



Department
of Health &
Social Care

What is NHS Continuing Healthcare?

An easy read guide for people with learning disabilities



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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 and 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.



There is a list of hard words at the back of the book to tell you what each word means.

This book is just to tell people with learning disabilities about NHS Continuing Healthcare. There is a bigger book where doctors, nurses and social workers will read about it.



Who helped to write this book?

In 2014 these people helped to write this book:

Denise Gentry, Clinical Nurse Specialist, South West London and St George's Mental Health NHS Trust

John Burley, User Involvement Co-ordinator, Leeds and York Partnership NHS Foundation Trust, with the Leeds Learning Disability Reference Group and members of the Your Health Matters Project

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Kingston Easy Information Group

Jim Ledwidge, Trish O'Gorman and Karen Scarsbrook on behalf of the National Policy Advisory Group for NHS Continuing Healthcare Manchester People First

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Special thanks to Denise, Laura and the Kingston Easy Information
Group for all their help.

This book was checked and some things were added in 2018.



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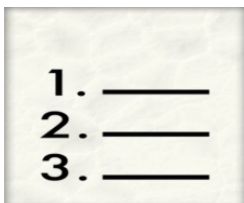
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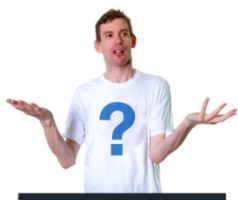
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Who can get NHS Continuing Healthcare?



NHS Continuing Healthcare is for people who need a lot of help because of their health and care needs.



Some people need help because they have a lot of difficulty with things like:

- breathing
- eating and drinking
- taking medicines
- moving about
- memory and thinking.





If you need help with some of these difficulties **NHS Continuing Healthcare** might be for you.



It does not matter where you live in England.

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.



What is NHS Continuing Healthcare?



NHS Continuing Healthcare
pays for help and care.



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



Social services



People who need a lot of help because of their health and care needs may get **NHS Continuing Healthcare**.



You have a right to have **NHS Continuing Healthcare** as a **Personal Health Budget**.

Find out more about this on page 27.

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.



Who will help you find out about NHS Continuing Healthcare?



You or your family can ask about **NHS Continuing Healthcare**.

You can ask:

- your social worker
- your family doctor
- a nurse or another health worker.



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





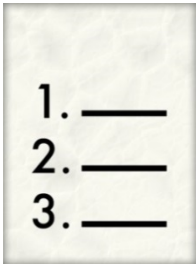
Do you have other questions?



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.



Now go to Step 1 to see what happens next....



1. _____
2. _____
3. _____

What will happen at each step?

There are 7 steps.

Read on to find out about each step.



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.



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.

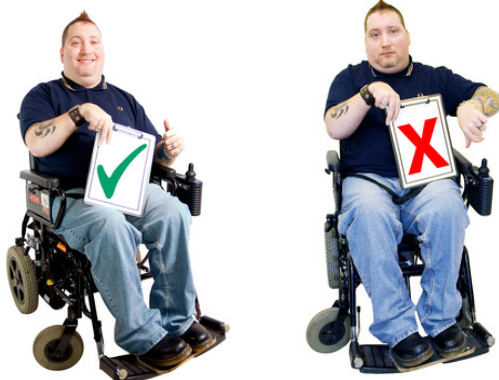


They will fill in a form called a **Checklist**. You can ask for a copy.



They will ask you if you have any questions.

Step 2



They will use the **Checklist** to decide if you do or do not go on to Step 2.



Step 2: The full assessment

Step 1  Step 2

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.



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



They will ask if it is OK to 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 might get everyone together for a big meeting.



They will fill in a big form called the **Decision Support Tool**.



They will ask you if you have any questions.



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 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 if you get NHS Continuing Healthcare



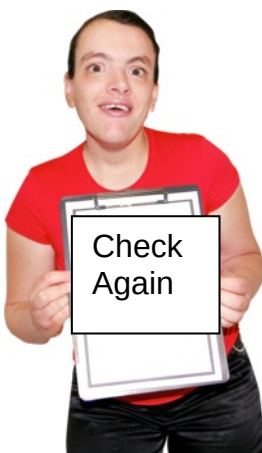
The health worker will go to your local **NHS Clinical Commissioning Group**. In your area this might be called the “panel”. The health worker will ask them to decide if you will get **NHS Continuing Healthcare**.



They will use all the information the health worker collected about you.



They will tell you what they decide.



If the **NHS Clinical Commissioning Group** says ‘No’ and you are not happy with that you can say so. You can ask them to look at all the information again.



Social Services

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.



If the **NHS Clinical Commissioning Group** says 'Yes' they will choose someone to work with you.

They might be called:

- a Case Manager
- a Care Manager
- a Community Nurse.

—————> Step 5

Now go to Step 5.

The **NHS Clinical Commissioning Group** for your area is the group that decides about most health services in your area. They decide how to spend NHS money.



Step 5: Your health money and how it can be used



NHS Continuing Healthcare money is for all 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 have a **Personal Health Budget**. Read more about this on pages 27 to 29.

Or

B. You can let your local NHS Clinical Commissioning Group and your worker decide about your help and care. Read more about this on page 30.

A. You can have 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.

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 control the money. You can get help with this.



You can ask for easy read information about **Personal Health Budgets** if you would like to know more.



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

- B.** You can let your local **NHS Clinical Commissioning Group** and your worker decide about your help and care.



The **NHS Clinical Commissioning Group** 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. Some people want this.



Step 6: The help you could 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 go on with 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.



You might have help with some or all of these things:

- a place to live – home!



- help at home



- help with travelling

Application Form

	Name
	Address
	Education
	Work Experience



- 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).



Step 7: Finding out if all your help and care is working



After 3 months the health worker will check how your help and support are working.



Then they will check every year.



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.

The health worker may also check if you still need **NHS Continuing Healthcare**.



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



Other things you should know



It does not matter where you live.



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



Your health worker must 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.



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 you do not want **NHS Continuing Healthcare** you can ask the NHS to look again at the form with all your information (Steps 2 and 3).

This is not easy. If the NHS says you should have **NHS Continuing Healthcare** then social services (the council) will not pay for your help and care.



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

1. Easy read information



Health and health care

Easy Health website <http://www.easyhealth.org.uk/>



Planning your support

Foundation for People with Learning Disabilities website

<http://www.learningdisabilities.org.uk/publications/personal-planning-book/>



Personal Health Budgets

Easy read booklet on integrated personal commissioning

<https://www.thinklocalactpersonal.org.uk/Latest/Being-in-charge-of-your-own-services/>

<http://www.personalhealthbudgets.england.nhs.uk>

The website is not easy read but you can get the

easy read guide there



Making decisions

Easy read books about the Mental Capacity Act

<https://www.peoplefirstinfo.org.uk/money-and-legal/legal/making-your-own-decisions-mental-capacity-act-2005/>

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

2. Information that is not easy read

Information for families about NHS Continuing Healthcare

'What do I need to know about NHS Continuing Healthcare?'

<https://www.mentalhealth.org.uk/learning-disabilities/publications/what-do-i-need-know-about-nhs-continuing-healthcare>

NHS England film about NHS Continuing Healthcare

<https://www.youtube.com/watch?v=DdTqGTPSRb8>

Information from the Department of Health about NHS Continuing Healthcare

<https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care>

Information about Personal Health Budgets

Personal Health Budgets website

<https://www.england.nhs.uk/personal-health-budgets/personal-health-budgets-for-people-with-learning-disabilities/>

This includes a guide on making Personal Health Budgets available to people with learning disabilities.

peoplehub peer support network <http://www.peoplehub.org.uk/>

inControl series of factsheets on self directed support, including one on Personal Health Budgets <http://www.in-control.org.uk/resources/factsheets.aspx>

Information about the Mental Capacity Act

Pack for family carers https://www.hft.org.uk/resources-and-guidance/disability-rights-and-legal/mental-capacity-act/?_sf_s=mental+capacity

Information about planning support

Think Local Act Personal website

<https://www.thinklocalactpersonal.org.uk/personalised-care-and-support-planning-tool/What-is-personalised-care-and-support-planning/>

Making health information easy read

Easy on the i website <http://www.easyonthei.nhs.uk/>

A Picture of Health website <http://www.apictureofhealth.southwest.nhs.uk/>

Note: We checked all the website links in March 2018



List of hard words and what they mean

Checklist

The name of the form that is filled in by the worker who asks questions to see if you should have a big assessment for NHS Continuing Healthcare.

Decision Support Tool

The name of the form that is used by the nurse or other health worker who does the big assessment to see if you should get NHS Continuing Healthcare.

Direct payment

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

NHS Clinical Commissioning Group

This is the group that decides about most health services in your area. They decide how to spend NHS money.

NHS Continuing Healthcare

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

Personal Budget

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.

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 used.