

10D

NHS Continuing Healthcare (CHC)

Information for people with or affected by Motor Neurone Disease (MND)

If you have health needs that are severe, difficult to manage or changing quickly, you may be entitled to NHS Continuing Healthcare (CHC). If you qualify, CHC support can improve your quality of life and help you get appropriate care. This information sheet explores how to apply, as this can be complicated. The content includes:

1. What is NHS CHC?
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 highlights quotes from people living with or affected by MND or Kennedy's disease.



This symbol highlights our information resources to help you explore further. Find out how to download or order printed copies in section 6: **How do I find out more?**

1. What is NHS CHC?

NHS CHC is a package of ongoing health and social care arranged and funded by the NHS. To qualify, you need to be assessed as having a primary health need.

CHC can be similar to a support package from adult social care services, but covers your health needs and your social care needs. It is designed to cover your total assessed needs you have that your local authority are unable to provide. You do not have to pay towards this, as it is entirely funded by the NHS. The care can be provided in any setting. This will be agreed between you or your chosen representative if you have one, the continuing healthcare team and your case manager.

At a glance CHC is:

- health and social care delivered to you by the NHS for free
- to help meet the extra needs that come with a new injury, illness or disability
- based on assessment by health and social care professionals
- only available for people assessed as having a primary health need (this means your main need must be health related)
- assessed on your individual needs, not because of a diagnosed condition.



See section 3: **What happens if my application is approved?**

Where does this apply?

This information sheet applies to England.

For the source guidance, see the National Framework for NHS Continuing Healthcare and NHS-funded nursing care for England at:

[gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care](https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care)

If you live in Wales

Local health boards are responsible for local health services and many of the rules for CHC that apply in England also apply in Wales, although there are some differences. Contact Health in Wales (NHS Wales) for more information.

If you live in Northern Ireland

In Northern Ireland, there is no guidance on CHC. 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

NHS CHC has been replaced in Scotland by Hospital Based Complex Clinical Care. You'll only qualify for this if your care needs must be met in a hospital. This is then followed by a financial and clinical assessment.

See Care Information Scotland for more details:
careinfoscotland.scot/hospital-based-complex-clinical-care



See section 6: **How do I find out more?** for other organisations.

Who can get NHS CHC?

Everyone has the right to ask for an assessment for CHC. A health or social care professional needs to refer you to the continuing healthcare team at your local integrated care board (ICB). ICBs are NHS organisations that arrange the delivery of NHS services in England.



"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 we had it...this information sheet would have helped."

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 causing concerns in managing your care.

Will NHS CHC 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.



See information sheet **10A Benefits and entitlements**.

2. How do I get assessed?

If you think you may be eligible for CHC, ask your GP or another member of your health and social care team if they think you should be assessed.



See heading in this section: **What happens during the screening process?**

Beacon Continuing Healthcare

This is a not-for-profit service. An independent social enterprise, partially funded by NHS England, offering up to 90 minutes of free advice on NHS CHC. They can help you find out if you are likely to qualify for CHC, and how to navigate the assessment and appeal processes, if needed.



See section 6: **How do I find out more?** for contact details.

Trained advisers can give information over the phone or in writing, at any stage of the process. This can involve more than one phone call or more than one letter, as long as the whole process is under 90 minutes. More guidance can be given if your application is refused.

How will I be assessed for NHS CHC?

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 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.

All ICBs follow the same framework for their assessments.



“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.”

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 CHC if you score:

- two or more As
- five or more Bs
- one A and four Bs
- an A in one of the following four domains:
 - breathing
 - behaviour,
 - drug therapies and medication
 - 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 doesn't mean you qualify for CHC. It means you need the full assessment to work out if you are eligible. You or your representative should be told in advance when the checklist is going to be completed and included in that process.

The person completing the checklist should:

- record everything in detail (for example, rather than just recording swallowing problems, they should describe how these affect you, such as any weight lost, episodes of choking or repeated chest infections)
- consider the domain for psychological and emotional needs
- be aware of the emotional impact of MND (such as anxiety about breathing difficulties or choking)
- describe your communication needs in detail (such as needing someone to set up your equipment or support your conversations).

Your checklist must be completed by a health or social care professional, not by yourself or a family member. To see what it includes, download the checklist at: [gov.uk/government/publications/nhs-continuing-healthcare-checklist](https://www.gov.uk/government/publications/nhs-continuing-healthcare-checklist)

What happens during the full assessment?

If the checklist result is that you should have a full assessment, your local continuing healthcare team will contact you and the person who referred you, to arrange this. The full assessment uses a Decision Support Tool (DST) to work out if you are eligible for CHC. This tool 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 under 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 should be eligible for CHC if you are found to have a clear primary health need. This is the case if you score 'severe' in 2 domains or you have a 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:

- a priority level of need
- two severe levels of need
- a severe level combined with other levels of need
- multiple high and moderate levels of need.

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.



See information sheet **P7 - NHS Continuing Healthcare for MND** which can be given to your CHC assessor.

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 members of your health and social care team cannot 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 a local neurological clinic, these professionals should know your needs well.

The different professionals should use all the information they know about you to work out your levels of need.

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 and their views should be considered if you wish.

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.

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 ICB 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.



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

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.

Is there a fast track system?

Yes. If your condition is getting worse very quickly or 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 no strict definition of what counts as the end of life stage, and it is not needed for eligibility. 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.

The Fast Track Pathway Tool will be completed by a doctor or a registered nurse and should be accepted by the ICB 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 co-ordinator 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. Fast Track funding is not awarded indefinitely and will be regularly reviewed.



“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.”

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 the time from receipt of the checklist to the decision being made is more than 28 days, the funding should start from day 29.

After assessment, you will be supported by a CHC co-ordinator or case manager, to plan ongoing care. They will discuss your preferences with you or your representative.

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.

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 that can't be provided by your local authority or NHS service.

Support from adult social care services is means tested, so you may have been paying towards that part of your care, depending on your household income and savings. However, 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, the space must be safe and meet all your health and social care needs.

If the care is to be provided in a nursing care home, your preferences should be taken into account. However, you may only be able to choose from a limited range of care homes when care is being provided through CHC. The amount of choice will vary depending on your area and local integrated care board (ICB).

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 your local ICB whether the home can continue to meet your needs. If it can, this will be paid for through CHC funding.

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 is because CHC is based on your assessed needs and not your ability to pay.

It is wrong to impose a charge on you, so ICBs will not allow you to pay for the extra costs even if they are non essential.

Your ICB will work with you during the whole process, but this means you may have to move to a new nursing care home. The ICB should demonstrate that they've tried all available options and have a duty to take into account your preferences.

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? (England only)

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. Personal health budgets are only available in England.



See information sheet **10F – Personal health budgets** .

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).

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

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 change, contact your integrated care board (ICB). Tell them that your needs have changed and you would like a review.

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 eligible for 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. For example, 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.

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

Can I appeal the decision?

Yes. If you disagree with the outcome of your assessment, you have the right to appeal.

The first stage is to ask your ICB to look at your case again, where you can include any extra evidence you feel has been missed. This is called asking for a 'local resolution'.

You have 6 months from the date of the decision to lodge your appeal.

If you are still unhappy with the decision after this, then you can ask the NHS for an independent panel review. You will be given a form which must be completed and sent back within six weeks of receiving it, along with any additional evidence or supporting statements.

It can be helpful to give yourself time to fully prepare before asking for an independent review, due to this short timescale.

You should be given details of how to appeal when you receive 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 still 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, if being delivered in a nursing care home.

Do I need to have an assessment for NHS-funded nursing care?

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 ICB 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 ICB for the decision to be reviewed.

6. How do I find out more?

Other organisations

We cannot endorse organisations, but the following may help your search for further information. Our MND Connect helpline can help you find organisations. See contact details later in this section, under the heading: Our support.

Adult social care services

Contact them to arrange a needs assessment or carer's assessment.

Website: Search for:
find your local council at **gov.uk** (England and Wales)
health and social care trusts at **nidirect.gov.uk** (Northern Ireland)
find my council at **careinfoscotland.scot** (Scotland)

Advicenow

Online information on rights and legal issues in England and Wales.

Website: **advicenow.org.uk**

Age UK

Guidance for older people, including topics like CHC.

Tel: 0800 055 6112

Website: **ageuk.org.uk**

Beacon Continuing Healthcare

Representation for families navigating the CHC system.

Tel: 0345 548 0300

Website: **beaconchc.co.uk**

Citizens Advice

Free, confidential advice to help resolve legal, money and other problems.

Tel: 0800 144 8848 (England)

0344 477 2020 (Wales)

Website: **citizensadvice.org.uk** (England)

citizensadvice.org.uk/wales (Wales)

citizensadvice.org.uk/nireland (Northern Ireland)

Disability Law Service

Legal advice and information.

Tel: 020 7791 9800

Email: **advice@dls.org.uk**

Website: **dls.org.uk**

Government information

Online government information about benefits and support.

Website: **gov.uk** (England and Wales)

nidirect.gov.uk (Northern Ireland)

gov.scot (Scotland)

Hospice UK

Guidance and a search facility for hospices in the UK.

Tel: 020 7520 8200
Email: through the website contact page
Website: hospiceuk.org

Local Authority Welfare Rights Officers

Can advise and assist in matters relating to social care and benefits.

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

MND Scotland

Care, information and research funding for people affected by MND in Scotland.

Tel: 0141 332 3903
Email: info@mndscotland.org.uk
Website: mndscotland.org.uk

NHS and UK healthcare

Information about NHS services and healthcare across the UK.

Website nhs.uk

Telephone 111 (for urgent medical advice in England, available 24/7)

Website 111.nhs.uk (For England)

Telephone 111 (for urgent medical advice in Wales, available 24/7)

Website 111.wales.nhs.uk (For Wales)

Telephone Find individual trusts in Northern Ireland on website contact page

Website hscni.net (For Northern Ireland)

Telephone 111 (for urgent medical advice, available 24/7)

Website nhs24.scot (For Scotland)

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| | |
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| Claire Lang | MND Clinical Nurse Specialist, Leeds MND Care Centre |
| Chris Blease | Information and Advice Service Manager, Beacon CHC |

References

References used to support this resource are available on request:

Email: infofeedback@mndassociation.org

Or write to:

Information feedback,
Motor Neurone Disease Association
Francis Crick House
6 Summerhouse Road
Moulton Park
Northampton NN3 6BJ

Further information

We offer a wide range of information about MND and Kennedy's disease. You may find the following resources helpful, relating to this sheet.

Information sheets

- 1A About the NICE guideline on MND
- 10A Benefits and entitlements
- 10B What is social care?
- 10C Disabled Facilities Grants
- 10E Work and motor neurone disease
- 10F Personal health budgets

Booklets

- Types of care
- Personal care
- Caring and MND - quick guide
- What should I expect from my care?

Large guides

- Living with MND
- Caring and MND - support for you
- End of life: a guide for people with motor neurone disease

Search for information by need at: mndassociation.org/careinfofinder

Find information for professionals at: mndassociation.org/professionals

Download our information at: mndassociation.org/publications

Find information in other languages at: mndassociation.org/languages

Order printed copies from our MND Connect helpline (see Our support next).

Our support

Every day we support people affected by motor neurone disease, campaign for better care and fund ground-breaking research. Because with MND, every day matters.

We also support people affected by Kennedy's disease.

MND Connect

Our helpline offers practical and emotional support, information and signposting to people with MND, carers, family and professionals. Find out more and current opening times at: mndassociation.org/mndconnect

Tel: 0808 802 6262

Email: mndconnect@mndassociation.org

Support services

Find out about our support services at: mndassociation.org/our-services

Local and regional support

Find out about our branches and groups at: mndassociation.org/local-support

MND Association Benefits Advice Service

For help to identify claims and how to apply, visit: mndassociation.org/benefitsadvice or call our MND Connect helpline.

Tel: 0808 802 6262

MND Association website and online forum

Website: mndassociation.org

Online forum: forum.mndassociation.org

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 give feedback on this or any of our information sheets, access our online form at: **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
Motor Neurone Disease Association
Francis Crick House,
6 Summerhouse Road,
Moulton Park
Northampton NN3 6BJ

Would you like to help with user review of our information?

If you are living with MND or Kennedy's disease, or you are a carer, contact us at: **infofeedback@mndassociation.org**

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