

## Frequently Asked Questions about CFS/ME

### **Q. What causes CFS/ME?**

A. The exact cause of CFS/ME is unknown. However, extensive research has shown there are areas that are fairly consistent for most individuals and that the onset of CFS/ME is usually associated with a viral illness (such as glandular fever), significant life stresses or emotional events and other illness or a combination of them all. For example, having glandular fever means you are much more likely to get CFS/ME without appropriate early management.

### **Q. Are the symptoms 'all in my head'?**

A. No. CFS/ME symptoms are real physical symptoms. Many people come to this question as a result of failing to find a concise explanation as to why they continue to experience symptoms associated with CFS/ME or from feeling disbelieved.

CFS/ME symptoms may be exacerbated by unhelpful patterns of boom-bust activity or by stress. In some cases it might not be clear why the symptoms have continued for so long but that does not mean it is 'all in the mind'. We do know that the symptoms associated with CFS/ME present a complex interaction of physical, psychological, social and emotional factors and a greater understanding of such factors and how they work to maintain the difficulties is helpful for recovery.

### **Q. Should I take Anti-Depressants?**

A. It is always difficult to give specific advice about medication without knowing the details of particular difficulties and you should discuss this with your doctor. Some anti-depressants have been found to be helpful in cases of CFS/ME, e.g. amitriptyline for regulating sleep and reducing pain. However, there is little evidence that other anti-depressants, e.g. Prozac, are helpful in cases of CFS/ME unless there is also a diagnosis of depression. However, a presentation of CFS/ME as well as Depression is quite common due to the effects of the illness and symptoms.

**Q. How can I improve my concentration or memory?**

A. Firstly consider the task that you have set yourself and think about how exhausting and/or demanding it will be to achieve. Think about breaking tasks into smaller components and gradually increasing the amount of time spent on the activity. Begin by doing easier tasks that require less concentration and then build up the time spent on an activity and the complexity of tasks as your concentration level improves. Remember to keep a check on how you are coping and recognise achievements. Concentration will improve with time if approached in a gradual structured way. (Also see the Memory and CFS/ME handout).

**Q. How do I deal with a setback?**

A. Setbacks are a normal but difficult part of having CFS/ME. Symptoms fluctuate over time and you will have times when fatigue and other symptoms worsen. If you experience a marked increase in symptoms it is important to:

- Keep calm.
- Use relaxation.
- Increase rest as appropriate.
- Try to continue with low level activities.
- Consider ways to ensure that activities are manageable eg breaking into small tasks.
- Re-schedule demanding activities to another day.
- Review the balance in your day, in terms of:
  - o Activity and rest/ relaxation.
  - o Needs (those activities you need to do)
  - o Wants (those you enjoy and give you pleasure).

Consider possible reasons for the setback e.g. over activity/ new illness or injury/ other concerns. Are there any strategies you could use to resolve these? (Also see the 'Managing a Setback' handout).

**Q. What should I do when I have a cold or flu?**

A. People with CFS/ME will still experience other injuries and illnesses with the rest of the population. Many people find that colds may temporarily exacerbate their CFS/ME symptoms. Usual cold or flu management is advised such as taking care of yourself, increasing rest for a few days, lower your activity level to what is comfortable for you, drink plenty of fluids and keep warm. TLC is important too!

**Q. I think my fatigue is getting worse. What should I do?**

A. As discussed above setbacks are part of the experience of CFS/ME. It is important to discuss and review changes in your symptoms with your doctor or therapist. See the plan for managing setbacks as well as considering the following.

- Have you made any recent changes in your activity levels?
- If so, were they made too quickly/ did you increase your activity levels too much?
- What happened this week/ within the past 48 hours?
- Review the balance to your day - are you changing activities frequently, and incorporating periods of relaxation/ rest to ensure that you do not overdo things?
- Are there other factors that may be increasing your symptoms eg. A cold, stress or anxiety, increased demands. Acknowledging, problem solving and getting support for these other difficulties is also important.

**Q. Does exercise harm me?**

A. Graded and well monitored exercise has been shown to be beneficial to individuals with CFS/ME. Research has shown that a guided, gradual and incremental exercise programme can help individuals who suffer from CFS/ME aka GET (Graded Exercise Therapy). It works by helping you to gradually adapt to physical activities that you have been unable to do since becoming unwell. GET's starting point is your own current level of ability and helps you to work towards your own physical goals and objectives. GET programmes can be developed to improve your overall strength, fitness and movement to allow you to do this. (See GET Guide to download).

If you undertake a sudden and noticeable increase in your activity or exercise levels this will likely result in a temporary increase in symptoms or a setback. Whilst distressing, it does not mean that you have damaged yourself or harmed your muscles and can be managed like other setbacks. Exercise and activity should be increased in a gradual manner and discussed with your therapist.

**Q. How will I know when I am better?**

A. Before asking this question it is good to work out what 'better' means to you. Sometimes people find that after they have improved their routine and found ways to manage their CFS/ME symptoms better that they start to feel "normal". Full recovery for different people means

different things and some patients look back on the very busy lives that they were living before they became unwell and decide that they would not wish to return to that level again. Our priorities change throughout life and having an illness often means that people look at their lives in a different way.