Using a DVD to help people with chronic fatigue syndrome learn the technique of pacing

A DVD and booklet were developed to help people with chronic fatigue syndrome to achieve a balance between rest and activity through pacing.

**INTRODUCTION**

The Shropshire Enablement Team at Telford and Wrekin PCT is a specialist community rehabilitation service for people with head injuries, stroke, progressive neurological conditions or chronic fatigue syndrome (CFS)/myalgic encephalomyelitis or encephalopathy (ME). The team has been working with people with CFS/ME since 2005 and clients are taught the principles of pacing both within CFS/ME management groups and on a one to one basis.

**CFS/ME**

CFS/ME is a long term and relatively common condition that causes substantial ill health and disability in people of all ages. It is thought to affect approximately 240,000 people in the UK (Devanur and Kerr, 2006). Women are more susceptible than men, with many studies showing that 75% or more of patients are female. The most common age of onset is 29-35 years (Prins et al, 2006).

Fukuda et al’s (1994) definition of CFS/ME is most commonly used in clinical diagnosis and research, and patients must meet specific criteria for diagnosis. The severity of the condition varies, but it leaves many people unable to work or attend school – many are housebound or even confined to bed for long periods.

The causes of CFS/ME are not fully understood but are thought to be multifactorial (Prins et al, 2006). Factors that may trigger the condition include a range of infections, exposure to toxins or vaccinations, and emotional stress (Devanur and Kerr, 2006).

There also appear to be predisposing factors such as gender and genetics, with twin studies showing a higher incidence in certain families (Prins et al, 2006). CFS/ME is classified as a neurological disorder by the World Health Organization (Shepherd, 2006).

**PACING**

Pacing is helpful in managing a variety of conditions, such as fatigue in MS, and in pain management. The technique allows patients to take control of their condition, manage it better and improve quality of life.

When used to treat CFS/ME, pacing involves achieving the correct balance between rest and activity, and establishing a daily routine which can be carried out on both good and bad days. The keys to pacing, particularly with CFS/ME, are:

- Knowing when to stop and rest;
- Taking a flexible approach;
- Staying within one’s own limits.

The technique is suitable for people with mild, moderate or severe forms of the condition. Many people with CFS/ME get caught in a vicious circle of “boom and bust”. They do too much on good days, which results in a subsequent increase in symptoms that means they need a period of prolonged rest. If this pattern continues, many people find the amount they can do on a good day decreases progressively. The aim of pacing is to break this pattern, enable clients to stay within their energy limits and never totally exhaust themselves.

When learning to pace, clients are encouraged to keep a daily diary recording their activities, timings and fatigue levels. This allows them to reflect on their daily routine, and gain an understanding of their energy patterns. They are also asked to break daily activities into high, medium and low energy demand. These will be different for
each individual. Clients are also encouraged to recognize that emotional situations can be extremely draining and to be aware of this when planning their day.

To pace effectively, a baseline of activity needs to be set; this is a comfortable level of activity that can be managed on both good and bad days without causing an increase in symptoms. Activities also need to be prioritized—jobs that must be done, such as washing and dressing, can be given high importance, while non-essential tasks can be left or delegated. It is also important to plan some enjoyment in the day.

Clients are then asked to plan a whole week, taking care to do about the same amount of activity each day. Planning ahead is an essential part of pacing. Once clients are comfortable with their daily routine and have established a baseline that they can maintain, they can begin to increase their activity, although this must be done gradually. Once they gain more control over their condition, they can begin to set targets, such as to be able to walk to a nearby shop once a day. These targets can then be worked towards and slowly incorporated into their weekly plan.

AN INFORMATION RESOURCE

Advising people about pacing has always been part of the team’s approach, but it was clear that although pacing is simple in theory, it is challenging to put into practice. We decided to create a resource which both educated and motivated clients to apply pacing in their daily lives. The resource was intended both for local use, supported by our service, and for use by teams nationwide. It can also be used as a self-help tool by people with CFS/ME and their families.

The DVD SETting the Pace was made in association with the Rural Media Company, using special project money from the local PCT. It explains the concept of pacing through the experiences of seven people with CFS/ME of varying severity. Men and women from late teens to middle age talk about their daily lives, experiences and how pacing has helped them gain more control over their condition.

For example, one client said: “Pacing helps me to set myself targets for the day, making sure that I’m not wearing myself out… I pace myself with my tasks, carrying out activities, resting then doing another activity, but making sure that I give myself enough time to relax and to recharge afterwards so that the next day isn’t jeopardised.”

The booklet accompanying the DVD is a step by step guide to pacing, with charts, diagrams and quotes from the seven participants. For example, one talked about how she saves energy: “I have a downstairs cupboard with an airing cupboard which contains my clothes, underwear, socks, towels etc so that once I’ve had my shower in the morning I haven’t got to go back upstairs to get dressed.” There are also tasks for readers to complete. Both the DVD and booklet are divided into sections, including keeping a diary, setting priorities, planning a week, increasing activity, tips for saving energy and family and relationships.

USE IN PRACTICE

Occupational therapists in the team use the booklet/DVD in several ways. It is given to clients at the end of CFS/ME courses and is played within groups to promote discussion and introduce the concept of pacing. It is also sometimes given to clients who have attended the clinic and say their main problem is pacing.

Most client feedback has been positive and they feel it helps them better understand the principles of pacing. An occupational therapist in Birmingham reports that clients like the fact it gives them different perspectives on how people feel and cope with the condition. Some also report it has given them hope they can manage their condition more effectively.

SETting the Pace has been reviewed by several national ME associations and the Specialist Section – Neurological Practice produced by the College of Occupational Therapists (tinyurl.com/specialist-section). Thompson (2009), a retired GP and patient with CFS/ME, wrote for the ME Essential: “This DVD and booklet is a welcome addition to the understanding of pacing. There is a lot of controversy between the value of GET (graded exercise therapy) and pacing but most people who have experience of both would strongly recommend pacing as the way towards recovery or, at least, remission of ME… I especially liked the quotes from participating patients that give an idea of the variety of interests and hobbies they take part in and how they alter their involvement to fit with their energy reserves.”

West (2009) wrote for InterAction, the Action for ME magazine: “Overall I found the booklet well set out and very easy to read, providing me with a better understanding of the pacing process. The DVD showed how I can put the techniques into practice in a way suitable to my energy levels.”

CONCLUSION

Experience so far with the DVD and booklet suggests they are easy to use and enable patients with CFS/ME to gain more control over their condition by living life in a more paced fashion. We would welcome approaches from other services who would like to know more about this new resource.

Clips of the DVD are on the Rural Media Company website at www.ruralmedia.co.uk

REFERENCES


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