





### British Psychological Society (BPS) ME/CFS Guidelines

October 2025 Update

Welcome to the second BPS ME/CFS Guidelines update. We've made some great progress since last time. We had such a huge response to the survey that we have secured funding from the BPS Division of Clinical Psychologists and recruited an Assistant Psychologist to help us process the data. Hopefully we'll be able to include more about that in our next update. We can't share too much just yet as we're planning to write a research paper to share your views with the wider community and it could affect our chances of getting it published. Your comments have been really useful to help us shape the guidelines. We're including lots of quotes like the ones below.



"Always keep in mind that you are helping a physically ill person cope with the psychological impact of that illness, rather than a person who you believe to be affected by psychosomatic-induced illness."

"It took me 16 years to accept my ME/CFS but once I did it actually made life a little bit easier as I wasn't battling it so much."

"If you are not improving no matter how hard you try, then it is not your fault, it is the illness."

"I love seeing my counsellor.
As a carer, it's important to have an outlet and help to navigate the new landscape. It can be exhausting."

For this update, we'd like to introduce you to some of the people working on the guidelines. This means it's quite long, so please take your time and pace your energy as needed (see page 7 for our future plans). There are four core members of the team, as well as two representatives from ME/CFS charities and a group of psychologists writing the guidelines. Most of us have ME/CFS ourselves or a family member who does and/or work with people who have ME/CFS.

## **Nita Baker** Project Co-lead



I am a Consultant Clinical neuropsychologist, and I am the clinical lead for the Physical Health Psychology service in Midlands Partnership University Foundation NHS Trust. I am a member of the British Psychological Society and in particular, a committee member for the Faculty of Clinical Health Psychology who are supporting the need for these guidelines.

I first started working with people who had a diagnosis of ME/CFS over 25 years ago. We established a small multi-disciplinary service when the Rehab Consultant that I worked with at the time had the insight that people with this condition may benefit from support, including psychological support, to manage the various challenges this condition brings. We established good working relationships with the local support group in Staffordshire at that time, who helped us think about what worked and what didn't work from the service. The importance of getting that feedback from those with lived experience has stayed with me and the chance to work on these good practice guidelines with Experts by Experience has been invaluable.

I am currently involved in writing various sections of the guidelines including working psychologically with people with ME/CFS from assessment to intervention as well as the roles of psychologists and specialist services. I am looking forward to seeing these guidelines published and positively influencing the psychological care that people receive going forward.



# Sara Meddings Project Co-lead

I have been a clinical psychologist for 30 years and am a member of The British Psychological Society (BPS). I have been living with ME for 25 years. I continued working despite the ME/CFS until five years ago when I relapsed. My clinical work was not with people with ME, but having a long-term condition myself influenced the kind of psychologist I was and my approach to

working alongside people with lived expertise. I got involved with the BPS input to the Department of Health work on implementing the NICE guidelines on ME/CFS. It seemed a good opportunity to combine my professional and lived experience.

Joan, Louise, Nita and I proposed that the BPS co-produce good practice guidelines for psychologists working with ME/CFS. Whilst ME/CFS is not a psychological condition, and psychology is not for everyone, many people have been helped by psychologists e.g. to cope and come to terms with the grief, to learn to pace and rest or to find ways to continue working. We then advertised for others to get involved. We were delighted to appoint Katherine (Action for ME) and Russell (ME Association) to work with us along with psychologists from different areas.

I am co-leading the project with Joan, Louise and Nita. I have been working closely with Russell and Katherine to ensure the voice of people with ME/CFS is heard. We really appreciate the time so many of you have taken to inform us of your views and experiences. I have also been co-writing different sections e.g. on work and families and carers.

It has been hard work but also a real pleasure to work alongside so many psychologists and Experts by Experience who want to improve the lives of people with ME/CFS. It is taking us a bit longer than we anticipated to co-write a first draft but we feel it is important to genuinely co-produce and bring together different ideas and this can take time. We hope the BPS good practice guidelines for psychologists working with ME/CFS in 2026 will make a difference.

#### **Joan Crawford**

#### **Project Co-lead**



I was diagnosed with ME/CFS in 2004, after acquiring several tick-borne infections. Prior to this I worked as a Chemical Engineer in high-risk food and chemical processing plant management. Unfortunately, the treatment and recovery process took a long time. I was, however, able to slowly retrain as a Counselling Psychologist.

As a clinician, I was part of the Priority Setting Partnership (PSP) for ME with the James Lind Alliance, which identified people with ME/CFS's top priorities for future research. More recently I was one of the BPS representatives for the DHSC Attitudes and Education working group for ME/CFS.

My research has focused on measuring objectively the neuropsychological deficits people with ME/CFS have, which include problems with verbal learning, attention, memory, reaction time tasks, fine and gross motor control and auditory information processing. I have also assessed qualitatively ME/CFS patients' experiences of psychotherapy.

I have published several papers and multiple letters in peer reviewed journals highlighting problems with poor quality research methods, overreach and bias in relation to ME/CFS and Medically Unexplained Symptoms (MUS). For example, research on treatments can be misleading when it relies mostly on people's subjective personal reports of how they feel, especially if the study isn't blinded (where participants don't know what treatment they are getting). This can create bias because people's expectations may influence their answers. In contrast, more reliable real-world measurements are rarely used, which can lead to the benefits of treatments being overestimated.

In an article for Action for ME's *InterAction* magazine, I explained how institutions and authorities sometimes struggle to cope with uncertainty, ambiguity and witnessing suffering, which can lead them to doubt or misunderstand patients. My colleagues and I also published a paper challenging the reliability, credibility and coherence of the MUS model which can result in patient invalidation and harm.

Developing a good practice guideline for psychologists to work well with people with ME/CFS is important to ensure up-to-date knowledge, sensitivity to patients' specific needs, and appropriate support for them and their families. Given the limited biomedical understanding of ME/CFS, historically there has been overreach in the psychological, behavioural and social domains which has not translated into effective improvements or outcomes for patients.

It is important that patients have confidence that psychologists will both understand their experiences and are up-to-date with appropriate therapeutic support options. Psychologists have skills in detailed assessment, formulation (an understanding of the person and their difficulties in context) and communicating this, including in advocating for patients, and helping patients better understand themselves and their situations.



#### **Louise Kenward**

**Project Co-lead** 

I worked as a psychologist for nearly 20 years, working with mental health, substance misuse, and forensic services in multi-disciplinary teams. More severe prolonged illness meant I had to leave my career in the NHS. Living with chronic illness my whole adult life, this was exacerbated with post-viral illness in 2011 – since then I have been diagnosed with multiple energy-limiting conditions (POTS, Long Covid, ME/CFS, HSD, and MCAS).

In 2020, I set up <u>ZebraPsych</u> with the aim of raising awareness of energy limiting conditions and advocating for a change to the NICE guidance for people with ME/CFS, including GET and CBT to be dropped/downgraded from the guidelines. I curated and edited the anthology,

'Moving Mountains: Writing Nature Through Illness and Disability', and was named in the 2023-24 Disability Power 100 list for the anthology and my work for people with ME/CFS.

I have most recently worked on the AHRC 'Imagining Future Healthcare' project with Liverpool University and am currently a postgraduate researcher at Manchester Metropolitan University.

I have been leading several sections of the good practice guidelines and have most recently been working on the sections titled 'alternative/additional diagnoses', 'equality, diversity, and inclusivity', and 'benefits and the DWP'. I hope the production of these guidelines will bring much needed change for people living with ME/CFS.



# Katherine Langford Action for ME Volunteer

I've had ME/CFS for 24 years. I wrote an <u>article for the British Psychological Society</u> about the need for ME/CFS to be treated as a physical illness. Sara saw my article and invited me to help with the guidelines. I was keen to be involved as when I was first ill, I saw a paediatrician who clearly thought I was school phobic and could get better if I wanted to. Following his bad medical advice made me significantly worse and I'm still recovering from it over two decades later.

I hope these guidelines will help people avoid the same pitfalls and stop ME/CFS being psychologised. I'm volunteering for Action for ME to enable people with ME/CFS to input into these guidelines.

So far, I've helped run two focus groups, set up the survey we conducted and have been helping to analyse the results. I've been finding different quotes we can use in the guidelines about things like severe ME, being a carer and managing ME on top of comorbidities like autism. When we have meetings, it's my job to share what you've all said in the survey.

It's been really interesting working with such knowledgeable psychologists like Sara and Kate. We're making really good progress, although it's turning out to be more work than everyone anticipated! You can email me at <a href="mailto:katherine.volunteer@actionforme.org.uk">katherine.volunteer@actionforme.org.uk</a>





### **Russell Fleming**

#### The ME Association

I was committed to an enjoyable 14-year career in private banking and living on the island of Jersey, when a holiday abroad led to a nasty virus and hospitalisation. That was 25 years ago, and despite futile attempts to return to work, I didn't recover my health and early retirement – at the age of 31 – was the only viable option.

The ME/CFS diagnosis, the lack of understanding about the condition and its impact and my inability to return to work, had a very detrimental effect on my mental as well as my physical health. When I was able to engage with healthcare professionals there were few who understood and trying to find someone capable of helping me learn to accept, adapt and accommodate to a life with ME/CFS was virtually impossible.

Psychologists and other professionals who have developed a keen understanding of ME/CFS or a willingness to learn can play an important role in helping us live better lives. The BPS good practice guidelines are an opportunity to ensure that even more psychologists can have a good grounding in this condition and improve the care that they provide.

There are over 15 psychologists, like Kate (see below), who are helping to write the guidelines overseen by the Co-leaders. They are from various fields of psychology such as clinical, educational, counselling, neuropsychology and forensic. All the psychologists, including the Co-leaders, are volunteers.

**Kate Chapple**Writing Group Member



I have been a qualified Clinical Psychologist for nearly 10 years, working within a specialist service for children and young people with various types of chronic fatigue for the past 8.5 years. This service offers assessment and support for children and young people with chronic fatigue resulting from a range of conditions, including those with ME/CFS.



I do not have lived experience of the condition but have worked with many young people and their families over the years to support them to understand what is going on, find ways to best manage their condition and to work with the psychological impact that can accompany having such a debilitating illness.

I am really excited to be part of the working group writing these guidelines and particularly to be joining a group with such a huge amount of personal experience to share and I am so thrilled we have input from Katherine and Russell. I am particularly keen to ensure that children, young people and their families are represented within the guidance.

The conversations we have had as small working groups have been so rich and full of ideas about how psychologists can support people impacted by ME/CFS. I think one challenge is going to be to distil such a huge wealth of knowledge and experience into the guidelines, but I am sure we can produce something that is going to be really valuable.

#### **Future Plans**

Over the next six months, we will be working on completing a first full draft of the guidelines. We will contact a small number of individuals to ask for their feedback on specific sections. After that, we will also hold an online webinar to tell you about the guidelines and allow those who weren't selected as part of the focus groups to offer feedback too. Further details will be in our next update.

We want to make sure that these guidelines reflect the views of people with ME/CFS. There will be several more drafts after all the different stakeholders (such as people with ME/CFS, ME charities, psychologists and doctors) have submitted feedback.

We hope that the guidelines will be published in summer 2026. This is subject to change as so many of the team have ME/CFS themselves.

Please feel free to contact us at <a href="mailto:katherine.volunteer@actionforme.org.uk">katherine.volunteer@actionforme.org.uk</a>







