

Information for Partners, friends and relatives

‘To equip people affected by CFS / ME with the skills for self-management towards a better quality of life’.



Pride in our older people's and adult community services

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What does a diagnosis of CFS/ME mean for your partner, relative or friend?



Being given a diagnosis of Chronic Fatigue Syndrome/ME (CFS/ME) can mean very different things to different people. For some it can be a relief to at last have a name for all the changes that have been happening in your body. The importance of feeling believed that there is something physically wrong cannot be underestimated. To others being given a diagnosis of CFS/ME can lead to a range of fears and uncertainties including why they are ill, what can be done about it, what this condition means for their future and where they might turn to for help.

What is clear, however, is that most patients with CFS/ME share a similar experience in coming to a diagnosis of CFS/ME. They have made numerous visits to their GP's, have possibly been sent to see many hospital specialists and endured multiple tests and examinations. They often have stories to tell of the way they have not been believed or understood.

“It's not like having a broken leg. People can't see how unwell you feel. “

They think it doesn't really exist”.

“The doctor wanted to put it all down to stress. He made me feel like he thought I was making it up, like it was all in my head”.

Even when patients are given a diagnosis for their symptoms, the uncertainty can continue. As yet, researchers looking into CFS/ME can only make best guesses at what causes it and why some people suffer more than others. Encouragingly though more research is now being done into this condition and we remain hopeful that this will eventually provide more answers into this complex condition. What we do know is that people can recover from CFS/ME, and learn to manage their symptoms in a way that leads to a rewarding and meaningful life.

Symptoms and Feelings

Your partner, relative or friend might experience any or many of the following symptoms:

- Unexplained, continuous or worsening fatigue for no apparent reason; e.g. too much work or exercise, lack of sleep etc.
- Physical or mental fatigue that is not alleviated by rest.
- Unable to do as many things at work, school, socially and at home as they used to.
- Problems with concentration, memory, and/or word finding difficulties.
- Sore throat.
- Swollen glands in the neck or under arms.
- Generalised muscle pain/tenderness.
- Pain in several joints.
- Increased sensitivity to light and sound.
- Headaches.
- Waking up feeling as tired as when they went to bed.
- Feeling tired for more than a day after undertaking physical or mental activity.

Some common feelings associated with CFS /ME are:

- Despair
- Frustration and Guilt
- Sadness
- Isolation
- Hopelessness
- A fluctuation between the above emotions

CFS/ME can express itself in many different ways. No two people are likely to share identical symptoms and they will have their own particular view on which symptoms are the most difficult to manage. Symptoms may also vary over time. It is very common to see a pattern of symptoms improving and then worsening again over days, weeks or even months. Not being able to predict how well or unwell one might be at any given time can be particularly difficult to bear.

You may hear some of these statements:

“I am always worried about letting people down. I can’t agree to do anything because I don’t know if I’ll be well enough”

Or,

“When I feel a little better, I have to do as much as I can, pack it all in as I know it is only a matter of time before I become unwell again.”

These types of thoughts can also perpetuate boom/bust ‘activity cycling’ which can further deplete energy. Activity cycling is explained below.

What is the activity cycle?

Often people with CFS/ME describe having varying amounts of energy from one day to another or even within the same day. A lack of control of this energy may be experienced with an inability to decide whether or not to attempt an activity. This lack of energy may lead people to attempt to do too much on a better day. A period of increased fatigue and feelings of frustration and despair often follow this. This is referred to as the boom and bust approach or activity cycle:

Treatment Approaches:

Your family member/friend will be offered appointments to see an occupational therapist to look at self management strategies, for which the main approaches are:

Initially Stabilising and grading activity - this means balancing activity so that the day is divided into periods of rest and activity. It will help with managing the day better and gives the person more control of how much they do.

Rest and relaxation- Considering a balance of activity and short periods of rest, with the use of relaxation techniques (meaningful to the person) being part of an important foundation to reduce ‘boom and bust’ patterns.

Establishing a baseline – this is a realistic level of activity that the person can maintain on a daily basis and gradually build upon.

Graded Exercise Therapy – this is a prescribed programme of Activity/exercise that is realistic in terms of the person's energy levels. It helps to improve stamina & tolerance to activity.

Cognitive Behavioural Therapy – this looks at how a person's thoughts, feelings, behaviours & physical state interact & provides coping strategies to help deal with related difficulties.

Teaching of techniques to help improve pain, memory, concentration, sleep and diet.

Talking openly about feelings

The type of emotional reaction a person may have to CFS/ME is as varied as the personalities of the people diagnosed. There is no right or wrong way to react. What we can say is that for many there will be a deep sense of sadness, possibly even grief, at the many losses being unwell for a long time can bring. Feeling low in mood or anxiously worrying about the future can be very normal reactions to have. People with CFS do not always express their feelings very readily. Here are some of the many reasons patients we have seen have given for this:

“If I talk about being upset, anxious or low, everyone immediately assumes it's a problem in my head and not in my body”

“My husband already has to put up with so much because of this condition; I can't let him know how low I feel as well”

“People don't want to hear about all my moans and groans, so I just tell them I'm fine when really I'm not”

We might agree that it isn't good for a person with CFS/ME to talk endlessly and exclusively about their negative feelings, and certainly it isn't good for the person at home who hears this. In our experience, however, patients often come to find that direct and open expression of thoughts and feelings can help to get the feelings out where they might be better managed, this can deepen others understanding of their condition and can even reassure their loved ones that they are able to speak up when things get really bad. This might mean that you, as the relative, can spend less time, energy and anxiety trying to second guess how well or otherwise your relative is coping in themselves.

Being open about the experience of this condition and the many ways it can affect many might be a first step towards your relative being able to clearly tell you what they do, and don't, need from you. Many relatives have said that it is very important to them to know what to do to help and when, and being able to give themselves some time off duty when told that nothing is needed.

For a small number the emotional reaction to being physically unwell can become so intense it becomes a significant problem in its own right. If you think this might be happening to your relative it is important that you encourage them to seek help through their GP.

CFS/ME affects you too!

CFS/ME does not only affect the person with it. You have probably found that your life with your partner/relative/friend has changed enormously since they have become unwell. Whilst you might not share the physical symptoms in common, many partners/relatives report high levels of worry and upset at the changes the condition has brought to both their relatives and their own lives. CFS/ME can affect many areas of your shared life such as:

- Being able to do things together that you used to enjoy together
- Seeing friends and joining in with a social life
- Changes to your intimate physical relationship

- Balancing roles and obligations in the family – earning money, looking after children, household chores, etc
- Financial pressures

Helping your partner/relative manage their condition

Most partners/relatives underestimate just how much their support and care is appreciated. The first thing you should do is to recognise all the ways you bring physical help, emotional support and understanding to your relative already. It is also very important that you save enough time and energy to look after yourself. A partner/relative, who is run down, exhausted, and stressed can be of little help and needs to teach the patient to look after themselves by example. Although patients often find it difficult to say, for fear of sounding ungrateful, the last thing they need is the added burden of worrying that you are going to make yourself sick! They say they appreciate help when it is asked for and appreciate the space to get on with managing their condition for themselves when it is not.

You may find that your role as a main support can become overwhelming. It may be helpful for you to seek advice from your GP or check for local support services for carers.

For the patient embarking on any treatment for CFS can be a daunting experience. It requires motivation, commitment and concentration, a great deal of effort and a belief that things can improve. As the relative/friend you can help by being familiar with the advice being given, offering encouragement and support, offering help to get back on track when things go wrong and encouraging perseverance. It may be useful for you to familiarise yourself with the self help booklet given at assessment or to read the group session information they bring home each week.

Questions you might want to ask and discuss openly:

- What sense have you and they made of what the diagnosis means?
- What thoughts do you and they have about why they have become unwell?
- What do you and they think the future holds for you both?

- How do they feel in themselves? How do you feel?
- Do they feel able to share their feelings and what might stop them?
- Do they know what they can do to best manage their condition?
- How can you help them in this?
- Are there things they would like you to do more of, and things they might like you to do less often?
- Is it always easy to talk openly about the way CFS/ME affects you both?
What stops you?

Providing Practical Help

- ✓ Encourage the person to stick to their routine and their established activity baseline (in line with the advice being given by our service).
- ✓ Encourage them to stick to their Graded Exercise Therapy programme.
- ✓ Consider negotiating a win/win around topics such as daily tasks, social activities, home environment and responsibilities.
- ✓ You can help a person with memory problems by:
- ✓ Simplifying the information you give by reducing the amount of information that is given at once.
- ✓ Repeating or paraphrasing information that is given and encouraging the person to write things down.

Above all it is important that the person with CFS/ME learns to manage the condition themselves, try to allow them to do what they can for themselves, offer support and encouragement as they learn, as it can take time for the strategies being taught to take effect.

On bad days a hug and an encouraging statement can go along way! Adjustment and acceptance of the condition can take time and we all go at different paces depending on our personal circumstances.

The Peterborough & Cambridgeshire CFS/ME service can support partners/relatives as well with advice if needed, but it is important to mention that confidentiality

regarding the patient will not be broken unless prior agreement with the patient is sought.

Adult CFS / ME Service

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Leaflet published: May 2019
Leaflet review date: May 2020

Patient Advice and Liaison Service

For information about CPFT services or to raise an issue, contact the Patient Advice and Liaison Service (PALS) on Freephone 0800 376 0775, or e-mail pals@cpft.nhs.uk

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Please call **NHS 111** for health advice and support.

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