



*“Supporting sufferers and their families”*

## Information Sheet for Carers, Family and Friends of People with ME

It's not easy to be a friend or to look after someone with ME, but if you do it well, you can take great pride in knowing that you have made a real difference to them and their quality of life.

It is often helpful to try to understand what having ME is like for the person who is suffering from this illness.

There is a great deal of misconception about ME, not only in the medical world but in the media as well and, therefore, in the perception of the general public about ME. It is often called Chronic Fatigue Syndrome or CFS/ME and this leads to the confusion that having ME is all about fatigue. It is not, and in a poll by the 25% ME group [for severe sufferers of ME] fatigue did not even come in the top seven symptoms listed by the respondents.

Sadly, having ME is much more than fatigue and usually involves: malaise; flu like symptoms; loss of thermostatic stability; pain; worsening of symptoms from exercise or stress; hypersensitivity to noise and light; difficulty in information processing & concentration; gastric symptoms such as nausea, Irritable Bowel Syndrome; sensitivity to certain foods and chemicals such as cleaning products or perfume ;

People with ME have very little strength and stamina. They may also be in pain and it should be stressed that they feel generally ill all the time as well as disabled.

## **How you can help - as a carer:**

Give the person with ME as much help as you can. This may involve making their meals, fetching and carrying things for them and making sure that they get adequate rest periods. They may need assistance with reading letters and filling in forms.

They may need help with getting about such as lifts from door to door if they are able to go out and someone to make sure they are safe. Many sufferers feel dizzy or disoriented when they move around and when they have stand for more than a short time. It is a good idea to carry a folding chair in the car so that the person with ME can sit down if necessary.

Make sure that the person is kept warm and comfortable at all times. The temperature regulation system in the brain is malfunctioning in this illness. If the person says they are cold, for example, they may need heating, even though you yourself are hot!

**N.B** - People with severe ME will need help with personal care. When you are helping them, remember that all their muscles are very painful to touch. Please be very gentle. Try to work quickly and quietly, so they don't get tired... and be sure to keep them warm.

Try not to talk too much. When you must talk - keep your voice slow and quiet. You may have to repeat things if the person with ME has difficulty with information processing – be patient!

Work from written instruction when possible, to save tiring the patient. The energy which they save can be channelled into the recovery process and improving their quality of life... DON'T try to push people with ME into doing things they feel they are not able to do... this will make their condition deteriorate.

*People with ME would like to tell you – if they had the spare energy! - it is not that they don't enjoy talking to you but rather that they find conversation very tiring after a bit. This is because talking involves using both physical and mental energy and takes a great deal of concentration. Often they will stop talking quite suddenly as their body is telling them to conserve what energy they have left. Please don't be offended by this.*

Some people with M.E can also be light and noise sensitive, and so you should avoid speaking or making any noise when you're in the same room... Earplugs and dark sunglasses can be useful aids.

They need an environment that is quiet. It may help to ensure that they are not disturbed by other family members etc. when they need to rest. It will also

probably be necessary to keep the room dim by closing curtains. Do not use bright light bulbs.

Always remember that what seems trivial to you is important to someone with ME, because they have very little left... Don't make judgments about what is important. If someone seems upset and frustrated, just imagine how you would feel in their position. It would be abnormal if they were happy all the time.

*People with ME would like to tell you – that, for example, drinking out of a favourite mug or having a treasured card, letter or note within reach can make the world of difference to people who are very sick. They are not trying to be difficult but just trying to keep their spirits up. Try to make sure that you don't take away the little pleasures by putting practicalities first all the time.*

Many people who have M.E. feel very emotional at times. Some have anxiety. These problems are part of the illness process and also a result of having such a frustrating condition.

Some sufferers will want to talk about how they are feeling if they have the energy. Please be patient with them and accept how they feel. Always be encouraging and don't give up hope – this means so much to sufferers who sometimes, understandably, can feel very low in spirits. To have someone reassure them that they will improve one day makes such a difference.

The symptoms can worsen very suddenly. If this should happen, the person will need to lie down immediately in a quiet, darkened room and rest.

In its severe form, some ME sufferers may not always be able to speak, or move.

Because of the severity of the condition in some people, it is very important to act quickly in response to any requests. Keeping the temperature stable, and supplying food and drink is not only essential for comfort, but the ME body can very quickly go into shock if these issues are not addressed promptly.

Living with severe ME is very, very difficult. Treating people with respect and dignity helps greatly to ease their suffering. Just imagine how you would feel stuck in bed each day, never knowing if you'll ever get better.

Information and help about dealing with people severely affected by ME is available from the

**25% Group:** Tel: 01292 318611. Website: [www.25megroup.org](http://www.25megroup.org)

### **How you can help - as a friend:**

Accept the fact that your friend with ME has a real organic illness. They are not making it up nor is it 'all in their mind'

Accept the fact that your friend with ME is not always able to see you or speak to you. This is not because they don't want to – they would dearly love to have a 'normal' social life – but because they can't.

ME is a fluctuating illness and people with ME often cannot tell how they will feel from hour to hour, day to day or week to week and, therefore, they cannot plan in advance. If they do make a date and time to meet you, they may have to cancel at short notice.

*People with ME would like to tell you - they understand that you, as a friend, may get fed up with this state of affairs but hope that you will be patient with them. They are doing their best to get better!*

If you are not able to see or speak to your friend for some time perhaps you could send a note or a letter. You don't have to dwell on their illness – just say you are thinking of them. A short chatty cheerful letter about what you've been doing will probably be very welcome. People with ME like to know there is something out there worth getting better for!