Department
of Health &
Social Care

Improving the lives of people with ME/CFS

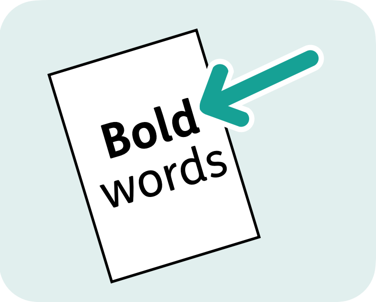
What we found out from our survey

Easy Read

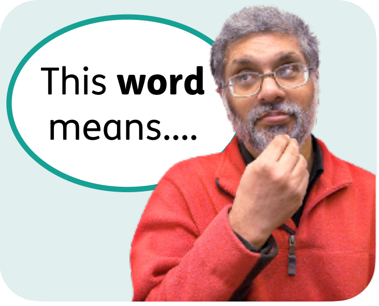
Easy Read

This is an Easy Read version of some information. It may not include all of the information but it will tell you about the important parts.

This Easy Read booklet uses easier words and pictures. Some people may still want help to read it.



Some words are in **bold** - this means the writing is thicker and darker. These are important words in the booklet.



Sometimes if a bold word is hard to understand, we will explain what it means.

Blue and underlined words show links to websites and email addresses. You can click on these links on a computer.

What is in this booklet

About this booklet

This booklet is from the Department of Health and Social Care.

In 2023, we shared our plan for improving the lives of people with **myalgic encephalomyelitis and chronic fatigue syndrome (ME/CFS)**.

We will explain more about this in the next part of the booklet.

We then shared a **survey** which asked people what they thought of our plan.

A **survey** is a set of questions for you to answer.

This booklet will explain what we learned from people's survey answers.

Myalgic encephalomyelitis and chronic fatigue syndrome (ME/CFS)

We say myalgic like this **my - al - jick** and encephalomyelitis like this
en - seffo - mile - eye - tiss.

Myalgic encephalomyelitis and chronic fatigue syndrome (ME/CFS) is a serious health condition.

We will call myalgic encephalomyelitis and chronic fatigue syndrome **ME/CFS** in the rest of this booklet.

About our plan

Our plan to improve the lives of people with ME/CFS has 3 main parts:

1. **Research** - we want to find out more about ME/CFS.

2. **Changing attitudes** - we want to change the way professionals and the public think about ME/CFS and the people who have it.

3. **Quality of life** - we want to improve the lives of people with ME/CFS by listening to what they need.

You can read the Easy Read copy of our plan here: https://www.gov.uk/government/consultations/our-plan-to-improve-the-lives-of-people-with-mecfs-easy-read

About our survey

Our survey asked people what they thought about:

- The 3 main parts of our plan.

- Other issues that are included in our plan.

- The ways we will improve the lives of people with ME/CFS.

  We call these **actions**.

- The language we use to talk about people with ME/CFS.

3338 people answered the questions in our survey.

In this booklet, we will go through people's answers to the questions.

Questions about research

The first main part of our plan is about **research**.

Research means collecting information about something to find out more about it.

People who do research are called **researchers**.

What people said

We asked people if they agreed with what our plan says about research.

Almost everyone who answered said they agreed with what our plan says.

We also asked people how the research part of our plan could be better.

Almost half of the people who answered said this part of the plan could have more information.

People also said:

- More money needs to be spent on research into ME/CFS.

  There should be money set aside that is just for research into ME/CFS.

- We should make sure more research into ME/CFS is happening.

  1 way we could do this is by supporting more researchers to take part in research into ME/CFS.

People also said:

- Research should look into different parts of ME/CFS and the lives of the people who have it.

- People with ME/CFS and professionals who support them should be included in research.

- We should help people with ME/CFS and their carers to trust research about ME/CFS.

Questions about changing attitudes

Changing attitudes means changing the way **professionals** and the public think about ME/CFS and the people who have it.

When we say **professionals**, we mean anyone who supports people with ME/CFS, like health and social care professionals.

What people said

We asked people if they agreed with what our plan says about changing attitudes.

Almost everyone who answered said they agreed with what our plan says.

We also asked people how the changing attitudes part of our plan could be better.

Half of the people who answered said this part of the plan could have more information.

People also said:

- There should be more **mandatory** training about ME/CFS for lots of different professionals.

  Mandatory means the training **has** to be done, and professionals do not have the choice to not take part.

- Our plan does not always use the right words to describe ME/CFS.

People also said:

- Health care professionals do not always offer good quality support.

  For example, they often do not see when someone is showing signs of having ME/CFS.

- Many people with ME/CFS have been upset about the way they have been treated by professionals.

  Professionals must know how to treat people with ME/CFS with respect.

- All information and training about ME/CFS should be kept up to date with correct information.

- People with ME/CFS should help to plan training about ME/CFS.

Questions about quality of life

Quality of life is about improving the lives of people with ME/CFS by listening to what they need.

What people said

We asked people if they agreed with what our plan says about improving quality of life.

Almost everyone who answered said they agreed with what our plan says.

We also asked people how this part of our plan could be better.

Half of the people who answered said the quality of life part of our plan could have more information.

People also said:

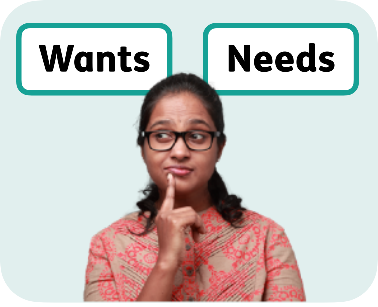
- Everyone needs to have a better understanding of:

  - What **severe ME/CFS** and **mild ME/CFS** are.

  - The seriousness of ME/CFS and how it changes the quality of a person's life.

- There should be more support for the families of people with ME/CFS.

People also said:



- We need to be more clear about the differences between the **wants** and **needs** of people with ME/CFS.

- People with ME/CFS and their families must get support with money.

- There are not enough treatments for ME/CFS, and not enough money is being spent on finding new treatments.

- Not enough activities make changes so that people with ME/CFS can take part in them.

Other issues

Support for children and young people

Almost everyone agreed with what our plan said about supporting children and young people with ME/CFS.

People also said:

- Children and young people should be believed if they speak up about having signs of having ME/CFS.

- Places of education should make changes to better include children and young people with ME/CFS.

- Places of education should understand it is very hard for a child or young person with ME/CFS to go to school in person.

People also said:

- Places of education should offer more support to children and young people with ME/CFS.

- Families of children with ME/CFS find it hard to get support for their child early on in their life.

- Families of children with ME/CFS should get support with money.

Health care services

Almost everyone agreed with what our plan said about health care services for people with ME/CFS.

People also said:

- We should be clearer about how we will help stop issues that health care services face when supporting people with ME/CFS.

- **All** health care services for people with ME/CFS should offer good quality support.

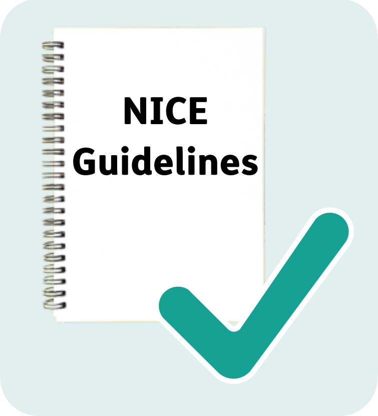
- There should be more health care services for people with severe or very severe ME/CFS.

People also said:

- People with ME/CFS should get support earlier on in their lives.

- Health care professionals should believe people who are showing signs of having ME/CFS.

  They must not blame the person for the signs they are showing.



- Health care services must follow what the **NICE guidelines** say about ME/CFS.

  The **NICE guidelines** explain how health care services should support people.

Social care services

Almost everyone agreed with what our plan said about social care services for people with ME/CFS.

People also said:

- People with ME/CFS are not told about the social care support they can get.

- Health care services, social care services and money support services should all work together to support people with ME/CFS.

- People with ME/CFS get bad social care because their carers have not had any training about ME/CFS.

People also said:

- People with ME/CFS have to get social care support from their families.

- They do not agree that people with ME/CFS can only get social care support if they get benefits.

- People with ME/CFS and their families should be offered an **advocate.**

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

Welfare support

Welfare support is all support that helps people with ME/CFS be able to live the life they want.

Almost everyone agreed with what our plan said about welfare support for people with ME/CFS.

People also said:

- People with ME/CFS should get support to take part in **benefits assessments**.

  A **benefits assessment** is when you meet with a professional to work out what benefits you need.

- People with ME/CFS find it hard to get benefits.

  This needs to change.

People also said:

- Health care professionals should be involved in the benefits assessments of people with ME/CFS.

- The professionals who decide whether a person gets benefits need to know more about ME/CFS.

Jobs and working

Almost everyone agreed with what our plan says about helping people with ME/CFS find and keep a job.

People also said:

- Employers should know more about ME/CFS so that:

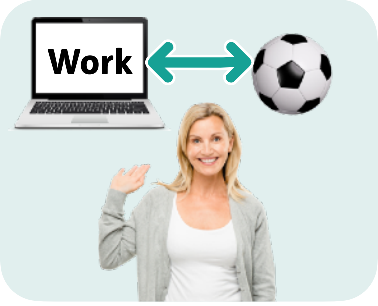
  - They know how to hire people with ME/CFS.

  - They can support their employees who have ME/CFS.

- The government needs to do more to help disabled people get jobs.

People also said:

- People with ME/CFS do not get enough support with finding a job and keeping a job.



- People with ME/CFS should get more support to balance having a job and doing other things they enjoy.

Our actions

Our plan includes some ways we will help improve the lives of people with ME/CFS.

We call these **actions**.

We asked people if they agreed with our actions.

Almost everyone said they agreed with our actions.

We also asked people how our actions could be better.

Our research actions

People said:

- We should be clearer about how much money we will spend on research into ME/CFS.

- We should write a plan that explains what research we will do over the next few years.

Our changing attitudes actions

People said:

- We should offer training to more types of professionals.

- We should offer schools more help with supporting children and young people with ME/CFS.

People said we need a better action plan for changing attitudes.

Our quality of life actions

People said:

- We need better actions to improve the lives of people with ME/CFS.

  They also need to include more mental health support.

- We need better ways of making sure these actions happen.

- We need to support different types of organisations that help people with ME/CFS, like charities.

The words we use

In our survey, we asked people about:

- Upsetting ways of describing ME/CFS.

- Upsetting ways that other people talk to people with ME/CFS.

- Better ways to describe ME/CFS.

- Better ways to talk to people with ME/CFS.

Upsetting words

People said:

- It is upsetting when people describe ME/CFS as ‘just being tired’.

  This does not show how serious ME/CFS is.

- It is hurtful when people do not take the time to ask about ME/CFS.

- Sometimes, people focus too much on how a person with ME/CFS should get better.

- It is upsetting and incorrect when people think that ME/CFS is a mental health condition.

People also said:

- It is hurtful when people do not believe people with ME/CFS when they talk about it.

- The way people think about **invisible illnesses** needs to change.

  Invisible illnesses are illnesses that people cannot see.

- People need to understand that ME/CFS can change for the person who has it.

  Some weeks, they may feel a lot worse than other weeks.

- It can be hard for someone with ME/CFS to explain their health condition to others.

Better words

People said:

- Other people should ask people with ME/CFS about their health condition.

- Other people should ask people with ME/CFS what help they need.

- Other people should support people with ME/CFS by learning about it.

- Other people should believe people with ME/CFS when they talk about their health condition.

What happens next?

We will use people’s answers to make our plan better.

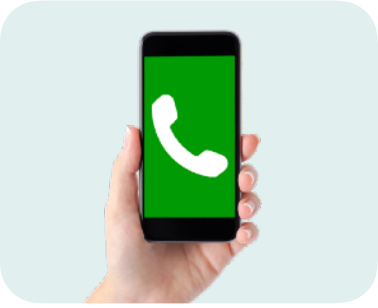
We want to share the final version of our plan by the end of June 2025.

Find out more

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

You can contact us by:

- Post:
  ME/CFS Delivery Plan
  Department of Health and Social Care
  39 Victoria Street
  London
  SW1H 0EU



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