

This is M.E.

This pack is to help professionals understand how my health is affected, and the best ways to support me.

This resource was published in May 2018 and is subject to revision and review by Action for M.E. and North Bristol NHS Trust later in 2018. Please see the back page for details of how to share your feedback.

Add
photo
here

My name is:

This booklet is designed to be completed by the person with M.E. or the person that knows them best. Because people change and M.E. changes, it will need to be updated from time to time.

What is M.E.?

I live with a condition called myalgic encephalomyelitis (M.E.), also diagnosed by the NHS as Chronic Fatigue Syndrome or CFS/M.E. Both of these names are used around the world, but this guide will call it M.E.

The main symptom of M.E. is fatigue, both mental and physical, which feels different from normal tiredness. This fatigue can be made worse by small amounts of physical, mental activity and the symptoms may worsen over a 2-3 day period after the activity. This is known as post-exertional malaise and it is a key feature of M.E. Along with this are a range of other symptoms. **I have indicated the symptoms that affect me in the table on the next page.**

Different people experience some symptoms more than others. For example, pain can be a big problem for some, and not for others. The condition affects people in different ways: some people are mildly affected, others moderately or severely affected. Some have frequent setbacks or relapses, whilst other people's symptoms are more stable.

It helps if carers and other professionals understand that just because an individual can manage an activity (eg. a conversation) one day doesn't necessary mean they can another: please don't be offended or surprised by this.

What causes M.E.?

Sometimes people develop M.E. following an infection, such as glandular fever. For other people, their illness may have been triggered by a significant amount of stress. A combination of an infection and stress is commonly reported. Occasionally, it seems to come "out of the blue".

The exact mechanisms underlying M.E. are still unknown. Our current understanding is that the nervous system and possibly the immune and endocrine systems of the body are likely to be involved in M.E. These systems are complex and operate at a deep level inside us. For this reason, someone with M.E. may look well on the outside, even if they are having a really bad day.

With M.E., the body's systems are thought to have become poorly regulated and hypersensitive. The body is in a constant state of "high alert" almost as if a switch has been thrown and the whole system is in a state of emergency. This is thought to be why the smallest of stressors such as noise, light, or physical activity can have a big impact on the symptoms of M.E. Often too much stimulation from things such as noise or light can result in someone with M.E. feeling worse the next day.

Activity and M.E.

People with M.E. often have varying symptoms from one day to another, or even within the same day. This can make it difficult to decide whether or not to attempt an activity. It can be tempting to try and do more on a better day. However, if someone with M.E. does too much in one day, they are likely to feel worse afterwards and have several days recovering. This can lead to big swings in activity over time, known as "boom and bust". This boom and bust pattern is unsustainable and over time and leads to a reduction in the level of activity a person can manage.

The information on this page is designed to help you understand some important things about me.

My full name

And the name I prefer to be known by

I currently live

The person who knows me best is

My hobbies and interests

Things that are important to me

I would also like you to know

The information in this section is designed to help you understand some of the ways that I am limited by M.E.

**My mobility is
(tick as appropriate):**

always limited

frequently limited

sometimes limited

rarely limited

This is how you can support me with this:

**My concentration and
memory are
(tick as appropriate):**

always limited

frequently limited

sometimes limited

rarely limited

This is how you can support me with this:

**I find communicating
with others
(tick as appropriate):**

always challenging

frequently challenging

sometimes challenging

rarely challenging

This is how you can support me with this:

**With regards to light
I have (tick as appropriate):**

This is how you can support me with this:

always high sensitivity

frequent high sensitivity

sometimes high
sensitivity

rarely high sensitivity

**With regards to sound
I have (tick as appropriate):**

This is how you can support me with this:

always high sensitivity

frequent high sensitivity

sometimes high
sensitivity

rarely high sensitivity

**My sleep is
(tick as appropriate):**

This is how you can support me with this:

always problematic

frequently problematic

sometimes problematic

rarely problematic

These are the things you need to know about my personal care:

This is how you can support me with this:

These are the things you need to know about my medication:

This is how you can support me with this:

These are the things you need to know about my diet:

This is how you can support me with this:

There are a number of things around the house that I would like regular help with. These are:

Managing my activity and baselines

One way of avoiding the boom and bust pattern of activity is to stick to a baseline. A baseline is the level of a particular activity that someone can manage consistently, without triggering off a bad day. It's essential to recognise that baselines are unique to each individual: even lifting an arm or sitting up in bed can be above the baseline for some people.

Baselines can be measured using the amount that someone does of a certain activity (eg. reading four pages), the length of time they do a certain activity for (eg. reading for five minutes), and sometimes the distance travelled doing a certain activity (eg. walking 10 meters). Baselines change over time and for some people – but not everyone – they can be slowly increased by consistently undertaking an activity.

My most valued activities	My current baseline for this activity

Useful contacts



UK charity Action for M.E. offers information, advice and support for everyone affected by M.E., including health, social care and other professionals supporting adults and children living with the condition.

Action for M.E., 42 Temple Street, Keynsham BS31 1EH

Tel: 0117 927 9551

Email: questions@actionforme.org.uk

www.actionforme.org.uk



North Bristol

NHS Trust

Bristol CFS/M.E. Service offers an outpatient service for people with CFS/M.E. living in Bristol, North Somerset and Gloucestershire, and advice and support to healthcare professionals about the clinical management of people with CFS/M.E..

Bristol CFS/M.E. Service, The Lodge,
Cossham Hospital, Lodge Road, Bristol BS15 1LF

Email: CFS.NHS.Bristol@nbt.nhs.uk

www.nbt.nhs.uk/our-services/a-z-services/bristol-chronic-fatigue-syndromeme-service/chronic-fatigue-syndromeme

Have you found this resource helpful? Is there a way we could improve it? We would love to hear your feedback to help make *This is M.E.* as useful as possible.

You can share your feedback by:

- **calling Action for M.E. on 0117 927 9551 or**
- **answering some short, simple questions online at www.surveymonkey.co.uk/r/ThisisMEfeedback**