why it is not suitable. See section 9.6.

Family member provides care as a part of your care package

If a CCG agrees to a home-based package and a family member or friend is an integral part of delivering your care plan, the CCG should identify and meet training needs to help them carry out this role.

In particular, the CCG may need to provide additional support to care for you whilst carer(s) have a break from caring responsibilities and assure them such support is available when required. This could mean you receive additional services at home or spend a period of time away from home (for example, a care home).

Note
If your carer provides, or is about to provide, informal care for you, they have a right to a separate carer's assessment and have eligible needs met to support them in the caring role. They can approach the LA social services department. See factsheet 41, *How to get care and support*.

At a later date, you want to move house to another CCG area

If you wish to move house, ask your funding CCG in plenty of time. It needs careful discussion between your current CCG and the CCG responsible for providing services after you move. Both CCGs will want to ensure continuity of care, that arrangements represent your best interests, and associated risks are identified.

Moves in the UK

If you wish to receive care in Wales, Scotland or Northern Ireland, regardless of setting, there needs to be discussion between your funding CCG and the relevant health body in your chosen country.

9.5 Advocacy if you lack capacity to consent to a care plan

A CCG or LA must instruct or consult an Independent Mental Capacity Advocate (IMCA) to act on your behalf if:

- it must make a '*best interests*' decision involving an accommodation change, hospital admission over 28 days, or other accommodation for more than eight weeks, or serious medical treatment, **and**
- you have no family member or friend willing and able to represent you or be consulted while reaching such a decision.

This process must also be followed in these circumstances even if you are not eligible for NHS CHC.

An IMCA aims find out your views, wishes and feelings about the issue by talking to you, people close to you and professionals who know you.

Staff must use an IMCA report to help reach a best interests decision. An IMCA can challenge a decision if it appears not to be in your best interests.

For more information, see factsheet 22, *Arranging for someone to make decisions on your behalf*.

Advocacy if you have capacity

When you have capacity to make care decisions, you can ask family members to help make your views known or ask the person co-ordinating your assessment about local advocacy services.

9.6 Personal Health Budgets and NHS CHC

Anyone receiving NHS CHC has the right to have a Personal Health Budget (PHB) with the expectation one will be provided, unless there are clear clinical or financial reasons why it should not.

What is a personal health budget?

A PHB is an amount of money you can spend to support your identified health and wellbeing needs and goals. It is not new money but money the NHS would otherwise spend on your care.

Your care and support plan describes how you would like to meet your goals, using your assigned budget. NHS staff sign off your plan once satisfied the goods or services you intend to purchase can meet your health and wellbeing needs and the budget is sufficient to do this.

Your care manager keeps your care plan and PHB management under review. You do not have to have a PHB and should only be offered as much control over managing your care as you want.

You can manage a PHB in one of three ways or in combination:

- a *notional budget* - the CCG holds the money but you are actively involved in choosing who delivers your care and support
- a *third party arrangement* - an organisation such as a trust, holds the money and in line with your agreed care plan, manages your care and the budget for you
- a *direct payment* - money is transferred to you or your nominee or representative, who contracts for necessary services or expenditure.

Note
Contact your NHS CHC manager to find out how a PHB could work for you and ways you can spend an allocated budget.

Using a direct payment to manage a NHS CHC PHB

The PHB direct payments scheme is broadly similar to that offered by a LA for social care. In some areas, the NHS and LA are working cooperatively to support the delivery of PHBs.

Some practicalities

Speak to your care manager to discuss your options and find out what support is available if you choose to have a PHB:

- is there a brokerage service to help you manage your care and PHB?
- if you opt for direct payments, is there a representative or suitable nominee who can take on full responsibility for this?
- would another way of managing it prove to be a better option?
- if you lack capacity to consent to or manage a direct payment, is there someone who can take on the responsibilities of your direct payment?

If you take the direct payment option, your care manager can explain the duties placed on you, a nominee or representative. You may consider employing a personal assistant to help manage your health, care and wellbeing needs. This means understanding responsibilities of being an employer such as:

- how to recruit a personal assistant?
- how to pick the right staff and arrange cover for holidays or sickness?
- payroll duties (this can be outsourced to a payroll company)
- do you need to pay into a pension scheme for a personal assistant?

A PHB direct payment must be paid into a bank account specifically set up for this purpose and held in the name of the person receiving it. You may need guidance on managing the budget and keeping records on what you spend money on.

If you are refused a health direct payment, are asked to pay back any money, or the CCG wants to bring the arrangement to an end, you are entitled to a review of the decision and if unsuccessful, you can use the NHS complaints procedure to try to resolve the problem.

Note
For more about PHBs see www.nhs.uk/choiceintheNHS/Yourchoices/personal-health-budgets/Pages/about-personal-health-budgets.aspx

10 Effect on benefits of NHS CHC funding

Disability benefits

Notify the Disability Benefits Centre if you get a disability benefit - Attendance Allowance (AA), Disability Living Allowance (DLA) or Personal Independence Payment (PIP).

If you receive NHS CHC in a *nursing* home, both care and mobility elements are suspended after 28 days after CCG funding begins or sooner if you have recently been in hospital.

If you will receive NHS CHC in a *residential* home, the care component of disability benefits is suspended after 28 days but you can continue to receive the mobility components of DLA or PIP.

If you will live at home with an NHS CHC care package, you can continue to receive these disability benefits. Check you are receiving them at the appropriate level.

State Pension

State Pension is not affected by eligibility for NHS CHC.

Pension Credit

You lose the severe disability element of your Pension Credit award if your AA or DLA (care), PIP (daily living component) stops.

11 Care planning if you do not go beyond Checklist

If you do not progress beyond the Checklist, a joint health and social care assessment identifies your needs. Subject to national social services eligibility criteria, your needs and views on how they can best be met form the basis of your agreed care plan.

Your care package may include community equipment such as aids and minor adaptations to assist with home nursing or daily living. You should not be asked to pay for aids or minor adaptations with fitting charge, if the cost is £1000 or less. If you need services from the NHS and social services, you have a means-test for needs that are the responsibility of social services. NHS services are free and can be provided in their own right on a regular or ad-hoc basis. They include:

- NHS-funded nursing care in a nursing home by a registered nurse
- rehabilitation and recovery services such as physiotherapy
- assessment and/or support from community-based NHS staff such as district nurses, continence nurses, specialist diabetic nurses
- palliative care services (emotional support and pain management) if you have been diagnosed with a terminal illness.

12 Retrospective reviews of NHS CHC eligibility

If you think you should have been considered for NHS CHC, you can raise this with social services, your care home manager or CCG continuing healthcare manager. If seeking a review in respect of a deceased relative, the CCG may require evidence to prove you are entitled to any money that may be forthcoming. This could be the Grant of Probate or Letters of Administration.

12.1 Cases of care between 1 April 2004 and 31 March 2012

In March 2012 the Department of Health announced deadlines for individuals (or their representatives) who wished to request an assessment for NHS CHC for periods of care between 1 April 2004 and 31 March 2012. The announcement related to *previously un-assessed periods of care*, where evidence suggests an assessment should have been conducted. CCGs completed these by March 2017 but some appeals are outstanding.

13 Refunds if NHS should have paid for your care

You may be entitled to a refund of care costs incurred if a CCG eligibility decision is:

- unjustifiably delayed, or
- revised after reconsideration using CCG local review process or IRP.

You may be entitled if a retrospective review indicates you should have been considered for NHS CHC, then assessed and found eligible. Annex F of the National Framework explains the refund policy that applies when eligibility decisions are delayed or disputed.

Refunds for unjustifiable delay in reaching a decision

If a CCG decides you are eligible but '*unjustifiably*' takes longer than 28 days to make a decision, it should refund the LA the costs of services provided from day 29 to the date they reach the decision. If you contributed towards the cost, the LA should reimburse your contributions.

If you paid all your care costs, the CCG should give you an ex-gratia payment to restore your finances to the state they would be in had the delay not occurred and to remedy any injustice or hardship you suffered as a result of the delayed decision.

Examples of '*justifiable*' delays include delays in receiving records or assessments requested from a third party or delays outside the CCG's control in convening a multi-disciplinary team. To avoid this, CCGs should aim to develop protocols to help meet the 28 day deadline.

Refunds following a revised decision

If a CCG's initial eligibility decision is revised, the CCG should reimburse any care costs incurred in the interim to the LA. If you contributed to the cost of your care, the LA should reimburse your contributions.

If you paid all your care costs, you should receive an ex-gratia payment directly from the CCG. The aim is to restore your finances to the state they would have been in had they made the correct decision at the outset and remedy any injustice because of the incorrect decision.

The period of reimbursement or ex-gratia payment starts from the date the CCG made its initial decision (or earlier if unjustifiable delay occurred) until the date the revised decision came into effect.

Refunds following a retrospective review

A retrospective review may show you were eligible for NHS CHC during the period under consideration. If so, the CCG must decide a fair and reasonable amount to offer you or your estate, if you were funding your care during that time. In reaching their decision, they must consider the circumstances of your case and be able to justify their offer of redress.

Redress following a retrospective review

The purpose of redress is solely to restore you to the financial position you would have been in had NHS CHC been awarded at the right time. Remedies should not lead to a complainant or the NHS making a profit or gaining an advantage.

CCGs must follow Refreshed Redress Guidance, published by NHS England on 1 April 2015, if:

- an NHS CHC eligibility decision was made on or after 1 April 2015, and
- the CCG identified the need for redress.

This guidance advises CCGs to apply the Retail Price Index to calculate compound interest for the period under consideration and aim to achieve a fair and reasonable outcome to the individual, which demonstrates an appropriate use of public funds. For more information, see: www.england.nhs.uk/ourwork/pe/healthcare/redress-guidance-ccgs/

Note
To dispute a CCG decision on whether to provide redress or on the amount provided, you use the NHS complaints procedure.

14 NHS-funded nursing care

NHS-funded nursing care is a fixed rate CCG payment made directly to local nursing homes as a contribution towards the cost of care provided to eligible residents by the home's registered nurses.

A registered nurse is likely to:

- provide hands-on nursing care
- supervise and monitor care provided by a non-registered nurse
- plan and review health needs in a care plan
- monitor and review medication needs
- identify and address potential health problems.

Note
Residential homes do not employ registered nurses. Residents receive necessary nursing care from NHS nurses based in the community, such as district nurses. Consequently, residential homes do not receive NHS-funded nursing care payments.

14.1 NHS-funded nursing care payments

NHS England reviews NHS-funded nursing care rates annually, usually in April. The following rates apply for year starting April 2017.

If you moved into a nursing home on or after 1 October 2007, you are on the single band of nursing care. The weekly rate is £155.05.

If you moved into a nursing home before 1 October 2007 and were on the high band in place at the time, the weekly rate is £213.32.

You remain on this high band until:

- you are no longer resident in a nursing home, or
- you become eligible for NHS continuing healthcare, or
- death, or
- a review suggests you no longer need nursing care, or
- a review suggests your nursing needs no longer match high band criteria; in which case you transfer to the single band rate.

If you self-fund your nursing home place, ask the home to tell you how the amount they ask you to pay takes account of this CCG payment.

NHS-funded nursing care payments do not affect eligibility for disability benefits such as AA, DLA or PIP.

14.2 How is eligibility for NHS-funded nursing care decided?

If it is proposed your best option is to move into a nursing home, staff must agree you are not eligible for NHS CHC before looking at eligibility for NHS-funded nursing care. Staff may reach this conclusion after completing the Checklist or a full assessment and MDT recommendation, after a period of intermediate care, on discharge from hospital or a review of your health and social care needs.

If a '*not eligible*' decision arises following a full assessment, the MDT records your registered nursing care needs in the DST. This information is then available when staff draw up your care plan.

14.3 Regular reviews of NHS-funded nursing care needs

The CCG should undertake a review no later than three months after its initial decision to make NHS-funded nursing care payments. The review is to reassess your nursing needs, make sure they are being met and confirm a nursing home place is still appropriate.

When staff review your need for NHS-funded nursing care, they must always consider your potential eligibility for NHS CHC. This involves using the Checklist or where indicated, carrying out a full assessment, including completion of the DST by an MDT.

A new DST is not required if:

- staff reached their initial decision following a positive Checklist and full assessment plus completion of a DST by a MDT, **and**
- there has been no material change in your needs that might lead to a different eligibility decision on NHS CHC and NHS-funded nursing care.

In this case, the reviewer must have a copy of the DST and consider each domain and previously assessed levels of need, in consultation with you and any relevant people present then who knew you. The reviewer should annotate and sign each domain, confirming they have considered each one and indicated any changes in need levels.

After the review, the CCG should tell you that despite meeting the Checklist threshold, they have not completed a new DST because there has been no significant change in your domain levels. You should receive a copy of the annotated, signed DST and be told you can ask for a review of this decision. If you remain dissatisfied after local reconsideration, use the NHS complaints procedure.

If you did not have a full assessment with completion of the DST or where a review indicates a possible change in eligibility, a positive Checklist must be followed by an MDT completed DST and recommendation on eligibility for NHS CHC.

Following the three month review, you should have a review at least annually or if your healthcare needs change significantly.

If you self-fund, the care home manager should explain CCG arrangements for reviews and ensure you have a review three months after you first move in and annually thereafter.

14.4 Admission to hospital or a short stay in a nursing home

If you are admitted to hospital, the home does not receive funded nursing care payments during your hospital stay. The NHS-funded nursing care guidance says CCGs should consider paying a retainer to help safeguard residents care home places while they are in hospital.

If you go into a nursing home on a temporary basis for a period of less than six weeks, you qualify for a NHS-funded nursing care payment. There is no need for a nursing needs assessment if the stay is for less than six weeks and you have already been assessed for nursing care in the community. This may apply if you have a trial period in a home or are admitted for respite care or in an emergency because your carer is ill.

Useful organisations

Beacon
www.beaconchc.co.uk/
Telephone 0345 548 0300

Beacon is a social enterprise offering a range of free and paid for services including up to 90 minutes of NHS England-funded independent advice about the NHS CHC assessment and appeals process and a full range of low cost advocacy services.

Disability Benefits Helpline
www.gov.uk/disability-benefits-helpline

DWP helpline providing advice or information about any claim for Disability Living Allowance, Personal Independence Payment or Attendance Allowance that you have already made.

Attendance Allowance (AA)
Telephone 0345 605 6055

Disability Living Allowance (DLA)
If you were born on or before 8 April 1948
Telephone 0345 605 6055

If you were born after 8 April 1948
Telephone 0345 712 3456

Personal Independence Payment helpline
Telephone 0345 850 3322

Local Healthwatch
www.healthwatch.co.uk
Telephone 03000 683 000

Each LA has a local Healthwatch that may run or can signpost to the local NHS independent advocacy service.

NHS Choices
www.nhs.uk/

NHS Choices provides web based information on NHS structures, services, health conditions and healthy living.

Office of the Public Guardian
www.gov.uk/browse/births-deaths-marriages/lasting-power-attorney
Telephone 0300 456 0300

The Office of the Public Guardian supports and promotes decision-making for those who lack capacity or would like to plan for their future under the *Mental Capacity Act 2005*.

Parliamentary and Health Service Ombudsman
www.ombudsman.org.uk
Telephone 0345 015 4033

The Parliamentary and Health Service Ombudsman (PHSO) can investigate complaints about NHS care or services or if you remain dissatisfied following an IRP decision about NHS CHC eligibility.

Age UK

Age UK provides advice and information for people in later life through our Age UK Advice line, publications and online. Call Age UK Advice or Age Cymru Advice to find out whether there is a local Age UK near you, and to order free copies of our information guides and factsheets.

Age UK Advice
www.ageuk.org.uk
0800 169 65 65
Lines are open seven days a week from 8.00am to 7.00pm

In Wales contact

Age Cymru Advice
www.agecymru.org.uk
0800 022 3444

In Northern Ireland contact

Age NI
www.ageni.org
0808 808 7575

In Scotland contact

Age Scotland
www.agescotland.org.uk
0800 124 4222

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Next update November 2018

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