Continuing Healthcare - should the NHS be paying for your care?

This factsheet explains when it is the duty of the NHS to pay for your social care.

It covers what NHS Continuing Healthcare is, who is eligible, how the assessment process works and what you can do if you are unhappy with the outcome of an assessment.
About Independent Age

Whatever happens as we get older, we all want to remain independent and live life on our own terms. That’s why, as well as offering regular friendly contact and a strong campaigning voice, Independent Age can provide you and your family with clear, free and impartial advice on the issues that matter: care and support, money and benefits, health and mobility.

A charity founded over 150 years ago, we’re independent so you can be.

The information in this factsheet applies to England only.

If you’re in Wales, contact Age Cymru (0800 022 3444, agecymru.org.uk) for information and advice.

In Scotland, contact Age Scotland (0800 12 44 222, agescotland.org.uk).

In Northern Ireland, contact Age NI (0808 808 7575, ageni.org).
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1. **What is NHS Continuing Healthcare?**

NHS Continuing Healthcare is a package of care that is arranged and funded by the NHS. It is given to people with complex physical and/or mental health needs that are caused by a disability, accident or illness.

NHS Continuing Healthcare is arranged and funded by your local Clinical Commissioning Group (CCG). It isn’t means-tested. If you’re eligible, the funding should cover the full cost of your accommodation and care.

Care funded by NHS Continuing Healthcare can be offered in anywhere – in a hospital, a care home, or in your home.

Throughout this factsheet we will refer to the National Framework for NHS Continuing Healthcare and NHS-Funded Nursing Care. This sets out who is eligible for NHS Continuing Healthcare, how the assessment process should work and what you can do if your application is not successful. You can download it from Gov.uk at [gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care](http://gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care)
2. Who is eligible for NHS Continuing Healthcare?

In order to qualify for NHS Continuing Healthcare, you must be assessed as having a primary health need.

There is no legal definition of what a primary health need is. You have a primary health need if your main need is for nursing and care services that are beyond what a local council could be expected to provide.

What is a primary health need?

An NHS Continuing Healthcare assessment should consider four particular characteristics of your health needs: their nature, intensity, complexity and unpredictability. You may have a primary health need if your assessment shows your health needs require a quantity and quality of care that only the NHS – not the council – can provide.

- **Nature of your needs**: This can refer to the features of your conditions and how they affect your health and wellbeing. An assessment could consider the type of medical help you need to manage your conditions and whether they will get better or worse.

- **Intensity of your needs**: This will consider the number, severity and duration of your needs or conditions. An assessment might look at chronic conditions which requires a certain type, length or level of care to manage.

- **Complexity of your needs**: Your needs might be complex if you have combination of symptoms or conditions that together make it harder to meet your needs. Complexity can also refer to the extent of treatment needed for a condition, or if you require specialist, urgent or timely care and treatment.
- **The unpredictability of your needs**: This considers how much your needs change, and the risk to your health if adequate and timely care is not provided. Someone with an unpredictable healthcare need is likely to have a fluctuating, unstable or rapidly deteriorating condition that needs careful monitoring.
3. The NHS Continuing Healthcare Assessment

The National Framework uses three forms to decide if you are eligible for NHS Continuing Healthcare. They are:

- **Checklist Tool**: this is usually the first stage of the assessment, used for screening applicants

- **Decision Support Tool**: this is usually the second stage, used during the full NHS Continuing Healthcare assessment

- **Fast Track Pathway Tool**: this is only used when someone is at the end of their life

**Requesting an assessment**

If you think you should have a NHS Continuing Healthcare assessment, you can ask a nurse, doctor, GP or social worker for one. Hospitals, GP surgeries and other NHS bodies must make sure you’re assessed if it appears you may have a need for NHS Continuing Healthcare.

You can also contact your CCG’s NHS Continuing Healthcare team to request an assessment. Find their details through NHS Choices (nhs.uk/Service-Search/Clinical-CommissioningGroup/LocationSearch/1)

**Good to know**

The first step of a NHS Continuing Healthcare assessment will usually be a screening process using the Checklist Tool. However, the Checklist may be skipped if it’s clear your needs will qualify for a full assessment using the Decision Support Tool. You may also have a fast-tracked assessment if you need end of life care.
The 12 care domains

To decide whether you have a primary health need, the NHS Continuing Healthcare assessment looks at the nature, intensity, complexity and unpredictability of particular healthcare needs. These are called care domains and include:

1. **Behaviour** – is your behaviour a risk to yourself, others or property? Can it be anticipated or minimised?
2. **Cognition** – does your disability or disease cause confusion, memory issues, disorientation or an inability to see risk?
3. **Psychological & emotional needs** – such as anxiety, mood disturbances, hallucinations or distress
4. **Communication** – how able you are to articulate your needs?
5. **Mobility** – your ability to walk or move about without support
6. **Nutrition** – what care do you need to make you get enough to eat and drink?
7. **Continence** – your control of your bladder and bowel
8. **Skin integrity** – the condition of your skin: poor skin integrity can include pressure sores, wounds or infection
9. **Breathing** – can you breathe independently or with support?
10. **Drug therapies and medication** – are your medication or pain difficult to manage safely?
11. **Altered states of consciousness** – when your mind is aware but not fully in control, putting you at risk of harm
12. **Any other significant needs**

The needs marked with a ‘*’ are considered more important and pressing than others.

We will return to this list later in this section as it explains how the assessment collects and uses information on these different care domains to see if you have a primary health need.
Stage One: The Checklist Tool

The Checklist Tool works out whether or not you’re likely to qualify for NHS Continuing Healthcare, and whether you need to have a full assessment.

The Checklist can be used by any health or care professional who is familiar with the National Framework and the Decision Support Tool (the next stage of the assessment). This could be a nurse, social worker, GP or other doctor, for instance.

You should be fully involved in the process, and can have a family member, carer or advocate with you when the assessment is taking place, to make sure that your views are taken into account.

How it works

The assessor will score you as either ‘A’ (highest need) ‘B’ or ‘C’ (no or low need) in each of the care domains listed earlier in this section.

You will be eligible for a full NHS Continuing Healthcare assessment if you have:

- Two or more care domains rated as ‘A’; or
- Five or more care domains rated as ‘B’; or
- One care domain as ‘A’ and four as ‘B’; or
- One care domain marked with an asterisk (*) rated as ‘A’ (these are considered priority needs)

You can download a copy of the Checklist Tool from the Department of Health website at gov.uk/government/uploads/system/uploads/attachment_data/file/213138/NHS-CHC-Checklist-FINAL.pdf. Before your assessment, consider what score you think you should get in the different care domains and what evidence of these needs you could provide.
After the Checklist has been completed

You and your carer (if you have one) should be sent a copy of the completed Checklist Tool and an explanation of the assessor’s decision as soon as possible. If the assessment shows you may have a primary health need, the CCG will then arrange a full assessment using the Decision Support Tool (DST). The DST assessment should be carried out within 28 days of your Checklist Tool assessment.

If the assessment finds you don’t meet the criteria for a full NHS Continuing Healthcare assessment, you have a right to ask your CCG to review and reconsider their decision. If you’re unhappy with the results of a review, you should be told how to make a complaint using NHS complaints procedures.

Stage Two: The Decision Support Tool and Multi-Disciplinary Assessment

Once your CCG receives your Checklist Tool and is told you might be eligible for NHS Continuing Healthcare, they will arrange your full assessment. This will be carried out by a multi-disciplinary team (MDT) of two or more people from health and/or social care backgrounds. This could be a:

- medical consultant or doctor
- ward nurse or specialist nurse
- psychiatric nurse
- speech and language therapist
- occupational therapist
- social worker or another social care professional.

You can nominate someone to help represent your views during the assessment, such as a relative, friend or an advocacy service. You and your representative should be fully involved in
the assessment where your needs are discussed. Your views about your healthcare needs and wishes for your future care should be recorded and taken into account.

You and your representative should also be given advice to help you understand the process.

For more information about independent advocacy and when you may find it useful, see our factsheet Independent advocacy (0800 319 6789, independentage.org).

**How the assessment works**

The multi-disciplinary team must use the Decision Support Tool to decide whether you qualify. The Tool is organised by the different care domains. Using the descriptions in the tool and a range of evidence, the team should decide whether your needs for each domain are none, low, moderate or high.

For some of the care domains, your needs can also be categorised as severe or priority. The only care domains where your needs can be considered 'priority' are the ones marked with an asterisk (*).

The team should also weigh up the overall risk to you from your condition or need, or the risk to others.

You will be assessed as having a primary care need and be eligible for NHS continuing healthcare if you have:

- a priority level score in one care domain
- two severe needs across all care domains with this level
- one domain recorded as severe, together with needs in a number of other domains
- a number of domains with high and/or moderate needs
Deciding whether you have a primary health need

Deciding whether someone has a primary health need can be complicated. If your needs don’t fit easily into the first eleven care domains, the team should still consider the extent and type of your needs and record this in the twelfth care domain section of the Decision Support Tool.

If the members of the multi-disciplinary team disagree about whether your needs are low, moderate, high, severe or priority, they must select the higher level and give a reason for doing so.

The final decision about whether you are eligible will be made using evidence from the completed Decision Support Tool as well as the team’s clinical judgement. The team should then make a written recommendation about your eligibility for NHS Continuing Healthcare at the end of the Decision Support Tool form before sending it to your CCG.

The CCG should follow the team’s recommendation except in exceptional circumstances. This could include:

- lack of evidence to support a recommendation
- a comprehensive assessment of your needs has not been carried out
- the Decision Support Tool is not fully completed.

The CCG’s decision not to follow the recommendation shouldn’t be influenced by financial reasons, where the care will be provided or who will deliver the care.

If you don’t qualify

Even if you don’t qualify for NHS Continuing Healthcare, the CCG and the council should always consider whether the assessment has shown you have care needs. If so, they should
arrange an appropriate assessment or services for you. This could include NHS Funded Nursing Care (see chapter 6).

**Good to know**

You can get NHS Continuing Healthcare for mental health care needs (including those caused by dementia) as well as physical health care needs. If you have mental health care needs, your assessment may involve a psychiatrist or other mental health professional.

The Alzheimer's Society ([0300 222 1122](tel:03002221122), [NHSCC@alzheimers.org.uk](mailto:NHSCC@alzheimers.org.uk)) runs a dementia helpline and has published a factsheets about eligibility for NHS Continuing Healthcare for people with dementia.

**Assessments for people at the end of their lives**

If you have a primary health need because of a rapidly deteriorating terminal condition which may be entering its final stages, a professional can recommend you for NHS Continuing Healthcare using the quicker Fast Track Pathway Tool assessment.

This Tool bypasses the Checklist and Decision Support Tools and should aim to ensure you receive care in your preferred location within 48 hours.

The Fast Track Pathway Tool assessment must be completed by an appropriate clinician. This could be a nurse, consultant or a GP responsible for your diagnosis, treatment or care. They should have the skills and knowledge about your needs or palliative care to make a clear recommendation about whether you are now approaching the end of life.

If a Fast Track Tool assessment recommends you should receive NHS Continuing Healthcare, this should be accepted straight away by your CCG.
How long will I have to wait?

You should receive a Checklist Tool assessment within 14 days of requesting one. If you need a full Decision Support Tool assessment, this should be done within 28 days of the CCG receiving the completed Checklist Tool or being told you need a full assessment.

If you need end of life care, a Fast Track Tool assessment should be carried out immediately and (if you’re eligible) care should be provided within 48 hours.

The final decision should be given to you and your carer as soon as possible in writing (although you may be told first in person about the outcome of the assessment). This letter should include:

- reasons for the CCG’s decision
- details of who to contact if you want more information
- a copy of the completed Tool(s)
- information on how to ask for a review or appeal if you don’t qualify
- timescales for review.
4. If your application is successful

Planning your care

If your assessment finds that you are eligible for NHS Continuing Healthcare, your CCG must identify, arrange and then monitor any services that you require to meet the health and social care needs identified in your assessment.

You should be involved in developing your care plan. The CCG should take your preferences and expectations into account, including your views about where you live and receive your care. The CCG should talk to you about the benefits and risks of care in different places (such as a nursing home or your own home) before deciding where you will receive care.

Once your care plan is agreed and you’re getting the services you need, the CCG will continue to manage your care. This should involve:

- coordinating all your services and support
- reviewing the quality of your services
- dealing with any problems or concerns
- making sure changes in your needs are met.

Personal Health Budgets

A Personal Health Budget (PHB) can give you greater choice, flexibility and control over your care by giving you a set amount of money to meet your health and care needs. Anyone receiving NHS Continuing Healthcare can ask for a PHB.

A PHB can be spent on a range of services, care and equipment – as long as it meets the needs and outcomes in your care plan. You will put together this care plan with your local NHS
team, and it will need to be approved by the Clinical Commissioning Group.

A PHB can be managed directly by you, a third party such as a family member or by the NHS. You can also receive a PHB as a direct payment. This is when the money is given to you directly to buy the services the CCG agree that you need.

More information about PHBs is available from NHS Choices (nhs.uk/personalhealthbudgets)

**Reviewing your eligibility and care plans**

Your care plan should be regularly reviewed and updated to make sure you’re getting the right care.

The CCG will also review your needs to ensure you’re still eligible for NHS Continuing Healthcare. NHS Continuing Healthcare doesn’t last indefinitely and can stop when your needs change: for example, if your condition improves.

You’ll be reviewed three months after you qualify for NHS Continuing Healthcare, and at least once a year after that. This includes if you’re at the end of your life and had a Fast Track Tool assessment.

During a review, your previous Decision Support Tool (DST) or Fast Track Tool should be looked at again. The review will consider whether your needs have changed. You and your carer should be present and consulted during any review.

If your review shows you may no longer be eligible for NHS Continuing Healthcare, a full multi-disciplinary team assessment using the DST form must be carried out before the final decision is made and any funding is withdrawn.

Once a decision has been made, you should get a letter about any changes. If the CCG decides you are no longer eligible for NHS Continuing Healthcare, you must be told how to ask for a review. Alternative funding arrangements must also be agreed.
with you and/or your local council and put into place before NHS Continuing Healthcare funding is stopped.

**Refunds and good will payments**

If the decision about your eligibility for NHS Continuing Healthcare is delayed or disputed, you may be eligible for a payment from your CCG to cover any payments you had to make in the meantime. This could be if you paid the local council or a private agency for care services and:

- the CCG took longer than 28 days to decide that you’re eligible for NHS Continuing Healthcare
- the CCG decided you weren’t eligible for NHS Continuing Healthcare but then revised its decision following a review
- the CCG decided you were eligible for NHS Continuing Healthcare after you disputed their decision.

**Can I be asked to contribute towards the cost of my care if I receive NHS Continuing Healthcare?**

NHS Continuing Healthcare is not means-tested. It should cover the full cost of both accommodation and care. However, there are specific occasions where you might be asked to make a contribution towards your care or services.

The first is if you’d like a service or accommodation that goes beyond what the CCG thinks is necessary. This could be a larger room in a care home. Or, if you were living in a care home before you became eligible for NHS Continuing Healthcare, it may be more expensive than another one the CCG thinks is appropriate for you.

However, it’s rare that you’d have to make a contribution towards your care in this case. The National Framework says a CCG should be able to identify and separately deliver the
elements of the service they are responsible for before letting you pay for a higher-cost service.

The CCG should also consider if a more expensive service or accommodation is necessary to meet your needs, or if a move from an existing care home to a cheaper home would have a negative effect on your health and wellbeing.

A second example would be if you would like a new service (or a more frequent service) that the CCG doesn’t consider essential to meeting your needs.

For example, you might be assessed as needing two sessions of physiotherapy a week, but you would like three. You could arrange and pay for an additional session from a private physiotherapist.

**How will my benefits be affected if I live at home?**

If you receive NHS Continuing Healthcare in your home, you can continue to claim disability benefits such as Disability Living Allowance (DLA), Personal Independence Payment (PIP) or Attendance Allowance (AA). If you have a carer who claims Carer’s Allowance, they can also keep this benefit.

**How will my benefits be affected if I live in a care home or hospital?**

If you live in a care home or hospital which is funded by NHS Continuing Healthcare and you receive Bereavement Allowance or Industrial Injuries Disablement Benefit, these will continue.

The amount of Pension Credit you receive won’t be affected as long as it does not contain a severe disability premium. However, you will lose your entitlement to Disability Living Allowance (DLA), Personal Independence Payment (PIP) or Attendance Allowance (AA) after 28 days.
If someone supporting you receives Carer’s Allowance, this will stop when your entitlement to DLA, PIP or AA stops.
5. **If your application isn’t successful**

If you’re turned down for NHS Continuing Healthcare, you have a right to ask your CCG to review your application if you:

- have been screened for NHS Continuing Healthcare with the Checklist Tool but haven’t been referred for a full assessment
- had a full assessment using the Decision Support Tool or Fast Track Tool and have been told you’re not eligible.

You can find the contact details for your CCG by calling NHS England (0300 311 2233) or by visiting the NHS Choices website (nhs.uk/Service-Search/Clinical-CommissioningGroup/LocationSearch/1)

**Requesting a review of your Checklist assessment**

If you had a Checklist Tool assessment but weren’t referred for an assessment using the Decision Support Tool, write to your CCG and ask them to reconsider its decision.

If possible, provide additional information about your conditions and needs in your letter. For example, if you think your score was too low for any Care Domains, can you show why this is? Is there any evidence of your needs (such as medical records or care plans) that should be considered in a new assessment?

The CCG must consider your request and write to you with their revised decision. If they still don’t think you need a full assessment, you can make a complaint using the NHS complaints procedure.
Requesting a review of your Decision Support Tool assessment

Your CCG should write to you after your assessment using the Decision Support Tool to explain whether you will receive NHS Continuing Healthcare or not. This letter should include the reasons why they think you do, or do not, qualify.

If the CCG doesn’t think you’re eligible, you can write to them and ask them to review their decision. You have six months from receiving the letter to request this review. The CCG should then carry out a review within three months (although in practice it can take longer).

You will need to explain why you’re requesting a review. You can explain if you disagree with:

- the way the assessment was carried out
- how information was used and interpreted by the assessors
- the final decision.

Your assessment will not have been carried out properly if:

- you and your carer weren’t involved
- relevant health professionals and other people caring for you weren’t invited to contribute
- the full Decision Support Tool assessment wasn’t carried out within 28 days of your Checklist Tool assessment
- the CCG changed how you were scored in a care domain, after the assessment.

You may disagree with the way information was gathered and used during the assessment if:

- you think the information recorded in your Decision Support Tool isn’t accurate or doesn’t fully describe your needs
• you can think of evidence that should have been used during the assessment (such as care plans) but was overlooked.

You may disagree with final decision if:

• the CCG didn’t explain why you don’t qualify
• the CCG didn’t follow the team’s recommendation
• you feel the CCG didn’t properly look at the nature, intensity, complexity or unpredictability of your needs.

To do...

If you haven’t already got copies of any completed tools, ask your CCG or NHS Continuing Healthcare coordinator for them.

The Independent Review Panel

If you disagree with the outcome of the CCG’s review, you can ask NHS England (0300 311 2233, england.nhs.uk) to look at the CCG’s decision through an Independent Review Panel (IRP). You have six months after the outcome of the review to apply.

NHS England may agree for your case to go straight to an IRP if using the CCG’s review process would unfairly delay things for you.

The IRP will look at:

• the procedure your CCG followed when deciding whether you were eligible for NHS Continuing Healthcare; or
• the CCG’s decision about your eligibility for NHS Continuing Healthcare.

Your IRP will collect evidence about your care needs – such as medical and care records – before meeting to discuss your case. You can ask to attend the meeting or submit your views
in writing. If you decide to attend, you can ask to someone for support or to speak on your behalf.

The IRP may recommend that your case is reconsidered by the CCG. Or the IRP may recommend you should be considered eligible for NHS Continuing Healthcare.

However, the panel could also recommend that you should not be considered eligible. The decision should be accepted by NHS England except in exceptional circumstances.

You, and any other people involved, should receive a copy of the panel’s record. If NHS England or the CCG decide not to accept the IRP's recommendation, they should explain write to you and the chair of the IRP to explain why.

To do...

You can ask Independent Age about how to make your argument for NHS Continuing Healthcare to the panel (0800 319 6789, advice@independentage.org).

The Parliamentary and Health Service Ombudsman

If you’re not satisfied with the outcome from the Independent Review Panel, you can complain to the Parliamentary and Health Service Ombudsman. You must make your complaint within 12 months of the IRP’s decision.

The Ombudsman investigates complaints and unfair decisions made by NHS bodies. Ideally, your case should already have been investigated by the CCG and NHS England before you contact the Ombudsman, but in special circumstances you may be allowed to take your case directly to the Ombudsman.
If you are unhappy with how the Ombudsman handles your case

If you feel the Ombudsman hasn’t fully considered your complaint or they have done something wrong, you can also make a formal complaint about the Ombudsman itself.

The Ombudsman’s decisions can also be subject to a judicial review. You must apply for legal advice and representation (usually within three months) if you’re not satisfied with the Ombudsman’s decision.

You can find legal specialists through the Law Society (solicitors.lawsociety.org.uk, 020 7320 5650).
Tips for appealing a NHS Continuing Healthcare decision

Getting organised:

- Ask for all the information provided and decisions made by the CCG in writing.
- Record the dates, times, names and details of conversations every time you speak to the CCG or another professional about your assessment or appeal.
- Gather all your documentation, for example care needs assessments, health records, completed Checklist Tool/Decision Support Tool/Fast Track Pathway Tools.
- Try to attend all meetings in person if you can, or ask a family member, friend or advocate to represent you.

Preparing for a review:

- Ask the CCG to explain in writing how and why they decided you weren’t eligible for NHS Continuing Healthcare.
- Write an account of your needs over a 24 or 48 hour period. Record the type and level of care you require and how your needs are managed. Record how your needs fluctuate. Consider any risks to yourself or others if care isn’t provided properly. Compare your account to the tool used to assess you – were your needs accurately recorded?
- Complete a copy of the Checklist Tool/Decision Support Tool/Fast Track Tool (depending on what stage of the assessment you are appealing). Score yourself against the care domains and think of evidence, people or examples to explain the level of your needs for each one.
- Check that all your medical and social care needs have been accurately recorded on the Tool used during your assessment, and highlight anything missed out.
Getting support:

- Find as many people who can support your case and help you show that you have a primary health need. This could include a social worker, GP, consultant, professional carer or family member.

- If you don’t have a family member or friend who can represent you at meetings or help with your appeal, ask your CCG for information about the local advocacy service.

- If you think you have a good case, you may need to be patient as the appeal process can take time. Don’t give up – many people have successfully appealed an NHS Continuing Healthcare decision.
6. NHS-Funded Nursing Care

If you do not qualify for NHS Continuing Healthcare, you may be eligible for NHS-Funded Nursing Care. This is a weekly payment of £155.05 from the NHS for people who live in a nursing home. The payment will help towards the care you receive from, or under the supervision, of a registered nurse. It doesn’t cover the accommodation, board or personal care costs of your care home fees.

It may sometimes be referred to as a Registered Nursing Care Contribution, which is the old name for this payment.

NHS-Funded Nursing Care is only paid if you are assessed as needing care in a nursing home. You’ll be assessed by a registered NHS nurse who will consider all of your nursing needs.

You should be considered for NHS Continuing Healthcare before a decision is reached about the need for NHS-Funded Nursing Care.

The payment is normally paid by the NHS to the nursing home. If you are paying for your own care, this payment should reduce the overall care home fee (depending on your contract with the home). If you’re getting funding from your local council towards your care home fees, this payment may instead reduce the local council’s contribution towards your care home fees.

For more general information about fees, see our factsheet Paying care home fees (0800 319 6789, independentage.org).
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The sources used to create this publication are available on request. Contact us using the details below.

Thank you

Independent Age would like to thank those who shared their experiences as this information was being developed, and those who reviewed the information for us.

What do you think?

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