



Appropriate use of cognitive behavioural therapy (CBT)

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Introduction

The 2021 NICE guideline for ME/CFS advises health professionals as follows (section 1.12.28):

"Discuss cognitive behavioural therapy (CBT) with adults, children and young people with ME/CFS (and their parents or carers, as appropriate). Explain:

- its principles, including that it may help them manage their symptoms, but it is not curative and
- any potential benefits and risks.

"The [NICE guideline] committee wanted to highlight that cognitive behavioural therapy (CBT) has sometimes been assumed to be a cure for ME/CFS. However, it should only be offered to support people who live with ME/CFS to manage their symptoms, improve their functioning and reduce the distress associated with having a chronic illness."

What is CBT?

CBT is a talking therapy.

The NICE guideline for ME/CFS advises (section 1.12.31) it "should only be delivered by a healthcare professional with appropriate training and experience in CBT for ME/CFS, and under the clinical supervision of someone with expertise in CBT for ME/CFS."

CBT for people with ME should, the NICE guideline says, aim "to improve their quality of life, including functioning, and reduce the distress associated with having a chronic illness; and does not assume people have 'abnormal' illness beliefs and behaviours as an underlying cause of their ME/CFS, but recognises that thoughts, feelings, behaviours and physiology interact with each other."

Instead of CBT, some disease experts recommend that patients manage their activities to stay within their "energy envelope" to prevent crashes and possible long-term worsening from post-exertional malaise (i.e. pacing).

This is the symptom management approach that the majority of people with ME consistently tell us offers them the most benefit.

Why did NICE change its recommendation on CBT?

In its comprehensive evidence review for the updated October 2021 guideline, the NICE guideline committee reports (page 376):

“The committee considered the clinical and cost effectiveness evidence alongside the qualitative evidence on the positive and negative experiences of CBT. The committee reflected that most of the clinical evidence showed no clinical difference but there was some benefit of CBT. They acknowledged there was some, but not consistent, evidence of benefit across the studies for general symptom scales, fatigue, physical functioning, exercise performance, return to work and adverse events when comparing CBT to usual care [...]

“The committee were familiar with many of the themes that emerged from the qualitative evidence. The committee noted the criticisms reported in the qualitative studies of CBT being used as a ‘treatment’ for ME/CFS and felt it important to highlight that CBT is not a curative intervention, but that it is one type of supportive psychological therapy which aims to improve wellbeing and quality of life and may be useful in supporting people who live with ME/CFS to manage their symptoms and cope with having a chronic illness.”

The PACE trial

The results of a large-scale study published in 2011, of adaptive pacing therapy, graded exercise therapy (GET) and CBT, called the PACE trial, found that some people with mild or moderate ME experienced a small degree of improvement after undertaking CBT and GET, and no significant improvement after adaptive pacing therapy.

However, the PACE trial was based on a flawed hypothesis that ME “was largely being maintained by abnormal illness beliefs and behaviours, along with inactivity and deconditioning” (Shepherd, 2017).

Repeated questions have been raised about the methodology of this trial, and the reliability of its results, including potential harm caused by GET.

If you decide you want to try CBT

The NICE guideline for ME advises the following about what CBT for people with ME should look like (sections 1.12.33 and 1.12.34):

"Explain what CBT involves so people know what to expect. Tell them that it:

- takes a non-judgemental, supportive approach to the person's experience of their symptoms and the challenges these present
- is a collaborative, structured, time-limited intervention that focuses on the difficulties people are having at that time
- involves working closely with their therapist to establish strategies to work towards goals and priorities that they have chosen themselves
- takes into account how symptoms are individual to each person, can fluctuate in severity and may change over time.

"CBT for people with ME/CFS should include the following components:

- developing a shared understanding with the person about the main difficulties and challenges they face
- exploring the personal meaning of their symptoms and illness, and how this might relate to how they manage their symptoms
- developing a self-management plan
- working together to adapt and refine self-management strategies to improve the person's functioning and quality of life, for example their sleep, activity and rest
- reviewing their plan regularly to see if their self-management strategies need to be adapted, for example if their symptoms or functioning change developing a therapy blueprint collaboratively with their therapist at the end of therapy."

No symptom-management approach should involve pushing you harder than you feel able or willing to manage, and you should always raise any concerns you have with the professional who is supporting you (see below).

A specialist therapist offering CBT for ME will use a number of cognitive strategies which aim to help you understand thoughts and beliefs that you have about ME and the way it affects you.

Because everyone's manageable level of activity is different, it's essential that any CBT therapist understands the limitations imposed by ME, and that many people with ME are unable to progress towards agreed goals, however carefully and gradually they try.

Other types of talking therapy

Counselling, including CBT, may also be offered through a service that's not specifically for people with ME, such as the Improving Access to Psychological Therapies (IAPT), as a way of coping with anxiety and depression.

Some people with ME experience anxiety, low mood, or depression.

It may be that you are experiencing one of these mental health issues as a result of living with ME, so it may be helpful to consider counselling support.

From April 2018, all clinical commissioning groups in England are required to offer IAPT services integrated with physical healthcare pathways.

In theory, this should mean that your GP should offer you the option of counselling, including CBT, if you are struggling with anxiety, depression or other mental health issue, alongside strategies that help you manage your physical symptoms (e.g. medication for pain and/or sleep).

However, we have heard reports that some people with ME are being offered CBT through the IAPT service, based on the incorrect premise that ME is what doctors call a Medically Unexplained Condition (MUS), i.e. one with a psychiatric basis.

ME is not MUS and categorising it as such contradicts the World Health Organisation's International Classification of Diseases, which states that ME is a neurological condition.

The NICE guideline also makes it clear that specialist services for ME are likely to be needed by a significant number of people with the condition; it is likely that the approach offered by MUS services would be inappropriate in many cases.

We would welcome your feedback on any experiences with the IAPT programme; please do [get in touch](#).

Programmes of support can vary considerably between services in what they offer and how they are structured.

This includes how much individual attention you receive from a physiotherapist or OT to assess your particular baseline.

You should ask as many questions as you need to in order to understand what approach will be used and what this will involve, before making a decision.

Please remember that it's your decision, and yours alone, which symptom-management approach you try, and which you don't.

You should never be pressured into trying an approach you feel strongly against or be dismissed for wanting to try something that you believe might be of value to you.

You have the right to refuse or withdraw from any treatment, approach or care plan without this affecting other aspects of your care, or future choices about care.



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