



TOD

NHS Continuing Healthcare

Information for people with or affected by motor neurone disease

If you have health needs that are severe, difficult to manage or changing quickly, you may be entitled to NHS Continuing Healthcare (CHC). This care is funded by the NHS and you will not have to pay towards your assessed care costs. Your primary need must be health-related to qualify. This will be decided by an assessment.

The assessment for NHS Continuing Healthcare is complex, detailed and can take a while to complete. This information sheet explains what this funding is for, the assessment process and the options available.

This information sheet covers the following sections:

- 1: **What is NHS Continuing Healthcare?**
- 2: **How do I get assessed?**
- 3: **What happens if my application is approved?**
- 4: **What can I do if my application is refused?**
- 5: **What is NHS-funded nursing care?**
- 6: **How do I find out more?**



This symbol is used to highlight **our other publications**. To find out how to access these, see *Further information* at the end of this sheet.



This symbol is used to highlight **quotes** from other people with or affected by MND.

This information sheet has been evidenced, user tested and reviewed by experts.

1: What is NHS Continuing Healthcare?

NHS Continuing Healthcare (CHC) is a package of ongoing care arranged and funded by the NHS. People who have been assessed as having a 'primary health need' are eligible for CHC.

CHC can be similar to a support package from adult social care services, but covers your health needs as well as your social care needs.

You do not have to pay towards this, as it is entirely funded by the NHS. The care can be provided to you in any setting. This will be agreed between you (or your representative), the continuing healthcare team and your case manager. For more information about how your care can be provided, see section 3: *What happens if my application is approved?*

Where does this apply?

This information sheet applies to England. See *Further information* at the end of this sheet for a link to the National Framework for NHS Continuing Healthcare and NHS-funded nursing care.

In Wales, local health boards are responsible for local health services and many of the rules for Continuing Healthcare that apply in England also apply in Wales, although there are some differences. Contact Health in Wales (NHS Wales) for more information. See *Useful organisations* in section 6: *How do I find out more?*

In Northern Ireland, there is no guidance on NHS Continuing Healthcare. However, health and social care services in Northern Ireland often follow NHS guidance, so a similar package of care may be offered. Contact your local health and social care trust for advice about what is available.

If you live in Scotland, contact MND Scotland for advice on NHS services. See *Useful organisations* in section 6: *How do I find out more?* for contact details.

Who can get NHS Continuing Healthcare?

Everyone has the right to ask for an assessment for NHS Continuing Healthcare (CHC). However, you need to be referred to the continuing healthcare team at your local Clinical Commissioning Group (CCG), by a health or social care professional. CCGs are NHS organisations that organise the delivery of NHS services in England.

You may be able to get CHC if:

- you have complex health issues and a high level of skill is needed to manage your care and treatment
- you need ongoing care
- your condition is changing quickly and this is causing concerns in managing your care.

See section 2: *How do I get assessed?* for information about which health needs are considered during the assessment.



"I managed to get in touch with the right person after a few calls and we were given a little care. We struggled to get more, but had no problem with CHC once it was established...this information sheet would have helped."

Will NHS Continuing Healthcare affect my benefits?

If you are living at home and you receive Attendance Allowance (AA), Personal Independence Payment (PIP) or Disability Living Allowance (DLA) and receive NHS Continuing Healthcare, your benefits will not be affected.

If you are living in a care home or go into hospital, your AA, PIP or DLA will stop on the 29th day after your NHS Continuing Healthcare starts.

Your state pension will not be affected.



For further information about benefits, see:
Information sheet 10A – *Benefits and entitlements*

2: How do I get assessed for NHS Continuing Healthcare?

If you think you may be eligible for NHS Continuing Healthcare, ask your GP or another member of your health and social care team if they think you should be assessed (see heading *What happens during the screening process?* below).

Beacon Continuing Healthcare are able to provide people in England with up to 90 minutes of free advice on NHS Continuing Healthcare. This service is funded by NHS England. Trained advisers can give you information over the phone or in writing, at any stage of the process. You could ask for more detail, or for guidance if your application has been refused. They can also help you find out if you are likely to qualify for CHC and how to navigate the assessment and appeal processes, if needed. More than one phone call can be made, or more than one letter written, as long as the whole process is under 90 minutes.

For contact details, see *Useful organisations* in section 6: *How do I find out more?*

How will I be assessed for NHS Continuing Healthcare?

To give a full picture of how your condition affects you and the support you need, the assessment should:

- be focused on your individual needs
- take your views into account

- include your family and carers in the assessment, if wished
- involve all the professionals involved in your care.

An application for NHS Continuing Healthcare (CHC) is usually done in two stages. The first stage is a checklist which needs to be completed by a health or social care professional. This is used to decide if the full assessment is needed, which is the second stage.



“A two hour and a four hour assessment did seem excessive, particularly for someone with MND, but the interviewers were so supportive that I felt grateful for their help in navigating the paperwork and all the bureaucracy.”

All CCGs follow the same framework for their assessments, but they may interpret the guidance slightly differently. This can sometimes cause differences in people getting CHC depending on where they live. See *Further information* at the end of this sheet for a link to the framework.

What happens during the screening process?

The screening tool, known as the checklist, looks at your needs using 11 headings, known as domains. You can have an advocate, family member or anyone else involved in your care with you during the screening.

The domains are:

- breathing*
- nutrition
- continence (using the toilet)
- skin
- mobility
- communication
- psychological and emotional needs
- cognition (thinking and reasoning)
- behaviour*
- drug therapies and medication (symptom control)*
- altered state of consciousness (conditions that affect consciousness, such as seizures)*.

The checklist is determined by your level of need.

Your needs will be scored in each domain as either being A, B or C, with:

- A scoring as ‘high needs’
- B scoring as ‘moderate needs’
- C scoring as ‘low needs’.

You will need a full assessment for NHS Continuing Healthcare if you score:

- two or more As
- five or more Bs
- one A and four Bs
- an A in one of the categories marked with * above (breathing, behaviour, drug therapies and medication, or altered state of consciousness).

If you have already been screened using the checklist and your needs have since changed, ask your health and social care team to complete the checklist again.

Passing the checklist stage does not mean that you qualify for CHC. It means you need the full assessment, which is used to work out whether you are eligible.

You or your representative should be included when the checklist is being completed. You should also be told in advance that the checklist is going to take place.

The person completing the checklist should:

- record everything in detail (for example, rather than stating that you have swallowing problems, describe how these affect you in as much detail as possible. This might include how much weight you have lost, any episodes of choking or repeated chest infections)
- consider the domain for psychological and emotional needs
- be aware of the emotional impact of MND (for example anxiety about breathing difficulties or choking)
- describe your communication needs in detail (such as needing someone to set up your equipment or to support you when communicating).

The checklist can only be completed by a health or social care professional, it cannot be completed by you or a member of your family. However, you can download a copy of the checklist to see what it includes, from:

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

What happens during the full assessment?

If the checklist finds you should have a full assessment, your local continuing healthcare team will contact you and the person who referred you, to arrange for the full assessment to be completed.

The full assessment uses a Decision Support Tool (DST) to work out if you are eligible for CHC. The DST goes into more detail and has 12 domains, the 11 included in the checklist, plus one more called 'any other significant needs'. See previous heading *What happens during the screening process?* for information on the 11 domains.

In the DST, the domain scores can range between:

- no needs (the lowest level)
- low needs
- moderate needs
- high needs
- severe needs
- priority needs (the highest level).

Give as much detail as possible. If you have symptoms that are being well managed, these should still be recorded in the assessment. Ensure that anything not captured by the 11 domains in the checklist is captured in 'any other significant needs'. With MND, this may include:

- saliva and secretion management
- fatigue (extreme tiredness, even after minor activity or if you have slept well)
- emotional lability (where you experience intense emotions, or emotional responses that do not match how you are feeling).

You have a clear 'primary health need' and should be eligible for CHC if you are assessed as having the priority level of need in any of the following domains:

- breathing
- behaviour
- drugs and medications
- altered states of consciousness.

Some domains only score up to a 'severe' level of need. You have a clear 'primary health need' if you are assessed as having two domains scoring in the severe level.

Other combinations of scores may also mean you are eligible for CHC. However, if you score mostly 'no needs' or 'low needs', you would be unlikely to receive CHC. The assessment should involve a range of professionals involved in your care, who know you well. If this is not possible, there should at least be either:

- one healthcare professional and one social care professional
- two healthcare professionals from different disciplines.

If it is not possible for members of your health and social care team to be at the assessment, the CHC assessor should ask all those involved in your care for information about you that may help them complete the full assessment. You will need to give permission for them to share information about you.

If you attend an MND care centre or network, or local neurological clinic, these professionals will know your needs well.

The different professionals should use all the information they know about you to work out what levels your needs are. Your own views about your health should also be recorded in the assessment. It may be helpful to have a family member or friend with you during the assessment.

At the end of the assessment, the health professionals will make a recommendation about whether or not you have a 'primary health need' and whether you should get NHS Continuing Healthcare.



"We did not have to wait long for the CHC interviews or the final decision."

A decision should be made in 28 days, however it can sometimes take longer. If it is going to take longer than 28 days, the CCG should tell you this. If your health starts getting much worse during that period, it is possible to switch to a fast track application at any time. See next heading *Is there a fast track system?*

Generally, you should not be assessed if you are in hospital. This is because your needs may not be accurate while in a hospital setting, compared to if you were at home. However if your needs are highly complex, you may have to be assessed while in hospital, before you are discharged.



We provide an information sheet for health and social care professionals who are assessing for CHC, to better understand how MND relates to the domains. You may find it helpful to share with them:

Information sheet P7 – *NHS Continuing Healthcare for MND*

Is there a fast track system?

Yes. If your condition is getting worse very quickly and your health and social care team feel you may be reaching the end of your life, they may complete the Fast Track Pathway Tool.

There is not a strict definition of what counts as the end of life stage. It is the responsibility of the professional who knows you well to base their decision on your case and your healthcare needs at the time.



"This information sheet helped me to engage with professionals, secure the fast track option and enable a better outcome for my stepson, who also had special needs."

The Fast Track Pathway Tool will be completed by a doctor or a registered nurse and should be accepted by the CCG without delay. They may not agree it straight away if there is not enough detail, so get your referral from a professional who knows you well and has good understanding of your needs. An MND care centre or network coordinator or another member of your multidisciplinary team (MDT) may be able to give a higher level of detail.

Once agreed, your care package will be arranged as quickly as possible. This should help you find your preferred place to receive care or arrange services to support you in your own home.

3: What happens if my application is approved?

If you get NHS Continuing Healthcare (CHC), the funding will start from the date the decision was made. If you are in hospital, the funding will start from the day you are discharged.

After your assessment, you will be supported by a CHC co-ordinator or case manager, to plan your ongoing care. They will discuss with you (or your representative) what your preferences are. For example:

- how you want your care to be delivered
- who you want to deliver your care.

This is known as a personalised approach and may give you more choice and control over your care. If your care will be delivered at home, you may be able to receive your CHC as a personal health budget. See later heading *What is a personal health budget?* for more information.

What will happen to my care from adult social care services?

If you are getting support from adult social care services (through your local authority), this will now be included and managed as part of your CHC instead. Your care provider may need to change at this point, as they may not have the skills to care for you if your needs have changed. You will be involved in these conversations if this is the case. If you do not qualify for CHC, you might be eligible for some joint funding, where the NHS and your local adult social care services both pay towards your care. This is usually provided if you are assessed as having a health need.

Support from adult social care services is means tested, so you may have to pay towards that part of your care, depending on your household income and savings.

You will not have to pay towards any care costs if you get CHC.

Where will my care be provided?

CHC can be provided in your own home, a nursing care home or a hospice. However, if your care needs are highly complex, it may not always be possible to provide care in your own home.

If the care is to be provided in a nursing care home, your preferences should be taken into account. However, you cannot choose any home or location when it is being provided through CHC. You may be offered a choice from a limited range of care homes. The amount of choice will vary depending on your local CCG.

What if I currently live in a nursing home?

If you live in a nursing care home, your care co-ordinator or case manager will discuss with the CCG whether the home can continue to meet your needs. If it can, this will be paid for through CHC.

If the cost of your nursing care in the home is more than the amount of money that has been agreed through CHC, you will not be able to pay the extra money yourself. This means you may have to move to a new nursing care home, though most CCGs try to avoid this.

However, you may be asked to pay towards the nursing home if the additional cost is for a bigger room, or a room with a view, rather than for the cost of care. If you are asked to pay towards your nursing care home fees and you receive CHC, ask the home exactly what these costs are for.

What is a personal health budget?

A personal health budget is an amount of money to support your health and wellbeing needs. If you want to stay in your own home to receive care, your CHC will be provided in the form of a personal health budget.

You will have an assessment with a healthcare professional, where together you will determine what your health and wellbeing needs are. Together, you will then work out how the money will be spent on meeting these needs. With a personal health budget, you can have more choice and control over the healthcare services you receive. For example, you may be able to use the money to pay for regular carers to come into your home, known as personal assistants (PAs).

Personal health budgets are only available in England.

If you receive NHS Continuing Healthcare, it is your right to receive this as a personal health budget, if you wish to.



For full details about personal health budgets, see:
Information sheet 10F – *Personal health budgets*

How often will my care be reviewed?

If you qualify for NHS Continuing Healthcare, you will have a review after three months to make sure your care package is working well and meeting your needs. Your care will then be reviewed yearly, or more often if your health needs change.

What if my needs change?

If your care needs increase between reviews, contact your CCG and tell them that your needs have changed and you would like a review.

If your health needs decrease a lot, you may no longer qualify for NHS Continuing Healthcare. In this situation, you may need to receive care from adult social care services. You may need to pay for some of this care, depending on how much you earn or have in your savings. Your health and social care team should explain this to you if this is going to happen.

4: What can I do if my application is refused?

After the screening or full assessment, you should receive a clear written response telling you if your application has been successful.

If you are not entitled to CHC, you may need a care package from adult social care services instead.

If you do not qualify for CHC but have some health needs, the NHS may still pay in part to help you. They may pay to support certain health needs within a joint package of care with adult social care services.

They could do this by providing NHS-funded nursing care, other services or money to help meet your needs (see section 5: *What is NHS-funded nursing care?*).

In time, your needs may increase and you may then qualify for CHC. In this case, you should ask for another referral to your local CCG from a health or social care professional.

Can I appeal the decision?

If you disagree with the outcome of the assessment, you can ask your CCG to look at your case again and you can include any extra evidence you feel has been missed. This is called making an appeal. If you are still unhappy with the decision after this, then you can ask NHS England for an independent panel review. This must be done within six months.

You should be given details of how to appeal with the letter informing you about your unsuccessful application.

5: What is NHS-funded nursing care?

If you live in a nursing care home and have been assessed as not eligible for CHC, you may be entitled to NHS-funded nursing care.

Nursing costs are paid for by the NHS and cannot be paid for by your local authority. In a nursing care home, the NHS pays the care home for the nurses that work there.

If you are funding your own placement in the nursing care home and found to be eligible for NHS-funded nursing care, your fees should be reduced by the amount the NHS pays to the care home. However, each individual nursing care home may differ, so ask yours directly how it works.

You may be able to get NHS-funded nursing care if all of the following apply:

- you have been assessed as needing the services of a registered nurse
- you have been assessed as not eligible for CHC
- you live in, or are moving into a nursing care home.

You may also be able to get NHS-funded nursing care for respite care in a nursing care home.

Do I need to have an assessment?

If you have already been assessed for NHS Continuing Healthcare, this will usually give enough information for a decision to be made about NHS-funded nursing care. If another assessment is needed, your CCG will arrange this.

Can I appeal the decision?

If you are not happy with the decision made about NHS-funded nursing care, you can ask the CCG for the decision to be reviewed.

6: How do I find out more?

Useful organisations

We do not necessarily endorse any of the following organisations, but have included them to help you begin your search for further information. Contact details are correct at time of print, but may change between revisions. If you need help to find an organisation, contact our MND Connect helpline (see *Further information* at the end of this sheet for details).

Adult social care services (often called social services)

Contact details for your local adult social care services can be found through your local authority, local council or local telephone directory. You may also find the following online information from GOV.UK useful:

Website: www.gov.uk/find-your-local-council

For Northern Ireland, search for *Health and social care trusts* at: www.nidirect.gov.uk

Advicenow

Advicenow is an independent, not-for-profit website providing online information on rights and legal issues in England and Wales.

Website: www.advicenow.org.uk

Age UK

Advice and support for older people, including information on NHS Continuing Healthcare across England, Wales and Northern Ireland.

Address: Tavis House, 1-6 Tavistock Square, London WC1H 9NA

Telephone: 0800 678 1602 (advice line)
0808 808 7575 (Northern Ireland)

Email: contact@ageuk.org.uk
advice@agecymru.org.uk (Wales)
advice@ageni.org (Northern Ireland)

Website: www.ageuk.org.uk
www.ageuk.org.uk/cymru
www.ageuk.org.uk/northern-ireland

Beacon Continuing Healthcare

Provide representation for families struggling to navigate the continuing healthcare system. In depth information about Continuing Healthcare on their website.

Address: 10 Napier Court, Barton Lane, Abingdon, Oxfordshire OX14 3YT

Telephone: 0345 548 0300

Email: through the website Talk To Us page

Website: www.beaconhc.co.uk

Citizens Advice

Helps resolve legal, money and other problems through free, independent and confidential advice.

Telephone: 03444 111 444 (England)

03444 772 020 (Wales)

Website: **www.citizensadvice.org.uk**

www.citizensadvice.org.uk/wales (Wales)

Disability Law Service

Free legal advice and representation for disabled people.

Address: The Foundry, 17 Oval Way, London SE11 5RR

Telephone: 020 7791 9800

Email: advice@dls.org.uk

Website: **www.dls.org.uk**

GOV.UK

The main government online information service for people in England and Wales , including help about benefits and government support schemes. (See NI Direct for Northern Ireland).

Website: **www.gov.uk**

Health and Social Care Northern Ireland (NHS Northern Ireland)

Online information on health and social care services in Northern Ireland.

Email: through the website contact page

Website: **www.hscni.net**

Health in Wales (NHS Wales)

Online information on NHS services in Wales.

Website: **www.wales.nhs.uk**

Local Authority Welfare Rights Officers

Can advise and assist in matters relating to social care and benefits. You may find the GOV.UK online contacts for local councils useful:

Website: **www.gov.uk/find-your-local-council**

MND Scotland

Provides care, information and research funding for people affected by motor neurone disease in Scotland.

Address: 2nd Floor, City View, 6 Eagle Street, Glasgow G4 9XA

Telephone: 0141 945 1077

Email: info@mndscotland.org.uk

Website: **www.mndscotland.org.uk**

NHS 111

The NHS telephone service if you need urgent, but not life-threatening, medical help or advice. Available 24 hours a day, 365 days a year.

Telephone: 111 (England and some areas of Wales)

NHS UK

The main online reference for the NHS, including information on continuing healthcare.

Website: www.nhs.uk

NHS Direct Wales

Similar to NHS 111 service, but for Wales.

Telephone: 0845 46 47 (or 111 if available in your area)

Website: www.nhsdirect.wales.nhs.uk

NI Direct

The equivalent of GOV.UK for Northern Ireland, providing government information on a variety of welfare subjects, including health services and support for disability.

Email: through the website contact page

Website: www.nidirect.gov.uk

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References

References used to support this document are available on request from:

Email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ

Further information

The information contained in this information sheet has also been checked against the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care October 2018 (Revised).

You can download the Framework at: <http://bit.ly/CHCFramework>

You cannot complete a CHC checklist yourself, however you can download a copy of the checklist, to see what it includes, from:

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

If you have any questions about the information on this sheet, please contact the MND Connect team.

You may find the following related information sheets useful:

Information sheet 10A – *Benefits and entitlements*

Information sheet 10B – *What is social care?*

Information sheet 10C – *Disabled Facilities Grants*

Information sheet 10E – *Work and motor neurone disease*

Information sheet 10F – *Personal health budgets*

You can also refer to our main guides:

Living with motor neurone disease – our guide to MND and how to manage its impact, including guidance about your finances

Caring and MND: support for you – comprehensive information for family carers, who are supporting someone living with MND

Caring and MND: quick guide – the summary version of our information for carers

End of life: a guide for people with motor neurone disease – open and honest information about end of life care.

You can download most of our publications from our website at:

www.mndassociation.org/publications or order in print from the MND Connect team, who can provide additional information and support.

MND Connect can also help locate external services and providers, and introduce you to our services as available, including your local branch, group, Association visitor or regional MND Association staff.

MND Connect

Telephone: 0808 802 6262

Email: mndconnect@mndassociation.org

MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park,
Northampton NN3 6BJ

MND Association website and online forum

Website: www.mndassociation.org

Online forum: <https://forum.mndassociation.org/> or through the website

MND Campaigns

We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society. Many of our campaigns are related to the benefits and financial support system.

Website: www.mndassociation.org/campaigning

We welcome your views

We'd love to know what you think we're doing well and where we can improve our information for people with or affected by MND, or Kennedy's disease. Your anonymous comments may also be used to help raise awareness and influence within our resources, campaigns and applications for funding.

To feedback on any of our information sheets, access our online form at: www.smartsurvey.co.uk/s/infosheets_1-25

You can request a paper version of the form or provide direct feedback by email: infofeedback@mndassociation.org

Or write to:

Information feedback, MND Association, Francis Crick House, 6 Summerhouse Rd,
Moulton Park Industrial Estate, Moulton Park, Northampton NN3 6BJ

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