

Department of Health & Social Care

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

What do you think?



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 survey



This is a survey from the Department of Health and Social Care.

We have written a plan to support people who live with myalgic encephalomyelitis / chronic fatigue syndrome (ME/CFS).

We would like to know what you think of our plan.

Your answers will help us to understand ME/CFS better and make our plan better in the future.

You need to send us your answers by 30 October 2023.

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





241,000



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.





This can last for months or years.



Very rarely people can die of ME/CFS.

Questions about you



Question 1: Which of these describes you best?

I have or I think I have ME/CFS



I have had ME/CFS in the past

I am or have been an unpaid carer for someone with ME/CFS

I am a family member, friend or supporter of someone with ME/ CFS but I do not provide care for them



Question 2: How would you describe the effects of ME/CFS on you or the person you know with ME/CFS in the past 3 months?

Not very bad
A little bad
Bad
Very bad
I am/they are getting better from the effects of ME/CFS
I am better now
I do not know
I do not want to say
I do not have and have never had ME/CFS



Question 3: How long have you or the person you support had ME/CFS?

Less than a year

1 to 5 years

6 to 10 years

11 to 20 years

Over 21 years

I do not want to say





Question 6: What is your sex?
Female
Male
I do not want to say





Question 8: What is your **ethnic background**?

Your **ethnic background** is your race and the country that your family came from.

White	
From more than 1 et background	hnic
Asian	
Black	
Other	
I do not want to say	



Questions about research



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



What our plan says

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.



We want to make sure that more money is spent on research into ME/CFS.



We need to check that the money is being spent on research in the right way.



Research into ME/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.



Question 10: How much do you agree or disagree with what we wrote in this part of the plan?

Please only tick 1 box.





Question 11: What do you think could make this part of the plan better?



If you would like to tell us anything else about this part of the plan, please write it here:



Questions about changing attitudes



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



What our plan says

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.



Question 12: How much do you agree or disagree with what we wrote in this part of the plan?

Please tick only 1 box.





Question 13: What do you think could make this part of the plan better?



If you would like to tell us anything else about this part of the plan, please write it here:



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 our plan says

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.



Question 14: How much do you agree or disagree with what we wrote in this part of the plan?

Please only tick 1 box.





Question 15: What do you think could make this part of the plan better?



If you would like to tell us anything else about this part of the plan, please write it here:



Questions about supporting children and young people with ME/CFS



We heard that children and young people with ME/CFS can struggle to get the right support.



They or their families may be reported as a **safeguarding** concern.

Safeguarding is a way of making sure that children and young people are not unsafe or being put in danger.



What our plan says

Changes should be made to support children and young people who cannot go to school.



Children and young people with ME/CFS should be supported to keep learning.



Safeguarding teams should get involved in children's or young people's lives only when they are needed.



Question 16: How much do you agree or disagree with what we wrote in this part of the plan?

Please only tick 1 box.





Question 17: What do you think could make this part of the plan better?



If you would like to tell us anything else about this part of the plan, please write it here:



Questions about health services



We heard that:

• People with ME/CFS can find it hard to get support and treatment from health services.



• Different health services treat ME/CFS in different ways.



• People with very bad ME/CFS can find it hard to use health services.



• Many ME/CFS services can find it hard to find staff and keep them working there.

What our plan says



- We want to:
- Make sure more people know about ME/CFS.



• Make sure more people know how people with ME/CFS can get support.



Question 18: How much do you agree or disagree with what we wrote in this part of the plan?

Please only tick 1 box.





Question 19: What do you think could make this part of the plan better?



If you would like to tell us anything else about this part of the plan, please write it here:



Questions about Adult Social Care



We heard that adults with ME/CFS and their carers can find it hard to get social care support.

What our plan says



- We want to:
- Make sure more people know about the support they can get from adult social care services.



• Support adult social care staff to know more about ME/CFS so they can support people better.



Question 20: How much do you agree or disagree with what we wrote in this part of the plan?

Please only tick 1 box.





Question 21: What do you think could make this part of the plan better?


If you would like to tell us anything else about this part of the plan, please write it here:



Questions about benefits support



We heard that children and adults with ME/CFS can find it hard to get the benefits they need.

What our plan says



- The Department for Work and Pensions wants to:
- Improve the way that disabled people and people with health conditions can use benefits services.



• Make sure people can trust their services.



Question 22: How much do you agree or disagree with what we wrote in this part of the plan?

Please only tick 1 box.





Question 23: What do you think could make this part of the plan better?



If you would like to tell us anything else about this part of the plan, please write it here:



Questions about help with finding and keeping a job



We heard that:

• There are not many jobs that can meet the needs of people with ME/CFS.



• Employers may not support people who have ME/CFS.



What our plan says

The Department for Work and Pensions wants to help more disabled people and people with health conditions to start work and stay in their jobs.



Question 24: How much do you agree or disagree with what we wrote in this part of the plan?

Please only tick 1 box.





Question 25: What do you think could make this part of the plan better?



If you would like to tell us anything else about this part of the plan, please write it here:



Questions about what we think needs to happen



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.



• 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.



Question 26: How much do you agree or disagree with how we think research into ME/CFS should be improved?

Please only tick 1 box.





If you would like to tell us anything else about this, please write it here:







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 will 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.





- Ask medical schools to teach their students about ME/CFS.
- Tell people about the new learning tool from NHS England when it is ready.
- On learning about ME/CFS, the Department for Education will:



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Department for Education

ME/CFS Guidance

- 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.
- 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/CES.



Question 27: How much do you agree or disagree with what we think needs to happen about changing the attitudes of health and other professionals, to ME/CFS?

Please only tick 1 box.





If you would like to tell us anything else about this, please write it here:

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.



How do I

complain?



- 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.



Question 28: How much do you agree or disagree with what we think needs to happen to improve the quality of life for people with ME/CFS?

Please only tick 1 box.





If you would like to tell us anything else about this, please write it here:



Questions about how ME/ CFS is described by others



We want to find out more about how people with ME/CFS might have been upset by the way that their condition is described.



We would like to know if you have heard these phrases and if you can think of a better way of describing them.

Feeling very tired all the time because you have ME/CFS

Some upsetting statements about this include:





Question 29: Have you heard these comments or something like them before?



No



Question 30: What do you think is a better way of talking about feeling very tired all the time because you have ME/CFS?

Trying to get better from ME/CFS

Some upsetting statements about this include:





Question 31: Have you heard these comments or something like them before?



No



Question 32: What do you think is a better way of talking about trying to get better from ME/CFS?



People thinking that ME/CFS is a mental health condition or that thinking in a certain way can change your health condition

Some upsetting statements about this include:





Question 33: Have you heard these comments or something like them before?





Question 34: What do you think is a better way of talking about ME/CFS, not saying it is a mental health condition or can be changed by thinking in a certain way?

Not having a medical test to show that someone has ME/CFS

Some upsetting statements about this include:





Question 35: Have you heard these comments or something like them before?

Yes

No



Question 36: What do you think is a better way of talking about there not being a medical test for ME/CFS?

There not being any clear signs that someone has ME/CFS

Some upsetting statements about this include:





Question 37: Have you heard these comments or something like them before?





Question 38: What do you think is a better way of talking about there not being any clear signs that someone has ME/CFS?



Pacing yourself so you do not use too much energy

Some upsetting statements about this include:





Question 39: Have you heard these comments or something like them before?





Question 40: What do you think is a better way of talking about pacing yourself so you do not use too much energy?

Finding it hard to explain why tiredness affects you a long time after being active

An upsetting statement about this is:







Question 42: What do you think is a better way of talking about tiredness affecting you a long time after being active?



Question 43: Please tell us your email address:

We may contact you in the future to ask you for more information.

How to tell us what you think

When you have answered the questions, please send the survey back to us by post to:



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



We will use your answers to:

• See if our plan includes the most important things for people with ME/CFS and their carers.



• Help us change any parts of the plan when we look at it again in the future.

Your personal information



We will follow the laws about how to keep your information safe.





The Department of Health and Social Care will be in charge of making sure your information is kept safe.

We will use any information you give us to:

• Understand what people who fill in the survey think.



• Contact you for more information, if you have said we can do that.



We will keep your personal information, like your name and contact details, for no more than 1 year.



We may keep your answers to the questions for no longer than 5 years.

If you are not happy with how your personal information is used, you should contact us by:



• Email: <u>data_protection@dhsc.gov.uk</u>



 Post: Data Protection Officer 1st Floor North 39 Victoria Street London SW1H 0EU If you are still not happy with how your personal information is used, you can complain to the Information Commissioner's Office by:



 Website: <u>www.ico.org.uk</u>



 Post: Information Commissioner's Office Wycliffe House Water Lane Wilmslow Cheshire SK9 5AF

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
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