

# 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

First published 2009. This edition published 2016.

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No general guidance can ever be a complete guide to the law, which also changes from time to time. Specialist legal advice should always be taken if you are in doubt.

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# Introduction

When someone is living with dementia, their needs will change over time as their condition progresses. Some people will require a very high level of care and support to meet these needs. This might be provided in their own home or in a residential or nursing home.

Finding out about what care you will have to pay for and what care is free is complicated, and applying for free care can be time-consuming and often confusing. Getting information can be difficult and the rules can be hard to understand. However, there is information and support available to help you, and the rules should be applied consistently across the country.

## Aims of this guide

This guide explains the difference between healthcare and social and personal care, and what this means for you in terms of whether you will have to pay for care. It then explains what NHS continuing healthcare is and the process of applying for it. This includes 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.

This guide refers to documents, terms and resources that are commonly used in relation to NHS continuing healthcare. See a glossary of these on page 3. There are also references to Alzheimer's Society factsheets, which go into more detail on specific topics.

This guide only applies to people living in England. People in Wales and Northern Ireland should look at Appendix 4 for organisations that can provide information about the rules there.

## Healthcare and social care

There are two organisations in the UK that are responsible for providing care to meet people's needs – the NHS and local authority social services. Healthcare is provided by the NHS, and is free. Social and personal care is provided by local authority social services, and you may have to pay for it.

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

Although healthcare and social care may seem to be separate things, it is sometimes difficult to identify the line between healthcare and social care. This is very important, because any decision about who is responsible for providing care can have significant financial consequences.

## Eligibility for NHS continuing care

Applying for NHS continuing healthcare can be time-consuming and complex, but it can be extremely beneficial if you are successful. However, it is important to understand that the NHS limits access to free care. 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.

# Glossary of terms and resources used in this guide

There are a number of key documents and resources that relate 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 applying for NHS continuing healthcare. Use the list below as a reminder of what these refer to.

- **Care needs portrayal**

A care needs portrayal is a document that a multi-disciplinary team (see below) can complete when carrying out an assessment for NHS continuing healthcare. It records a person's care needs and should be used as well as, rather than instead of, the Decision support tool (see below).

- **Checklist and checklist screening**

The [NHS continuing healthcare checklist \(revised November 2012\)](#) is a 'light-touch assessment' document that is used to help identify people who may qualify for NHS continuing healthcare assessment and who should then receive a full assessment (a process known as 'screening').

- **Clinical commissioning group (CCG)**

A clinical commissioning group is a local NHS body that is responsible for providing services in a particular area. It is responsible for carrying out assessments and making decisions about NHS continuing healthcare, as well as for providing the care if it is awarded.

- **The Decision support tool (DST)**

The [Decision support tool for NHS continuing healthcare \(revised November 2012\)](#) helps to bring together and record evidence of a person's care needs in one document. It is used by the assessor during a full assessment, and helps to inform their decision about whether an individual is eligible for NHS continuing healthcare.

- **Fast-track pathway tool**

The [Fast-track pathway tool for NHS continuing healthcare \(revised November 2012\)](#) is the assessment tool for determining whether a person is eligible to be fast tracked to receive NHS continuing healthcare when they are near the end of their life.

- **The Framework**

The [National framework for continuing healthcare and NHS-funded nursing care \(revised November 2012\)](#), which includes the [NHS continuing healthcare practice guidance](#), is a long document produced by the NHS. It describes the processes that all NHS agencies must follow when carrying out NHS continuing healthcare assessments.

- **Independent review panel (IRP)**

An independent review panel is a body that can be set up to assess whether a CCG has followed the correct procedures when assessing someone for NHS continuing healthcare. The IRP will tell the CCG of its decision, and the CCG should follow this.

- **Lasting power of attorney (LPA)**

A Lasting power of attorney is a legal tool that allows you to appoint someone to make certain decisions on your behalf, if you reach a point where you cannot make them yourself. There are two types of LPA – one that covers decisions about a person's finances and property, and one that covers decisions about their health and welfare. For more information see factsheet 472, **Lasting power of attorney**.

- **Mental capacity**

'Mental capacity' is the ability for someone to make a particular decision for themselves. For many people with dementia, there will come a time when they no longer have this ability, and they are said to 'lack capacity'. If this happens, someone will need to make decisions for them. For more information see factsheet 460, **Mental Capacity Act 2005**.

- **Multidisciplinary team (MDT)**

This is the team of people that carries out a full assessment for NHS continuing healthcare. It must consist of at least two professionals from different healthcare professions (such as GP, consultant or community mental health nurse) or one healthcare professional and one social care professional who is qualified in assessing people for care services. Other health and social care professionals involved in the person's care should also be included, where possible.

- **NHS England**

NHS England is the national body that runs the NHS in England. It oversees local services, such as hospitals and GP practices, and it is also responsible for setting up independent review panels.



- **Nursing home**

A nursing home provides personal care, much like a residential care home (see below), but also has a registered nurse on duty 24 hours a day. Some homes that are registered for nursing care will accept people with personal care needs who may need nursing care in the future.

- **Practice guidance**

The [NHS continuing healthcare practice guidance](#) is part of the Framework (see above). It is produced to support practitioners and others who implement NHS continuing healthcare to carry out their role correctly.

- **Primary health need**

A 'primary health need' is a key term that the Department of Health uses when it is deciding who is eligible for NHS continuing healthcare. If your needs are for healthcare, as opposed to 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 provides help with personal care such as washing, dressing and eating. In some residential care homes staff have had specialist training in dementia care.

### **Top tip**

Learn the technical terms and jargon surrounding NHS continuing healthcare. These terms are used frequently throughout this document, and you will hear them a lot during the assessment process. Knowing what they mean will allow you to be involved in discussions and understand the decisions that relate to your case.

# 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 a person's eligibility are made. For information about the assessment process itself, see chapter 2, Assessments for NHS continuing healthcare.

## NHS continuing healthcare

NHS continuing healthcare is not a particular type of care, treatment or support. It is the name given to a 'package' of care that the NHS provides to meet a person's care needs. The Department of Health 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 found to have a 'primary health need' as set out in this guidance. Such care is provided to an individual aged 18 or over, to meet needs that have arisen as a result of disability, accident or illness.'**

This means that someone assessed as eligible for NHS continuing healthcare (often referred to as CHC) will have all the care that 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, and will meet all their assessed needs. This includes what is normally called social care.

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

If a person is assessed as not eligible for NHS continuing healthcare, they may be expected to pay for the social care they receive. The local authority will carry out a financial assessment and a means test. This is when they look at a person's savings and income to decide how much they are able to pay. Depending on the results of the means

test, the local authority may fund some or all of their care. For more information see factsheets 532, **Paying for care and support in England**, and 473, **Personal budgets**.

## Primary health need

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

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

If a person is assessed as needing social care, rather than healthcare, then they will not be eligible for NHS continuing healthcare. Instead, they will receive care provided by social services, and this may need to be paid for.

Any decision about whether someone is eligible for NHS continuing healthcare must be based only on their needs. If a person is assessed as having a primary health need, they are entitled to NHS continuing healthcare. Their financial situation, or any financial constraints faced by the CCG, should not affect their eligibility. Nor should the setting in which the person is being cared for 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 professional.

The diagnosis of a particular disease or condition, such as dementia, cannot in itself entitle someone to NHS continuing healthcare. A person's needs alone will determine whether or not they are eligible.

## Determining primary health need

A person's needs will be assessed to decide ('determine') whether or not they have a primary health need. The CCG's continuing healthcare co-ordinator or, if the person is in hospital, other medical staff, will arrange this assessment. All assessments

should follow the procedure as it is set out in the Framework. Health and social care staff involved in the person's care should identify when an assessment is required, but this does not always happen.

### **Top tip**

Create a medical history for the person you care for. This will be useful when being assessed for NHS continuing healthcare, and in challenging a decision, if necessary. Keep this medical history regularly updated.

The assessment may take place in two stages. This is explained fully in chapter 2. If a full assessment takes place – often the second stage of the process – the CCG will use the Decision support tool (DST) to help determine whether someone has a primary health need. If the person is nearing the end of their life, the CCG will use the Fast-track pathway tool.

### **The Decision support tool (DST)**

The Decision support tool (DST) is the key tool used to record a person's care needs, and to help determine whether or not they have a primary health need. It has been developed so that assessments for NHS continuing healthcare are carried out as consistently as possible across the whole country.

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

- 1 behaviour (eg aggression or lack of inhibition)
- 2 cognition (eg learning disability)
- 3 psychological/emotional needs (eg distressing hallucinations or anxiety)
- 4 communication
- 5 mobility (eg risk of falls, inability to bear their own weight)
- 6 nutrition – food and drink (eg difficulty swallowing)
- 7 continence
- 8 skin, including tissue viability (eg pressure ulcers)
- 9 breathing (eg emphysema or chest infection)
- 10 drug therapies and medication: symptom control (eg help administering medication)
- 11 altered states of consciousness (eg coma)
- 12 other significant care needs.

A person's needs in each domain are assessed, and scored as **low, moderate, high, severe** or **priority**. Not all five scores will apply in all domains. For a full explanation of each domain see the notes that accompany the Decision support tool.

It is important that these 12 areas of need are not looked at in isolation, and that a person's needs in each of these areas are looked at in relation to the following key indicators:

- **Nature** – the characteristics of the person's needs (which can include physical health, mental health or psychological needs), their effect on the person and the type and quality of treatment they need.
- **Complexity** – how different symptoms interact to make the care the person needs more complex.
- **Intensity** – both the quantity and the severity of the person's needs and the support they need to meet them, including the need for sustained or ongoing care.
- **Unpredictability** – whether unexpected changes in the person's condition occur, the extent of these changes, and how this affects their level of risk and care needs. This also relates to the level of risk to the person's health if they do not receive the care they need.

The completed DST should outline exactly what care needs the person has, in each different area, and in relation to the four key indicators. This information is then used to inform the decision about 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 a primary health need:

- **priority** needs in any one of the four domains that carry this level (ie behaviour, breathing, drug therapies and medication, and altered states of consciousness), or
- two or more **severe** needs across all care domains.

The DST goes on to state that where there is:

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

this may also, depending on the combination of needs, indicate a primary health need.

It is important to note that there are only a few needs or combinations of needs that definitely add up to a primary health need, and these will only apply to some people. For many people, it will be the combination of a number of lower level needs that mean they have an overall primary health need, but there is no clear definition of where the line is. In these cases, the DST is only a guide, and it is sometimes hard to say when a person's needs constitute a primary health need. This can make the assessment process complicated and uncertain.

The DST says all factors that affect a person's care needs must be taken into account in deciding whether a person is 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 amounts to a primary health need. Each person's needs will be different and the DST must be used as a tool only, and not simply as a tick-box exercise. It is designed to gather and present information from the assessment in a way that assists consistent decision-making.

### **Fast-track pathway tool**

People who are nearing the end of their life, specifically those with 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 to allow end-of-life support to be set up. In these cases, the Fast-track pathway tool should be used to assess their needs.

However, doctors often cannot accurately say when a person with dementia is nearing the end of life, unless they have another condition as well. This means that the Fast-track pathway can be hard to apply to people with dementia.

### **Top tip**

In advance of an assessment, get a copy of all the documents that relate to the assessment process, including the Framework and the Decision support tool. Use them to do your own assessment of a person's needs. The documents are available on the gov.uk website.

## 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 needs in the DST has a number of possible weightings, but some needs cannot be weighted 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.

This is particularly true if the tool is not applied correctly. The Framework makes it clear that both the quality and quantity of care the person needs should be taken into account when deciding if they have a primary health need. For example, a large number of low-level nursing care needs could mean that someone cannot be left unsupervised and requires 24-hour care. This may not necessarily imply that they are eligible for NHS continuing healthcare, but it might.

You should also remember that a need should not be discounted just because it is being successfully managed – a well-managed need is still a need. It can sometimes be the case that, because a need is being well managed, it is not rated as highly as it should be in the assessment. If a person has a high level of need, it should be rated as such, even if the need is being successfully met.

## 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 CCG. This chapter explains how this assessment is done, including the different stages of the assessment, how it is carried out, and any difficulties you may have.

If you are not happy with the outcome of an assessment you can work through the appeal and review process (see chapter 3, *Appealing against assessments and the complaints procedure*).

### How to get an assessment

It is the CCG's responsibility to assess a person's needs if there is a possibility of them being found eligible for NHS continuing healthcare. If you are unsure whether an assessment has been carried out, or if you want to request one, contact your local CCG and ask for the NHS continuing healthcare co-ordinator. You can find out the name of this co-ordinator at your local GP surgery or through your local patient advice and liaison service, known as PALS. You can find PALS and your local CCG at [www.nhs.uk/servicedirectories](http://www.nhs.uk/servicedirectories)

You should ask the CCG for information about the process and when it will begin. You should also tell the CCG that you wish to participate fully in the assessment, and ask them to give you all the information you will need. This includes the Framework and the Decision support tool.

### Principles of the assessment

There are a number of principles that should underpin any assessment for NHS continuing healthcare.

- Assessments should be organised so that the person who is being assessed and their family and/or carers understand the process, and receive the advice and information they need to take part in 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 make the decision for them. For more information about when and how this is done 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 take into account the person's wishes about how and where care is to be delivered, and these should be documented.
- The assessment and decision-making process must be based on a person's health needs, not on their diagnosis.
- The assessment and decision-making process should be person-centred.
- Decisions – and the reasons for them – should be clear and transparent for everyone involved.
- All decisions will be culturally sensitive and client-centred.

## The assessment in brief

The assessment process may have two stages. The first part is known as a Checklist screening. This attempts to identify people who might be eligible for NHS continuing healthcare. If this stage shows that someone may be eligible, they will then have a full assessment. The full assessment is carried out by a multidisciplinary team of professionals, using the Decision support tool. Some people may not have the Checklist screening and may go straight to the full assessment.

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 patient's notes
- the decision (including the reasons why the decision was reached) should be sent, in writing, to the individual or their carer or representative, as soon as is reasonably practicable
- the CCG must explain to the person or their family how to ask for a review if they are not happy with the result of the assessment.

For people whose condition is rapidly becoming worse and who are near the end of their life, doctors or nurses may use the Fast-track pathway tool to enable them to receive care urgently.

## Checklist screening

The Checklist screening will be carried out by a nurse, doctor, social worker or other qualified healthcare professional. Each local CCG and local authority decides who can complete the Checklist, and these people should be trained in how to use it.

If the Checklist screening shows that the person may be eligible for NHS continuing healthcare, a full assessment must be carried out. The full assessment is referred to as a multidisciplinary team (MDT) assessment in the Framework, though you may occasionally hear some people refer to it as a Decision support tool or DST assessment.

If it is decided at the Checklist stage that the person does not require a full assessment, the CCG should clearly communicate this to the person, as well as their carers or representatives. The person or their carer can still request a full assessment and the CCG must fully consider this request.

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

### Top tip

Good record keeping is essential. Record the date, time, contact person and brief summary of all conversations with staff from your CCG, hospital, GP, care home, social services etc about the needs of the person you care for.

## Multidisciplinary team (MDT) assessment

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

In order to carry out an MDT assessment, the CCG will identify someone, or more than one person, to co-ordinate the process. This person will take responsibility for the assessment right up until the decision about funding has been made and a care plan has been written.

The key health and social care professionals involved in the person's care should contribute to this assessment, ideally as part of the MDT. If a professional cannot be part of the MDT they can at least be asked to provide evidence to contribute to the assessment.

The Practice guidance defines an MDT as:

- (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 individuals for community care services under section 47 of the National Health Service and Community Care Act 1990.

This means that a minimum of either two healthcare professionals, or a healthcare professional and someone from the NHS or the local authority, will form the MDT. The Framework makes it clear that the MDT should usually include health and social care professionals who are knowledgeable about the individual's needs.

The MDT's task is to look at all of the evidence about a person's care needs, use the Decision support tool to record their findings, and make a recommendation to the CCG as to whether the person has a primary health need. The CCG should follow this recommendation, except in exceptional circumstances.

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), but they should all offer an enhanced level of information about the person's needs. They should not be used instead of the Decision support tool, but rather alongside it to aid the collection of evidence.

During the process, you may find it useful to compare what the Framework and Practice guidance says with the input from the MDT. There is a section in the Decision support tool that allows the person's carer or representative to say what they see as the person's care needs. It is very important that you use this opportunity.

It is important to remember that a need should not be discounted in the assessment process just because it is being successfully managed. Well-managed needs are still needs and should be considered as such. For more information on this see page 11, Difficulties for people with dementia.

## Consenting to the assessment

The person 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 to do this (known as 'mental capacity'), the health professionals 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 should be independent of the local authority or NHS) to represent them during an assessment. This might be the person's attorney under a Lasting power of attorney, for example. Even where someone does not have a legal power, such as Lasting power of attorney, the person or people carrying out the assessment should take into account the views and knowledge of representatives.

### Top tip

You should 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?

## When and where assessments can take place

An assessment for NHS continuing healthcare can be carried out anywhere, including a hospital, residential or nursing care home, or in the person's own home.

### Hospital

If someone is leaving hospital and going into a care home, or will need a significant amount of care after leaving, the hospital should consider whether the person should have an NHS continuing healthcare assessment. The Framework says that the local authority should not be asked to take over responsibility for the person (and carry out an assessment of their care needs to plan their care) until the need for an assessment has been considered.

The Framework also says that before an NHS body, such as a hospital, passes on the details of someone it wants to discharge to a local authority (LA) social services department, it:

‘must take reasonable steps to ensure that an assessment for NHS continuing healthcare is carried out in all cases where it appears to the body that the patient may have a need for such care. This should be in consultation, as appropriate, with the relevant LA.’

In other words, a hospital should not discharge someone with dementia without considering whether or not they need NHS continuing healthcare. ‘Considering’ normally involves carrying out a Checklist screening, possibly carrying out a full assessment of the person’s needs, or even fast-tracking, where necessary. However, the Framework makes it clear that doing an assessment in hospital does not always give a true picture of how much care an individual really needs.

The Framework also states that, if possible, ‘NHS staff should get social services colleagues involved in these assessments’. This is good practice because it enables a social worker who is familiar with the person to contribute to the assessment. In addition, if the person is found not to be eligible for NHS continuing healthcare, or if their needs change in the future, social services may be involved in providing their care and so should be fully informed of the situation. The Framework also warns that local authorities ‘should not allow an individual’s financial circumstances to affect a decision to participate in any joint assessment’.

This means that many people with dementia leaving hospital should be considered for NHS continuing healthcare. However, in reality, few people have this explained to them and few are told when or how they can ask to be assessed.

For more information about what a hospital must do when discharging someone see The assessment in brief, on page 13. For further information on the hospital discharge process see factsheet 477, **Hospital care**.

### Top tip

Certain circumstances should trigger at least a Checklist screening for NHS continuing healthcare, such as being discharged from hospital, or moving into a care home. If you don’t think a Checklist screening has been carried out, or you are not sure, you should always ask whoever is in charge of the person’s care.

## Care home

People moving into nursing homes should automatically be considered for NHS continuing healthcare. However, this is not always the case and people’s needs are often not adequately identified.

If someone is receiving NHS continuing healthcare in a care home, this should be reviewed at least once a year. If someone is not currently receiving NHS continuing healthcare but is receiving registered nursing care in a care home, 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.

It has often been assumed that people in residential care homes (as opposed to nursing homes) are not eligible to receive NHS continuing healthcare. This assumption was based on the view that people with the most serious medical conditions and complex care arrangements would be cared for in a nursing home, rather than a residential home.

In fact, there are many people in residential homes with complex medical conditions who 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 it.

## In a person's own home

Someone who is living and being cared for at home can be assessed for NHS continuing healthcare there. To get an assessment, you should request this from a nurse, doctor, other healthcare professional, social worker, or your local CCG continuing healthcare team.

The details of your CCG can be found on the NHS choices website – see page 42 for the website address. If you cannot find the details of the continuing healthcare team, ask a healthcare professional involved in the person's care for details.

For people who are found eligible and receive NHS continuing healthcare in their own home, there are new ways of arranging care using a personal health budget. For more information see factsheet 473, **Personal budgets**.

### Getting NHS continuing healthcare at home

Someone with dementia can be eligible for 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 those with the most serious medical conditions would be cared for in a nursing home. This means it can be hard for someone cared for at home to be found eligible.

Sometimes, people who should be eligible for NHS continuing healthcare at home will wrongly be 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 her 2004 report, she 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 the NHS continuing healthcare you feel you deserve as a result of being cared for at home, you may want to quote the Pointon case as an example in your correspondence. For more details of this important case see Appendix 3.

## Results of the assessment

The CCG should inform you of the outcome of the assessment, with a clear explanation of its reasons within 28 days, both verbally and in writing.

If you disagree with the decision, you can say so. 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 their findings. Your request, along with any additional 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*.

Even if you have been successful, make sure you receive a copy of all the relevant paperwork, including the completed Decision support tool. This can be helpful in future, especially if NHS continuing healthcare is withdrawn.

### Top tip

When applying for, or challenging, a decision on NHS continuing healthcare, you should put your case in writing and keep a record of all correspondence.

## If NHS continuing healthcare is awarded

If someone is successful and receives NHS continuing healthcare, they do not have to pay any of the costs of that care. The NHS pays 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 found eligible, the person or their carer or representative will need to let the disability benefits centre know. Getting NHS continuing healthcare might affect whether or not a person can get other benefits.

If someone is receiving NHS continuing healthcare, their Disability living allowance, Personal independence payments and Attendance allowance will be affected. If their carer receives Carer's allowance, this may also be affected. A person's state pension will continue as before. Pension credit might be affected though.

If you are unsure about anything to do with benefit entitlements, contact your local benefits office, Citizens Advice or Age UK – see Appendix 4, Further information and support, for details.

Some people who are awarded NHS continuing healthcare may be living in a care home. If the CCG does not normally pay for services in that particular home, it will need to talk to care home staff to make sure the person's care needs can be properly met there. Sometimes the CCG might want to move the person to another home where it funds care and has available beds.

The CCG might also want to move the person to another home where their needs can be met at a lower cost. Sometimes the support the person prefers will be more expensive than other options and although cost is an important consideration, the starting point for agreeing the person's care and where it is provided should be their preferences and needs.

If you disagree with the care that is offered, try to solve the problem locally by discussing it with your CCG. If you are not successful, you may be able to complain. For more information see chapter 3, Appealing against decisions and the complaints procedure.

### Periodic reviews after being found eligible

A person's eligibility for NHS continuing healthcare is reviewed regularly. This is known as a 'periodic review'. Even when someone has been through the complex 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 people who have 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.



If the CCG decides to remove funding, you will have to cover the costs of providing care. If their decision is overturned in the future, any costs you have paid in the interim will be reimbursed, but it is important to think about how you would meet these costs should the funding be removed at any stage.

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

### Top tip

When applying for, or challenging a decision on, NHS continuing healthcare, you should put your case in writing and keep a record of all correspondence.

## 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

Someone receiving care in a nursing home may be able to receive NHS-funded nursing care. This is not a fully funded package of care like NHS continuing healthcare but is a set amount, paid by the NHS to the person's nursing home, to go towards the cost of their registered nursing care.

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

Someone who moves into a nursing home should automatically be assessed for NHS-funded nursing care. They should always have an assessment for NHS continuing healthcare first, and only if this is not awarded should they be considered for NHS-funded nursing care.

The NHS-funded nursing care contribution should be paid straight to the person's nursing home. This means it is often difficult for people to know whether they are receiving it. If you are unsure, you should ask the nursing home for a written breakdown of how the fees are being covered.

To decide who will meet the costs not being covered by NHS-funded nursing care, the local authority will carry out a financial assessment. This is to decide how much the person can contribute to 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 is a package of care that is funded by both the NHS and the local authority.

A joint package of care may be appropriate where someone has nursing or other health needs that are not significant enough to be a primary health need, but are too great to be covered by the NHS-funded nursing care contribution. There are not many examples of joint packages at the moment, but the number of joint packages of care being awarded is likely to increase.

A joint package of care might also be an option if the person has some healthcare needs, but they are not enough to be considered a primary health need. This is because the local authority is not legally allowed to provide some types of healthcare. If this is the case, the person's needs will need to be met by both the NHS and the local authority.

The costs of a joint package of care are decided by the CCG and the local authority together. They will make this decision by considering the person's needs and what the local authority can legally provide. Each CCG and local authority should have an agreement on how they deal with joint packages of care.

# 3 Appealing against decisions and the complaints procedure

If you think someone with dementia has been charged for care that should have been provided by NHS continuing healthcare, you may be able to appeal. This chapter explains the different steps you will need to take to appeal and how to make a complaint if you are not happy with the care you have been offered.

## Four steps to challenging an assessment decision

In order to appeal against a decision on NHS continuing healthcare eligibility you should follow these four steps. If you are successful at any stage, you will not need to carry out the next steps.

- 1 Prepare your case. You need to work out whether you have grounds for appeal and what they are, and find evidence to back up your case.
- 2 Ask the CCG to review your case. Explain why you want your case reviewed and why you think the person is eligible for NHS continuing healthcare.
- 3 If the CCG decides you are 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 judgment on it.
- 4 If you disagree with the outcome of the IRP, you can take your case to the Parliamentary and Health Service Ombudsman. They have the power to make a number of decisions about your case.

## Make sure you have a case

If, after a Checklist assessment, you are unhappy with the decision not to offer a full assessment, or feel the outcome of a full assessment is not right, you can appeal against the decision, but you must make sure you have grounds to do so.

Before appealing, it is important to consider carefully whether you might have a case. It cannot just be your general view that the wrong decision was made, there must be specific reasons. You should get hold of all the relevant documents and have solid reasons to ask for your case to be reviewed. Doing some research will save you a lot of time pursuing an unsuccessful appeal.

If you feel you have grounds for appeal and have not already done so, get a copy of the completed Decision support tool from the CCG and ask them for an explanation of how the decision was reached. Be clear about your grounds for challenging the decision.

Note that an appeal is not an option if you wish to challenge:

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

Any of the above would be dealt with by the complaints procedure. For more about the complaints procedure see page 33.

## Evidence

Having as much documentary evidence as possible will help you to make a strong case. You might want to look at the care needs portrayal (sometimes called an individual needs portrayal) and work out whether it was used to support the Decision support tool and the overall decision. You should also ask for social services, care home and NHS patient records. If you are asking for a review to look back over a period of time, look for copies of old assessments and reports showing the level of needs at that time. Care plans and notes, including any daily progress records from the person's care home, may also be useful. Your own notes on the person's medical history and needs will also be useful.

### Top tip

Request medical records from various bodies involved in the person's care, such as the hospital or GP. Social services may have carried out assessments that contain useful information. Ask to see any reports that the local authority has about the person.

File all the information you gather. For example, you might want to get a folder and file information under different headings, such as care home notes, nursing home notes, NHS continuing healthcare assessments, care plans, 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.

## Clinical commissioning group review

Once you have identified the grounds for your appeal and put together any documentary 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 receiving their decision to tell it that you want a review of the assessment (see below).
- The CCG has five working days to acknowledge in writing that it has received your request, and it must also provide you with information on the NHS continuing healthcare appeal process.
- The CCG must deal with your request, complete its review and make a further eligibility decision within three months of receiving your request. If there is a delay, it must inform you in writing and explain the reason for the delay.

In some cases, if you have good reason for missing the initial six-month deadline, you may still be able to ask for a review.

Information about the review process, along with timescales for review, should be available to the public. It is important to note that different CCGs may have different processes – for example, some CCGs refer appeals to a neighbouring CCG to look at. You should ask your CCG for details of how it deals with appeals.

### Top tip

Go and see the records yourself at the hospital rather than asking for them to be sent to you by post. If you request them via post you may not be sent all the information available.

## Contacting the CCG for a review

You should write to the chief executive of the CCG to request a review. You can find out the chief executive's name and address by looking at the CCG's website or the NHS Choices website (see Appendix 4, Further information and support).

Alternatively, you can speak to social services or your NHS continuing healthcare co-ordinator. A sample letter is shown overleaf. In your letter, ask the CCG for a review of the NHS continuing healthcare decision, and ask it to reconsider the way that the criteria have been applied.

## Top tip

When applying for, or challenging, a decision on, NHS continuing healthcare, you should put your case in writing and keep a record of all correspondence.

Your letter to the CCG might look something like the example shown below.

Date

Your address

Dear [name of chief executive]

I wish to appeal the decision of [my mother's] continuing healthcare assessment.

I believe that my [{relationship to you, eg 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 including documents supporting your argument].

[My {relationship to you} is in the late stages of {type of dementia} and is cared for at the {name} nursing home/residential home/in her own home. She can no longer {set out her needs, for example: 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 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 {relationship to you} meets the criteria.

.....

Please progress this review and update me as soon as possible.

Yours sincerely  
{Your name}

Insert here the details of the person on whose behalf you are complaining. For example:

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

Use this part of your letter to explain why you think the person meets the criteria for NHS continuing healthcare. Be brief – details about the person’s condition should be in their notes. Some aspects that may be important for people with dementia (they may apply to other people too) are given below. This is not an exhaustive list. You will probably be able to think of other aspects that apply to your particular case.

### **Emotional and psychological needs**

Health professionals often argue that, once a person with dementia has become too ill to display behaviour that is difficult to manage, 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 page 39).

When making your case, you should think carefully about how the person’s psychological needs affect them, for instance:

- Does the person have panic attacks or fits?
- Does the person become easily frightened, and do everyday care tasks have to be carried out in particular ways to take account of psychological factors?
- Does the person have hallucinations?

### **Predictability**

Some people assume that the needs of a person with advanced dementia are predictable and can be managed with only the occasional visit from the district nurse (except in nursing homes). You should think carefully about whether this is true. Make a list of issues the person has that are unpredictable and require an immediate response. These may include the psychological needs described above.

### **Quantity of healthcare needs**

No one should be denied NHS continuing healthcare because they do not require highly specialised care (see The Coughlan judgment 1999, page 39). You should record the care that the person requires during an average 24-hour period. It may be a good idea to do this on a number of occasions and keep a diary, then compare the outcomes to give a true picture of the care a person may require.

### **Medication**

Think carefully about any issues surrounding a person’s medication.

- What level of monitoring of medication does the person need?
- Are there issues about the side-effects of medication that also require monitoring?
- Are there complicated issues around administering medication? (For example, does the person require injections that must be given by a professional?)

## Incontinence

Along with incontinence, are there additional issues that need to be taken into account when someone is incontinent? These could include their increased susceptibility to urinary tract infections and skin breakdown.

## Mobility issues

Mobility issues can be more difficult for someone with dementia. For example, transferring a person using a hoist can be more complex and difficult for someone with 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 therefore doesn't co-operate. You could argue that moving a person with dementia requires skilled care beyond the basic manual handling training 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 heard anything after one month, phone the CCG to ask about the progress of your review.

In most cases, the CCG's first step will be to attempt a local resolution, which will usually be handled by a CCG review panel. Sometimes, a CCG may refer the review to a neighbouring CCG so that the decision-making process is impartial.

If the CCG says you have no case, you might be unhappy with its decision. This might be because of the way it has followed procedures or applied the Decision support tool. In this case, the next stage is to ask NHS England to consider your case for review by an independent review panel (IRP). You can request an IRP yourself, or the CCG may decide to call one.

## Independent review panel (IRP)

An IRP is a body with an advisory role that is set up by NHS England. It can look at whether the CCG correctly applied the Framework, and whether it followed the processes set out in the Practice guidance. The IRP can then make a recommendation as to whether the CCG's decision is valid. The CCG should accept the IRP's recommendation in all but extreme cases.

## Requesting an independent review from NHS England

To request an independent review by an IRP, you must send a letter to NHS England explaining your reasons for disagreeing with the CCG's decision and why you are asking for an independent review.



You should also write another brief letter to the person at the CCG who responded to you, telling them that you are not happy with the decision and want an independent review of your case. You should tell them that you have read the Framework and the associated assessment tools. You should also say that you believe that you are wrongly paying, or have paid, for care that should have been available on the NHS. There is a sample letter you can use overleaf.

In your letter – see example below – you should write briefly about the person’s condition. You might want to point out any issues that you mentioned in your original request for a review from the CCG, especially any that you feel have not been picked up or have been ignored.

Dear

The {name of the CCG} has reviewed the case of my [{relationship to you}, {name}, {date of birth}, {NHS number}, who lives at {name} nursing home/residential home/in his/her own home.]

I am not satisfied with its findings and wish to request an independent review of the case.

{Put here your reasons for not being satisfied with the original decision that you are not entitled to fully funded care. You might want to refer back to the information in the first sample letter on page 26, and consider the reasons listed in this guide as to 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

Once NHS England has received your request, it will consider all the information and decide whether or not to convene an IRP to review the case. If it decides not to, it should send you a letter explaining its reasons.

### Top tip

Try to attend all assessments and appeal or review hearings, for example an independent review panel.

The IRP will talk to a number of people when 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. It should also have access to independent clinical advice. It should talk to all of the people involved in the case, including the person with dementia, health and social services staff and any other relevant people. These people are all able to attend the panel, or alternatively they can put their views in writing.

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

If you would like an independent advocate to help you at this stage, ask your local PALS (patient advice and liaison service). You can find details of your local PALS at [www.nhs.uk/servicedirectories](http://www.nhs.uk/servicedirectories)

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 funded by the NHS, local authority, or both, they should continue to do so until the panel reaches a decision about their eligibility for NHS continuing healthcare.

The panel must share information with some people. These include a person's registered Lasting power of attorney for health and welfare, or a court-appointed deputy for welfare, if they have one. It should also share information with the individual's representative, if this is in the person's best interests. There are rules about what information can be shared and with whom, but the aim of these rules is to make the process and the decisions as transparent as possible.

### Making the most of your evidence to the IRP

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 the individual's health needs with the specific eligibility criteria and the care domains of the Decision support tool.

Look again at the list on page 27 that suggests things to think about when writing 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 involved in the person's care – for example, their GP, consultant, social services and any relevant care home records.

Even if you think you can manage without an independent advocate, you should think about taking someone with you to provide moral support and to discuss events with 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 take on for you.

### **Top tip**

If you think you have a strong case for NHS continuing healthcare, be persistent. It can be difficult and frustrating, but many people with dementia are awarded NHS continuing healthcare funding.

## **The review decision**

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

If the IRP agrees that the person being cared for should receive NHS continuing healthcare, it will tell your CCG. The CCG should then write to you explaining this decision.

### **If you are unsuccessful and the original decision is upheld**

If the IRP decides that your case is not valid, and agrees with the CCG's original decision, you will have to decide if you are satisfied with this outcome. If you are not, you need to think about whether you have a good enough case to proceed to the next stage. If you do, then you can refer your case to the Parliamentary and Health Service Ombudsman. For more information on this, see below.

### **If NHS England refuses you an independent review panel**

It is very unusual for NHS England to uphold the CCG's original decision and refuse a review by an IRP. The Framework says that this can only be done if NHS England considers that 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 are entitled to write to the Parliamentary and Health Service Ombudsman and ask for your complaint to be looked at.

## The Parliamentary and Health Service Ombudsman

The Parliamentary and Health Service Ombudsman is an independent body that can investigate complaints against some government departments, a range of public bodies 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 have 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 because you have been refused an IRP, or because the IRP upheld the CCG's original decision. The Ombudsman will be able to look at your case, focusing on whether the correct processes and procedures were followed.

They will write to acknowledge your complaint within two working days of receiving it. If the Ombudsman decides to investigate your complaint, they will explain the process to you. The Ombudsman recommends that people first call their helpline to check that they have a reasonable case and that they have tried to resolve the complaint as far as possible. The helpline number can be found on page 43.

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

If the Ombudsman decides not to investigate your complaint further, they will explain to you why they have come to that decision.

In some circumstances, the Ombudsman may ask a CCG to review a case again. The CCG may even be asked to go back to the start of the assessment process if an obvious mistake was found in the way processes were carried out.

### 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 important to have good records in order to make an effective case to the Ombudsman.

## If the Ombudsman tells you to complain

Sometimes, the Ombudsman will tell people to go through the local NHS complaints procedure. This is not the same as asking the CCG for a review of the person's need for NHS continuing healthcare, nor is it the same as the IRP.

This may seem like a backward step, but if the Ombudsman has identified an issue that needs to be looked at through the complaints process, it is important that you follow the correct process to get the best results.

## The NHS official complaints procedure

The complaints procedure deals with all kinds of complaints about the NHS, not just NHS continuing healthcare. You might want to complain because you have been told to by the Ombudsman, because you are unhappy with the criteria used for the assessment, or because you are unhappy with the treatment that you have been offered (see Make sure you have a case, page 23).

## The letter of complaint

Write to the chief executive of the CCG in which the person is being cared for. The process is essentially the same as writing to the CCG to request a review of an NHS continuing healthcare decision, except that you must specifically state that you are making an official complaint.

You can use a version of the letter requesting a review (see page 26). However, you may want to adapt it to include anything else you have learnt during the appeal process. Be sure to state that you are making an official complaint. This ensures that your letter is dealt with according to the NHS complaints procedure.

Keep a copy of the letter and all correspondence that follows it. From this point on, you should follow the complaints process using the notes in this document as you would if you were requesting a review from the CCG.

Eventually, if your complaint is not resolved, you may get to the Ombudsman again. The Ombudsman will either investigate your case or advise you what to do next.

# Appendix 1

## Some commonly asked questions

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

**A** No. Nobody receives free care purely because of their diagnosis of 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 as opposed to social care.

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

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

**Q Do I need a solicitor to appeal the continuing healthcare decision?**

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

Alzheimer's Society has a group of experienced and trained volunteers who can help guide you through the continuing healthcare appeals process. The volunteers are only able to help with cases where a decision has already been reached by the CCG, but the person disputes the decision and believes that they have grounds for appeal. Call the National Dementia Helpline on 0300 222 1122 for more information.

**Q If NHS continuing healthcare is awarded because my relative 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?**

**A** No, NHS continuing healthcare is not a lifetime award. A person is only eligible while they have a 'primary health need', so there will be regular assessments and 'periodic reviews' to check whether a person's 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.

However, it is not unusual for people to be found eligible and then, when reassessed, their needs are found to have changed and continuing healthcare funding is removed. For example, if a person exhibited behaviours that challenge and was found eligible because of this, but these behaviours lessen as their mobility is reduced, they may lose their continuing healthcare funding.

**Q 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 carried out, the assessor said that his needs had changed and his behaviour was no longer at ‘priority’ level. This means that his continuing healthcare funding will be removed. Is this acceptable?**

**A** No. A need such as 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 [...] will this have a bearing on NHS continuing healthcare eligibility’

# Appendix 2

## Getting access to a person's notes

It will probably be necessary for you to have access to a person's medical records if you want to appeal a decision relating to NHS continuing healthcare on their behalf. However, rules about patient confidentiality and data protection make it difficult to get access to another person's medical or social services notes.

As a rule, if someone decides in advance that they wish you to have access to their files, they should always write a clear instruction giving their consent. Often, however, people with dementia are not able to give such consent. For more information see the Data Protection Act 1998. The Information Commissioner can also advise about access to data – see Appendix 4, Further information and support.

## Power of attorney

If someone has completed and registered a Lasting power of attorney (LPA) for property and financial affairs or an Enduring power of attorney (EPA), the nominated person or 'attorney' has the legal power to make financial decisions on their behalf. However, an attorney can only access the person's medical notes for financial reasons. If the attorney thinks that the person is entitled to NHS continuing healthcare, this should be considered to be a financial reason.

If someone has completed and registered an LPA for health and welfare, the attorney has the legal power to make decisions that relate to the person's care and welfare. Attorneys with this power should be able to access a person's medical records, as often this is needed for them to carry out their role.

For more information about Lasting powers of attorney, as well as the previous Enduring power of attorney, see factsheet 472, **Lasting power of attorney**.

## When there is no attorney

Getting access to a person's medical notes can be harder for you if the person with dementia has not made an EPA or LPA. Some NHS bodies and social services departments are willing to release a personal file to a person's main carer, particularly if that carer is a close relative. However, this is not always the case.



The reasons given for refusing access usually involve either or both of the following:

- there is no legal right of access for anyone other than the patient
- the authority has a duty of confidentiality to the person.

This is not the whole story, however. The law requires the public and private interests in maintaining confidentiality to be weighed against the public and private interests in disclosure. This means that the authority in question (for example the NHS body or social services) must decide whether it is of more benefit to give someone access to the person's notes or not. What they decide will depend on the specific circumstances of the case and the best interests of the individual.

## The Mental Capacity Act

The Mental Capacity Act (2005) is the law that protects and supports people who do not have the ability to make certain decisions for themselves, known as 'mental capacity'. It explains who can make decisions for a person who lacks capacity and states that they must do so in the person's best interests.

The Act requires health and social care staff to consult anyone caring for the person or interested in their welfare (for example family, friends and unpaid carers) when deciding on their best interests. As a result, it should be much easier for carers to access medical notes and social services records of people with dementia, even if that person has not appointed a lasting power of attorney.

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

## Access under NHS continuing healthcare

The Framework also gives people who have no legal power – such as an LPA or deputyship (see As a last resort: deputies, overleaf) – certain rights to be able to access personal information, which may include medical records. It states that when deciding whether to share information with a third party who doesn't have a legal power, the professional involved must decide whether the following criteria are met:

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

If someone can show that these criteria are met, it should be possible for them to access personal information, such as medical records, in order to apply for NHS continuing healthcare.

The Framework also makes it clear that if there is an appeal, information can be shared with third parties. It states that:

‘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 (finance), deputyship (finance) or a registered Enduring power of attorney (EPA) looking to challenge an eligibility decision, or any other person acting in the person’s best interest to challenge an eligibility decision.’

### As a last resort: deputies

Some people will not have appointed an attorney, and will now not be able to because they lack capacity. If they need decisions made on their behalf that can only be decided by a court case, you will need to apply to the Court of Protection to become a deputy. A deputy is someone appointed by the Court of Protection to deal with a specific issue or range of issues on behalf of someone who lacks capacity and who does not have an attorney.

For more information see factsheet 530, **Becoming a deputy for a person with dementia.**

# Appendix 3

## Examples of case law

Three significant cases brought before English law have defined the principles upon which NHS continuing healthcare decisions are made. The circumstances and key findings of these are summarised below.

### The Coughlan judgment 1999

A decision about who provides care can have significant financial consequences for individuals with long-term health needs and their families. The Coughlan judgment came about because a clearer definition of the line between the responsibility of the NHS and social services for people's long-term care was needed. 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 secure NHS continuing healthcare, which went all the way to the Court of Appeal.

The court had to consider where the line should be drawn 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 the provision of accommodation, and of a nature that a social services authority can be expected to provide.

### The Pointon investigation 2003

A person's eligibility for NHS continuing healthcare should depend only on their care needs, and not on where they are living or who is providing the care. In spite of this, it is sometimes wrongly assumed that if a person is being cared for at home, their need is for social care rather than healthcare. The Pointon case was a landmark

because it demonstrated that a person living and receiving care at home can have a healthcare need, and therefore can be eligible for NHS continuing healthcare.

The case was brought by Mrs Barbara Pointon, carer of her husband Malcolm Pointon, who had advanced dementia. Having become concerned about his deterioration during his time in a nursing home she decided that he should be cared for at home. As Malcolm's dementia progressed however, he was unable to access healthcare services. Barbara Pointon therefore applied for NHS continuing healthcare for Malcolm, but he was found ineligible. She believed that the primary care trust (PCT) – the equivalent of today's 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 Department of Health guidance had not been properly followed because the assessment was too focused on physical needs and not psychological needs. Importantly, it also found that Barbara Pointon was providing a high level of personalised care with great skill, and the nursing care she provided was equal to, if not superior to, that which Malcolm Pointon would have received in a nursing home. The Ombudsman therefore 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 consistently applied 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, resident of a nursing home, had three times been assessed as not eligible for NHS continuing healthcare. She was receiving the (then) top band of Registered nursing care contribution (RNCC). She argued this was unlawful, since the criteria that had been applied in her case were contrary to the judgment in the Coughlan case. The judgment in her favour influenced the government to put in place a national policy.

This policy required the then PCT to look at the totality of a person's needs before making a decision on their eligibility for NHS continuing healthcare. It also 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, and 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, including NHS continuing healthcare in Wales and Northern Ireland

### Further information and support

#### **Age UK**

Tavis House

1–6 Tavistock Square

London WC1H 9NA

T [0800 169 8787](tel:08001698787) (general enquiries)

[0800 169 6565](tel:08001696565) (advice line)

E [contact@ageuk.org.uk](mailto:contact@ageuk.org.uk)

W [www.ageuk.org.uk](http://www.ageuk.org.uk)

Charity providing information and advice for older people in the UK.

#### **Citizens Advice**

Various locations

W [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 above or look in the phone book.

#### **Court of Protection**

PO Box 70185

First Avenue House

42–49 High Holborn

London WC1A 9JA

T [0300 456 4600](tel:03004564600)

E [courtofprotectionenquiries@hmcts.gsi.gov.uk](mailto:courtofprotectionenquiries@hmcts.gsi.gov.uk)

W [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 relating to people who lack capacity to make specific decisions for themselves.

**Independent Age**

18 Avonmore Road

London W14 8RR

T **0800 319 6789** (Advice line 9am–4.30pm Monday–Friday)

E [charity@independentage.org](mailto:charity@independentage.org)

W [www.independentage.org](http://www.independentage.org)

Charity offering free advice and information on care, benefits and social support, as well as volunteer befriending services for older people.

**Information Commissioner's Office**

Wycliffe House, Water Lane

Wilmslow

Cheshire SK9 5AF

T **0303 123 1113** (advice line)

E [casework@ico.org.uk](mailto:casework@ico.org.uk)

W [www.ico.org.uk](http://www.ico.org.uk)

Independent UK body that upholds information rights. It can offer support and advice on accessing a patient's notes.

**NHS Choices**

W [www.nhs.uk](http://www.nhs.uk)

[www.england.nhs.uk/ccg-details/](http://www.england.nhs.uk/ccg-details/) (CCGs in England)

NHS website that allows you to search for health services near you, including the details of every clinical commissioning group in England.

**Office of the Public Guardian**

PO Box 16185

Birmingham B2 2WH

T **0300 456 0300**

E [customerservices@publicguardian.gsi.gov.uk](mailto:customerservices@publicguardian.gsi.gov.uk)

W [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 those 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**

Millbank Tower

30 Millbank

London SW1P 4QP

T **0345 015 4033** (Helpline: 8.30am–5.30pm, Monday–Friday)

W [www.ombudsman.org.uk](http://www.ombudsman.org.uk)

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****NHS Wales**

W [www.wales.nhs.uk](http://www.wales.nhs.uk)

NHS website that allows you to search for health services in Wales.

**Age Cymru**

Tŷ John Pathy

13–14 Neptune Court

Vanguard Way

Cardiff CF24 5PJ

T **08000 223 444** (advice line)

W [www.ageuk.org.uk/cymru](http://www.ageuk.org.uk/cymru)

Charity providing information and advice for older people in Wales.

**Information on NHS continuing healthcare in Northern Ireland****Age NI**

3 Lower Crescent

Belfast BT7 1NR

T **0808 808 7575**

W [www.ageuk.org.uk/northern-ireland](http://www.ageuk.org.uk/northern-ireland)

Charity providing information and advice for older people in Northern Ireland.

**Health and Social Care in Northern Ireland**

W [online.hscni.net/](http://online.hscni.net/)

Website that allows you to search for health and social care services near you.

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# Further reading

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This publication has been reviewed by people affected by dementia and health and social care professionals. A full list of sources is available on request.

Last reviewed: January 2016

Next review due: January 2019

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

Alzheimer's Society is the UK's leading support and research charity for people with dementia, their families and carers. We provide information and support to people with any form of dementia and their carers through our publications, National Dementia Helpline, website, and more than 3,000 local services. We campaign for better quality of life for people with dementia and greater understanding of dementia. We also fund an innovative programme of medical and social research into the cause, cure and prevention of dementia and the care people receive.

If you have any concerns about Alzheimer's disease or any other form of dementia, visit [alzheimers.org.uk](https://www.alzheimers.org.uk) or call the **Alzheimer's Society National Dementia Helpline** on **0300 222 1122**. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)

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58 St Katharine's Way  
London E1W 1LB

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Code 813

