

Friends and family

The heart of the matter

We all need loving relationships. CFS/ME can change your relationships with yourself, your family, your friends and your partner. It can also affect finding a partner. The fear of CFS/ME getting worse can sometimes be more damaging than the condition itself and people around you may not be able to cope with this. They may distance themselves from you, or even leave. But there are many examples of people with CFS/ME who have found that when one relationship has ended, a better one has come along in its place. CFS/ME may change your views on what you look for in a partner; and deeper qualities may become more important than superficial ones. CFS/ME can deepen the bond between a couple as long as there is love, intimacy, communication and caring. With these, any sexual difficulties can be dealt with more openly; without them, a relationship may not survive. When one of you has CFS/ME, you may need to deal with important issues about roles, dependence and independence.

Having children

Having CFS/ME should not prevent you from having children. CFS/ME has no effect on fertility in men or women. Effective treatments are available for men who have problems getting erections. Pregnancy, delivery and breastfeeding can be normal, though drug treatments may need adjustment. Mothers tend to feel better during pregnancy, and it is thought this may be related to a decrease in immune system activity. However, after birth, there is a likelihood of a return to the previous level of illness you had before becoming pregnant. In general, mothers who have CFS/ME are no more disabled than other women with CFS/ME. But babies and young children can be very tiring, and you may need people to help so that you do not get too fatigued.

Support from other people

At some point you may need to ask for help, whether practical or emotional, from friends and family. It may not be easy for you to admit to needing help, and it may not always be obvious to others that you do need it. Try to be clear with yourself and other people about what you can and can't manage alone.

Working with CFS/ME

Lots of people with CFS/ME work in all kinds of jobs. Some still work full-time decades after CFS/ME is diagnosed, while others work part-time or from home.

Your choice

What hours you work, how long you continue working, and what kind of job you do depend on how CFS/ME affects you and how much fatigue you experience. If you have a job with long or rigid hours, or a lot of travelling or legwork, or if it requires strength or manual dexterity, you may have to think about changing it or re-training. Work can give you a sense of identity, status, achievement and personal satisfaction, as well as money. It is also a good way of meeting people. However, for some people with CFS/ME, work can be stressful and it is a relief to give it up or change jobs. Support and information on working are available from us, both for people with CFS/ME and for their employers.

Giving others a hand

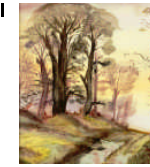
Many people find a great sense of fulfilment in voluntary work. There are many places where your talents could make a difference. It can also be a good way of getting out and meeting people. Looking after yourself, taking time to take care of yourself will help you make the most of life.

Help and support.

Group Contacts:

*Leger ME (01302) 787353 10 DN5 8QN
www.leger.me.uk*

Please note that this leaflet is intended to supplement the care provided by your doctor or health advisor.



Leger-ME:

*Supporting Myalgic Encephalopathy or Encephalomyelitis (ME),
Chronic Fatigue Syndrome (CFS),
Post Viral Fatigue Syndrome (PVFS),
Fibromyalgia Syndrome (FMS), Patients & Carers*

Adjusting to Life with Chronic Fatigue Syndrome (CFS/ME)

Making the most of life with CFS/ME

Having CFS/ME means living with uncertainty and adapting to changing situations. But you can still make the most of life. With a positive attitude, you can have a good quality of life no matter how CFS/ME is affecting you. Relationships, work, family and social life can still go on. You can be realistic without being pessimistic. You may need time to think through the impact of CFS/ME upon your life. You may have to make decisions about how you live, now and in the future. You may want to make choices about what you need from relationships, what kind of work you do, and how you spend your time, energy and money. You may need to reflect on changes in your self-image or to take a more flexible view of roles in relationships or at work.

Reacting to CFS/ME

Everyone reacts in different ways, but acknowledging how you feel and learning to accept changes will help you cope. It is common to feel shock, fear, grief and anger when you are told you have CFS/ME - shock at finding you have an incurable illness; fear of what might happen to you; grief at the potential loss of some physical abilities; anger because there is no cure. Family and friends can go through the same kinds of feelings as well.

Denying that you have CFS/ME is a common and understandable defence mechanism, particularly if your symptoms of CFS/ME are mild. These reactions can lead to sadness and depression accompanied by disturbed sleep patterns and changes in appetite. You may have feelings of helplessness or hopelessness due to decreased self-esteem, stress, loss of self-confidence, fear of rejection, and changes in self-image, life plans and goals. Not everyone reacts like this, but if you do, you may need the help of a counsellor, psychologist or psycho-therapist. You may also want to talk to other people with CFS/ME. You can learn how to cope with difficult feelings and start to see the light at the end of the tunnel.

Approaching things positively

Changing the way you think, accepting CFS/ME, accepting yourself and having close relationships with other people are probably the most important ways of getting the most out of life. Without these ingredients you run the risk of becoming angry, depressed, resentful, withdrawn and bitter.

Looking after yourself

Dealing with stress

Stress may make CFS/ME symptoms worse. While you may be able to avoid some stressful situations, there are others you cannot. The very fact of having CFS/ME is stressful unless you can come to accept it. It is a good idea to find ways of recognising and coping with stress. You may have to make changes in your work or relationships, cut back on financial commitments, or make practical changes to your lifestyle. Counselling, listening to music, exercising, taking up new hobbies, relaxation techniques like yoga, meditation and massage - even just keeping a sense of humour - can all help.

Listening to your body

Overdoing things can make CFS/ME symptoms worse and may trigger a relapse. Be careful not to push yourself too far, and learn to recognise when your body is telling you to rest. Doing too little, however, may make you feel depressed or lethargic. Regular, appropriate exercise is important, however CFS/ME affects you.

Recharging your batteries

Sleep has wonderful restorative powers, and lack of sleep can make CFS/ME worse. Remember the importance of rest when planning your work and social life. People with CFS/ME may need to sleep late in the morning, take a nap during the day, and go to bed early. If you have trouble sleeping at night, think about whether you need to adjust your routine, and talk to your GP or CFS/ME nurse if insomnia persists. Relaxation techniques may help, while specially designed beds are available to help with postural problems. If you feel drained of energy, rest can help recharge your batteries. Rest means doing absolutely nothing. Listen to your body if it tells you that you need to rest.

Keep active

Sensible activity, without overdoing it, can improve, rather than drain, your energy. Regular and frequent activity helps to maintain muscle tone and increases fitness, strength and stamina. It lifts your mood and releases tension so you can relax and sleep better.

Avoiding heat and humidity

With CFS/ME, you can be more sensitive to heat and humidity. You can cope with this by installing air conditioning, using fans, eating ice cubes and taking tepid baths and showers. You may also have to choose carefully where and when you go on holiday.

Eating and drinking

You need to maintain your strength by eating nutritious food. You may feel weak if you skip meals or eat only junk food. It is important to drink enough to avoid dehydration; if you reduce fluids so that you go to the toilet less often, you have an increased risk of getting bladder or kidney infections.

Having a social life

There is no reason why, with CFS/ME, you cannot still enjoy your social life, although it will be influenced by your levels of energy and your network of friends. It is important not to fall into the trap of isolating yourself just because you have CFS/ME.

Enjoying life

You may have CFS/ME, but you can still take up new challenges to keep life fun and stimulating. Quality of life and physical disability are not necessarily connected. Life can be satisfying regardless of your physical abilities. Making the most of life depends on your outlook and on knowing that help and support are there if you need them.

Coming to terms with CFS/ME

Acceptance

Accepting CFS/ME can be a challenge and you may need to take it in stages. The first step is accepting that you have CFS/ME. If symptoms of CFS/ME are obvious, you will need to decide when to tell other people. You may also need to make changes to your lifestyle or environment.

Feeling good about yourself

Living with CFS/ME can affect how you see yourself and how you relate to other people. If you cannot do things you once took for granted, you may find your self-image or sense of worth is affected. However, life does not have to stop if you have CFS/ME. You can help yourself by finding ways of retaining a sense of perspective. Things which may help you in accepting CFS/ME and in making the most of your life could include:

- living in the present rather than worrying about the future or hankering after the past;
- making the most of each day and enjoying each moment
- finding ways of reaching a calmer state of mind - meditation or yoga can be helpful;
- seeing life with CFS/ME as a new beginning, not just the end of something that was better.

Tips for feeling better about yourself

- Be good to yourself and don't criticise yourself.
- Appreciate the things that make you unique.
- Build on close relationships and friendships.
- Use connections with family, friends and the community to give you a sense of belonging.
- See people you want to see.
- Find things that give meaning and positive direction to your life.
- Only take on things you can finish.
- Identify goals you can achieve, and make progress in small steps.
- Plan enjoyable things to do.
- Always have something to look forward to.
- Think of yourself as succeeding, not failing.
- Praise yourself and others.
- Do things which enhance other people's regard and respect for you.
- Take time to take care of yourself.
- Keep your sense of humour alive.