

# When does the NHS pay for care?

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

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# Introduction

**When a person is living with dementia their needs will change over time as their condition gets worse. Some people will need a lot of care and support to meet their needs. They might receive this care in their own home or in a residential or nursing home.**

Finding out about what care is free and what care you will have to pay for is complicated. Applying for free care, such as NHS continuing healthcare, can also be time-consuming and confusing. This is because getting information can be difficult and the rules can be hard to understand. However there is information and support that can help you.

While there are sometimes differences in how the rules about free NHS continuing healthcare are applied, they should be applied consistently across the country.

## Aims of this booklet

This booklet is for carers and representatives of people with dementia. It aims to help them understand NHS continuing healthcare, including how to apply for it and how to appeal if it is not awarded. The information in this booklet may also be useful for other people who want to know more about NHS continuing healthcare.

This booklet explains the difference between social care and healthcare. This difference is important because it affects how care and support is paid for. The booklet then explains what NHS continuing healthcare is and how to apply for it. This includes information about who is eligible for NHS continuing healthcare, how you might be able to get it and what to do if your request for it is turned down.

The booklet refers to documents, terms and resources that are used a lot in relation to NHS continuing healthcare. These are all listed and explained in the glossary on **page 5**. The booklet also suggests Alzheimer's Society publications that you can read to get more information on specific topics.



The information in this booklet only applies to people who live in England. People in Wales and Northern Ireland should look at **Appendix 4 on page 53** for a list of organisations that can provide information about the NHS continuing healthcare rules in these countries.

## Healthcare and social care

Two organisations in the UK are responsible for providing care to meet people's needs – the NHS and local authority social services departments. Healthcare is provided by the NHS and it is free. Social care is provided by local authority social services and people may have to pay for it, depending on how much income or savings they have. A test that looks at a person's savings and income to decide how much they are able to pay is known as a 'means test'.

Social care includes things like helping someone to get dressed, helping them at mealtimes, or supporting them to get out and about. Healthcare includes things like treating, controlling or managing an illness, injury or disability.

Healthcare and social care may seem to be separate things, but it is sometimes difficult to know what is healthcare and what is social care. This is particularly true for people living with dementia. However the difference between healthcare and social care is very important because it decides whether the NHS or local authority social services is responsible for providing the care. Any decision about who is responsible for providing care can have a big impact in deciding who pays for the care.



**'No one told me about CHC – I just didn't know.'**

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Carer for a person living with dementia

## Eligibility for NHS continuing healthcare

Applying for NHS continuing healthcare can be time-consuming and complicated but there are benefits if you are successful.

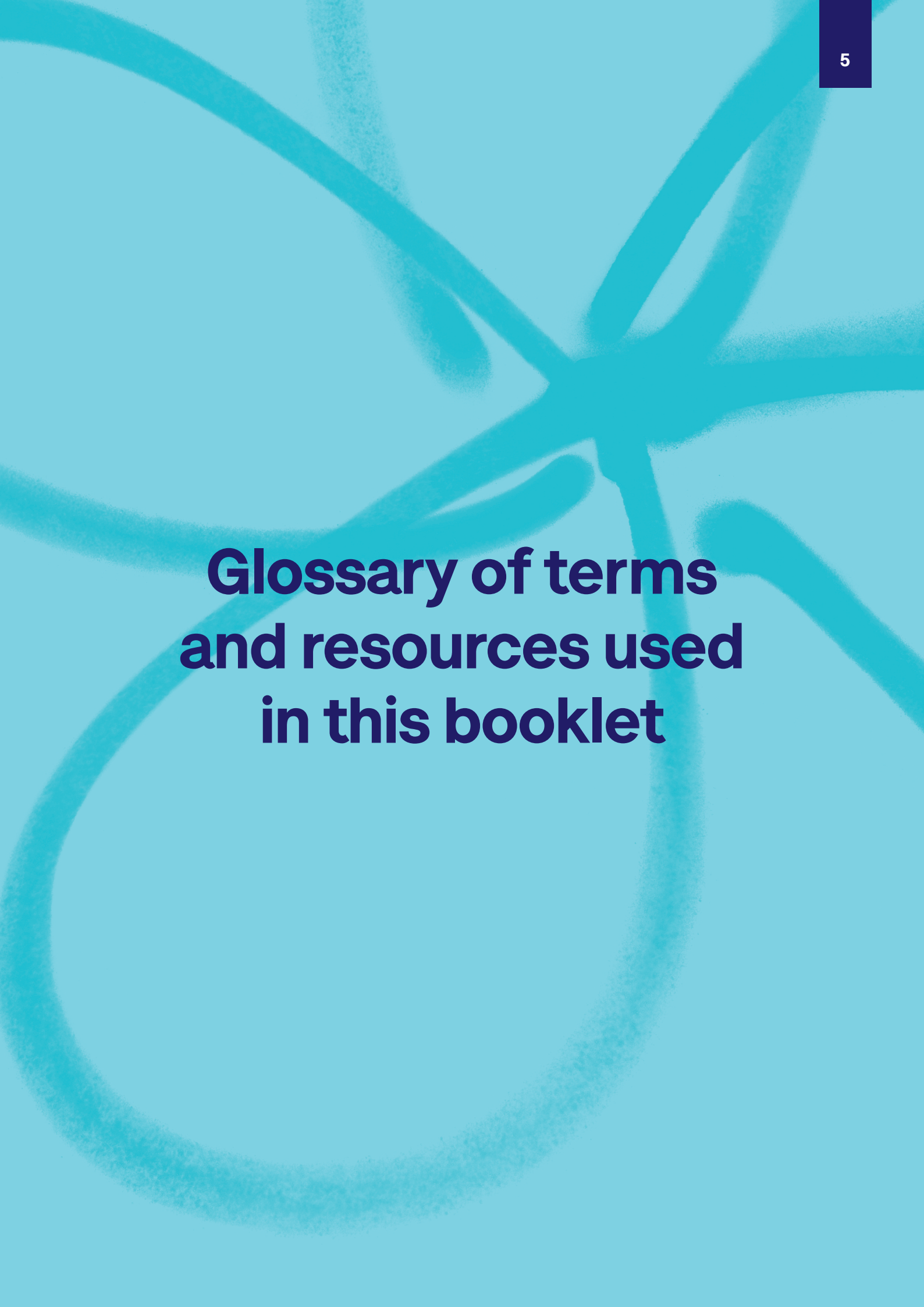
However it is important to understand that strict rules and criteria are used to decide who can receive it. Many people with dementia will not meet these criteria and will therefore not be eligible for NHS continuing healthcare.

“

**‘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 – I have been able to flick from page to page to gain a basic understanding of relevant issues and then re-read in detail for a deeper understanding. Thank you.’**

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Carer for a person living with dementia



# **Glossary of terms and resources used in this booklet**

There are a number of key documents and resources related to NHS continuing healthcare. Some of these are produced by the government and are available on the GOV.UK website at [www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care](http://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care). There are also a number of processes, terms and phrases that you will hear a lot when you are applying for NHS continuing healthcare. Use this list to help you remember what they refer to.

### Care needs portrayal

A care needs portrayal is a document that a multidisciplinary team (see 'Multidisciplinary team (MDT)' on page 7) may complete when they do an assessment for NHS continuing healthcare. It records a person's care needs. It should be used as well as, but not instead of, the Decision support tool (see 'The Decision support tool' (DST)).

### The Checklist and Checklist screening

The NHS continuing healthcare checklist (October 2018) (the Checklist) is a 'light-touch assessment' document that is used to help identify people who may qualify for NHS continuing healthcare and who should then receive a full assessment. It is sometimes known as 'screening'.

### Clinical commissioning group (CCG)

A clinical commissioning group (CCG) is a local NHS organisation that is responsible for providing services in a particular area. It is also responsible for carrying out assessments and making decisions about NHS continuing healthcare. It is responsible for providing and funding the care if it is awarded.

### The Decision support tool (DST)

The Decision support tool for NHS continuing healthcare (October 2018) (the DST) helps assessors bring together and record evidence of 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 NHS continuing healthcare. They may be a health and social care professional (such as a registered nurse or GP) or 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 is eligible for NHS continuing healthcare.

### The Fast-track pathway tool

The Fast-track pathway tool for NHS continuing healthcare (October 2018) is the assessment tool to work out whether a person is eligible to be fast tracked to receive NHS continuing healthcare. This should happen when a person is near the end of their life or if they have a condition that is getting worse very quickly and that may be reaching a final (terminal) stage.



## The Framework

The National framework for continuing healthcare and NHS-funded nursing care (revised in October 2018), which includes the NHS continuing healthcare practice guidance (see '**The Practice guidance' on page 8**), is a long document produced by the NHS. It describes the processes that all CCGs and professionals must follow when they carry out NHS continuing healthcare assessments.

## Independent review panel (IRP)

If a CCG decides a person is not eligible for NHS continuing healthcare and it then maintains this judgement after reviewing its decision, NHS England can set up an independent review panel (IRP). The IRP will decide whether the CCG followed the correct procedures when it assessed the person for NHS continuing healthcare. The IRP will tell the CCG its decision and the CCG should follow this decision.

## Lasting power of attorney (LPA)

A Lasting power of attorney (LPA) is a legal tool that allows you to appoint someone to make certain decisions on your behalf if you can't make the decisions yourself in the future. 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 certain decisions for yourself. For many people with dementia there will come a time when they can no longer do this and they are said to 'lack capacity'. 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. For more information see factsheet 460, **Mental Capacity Act 2005**.

## Multidisciplinary team (MDT)

This is the team of people who carry out a full assessment for NHS continuing healthcare. The team must include at least two professionals from different healthcare professions (such as a GP, a consultant or a community mental health nurse) or one healthcare professional and one social care professional who is trained and qualified to assess people for care services (such as a social worker or care manager). 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.

## 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)**' on page 7) for NHS continuing healthcare.

## Nursing home

A nursing home provides personal care, much like a residential care home (see '**Residential care home**') but it also has a registered nurse on duty 24 hours a day. Some homes that are registered to provide nursing care will accept people with personal care needs who may need nursing care in the future. In some nursing homes staff have had specialist training in dementia care.

## The Practice guidance

The **NHS continuing healthcare Practice guidance** is part of the Framework (see '**The Framework**' on page 7). It aims to support professionals who implement NHS continuing healthcare to follow the process and carry out their role correctly.

## Primary health need

A 'primary health need' is a key term that is used to decide who is eligible for NHS continuing healthcare. If your primary need is for nursing and/or healthcare, rather than social care, then you are said to have a 'primary health need' and you should receive NHS continuing healthcare.

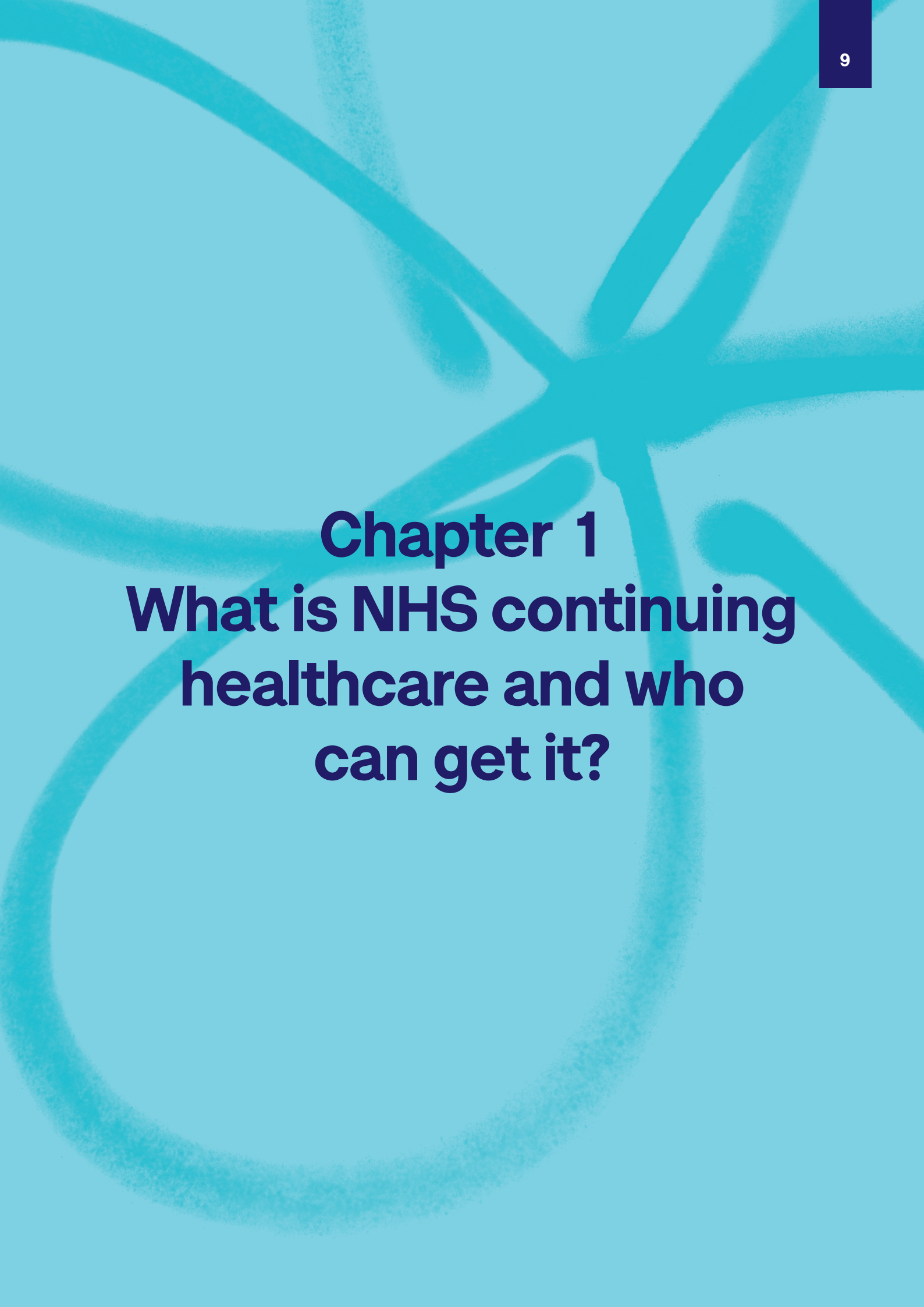
## Residential care home

A residential care home gives people help with personal care such as washing, dressing and eating. In some residential care homes staff have training or learn the skills needed to care for people with dementia.



## Top tip

Learn the technical terms and jargon around NHS continuing healthcare. These terms are used throughout this booklet and you will hear them a lot during the assessment process. Knowing what they mean will help you with discussions and to understand the decisions that relate to your case.



# **Chapter 1**

## **What is NHS continuing healthcare and who can get it?**

**This chapter explains what NHS continuing healthcare is, who is eligible to get it and how decisions about eligibility are made. For information about the assessment process itself see Chapter 2 ‘Assessments for NHS continuing healthcare’ on page 17.**

## NHS continuing healthcare

NHS continuing healthcare is not a particular type of care, treatment or support. It is the name for a ‘package’ of care that the NHS provides to meet a person’s needs. The Department of Health and Social Care defines NHS continuing healthcare in the Framework 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.’**



### Top tip

Talking Point is our online community. It is a place where people can share experiences, ask questions and get practical tips about living with dementia. It is free and is available 24 hours a day, every day of the year at [alzheimers.org.uk/talkingpoint](https://alzheimers.org.uk/talkingpoint)

This means that someone who is assessed as being eligible for NHS continuing healthcare (often referred to as ‘CHC’) will have all the care they need paid for by the NHS. 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 NHS continuing healthcare – including what is normally called ‘social care’.

For someone in a care home, NHS continuing healthcare funding covers both residential costs and food. For someone who is receiving NHS continuing healthcare in their own home, social care will be included in the care package but other costs such as rent, utility bills and food will need to be paid for. In some situations the NHS may pay a contribution towards utility bills if the person needs special equipment to meet their needs at home that may increase their bills.

If a person is assessed as not being eligible for NHS continuing healthcare, they may have their care provided by the local authority and they may have to pay for the social care they receive. The local authority will assess their needs and do a means test. This is a test to look at a person’s savings and income to decide how much they are able to pay for their care. Depending on the results of the means test, the local authority may fund some or all of the person’s care. For more information see factsheets 532, **Paying for care and support in England** and 473, **Personal budgets**.

## Primary health need

NHS England uses the idea of a 'primary health need' to help decide which treatment and other health services the NHS should provide (and pay for), and which services local authorities should provide (and may charge for). This idea comes from case law. This is law that is established by the decisions that have been made in previous court cases. For more information on how the idea of a 'primary health need' came about, see **'The Coughlan case 1999' in Appendix 3 on page 49.**

If a person's primary care need is for 'healthcare', they are eligible for NHS continuing healthcare. This means they have a 'primary health need' and the NHS is responsible for providing care for all of their needs. This can include social care (such as personal care) if it is part of the person's overall need. However it is important to remember that if a person's needs change and they are assessed as no longer having a 'primary health need', funding for NHS continuing healthcare can be removed.

If the person's main need is assessed as being for social care rather than healthcare, then they will not be eligible for NHS continuing healthcare funding. Instead they will receive care provided by social services. They may need to pay for this care depending on their income and savings. For more information see factsheet 532, **Paying for care and support in England.**

Any decision about whether someone is eligible for NHS continuing healthcare must only be based on the person's care needs. Their financial situation, or any budget restrictions that the CCG is facing, 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.

People are not automatically entitled to NHS continuing healthcare because they have a certain diagnosis (such as dementia). The decision about whether someone is eligible for NHS continuing healthcare will be based on their needs not their condition.



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

## Deciding if someone has a ‘primary health need’

A person will need to have an assessment to decide (determine) whether or not they have a ‘primary health need’. The CCG’s continuing healthcare co-ordinator will arrange this assessment. All CCGs should have a staff member who co-ordinates NHS continuing healthcare assessments – they are called continuing healthcare co-ordinators. Other medical staff such as a nurse or doctor may arrange the assessment if the person is in hospital. All assessments should follow the procedure set out in the Framework.

Health and social care staff who are involved in the person’s care should identify when the person needs to be assessed for NHS continuing healthcare. However this does not always happen.

The assessment may take place in two stages – the rest of this chapter has more information about these. See **Chapter 2 on page 17** for a full explanation about the assessment process.

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, where the CCG 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 CCG will use the ‘Fast-track pathway tool’.

## The Checklist

For most people who are applying for NHS continuing healthcare, the first step is the ‘Checklist’. This is essentially a screening process. No other screening tool can be used except the Checklist. For some people the process will begin with a full multidisciplinary team (MDT) assessment using the Decision support tool (DST) without using the Checklist. For example if health and social care professionals decide that it is not necessary to use the Checklist or if the person is being assessed via the Fast-track pathway tool (see **page 15**).

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

NHS England says that people should ideally not be assessed in hospital, if possible. In some cases people could be discharged before they have an assessment for NHS continuing healthcare so that it shows their longer-term needs. These needs may be less obvious while the person is in hospital.



### 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 the person is being assessed for NHS continuing healthcare and for challenging a decision, if necessary. Keep this medical history regularly updated.



## The Decision support tool (DST)

The Decision support tool (DST) is used during the MDT assessment to record a person's care needs and to help determine whether they have a 'primary health need'. The DST has been developed so that assessments for NHS continuing healthcare are as consistent as possible across the whole country.

The DST aims to bring together and record a person's needs within 12 types or areas of need known as 'care domains':

- 1 behaviour (such as aggression or lack of inhibition)
- 2 cognition (such as a learning disability)
- 3 psychological and emotional needs (such as distressing hallucinations or anxiety)
- 4 communication (such as signing, or using Braille, pictures, hearing aids or other communication technology)
- 5 mobility (such as risk of falls, difficulties standing or walking)
- 6 nutrition – food and drink (such as difficulty swallowing)
- 7 continence (such as help with catheters, managing constipation or urine infections)
- 8 skin (such as pressure ulcers)
- 9 breathing (such as emphysema or chest infection)
- 10 drug therapies and medication – symptom control (such as help managing medication)
- 11 altered states of consciousness (such as coma)
- 12 other significant care needs.

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. For a full explanation see the user notes in the DST under the heading for each domain.



It is important that the 12 areas of need are not looked at in isolation. A person's needs in each area must also be considered in relation to the following key indicators:

- **nature** – for example whether the person has physical health, mental health or psychological needs, as well as their effect on the person and the type of treatment they need
- **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** – whether there are unexpected changes in the person's condition, the extent of these changes and how this affects their level of risk and care needs. This also relates to the level of risk there is 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 and in relation to the four key indicators listed in the blue box on **page 13**. This information is then used to help decide whether the person has a 'primary health need' and is therefore eligible for NHS continuing healthcare.

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

- **priority** 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
- 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.

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**‘Social services sign you off as “stable” if you’ve not been in touch, but dementia is not stable.’**

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Person living with dementia

It is important to understand that many needs or combinations 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 and uncertain.

The DST states that all the factors that affect a person's care needs must be considered to decide whether they are eligible for NHS continuing healthcare. 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 and the DST must be used as a tool and not simply a tick-box exercise. The DST is designed to gather and present information from the assessment in a way that helps consistent decision-making about who is eligible for NHS continuing healthcare.

## The Fast-track pathway tool

People who are nearing the end of their life, specifically people who have a 'rapidly deteriorating condition that may be entering a terminal phase', may be assessed as having a 'primary health need'. They may urgently need NHS continuing healthcare funding – for example to allow them to go home to die or so that end-of-life care can be set up. In these cases, the Fast-track pathway tool should be used to assess their needs.

However, it can be difficult to know when a person with dementia is nearing the end of their life, unless they have another condition as well (such as cancer). This means the Fast-track pathway can be hard to apply to people with dementia.



### Top tip

Before an assessment for NHS continuing healthcare, get a copy of all the documents that relate to the assessment process, including the Framework and the Decision support tool (DST). These documents are listed on **page 54** and available on the gov.uk website. Use them 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 about whether the person should receive NHS continuing healthcare.



**'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.'**

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Carer for a person living with dementia

## Difficulties for people with dementia

The way the NHS defines a 'primary health need' can make it difficult for people with dementia (as well as people with some other conditions) to be found eligible for NHS continuing healthcare.

Each of the 12 areas of need in the Decision support tool (DST) (listed on **page 13**) has a number of possible ratings, but some needs can't be rated as highly as others. For example 'psychological and emotional needs' and 'communication' do not have a severe rating, but 'behaviour' and 'altered states of consciousness' do. This may make it harder for people with dementia to be found eligible for NHS continuing healthcare.

This is particularly true if the DST is not applied correctly. The Framework is clear that both the quality and quantity of care that the person needs should be taken into account to decide whether they have a 'primary health need'. For example having a lot of low-level nursing care needs could mean that someone can't be left unsupervised and requires 24-hour care. This won't necessarily imply that they are eligible for NHS continuing healthcare, but it might do.

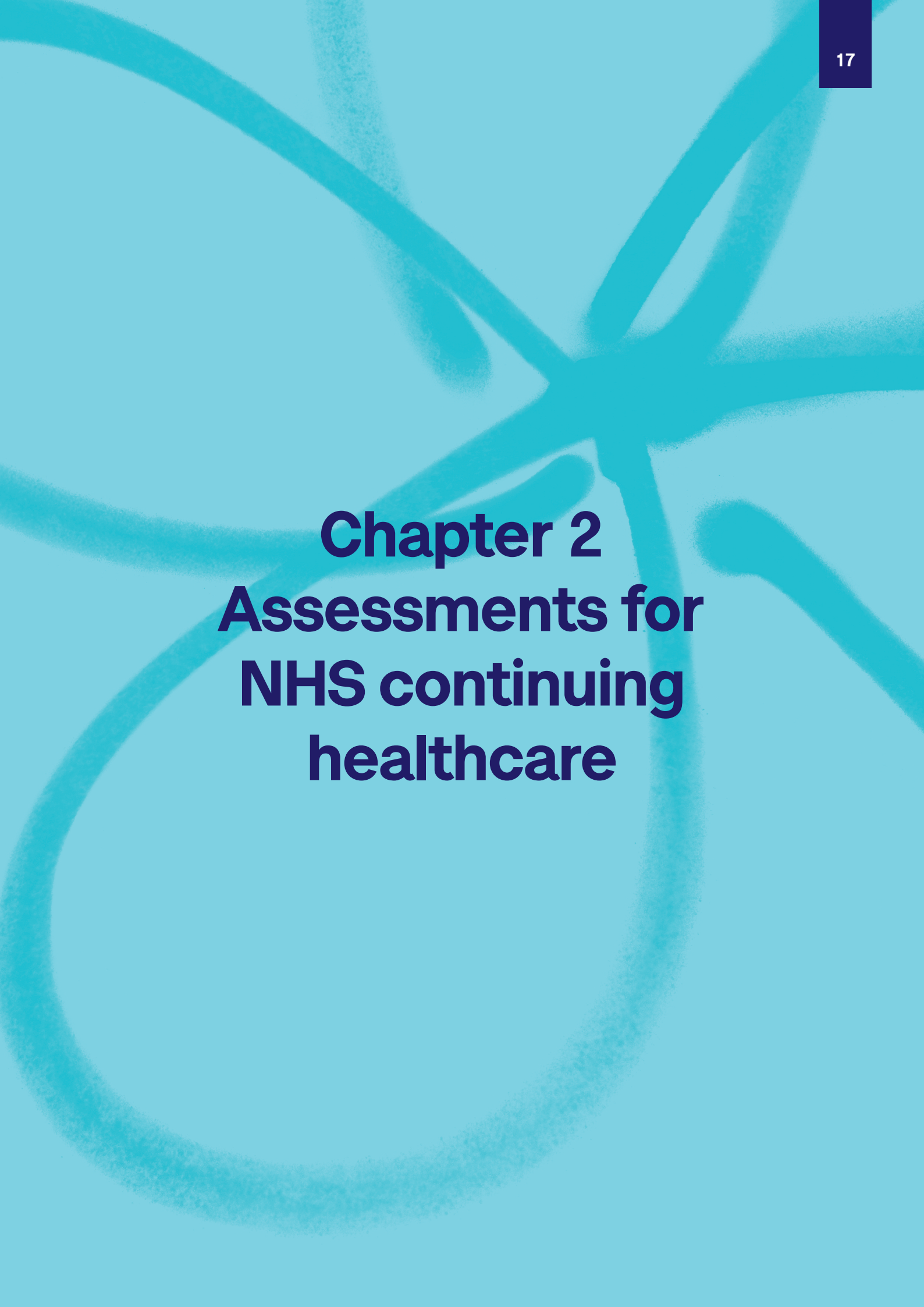
Remember that a managed need is still a need and it should be included. If a need is being well managed, it is sometimes not rated as highly as it should be in the assessment. However if a person has a high level of need it should be rated as high, even if the need is being met.



**'They don't seem to understand dementia at all.'**

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Carer for a person living with dementia



# **Chapter 2**

## **Assessments for NHS continuing healthcare**

**To find out whether someone is eligible for NHS continuing healthcare, they must have their needs assessed by their clinical commissioning group (CCG). This chapter explains how this assessment is done. It explains the different stages of the assessment, how it is carried out and difficulties you may have.**

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 29.**

## How to get an assessment

It is the CCG's responsibility to assess a person's needs if there's a possibility that they will be found eligible for NHS continuing healthcare. If you don't know whether an assessment has been carried out, or if you want to request one, contact your local CCG and ask to speak to the NHS continuing healthcare co-ordinator. You can find the CCG's contact details at your local GP surgery or through your local Patient Advice and Liaison Service (PALS). You can find your local PALS and CCG at [www.nhs.uk/service-search](http://www.nhs.uk/service-search)

Ask the CCG for information about the assessment process and when it will begin. Also tell the CCG that you want to participate fully and contribute to the assessment. Ask them to give you all the information you will need in advance, including the Framework and the Decision support tool (DST).

Whether or not the person is found eligible for continuing healthcare, if their needs change in the future it is important to ask for them to be reassessed.



### Top tip

Try to take part in assessment meetings and understand which documents have been used as evidence. For example, have the care home or hospital notes been taken into account?



## Principles of the assessment

Any assessment for NHS continuing healthcare should be based on the following principles.

- Assessments should be organised so that the person who is being assessed and their family or representatives understand the process. A representative may be the person's partner, friend or family members. The person and their representatives should receive the advice and information they need to take part in the assessment and discussions about their future care.
- The person being assessed should give their full consent to the assessment before it begins. If the person lacks the mental capacity to give consent, someone may need to give consent for them. For more information see factsheet 460, **Mental Capacity Act 2005**.
- NHS continuing healthcare is available in any setting, so the assessment can also be carried out in any setting – including the person's own home.
- 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 assessment and decision-making process must be based on a person's health needs, not on their diagnosis.
- The decisions that are made during the assessment and the reasons for them should be clear and transparent for everyone involved, and they should be available in writing.
- If the person's representative or carer disagrees with any part of the assessment, this should be recorded in the Decision support tool (DST).
- The assessment and decision-making process should focus on the person, including being sensitive to their cultural background.



### Top tip

Good record-keeping is essential. For example, you should record the date, time, name of a person to contact and a brief summary of all conversations you have about the needs of the person you are caring for. This includes conversations with staff from the CCG, hospital, GP, care home and social services.

## Consenting to the assessment

The person who is being assessed for NHS continuing healthcare should give their informed consent before the assessment begins, if they are able to. If the person lacks the ability ('mental capacity') to do this, the health professionals who are carrying out the assessment should follow the Code of Practice set out in the Mental Capacity Act 2005. For more information see factsheet 460, **Mental Capacity Act 2005**.

A person may choose a family member or other person (who is independent of the local authority or NHS) to represent them during the assessment. This might be the person's 'attorney' under a Lasting power of attorney (LPA) – see the definition of LPAs on **page 7**. Even if a representative doesn't have a legal power (such as an LPA), the person or people who do the assessment should take the views and knowledge of representatives into account.

## The assessment in brief

The assessment process may have two stages. The first stage is known as a 'Checklist screening'. This is a light-touch assessment to identify people who might be eligible for NHS continuing healthcare. If this shows that a person may be eligible, the second stage will be for them to have a full assessment. The full assessment is carried out by a multidisciplinary team (MDT) of health and social care professionals, using the Decision support tool (DST). Some people may not have the Checklist screening but instead go straight to the full assessment using the DST.

If a person's condition is rapidly becoming worse or they are near the end of their life, doctors or nurses may use the Fast-track pathway tool to enable the person to receive care urgently. This will remove the need for the Checklist or full assessment using the DST.



The Framework makes it clear that:

- the CCG must keep the person's representative or carer fully informed at all stages of the assessment
- the result of any decision must be recorded in the person's notes
- the decision (including the reasons why the decision was reached) should be sent to the individual or their carer or representative in writing, as soon as possible
- the CCG must explain how the person or their representative can ask for a review if they are not happy with the result of the assessment.

## Checklist screening

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, or local authority staff like social workers, care managers or social care assistants.

The CCG and local authority identify and agree on who can complete the Checklist. As far as possible they should choose staff whose day-to-day work involves assessing or reviewing people's needs.

If the Checklist screening shows that the person may be eligible for NHS continuing healthcare, a full assessment must be carried out.

The Framework refers to a full assessment as a 'multidisciplinary team (MDT) assessment'. You might sometimes hear people call it a 'Decision support tool assessment' or 'DST assessment'.

If at the Checklist stage it is decided that the person doesn't need a full MDT assessment, the CCG should clearly communicate this to the person and their carers or representatives. The person or their carer can still request a full assessment and the CCG must fully consider this request.

Remember that the Checklist has a fairly low threshold. This means that although lots of people may meet the criteria at this stage, many people who go on to have a full assessment will not be found eligible for NHS continuing healthcare.



A person will need a full assessment if the Checklist finds they have any of the following:

- high levels of need in two or more care domains (see **page 13**)
- moderate levels of need in five or more domains, or one high level of need and four moderate levels of need
- one high level of need in one of the four domains that carries a priority level in the DST and any level in other domains.

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

## Multidisciplinary team (MDT) assessment

When a person has been referred for a full assessment to see whether they are eligible for NHS continuing healthcare (usually after the Checklist has been used), a multidisciplinary team (MDT) must assess whether a person has a 'primary health need'. The MDT will do this using the Decision support tool.

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

The CCG will identify someone to co-ordinate the MDT assessment. This person will be responsible for the assessment process until the decision about NHS continuing healthcare 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 MDT assessment, ideally 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 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 usually include health and social care professionals who know about the person's needs, whenever possible. 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, use the Decision support tool to record their findings, and make a recommendation to the CCG about whether the person has a 'primary health need'. The CCG should follow the MDT's recommendation, except in exceptional circumstances. If this happens they should explain in writing their reasons for this decision.

In addition to the Decision support tool, a 'care needs portrayal' (sometimes called an 'individual needs portrayal') may also be completed during the assessment. Care needs portrayals vary from one CCG to another (and some local authorities produce them too). However they should all give more information about the person's needs than the Decision support tool. The care needs portrayal should be used alongside the Decision support tool to collect evidence – not instead of the tool.

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 the definitions of these documents on **pages 7 and 8**). There is a section in the Decision support tool where the person's carer or representative can say what they think the person's care needs are and have their views recorded. It is very important that you do this.

## When and where assessments can take place

An assessment for NHS continuing healthcare can be carried out anywhere. This includes a hospital, a residential or nursing care home, or the person's own home. People should be supported so the assessment can be done in the location that is most suitable for their current and ongoing needs.

### In hospital

If a person is leaving hospital and they will need a significant amount of care after they have left, the hospital should consider whether the person should have an NHS continuing healthcare assessment.

The Framework says that if someone is ready to be discharged from hospital, the assessment process should not be allowed to delay them leaving hospital.

The Framework also says the local authority shouldn't be asked to take responsibility for the person (and carry out an assessment of their social care needs to plan their care) until the need for an NHS continuing healthcare assessment has been fully considered.

A hospital should not discharge a person with dementia without considering whether or not they need NHS continuing healthcare. 'Considering' can mean a number of things, including carrying out a Checklist screening, or possibly carrying out a full assessment of the person's needs, or even using the Fast-track pathway where that is necessary.

However, the Framework makes it clear that doing an assessment in hospital does not always show how much or what type of care a person really needs. Therefore it is sometimes appropriate to discharge the person from hospital and then do the assessment for NHS continuing healthcare at a later date (as explained on **page 12**). At that point their ongoing needs may be clearer, so the assessment is more likely to show their long-term needs. An 'interim package of care' must be arranged until it is appropriate to do the assessment – usually up to six weeks after the person is discharged from hospital. Therefore the assessment may take place while they are in intermediate care – for example receiving care in their own home or in a community hospital.

Local authority staff as well as health professionals should be involved in the assessment process in a way that makes planning and decisions about the person's care effective and consistent. This is good practice because it means a social worker who is familiar with the person can contribute to the assessment. Also, if the person is not eligible for NHS continuing healthcare or if their needs change in the future, social services may become involved in providing their care, so they should be fully informed about the situation.



**Remember that a need shouldn't be discounted in the assessment process just because it is being successfully managed. Well-managed needs are still needs, as explained in 'Difficulties for people with dementia' on page 16.**

Many people with dementia who are leaving hospital should be considered for NHS continuing healthcare. However few people have this explained to them and they are not told about the NHS continuing healthcare assessment process.

## In a care home

A person who is moving into a care home permanently should be considered for NHS continuing healthcare, even though they may not be found eligible for it. This is particularly important if they are moving into nursing care. If they are not considered, the person's needs may not be identified.

If someone is receiving NHS continuing healthcare in a care home, their care will be reviewed at least once a year. If someone is not receiving NHS continuing healthcare but they are receiving registered (funded) nursing care in a care home (see **page 28**), the Checklist screening should be completed as part of the annual review of their registered nursing care. If the Checklist screening shows they may be eligible for NHS continuing healthcare, they will then have a full assessment.



## Top tip

**Certain circumstances could lead to at least a Checklist screening for NHS continuing healthcare – for example a person being discharged from hospital or moving into a care home. If you don't think a Checklist screening has been carried out or you're not sure, you should always ask whoever is in charge of the person's care.**

People who are living in a care home but not receiving NHS continuing healthcare funding should be considered for it if their needs change. You may need to ask the care home manager or a member of staff to arrange an NHS continuing healthcare assessment.

It is often assumed that people who are in a residential care home (rather than a nursing home) are not eligible to receive NHS continuing healthcare. This assumes that people who have the most serious medical conditions and complex care are cared for in a nursing home, rather than a residential home. In fact, many people in residential homes have complex medical conditions and they may be eligible for NHS continuing healthcare. However, because of the way their needs are assessed it may not be easy for them to receive continuing healthcare.

## In a person's own home

A person who is living and being cared for at home can be assessed for NHS continuing healthcare in their own home. To get an assessment, speak to a nurse, doctor, other healthcare professional, social worker, or the continuing healthcare team at your local CCG.

You can find the contact details for your CCG on the NHS website (see **page 52** for the website address). If you can't find the details of the continuing healthcare team, ask a healthcare professional who is involved in the person's care for the details.

For people who are found eligible and receive NHS continuing healthcare in their own home, there are new ways to arrange care by using a personal health budget. For more information see **'Personal health budgets'** on **page 26**.





## Getting NHS continuing healthcare at home

A person can be eligible to receive NHS continuing healthcare funding to cover the costs of their care at home. However, as with people in residential care, it is sometimes wrongly assumed that people who have the most serious medical conditions would be cared for in a nursing home. This means it can be hard for someone who is cared for at home to be found eligible for NHS continuing healthcare.

Sometimes, people who should be eligible for NHS continuing healthcare at home are wrongly charged for their care. This happened in the case of Malcolm Pointon and his wife Barbara. When the Parliamentary and Health Service Ombudsman reviewed the case in 2004, the Ombudsman found that Malcolm and his wife had been paying for care at home that should have been available on the NHS.

If you have problems getting NHS continuing healthcare at home, you may want to mention and discuss the Pointon case. There might be parts of the case that support your own argument. For more details about this case see **'The Pointon investigation 2003'** in **Appendix 3** on **page 50**.

## Results of the assessment

After the MDT assessment and within 28 days of the Checklist being received by the CCG, the CCG 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.

If you disagree with the decision, you can ask the CCG to look at the decision again. Ask for all the paperwork relating to the assessment, including the completed Decision support tool, so that you can show exactly where you disagree with the findings. Your request for the CCG to look at the decision again, as well as any more information you might want to provide, should be considered fully. For more information on what to do if you disagree with a decision see **Chapter 3 'Appealing against decisions and the complaints procedure'** on **page 29**.



### Top tip

When you are applying for, or challenging, a decision on NHS continuing healthcare, 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 NHS continuing healthcare, make sure you receive a copy of all the relevant paperwork, including the completed Decision support tool. This can be helpful in the future, especially if NHS continuing healthcare is withdrawn at a later date.

## If NHS continuing healthcare is awarded

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

If the person receives benefits and is found eligible for NHS continuing healthcare, they or their representative will need to tell the Department for Work and Pensions. See **Appendix 4 ‘Further information and support’ on page 51** for details.

If the person is receiving NHS continuing healthcare, any benefits they receive may be affected – for example Disability living allowance, Personal independence payment and Attendance allowance. If their carer receives Carer’s allowance, this may also be affected. Not all benefits will be affected – for example the person’s state pension will continue as before. However their pension credit might be affected. There are different rules depending on whether a person receives care at home or in a care home.

If you are unsure about benefit entitlements, contact your local Citizens Advice or Age UK. See **Appendix 4 ‘Further information and support’ on page 51** for details.

Some people who are awarded NHS continuing healthcare may already be living in a care home. If the CCG doesn’t normally pay for services in that particular home, it will need to talk to the care home staff to make sure they can properly meet the person’s care needs. Sometimes the CCG might want to move the person to another home where it pays for care and has available beds.

The CCG might also want to move the person to another home that can meet their needs at a lower cost. Sometimes the care and support that the person prefers will 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 and where it is provided, rather than the cost.

If you disagree about whether the person should have to move or about the care that is offered, try to solve the problem locally by discussing it with your CCG. 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 29**.

## Personal health budgets

Adults who receive NHS continuing healthcare have a right to receive a personal health budget. This is money to support their health and wellbeing. The person or their representative and the local continuing healthcare 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 and support 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 continuing healthcare co-ordinator at your local CCG for written information about how personal health budgets work.

### Periodic reviews after being found eligible

A person's eligibility to receive NHS continuing healthcare 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 three months after the initial decision and then annually after that. 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 continuing healthcare funding removed after a periodic review. You can appeal against this decision. For more information about how to appeal, see **Chapter 3 'Appealing against decisions and the complaints procedure'** on page 29.

If you appeal against the decision, the CCG will need to show why the person is no longer eligible for funding. This means they must show how the person's condition has improved. However if the CCG says that the person's need has stabilised because their condition is now well-managed, this may be an inappropriate reason for the person not to receive funding. This is discussed on **page 16**.

It's important to think about how the person's care costs would be paid if the CCG removed NHS continuing healthcare funding. If the person is not eligible for continuing healthcare funding at this stage, the continuing healthcare co-ordinator should contact the local authority and ask them 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 NHS continuing healthcare funding is removed at any stage. For more information see factsheet 532, **Paying for care and support in England**.

If the CCG'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

If a person is not awarded NHS continuing healthcare, they may still be able to get other types of funding to help with the cost of their care.

### NHS-funded nursing care

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

NHS-funded nursing care is not a fully-funded package of care like NHS continuing healthcare. It is a set amount that is paid by the NHS directly to the person's nursing home to go towards the cost of their registered nursing care. NHS-funded nursing care is only available to people who are in a nursing home.

A person who moves into a nursing home should automatically be considered for NHS-funded nursing care. However they should have an assessment for NHS continuing healthcare first, before NHS-funded nursing care is considered.

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

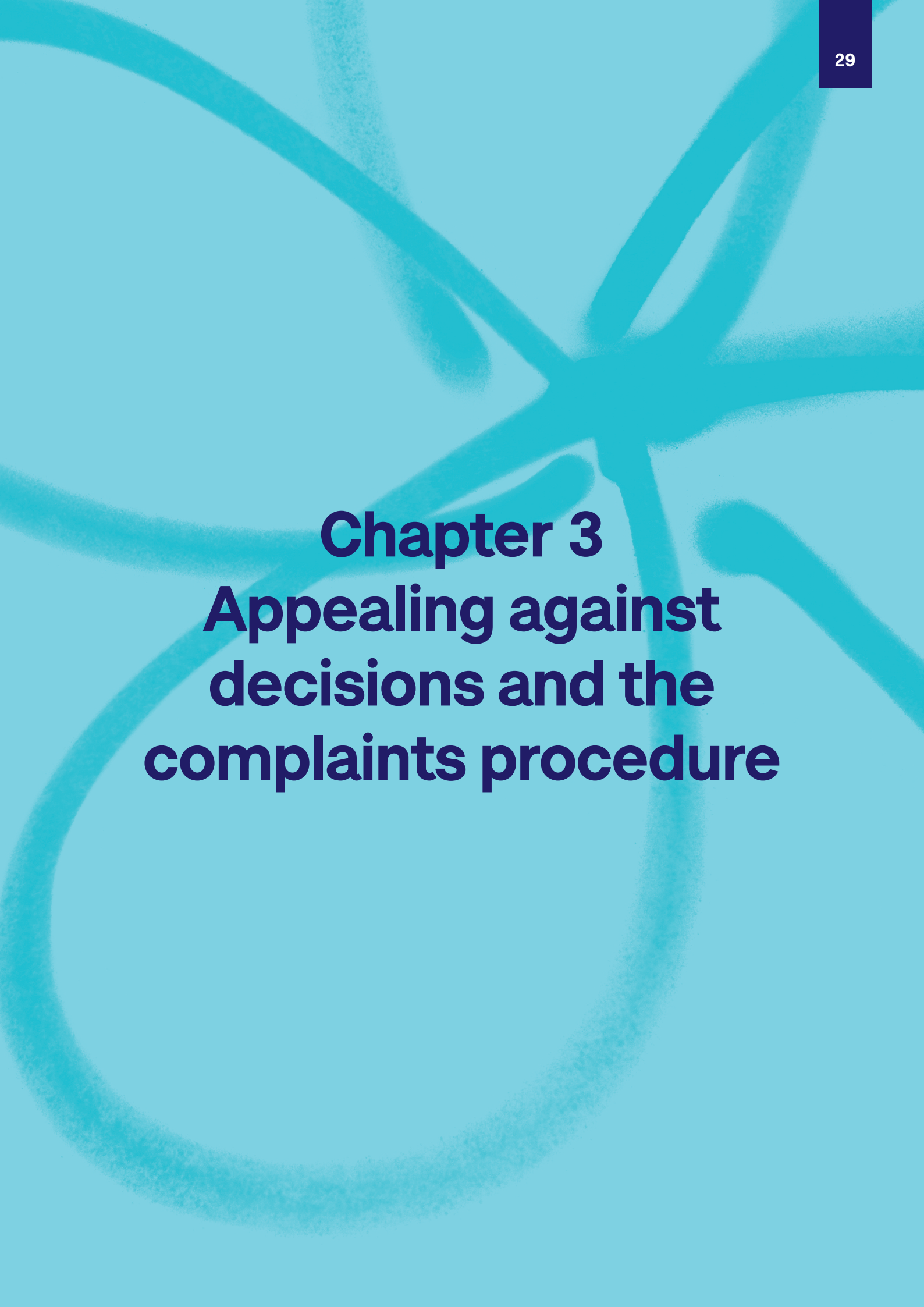
### Joint packages of health and social care

Another option for people who are not awarded NHS continuing healthcare is a joint package of care. This may be appropriate if the person has nursing or other health needs that don't make them eligible for NHS continuing healthcare but that can't be covered by the NHS-funded nursing care contribution alone.

Joint packages of care are funded by both the NHS and the local authority. 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 savings.)

The costs of a joint package of care are decided by the CCG and the local authority together. They will make this decision by looking at the person's needs and what the local authority can legally provide – local authorities are not legally allowed to provide some types of healthcare. Each CCG and local authority should have an agreement about how they deal with joint packages of care.

There are not many examples of joint packages at the moment, but the number of packages that are being awarded is increasing. Ask the continuing healthcare co-ordinator at your CCG for more information to find out whether a joint package of care is appropriate if the person has been turned down for NHS continuing healthcare.



# **Chapter 3**

## **Appealing against decisions and the complaints procedure**



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

## Three steps to challenging an assessment decision

If you plan to appeal against a decision about eligibility for NHS continuing healthcare, start by preparing your case. Work out whether you have good reasons to appeal and what they are, and find evidence to back up your case.

Then follow the three steps listed here. If you are successful at any stage, you won't need to carry out the next step(s).

- 1** Ask the CCG to review your case. Explain why you want your case to be reviewed and why you think the person is eligible for NHS continuing healthcare.
- 2** If the CCG 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 CCG's decision and make a judgement on it.
- 3** If you disagree with the outcome of the IRP, you can take your case to the Parliamentary and Health Service Ombudsman. The Ombudsman has the power to make a number of decisions about your case.



### Top tip

Alzheimer's Society has experienced and trained volunteers who can help guide you through the NHS continuing healthcare appeals process. The volunteers are only able to help with cases where a person is living with dementia and the CCG has already decided they are not eligible for NHS continuing healthcare, but the person believes they have grounds for appeal. Call us on **0333 150 3456** for more information.



## Make sure you have a case

After a full assessment, if you disagree with the decision about eligibility for NHS continuing healthcare and you think you have grounds for appeal, get a copy of the completed Decision support tool from the CCG. Also ask the CCG to explain how the decision was reached. The Decision support tool and explanation should be sent to you when you are told about the decision, but this does not always happen. You should also be sent information about how to appeal.

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. You must have specific reasons. Gather all the relevant documents and evidence about the assessment and make sure you have good reasons to ask for your case to be reviewed. Doing some research will save you a lot of time pursuing an unsuccessful appeal.

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

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

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 42**.



**'I couldn't have done it without Alzheimer's Society. I would have given up without your support.'**

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Carer for a person living with dementia

## Evidence

Having as much written evidence as possible will help you make a case. If there is a care needs portrayal (sometimes called an 'individual needs portrayal'), look at it and work out whether it was used to support the Decision support tool and the overall decision. Also ask for any relevant social services, care home and NHS patient records.

If you are asking for a review to look back over a specific period of time, look for copies of old assessments and reports that show the person's level of needs at that time. It will also be useful for you to gather care plans and notes, including any daily progress records from the person's care home, and 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 you could use a folder to file information under different headings such as 'care home notes', 'nursing home notes', 'NHS continuing healthcare assessments', 'care plans' and 'letters and your comments'.

For more information on how to access a person's medical notes see **Appendix 2 'Getting access to a person's notes' on page 45.**



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

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Carer for a person living with dementia

## Clinical commissioning group (CCG) review

After you have identified the grounds for your appeal and gathered any evidence to back it up, you will need to ask the CCG to review its original decision.

- You must write to the CCG within six months of the date on the decision letter and say that you want a review of the assessment (see the example letter on **page 34**). In some cases, if you have a good reason for missing the initial six-month deadline, you may still be able to ask for a review.
- The CCG must acknowledge in writing that it has received your request to reconsider its decision. It must also give you information about the NHS continuing healthcare appeal process.
- The CCG 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 CCG's appeals process, as well as timescales, must be available to the public. All CCGs must also have an NHS continuing healthcare local resolution process that is fair, transparent and includes timescales.

### Contacting the CCG for a review of its decision

Contact your CCG's NHS continuing healthcare co-ordinator to request a review of the decision. You must put your request in writing. In your letter, ask the CCG to review the NHS continuing healthcare decision and to reconsider the way the criteria have been applied. Send a copy of your letter to the person at the CCG who deals with its appeals process. This person should be named in the decision letter you received from the CCG. They may be the CCG's chief executive or someone in the CCG's NHS continuing healthcare team.

Your letter to the CCG might look like the example on **page 34**.

## Example of a letter to the CCG to request a review of its decision

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

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

[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.]

**[My mother] is in the late stages 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: can no longer communicate verbally but her erratic behaviour suggests that she 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].**

**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 NHS continuing healthcare. 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.

## Emotional and psychological needs

Health professionals often argue that if a person's condition has progressed so that they no longer behave in a way that is difficult to manage or they appear not to be able to communicate, then they no longer have any emotional or psychological needs. However the Parliamentary and Health Service Ombudsman did not accept this argument in her investigation into the case of Malcolm Pointon (see **'The Pointon investigation 2003' on page 50**).

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, and do everyday care tasks need to be done in particular ways because of the person's psychological needs?
- Does the person have hallucinations or delusions?

## Predictability

Some people assume that the needs of a person with advanced dementia are predictable and can be managed with only occasional visits from a district nurse (unless the person is in a nursing home). Think carefully about whether this is true. Make a list of issues the person has that are unpredictable and need an immediate response. These may include psychological needs as described in the case of Malcolm Pointon (see **'Emotional and psychological needs'**).

## Quantity of healthcare needs

No one should be denied NHS continuing healthcare because they do not need highly specialised care (see **'The Coughlan case 1999' on page 49**). 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

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

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) and problems with their skin, such as having an increased risk of sores and infections.

## Mobility issues

Mobility issues can be more difficult for someone with dementia. For example, using a hoist to transfer a person can be more complex and difficult if they have dementia than for someone who does not have dementia. This is because a person with dementia may not be able to understand what is happening and become distressed or agitated when someone tries to use a hoist. You could argue that moving a person with dementia requires skilled care beyond the basic manual handling skills that you would expect from a professional care assistant.

## The CCG's response

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

In most cases the CCG 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 CCG. In other cases the CCG will arrange a formal panel meeting to discuss its decision. Whether there is an informal meeting or a formal panel meeting with the CCG, a written account should be shared with the person's representative after the meeting.

If the CCG says you have no case, you might be unhappy with its decision. This might be because of the way the CCG 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 CCG may decide to call one. The CCG must give you information about how to contact NHS England and ask for an IRP to be set up.



### Top tip

**When you are applying for, or challenging, a decision on NHS continuing healthcare, put your case in writing and keep a record of all the correspondence you have with the CCG and NHS England.**

## Independent review panel (IRP)

An independent review panel (IRP) is set up by NHS England and it has an advisory role. It can look at whether the CCG applied the Framework correctly, and whether it followed the processes set out in the Framework and the Practice guidance. The IRP can then make a recommendation about whether the CCG's decision is valid. The CCG 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 that explains why you disagree with the CCG's decision about its review and why you are asking for an independent review. There is a sample letter you can use on **page 37**.

See **Appendix 4 'Further information and support' on page 51** 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 you mentioned in your original request for a review by the CCG, especially any that you think have not been picked up or have been ignored.

You could also write another brief letter to the person at the CCG who responded to you with the decision about the CCG'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.



## Example of a letter requesting an independent review

Dear [name of the NHS England contact]

The [name of the CCG] 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.

**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 34 and consider the reasons outlined throughout this booklet about why people are often refused funding for NHS continuing healthcare.**

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]

## 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 clinical advice from health and social care professionals. It should talk to all the people involved in the case, including 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 the continuing healthcare co-ordinator at the CCG who's responsible for your case about how to find an advocate.

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 a decision about whether the person is eligible for NHS continuing healthcare.

The panel must share some of the person's health and personal information with certain people. This includes the person's registered Lasting power of attorney (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.



### Top tip

Try to attend all the assessments and appeal or review hearings – for example if there is an independent review panel.

## Making the most of your evidence to the independent review panel

It is important to make a strong case if you are attending a review panel. The best way to do this is to explain why you think the person should be receiving NHS continuing healthcare by comparing their health needs with the specific eligibility criteria and the care domains of the Decision support tool (see **page 13**).

Look at the areas identified on **page 35** that suggests things to think about when you write to a CCG. Write down what you want to say and practise saying it before the meeting. Try to get copies of notes from anyone who has been involved in the person's care – for example their GP, consultant, social services and any relevant care home records.



### Top tip

Even if you think you can manage without an independent advocate, think about taking someone with you to provide moral support and so you can 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.’**

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Carer for a person living with dementia

## The independent review panel decision

### If your review is upheld and NHS continuing healthcare is awarded

If the IRP agrees that the person should receive NHS continuing healthcare it will tell your CCG. The CCG 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 CCG'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 it agrees with the CCG'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 **page 41** for more information on this.

### If NHS England refuses to set up an independent review panel

It is unusual for NHS England to uphold the CCG'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.

“

**‘While Dad was in hospital, I applied for NHS continuing healthcare funding. He was doubly incontinent, unable to feed himself and confined to a wheelchair, but social services told me that I didn’t stand a chance of getting the funding.’**

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Carer for a person living with dementia

## The Parliamentary and Health Service Ombudsman

The Parliamentary and Health Service Ombudsman is an independent organisation that can investigate complaints against some government departments, a range of public organisations in the UK, or the NHS in England. The Ombudsman can investigate complaints that these organisations have not acted properly or fairly, or that they've provided a poor service, as long as the complainant (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 CCG's original decision not to award NHS continuing healthcare. 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 begin by calling its helpline to check they have a reasonable case and that they have tried to resolve the complaint as far as possible. See the Ombudsman's helpline number on **page 52**.

The Ombudsman has the power to make a number of different decisions about your case. It can decide to grant NHS continuing healthcare, but there are also a number of other possible outcomes. The Ombudsman will explain these to you if it decides to investigate your case.

If the Ombudsman decides not to investigate your complaint further, it will explain why it has made that decision.

In some circumstances the Ombudsman may ask a CCG to review a case again. It may even ask the CCG to go back to the start of the assessment process if it finds 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 (which is explained on **page 42**). This is not the same as appealing against a CCG decision about NHS continuing healthcare, 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. If the Ombudsman has identified 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.**

## The NHS official complaints procedure

The NHS complaints procedure deals with all kinds of complaints about the NHS, not just NHS continuing healthcare. You might want to make a complaint because you have been told to do so by the Ombudsman, or because you are unhappy with the criteria used for the assessment, or because you are unhappy with the care package or treatment that you have been offered (see **'Make sure you have a case'** on page 31).

### Your letter of complaint

Write a letter of complaint to the chief executive of the CCG that is responsible for providing the person's care. You must state that you are making an official complaint.

You can use a version of the example letter to request a review (on **page 37**), 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 NHS complaints 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 eventually lead you to the Parliamentary and Health Service Ombudsman again. If this happens, the Ombudsman will either investigate your complaint or advise you about what to do next.



# Appendix 1

## Common questions

### Question

**Is it true that people with dementia automatically receive free care?**

### Answer

No. Nobody receives free care just because they have been diagnosed with dementia (or any other condition). Some people with dementia may qualify for free NHS continuing healthcare, but only if their primary need is for healthcare rather than social care.

### Question

**If someone is told they are not eligible for NHS continuing healthcare but they disagree, can they appeal against that decision?**

### Answer

Yes, if the person or their representative thinks they have a good reason to question the decision. There is a process, starting with the CCG, where the person or their representative can say they disagree with the decision and why. They can ask the CCG to review the decision and consider it again.

### Question

**My relative is well cared for and behaviour that some people previously found challenging has reduced because staff in the nursing home are skilled and understand his needs. When his needs were reviewed and a new assessment was carried out, the assessor said that my relative's needs had changed and his behaviour was no longer at 'priority' level. This means his continuing healthcare funding will be removed. Is this acceptable?**

### Answer

It may be appropriate to challenge this decision. A need like this, even if it is being well managed, is still a need. If the skilled care is removed it is highly likely that the challenging behaviours will return. The Framework says:

**'The decision-making rationale should not marginalise a need just because it is successfully managed: well-managed needs are still needs. 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.'**

## Question

**Do I need a solicitor to appeal an NHS continuing healthcare decision?**

## Answer

No. It is not necessary to use a solicitor to appeal a continuing healthcare decision, although if your case is very complex you may want to do so. The information in this booklet will help you conduct your own appeal.

A number of other organisations advertise that they can help with continuing healthcare appeals on a 'no win, no fee' basis. We don't recommend that you use them because their fees are often very high and people are sometimes put under a lot of pressure to continue with their case even if they want to withdraw.

Alzheimer's Society has experienced and trained volunteers who can help guide you through the NHS continuing healthcare appeals process. The volunteers are only able to help with cases where a person is living with dementia and the CCG has already decided they are not eligible for NHS continuing healthcare (but the person believes they have grounds for appeal). Call us on **0333 150 3456** for more information.

## Question

**If NHS continuing healthcare is awarded because the person has a 'primary health need', does that mean all of their care will be paid for by the NHS for the rest of their life?**

## Answer

No, NHS continuing healthcare is not a lifetime award. A person is only eligible while they have a 'primary health need'. There will be regular assessments and 'periodic reviews' to check whether their needs have changed. But as long as they continue to be assessed as having a 'primary health need', their care will be fully funded by the NHS, and this will cover all health and social care costs.

It's not unusual for a person to be found eligible but then, when they are reassessed, for it to be found that their needs have changed and NHS continuing healthcare funding is removed. For example, if a person was found eligible because they were behaving in ways that challenge but these behaviours have reduced as their mobility has got worse, they may lose their continuing healthcare funding. It is important to be aware of this. If NHS continuing healthcare funding is removed, the person may then have to pay for some or all of their care. For more information see factsheet 532, **Paying for care and support in England.**

# Appendix 2

## Getting access to a person's notes

**If you want to appeal against a decision about NHS continuing healthcare on behalf of another person, you'll need their medical records. However there are rules about patient confidentiality and data protection that make it difficult to get access to another person's medical, care home or social services notes.**

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 how to make a subject access request see booklet 882, **Accessing and sharing information on behalf of a person with dementia** or the Information Commissioner's Office website (listed in **Appendix 4 'Further information and support'** on page 51).

Generally, 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 for this to happen. However people with dementia are often not able to give such consent because they don't have the ability (the 'mental capacity') to make this decision. See the definition of 'mental capacity' on **page 7** and '**The Mental Capacity Act**' on **page 48** for more information.

### Attorneys and deputies

If a person with dementia has a Lasting power of attorney (LPA) for health and welfare, a person ('the attorney') will be appointed to make certain decisions for them, including about their care and welfare. The attorney should be given access to the person's medical 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 for the person. The attorney can only access the person's medical notes for financial reasons. However if the attorney thinks the person is entitled to NHS continuing healthcare, this is generally considered to be a financial reason.



**'I was completely disempowered because I couldn't get the information I needed. I didn't know where to go to get it.'**

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Carer for a person living with dementia

Some people with dementia won't have appointed an attorney and will now not be able to because they lack the mental capacity to do so. If this is the case for the person you are caring for and decisions need to be made for them that can only be decided by a court case, you will need to apply to the Court of Protection to become the person's deputy. A deputy is appointed by the Court of Protection to deal with a specific or range of issues for a person who lacks capacity and doesn't have an attorney. 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 deputies 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 attorney acting under an LPA and that they need the person's medical records to help them apply for NHS continuing healthcare. 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 as the person's attorney or deputy.

## 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 – particularly if they are a close family member. 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
- 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 crucial 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 the rights about accessing another person's personal information that are set out in the Framework and other relevant laws, such as the Mental Capacity Act. See **pages 47 and 48** for more information about these.



**‘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 Framework gives a third party (for example a family member or someone who is representing them such as an advocate) certain rights to access an individual's personal information, even if they don't have legal power like an LPA or deputyship. This personal information may include medical records. When a professional is deciding whether to share information with a third party who doesn't have 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 (such as medical records) to apply for NHS continuing healthcare. The Framework says information can be shared with third parties if there is an appeal about NHS continuing healthcare funding.

As well as an LPA for health and welfare, the Framework says:

**'There are a number of situations where a third party may legitimately be given information so long as the above principles are followed. Some common examples include:**

- **someone making care arrangements who requires information about the individual's needs in order to arrange appropriate support,**
- **someone with an LPA (property and finance), Deputyship (property and finance) or a registered Enduring power of attorney (EPA) seeking to challenge an eligibility decision, or any other person acting in the person's best interest to challenge an eligibility decision.'**

Therefore if you request another person's records, state that the Framework gives you a right to access the records and that it is in the person's best interests for you to have them. 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 NHS continuing healthcare and 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.'**

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Carer for a person living with dementia

## 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. 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 – for example their family, friends and unpaid carers. As a result, carers should be able to access the medical notes and social services records of people with dementia, even if the person has not appointed an LPA.

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

The Framework also says that information can be shared with third parties when it's in the person's best interests, as under the Mental Capacity Act. This is why if you submit a subject access request you should explain why you need the information and why it is in the person's best interests for you to have access to it.



# Appendix 3

## Examples of case law

**Three significant legal cases in England have defined the principles that are used to make decisions about who is eligible for NHS continuing healthcare. The circumstances and key findings of these cases are summarised here.**

### The Coughlan case 1999

A decision about who provides care can have significant financial consequences for people who have long-term health needs and their families. The Coughlan case came about because there was a need to clearly define when the NHS and social services are responsible for people's long-term care. This landmark case affected the way the law was interpreted and how the NHS and local authority social services took on the responsibility.

This case was brought by Pam Coughlan. She was left seriously physically disabled after a car accident. Her care was funded by the NHS until her nursing home was closed and responsibility for her care transferred to social services. She pursued a case against the NHS to get NHS continuing healthcare. Her case went all the way to the Court of Appeal.

The court had to consider where to draw the line between long-term care that is the legal responsibility of the NHS and long-term care that is the legal responsibility of social services. It ruled that because Pam Coughlan had a 'primary health need', her care was the responsibility of the NHS.

It decided that although social services could provide nursing care, it can only do so when it is 'merely incidental or ancillary' to providing accommodation and social care. This can be unclear and hard to define. However it means that social services can only provide limited nursing care if a person's main care needs are for social care and accommodation. The Coughlan case highlighted the fact that there are limits to the type of care that a social services authority can legally be expected to provide. If a person needs nursing care beyond these limits it should be provided by the NHS.

## The Pointon investigation 2003

Whether a person is eligible for NHS continuing healthcare should depend only on their care needs. It should not depend on where they are living or who is providing the care. If a person is being cared for at home, it is sometimes wrongly assumed that their need is for social care rather than healthcare. The Pointon case was a landmark because it demonstrated that a person who is living and receiving care at home can have a healthcare need, and they can be eligible for NHS continuing healthcare.

The case was brought by Barbara Pointon. She was caring for her husband Malcolm who had advanced dementia. Having become concerned about his deterioration while he was in a nursing home she decided that he should be cared for at home. However as Malcolm's dementia progressed he was not able to access healthcare services. Barbara Pointon applied for NHS continuing healthcare for Malcolm, but he was found ineligible. She believed the primary care trust (PCT) – the equivalent of today's clinical commissioning group (CCG) – had unfairly applied the assessment criteria and imposed conditions that were impossible to meet at home, such as the frequent intervention of a trained nurse. As a result, she took the case to the Parliamentary and Health Service Ombudsman.

The Ombudsman found that the guidance had not been properly followed because the assessment was too focused on physical needs and not psychological needs. Importantly, it found that Barbara Pointon was providing a high level of personalised care and that this was equal to, if not superior to, the care that Malcolm would have received in a nursing home. The Ombudsman concluded that the assessment had been carried out incorrectly and that Malcolm Pointon did have a healthcare need and was eligible for NHS continuing healthcare at home.

## The Grogan case 2006

The procedures and criteria for NHS continuing healthcare should be applied consistently across the country. However, there was no national policy for NHS continuing healthcare and NHS-funded nursing care until the Grogan case in 2006.

Mrs Grogan, who lived in a nursing home, had three times been assessed as not being eligible for NHS continuing healthcare. She was receiving the (then) top band of Registered nursing care contribution (RNCC). She argued that this was unlawful because the criteria that had been applied in her case were contrary to the judgment in the Coughlan case (see **page 49**). The judgment in Mrs Grogan's favour influenced the government to introduce a national policy.

This policy required the then PCT to look at the totality of a person's needs before it decides whether they are eligible for NHS continuing healthcare. It stated that just because someone's needs were being met through NHS-funded nursing care, this didn't mean they may not be eligible for NHS continuing healthcare. It also stated that anyone whose needs were equal to or greater than Ms Coughlan should be entitled to fully funded NHS care.

# Appendix 4

## Further information and support

### Other useful organisations

#### Age UK

0800 678 1602 (advice line, 8am–7pm)  
[www.ageuk.org.uk](http://www.ageuk.org.uk)

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

#### Citizens Advice

0800 144 8848 (for England)  
 0800 702 2020 (for Wales)  
[www.citizensadvice.org.uk](http://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. To find your nearest Citizens Advice, use the website or look in the phone book.

#### Court of Protection

0300 456 4600  
[courtofprotectionenquiries@justice.gov.uk](mailto:courtofprotectionenquiries@justice.gov.uk)  
[www.gov.uk/courts-tribunals/court-of-protection](http://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.

#### Disability Service Centre

[www.gov.uk/disability-benefits-helpline](http://www.gov.uk/disability-benefits-helpline)

#### Attendance allowance (AA)

0800 731 0122 (8am–3.30pm Monday–Friday)

#### Disability living allowance (DLA)

If you were born on or before 8 April 1948 –  
 0800 731 0122 (8am–3.30pm Monday–Friday)

If you were born after 8 April 1948 –  
 0800 121 4600 (9am–5pm Monday–Friday)

#### Personal independence payment (PIP)

0800 121 4433 (9am–5pm Monday–Friday)

The Disability Service Centre provides information and advice about Attendance allowance, Disability living allowance and Personal independence payment.

#### Independent Age

0800 319 6789 (helpline, 8.30am–6.30pm Monday–Friday)  
[advice@independentage.org](mailto:advice@independentage.org)  
[www.independentage.org](http://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](http://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](http://www.nhs.uk/service-search)

You can use the NHS website to search for health services near you, including the details of every clinical commissioning group (CCG) in England.

## NHS England

0300 311 2233 (9am–3pm Monday–Tuesday, Thursday–Friday, 9.30am–3pm Wednesday)  
[england.contactus@nhs.net](mailto:england.contactus@nhs.net)  
[www.england.nhs.uk](http://www.england.nhs.uk)

This national organisation runs the NHS in England. It oversees CCGs. 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 CCG.

## Office of the Public Guardian

0300 456 0300 (9.30pm–5pm Monday–Tuesday, Thursday–Friday, 10am–5pm Wednesday)  
[customerservices@publicguardian.gov.uk](mailto:customerservices@publicguardian.gov.uk)  
[www.gov.uk/government/organisations/office-of-the-public-guardian](http://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](http://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](mailto:advice@agecymru.org.uk)  
[www.agecymru.org.uk](http://www.agecymru.org.uk)

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

### NHS Wales

[www.wales.nhs.uk/ourservices/contactus/  
healthservicesnearyou](http://www.wales.nhs.uk/ourservices/contactus/healthservicesnearyou)

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](mailto:advice@ageni.org)  
[www.ageuk.org.uk/northern-ireland](http://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](http://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 (2018)  
**National framework for NHS continuing healthcare and NHS-funded nursing care**  
 Available at: [www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care](http://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care) [Accessed November 2022]

Department of Health and Social Care (2018)  
**NHS continuing healthcare checklist**  
 Available at: [www.gov.uk/government/publications/nhs-continuing-healthcare-checklist](http://www.gov.uk/government/publications/nhs-continuing-healthcare-checklist) [Accessed November 2022]

Department of Health and Social Care (2018)  
**Decision support tool for NHS continuing healthcare (DST)**  
 Available at: [www.gov.uk/government/publications/nhs-continuing-healthcare-decision-support-tool](http://www.gov.uk/government/publications/nhs-continuing-healthcare-decision-support-tool) [Accessed November 2022]

Department of Health and Social Care (2018)  
**Fast-track pathway tool for NHS continuing healthcare**  
 Available at: [www.gov.uk/government/publications/nhs-continuing-healthcare-fast-track-pathway-tool](http://www.gov.uk/government/publications/nhs-continuing-healthcare-fast-track-pathway-tool) [Accessed November 2022]

**The 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 Clinical Commissioning Groups (Responsibilities and Standing Rules) Regulations 2012**  
 Available at: [www.legislation.gov.uk/ukxi/2012/2996/contents/made](http://www.legislation.gov.uk/ukxi/2012/2996/contents/made) [Accessed November 2022]

**These Regulations were amended by:**

The Stationery Office (2013)  
**The National Health Service Commissioning Board and Clinical Commissioning Groups (Responsibilities and Standing Rules) (Amendment) Regulations 2013**  
 Available at: [www.legislation.gov.uk/ukxi/2013/2891/regulation/3/made](http://www.legislation.gov.uk/ukxi/2013/2891/regulation/3/made) [Accessed November 2022]



# Further reading

Department of Health (2013)

## **NHS continuing healthcare and NHS-funded nursing care: Public information leaflet**

Available at: [www.gov.uk/government/publications/nhs-continuing-healthcare-and-nhs-funded-nursing-care-public-information-leaflet](http://www.gov.uk/government/publications/nhs-continuing-healthcare-and-nhs-funded-nursing-care-public-information-leaflet) [Accessed November 2022]

NHS England (2014)

## **NHS Continuing Healthcare: Independent review process – public information guide**

Available at: [www.england.nhs.uk/publication/nhs-continuing-healthcare-independent-review-process-public-information-guide](http://www.england.nhs.uk/publication/nhs-continuing-healthcare-independent-review-process-public-information-guide) [Accessed November 2022]

Parliamentary and Health Service Ombudsman

## **How we can help with complaints about continuing healthcare funding**

Available at: [www.ombudsman.org.uk/making-complaint/what-we-can-and-cant-help/how-we-can-help-complaints-about-continuing-healthcare-funding](http://www.ombudsman.org.uk/making-complaint/what-we-can-and-cant-help/how-we-can-help-complaints-about-continuing-healthcare-funding) [Accessed November 2022]

Department of Health and Social Care (2018)

## **What is NHS continuing healthcare? Easy-read leaflet**

Available at: [www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care](http://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care) [Accessed November 2022]

# Notes





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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: Luke Clements, Cerebra Professor of Law and Social Justice, The School of Law, Leeds

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

To give feedback on this booklet, or for a list of sources, please email **[publications@alzheimers.org.uk](mailto:publications@alzheimers.org.uk)**

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(Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)



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