

## 'ME' and my carer

### Information for people with ME/CFS to help carers

#### Message to the ME/CFS sufferer

Few people really understand what effect ME/CFS has on you.

Even close members of your family do not always fully understand and – even if they do – they sometimes need reminding!

With outside carers, this may be a difficult problem as there are still a lot of people who do not know much about this illness.

To help, The ME Association has produced this leaflet which will help you get across the complexities of ME/CFS and how it affects you.

It describes some of the basic characteristics of the illness and lists symptoms you have and the degree to which you have them. It also spells out those tasks which are difficult or impossible for you to carry out unaided.

Fill it out, arrange for photo-

<p><b>Name</b> _____</p> <p><b>Address</b> _____</p> <p>_____</p> <p>_____</p> <p><b>Post code</b> _____</p> <p><b>Date of birth</b> _____</p> <p><b>Number of months/years I have had ME/CFS</b> <input type="checkbox"/></p>
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copies and give copies of it to any carer who needs to understand your symptoms.

Above is a space for your name, address and date of birth. This may be useful if you have carers from organisations such as your local authority. They can then keep a copy on file as well as you giving copies to all the carers who help you.

Following that is a short explanation about ME/CFS for your carer(s), a list of tasks and a list of symptoms with which you need help. Tick those tasks and symptoms that apply to you.

At the end, add anything that you feel may be relevant to your ME/CFS

#### Message to the carer

**ME/CFS is a disabling illness – although the visible signs and restrictions that people normally associate with being disabled may not always be obvious.**

Some people with ME/CFS often look well, yet feel ill. One minute they can do something and the next – they cannot.

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**Message to the carer... from page 1**

ME/CFS is characterised by severe fatigue that is made worse by minimal physical or mental exertion.

Sufferers can be exhausted by a short conversation, by taking a shower or going to the lavatory.

This is not tiredness. This is a complete and utter lack of energy, and it can be frightening in its intensity.

They frequently suffer from cognitive dysfunction (“brain fog”) which is an inability to

think straight, to find words.

Even the most sympathetic person may not understand the difficulties with talking too much or too quickly, making too much noise, not providing appropriate meals, not being clear which areas of care need to be covered. Much of this ‘lack of communication’ will be because a sufferer does not have the strength or energy to go through the explanations.

Do you remember how ill you felt the last time you had flu or a really severe virus?

Your body aches. You felt dizzy. You were cold and shivery. You couldn’t think

straight. Every noise and bright light hurt your senses.

That’s how people with ME/CFS feel when they are having a bad spell. And – for some – that is all the time. They may be too unwell to talk for more than a few moments.

ME/CFS is recognised by the World Health Organisation as a neurological illness. Although biomedical research is taking place, there is still no known cause, no simple diagnosis and no cure.

The severity and symptoms of ME/CFS varies from person to person and can fluctuate from day to day.

**Here are tasks that I need help with ALL, MOST or SOME of time:**

*ALL of the time*  
*MOST of the time*  
*SOME of the time*

I require wheelchair assistance.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am only able to walk a short distance.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am unable to climb stairs.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I require help with washing and bathing.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I require help with dressing/undressing.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I require help with going to the lavatory.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I require help with shopping.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I require help with meal preparation.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I require help with eating.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I need to take rests (add details).....			
Add anything that relates to your ME/CFS and is not included in the list			
.....			
.....			

**Please also read our leaflet ‘Caring for a person with ME’, which is available from The ME Association, price £1. This leaflet looks at what carers have to face when they take on their caring role and at some of the questions, concerns and problems they may have. It also gives details of other sources of information and support.**

**Here are symptoms that I have  
ALL, MOST or SOME of time:**

*ALL of the time*  
*MOST of the time*  
*SOME of the time*

<b>SYMPTOMS</b>	<i>ALL of the time</i>	<i>MOST of the time</i>	<i>SOME of the time</i>
<b>Muscle fatigue</b> .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Pain</b>			
In my muscles.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In my joints.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In my nerves.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
In my glands.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Muscle spasms.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Cognitive dysfunction = brain fog</b> .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Dizziness or balance problems</b> .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Headaches (specify if migraines)</b> .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Sensory problems</b>			
Sensitivity to loud noises.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sensitivity to bright lights.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Numbness.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Pins and needles.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Sensitivity to smells – eg perfumes.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Sleep disturbances</b>			
Hypersomnia (excessive sleep).....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Poor quality sleep.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Unrefreshing sleep.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Palpitations</b> .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Low blood pressure</b> (leading to faintness..... when rising from a seated position)	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Cold hands and feet</b> .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Sore throats</b> .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Enlarged glands</b> .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Allergies</b>			
Drugs.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Chemicals.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Irritable Bowel Syndrome / indigestion</b> .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Nausea and sickness</b> .....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
<b>Hearing Problems</b>			
Tinnitus – strange noises in the ear.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Extreme sensitivity to sound.....	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>