Good Practice Guidelines for Psychologists Working with People with ME/CFS November 2024 Update

Welcome to the first update on the development of guidelines for psychologists working with people with ME/CFS. The British Psychological Society is co-producing good practice guidelines on ME/CFS with assistance from Action for ME and the ME Association. You can read more about this project on the Action for ME and ME Association websites. It is important to us to have a high amount of involvement from people with ME/CFS and their carers, family and friends. Russell Fleming and Katherine Langford represent the ME Association and Action for ME on the working group. A number of the psychologists leading the project and others working on it also have lived experience of ME/CFS.

We would like to thank everyone who has contributed for your valuable input. So far, we have held two focus groups and conducted an online survey which has been completed by 861 people. We were concerned that people who have severe ME/CFS might not be well enough to fill in the survey, but actually nearly 1 in 3 of people who responded classed themselves as severely or very severely affected. That is a higher proportion than we might have expected, as it is estimated that around 1 in 4 people with ME/CFS are severely affected, so it is really positive we have had so much representation from them.

We have also compiled a list of 304 people who are interested in helping further. We have been overwhelmed by the people willing to spend their time and limited energy to help us create these guidelines.

What people with ME/CFS and their relatives and carers told us

It has been really clear that people want us to include in the guidelines that ME/CFS is not psychological. It is a physical illness. As with any long-term debilitating illness, like MS and cancer, it does have a psychological impact which psychologists may be able to help with. For example, people talked a lot about feelings of grief, loss and trauma because of losing their old life.

We received lots of useful feedback about things like how to make appointments accessible (e.g. shorter sessions, flexible times, alternative formats such as video calls, dim lighting); what helps like pacing; details for specific groups like those who are severely affected and carers. We now have useful quotes which we can use throughout the guidelines to help psychologists understand the symptoms of ME/CFS (such as post exertional malaise), what having ME/CFS is like and the impact that not being believed by doctors or receiving incorrect medical advice can have on someone’s physical and mental health.

What People Want in the Guidelines

What ME/CFS is - Symptoms and how these fluctuate

ME is not psychological, but it has psychological consequences

What helps – pacing, tools used with other patients with serious physical illnesses

That it is real, debilitating and can affect people in many different ways

Co-morbidities and adapting treatments – suggestions that work for other patients may not apply to PwME

Multidiscipline treatment – co-ordination between specialists

Severe ME

Family and carers

Sessions could be more accessible e.g. shorter, virtual

Value of lived experience

Trust and being listened to without judgement

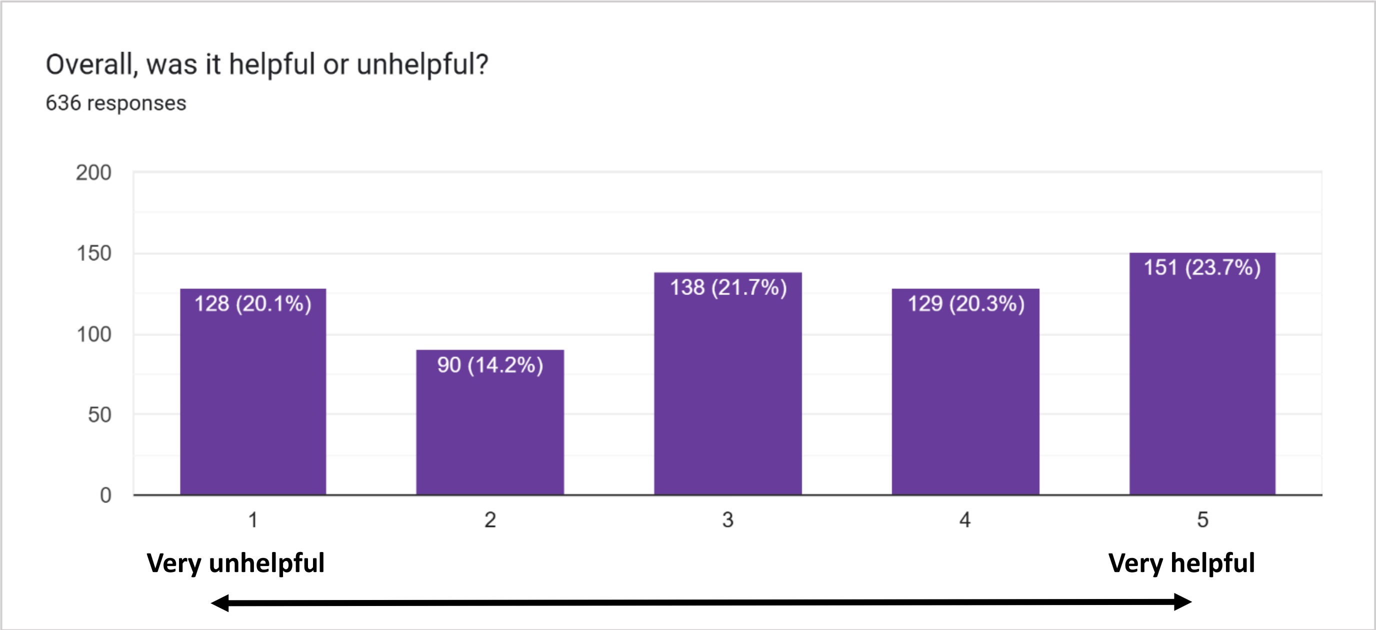
There are no one-size-fits-all answers

Support around the grief of losing your old life

To help people live as well as they can with ME

Seeing a Psychologist

Over 3/4 of people submitting a survey have seen a psychologist or another type of therapist. We asked them to rate how helpful they had found it. This chart of the results sums up our data from the survey so far. As you can see, slightly more people found seeing a psychologist helpful than unhelpful, although there was a fairly even split over the different ratings.



Pictured above: People's responses to how helpful they found seeing a psychologist.

The survey results indicate that seeing a psychologist can be really helpful when done right. People talked about how valuable it was having someone to listen without judgement, making them feel believed and validated and not alone. It can feel really lonely grappling with a physical illness that few understand. A psychologist can be particularly helpful if someone has thoughts and feelings people don't feel they can share with friends and family. While psychology cannot cure ME/CFS, people said psychologists can help people come to terms with, accept and manage their illness.

“It was great to have an outlet where I could be truly angry and upset about being ill and have a space to express that safely. Just being able to identify that rush of emotion and learn to sit and let it go with it has been incredibly beneficial ever since.”

“You can help support patients to handle this life transition, the grief, the stress that comes from having this illness without removing it.”

Quotes from survey responses

When asking people about their negative experiences of seeing a psychologist, they mentioned things like being told that their ME/CFS was a mental illness, feeling pressured into inappropriate ‘treatments’ like exercise, the psychologist convincing them their ME/CFS was a figment of their imagination or the psychologist not believing ME/CFS is a real condition. We intend to address these experiences in the guidelines to help ensure that more people can have positive experiences with psychologists and receive the support and information they need.

“We are learning our new restricted capabilities, learn with us side by side with no judgment. We are doing the best we can.”

“Remember we are human beings. We are fighting every day to think of reasons why we should carry on. Please help give us reasons to. Help us find positives and look for little successes. We have lost who we were and what we were capable of. Most of us lose everything we based our identity from.”

“ME is a neurological condition, it is a fluctuating life limiting condition that affects every part of the patient’s life.”

“Any outcome measures (that rate the success of a programme) should not depend on the patient “improving physically”. It should be possible to judge an intervention as “successful” even if the patient ends up doing less. For example, it could be seen as successful if the patient is having fewer PEM set-backs, fewer problems with activities of daily living, and/or a more comfortable life.”

“Psychologists should provide belief, validation, and support, helping us endure the challenges of living with this illness. The focus should be on helping us navigate the emotional toll, such as self-blame, isolation, and grief, rather than attempting to fix or change the physical reality of ME/CFS.”

Future Plans

So far, we have analysed the surveys to look in detail at what people want to see in the guidelines, including what you want psychologists to understand and how you think they should work with people with ME. We extended the deadline to encourage more people from black and Asian minority groups and more young people under 25 to respond. It is important to collect this data as people of different ages and from different backgrounds can potentially have different experiences and face different problems.

Our next step is to fully analyse the results of the whole survey. After having such an amazing response, we feel obligated to write a research paper and try to get our results published where health professionals will see it. Many of the survey responses have been very moving as people have shared difficult experiences. It is clear from many of the submissions that this is a topic which people feel strongly about and we wish to do you justice after you have spent your precious energy helping us.

Representatives from the British Psychological Society, Action for ME and the ME Association have now met with psychologists who have volunteered to help write the guidelines. We presented preliminary results from the survey. We have formed writing groups for the different sections of the guidelines, such as what ME/CFS is, assessment, therapeutic interventions, people who are severely affected, young people and education, links with long covid, as well as information and support for carers. We are hoping to have a draft of most sections written in the New Year. However, as most of the core working group have ME/CFS themselves, this is health dependant.

As the guidelines progress, we will be in touch with those who have volunteered to help further in order to ask about your experiences on specific topics. We also intend to ask some of you to provide feedback on the draft guidelines once they are written. We are planning to break this down into groups so that people can read and comment on smaller sections of the guidelines, rather than having to read the whole document (although they will be welcome to do so). The whole project is expected to take 14 months, with input from the ME/CFS community into drafts at each stage.

We will send out another update in the New Year. In the meantime, if you have any questions then please contact BPSGuideline@meassociation.org.uk.