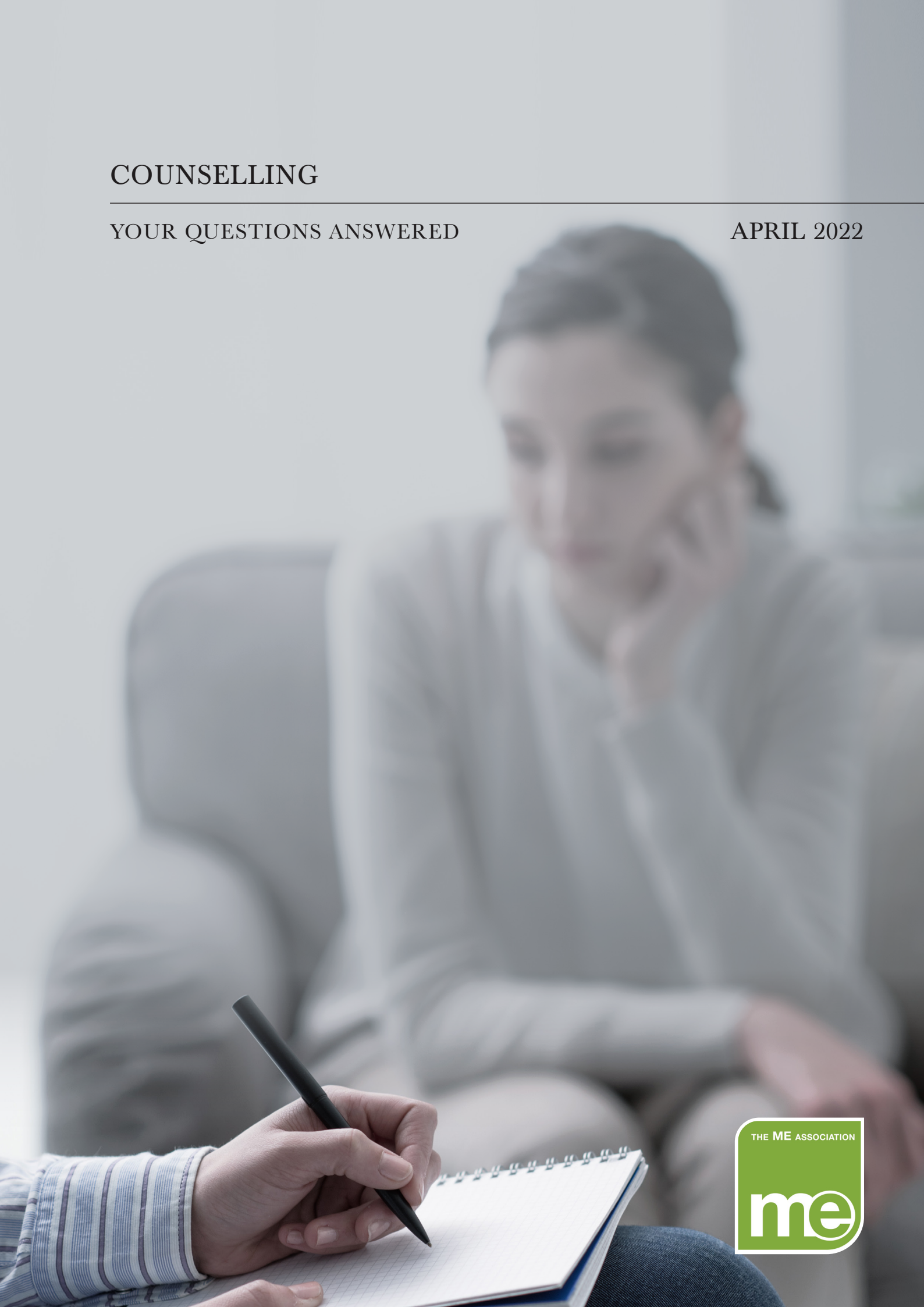


COUNSELLING

YOUR QUESTIONS ANSWERED

APRIL 2022



COUNSELLING: YOUR QUESTIONS ANSWERED

INTRODUCTION

We all need support from time to time. ME/CFS can be a very difficult condition to try and manage alone.

While some of us can find it from family or friends, there will be times when independent support will be something you might want to consider.

Speaking to a professional who can help with the emotional impact of ME/CFS is nothing to be ashamed of and can be essential when it comes to improving mental health and wellbeing.

While we regard ME/CFS as being a physical condition, caused and perpetuated by an underlying disease process, learning how to cope with any understandable mental anguish, will help to make daily life that bit easier.

Professional counselling and therapy can help you deal with specific worries or concerns and teach you how to accept, adapt, and to reach an accommodation with ME/CFS and the life you have now.

WHAT IS COUNSELLING AND HOW COULD IT HELP YOU?

Counselling is defined as a talking therapy that involves a qualified therapist (counsellor, psychotherapist, or, psychologist) listening to you and helping you to find ways of dealing with the emotional aspects of your illness.

A qualified therapist will not tell you what to do or give you advice; they will listen and help you come to terms with your illness and the loss of the life you previously enjoyed.

They will help you focus on your life now, and work with you to deal with any anxieties, fears, hopelessness and uncertainties you might have.

Talking to a therapist can be exhausting, especially when discussing emotions, but it can be very worthwhile.

You need to consider the likely effect each session might have and discuss the option of having shorter sessions or of taking a break during sessions if you need one.

It might be more convenient to arrange telephone or video consultations if these are available, rather than having to travel and meet your therapist in person each time, particularly if you are restricted to your home or going through a bad patch.



Counselling: Your Questions Answered was written by Dr Lisa Dvorjetz, Advisory Psychologist to the ME Association.

Dr Lisa Dvorjetz is an accredited counselling psychologist with both the British Psychological Society and the Health and Care Professions Council.

Lisa is currently working within the NHS and private practice with people who have long-term health conditions.

We know her well. She has been volunteering as an ME Connect helpline supervisor since 2013.

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COUNSELLING: YOUR QUESTIONS ANSWERED

BOOKING A SESSION WITH A THERAPIST

It is important that you feel comfortable with your therapist, psychotherapist, or psychologist and it may take a while to find one you feel is suitable. If you obtain a referral via your GP to an NHS counsellor or psychologist you will most likely need to take what is on offer.

You might be able to speak to the therapist in advance to assess compatibility, especially if you can afford to go private.

Try to keep an open mind, especially with the first couple of sessions, but if you don't get on with the therapist then ask your GP to see someone else.

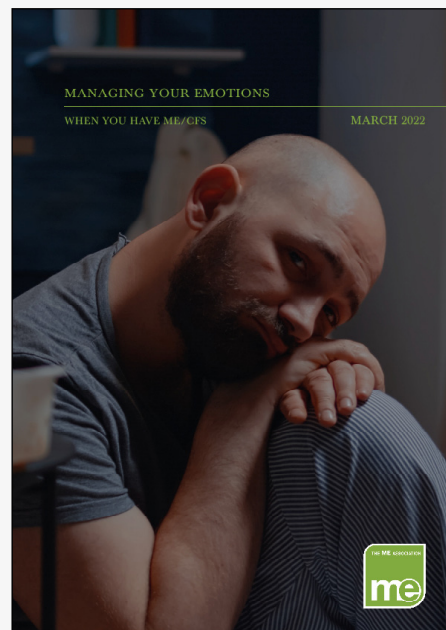
Covid Pandemic

Largely because of the Covid pandemic, many therapy services are now available and some are offering telephone consultations. If you are unable to attend an appointment in person, because you are house- or bed-bound or worried about Covid transmission, then be sure to let your GP know and you may still be able to get a virtual appointment.

However, the pandemic has also meant there is a bigger demand for such services, so waiting lists might mean your appointment is delayed. If you feel your need is urgent then please ensure your GP is aware and you might get an appointment sooner.

WHAT QUESTIONS SHOULD I ASK BEFORE STARTING THERAPY?

- Ask about their qualifications and whether they are registered with the British Association for Counselling and Psychotherapy (BACP), UK Council for Psychotherapy (UKCP), or British Psychological Society (BPS).
- If you are having private therapy ask what the cost for each session will be.
- Ask about the type of counselling on offer, the number of sessions you will receive, and what they will involve.
- Ask if you can have a preliminary session to assess how you get on with the chosen therapist. Then, if you agree to proceed, your therapist may want to establish a 'contract'. Here you would both agree on the focus of the sessions, length of each session and, perhaps, the number of sessions you will have. And, if you have chosen to go private, then the fee and your method of payment.



The MEA has produced two helpful leaflets, **Managing Your Emotions, and Anxiety & Panic Attacks**. They can be found on our website here:

Managing Your Emotions:
<https://tinyurl.com/z7zs48>

Anxiety & Panic Attacks:
<https://tinyurl.com/3vrrf4j>



COUNSELLING: YOUR QUESTIONS ANSWERED

■ If you have obtained a referral to an NHS ME/CFS specialist service then hopefully the therapist or psychologist you see will have a better understanding of the illness. Whether you have a therapist who has knowledge or experience with ME/CFS, they will want to hear about your personal experience living with the condition.

If you need additional information about ME/CFS to share with your therapist, then the ME Association has a large range of literature available in the website shop, including a section on Mental Health:

<https://tinyurl.com/hcteh4zj>

WHERE CAN I FIND A COUNSELLOR OR SOMEONE WHO WILL LISTEN?

1. NHS Primary & Secondary Care

Ask your GP: For most people this will be their first port of call. GPs should provide ongoing care and support to people with ME/CFS and be capable of following the recommendations in the 2021 NICE clinical guideline.

The NICE clinical guideline provides detailed recommendations to the NHS and social care services and is a recommended read for all patients, families and carers.

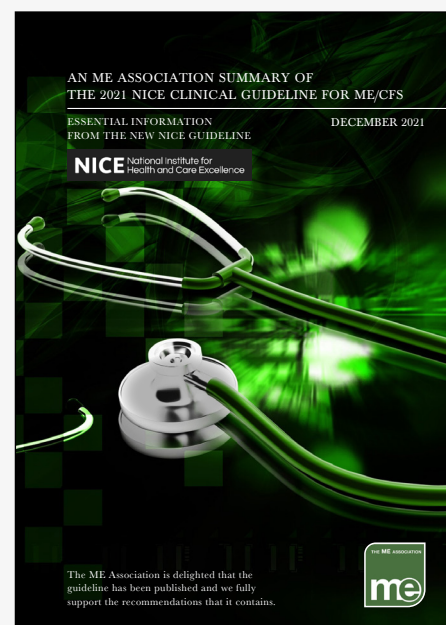
You and your GP can determine if a referral to an NHS counsellor or an ME/CFS specialist service is required, or if there is more your GP can do to support your needs.

Should you decide on a referral, it might be preferable if one is made to a local ME/CFS specialist service that includes a clinical psychologist who will have the necessary experience and a professional interest in helping people with the condition.

Everyone with ME/CFS is entitled to a referral to a specialist service even if one is not available in your area. Often the service will provide a fixed number of outpatient appointments that are aimed at confirming a diagnosis, helping you learn how to best manage your condition, and providing help with mental health.

More information about ME/CFS specialist services and the help they can offer can be found in the NICE guideline, or you can visit the service's website (see page 5).

A clinical psychologist can help with the emotional or mental health issues that often occur as a result of ME/CFS and will work to improve your wellbeing. Counselling or therapy will be



The ME Association has produced a free booklet summarising the NICE clinical guideline that can be downloaded from the website shop:

<https://meassociation.org.uk/ek50>



COUNSELLING: YOUR QUESTIONS ANSWERED

provided over a number of sessions that might be delivered face-to-face or remotely via video or telephone. If you are unable to access the service in person, it might also be possible to arrange home visits.

You can find out if there is an ME/CFS specialist service in your area, and what they currently offer, by visiting the MEA website and entering your postcode:

<https://meassociation.org.uk/nhs-me-cfs-specialist-services/>

2. Private counselling services

■ **British Association of Counselling and Psychotherapy (BACP):**

<https://tinyurl.com/bh6ncdux>

■ **The UKCP Counselling Directory:** Enter your postcode for a therapist near you, click on What's worrying you and then scroll down to find CFS/ME: <http://www.counselling-directory.org.uk>

■ Look on the **UK Council for Psychotherapy** website for a therapist in your area: <https://www.psychotherapy.org.uk/>

■ It is also possible that both the **BACP** and the **Counselling Directory** will have details of counsellors who will work with you by telephone or online.

3. Telephone helplines

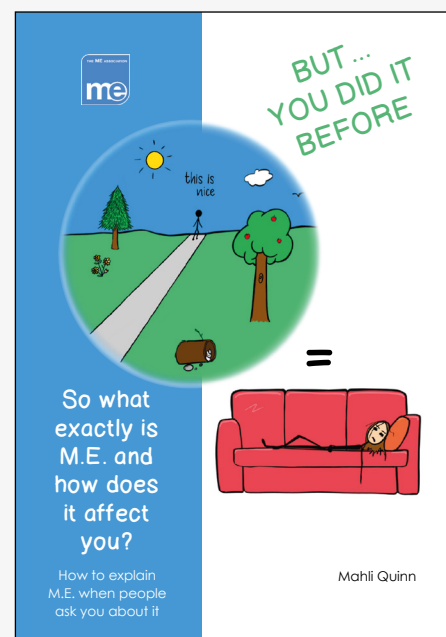
Telephone helplines are not a replacement for one-to-one counselling, but can provide an essential service if you need to talk to someone who is trained to listen without judgement or pressure.

ME Connect is the MEA's telephone helpline. If you need to talk to someone about any aspect of life with ME/CFS, please give us a call: 0800 538 5200 We are available 365 days a year.

<https://meassociation.org.uk/about-the-mea/telephone-helpline/>

The Samaritans are available day or night, for anyone who's struggling to cope, who needs someone to listen. Whatever you're going through, you can call them at any time, from any phone for FREE: 116 123.

<https://www.samaritans.org/>



MEA Information and Support

We have a large range of literature available to download from the website shop, including a section about the understandable effect of ME/CFS on Mental Health:

<https://meassociation.org.uk/me-association-shop>

■ **But... You Did It Before**, by Mahli Quinn, provides a great explanation of the impact of ME/CFS. It is available to order from the website shop:

<https://tinyurl.com/uvhv2af3>

■ If you need to talk to someone please contact the **ME Connect** telephone helpline on **0800 538 5200**

Lines are open 365 days a year.

COUNSELLING: YOUR QUESTIONS ANSWERED

CONFIDENTIALITY

Accredited counsellors/therapists work within a code of confidentiality. This means that what is talked about within sessions stays between the two of you.

There are one or two exceptions to this – for example, if the therapist perceives that you or another person may be 'at risk'. In this case confidentiality stretches to a wider 'team' including your GP and the counsellor's manager or supervisor in order to keep you safe.

You can ask your therapist about confidentiality; for example, you could ask whom it remains between and when/if this would be broken.

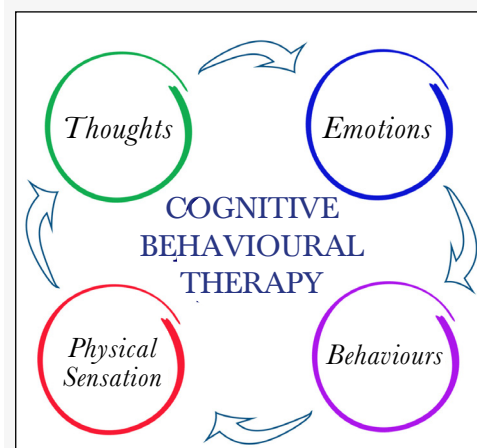
HOW TO GET THE MOST OUT OF YOUR THERAPY SESSIONS

Before you attend your appointment, you may want to take some time to write a list of the key things you want to discuss. Consider what you want to get out of these sessions and why you feel you need them. Taking time to prepare will mean the sessions are more focused and relevant.

For example:

- I need help coping with the mental burden of this condition and learn better ways to reduce my mental anxiety,
- I need help in dealing with my family and friends who don't understand,
- My attempts at managing and living with ME/CFS are failing and I need help,
- I have lost so much and am having to live with so little, I don't know where to turn,
- I am feeling isolated and alone and worry I am not strong enough to continue this struggle with ME/CFS,
- I am having trouble with my relationship.

When you begin your therapy sessions, new issues or concerns might reveal themselves. Raise them with your therapist, so that they can be added to your counselling/therapy 'agenda' and discussed in future sessions.



THE NEW NICE
GUIDELINE IS MORE
CONDUCTIVE TO THE
VIEW THAT CBT
CAN HELP PEOPLE
COPE WITH THE
UNDERSTANDABLE
EMOTIONAL IMPACT
OF HAVING ME/CFS

COUNSELLING: YOUR QUESTIONS ANSWERED

What happens if I have some counselling/therapy sessions and STILL don't feel any better?

Some people are uncertain about what to expect from therapy and are puzzled at first if they don't feel any better.

Be open and honest with your therapist and tell them if the therapist is not helping. Bear in mind, however, that exploring your emotions for the first time can, for some people, make things feel worse before they get better and if you can get past the initial sessions, counselling will be helpful.

Counselling/therapy will not 'fix' you. It isn't a magic bullet, but it can provide a safe and independent space to talk through your problems which in itself might be enough to provide some measure of relief.

It can also provide helpful tools that enable you to put things into perspective, better manage unhelpful emotions, and any other issues you have; such as learning to accept a change in circumstances and to adapt to a new way of life as a result of ME/CFS.

WHAT ARE THE MAIN APPROACHES, METHODS AND TECHNIQUES?

There are a great many counselling methods and techniques; you can find an A-Z list on the British Association of Counselling and Psychotherapy website:

<https://www.bacp.co.uk/about-therapy/types-of-therapy/>

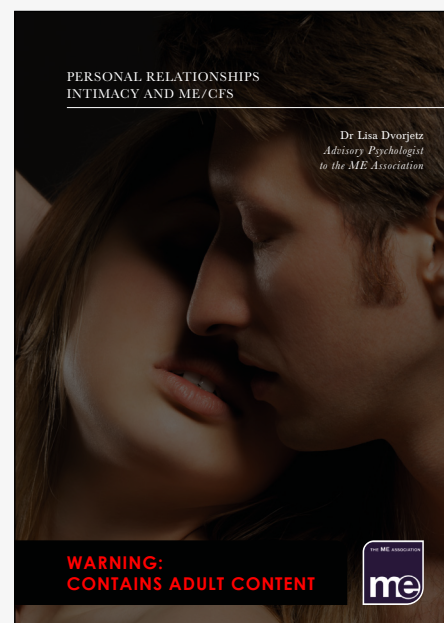
We can't suggest a specific counselling method as the kind of counselling you decide to have needs to be right for you.

You may like to have a chat with a therapist about the method he or she will use before you commit to your sessions. In this leaflet we briefly describe three of the main approaches used.

1: Person-Centred Counselling

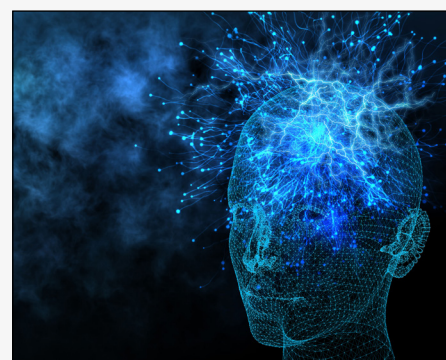
The aim of person-centred counselling is to help people understand themselves better in order to make changes and grow. Here the therapist will empathetically reflect back to you what they have heard.

They may challenge what you say – for example, they might point out inconsistencies or communicate things back to you in such a way that leads you to question why you are having certain thoughts and feelings.



If you have ME/CFS and are experiencing problems with a relationship, then you might like to read the MEA's booklet: **Personal Relationships - Intimacy and ME/CFS**. It can be downloaded from the website shop:

<https://tinyurl.com/faxbfxcx>



COUNSELLING: YOUR QUESTIONS ANSWERED

With person-centered counselling, the therapists do not offer solutions or advice. But talking through the various issues you have can help to clear your mind and can also help you to find your own way forward.

Many people with ME/CFS have said that it is helpful to have someone to talk to who seems to genuinely appreciate what they are going through.

2: Cognitive Behavioural Therapy (CBT)

CBT basically involves both a cognitive approach (looking at our thoughts) and a behavioural approach (the things we do).

It explores the way we think, the way we behave, how we feel and how our bodies respond. It is a practical therapy with an emphasis on skills and techniques which can be used outside of the sessions.

The aim is to improve your quality of life and day-to-day functioning through monitoring activity levels and noting whether the way you think about bad situations is making you feel worse.

Although some people have found CBT helpful, others have found it quite hard work. It is important to ask what the CBT will involve and to explain what your own energy levels are.

The ME Association has had serious reservations about certain types of CBT where it was assumed that abnormal illness beliefs and behaviours were perpetuating the condition, and where CBT was believed to be curative.

Patient survey evidence has strongly endorsed the kind of CBT that supports a person with ME/CFS in helping them cope with what can be a devastating disability.

The NICE Clinical Guideline for ME/CFS (2021)

The new NICE guideline, which provides a framework of recommendations to the NHS and social care services, is more conducive to the view that CBT can help people cope with the understandable emotional impact of having ME/CFS.

Most multidisciplinary ME/CFS specialist services will have a psychologist available who can provide emotional support and CBT as required.



“Working with my integrative therapist was one of the best decisions I ever made – without that work I may not have made it back to university. She helped me to get to know my own limits, etc. and to reduce the frequency and severity of flare-ups.”

COMMUNITY COMMENT
ME ASSOCIATION'S FACEBOOK



COUNSELLING: YOUR QUESTIONS ANSWERED

NICE Guideline Extracts:

"The [guideline] committee wanted to highlight that 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."

1.12.29 Only offer CBT to adults, children and young people with ME/CFS if, after discussing it (see recommendation 1.12.28), they would like to use it to support them in managing their symptoms.

1.12.32 Explain that CBT for people with ME/CFS:

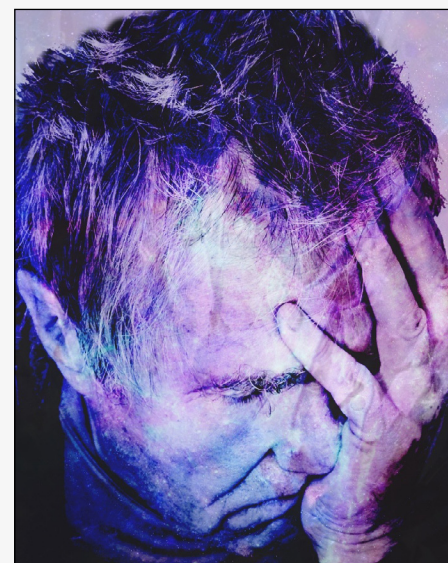
- aims to improve their quality of life, including functioning, and reduce the distress associated with having a chronic illness
- does not assume people have 'abnormal' illness beliefs and behaviours as an underlying cause of their ME/CFS, but recognises that thoughts, feelings, behaviours and physiology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

1.12.33 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.

1.12.34 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



"It can really help to phone and speak to a counsellor first to see if you feel he or she is someone you can work with."

COMMUNITY COMMENT
ME ASSOCIATION'S FACEBOOK



COUNSELLING: YOUR QUESTIONS ANSWERED

- developing a therapy blueprint collaboratively with their therapist at the end of therapy.
- The ME Association has produced a free booklet summarising the guideline that can be downloaded from the website shop: <https://meassociation.org.uk/ek50>

3: Mindfulness

The aim of Mindfulness is a focus on the 'here and now' –being aware of thoughts, feelings and sensations as they happen, moment by moment without judgement.

It can help us to take a step back from our thought patterns and see them as just thoughts. Mindfulness suggests that seeing the present moment clearly can help to positively change the way people view their lives, their emotions and any anxieties they may have.

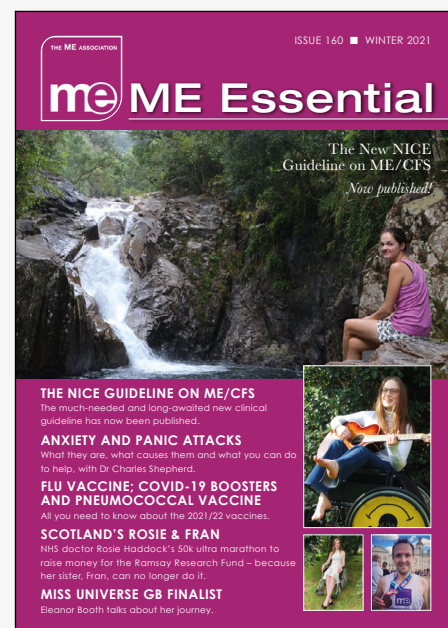
This can help to reduce the distress that many people experience when they think about upsetting things or have uncomfortable physical feelings; learning to accept what is happening rather than fighting it and becoming less frightened of thoughts and feelings. With time and practice, mindfulness suggests that we can learn to notice when our minds wander and then bring our focus back to the present moment.

CAN COUNSELLING OR THERAPY REALLY HELP?

You do not need to have a mental health condition to see a therapist. But it is understandable that with a condition like ME/CFS there will be times when you find it hard to cope and when depression might be a concern.

Counselling can help you to 'step back' and look at how you are coping with daily life, and how things are affecting you. This can help you to manage your symptoms better and address any impact the illness is having on your behaviour and emotions.

Therapy can help you come to terms with and adjust to your illness and disability; it can provide a safe space where you can talk openly about the difficulties you are experiencing, and work with a counsellor to discover better ways of managing a life with ME/CFS.



BECOME A MEMBER OF THE MEA

For a small subscription you can receive quarterly issues of **ME Essential** magazine, keep updated with the latest information on ME/CFS and with stories from other members of the charity.

You don't have to be personally affected by ME/CFS to join the ME Association. Membership is available to carers, family-members, and anyone with a professional interest in the condition.

Annual membership costs:

£18.00 (UK residents and BFPO)

£24.00 (Mainland Europe including Republic of Ireland)

£30.00 (Rest of the World)

Visit the website shop to find out more:

<https://tinyurl.com/yu89nuzx>



COUNSELLING: YOUR QUESTIONS ANSWERED

Counselling and therapy are not treatments or cures for ME/CFS. They are available to help you learn how to live with your illness in a way that is not as exacting on your emotional health.

FEEDBACK

The ME Association welcomes feedback about this guide.

Please send any comments to:

The ME Association
7 Apollo Office Court, Radclive Road, Gawcott
Bucks MK18 4DF

or email: feedback@meassociation.org.uk

THE ME ASSOCIATION'S 'PURPLE BOOK'

The latest edition of **ME/CFS/PVFS - An Exploration of the Key Clinical Issues** is an authoritative publication representing the most comprehensive, evidence-based summary of PVFS/ME/CFS currently available. It contains everything that health professionals and patients need to know about this devastating neurological disease and comes highly recommended.

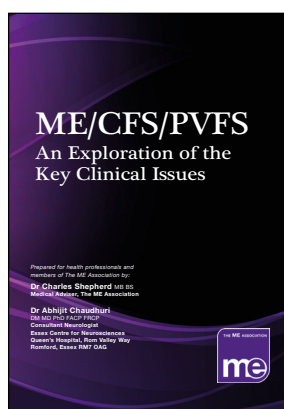
Price £10.00 (UK/BFPO)

Order from the ME Association website shop:

<https://tinyurl.com/4f55bhmc>

Alternatively, call our office on 01280 818963 or you can purchase a Kindle version from Amazon:

<https://tinyurl.com/y667ewcf>



THE ME ASSOCIATION WEBSITE SHOP

The ME Association has the UK's largest range of literature providing reliable information about all aspects of life with ME/CFS.

Leaflets, booklets, and guides can be downloaded from the website shop, and books and merchandise ordered online.

Categories include:

Medical Management; Mental Health; ME Connect; Diet & Nutrition General Information; Fundraising Leaflets; Benefits & Social Care; 'To Whom It May Concern' letters

Visit the website shop:

<https://meassociation.org.uk/shop>

Disclaimer: The ME Association cannot give personal advice and does not accept responsibility as to the suitability or otherwise of the counselling services and methods that might be entered into or for the quality of the counselling received. We recommend that individuals who feel they need counselling approach their doctor in the first instance. Information in this leaflet is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS.

