fom
Faculty of Occupational Medicine

NHS
Plus

Occupational aspects of the management of chronic fatigue syndrome/myalgic encephalomyelitis: evidence-based guidance for employees

Introduction

Chronic fatigue syndrome (CFS)/Myalgic encephalomyelitis (ME) can have a dramatic effect on your life. Because of your symptoms, it is hard to think about how you can manage at work or even if you should return to work. Although there are still many uncertainties about the management of CFS/ME this leaflet provides a guide to some of the things that can help you get back to work and gives advice about working while recovering from CFS/ME. The recommendations are based on current research.*

What is CFS/ME?

CFS/ME is an illness characterised by disabling post- exertional fatigue (tiredness) and other symptoms, which may include poor concentration, sleep disturbance, headaches, and musculoskeletal pain. These symptoms need to have been present for at least six months for a firm diagnosis to be made although a presumptive diagnosis may be made much earlier.

* *Occupational aspects of the management of chronic fatigue syndrome: a national guideline.* NHS Plus. London 2006.

CFS/ME affects approximately four per thousand of the population. Although it can occur at any age, the onset is more common in people in their 20s, 30s or 40s and the illness affects women more than men.

As with other chronic illnesses, some people with CFS/ME go on to suffer from depression or anxiety. Where these occur they should also be treated. Most people who develop CFS/ME are previously healthy individuals with no significant medical or psychiatric history.

A feeling of being ‘tired all the time’ is very common. Fatigue that persists for several months or more is often referred to as ‘chronic fatigue’. It can have many different causes and should not be automatically labelled as CFS/ME.

Will people with CFS/ME get better?

Published research into CFS/ME suggests that, while few sufferers recover fully, some improve enough to return to some form of work. Around 40% of individuals improve to some degree over time. Unfortunately, some sufferers deteriorate and become severely affected.

Prompt delivery of appropriate management strategies may increase the likelihood of recovery and a return to work.

Should I be at work with my symptoms?

If you are still working it is a good idea to try to stay at work – provided you are able to cope with the hours and tasks involved and this does not aggravate your symptoms. You should discuss how you feel with your general practitioner or occupational health adviser and follow their advice.

When we have time off from work, it is easier to lose our 'work hardiness'. It becomes more of an effort to work and work becomes more fatiguing; this in turn makes it even more of an effort to work, and so on. However, an adequate period of rest and convalescence following an illness is often needed for recovery to take place. Where you are able to continue to work or are returning after time off, your occupational health professional may be able to help you organise a reduction in hours or workload with your employer. You can also discuss how to build up your work over a period of time.

I would like to get back to work but I am worried that I will not cope with the workload

It can feel daunting to go back to work, especially when you think of the workload you had before your illness. If you start with reduced hours, you are more likely to manage to build up your fitness. It is important for you to talk to your employer and plan how you are going to manage this. Ideally, your employer will speak not only to you but also to your occupational health professional (who will be able to communicate with your doctor or specialist) and human resources.

You can then start planning your return. You will need to have clear targets so that you know what you are aiming for in terms of both your workload and your hours, even though you may have to adjust these targets as time goes on. Doing 'all or nothing' should be avoided. But you need to be clear about how you will avoid peaks and troughs in work demands and at what intervals you will take breaks. Your manager also needs to know so that not too much or too little is expected of you.

What else could be considered in planning my return to work?

Managing your illness and planning for a return to work needs considerable thought. The National Institute for Clinical Excellence (NICE) has published a Guideline for the diagnosis and management of CFS/ME which include directions to Health Professionals. The Guideline requires that the choice of management strategy should be based on a thorough assessment of patient preferences and needs; their skills, abilities and goals for managing their condition; the severity of their symptoms and their physical and cognitive functioning. Patients retain the right to refuse any component of a management programme and can withdraw at any time.

The therapy options described below form part of the management strategy to facilitate return to work:

- Cognitive behavioural therapy (CBT) has been shown to be helpful for some individuals but not for all. CBT is a structured form of psychotherapy. The duration of treatment with CBT varies between individuals and is generally undertaken over a period of six to 12 months. CBT is used to assist people to cope with the emotional impact of a variety of illnesses, including cancer.

- Graded exercise therapy (GET) also appears to be helpful for some individuals but must be approached with caution, especially where you are moderately or severely affected by post exertional fatigue. GET is, in theory, a carefully structured programme designed to gradually increase aerobic activity. It is a more planned intervention than simple advice to exercise more. If undertaken, it must be supervised by health professionals with experience in GET and ideally on a one to one basis.
- Pacing is a treatment in which individuals gradually increase their physical and mental activity without exceeding their limitations. People with CFS/ME report finding pacing very helpful but, there is only very limited published research to show how effective this is. Pacing is being studied in the UK and the results are due in 2009.
- If you feel that work contributed in developing your fatigue, this issue needs to be addressed. It is important that you communicate your needs as an employee to your employer. This

can feel difficult, especially if you have had problems with your boss or a colleague. Occupational health and human resources can help you tackle these issues.

Other advice on returning to work:

- You may need to start by building up your work or work-related skills at home.
- You may need to start with very reduced hours and gradually increase them.
- You may need to start with a much reduced workload and gradually build it up.
- You will need to ensure that you have regular breaks.
- You will need regular reviews with your occupational health professional, who can help you assess your progress and targets.
- It is generally helpful to try to have a healthy lifestyle. Your doctor or specialist will encourage you to have a good diet and adequate rest and to gradually build up your activity.
- It will help if your family and friends also continue to encourage and

support you so that you do not feel you are doing this on your own.

What problems can I expect?

It is not unusual to have relapses, even with the most carefully planned return to work. You will probably find that recovery from CFS/ME is not an even process and you may have 'bad' days or weeks, which can feel very discouraging.

When you live with an illness day to day, it is often difficult to see progress over time. So if you have a bad day, it is sometimes helpful to think back to what you were like a month, three months or six months ago. You may be surprised at what you have achieved and how far you have come. The fluctuating nature of the illness is widely acknowledged but, depending on the stage and severity of the illness, some degree of improvement is the norm. You should never underestimate what you can achieve and how much you have done to get this far.

Income Protection Schemes

You may have an Insurance Company operated "Permanent Health Insurance" (PHI) policy (also now called Income Protection Schemes) These usually commence after a prolonged period of absence from work – often three months or more.

HELP FROM THE DWP AND OTHER GOVERNMENT AGENCIES

You can do a limited amount of certain types of voluntary unpaid work and 'permitted' paid work whilst claiming incapacity benefit. This can be a useful way of testing your ability to return to work. If you are planning to return to part-time work, check with the DWP as to how this will affect your benefit status. There are various forms of practical and financial support available to people who return to work after a period of ill health. A disability employment adviser at your local Job Centre Plus can go through these options.

Could I take ill-health retirement?

This is not a first choice. It is always better to consider some of the management options first. Research shows that most people feel better about themselves if they can work.

CBT and GET may increase the likelihood of some people with CFS/ME returning to work. While these management strategies are not be suitable for everyone, you should consider them and discuss them with your doctor before considering ill-health retirement.

The Disability Discrimination Act 1995
This Act gives you certain rights as an employee where an illness is likely to last for 12 months or more. This Act requires your employer to make reasonable adaptations to your work in accordance with your disability.

NHS
Plus

recycle
When you have finished
with this please recycle it

50% recycled
This is printed on
50% recycled paper

287954 1p 0.5k May 08 (BAB)
Produced by COI for the Department of Health
www.nhsplus.nhs.uk
www.facoccmed.ac.uk