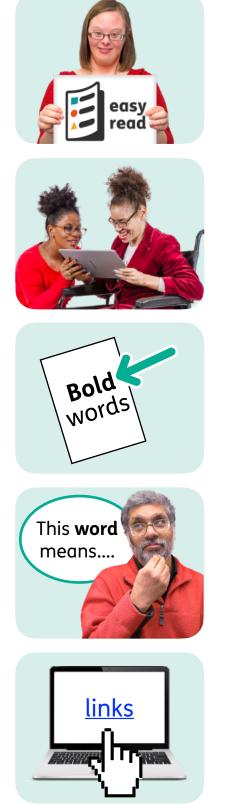


Department of Health & Social Care

Our plan to improve the lives of people with myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS)



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. You may still want help to read it.

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

These are words that some people will find hard. When you see a bold word, we will explain it in the next sentence.

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

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About this plan



This is a plan to improve the lives of people with myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS).



The plan has been written together with people who have ME/CFS, support workers, health and other professionals and the Department of Health and Social Care.



We want to know if there's anything else that should be in this plan.



Please tell us what you think by answering the questions in the separate Easy Read survey.

Myalgic encephalomyelitis (ME) and chronic fatigue syndrome (CFS)





We say myalgic encephalomyelitis like this: **"my - al - jick en - seffa - lo - mile - eye - tiss".**

Myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS) is a health condition that affects people for a long time.

We will call the condition ME/CFS in the rest of this booklet.



Around 241,000 children and adults have ME/CFS in the UK.



It is not clear how people get ME/CFS.



There are 4 main signs that someone has ME/CFS:

1. Feeling so tired that you cannot do anything. This does not get any better if you have a rest.



2. Feeling very tired after doing an activity, which can get worse hours or days after the activity.



3. Not feeling rested after sleep or not sleeping very well.



4. Finding it difficult to think or remember things.



These 4 signs can affect people in different ways.



Around 1 in 4 adults with ME/CFS:

• Cannot leave the house or their bed.



• Need care 24 hours a day.



This can last for months or years.



Very rarely people can die of ME/CFS.

Why we need a plan



ME/CFS affects the lives of many adults and children in the UK.



It can stop people from taking part in everyday activities, like:

- Spending time with friends and family.
- Using services like everyone else.



• Going to school or work.



We want to be able to support people with ME/CFS to have a better quality of life.

This plan sets out what is going to be done.

The plan



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

1. **Research** - this is about finding out more about ME/CFS to better understand it and find better treatments.



2. **Changing attitudes** - this is about changing how health and other professionals think about ME/CFS and the people who live with it.



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

Research



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



At the moment, we do not know enough about ME/CFS. More research needs to be done.



We need to find out more about:

• Why people get ME/CFS in the first place.



• How to treat ME/CFS.



There needs to be more money spent on research into ME/CFS.



But we also need to check that the money is being spent on research in the right way.



Research into MS/CFS needs to be done in a way that is fair to everyone, like making sure it includes people from different backgrounds.



People with ME/CFS and their carers don't always trust the research that is being done.

This needs to change.

What we are going to do

These are the things that will be done to improve research into ME/CFS:

• Support a new research plan that will help to improve the research that is being done into ME/CFS.

Work to raise money for more research into ME/CFS.



More

Plan

• Make more researchers aware of the money that is available to do new research.



• Set up working groups that can make sure research is being done in the right way, and that is it fair to everyone.



• Support the research working group to share examples of good research that can help new researchers in their work.



• Support work with training providers to improve their training for health professionals about ME/CFS.

Changing attitudes



Because there is not enough information and training about ME/CFS, it is difficult for health and other professionals to fully understand it.

This can make it hard for health and other professionals to:



• Recognise when someone has ME/ CFS.



• Support people with ME/CFS in the best way.



People with ME/CFS and their carers don't always feel like they are being treated with respect by health or other professionals.

This needs to change.

What we are going to do

These are the things that will be done to change the attitudes of health and other professionals about ME/CFS:

• Find out what health and other professionals need to better understand ME/CFS and the people who live with it.



• NHS England to make an online learning tool about ME/CFS that can be used by health professionals and the public.



• NHS England and NHS Health at Work Network will update the information they have on their websites about ME/CFS.



- On learning about ME/CFS, the Department of Health and Social Care will:
 - Ask ME/CFS groups to work on a learning tool, like stories or videos.



- England
- Ask medical schools to teach their students about ME/CFS.
- Tell people about the new learning tool from NHS England when it is ready.

- England
- On learning about ME/CFS, the Department for Education will:
 - Help people working in education and health settings to use the new learning tool from NHS England when it is ready.

 Update guidance for local councils about how children who cannot go to school can be supported.

The Department for Education has already updated its guidance about this.

- Share guidance from Action for ME about children's social care.
- The British Association of Social Workers will help to share information about ME/CFS with social workers.
- The General Medical Council will include ME/CFS in the test that doctors have to pass to work as doctors.



General

Medical

Council



action for me

Child social care

guidance





- The Royal College of Physicians will make sure that their training on ME/CFS changes as new information is found through new research.
- Health professionals and people with experience of ME/CFS will work together to write a guide on how to talk about ME/CFS.

Quality of life



Living with ME/CFS can affect different people in different ways.

We have agreed on 6 main areas that need to change to improve the lives of everyone with ME/CFS:



1. Improving people's overall quality of life so they feel included and able to make the most of their lives.



2. Supporting children and young people with ME/CFS from an early age, in schools and training to get a job.



3. Improving health services for people with ME/CFS and making it easier for them to get the support they need.



4. Adult social care support so that adults with ME/CFS can get the help they need in their everyday lives.



5. Support from benefits so that people with ME/CFS get money from the government to help pay for the things they need to live.



6. Supporting people with ME/CFS to find a job and do their job.



Another part of improving the lives of people with ME/CFS is to help everyone to better understand ME/CFS.

What we are going to do

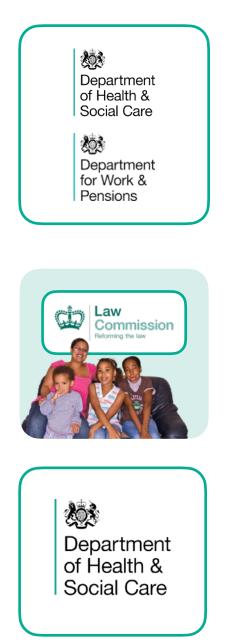
These are the things that will be done to improve the quality of life for people living with ME/CFS:

- The Department of Health and Social Care will work with ME/CFS groups to:
 - Tell more people with ME/CFS and their carers about the support they can get.
 - Tell more people with ME/CFS and their carers about how they can complain about their care or treatment if it is not good enough.
 - Look into the best ways to make more members of the public aware of ME/CFS.









- The Department of Health and Social Care and the Department for Work and Pensions will work with ME/CFS and other disability groups to share information about the support they can get.
- The Law Commission will look at the laws about social care to make it clear what support children and families with ME/CFS can get.
- The Department of Health and Social Care will think about how to better support health providers to understand the needs of people with ME/CFS.



- The Department of Health and Social Care will work to:
 - Provide support for children and young people with ME/CFS as soon as they start to need it.



Department for Work &

Pensions

• Keep children and young people with ME/CFS safe from harm and abuse.

• The Department for Work and Pensions will make its services easier for everyone to use.

Next steps



Thank you to everyone who helped to write this plan, especially people living with ME/CFS, their families, carers and support workers.



We want to carry on checking how work on this plan is going, to make sure it is working.



We will work with a new ME/CFS Delivery Group to do this.

The group will include lots of people who are in charge of services, people with ME/CFS, their families, carers and support workers.



This group will meet every 6 months to check that the things we agreed to do in this plan are happening.

Find out more



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

You can contact us by:

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



• Phone: 0300 790 4007



• Email: mecfs@dhsc.gov.uk

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