

How can supporters help?

Chronic fatigue syndrome or ME (CFS/ME) is a condition that not only affects the person who has it, but also their family, friends and colleagues. If someone you know has CFS/ME, there may be times when you feel a bit overwhelmed and uncertain as to the best way to offer support. This leaflet sets out some suggestions of ways you can help your relative or friend.

Your role

Family, friends and colleagues can be very important in helping people with CFS/ME. It is easy to fall into a pattern of seeing the person with CFS/ME as a “patient and feeling like a carer and losing your previous role as friend/colleague/ relative/lover.

Sometimes supporters feel a burden of responsibility, wanting to take on the activities which they feel might be beyond the capability of the person concerned. For example, the person might be keen to do some gardening or go for a walk but you dissuade them from doing this because *you* are anxious they will over-do it. It might be more helpful to suggest that they pace new or extra activity and take regular breaks.

Whilst at the Barts CFS/ME service your relative or friend will be learning how to manage their adjustment to the illness, working towards recovery and developing skills to manage their symptoms better. Part of this involves pacing or activity management, which means that they will be taking frequent or planned rest periods and developing a stable and realistic baseline of activity, rather than a cycle of over and under-activity. It is important to allow people with CFS/ME to make their own decisions and take responsibility for the activities they can and cannot manage and support them in this process. If you do too much and become over-responsible you may make people feel helpless and it may be difficult for them to get back to these tasks and maintain responsibility for themselves. If you do too little, they may feel uncared for, misunderstood or isolated. It can be hard to know if you are doing too much or too little and what the best way to give support may be!

Encouragement

Sometimes people with CFS/ME may lack confidence or feel anxious when tackling activities. It may not seem worth the effort to go for a short walk because of the fear that it may make the symptoms worse or because it seems too small a task. It may also be difficult to concentrate on a book or TV programme when one has symptoms. It will help a lot if you notice the things your friend or relative is doing and offer praise and encouragement. A small comment such as “well done” can be very encouraging, try and notice and recognise even small achievements. Having symptoms can often mean that the focus of conversation can be on limiting aspects of illness and it may be hard to notice positive changes.

How are you today?

While talking about symptoms shows that you are concerned, it is important that your relationship and conversations reflect your other interests and concerns. Questions like “How are you?” are automatic greetings in our society and they can be hard to avoid but can focus attention on difficulties. Asking “How did doing such and such go?” or “Did you see X today?” may open up different conversations. It may also help to focus on areas of common interest, it can get tiring for both of you to talk about illness too much!

Enjoying yourself

We can often prioritise tasks or chores which strike us as being more important and neglect having fun and doing pleasurable things. People with CFS/ME it is often even more difficult to set aside time for leisure and pleasure. As a relative or friend it may be easier for you to suggest and encourage pampering and enjoyment. These are usually morale-boosting and it may be easier for someone with CFS/ME to prioritise and set time aside for pleasurable activities if you help them to realise that it is important for you as well.

Still the same old person I was

The friend or family member with CFS may seem to be different now from how you remember them. The process of adjusting to the changes whilst they are ill, will be difficult not just for them, but for you too. It is important to remember that these changes need not deprive them of opportunities to have a valued role in the family, take responsibility for their own decisions, take on new challenges and activities and still get pleasure out of life. You can remind them of this and your support may be very important in helping them to make and maintain positive changes whilst they are getting better.

How do YOU feel?

Sometimes it is easy to forget how difficult it can be for relatives and friends of someone with CFS/ME. You may experience a range of emotions- sadness, worry, fear, frustration or anger at some point. It is normal for relatives and friends to feel this way when someone is unwell, particularly when there is uncertainty and unpredictability about the condition. People with CFS/ME may also experience changes in their mood. This is likely to affect you as well and what you feel able to do. For example, if you feel frustrated at their limitations you might try to make up for this by pushing them a bit or doing extra tasks for them. Sometimes it can be helpful to talk together about how you are feeling and what is helpful and unhelpful for you both. It is important to make time for yourself and not be too hard on yourself when you feel that you should be doing more. Getting support for yourself is an important part of giving support to others.

HELPFUL THINGS YOU CAN DO WHEN GIVING AND GETTING SUPPORT

- ❖ actively listen, check out you are both on the same page
- ❖ be encouraging and recognise achievements of all shapes and sizes
- ❖ check out your assumptions – ask questions
- ❖ be understanding and patient
- ❖ share experiences, have fun together
- ❖ problem solving and decision making together
- ❖ hold on to positives – being hopeful when other person is feeling low
- ❖ acknowledge achievements/progress as they are made some more
- ❖ remind people of past achievements and progress – how far they've come
- ❖ be accepting
- ❖ make suggestions (rather than ordering or telling off)
- ❖ respect others decisions, even if you don't agree with them.
- ❖ looking at how many ways you are able to give support
 - practical assistance with tasks eg. shopping, cooking
 - physical affection – hugs, massage
 - advice (when asked for)
 - listening
 - having fun and good times
 - giving person space to be on their own.
- ❖ asking what the other person wants/needs at the time...there are so many different ways to offer support – there is only one way to find out which one is most needed/wanted at the time...ask!
- ❖ be specific about what you need or want or are able to offer (people can't read your mind no matter how much they love you) ...
- ❖ support yourself- take time out, take care of yourself!