NHS care for people with long term health needs

Easy Read version of ‘National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care - July 2022’
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In this Easy Read document, difficult words are in **bold**. We explain what these words mean in the sentence after they have been used.

Some words are *blue and underlined*. These are links which will go to another website which has more information.
Introduction

The Government has written this guidance to explain how the NHS manages:

- **NHS Continuing Healthcare.**

  **NHS Continuing Healthcare** pays for help and care for people who need a lot of help because of their health. The NHS pays for this.

- **NHS-funded Nursing Care.**

  **NHS-funded Nursing Care** is care from a nurse in a care home, paid for by the NHS.

Please now move on to the next page
What is this book about?

This book is about money from the NHS to pay for help and care.

This is called NHS Continuing Healthcare.

This book is for:

- People with learning disabilities.
- Family carers.
- Anyone who helps a person with learning disabilities.
You can look at the book on your own. Or you can ask someone to look at the book with you and talk about what it says.

At the end of the book you can find where you can get more information including a leaflet about NHS Continuing Healthcare. Some of the information may not be Easy Read.

There is also a list of difficult words which will tell you what each word means.

These words are also in bold throughout the book. We explain what these words mean in the sentence after they have been used.

Some words are blue and underlined. These are links which will go to another website which has more information.
What is NHS Continuing Healthcare?

NHS Continuing Healthcare pays for help and care for people who need a lot of support because of their health. The NHS pays for this.

What is NHS-funded Nursing Care?

NHS-funded Nursing Care is care from a nurse in a care home, paid for by the NHS.

NHS-funded Nursing Care and NHS Continuing Healthcare have to follow rules set out by the law.
What is social care?

Some people have their help and care paid for by social services (the council).

You might need help with some or all of these things:
- A place to live – home.
- Help at home.
- Help with travelling.
- Help with a job or other things to do in the day.
• Help to do things that are fun, like seeing friends or going to see a play.

• Help to look after someone else (being a carer).

Please now move on to the next page
Who can get NHS Continuing Healthcare?

You have to be over 18 years old.

You may be able to get NHS Continuing Healthcare if you:

- Are disabled.

- Had an accident.

- Have an illness.

NHS Continuing Healthcare is for people who need a lot of help because of their health.
Some people need help because they have difficulty with things like:

- Breathing.
- Eating and drinking.
- Taking medicines.
- Moving about.
- Memory and thinking.

If you need help with some of these things NHS Continuing Healthcare might be able to help you.
If you are very ill and need a lot of help in a hurry a doctor or nurse can decide to give you NHS Continuing Healthcare straight away. This is called Fast Track.

It does not matter where you live in England.

It does not matter how much money you have or if you get benefits or not.

It does not matter whether you live on your own or with other people.

If you are a carer you might want to find out if the person you care for should get NHS Continuing Healthcare.
You can use the information in this book for yourself or other people.
Who will help you find out about NHS Continuing Healthcare?

You, your family or your advocate can ask about NHS Continuing Healthcare.

You can ask:

- Your social worker.
- Your family doctor.
- A nurse or another health worker like an occupational therapist.
You might want a family member, friend or advocate to help you think about and ask questions.

It is a good idea to ask questions about NHS Continuing Healthcare.

You can ask questions like these:

- Who decides about NHS Continuing Healthcare in my area?

- Can I have NHS Continuing Healthcare as a **Personal Health Budget**?

  A **Personal Health Budget** is when the NHS tells you how much money there is for your help and care. You agree with the NHS how the money will be spent.

- Does NHS Continuing Healthcare make a difference to my benefits?
• Can I have NHS Continuing Healthcare as a **direct payment**?

A **direct payment** is when you are given money to pay for your help and care. You control the money.

Do you have other questions?

To find out whether you should get NHS Continuing Healthcare, you will need to do an **assessment**.

An **assessment** is when you meet with a team of health professionals or social care workers to work out what help and care you need.
Assessment

Assessments have to follow the Government’s guidelines on how to assess you for NHS Continuing Healthcare.

The team will give information to your local Integrated Care Board. The Integrated Care Board for your area is the organisation that decides about most health services in your area. They decide how to spend NHS money.

Your local Integrated Care Board must assess any person who may need NHS Continuing Healthcare by following the law.

They will decide if the NHS should pay for your help and care.
They will ask you to answer questions during the assessment, and you can say what you want and what you think.

Before the assessment you will be asked to decide whether you want your family, a friend, or an advocate to help you at the assessment.

If you cannot make an important choice yourself, a ‘best interests’ decision may be made by others. A ‘best interests’ decision means that the decision must be what is best for the person, not anyone else.

The ‘best interests’ decision must be based on what is happening and what the person would want for themselves.
**Person centred**

**Person centred** means that the way we work should be right for each individual person.

We will work in a way that is person centred.

We will be person centred when we:

- Check to see if you need NHS Continuing Healthcare.
- Plan the services you need.
- Give you the services you need.
We will ask you what you want and what you think.

**Advocate**

We will also involve your **advocate**, if you want.

An **advocate** is someone who helps you to speak up, or speaks up for you.

This can be an independent person, or sometimes this can be a family member or a friend.

**Fair to everyone**

We will make sure we are being fair to everyone.

Everyone should have a fair chance to have:

- An assessment.
• A care service.

• The support they need.

Please now move on to the next page
What will happen at each step of the assessment?

Read on to find out how the assessment for NHS Continuing Healthcare works and what will happen at each step.

There are 7 steps. Read on to find out about each step.

Please now move on to the next page
Can I have an advocate?

Can I ask you some questions?

Step 1: Checklist

A social care worker or a health worker like a nurse will come and see you.

This might be part of your usual review meeting.

You can have a member of your family, a friend or advocate to help you.

You can ask about having an advocate if you do not have one.

The worker will ask if it is OK to ask you questions.
They will ask about your health and the help you need.

You can show them your person centred plan and other plans.

You can say what you want and think.

They will want to talk to your family or other people who support you. They will check if this is OK.

They may talk to other people who know you, like your doctor, nurse, social worker or other staff from the community team. They will want to look at the information those people keep about you.
They will fill in a form called a Checklist.

You can ask for a copy.

They will ask you if you have any questions.

They will use the Checklist to decide if you do or do not go on to Step 2.
Step 2: The big assessment

If you go on from Step 1, this is what happens next.

A health worker like a nurse will come and see you.

They might bring someone else with them like a social worker or another health worker. They might come more than once.

They can come and see you at home or somewhere else if you prefer.

You can have someone with you – like a member of your family, a friend or advocate.
The health worker will ask you if it is OK to ask you more questions.

They will ask more questions about your health and the help you need.

You can show them your person centred plan and other plans.

You can say what you want and think.

They will want to talk to your family and other people who support you.

They will check if this is OK.
They may talk to other people who know you, like your doctor, nurse, social worker or other staff from the community team. They will want to look at the information those people keep about you.

The health worker will bring everyone together for a big meeting called the **Multi-Disciplinary Team** meeting. The **Multi-Disciplinary Team** is a group of health and social care workers looking at your information together.

They will discuss your health and care needs and how big your needs are.

They will fill in a big form called the **Decision Support Tool**. This is the name of the form that is used by the Multi-Disciplinary Team to see if you should get NHS Continuing Healthcare.
Do you have any questions?

They will ask you if you have any questions.

Please now move on to the next page
Step 3: Agreeing what is written about you

When the health worker has collected all the information they need they will write about what they have seen and heard.

They will think about how big your health needs are.

They will ask you and your family or advocate if you agree with what they have said.

If you do not agree you can say so. They will write down what you say about why you disagree.
Step 4: Decision about the money

The health worker will go to your local Integrated Care Board.

The Integrated Care Board for your area is the organisation that decides about most health services in your area. They decide how to spend NHS money.

In some areas, the local Integrated Care Board who will decide whether you get NHS Continuing Healthcare will have a group of people making the decision. This is called a ‘panel’.

The health worker will ask them to decide if you will get NHS Continuing Healthcare.

They will use all the information the Multi-Disciplinary Team collected about you. They will tell you what they decide.
If the Integrated Care Board says ‘Yes’ to paying for your help and care, they will choose a person to work with you.

This person might be called:

- A Case Manager.
- A Care Manager.
- A Community Nurse.
If the Integrated Care Board says ‘No’ to paying for your help and care, and you are not happy with that you can say so. You can ask them to look at all the information again.

If you do not get NHS Continuing Healthcare:

- Sometimes the NHS will agree with social services (the council) that they will pay together for the help you need. This is called joint funding.

- Sometimes the NHS will decide if you should have **NHS-funded Nursing Care**.

**NHS-funded Nursing Care** is care from a nurse in a care home, paid for by the NHS.
Step 5: Your health money and how to use it

NHS Continuing Healthcare money is for your help and care, not just health care.

It is important to make sure the plan for the money is about all your help and care.

If you are getting support or money from social services (the council) this will change over to NHS Continuing Healthcare.

Sometimes social services go on giving some help too.

If you get NHS Continuing Healthcare there are different ways you can have it.

These are on the next page.
A. You can ask for a Personal Health Budget. Read more about this on pages 36 to 38.

B. You can let your local Integrated Care Board and your worker decide about your help and care. Read more about this on page 39.

Please now move on to the next page
A. You can ask for a Personal Health Budget

A **Personal Health Budget** is like a **Personal Budget** from social services (the council), but the money comes from the NHS.

You have a right to have NHS Continuing Healthcare as a Personal Health Budget as long as this is good for you and the NHS.

You can ask for a copy of the Easy Read book about Personal Health Budgets if you would like to know more.

A **Personal Budget** is when social services (the council) tell you how much money there is for your help and care. You agree with them how it will be used.
There are 3 ways you can have a Personal Health Budget:

1. **Budget (money) held by the NHS.** The NHS tells you how much money there is for your help and care. You say how you want the NHS to spend the money.

2. **Budget (money) held by someone else.** The NHS tells you how much money there is for your help and care. An organisation, like a charity or a support service, looks after the money for you. They help you decide how you want to spend it.

3. **Direct payment.** The NHS gives you the money to buy and manage your own help and care. You can ask for a copy of the easy read book about Personal Health Budgets if you would like to know more.
You can ask your local Integrated Care Board about Personal Health Budgets.

You can use this book to say if you want a Personal Health Budget.

Please now move on to the next page
B. You can let your local Integrated Care Board and your worker decide about your help and care.

The Integrated Care Board could offer you help at home. They might pay support workers or nurses to do this.

Or they might offer you a place in a care home.
Step 6: The help you will get

You may have a person-centred plan already. You may have a Health Action Plan or recovery plan too.

You may want to look at all your plans again when you know how much money you will have for your help and care.

You might decide all your help is just fine.

You can talk to your health worker about using NHS Continuing Healthcare to pay for the help you have now.
You might want to make some changes in your help.
You can talk to your health worker about using NHS Continuing Healthcare to get the new kinds of help you need.

Your support plan should say how NHS Continuing Healthcare will help you live your life.
Remember - this is about all your help and not just health care.

Your care plan will then be used to put together a care package for you.

If the Integrated Care Board has decided that you should get NHS Continuing Healthcare, the NHS will pay for this care package.

Once the NHS has decided it will pay for this care package, you or your local council do not have to pay for it.
You can decide if you want to get this care or not.

If you do not want the NHS care package, then you may have to pay for your care yourself.

If you cannot make an important choice yourself, a ‘best interests’ decision may be made by others.

A ‘best interests’ decision means that the decision must be what is best for the person, not anyone else.

The ‘best interests’ decision must be based on what is happening and what the person would want for themselves.
A care package

A care package is all the different types of care that are going to be provided for you.

Your care package could include:

- Medical and nursing care.

- Social care - support with everyday tasks.

- Accommodation in a care home - somewhere to live.

NHS Continuing Healthcare does not pay for your housing if you live in your own home.
The NHS will pay for your care package. They will find the right health and care services to provide the care you need.

Or you may have a Personal Health Budget - see pages 36 to 38.
Step 7: Finding out if all your help and care is working

The health worker will check how you are getting on.
You can talk to them if you need some changes in your help and care.

You can look at your support plan (from Step 6) and make sure it is still right for you.

After 3 months the health worker should check if your care plan still meets your help and care needs.

They may also check whether you still need NHS Continuing Healthcare.
Then they should check every year.
Other things you should know

It does not matter where in England you live.

NHS Continuing Healthcare can pay for your help at home or in a care home.

Your health worker will ask you questions and will listen to what you want and write this down.

You might have to explain very carefully what is right for you and why.

Your help can stay the same unless there is a good reason to change it.
If you live at home your benefits should not change. If you live in a care home some of your benefits might stop.

NHS Continuing Healthcare is instead of some benefits in a care home.

If the Integrated Care Board says ‘No’ to paying for your help and care and you are not happy with that you can say so.

You can ask them to look at all the information again.

If you are not happy with your support plan you can ask for it to be looked at again.

Ask your worker how to do this.
Useful things to look at

Easy Read information

1. Personal Health Budgets Easy read guide:
   NHS England » All about personal health budgets (easy read guide)

   The website is not easy read but you can get the easy read guide there.

2. Changes to the law and guidance about making your own decisions (easy read):
   Changes to the law and guidance about making your own decisions (easy read) - GOV.UK (www.gov.uk)

   The website is not easy read but you can get the easy read guide there.
Information that is not Easy Read

1. Information from the Department of Health and Social Care about NHS Continuing Healthcare and NHS-funded Nursing Care:
   [NHS continuing healthcare and NHS-funded nursing care - GOV.UK (www.gov.uk)]

2. Public Information Leaflet from the Department of Health and Social Care about NHS Continuing Healthcare and NHS-funded Nursing Care:

3. The laws NHS Continuing Healthcare and NHS-funded Nursing Care have to follow:
   [www.legislation.gov.uk/uksi/2012/2996/part/6/made]
4. Information about Personal Health Budgets:
What is a personal health budget?
- NHS (www.nhs.uk)
Difficult words and what they mean

Best Interests Decision

If you cannot make an important choice yourself, a ‘best interests’ decision may be made by others.

This means that the decision must be what is best for the person, not for anyone else.

The ‘best interests’ decision must be based on what is happening and what the person would want for themselves.

The decision is made following a law called the Mental Capacity Act. This law sets the rules for how this is done.
The person making the decision must think about these questions:

- Can the decision wait until a time when the person can make it themselves?

- How can the person be helped to make the decision themselves?

- What do other people who know the person think?
The person making the decision may:

- Talk to people who know and care about you.

- Talk about what you like, what you dislike and what works for you, including how you feel and what you believe in.

- Talk about what they think you would choose for yourself.

- Talk about the choices for your care and the best way to help you.
Other difficult words and what they mean

**Checklist** - The name of the form that is filled in by a health worker or a social care worker who asks questions to see if you should have an assessment for NHS Continuing Healthcare.

**Decision Support Tool** - The name of the form that is used by the team of health workers or social care workers who do the big assessment to see if you should get NHS Continuing Healthcare.

**Direct Payment** - When you are given money to pay for your help and care. You control the money.
**Integrated Care Board** - The Integrated Care Board for your local area is the organisation that decides about most health services in your area.

They decide how to spend NHS money.

**Multi-Disciplinary Team** - A group of health and social care workers looking at your information together.

**NHS Continuing Healthcare** - NHS Continuing Healthcare pays for help and care for people who need a lot of help because of their health.

The NHS pays for this.

**Panel** - In some areas, the local Integrated Care Board who will decide on NHS Continuing Healthcare will have a group of people making the decision, which is called a panel.
Personal Budget - When social services (the council) tell you how much money there is for your help and care. You agree with them how it will be used.

Personal Health Budget - When the NHS tells you how much money there is for your help and care. You agree with the NHS how the money will be used.

Please now move on to the next page
For more information

You can look at our website here: www.gov.uk/dhsc

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