MANAGEMENT FILE

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MEA membership costs £18 a year for people living in the UK/BFPO.
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COGNITIVE BEHAVIOURAL THERAPY

WHAT IS COGNITIVE BEHAVIOUR THERAPY (CBT)?

CBT is a psychological ('talking') treatment that is mainly used to treat a wide range of mental health conditions. So it is normally administered in a mental health setting.

CBT is also sometimes used as part of the management of physical illnesses where it aims to improve quality of life and day-to-day functioning.

The basic aim of CBT is to challenge 'faulty' thoughts, beliefs and behaviours relating to an illness. So it comes in two parts.

Cognitive therapy is designed to challenge, modify or remove what are regarded as unhelpful or negative thoughts and beliefs about an illness.

Behaviour therapy is designed to change the way you behave in response to these unhelpful thoughts.

The underlying theory behind CBT is that unhelpful thoughts and behaviour patterns play a significant or major role in a number of mental health problems where it may be the only or primary form of treatment. Hence its use in conditions such as anxiety, depression, obsessive-compulsive behaviour, panic attacks, and phobias.

In the management of physical illnesses, CBT can be used where coping strategies or psychological distress are hampering recovery.

In this situation, CBT is not claimed to treat the underlying disease process.

It can also be used to address specific problems or symptoms. For example, there 's been a trial that examined how CBT might be used to help people with multiple sclerosis deal with fatigue – which can be one of the most disabling features of this neurological condition.

The therapist will therefore seek to identify what are regarded as unhelpful thoughts and beliefs and demonstrate how these can be replaced with more positive and helpful thoughts and behaviour.

CBT concentrates on the 'here and now' in your life – what you think and do – rather than delving into events, conflicts and difficulties dating back to childhood, or the time before you became ill.

CBT can be used by itself or in combination with drugs such as antidepressants. The decision is made on the severity and nature of symptoms being treated.

WHY DOES CBT CAUSE SO MUCH CONTROVERSY?

CBT has always been regarded as a very controversial form of treatment in relation to ME/CFS – mainly because it is often recommended as an effective treatment on the basis that this illness is essentially maintained by unhelpful thoughts and behaviours rather than any form of underlying physical disease process.

However, the way in which CBT is put into practice in relation to ME/CFS varies considerably.

Where it is delivered in a mental health setting, the therapist may well concentrate on the unhelpful thoughts and behaviour model on the basis that there is no significant 'disease' present. In this case someone with ME/CFS may, not surprisingly, find the idea unacceptable or objectionable.

But CBT is also delivered in non-mental health settings by other types of health professionals .

In these cases, CBT may be far more orientated towards practical coping strategies in relation to activity and symptoms such as pain and sleep disturbance.

In this case, CBT is being used on the basis that the underlying problem in ME/CFS is a physical illness, and is therefore likely to be far more acceptable to someone with ME/CFS.

WHAT IS THE EVIDENCE IN SUPPORT OF CBT?

The Chief Medical Officer's report into ME/CFS noted that the views of patients and clinicians had to be given just as much consideration as the results from clinical trials that have assessed the value of CBT.

- Several randomised controlled clinical trials have shown that CBT can sometimes be of help to some people with ME/CFS.

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However, in other trials, CBT has produced little or no significant benefit – *see box.*

- In patient feedback to the CMO report only 7% of people found CBT to be "helpful"; 67% reported "no change"; and 26% said it made their condition "worse".
- Clinicians who provided feedback to the CMO report had mixed views on the value of CBT.

WHAT DOES THE NICE GUIDELINE ON ME/CFS RECOMMEND?

The NICE guideline recommends that everyone with mild to moderate ME/CFS should be offered a course of CBT.

The guideline makes no such recommendation for the more severely affected group or for children and adolescents – mainly because there is little or no research evidence from clinical trials in these groups of people to support its use.

The NICE guideline emphasises the fact that psychological treatments such as CBT must be carried out through a process of mutual agreement between patient and therapist. There should never be any form of coercion to take part in CBT – especially in relation to benefit entitlement.

The NICE guideline also states that approaches such as CBT and graded exercise should only be administered by health professionals who have developed the necessary expertise in dealing with ME/CFS.

HOW IS CBT DELIVERED?

CBT isn't a one-off treatment.

In the case of ME/CFS, an initial assessment has to be made. If it is decided that a course of CBT would be appropriate, patient and therapist will then meet for a series of roughly hourly sessions either weekly or fortnightly. A course of CBT will normally last for 12 to 16 sessions.

You will be asked to monitor your progress week by week and probably keep a diary to record what you do and how you feel. The diary will be reviewed at each appointment.

CBT can also be delivered in group sessions or via the telephone.

WHAT HAPPENS IN PRACTICE?

As already noted, there is a spectrum of approaches regarding the way CBT is put into practice. So, if you are going to be referred for a course of CBT, it is important to discuss with your referring doctor, and the therapist involved, what sort of approach is going to be taken and what you are going to be asked to do.

A course of CBT should involve you and the therapist agreeing on a number of changes or targets/goals relating to how you manage various aspects of your illness. These will cover a wide range of physical and mental activities.

The physical activity component may well include a graded exercise programme – another controversial approach to the management of ME/CFS – or it may be based on an approach which is much closer to pacing your activities.

Particular attention is likely to focus on symptoms such as pain and sleep disturbance – where they occur – and how you currently cope with them.

And where problems such as anxiety, depression, mood disturbance, perfectionism or stress co-exist with ME/CFS, these will form another key part of the treatment programme.

As well as what happens during the actual appointments with the therapist, you will be given some 'homework' to do on your own in between appointments.

WHAT IS THE REFERRAL PROCESS?

Although CBT is sometimes delivered in a general practice setting, there is no evidence that this is effective in the case of ME/CFS. So, if you want to try CBT, this will normally involve asking your GP to refer you to a hospital-based service where a therapist with the necessary experience in ME/CFS will be available.

Outside specialist referral centres for ME/CFS, it is often very difficult to find therapists with the necessary expertise. And you may have to join a very long waiting list to receive CBT in some parts of the country.

Various health professionals – psychologists, psychiatrists and cognitive therapists – work in the private sector. Charges vary considerably and you will need to find out whether the therapist has any experience of dealing with people who have ME/CFS.

There is a British Association for Behavioural and Cognitive Therapists. Their website is at www.babcp.org.uk

WHAT IS THE MEA's POSITION ON CBT?

The MEA does not accept the conclusion that ME/CFS is largely or wholly maintained by unhelpful beliefs and behaviours. Consequently, we would not endorse any form of behaviour treatment that is purely based on this idea.

We do, however, accept that a psychological approach that accepts the presence of an underlying physical illness, and so aims to improve practical coping strategies relating to physical and mental health, can sometimes be helpful – provided it is carried out with mutual agreement of the therapist and patient.

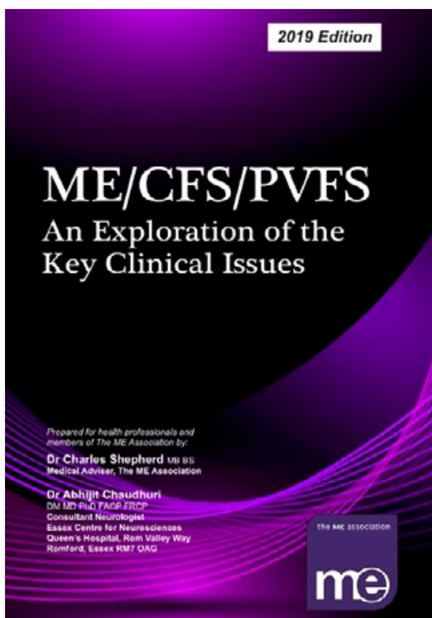
FURTHER INFORMATION ON CBT

- A more detailed description of CBT can be found on pages 242 - 245 of my book *Living with ME.*
- A summary for doctors, including clinical trials involving

CBT, can be found in section 7:6 of *ME/CFS/PVFS: an exploration of the key clinical issues.*

- Section 4.4.2.2 in the Chief Medical Officer's report covers CBT – the report can be downloaded from the MEA website at www.meassociation.org.uk/wp-content/uploads/

Medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your own doctor. The ME Association recommends that you always consult your own doctor or healthcare professional about any specific problems. We also recommend that any of the medical information provided by The MEA in this leaflet is, where approproiate, shown to and discussed with your doctor.



Our clinical and research guide. Available only from The ME Association or online here:
https://tinyurl.com/y6uddnwm
Price £9

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