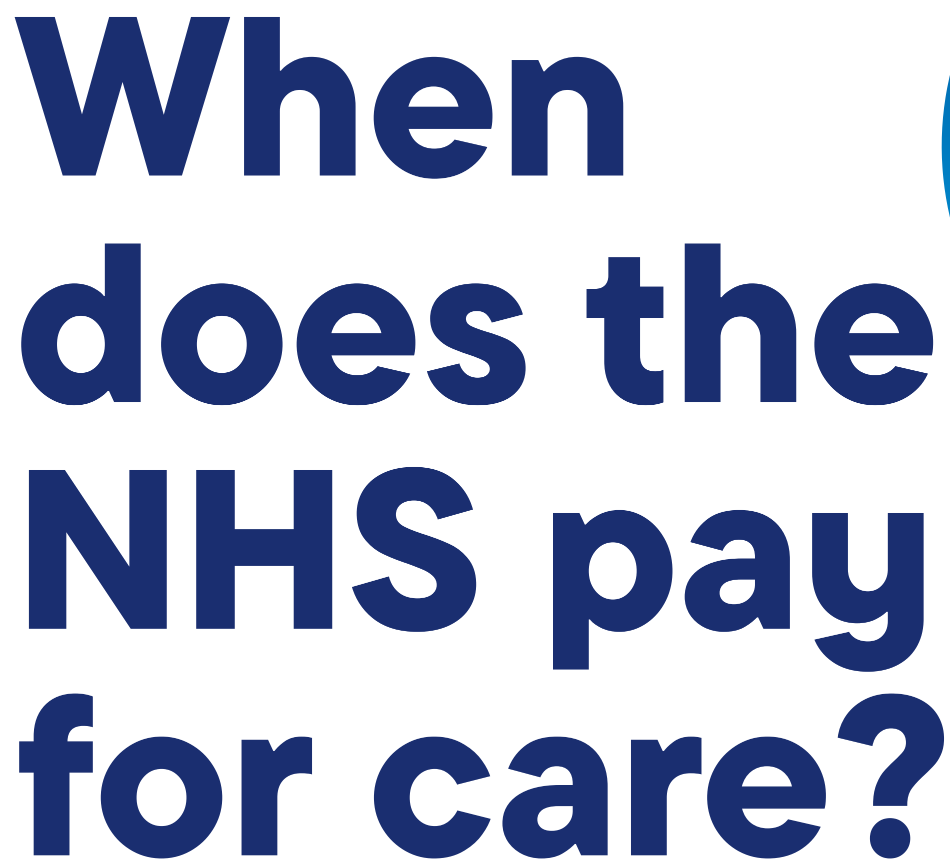
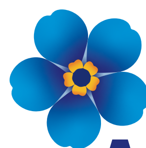


When does the NHS pay for care?

How to apply for NHS continuing healthcare in England and how to appeal if it's not awarded



Alzheimer's Society

Together we are help & hope for everyone living with dementia

“

I was desperate, alone and bewildered when I started researching information to help prepare myself for meetings with my mother’s NHS continuing healthcare assessors but this booklet is very helpful.

Carer for a person living with dementia

”

Contents

About this booklet 2

Glossary of terms to help you 3

1 NHS continuing healthcare and who can get it 6

2 Assessments for NHS continuing healthcare 15

3 Appealing against decisions and the complaints procedure 28

Appendices 42

Other useful organisations 48

References 51

About this booklet

Dementia can affect people differently but, in general, symptoms do get worse as the condition progresses. This means the person's needs will change and there may come a time when they need a lot more care and support. If the person with dementia has a health support need, they may be eligible for NHS funding. This comes under NHS continuing healthcare (CHC).

This booklet is for carers or representatives (partner, friend or family members) of a person with dementia. It explains how you can apply for CHC and what the process involves. It also describes who is eligible for CHC, how you might be able to get it and what to do if your request is turned down.

To better understand what CHC is, see 'NHS continuing healthcare and who can get it' on page 6. You might also want to look at the NHS leaflet explaining CHC. See link for this leaflet under 'NHS' in 'Other useful organisations' on page 49.

Applying for CHC can be difficult and emotional. Our guidance and practical tips can help you. It may also help you to talk to others who are going through the same process. See 'Emotional and peer support' on page 19.

The information in this booklet only applies to people who live in England. See 'Other useful organisations' on page 50 for NHS continuing healthcare in Wales and Northern Ireland.

Glossary of terms to help you

There are specific terms that are used a lot throughout the CHC process. We have listed these on the next two pages to help you understand their meaning and how that can help you.

The Checklist and Checklist screening

The CHC checklist (the Checklist) is a 'light-touch assessment' document. It is used to see who may qualify for CHC and who should then receive a full assessment. This is sometimes known as 'screening'.

The Decision support tool (DST)

The Decision support tool helps assessors evidence a person's care needs in one document. An assessor is someone who carries out an assessment to see whether a person is eligible to receive CHC funding. They may be a health and social care professional, such as a registered nurse or GP. They may also be local authority staff, such as a social worker, care manager or social care assistant. Assessors use the DST during a full assessment. It helps them decide whether a person can receive CHC funding.

The Fast-track pathway tool

The Fast-track pathway tool is a quick process assessment tool. It is used to work out whether a person is eligible to receive CHC funding. This should happen when a person is near the end of their life. It could be a condition that is getting worse very quickly and may be reaching a final (terminal) stage.

Independent review panel (IRP)

If the ICB decides a person is not eligible for CHC, NHS England can set up an independent review panel. The IRP will decide whether the ICB followed the correct procedures when it assessed the person. The IRP will tell the ICB its decision and the ICB should follow this decision.

Integrated Care Board (ICB)

An Integrated Care Board is the body responsible for local NHS services. It carries out assessments and makes decisions about Funded Nursing care and CHC. Integrated care boards (ICBs) replaced Clinical Commissioning Groups in England from 1 July 2022. The ICB is responsible for providing and funding CHC if it is awarded.

Lasting power of attorney (LPA)

A Lasting power of attorney is a legal tool that allows the person with dementia to appoint someone to make certain decisions on their behalf. This is if they aren't able to make the decisions themselves. There are two types of LPA. One covers decisions about a person's finances and property. The other covers decisions about their health and welfare. For more information see factsheet 472, **Lasting power of attorney**.

Mental capacity

'Mental capacity' is the ability to make a particular decision at a particular time. This can affect a person with dementia. A person's ability to make decisions can change over time and they may be able to make some decisions but not others. If a person does lack capacity to make a decision, someone will need to make the decision for them. See Appendix 2 The Mental Capacity Act 2005 on page 47, and factsheet 460, **Mental Capacity Act 2005** for more information.

Multidisciplinary team (MDT)

The MDT is the team of people who come together to carry out a full assessment for CHC. The team must include at least two people from different healthcare professions. This could be a GP, a consultant or a community mental health nurse. It must also include a healthcare and social care professional. These must be trained and qualified to assess people for care services. Examples include social workers or care managers. It is important that other health and social care professionals who are involved in the person's care are also included in the MDT, where possible.

The National framework

The National framework, referred to in this booklet as 'the Framework', includes the CHC practice guidance. This is a long document produced by the NHS. It describes the process that all ICBs and professionals must follow when they carry out assessments. The Framework is not legally binding, but ICBs must 'have regard to it' to comply with NHS Standing rules. 'Have regard to' usually has a specific meaning in law – it means to follow unless there is good reason not to do so.

NHS England

NHS England is the national organisation that runs the NHS in England. It oversees local services, such as hospitals and GP practices. It is also responsible for setting up independent review panels. See 'Independent review panel (IRP)'.

Nursing home

A nursing home provides nursing care in addition to day-to-day personal care and has a registered nurse on duty 24 hours a day. Nursing homes are registered with the Care Quality Commission (CQC).

The Practice guidance

The CHC Practice guidance is part of the National Framework. See 'The National Framework'. It helps professionals to follow the process of CHC to carry out their role.

Primary health need

A 'primary health need' is a key term that is used to decide who is eligible for CHC. If your primary need is for healthcare rather than social care, then you are said to have a primary health need. This means you should receive CHC funding.

Representative

Throughout this booklet, you will see the term 'representative' used. This is a carer, family member or friend who is supporting the individual through the process. It also includes anyone acting in a more formal capacity. This can be a Lasting Power of Attorney or a Deputy (both for Health and Welfare or Property and Affairs).

Residential care home

A residential care home helps its residents with personal care such as washing, dressing and eating. Residential care homes also have to be registered with the CQC.

1 NHS continuing healthcare and who can get it

This chapter explains the difference between healthcare and social care. It describes what NHS continuing healthcare (CHC) is. It also explains who can get it and how decisions are made. For information about the assessment process, see '**Assessments for NHS continuing healthcare**' on page 15.

In this section

The difference between healthcare and social care 7
What is NHS continuing healthcare (CHC)? 8
Key points to keep in mind 10
The 12 care domains 12
The Fast-track pathway tool 14

1

The difference between healthcare and social care

Healthcare and social care are separate things, but it is sometimes difficult to know the difference. This is particularly true for people living with dementia.

The difference between healthcare and social care is very important. It decides whether the NHS or local authority is responsible for meeting a person's care needs. They may arrange or provide the care a person needs or allocate a budget for the person to arrange it themselves. Any decision about who is responsible for meeting care needs can have a big impact in deciding who pays for it.

There are two organisations in the UK that are responsible for funding care to meet people's needs. These are the NHS and local authority social services. Here are the main differences in healthcare and social care:

- **Healthcare** is provided and funded by the NHS and it is free of charge for the patient.
- **Social care** is provided by local authority social services. However, it is not always funded by them. People may have to pay for it, depending on how much income or savings they have.

Social care includes helping someone with dressing, mealtimes or getting out and about. Healthcare includes treating, controlling or managing an illness, injury or disability.

It's all so unfamiliar and complicated. I've never had to do something like this before. But I feel I've got justice now and had my say.

Carer for a person living with dementia

What is NHS continuing healthcare (CHC)?

NHS continuing healthcare (CHC) is not a particular type of care, treatment or support. The Department of Health and Social Care defines NHS continuing healthcare as:

'a package of ongoing care that is arranged and funded solely by the NHS where the individual has been assessed and found to have a primary health need as set out in this National Framework. Such care is provided to an individual aged 18 or over, to meet health and associated social care needs that have arisen as a result of disability, accident or illness.'

This means that someone who is assessed as being eligible for CHC will have all the care they need paid for by the NHS. This is for both their health and social care. They will not have to pay themselves regardless of their income or savings.

This package of care can be provided in a care setting or in a person's own home. It will meet all the person's needs that were identified during their assessment for CHC, including social care.

For someone in a care home, CHC covers all their healthcare and social care costs. It also covers regular board and accommodation costs such as food. For someone who is receiving CHC in their own home, social care will still be included in the care package. However, other living costs such as rent, mortgage payments and utility bills will not usually be covered. Accommodation costs are only covered where specific accommodation is necessary to meet health needs.

What is a primary health need?

NHS England uses the idea of a 'primary health need' to decide who is eligible for funding. This helps to decide which treatment and health services the NHS should provide and pay for. It also decides which services local authorities should provide and may charge for.

People are not entitled to CHC just because they have a certain diagnosis, such as dementia. Eligibility is not based on the reason they need help or support. The decision whether someone is eligible for CHC will be based on their needs not their condition.

The Framework says that:

"An individual has a primary health need if, having taken account of all their needs (following completion of the Decision Support Tool), it can be said that the main aspects or majority part of the care they require is focused on addressing and/or preventing health needs."

Although the care a person needs may protect their health and sustain their life, it does not mean that it will be considered healthcare. For example, food, drink, and warmth are personal social care needs. You can be very dependent on care and support, but what you need to keep you healthy could fall under personal social care.

If a person is assessed as having a primary health need, they are eligible for CHC. The NHS is then responsible for providing funds to meet all of their needs. This can include social care, such as help to wash and dress, if it is part of the person's overall need.

If the person's main needs are assessed as social care rather than healthcare, then they will not be eligible for CHC funding. The local authority will assess their needs and finances. Depending on the results of that assessment, they may fund some or all of the person's care.

For more information see factsheet 532, **Paying for care and support in England.**

A local authority isn't legally allowed to meet health needs which are the responsibility of the NHS. However, if someone is assessed as not having a primary health need, but does have some health needs, the local authority may be able to help. This will depend on whether the health needs are 'incidental or ancillary' to their social care package - and of a nature which a local authority can provide. For example, local authorities may sometimes administer medication in addition to a social care package. But if a person is assessed as only needing administering medication, the NHS would be responsible for this, not the local authority.

Any decision on whether someone is eligible for CHC must only be based on the person's care needs. Their financial situation, or any budget restrictions by ICB, should not affect whether the person is eligible. The decision should also not be affected by where the person lives or their relationship to the person who cares for them. For example, it doesn't matter if they live at home and their carer is a family member rather than a health or social care professional.

1

1

Key points to keep in mind

- Just because a person has dementia, it doesn't mean they are automatically entitled to CHC.
- You don't need to be living in a care home or a nursing home to be found eligible for CHC.
- A person with dementia will be eligible for CHC if they are assessed as having a 'primary health need'. This means managing health issues is the most important aspect of their care.
- If a person's main needs are assessed as being for social care, such as help with getting dressed, rather than healthcare, then they will not be eligible for CHC funding.
- Although the care a person needs may protect their health and sustain their life, it does not mean that it will be considered healthcare.
- A solicitor is not needed to make a claim for CHC, or appeal against a decision. Some people choose to pay for professional expertise as CHC is a complex topic. Success is still not a guarantee.
- If you are refused CHC at the Checklist or assessment stage, there is no time limit on when you can restart the process by applying again. Some CHC specialists recommend three to six months.
- If the person's needs have changed since their last Checklist or assessment, you should apply again as soon as possible.
- If CHC is awarded, it is not guaranteed for life. You will have regular reviews. Even if a person's condition worsens, CHC may be withdrawn if their healthcare needs change.
- Whether a person is eligible for CHC funding or not, they can still access NHS services. This means they can still get support from their GP and community nursing team, and receive hospital care.
- CHC and the NHS Funded Nursing care contribution are not the same thing. See NHS Funded Nursing care on page 26.
- The CHC assessment process can be difficult and exhausting. It may help you to talk to others and have support. See 'Emotional and peer support' on page 19.
- If you need to appeal, ask about timescales at the beginning of the process as they can vary. Make a note of these so you don't run out of time.
- Professionals should either 'complete' or 'refer' to the ICB for the completion of a Checklist wherever there 'may be a need'. If someone requires a long-term care home placement with nursing, or has significant support needs, a Checklist would be expected to be completed.

Deciding if someone has a 'primary health need'

A person will need to have an assessment to decide whether or not they have a primary health need.

All ICBs should have a staff member who arranges CHC assessments. They are usually called co-ordinators. All assessments should follow the process set out in the Framework.

Health and social care staff involved in the person's care should identify when the person needs to be assessed for CHC. However, this does not always happen. An assessment can be requested by a person with dementia or their representative by contacting the ICB directly. See 'Other useful organisations' on page 48.

The assessment may take place in two stages. The first stage is usually the Checklist screening carried out by a health or social care professional. The second stage is usually a full multidisciplinary team (MDT) assessment. This is where the ICB will use the Decision support tool (DST) to help decide whether the person has a primary health need. However, if the person is nearing the end of their life, the ICB will use the Fast-track pathway tool.

See 'Assessments for NHS Continuing Healthcare' on page 15 for a full explanation of the assessment process.

Top tip

Before an assessment for NHS continuing healthcare, get a copy of all the documents that relate to the assessment process. This includes the Framework and the Decision support tool. These documents are available on the gov.uk website. See 'Other useful organisations' on page 48. Use these to do your own assessment of the person's needs. Also gather any of the person's care or medical records that you think will help the assessors make a decision. Speak to their treating clinicians who may also be supportive.

1

The 12 care domains

The Checklist and the Decision support tool are used during the assessment process to decide if someone can receive CHC funding. They aim to assess and record a person's needs across areas known as 'care domains':

1. **breathing** - such as shortness of breath requiring inhalers
2. **nutrition** – food and drink, such as difficulty swallowing
3. **continence** - such as use of catheters or experiencing chronic urine infections
4. **skin** - such as pressure ulcers
5. **mobility** - such as risk of falls, difficulties standing or walking
6. **communication** - such as signing, Braille, pictures, hearing aids or other communication technology
7. **psychological and emotional needs** - such as distressing hallucinations or anxiety
8. **cognition** - such as disorientation to people, place and time
9. **behaviour** - such as aggression or lack of inhibition
10. **drug therapies and medication** – symptom control, such as help managing medication
11. **altered states of consciousness** - such as seizures or transient ischaemic attacks (mini-strokes)
12. **other significant care needs**.

At the Checklist stage, a person's needs in each care domain are assessed and scored as either A, B or C. The Checklist describes in detail what needs the person may experience to be assessed as having each score. The 'other significant care needs' domain is not included at the Checklist stage.

At the full assessment stage, a person's needs in each care domain are assessed and scored as being none, low, moderate, high, severe or priority. However, not all six scores apply in all the domains. More detailed explanations can be read in the user notes in the DST under the heading for each domain.

Key characteristics

If someone is referred for a full assessment for CHC, it is important that the '12 care domains' are not looked at in isolation. A person's needs in each area must also be considered in relation to the following key characteristics:

- **nature** – if the person has physical health, mental health or psychological needs. Their effect on the person and the type of treatment they need will be considered
- **complexity** – how different symptoms interact to make the care that the person needs more complex
- **intensity** – the amount and severity of the person's needs and the support they need to meet them, including if they need ongoing care
- **unpredictability** – if there are unexpected changes in the person's condition and how these affect their level of risk and care needs. This relates to the level of risk to the person's health if they don't get the care they need.

The completed DST should outline exactly what care needs the person has in each different domain. This should be in relation to the four key characteristics listed on page 12. The information is then used to help decide whether the person has a primary health need and is eligible for CHC funding.

The summary sheet in the DST says that either of the following would indicate that the person has a primary health need if:

- they have needs in any one of the four domains where a priority score is possible (behaviour, breathing, drug therapies and medication, and altered states of consciousness) or
- they have two or more severe needs across all the care domains.

The DST also says that, depending on the combination of the person's needs, a 'primary health need' may be indicated where a person has:

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

It is important to understand that many needs or a group of needs do not always add up to a primary health need. For some people it will be having a combination of a number of lower-level needs that means they have an overall primary health need. However, there is no clear definition.

The DST is only a guide and it is sometimes hard to say when a person's needs add up to a primary health need. This can make the assessment process complicated. The DST states that all the factors that affect a person's care needs must be considered to decide whether they are eligible for CHC. This includes how the person's different care needs interact, their overall need and any risk assessment evidence.

It is important to remember that the DST is only a tool that informs decision making. It does not give any absolute criteria, rule or set of rules that say what qualifies as a 'primary health need'. Each person's needs will be different. The DST must be used as a tool to gather information and not simply a tick-box exercise.

The Fast-track pathway tool

A person with dementia who is nearing the end of their life may be assessed as having a primary health need. They may urgently need CHC funding. This can help them to receive end-of-life care at home. In these cases, the assessment process outlined in chapter 2 'Assessments for NHS continuing healthcare' on page 15 should not be followed.

It can be difficult to know when a person with dementia is nearing the end of their life, unless they have another condition such as cancer. Signs that death is imminent can include being unable to take food or fluid, a low level of consciousness and difficulty breathing.

However, the Fast-track pathway tool can be completed by an appropriate clinician prior to these types of symptoms. Eligibility is based on whether a registered nurse or doctor assesses that the person has a 'rapidly deteriorating condition which may be entering a terminal phase'. No time frame needs to be specified.

2 Assessments for NHS continuing healthcare

To see if someone can get CHC funding, they must have their needs assessed by their Integrated Care Board (ICB). This can be straightforward for people with clear healthcare needs. But for more complicated cases, it can be a difficult and emotional process.

This chapter can help you to prepare for the complex assessment process. It explains the assessment stages, important steps you need to take and what to expect. It also highlights the emotional aspect of the assessment process and the need for support.

If you are not happy with the outcome of an assessment, you can work through the local review and appeal process. For more information see Chapter 3 ‘Appealing against decisions and the complaints procedure’ on page 28.

In this section

Involvement and consent	16
How to get an assessment	17
The assessment process	18
If NHS continuing healthcare is awarded	23
If NHS continuing healthcare is not awarded	26

Involvement and consent

The person with dementia should be supported to take part in the assessment and reviews with their representative. Their views should be considered. There are also legal rules about getting the person's consent to some parts of the process. These include consent to any physical examination and to the sharing of personal information with family and friends.

If the person has the ability (known legally as the 'mental capacity') to consent to these things, then it is their right to do so or not. If they don't consent, the professionals involved should explain the consequences of refusing to them.

If the professionals have to proceed on the basis of existing paper records only (which they could do) that may result in a less accurate assessment. A physical examination or the views of friends or family may help to build a more complete picture.

If the person lacks the mental capacity to consent to a physical examination or to information sharing, a best interests decision will need to be made. This is in line with the Mental Capacity Act 2005. This decision will usually be made by the professionals involved. They must take account of the views of those caring for the person, and the wishes and feelings of the person themselves. But if the person has an attorney (LPA) or deputy for health and welfare, they will be able to decide.

Whoever is making the decision should take account of the views of the person themselves and of those close to them. Even if it is decided it is not in the person's best interests to proceed with a physical examination and/or information sharing, the assessment could still go ahead without them.

For more information about mental capacity and best interests decision making see factsheet 460, **Mental Capacity Act 2005**.

How to get an assessment

It is the ICB's role to assess a person's needs if there's a chance that they will be found eligible for CHC. This is a fairly low threshold as there doesn't need to be information which shows that they will be eligible, only that there is a prospect of this happening.

If you don't know whether an assessment has been carried out or if you want to request one, contact your local ICB. Ask to speak to the CHC co-ordinator. You can find the ICB's contact details at your local GP surgery or on the NHS website. See 'Other useful organisations' on page 48. You can ask the ICB for information about the assessment process, including the National Framework and the Decision support tool (DST). Whether or not the person is found eligible for CHC, if their needs change in the future it is important to ask for them to be reassessed.

Top tip
Good record-keeping is important for an assessment. Recording the date, time and name of a person to contact plus brief summaries of all conversations will help the assessment process. This includes discussions with staff from the ICB, hospital, GP, care home and social services. Unfortunately notes made by professionals in their own records may not always be detailed.

The assessment process

The assessment process will usually have two stages:

Stage one - Checklist screening

The first stage involves a 'simpler' assessment to see if the person could be eligible for CHC. This is called a 'Checklist screening'. If this stage shows that the person may be eligible, the second stage will be for them to have a full assessment. See 'Stage two – Multidisciplinary team (MDT) assessment' on page 20.

For most people who are applying for CHC, they will need to go through a Checklist screening. However, some people may not have the Checklist screening. They would go straight to the full assessment using the DST and the full multidisciplinary team (MDT). This would be the case where health and social care professionals decide that it is not necessary to use the Checklist.

The Checklist does not show that a person will necessarily be eligible. It only shows whether they should have a full assessment to see if they should receive CHC.

The Checklist can be completed by a variety of health and social care professionals who have been trained to use it. This could include registered nurses, GPs and other healthcare professionals, social workers, care managers or social care assistants. As far as possible, these should be staff whose day-to-day work involves assessing or reviewing people's needs.

The professional completing the Checklist should compare the needs of the person with dementia to the descriptors in each care domain. See 'The 12 care domains' on page 12. Note that the 'other significant care needs' domain is not included at the Checklist stage.

A positive Checklist

The Checklist uses A, B and C to score each domain. A person will require a full assessment if:

- an 'A' has been selected in two or more care domains, indicating a high level of needs
- a 'B' has been selected in five or more domains, indicating a moderate level of needs
- one 'A' and four 'B's have been selected
- one 'A' has been selected in any of the following four domains: altered states of consciousness, breathing, behaviour or symptom control. Any level can be selected across the other domains.

Staff can recommend that a person has a full assessment even when this threshold is not met.

Remember that the Checklist has a fairly low threshold. This means that, although many people may meet the criteria at this stage, they may not be eligible for CHC after the full assessment.

A negative Checklist

At the Checklist stage it may be decided that the person doesn't need a full MDT assessment. If this is the case, the ICB should clearly communicate this to the person and their representative. A full assessment can still be requested and the ICB must fully consider this request.

If you disagree with a negative Checklist, you can ask the ICB to reconsider. Include any additional information you think is relevant. Plus, which scores you think should have been assessed differently. If you disagree with the final decision, you can follow the NHS complaints procedure. See page 41.

The person may have a negative Checklist but have been assessed as having nursing needs that would be best met in a nursing home. If this is the case, they may be eligible for Funded Nursing Care Contribution instead. See 'NHS-funded nursing care' on page 26 for more information.

Top tip

If professional carers are involved in the person's care, encourage them to keep full notes about their daily needs. These notes can then be used during the assessment along with information from other professionals, such as the person's GP.

Emotional and peer support

Whether CHC funding is or isn't awarded, the process of getting a decision can be exhausting and stressful. Especially if you feel strongly that the person has a case and need to appeal.

You may have moments of frustration, upset and worry. But you may also have moments of success and hope. Your efforts are helping the person with dementia to have their health needs met. But it is important that you take care of your own health needs too.

If you feel you are becoming stressed and overwhelmed, it may help to talk to other people. This can be your GP, family and friends, or others in your situation. If you have a good relationship with a professional involved in the CHC process, it may help to share your worries with them. When you are concerned for a vulnerable person's needs, it is only natural to have strong emotions. These feelings are common and expected.

You may find it helpful to read our health and wellbeing tips for carers in our factsheet 523, **Carers – looking after yourself**.

You may also like to talk to others who are going through the CHC assessment process. There is a support thread dedicated to CHC on our online community Dementia Support Forum. This is a place where people can share experiences, ask questions and get practical tips. Visit **forum.alzheimers.org.uk**

Stage two – Multidisciplinary team (MDT) assessment

The MDT assessment is the full assessment for NHS continuing healthcare. The aim of this assessment is to consider a person's physical, mental, psychological and emotional needs. This is to build a complete picture of their care needs.

When a person has been referred for a full assessment, the MDT must assess whether a person has a primary health need. This is usually after the Checklist has been used.

2

The MDT will do this using the Decision support tool (DST). This tool records a person's care needs to help determine whether they have a primary health need. The DST ensures assessments for CHC are as consistent as possible across the whole country.

The Integrated Care Board (ICB) will identify someone to co-ordinate the MDT assessment. This person will be responsible for the assessment process until the decision has been made and a care plan has been written.

The key health and social care professionals who are involved in the person's care should contribute to the assessment by being part of the MDT. If a professional can't be part of the MDT, they can at least be asked to provide evidence for the assessment.

The Framework defines an MDT as: '… a team consisting of at least:

i) two professionals who are from different healthcare professions, or
ii) one professional who is from a healthcare profession and one person who is responsible for assessing persons who may have needs for care and support under part 1 of the Care Act 2014.'

This means that the MDT will include at least two healthcare professionals. Or a healthcare professional and someone from the NHS or the local authority. The Framework makes it clear that the MDT should include health and social care professionals who know about the person's needs. This may be in addition to the two mandatory MDT members.

The MDT's job is to look at all the evidence about a person's care needs. Using the DST, they must record their findings and make a recommendation to the ICB. This recommendation is whether or not the person has a primary health need.

The assessment should consider the person's wishes about how and where care is delivered. These wishes should be documented, for example in an advance statement.

For more information see factsheet 463, **Advance decisions and advance statements.**

The person and their representatives should receive the advice and information they need to take part in the assessments. This would include information for discussions about future care.

During the process you may find it useful to compare the findings of the MDT with what is stated in the Framework and the Practice guidance. See 'Glossary of terms to help you' on page 3.

There is a section in the DST where the person's representative can say what they think the person's care needs are. They will have their views recorded. If the person's representative disagrees with any part of the assessment, this should be recorded too. It is very important that you do this.

The ICB must keep the person's representative fully informed at all stages of the assessment. Any decisions must be recorded in the person's notes.

When and where assessments can take place

CHC assessments should be carried out at the best location for the person with dementia. This should normally be a community setting such as the person's own home, a care home or a nursing home.

Assessment should also take place when their ongoing needs are clearer. If someone has been discharged from hospital, this will usually be after a period of recovery, where possible.

To ensure that everyone involved with the person's care can make the assessment, ICBs now offer virtual assessments. This is where participants dial in using video-tele-conferencing. Sometimes the meeting will be a hybrid, with some people attending face-to-face and some people making use of technology. This can be helpful, allowing professionals to attend despite busy workloads. It can also be helpful for people with mobility issues or other barriers such as transport to attend meetings.

However, a virtual assessment may not suit everybody. If you would prefer a face-to-face assessment and the ICB haven't offered one, let them know. ICBs must consider the best option for the individual.

Top tip
Create a medical history for the person you are caring for. For example, write down all their past and current medical conditions and treatment. This will be useful when they are being assessed for CHC and for challenging a decision, if necessary. Keep this medical history regularly updated.

Results of the assessment

ICBs should follow the MDT's recommendation, except in special circumstances. The ICB should inform you in writing about the outcome of the assessment, with a clear explanation of how the decision was reached. It should also include written information about how you can request a review of its decision.

This should be within 28 days of them receiving the completed Checklist, but it can take longer. If there is a delay without good reason, any care costs from the 28th day should be backdated.

If you disagree with the decision, you can challenge it. For more information on what to do if you disagree with a decision see 'Appealing against decisions and the complaints procedure' on page 28.

Top tip

When you are applying for or challenging a decision on CHC, put your case in writing and keep a record of all correspondence. Even if you have been successful and the person has been found eligible for CHC, make sure you receive a copy of all the relevant paperwork. This includes the completed Decision support tool (DST). This can be helpful in the future, especially if CHC is withdrawn at a later date.

Each care domain has a maximum level of need. Some common difficulties for people with dementia such as communication, cognition and nutrition cannot be scored as a priority in the Decision support tool (known as a DST).

Continence and emotional needs don't even carry the lesser 'severe' level of need. This can make it more difficult for people with dementia to succeed in claiming CHC. However, it is still possible to be assessed as having a primary health need even without those levels being available.

If NHS continuing healthcare is awarded

If someone is successful and receives CHC, they will not have to pay any of the costs of their care. The NHS will pay the full cost. The care can be provided in any setting which can meet their needs, whether the person is in a nursing home, a residential care home, or their own home.

Some people who are awarded CHC may already be living in a care home. If the ICB doesn't normally pay for services in that particular home, it will need to talk to the care home. This is to make sure they can properly meet the person's care needs. Sometimes the ICB might want to move the person to another home which costs less and has available beds.

The care and support that the person prefers may be more expensive than other options. Although cost is important, the person's needs and preferences should be the starting point for agreeing their care. Changes to homecare packages or care home places can be confusing for people with dementia. They often prefer familiarity and routine.

If you disagree with the care that is offered, try to solve the problem locally by discussing it with your ICB. Discuss any changes you think could be a risk to the person's health and wellbeing, and why. If this doesn't work, you may be able to complain. For more information see Chapter 3 'Appealing against decisions and the complaints procedure' on page 28.

You cannot top-up CHC packages like you can social care packages. But you can pay for additional private services, separate to the funded package. An example is aromatherapy. Any top-up should not be necessary to meet the needs identified in your care plan. If you don't think the package you have meets your needs you can ask for a review.

Personal health budgets

Adults who receive CHC have a right to receive their funding as a personal health budget. This is money to support their health and wellbeing. The person or their representative and the local CHC team will plan how to use the money. The plan will set out:

- the person's health and wellbeing needs
- the health outcomes they want to achieve
- the amount of money in the personal health budget
- how to spend the money – for example employing a personal assistant to help with personal care or to help the person go to a social event.

A personal health budget gives the person more freedom to manage their healthcare, in a way that suits them. This may include treatments, equipment and personal care. It is similar to a 'personal budget', which allows people to manage and pay for their social care needs.

However, a personal health budget will not be helpful for everyone, and it won't always be the best way to receive support. Ask the CHC co-ordinator at your local ICB for written information about how personal health budgets work.

Benefits and CHC

If the person receives benefits and is found to be eligible for CHC, you will need to inform the Department for Work and Pensions.

If someone receives CHC at home, benefits will usually continue as normal. This includes state pension, pension credit and disability benefits. For example, Personal independence payment and Attendance allowance.

If someone receives CHC in a care home, Attendance allowance and the care part of Personal independence payment will usually stop after 28 days. State pension and the mobility part of Personal independence payment will continue. Pension credit can continue, but the amount may change.

If someone receives CHC in a nursing home, Attendance allowance and both parts of Personal independence payment will usually stop after 28 days. State pension will continue as normal. Pension credit can continue, but the amount may change. If their carer receives Carer's allowance, this may also be affected.

If you are unsure about benefit entitlements, contact your local Citizens Advice or Age UK. See 'Other useful organisations' on page 48.

Periodic reviews after being found eligible

A person's eligibility to receive CHC is reviewed regularly. This is known as a 'periodic review'. Even when someone has been through the assessment process and has been found eligible, their case will be reviewed again. This is usually after three months and then every year. It will also be reviewed if the person's care needs change.

It is not unusual for a person who has complex healthcare needs to have their CHC funding removed after a periodic review. Removal of funding does not imply improvement; it's the needs that have changed. A person may have increased personal care needs but the healthcare interventions may have lessened or stabilised. You can appeal against this decision. For more information about how to appeal, see 'Appealing against decisions and the complaints procedure' on page 28.

If you appeal against the decision, the ICB will need to show why the person is no longer eligible for funding. This means they must show how the person's needs have changed. However, if the ICB says that the person's need has stabilised as their condition is now well-managed, this isn't a reason for the person not to receive funding. The framework is clear that "Only where the successful management of a healthcare need has permanently reduced or removed an ongoing need, such that the active management of this need is reduced or no longer required, will this have a bearing on NHS Continuing Healthcare eligibility."

If the person is no longer eligible for CHC following review, the co-ordinator should contact the local authority. This is to assess the person's care and support needs. After this assessment, the local authority will assess the person's finances to work out how much they should pay. It is important to think about how the person would meet these costs if the CHC funding is removed at any stage.

If the ICB's decision is overturned in the future, any costs that have been paid in the interim by the person or the local authority will be repaid.

If NHS continuing healthcare is not awarded

When CHC is not awarded, the person with dementia may be referred for social care. They may also be referred for other types of funding, such as NHS-funded nursing care and joint health and social care packages. It can help to ask what other funding options are available.

NHS-funded nursing care

The criteria to receive NHS-funded nursing care are lower than the criteria for CHC. This means a person may be eligible for NHS-funded nursing care even if they are not awarded CHC.

NHS-funded nursing care is not a fully funded package of care like CHC. It is a set amount that is paid by the NHS to go towards the cost of a person's nursing care. NHS-funded nursing care is only available to people who are in a nursing home. You may be eligible for the contribution whether you are a permanent resident or your stay in the nursing home is short-term, for example, respite.

A person who moves into a nursing home should automatically be considered for NHS-funded nursing care. However, they should be assessed for CHC beforehand.

NHS-funded nursing care contribution is paid directly to the person's nursing home. This means it is often difficult to know whether a person is receiving it. If you're not sure, ask the nursing home for a written breakdown of how the fees are being covered.

To decide who will meet the care costs that are not being covered by NHS-funded nursing care, the local authority will do a financial assessment. This will decide how much the person can pay for their own care and how much, if anything, will be paid by the local authority.

Joint packages of health and social care

Another option for those who are not awarded CHC is a joint package of care. This may be arranged and funded jointly by the local authority and the ICB.

The person may have to pay for some or all of the social care part of a joint package of care. This will depend on their circumstances and on the results of a means test to decide how much they can pay. A means test works out how much the person can pay based on their income and capital:

- **income** – this refers to any money the person receives regularly. For example, this could be a pension. It can also include benefits such as Universal credit or the Guarantee credit element of Pension credit.
- **capital** – this refers to any other assets the person has. This includes savings and investments, such as stocks and shares. In some cases, it includes the value of the person's home (for example, when paying for care home fees). It does not include personal possessions, such as jewellery.

Joint packages may be considered if the person has health needs beyond what the local authority can legally provide. This is if they do not have a primary health need to qualify for CHC. Joint packages of care are fairly rare for older adults.

For more information see factsheet 532, **Paying for care and support in England**.

2

3 Appealing against decisions and the complaints procedure

If you think a decision about CHC funding for someone with dementia is wrong, you may be able to appeal. This chapter explains the different steps to do that. It also explains how to make a complaint if you are not happy with the care the person has been offered.

In this section

How to challenge an assessment decision 29
How to make a complaint 41

How to challenge an assessment decision

If you plan to appeal against a decision about CHC, start by preparing your case. Work out whether you have good reasons to appeal and what they are. Then gather evidence to back up your case. The following steps and tips can help prepare and guide you.

The three steps to challenging a decision

There are three appeal stages, but if you are successful at any stage, you won't need to carry on to the next.

1. **Ask for a local resolution**. Ask the ICB to review your case. Explain why you want your case to be reviewed and why you think the person is eligible for CHC. You should have six months from the date on your outcome letter to request a review of the decision. The ICB then have three months from the date of your request in which to complete the local review stage.

2. **Ask for an Independent review**. If the ICB decides the person is still not eligible, you can request a review from an Independent review panel (IRP). It will be able to investigate the ICB's decision and make a judgement on it. You should have six months from the day you are notified of the ICB's decision to request an Independent review. Once you have requested one, an ICB can then give a shorter deadline to submit written evidence. So you may wish to gather evidence or seek advice before requesting the review. The NHS Commissioning Board must arrange an IRP within three months of your request.

3. **Contact the Parliamentary and Health Service Ombudsman**. If you disagree with the outcome of the IRP, you can take your case to the Parliamentary and Health Service Ombudsman. You should do this within 12 months. Their role is to investigate whether the correct processes were followed in making the decision. Not whether the decision was correct. The Ombudsman has the power to make a number of decisions about your case.

3

1 Ask for a local resolution

You may disagree with the decision about eligibility for CHC and feel you have grounds for appeal. If so, it is important that you take the following steps:

Make sure you have a case

Before you appeal, be clear about your reasons for challenging the decision. Consider carefully whether you have a case. It can't just be that you think the wrong decision has been made or that you feel paying for care is unfair. You must have specific reasons. Doing some research will save you a lot of time pursuing an unsuccessful appeal. Consider:

- Detailing which score they should have received in each domain and why. Is there something to evidence this? For example, entries in the person's care notes.
- Highlighting any evidence that you think wasn't properly considered at the assessment. For example, there may be experiences you shared in relation to a care domain which were dismissed and not included, with no reason given. Or, for example, a certain specialist was not consulted who could have provided evidence about the domain.
- Highlight where you believe the framework has not been followed. For example, did the MDT not include two professionals? Were family and other professionals not given the opportunity to contribute?

Be aware that an appeal is not an option if you want to challenge:

- the actual criteria used for the CHC assessments
- the treatment that someone has received
- the type and location of any NHS-funded continuing healthcare services that are offered
- the content of any alternative care package that is offered.

Any of these points would be dealt with by the complaints procedure rather than as an appeal. For more information about the 'NHS official complaints procedure' see page 41.

Top tip
Alzheimer's Society has experienced and trained volunteers who can help guide you through the CHC appeals process. The volunteers are only able to help with cases where it is believed there are grounds for appeal. This is after a decision by the ICB that they don't qualify. Call us on **0333 150 3456** for more information.

Gather evidence

The documents needed to begin a challenge include a copy of the DST and the ICB's decision letter. You should also request supporting evidence that the panel has looked at and possibly referred to in the DST.

There should be a list of the documents that the team have reviewed on the Decision support tool (DST). It is in the 'Personal Details' section at the beginning. It comes under the heading 'Please list the assessments and other key evidence that were taken into account in completing the DST, including the dates of the assessments'. A representative should be able to view this evidence so they can act in the interests of their family member or friend.

You may wish to request this evidence from the ICB. At the same time inform them that you wish to appeal, initially writing something along these lines:

'I am writing to indicate my intention to appeal the decision not to award continuing Healthcare. Please make all information that supports your decision rationale available to me. I will follow up this letter with my challenge once I have received the aforementioned evidence'.

Having as much written evidence as possible will help you make a case. If relevant, this may include:

- Social worker reports
- GP summary
- Care home notes
- Previous DSTs
- Deprivation of Liberty Order
- Physiotherapy assessment
- Behavioural assessment
- Speech and language therapy (SALT) assessment
- Occupational therapy assessment
- Current care plan
- Diary indicating needs and interventions
- Specialist medical and nursing assessments. For example, from a tissue viability nurse, respiratory nurse, dementia nurse
- Falls risk assessment
- Standard scales, such as the Waterlow score
- Psychiatric nurse assessments
- Psychiatric reports
- Gerontologist reports.

3

A 'care needs portrayal' is a document detailing all the medical evidence in date order. If there is one, take a look at it and work out whether it was used to support the DST and the overall decision.

If you are asking for a review to look back over a specific period of time, look for copies of old assessments and reports. These will show the person's level of needs at that time. It will also be useful for you to gather care plans and notes. These should include any daily progress records from the person's care home. Plus your own notes on the person's medical history and needs.

Top tip
Request medical records from the various organisations involved in the person's care, such as the hospital or GP. Social services may also have carried out assessments that contain useful information. Ask to see any reports they have about the person. File all the information you gather. For example - care home notes, nursing home notes, assessments, care plans and letters and your comments. For more information on how to access a person's medical notes see Appendix 1 'Getting access to a person's notes' on page 43.

"I've started writing things down now, that way it counts."

Carer for a person living with dementia

Emotional and psychological needs

When you are making your case, think carefully about how the person's psychological needs affect them. For example:

- Does the person have panic attacks or fits?
- Does the person become easily frightened?
- Do everyday care tasks need to be done in set ways because of the person's psychological needs?
- Does the person have hallucinations or delusions?
- Are they withdrawn and no longer engage with their care or activities?
- Do they show challenging behaviour to themselves or others, such as self-injury or harm?

Some people assume that the needs of a person with advanced dementia are predictable. They feel that needs can be met with occasional visits from a district nurse, unless the person is in a nursing home. Think carefully about whether this is true. Give examples of where there have been unpredictable needs with no triggers identified. This may have also caused complexity impacting more than one domain. For example: 'The person became frightened with no known cause. As this wasn't immediately addressed it went on to prevent them from engaging with nutrition or continence support'.

Day-to-day needs

You do not need highly specialised care to be eligible for CHC. Write down the care that the person needs during an average 24-hour period. It is a good idea to do this over a number of days. Keep a diary to give a true picture of the care the person may need.

Medication needs

Think carefully about any issues around the person's medication.

- Does the person's medication need to be monitored?
- Are there issues about the side effects of medication that also need to be monitored?
- Are there complicated issues around giving the medication? (For example, does the person need injections that must be given by a professional?)

Incontinence needs

If the person is incontinent, are there related issues that need to be considered? These could include their increased risk of developing urinary tract infections (UTIs). What about skin problems, such as having an increased risk of sores and infections? Or stoma and catheter care, which can need nursing support or specialist care?

Mobility needs

Mobility issues can be more difficult for someone with dementia. For example, using a hoist to transfer a person with dementia can be more complex than someone who does not have the condition. This is because a person with dementia may not be able to understand what is happening. They can then become distressed or agitated when someone tries to use a hoist. You could argue that moving a person with dementia requires specialist care that a professional care assistant isn't trained to do.

An Integrated Care Board (ICB) review

If you have identified the grounds for your appeal and gathered evidence to back it up, you will need to ask the Integrated Care Board (ICB) to review its original decision.

This is sometimes known as local resolution. Ask for a copy of the ICB's review timescales so you can make a note about deadlines. You can then do the following:

- Request a review in writing.
- In your letter, ask the ICB to review the decision and to reconsider the way the criteria have been applied. See the example letter on page 35.
- Send a copy of your letter to the person at the ICB who deals with its appeals process. This person should be named in the decision letter you received from the ICB. They may be the ICB's chief executive or someone in the ICB's CHC team.
- The ICB must acknowledge in writing that it has received your request to reconsider its decision. It must also give you information about the CHC appeal process.
- This review stage may include an informal discussion between both parties. This provides an opportunity for the ICB to explain their decision. And for the representative of the person with dementia to discuss any information which wasn't considered. This may be followed by a formal meeting.
- The ICB must deal with your request, finish its review and make a further decision about the person's eligibility promptly. If there is a delay, it must let you know in writing and explain the reason for the delay. Information about the ICB's appeals process, as well as timescales, must be available to the public. All ICBs must also have a CHC local resolution process that is fair, transparent and includes timescales.

Example of a letter to the ICB to request a review of its decision

[Date]

[Your address]

Dear [name]

I wish to appeal the decision of [my mother's] continuing healthcare assessment. I believe that [my mother, name, date of birth, NHS number] has been wrongly refused NHS continuing healthcare. Below are the reasons I believe that the wrong conclusion has been reached. I attach/enclose the relevant documents. [Include this sentence if you are providing documents to support your argument.]

In this section insert the details of the person you are appealing on behalf of. The following is an example.

[My mother] is in the late stage of [type of dementia] and is cared for at [name of the nursing home/residential home/in her own home]. She [Set out her needs. For example, she can no longer communicate verbally but is often very distressed and the staff struggle to care for her. She is doubly incontinent, has mobility problems and is at risk of falls. She is also diabetic, is losing weight and has pressure sores].

Add this sentence if the person being cared for is in a residential home or their own home.

You will be aware that the Department of Health and Social Care has stated that people can receive NHS continuing healthcare whether they are in a nursing home, residential care home or their own home.

The basis of my request is that I believe [my mother] meets the criteria. Please progress this review and update me as soon as possible.

Yours sincerely,

[Your name]

Use this part of your letter to explain why you think the person should be found eligible for CHC. Be brief – you should find information about the person's condition in their notes. Some aspects that may be important for people with dementia are outlined here. These may apply to other people too. It is not an exhaustive list. You will probably be able to think of other aspects that apply to your case.

The ICB's response

The ICB should respond promptly to your letter. If you have not received a reply within one month, phone the ICB to ask about the progress of your review.

In most cases the ICB will begin by arranging an informal discussion with the person who requested the review of its decision. A written summary of this discussion should be given to both the person and the ICB. In other cases, the ICB will arrange a formal panel meeting to discuss its decision. Whether there is an informal meeting or a formal panel meeting, a written account should be shared with the person's representative afterwards.

If the ICB says you have no case, you might be unhappy with its decision. This might be because of the way the ICB has followed procedures or applied the Decision support tool. In this case, the next stage is to ask NHS England to consider referring your case to be reviewed by an Independent review panel (IRP).

You can request an IRP yourself, or the ICB may decide to call one. The ICB must give you information about how to contact NHS England and ask for an IRP to be set up.

2 Ask for an independent review

An Independent review panel (IRP) is set up by NHS England and it has an advisory role. It can look at whether the ICB applied the Framework correctly. It can also check that it followed the processes set out in the Framework and the Practice guidance. The IRP can then make a recommendation about whether the ICB's decision is valid. The ICB should accept the IRP's recommendation unless there are exceptional circumstances.

Requesting an independent review from NHS England

To request an independent review by an IRP, you must send a letter to NHS England explaining why you disagree with the ICB's decision. You need to state why you are asking for an independent review. There is a sample letter you can use on page 37. See 'Other useful organisations' on page 48 for details about how to contact NHS England.

In your letter, write briefly about the person's condition. You might want to point out any issues mentioned in your original request. These can include any points that you think have not been picked up or have been ignored.

You could also write another brief letter to the person at the ICB who responded to you with the decision about the ICB's review. Tell them you are not happy with the decision and that you want an independent review of your case. Tell them that you have read the Framework and the associated assessment tools. Also tell them that you believe you are wrongly paying, or have paid, for care that should have been available on the NHS.

You may want to say again that this isn't because you think it's unfair. There must be evidence to show why you disagree and why, if the assessment had been carried out properly, the person would have qualified for CHC.

Top tip
Keep a record of all the correspondence you have with the ICB and NHS England.

Example of a letter requesting an independent review

Dear [name of the NHS England contact]

The [name of the ICB] has reviewed the case of [my mother, name, date of birth, NHS number], who lives at [name of nursing home/residential home/in her own home]. I am not satisfied with its findings and want to request an independent review of the case.

Please let me know if and when a review of my case will take place and give me details of when I can attend.

Yours sincerely,

[Your name]

Put here the reasons why you're not satisfied with the original decision that the person is not entitled to fully funded care. Refer back to the information in the sample letter on page 35. Consider the reasons outlined throughout this booklet about why people are often refused funding for NHS continuing healthcare.

3

The Independent review panel

After NHS England has received your request, it will consider all the information and decide whether to set up an IRP to review the case. If it decides not to, it should send you a letter to explain why.

The Independent review panel (IRP) will talk to a number of people when it is looking at a case. It should ask the person's family or carer for their views, even if they have no legal power to act on the person's behalf.

The IRP should also be able to get independent advice from health and social care professionals. It should talk to all the people involved in the case. This includes the person with dementia where possible, health and social services staff and any other relevant people. These people can all attend the panel, or they can put their views in writing.

If a person finds it difficult to express their own views, the Framework says they can have a representative present at the IRP. This might be a relative, carer or advocate. The panel must be satisfied that the representative is accurately representing the person's views and has no conflict of interests.

If you would like an independent advocate to help you at this stage, ask your continuing healthcare co-ordinator about how to find one.

The IRP must keep the person's representatives fully informed about the process and how long it is expected to take. If the person is already receiving care that is funded by the NHS, the local authority or both, they should continue to receive that care until the IRP reaches its decision.

The panel must share some of the person's health and personal information with certain people. This includes the person's attorney under an LPA for health and welfare or a court-appointed deputy for welfare if they have one. It should also share information with the person's representative, if this is in the person's best interests.

There are rules about what information can be shared and who it can be shared with. These rules aim to make the process and the decisions as transparent as possible rather than to make it more difficult.

Make the most of evidence available at the independent review panel. See 'Make sure you have a case' on page 30 and 'Gather evidence' on page 31 for more details.

Top tip

Even if you think you can manage without an independent advocate, consider taking someone with you for moral support. It may help you to discuss the events afterwards. It might also be useful to take notes of what the panel says and the questions they ask. This is another role that a friend or supporter might be able to do for you.

I kept a diary of visits with my father in the nursing home. It briefly noted issues that arose with his care and behaviour and proved very helpful when we attended the Independent review panel.

Carer for a person living with dementia

The Independent review panel decision

If your review is upheld and CHC is awarded
If the IRP agrees that the person should receive CHC, it will tell your ICB. The ICB should then write to you to explain this decision.

Any fees for care that have been paid by the person or the local authority during the time when the NHS should have been funding the care will be repaid with interest. NHS England has a 'redress policy' for this purpose. Ask the ICB's continuing healthcare co-ordinator for details about this policy.

If you are unsuccessful and the original decision is upheld
If the IRP decides that your case is not valid and agrees with the ICB's original decision, you will have to decide whether you are satisfied with this outcome. If you are not, you need to think about whether you have a good enough case to move on to the next stage. If you do, you can refer your case to the Parliamentary and Health Service Ombudsman. See 'Contact the Parliamentary and Health Service Ombudsman' on page 40.

If NHS England refuses to set up an independent review panel

It is unusual for NHS England to uphold the ICB's original decision and refuse a review by an IRP. The Framework says this can only be done if NHS England thinks the 'individual falls well outside the eligibility criteria or where the case is very clearly not appropriate for the panel to consider'. If this happens, you can write to the Parliamentary and Health Service Ombudsman and ask for your case to be looked at.

Top tip
It can be difficult and frustrating but if you think you have a strong case for NHS continuing healthcare, be persistent at every stage of the process.

3

3 Contact the Parliamentary and Health Service Ombudsman

The office of the Parliamentary and Health Service Ombudsman is an independent organisation that investigates complaints. These are complaints against some government departments, a range of public organisations in the UK and the NHS in England. The Ombudsman can check if these organisations have not acted properly or fairly. This is as long as the person making the complaint has tried to resolve the issue locally first.

You can contact the Ombudsman if you have been refused an IRP, or if the IRP upheld the ICB's original decision not to award CHC. The Ombudsman will be able to look at your case and will focus on whether the correct processes and procedures were followed. The Ombudsman's office will usually contact you to acknowledge your complaint within five working days of receiving it. If the Ombudsman decides to investigate your complaint, it will explain the process to you.

The Ombudsman recommends that people first call its helpline. This is to check they have a reasonable case and if they have tried to resolve the complaint as far as possible. See the Ombudsman's helpline number in 'Other useful organisations' on page 48.

The Ombudsman has the power to make a number of different decisions about your case. They can't make the ICB change their decision or make their own decision about whether someone is eligible for CHC. However, if there is fault, they will say what they think the ICB need to do to put things right. The Ombudsman will explain these to you if they decide to investigate your case.

If the Ombudsman decides not to investigate your complaint further, their office will explain why they have made that decision.

In some circumstances the Ombudsman may ask an ICB to review a case again. They may even ask the ICB to go back to the start of the assessment process if they find an obvious mistake in the way the process was carried out.

If the Ombudsman tells you to complain

The Ombudsman will sometimes tell people to go through the NHS official complaints procedure – see 'The NHS official complaints procedure' on page 41. This is not the same as appealing against an ICB decision about CHC, nor is it the same as the independent review panel (IRP).

It might seem like a backward step, but the local NHS complaints process is aimed at a different type of dispute. The Ombudsman may identify an issue that needs to be looked at through the local NHS complaints process. It is important that you follow the correct process to get the best results.

Top tip
Be aware that the Parliamentary and Health Service Ombudsman has the final say if you have exhausted the local complaints system. It is therefore important to have good records so that you can make an effective case to the Ombudsman.

How to make a complaint

The NHS official complaints procedure

The NHS complaints procedure deals with all kinds of complaints about the NHS, not just CHC. You might want to make a complaint because you have been told to do so by the Ombudsman. You could also be unhappy with the criteria used for the assessment or with the care package you have been offered. See 'Make sure you have a case' on page 30.

Your letter of complaint

Write a letter of complaint to the chief executive of the ICB that is responsible for providing the person's care.

You can use a version of the example letter to request a review (See 'Example of a letter to the ICB to request a review of its decision' on page 35), but you may want to adapt it. Make sure you state that you're making an official complaint. This will make sure your letter is dealt with according to the CHC procedure.

Keep a copy of your letter and all the correspondence that follows it. From this point on, you should follow the complaints process and use the information throughout this booklet to guide you.

If your complaint is not resolved, this process may lead you back to the Parliamentary and Health Service Ombudsman. If this happens, the Ombudsman will either investigate your complaint or advise you about what to do next.

Appendices

In this section

Appendix 1 – Getting access to a person’s notes 43
Appendix 2 – The Mental Capacity Act 2005 47

Appendix 1
Getting access to a person's notes

If you want to apply for or appeal against a decision about CHC on behalf of another person, you'll need their medical and care records. However, there are rules about patient confidentiality and data protection. This makes it difficult to get access to another person's medical, care home or social services notes – even if they are your partner.

To formally request access to another person's records you need to make a 'subject access request' to the organisation. For example, if you want to access the person's hospital records you should send your request to the hospital. For information about this see booklet 882, **Accessing and sharing information on behalf of a person with dementia**. You can also visit the Information Commissioner's Office website listed in 'Other useful organisations' on page 48.

If a person decides in advance that they want you to have access to their records and notes, they should write a clear instruction that gives their consent. However, people with dementia are often not able to give such consent because they don't have the ability (mental capacity) to make this decision. See the definition of 'mental capacity' on page 47 for more information.

> **I was completely disempowered because I couldn't get the information I needed. I didn't know where to go to get it.**
>
> Carer for a person living with dementia

Attorneys and deputies

A person with dementia may have made a Lasting power of attorney (LPA) for health and welfare appointing an attorney to make certain decisions for them. This is if they can no longer make those decisions themselves. This includes their care and welfare. The attorney should be given access to the person's medical and care records because they will often need these records to carry out their role.

If a person has an LPA for property and financial affairs or an Enduring power of attorney (EPA), the attorney has the legal power to make financial decisions on their behalf. The attorney can only access the person's medical or care notes for financial reasons. However, if the attorney thinks the person is entitled to CHC this is generally considered to be a financial reason.

Some people with dementia won't have appointed an attorney but a deputy may have been appointed for them by the Court of Protection. A deputy may deal with a range of issues for a person who lacks capacity to deal with the issues themselves. A deputy should be able to access a person's records and notes when they need them to carry out their role.

For more information see factsheet 530, **Deputyship**.

A person's attorney or deputy will often still need to make a subject access request for the person's records. When they make the request, they can explain that they are acting as an attorney or deputy and why they need the information to perform this role. For example, they can explain that they are the person's LPA attorney and need the person's medical records to help them apply for CHC. The attorney or deputy may have to provide the original LPA (or a certified copy) or the deputy court order to prove that they have the legal power to act for the person.

When there is no attorney or deputy

Getting access to a person's medical notes can be harder if the person doesn't have an attorney or a deputy. Some NHS organisations and social services departments are willing to release a personal record to a person's main carer. This is usually if they are a close family member, but this is not always the case.

An organisation's reasons for refusing to give access to a person's records usually include either or both of the following:

- there is no legal right of access for anyone other than the patient or an attorney or deputy
- the organisation has a duty of confidentiality to the person with dementia.

You can still submit a subject access request if the person with dementia doesn't have an attorney or deputy. However, when you do this it's important to explain:

- why you need the information
- why it is in the person's best interests for you to have this information
- why it isn't harmful to the person for you to have this information.

It may also help if you outline why you believe you are entitled to the information. You can refer to the definitions of the National Framework on page 5 and the Mental Capacity Act on page 4.

> **They said my Mum's LPA was for financial affairs, so I couldn't see the records.**
>
> Carer for a person living with dementia

Access under NHS continuing healthcare

The National Framework says that it may be possible for someone who doesn't have a legal power such as an LPA or deputyship to request personal information. This includes care and medical records. This could be where the person themselves lacks mental capacity to consent to the information being shared and where there is someone representing them informally. When a professional is deciding whether to share information with a third party who doesn't have a legal power, the Framework says they must use the following criteria:

- Any decision to share information must be made in the person's best interests.
- The information that is shared should only be what is necessary for the third party to act in the person's best interests.

If a person can show that these criteria are met, it should be possible for them to access another person's information to apply for CHC or make an appeal.

If you request another person's records, state that the National Framework allows you to access the records as it is in the person's best interests under the Mental Capacity Act 2005 (see appendix 2 on page 47). It may help if you explain exactly why it's in the person's best interests. For example, explain that you are representing them to receive CHC. Say that this will make sure they get the care and treatment they need and the funding they are entitled to.

"They quoted Data Protection and Freedom of Information Acts at me and said I could not see Mum's care home notes. They said I couldn't have the information because her notes were private, so I couldn't see them."

Carer for a person living with dementia

Appendix 2
The Mental Capacity Act 2005

The Mental Capacity Act 2005 is the law that protects and supports people who don't have the ability to make certain decisions for themselves. This ability is known as 'mental capacity'. The Act explains who can make decisions for a person who lacks capacity to make them. It also says that they must make the decisions in the person's best interests.

When health and social care staff are deciding on a person's best interests, the Act says they must consult anyone who is caring for the person or interested in their welfare. This includes their family, friends and unpaid carers. As a result, carers should be able to access the medical and care notes and social services records of people with dementia. As long as those are relevant to best interests decision making. That is the case even if there is no LPA attorney or deputy.

For more information see factsheet 460, **Mental Capacity Act 2005.**

Other useful organisations

Age UK

0800 678 1602 (advice line, 8am–7pm)
www.ageuk.org.uk

Age UK is a charity that provides information and advice for older people in the UK.

Beacon

0345 548 0300
www.beaconchc.co.uk

Beacon can provide expert advice and representation at any stage of the assessment or appeal process. You can contact them directly to access a bespoke service. They aim to respond within three working days.

Beacon are commissioned by NHS England to provide up to 90 minutes of free information and advice, but any advice and representation over this would be charged for. Their rates are published for transparency on their website.

Citizens Advice

0800 144 8848 (for England)
0800 702 2020 (for Wales)
www.citizensadvice.org.uk

Citizens Advice offers free, confidential, impartial and independent advice to help people resolve problems with debt, benefits, employment, housing and discrimination.

Court of Protection

0300 456 4600
courtofprotectionenquiries@justice.gov.uk
www.gov.uk/courts-tribunals/court-of-protection

The Court of Protection is a specialist court for all issues that relate to people who lack capacity to make specific decisions for themselves.

Independent Age

0800 319 6789 (helpline, 8.30am–6.30pm Monday–Friday)
advice@independentage.org
www.independentage.org

Independent Age is a charity that offers free advice and information on care, benefits and social support, as well as volunteer befriending services for older people.

Information Commissioner's Office
0303 123 1113
www.ico.org.uk

The Information Commissioner's Office is an independent UK organisation that upholds information rights. It can offer support and advice on accessing a patient's notes.

NHS
www.nhs.uk/service-search

You can use the NHS website to search for health services near you, including the details of every Integrated Care Board (ICB) in England.

www.nhs.uk/nhs-services/find-your-local-integrated-care-board/

CHC patient information leaflet:
https://www.gov.uk/government/publications/nhs-continuing-healthcare-and-nhs-funded-nursing-care-public-information-leaflet/public-information-leaflet-nhs-continuing-healthcare-and-nhs-funded-nursing-care–2

NHS England
0300 311 2233 (9am–3pm Monday–Tuesday, Thursday–Friday, 9.30am–3pm Wednesday)
england.contactus@nhs.net
www.england.nhs.uk

This national organisation runs the NHS in England. It oversees ICBs. It is also responsible for setting up Independent review panels (IRPs) for NHS continuing healthcare when people have exhausted the local appeals process with the ICB.

Office of the Public Guardian
0300 456 0300 (9.30pm–5pm Monday–Tuesday and Thursday–Friday, 10am–5pm Wednesday)
customerservices@publicguardian.gov.uk
www.gov.uk/government/organisations/office-of-the-public-guardian

The Office of the Public Guardian supports and promotes decision-making for people who lack capacity or would like to plan for their future, within the framework of the Mental Capacity Act 2005. It provides free booklets on Enduring and Lasting powers of attorney and deputyship.

Parliamentary and Health Service Ombudsman
0345 015 4033 (helpline, 8.30am–5pm Monday–Thursday, 8.30am–12pm Friday)
www.ombudsman.org.uk

The Parliamentary and Health Service Ombudsman makes final decisions on complaints that have not been resolved by the NHS in England, UK government departments and other UK public organisations.

Information on NHS continuing healthcare in Wales

Age Cymru
0300 303 44 98 (advice line, 9am–4pm Monday–Friday)
advice@agecymru.org.uk
www.agecymru.org.uk

Age Cymru is a charity that provides information and advice for older people in Wales.

NHS Wales
https://www.nhs.wales/hpb/contact-us/

You can use this NHS website to search for health services in Wales.

Information on NHS continuing healthcare in Northern Ireland

Age NI
0808 808 7575 (advice line, 9am–5pm Monday–Friday)
advice@ageni.org
www.ageuk.org.uk/northern-ireland

Age NI is a charity that provides information and advice for older people in Northern Ireland.

Health and Social Care in Northern Ireland
online.hscni.net

This website allows you to search for health and social care services near you.

References

The following four documents set out the principles and processes of the National framework for NHS continuing healthcare. They are all available online:

Department of Health and Social Care (Revised July 2022) National framework for NHS continuing healthcare and NHS-funded nursing care. Available at: **https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care**

Department of Health and Social Care (published 2018, updated October 2022) NHS continuing healthcare checklist. Available at: **https://www.gov.uk/government/publications/nhs-continuing-healthcare-checklist**

The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012. Available at: **https://www.legislation.gov.uk/uksi/2012/2996/regulation/21/made**

Easy read version:
https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care-easy-read

Department of Health and Social Care (published 2018, updated October 2022) Decision support tool for NHS continuing healthcare (DST). Available at: **https://www.gov.uk/government/publications/nhs-continuing-healthcare-decision-support-tool**

Department of Health and Social Care (published 2018, updated August 2022) Fast-track pathway tool for NHS continuing healthcare. Available at: **https://www.gov.uk/government/publications/nhs-continuing-healthcare-fast-track-pathway-tool**

The National Framework is published by the Department of Health and Social Care. It is underpinned by:

The Stationery Office (2012) The National Health Service Commissioning Board and Integrated Care Boards (Responsibilities and Standing Rules) Regulations 2012. Available at: **www.legislation.gov.uk/uksi/2012/2996/contents/made**

These Regulations were amended by:
The Stationery Office (2013) The National Health Service Commissioning Board and Integrated Care Boards (Responsibilities and Standing Rules) (Amendment) Regulations 2013. Available at: **www.legislation.gov.uk/uksi/2013/2891/regulation/3/made**

This revised National Framework takes account of legislative changes brought about by the Health and Care Act 2022. Available at: **https://www.legislation.gov.uk/ukpga/2022/31/contents/enacted**

Further reading

Department of Health (updated August 2022) NHS continuing healthcare and NHS-funded nursing care: Public information leaflet. Available at: **https://www.gov.uk/government/publications/nhs-continuing-healthcare-and-nhs-funded-nursing-care-public-information-leaflet/public-information-leaflet-nhs-continuing-healthcare-and-nhs-funded-nursing-care–2**

NHS England (updated August 2023) NHS Continuing Healthcare: Independent review process – public information guide. Available at: **https://www.england.nhs.uk/publication/nhs-continuing-healthcare-independent-review-process-public-information-guide/**

Parliamentary and Health Service Ombudsman: How we can help with complaints about continuing healthcare funding. Available at: **https://www.ombudsman.org.uk/making-complaint**

First published: 2009
Last reviewed: 2024
Next review due: 2027

Our information is based on evidence and need, and is regularly updated using quality-controlled processes. It is reviewed by experts in health and social care and people affected by dementia.

Reviewed by: Fiona Scolding KC, Barrister, Landmark Chambers and Clare English, Chartered Legal Executive, Martin Searle Solicitors

This booklet has also been reviewed by people affected by dementia.

To give feedback on this booklet, or for a list of sources, please contact **publications@alzheimers.org.uk**

This publication contains information and general advice. It should not be used as a substitute for personalised advice from a qualified professional. Alzheimer's Society does not accept any liability arising from its use. We strive to ensure that the content is accurate and up to date, but information can change over time. Please refer to our website for the latest version and for full terms and conditions.

© Alzheimer's Society, 2024. All rights reserved. Except for personal use, no part of this work may be distributed, reproduced, downloaded, transmitted or stored in any form without the written permission of Alzheimer's Society. Alzheimer's Society maintains editorial independence over the content of this publication.

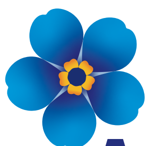
Registered charity no. 296645. A company limited by guarantee and registered in England no. 2115499. Alzheimer's Society operates in England, Wales and Northern Ireland.

At Alzheimer's Society we're working towards a world where dementia no longer devastates lives. We do this by giving help to everyone who needs it today, and hope for everyone in the future.

We have more information on **Needing greater support with care**.

For advice on this, or any other aspect of dementia, call us on **0333 150 3456** or visit **alzheimers.org.uk**

Thanks to your donations, we're able to be a vital source of support and a powerful force for change for everyone living with dementia. Help us do even more, call **0330 333 0804** or visit **alzheimers.org.uk/donate**



Alzheimer's Society

Together we are help & hope for everyone living with dementia

Alzheimer's Society
43–44 Crutched Friars
London EC3N 2AE

0330 333 0804
enquiries@alzheimers.org.uk
alzheimers.org.uk

Code 813