

# Living Well with Long-Term Conditions

A Report.

Accessible version.



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# Introduction

There are 2 million people in Scotland with long-term conditions. This is a problem with your health that lasts for more than a year. There are lots of long-term conditions. Cancer, epilepsy and asthma are all examples of long-term conditions.

People with long-term conditions need good services, support and information to make their lives better.

The Long Term Conditions Alliance Scotland is a new organisation. It is made up of many voluntary groups and charities that deal with different conditions. They want to:

- > Change things by telling people what they want
- > Make things better
- > Help voluntary and community groups
- > Make things fairer in the NHS.



The Long Term Conditions Alliance Scotland is working with NHSScotland to make things better for people with long-term conditions.

They asked 400 people to come to meetings in Glasgow and Aberdeen. Most people had long-term conditions. Some people cared for someone with long-term conditions. Some people worked for the NHS, a council or a voluntary organisation. This reports tells you what they said.

# Being Involved

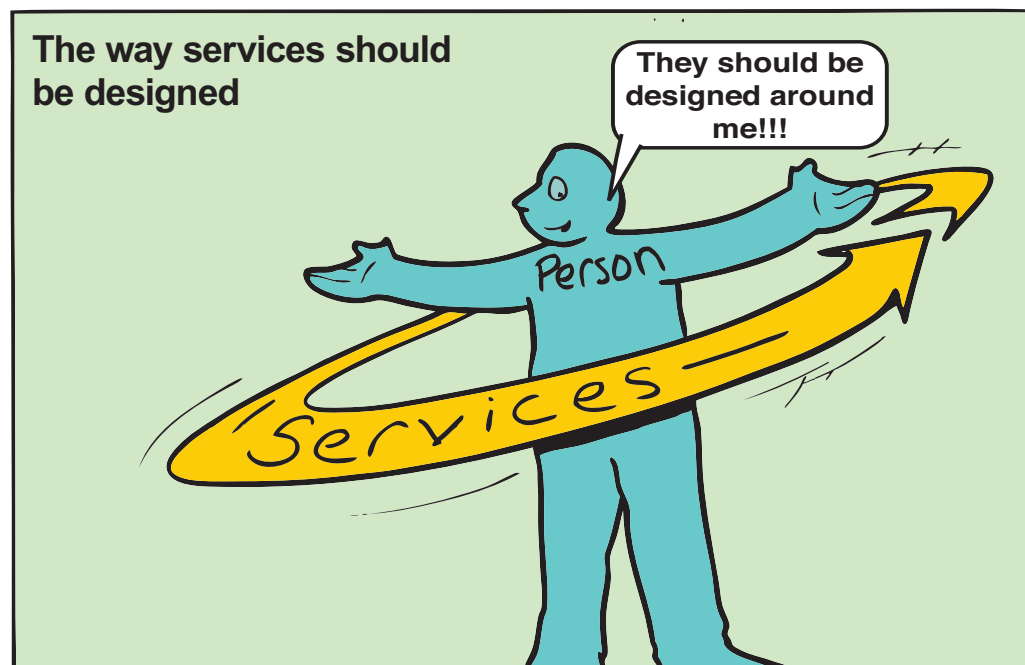
People with long-term conditions and their carers want NHS workers to be better at listening to them. They want NHS workers to believe what they tell them.

People with long-term conditions want to decide what happens to them.

People want NHS workers to understand what carers do. They want carers to get more support to do it. Carers need more information about other services.

When a person they support cannot remember things, carers want to be allowed to see the doctor with them.

Carers need help for times when they cannot be there and more support in emergencies.



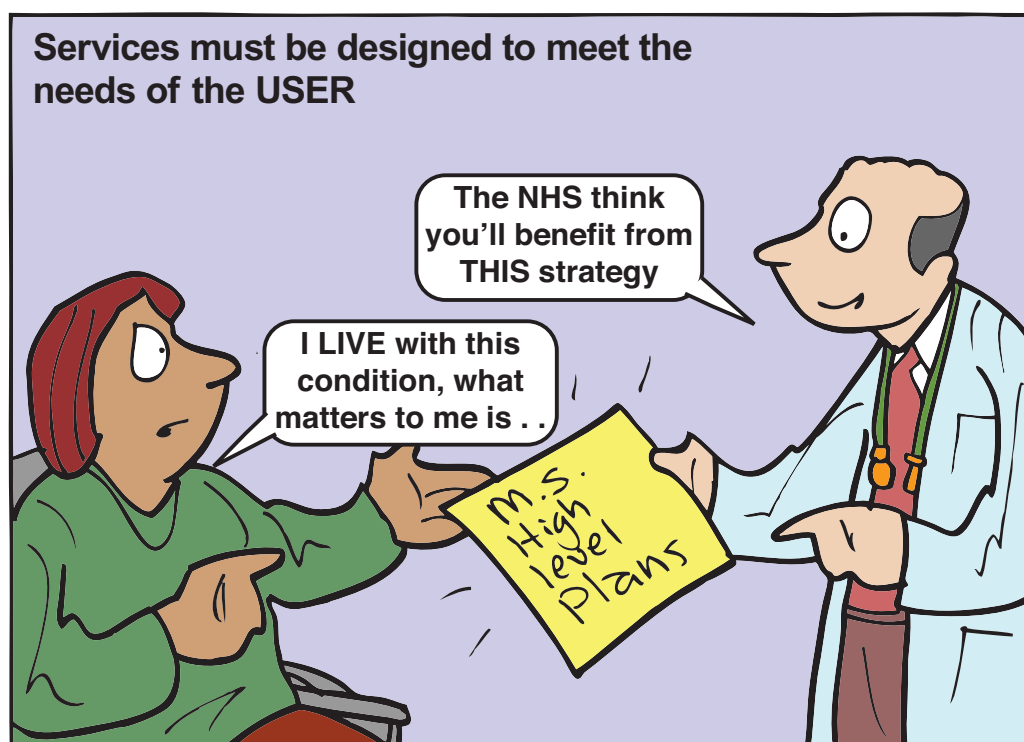
# Managing Your Condition

The Scottish Executive thinks that self-management is a good thing. This means that people will learn how to manage their long-term conditions at home. People will still get care from the NHS as well.

Most people thought that this was a good idea. Some people were worried about it.

People said these things would help them manage their condition.

- > Courses to teach them what to do.
- > Support groups to meet other people who manage their conditions.
- > Access to complementary therapies. A complementary therapy is non-medical treatment, like aromatherapy or reflexology.
- > More confidence and self-esteem. People want to learn how to feel better about themselves.



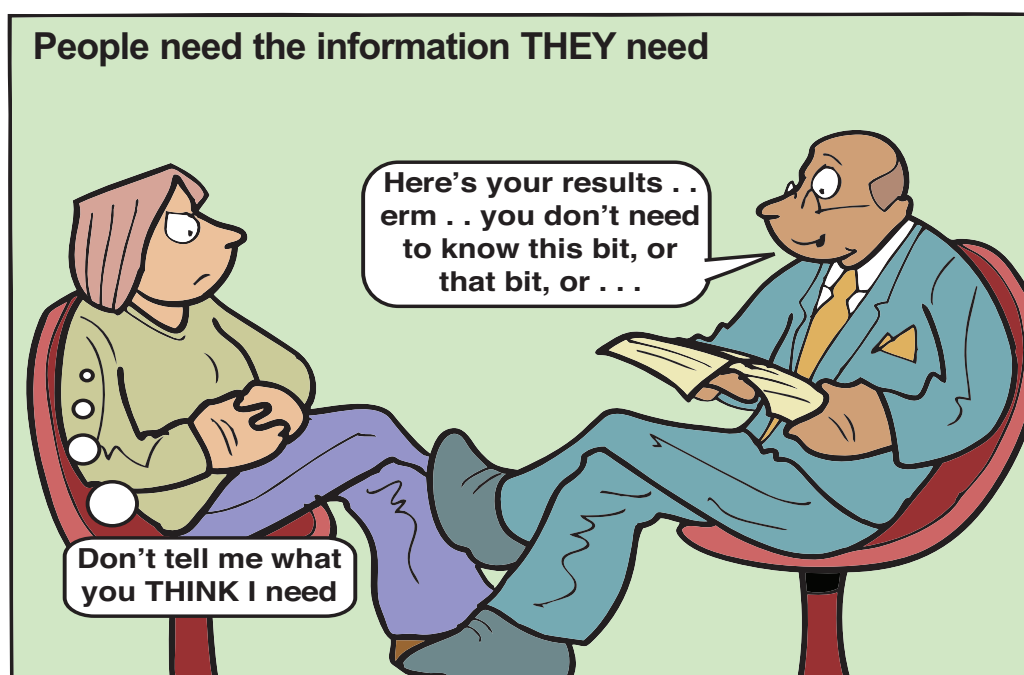
- > Access to talking therapies, like counselling. People with long-term conditions can be depressed. Talking therapies can help with this.

Carers can help people to manage their conditions. But carers need support to do this. Everyone said a key worker could help. Carers want to phone, text or email a key worker.

# Communication and Information

People said that getting the right information was very important.

They want better information when they are first told about their condition. They want this information from a key worker.



They said they needed better information about

- > Services
- > Voluntary organisations that can help them.

They want the information to be accessible. This includes leaflets that are easier to read.

People want all the information about their condition written down. They want this in one place. This is called a “patient passport”. When people meet someone new they can show them their patient passport. This means people do not have to tell their story every time they meet someone new.

People want NHS staff to stop using words they do not understand.

People said that they were treated unfairly because of their condition. Newspapers, radio and television need to be more careful about how they show people with long-term conditions.

People want the public to understand more about their conditions.



# Working Together

People want the NHS, local councils and voluntary organisations to work together to make things better.

People want to choose where they get a service from.

Voluntary organisations should get money to help people to understand their conditions. This money would be used to train carers too. This will help people to look after themselves better. People will be healthier.



# The NHS

People want one person in the NHS who they can talk to.

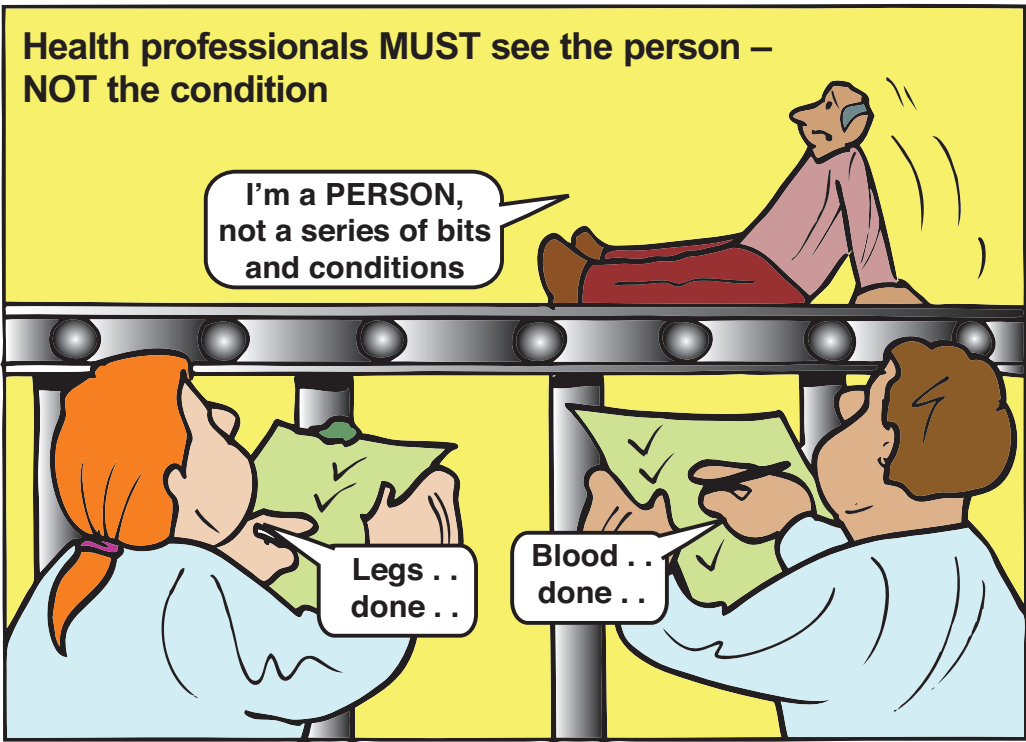
This person is called a key worker.

The key worker would:

- > Find out information
- > Support the person with a condition and their carer
- > Know where to go to get more help
- > Help the person deal with things like money and benefits.

NHS staff should learn more about long-term conditions when they are studying and training. They should keep learning about long-term conditions.

GPs need to know more about other services and what they do.



# Services

People want more services. They said that services for people with long-term conditions and their carers need more money.

People want services all over Scotland. For example, some places do not have enough speech therapists.

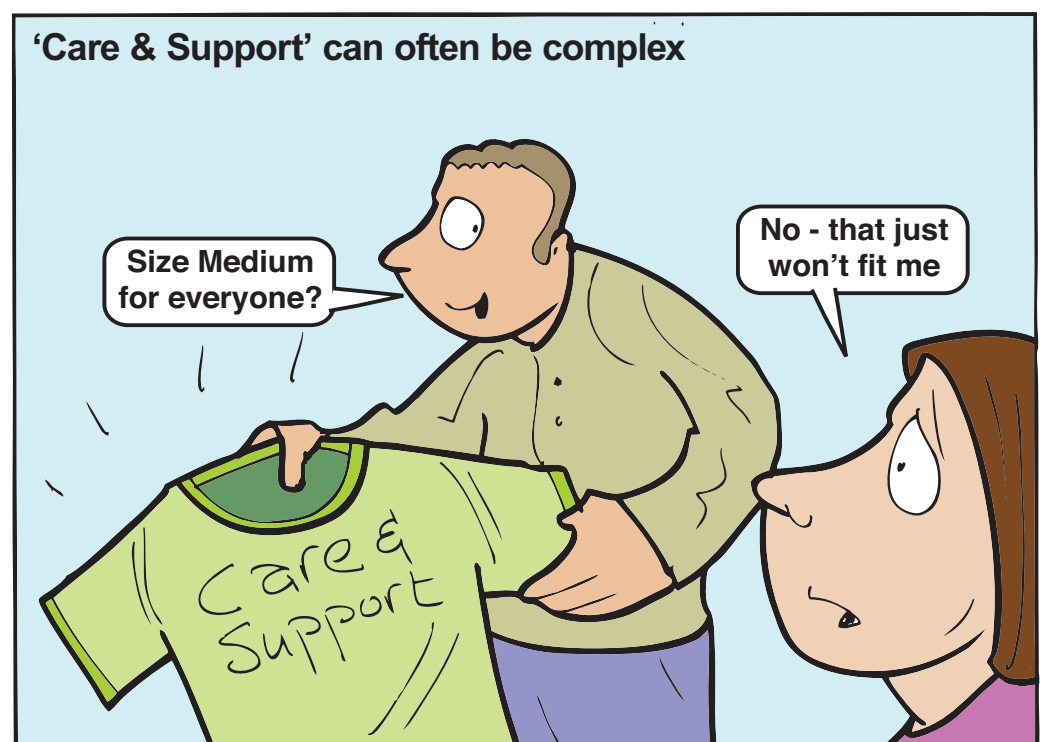
People want NHS and other staff to work better together. They should share their ideas and problems. This will help make services better.

People want everyone with a long-term condition to get equal care.

People want to know what services can and cannot do.

People want to go to just one place to get told what is wrong with them.

They want NHS workers to be better at telling them bad news.



People want to talk to counsellors. This will really help when they are told that they have a long-term condition.

People want key workers to tell them what services are available. They said it was important for the NHS to arrange this.

People with long-term conditions, their carers and NHS workers should all decide together what care people should get.

People want to see NHS workers in places like libraries and leisure centres.

Many people have more than one long-term condition. They want hospitals to be better at making appointments so that they are all at once. They want NHS workers to know all the other medicines they take.

People wait too long to get an outpatient appointment. They also wait too long for tests. They want clinics where you can just turn up. They want to hear about tests sooner.

People living in the countryside find it hard to get transport to hospital.

People liked single points of access. This is when they can arrange lots of different services in one place.

People want free medicines for all long-term conditions.

People want NHS experts to support people with long-term conditions.

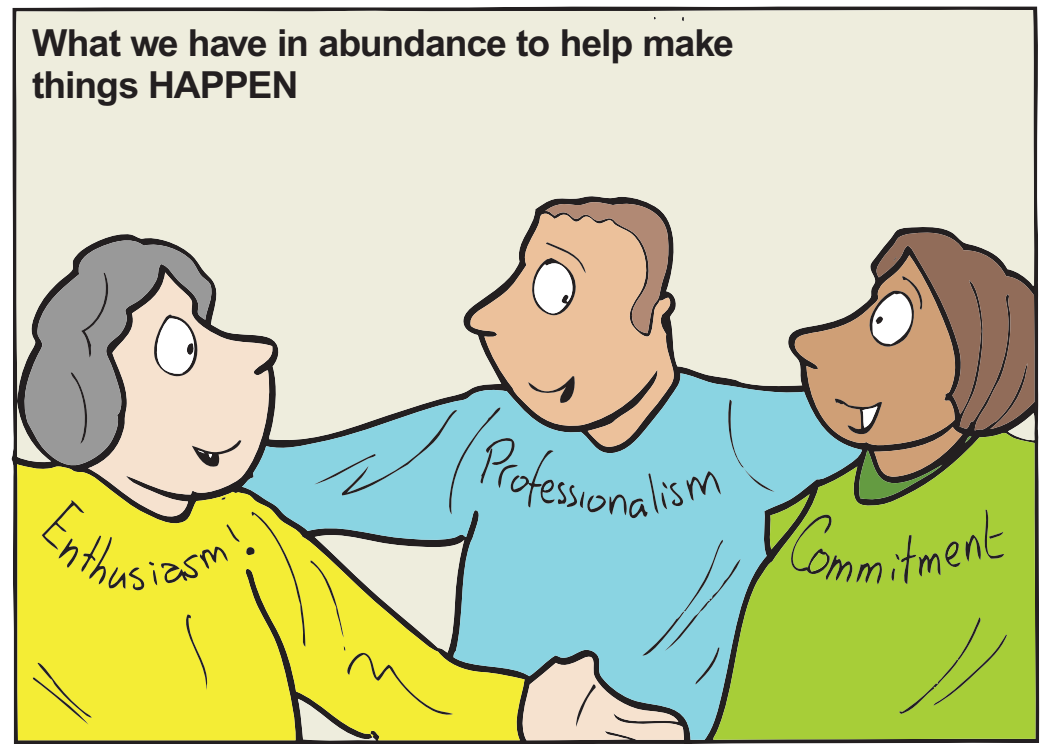
# What happens next?

The meetings in Glasgow and Aberdeen were very important events. They gave a clear message to NHSScotland.

The main thing people want is for NHS workers to listen to them and give them better services.

People at the meetings also said that there were lots of good things happening in Scotland.

NHSScotland promised that when they plan new services, they will remember all the things that people said.



# What Words Mean

**NHS** – the National Health Service. Hospitals and doctors' surgeries and clinics are all part of the NHS. Any medical treatment that you do not pay for is usually part of the NHS.

**Complementary Therapies** – these are non-medical treatments that may help you to stay healthy. Massage and reflexology are complimentary therapies.

**Self-esteem** – this is the way you feel about yourself. If you feel good about yourself, you have high self-esteem.

**Counsellor** – a trained person who you can talk to about anything that you are worried about. Everything you tell the counsellor is private.

**Patient Passport** – all the details of your long-term condition would be written down in your patient passport. When you meet a new NHS worker, they could read your passport to find out about you.

**Key worker** – this is the person in the NHS that you would contact to find out information about your treatment or what services there are.

**GP** – this is your family doctor. GP stands for General Practitioner.

**Managed Clinical Network** – this is when a group of professionals all work together to make sure that everyone gets a good service.

**Outpatient** – this is somebody who gets day treatment in hospital. Someone who stays in hospital overnight is called an inpatient.

**Single Point of Access** – this is one place where you can go to arrange all the services that you need.

**Talking Therapies** – when you can talk about how you are feeling to people who are trained to listen. Counselling is a talking therapy.



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[www.scotland.gov.uk](http://www.scotland.gov.uk)

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