

ME Association CBT GET and Pacing Survey. Questions answered and remarks commented on

1	My course was a multi-component course, not restricted to any one of GET, CBT or Pacing. Why haven't you allowed for a separate section to cover this and how do I fill the survey in to show this?	This is the question we are being asked most. If we had included another section, people would ignore the Pacing, GET and CBT sections which we don't want them to do. Also, we felt that to provide for another section in an already long and complex survey would over-complicate things. If your course or consultation had a slant in a CBT, GET or Pacing direction, chose that section. I have been sent e.g. some course notes which are called 'CFS Recovery Book'. Their accent is on Pacing although 'Pacing' does not appear in the title and there were sessions on psychological coping (a CBT topic), exercise including GET, medical management, sleep & diet. So I expect the person who sent me those notes will complete the section about Pacing courses and include details on what other topics were covered. If your course or consultation did not have a slant in any direction then choose any therapy you like and tell us that and we will understand the circumstances.
2	This is a very difficult survey for someone with severe ME to complete. It has exhausted me.	It is difficult for severely affected people and we are very aware of the energy constraints on them and that we are asking them to dig deep into their energy reserves to complete this. But to be in a position to influence the NICE Guidelines Review Committee or the NHS we have to produce detailed evidence. So we need the help of everyone, including severe sufferers, to produce this evidence and without that help the survey report will not have the effect we want it to. Some people are reporting that it takes just 30 to 40 mins to complete and the vast majority have been able to complete without any problems However, for some it is a problem and, whilst we thank everyone for their efforts, particular thanks goes to severe sufferers.
3	How are brain fogged people expected to remember?	Again, we are very aware of how difficult this is for some people. But if we don't ask these questions we won't get any answers and we have included as many 'don't know/can't remember' s as possible without making the survey ineffective.
4	The survey goes round and round the houses asking the same questions lots of times	No it doesn't go round the houses! What it does is to ask the same questions about courses and self management of symptoms for all three therapies - so that is 6 repeats to allow for 6 different sets of information that we need. There are also 3 shorter parts to see when and why people have not been offered NHS courses or have refused them and some of the questions appear again in those parts. To get the information we need, it was impossible to set questions out in any other way.
5	The benefits part made it sound as if I didn't need benefits	The questions about benefits are not in the survey because the need for benefits is being assessed. They are there because a change or otherwise in benefits is a good measure of success or failure of a therapy. There is an open question at the end of each section where you can tell us anything you think we need to know and you could add something there about benefits (or anything else, of course) if you feel it would help the survey report.

6	Why has The ME Association done an about turn and is now supporting CBT and GET?	It hasn't! What it has done is to produce an impartial set of questions and that is essential in any survey
7	The survey assumes a CBT course is about challenging negative beliefs but mine was about my personality and self-esteem and how these were stopping me self managing my ME as well as possible	We certainly don't make any assumptions about CBT (or any) courses – quite the contrary – and there are specific questions to find out different aspects of all three therapies - including the open questions. We felt the need to give some examples of each of CBT, GET and Pacing principles for those people who had not had experience of them. But they are only examples. To go into more detail was impossible in a survey of this kind
8	Some attempt should have been made to identify which symptoms people suffer to allow subsets to be distinguished, so the survey could tell us that people with (or without) particular sets of symptoms are helped or made worse by particular therapy	If enough people complete this survey and give us enough information that is exactly the sort of thing that we should be able to identify and is why we have asked detailed questions about symptoms
9	The thesis of therapeutically exercising (GET) ME patients is fundamentally flawed	One of the reasons we need to find out is what courses actually involve is to see if there is the need for better research - not just on GET - remember that there has been no substantive research on Pacing. Some people are saying that they are fed up with research but some good research is still necessary and will take place anyway and to point the right direction for research could be a very good use of this report.
10	Would you like my course notes?	Yes please! Or your consultation notes. You can post or email them to us (anonymously if you wish - just blank out your name). The analysis of those may help greatly with the evidence. Email gill.briody@meassociation.org.uk or post them to Mrs Gill Briody, Ramsay Research, The ME Association, 7 Apollo Office Court, Radclive Road, Gawcott, Bucks, MK18 4DF. Tell us (because we won't be able to link the notes with the survey answers) the approx year of the course, how many sessions there were in a course, how many sessions you attended, if the course was a group one about how many people were in the group and how you appraised the notes and the course.