RESULTS OF THE FORWARD-ME SURVEY FOR CBT AND GET

We are pleased to be able to let you see the results of the recent survey conducted on behalf of Forward-ME.

All the raw data was analysed and inserted into a comprehensive report by Professor Helen Dawes and Her team at Oxford Brookes University.

Bearing in mind that this survey was organized at very short notice and that we are aware that there are some shortcomings such as a selective bias in that only people with on-line access and the ability to complete the questionnaire were included, we are very grateful to all who responded so quickly.

The results have been well received by the Chairman of the NICE Guideline Development Group and will, we hope, be helpful to the Group as they develop the new guideline for ME/CFS.

Executive Summary from Forward ME

This survey was commissioned by Forward ME following discussions between the Chair and Vice-Chair of the NICE Guideline Development Group, Members of Parliament and the Chair of Forward-ME about the lack of up-to-date data about providing additional patient evidence relating to long-term outcomes and harms following Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET).

The survey was designed by a steering group of Forward ME members and an independent research unit within Oxford Brookes University, Oxford Clinical Allied Technology and Trials Services Unit (OxCATTS), was engaged to undertake the survey, collate, analyse and report on the response.

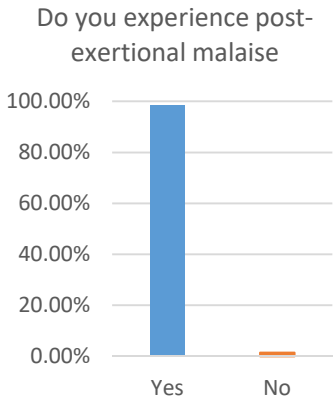
Due to the short timescales involved, the survey was only available online and it was not possible to allow paper responses. Please note, this will mean that a number of people with ME, particularly those who are severely affected, will not have been able to have their experiences considered.

The survey was designed to gather evidence from people who have been offered CBT and/or GET based on the current NICE Guidelines since 2007. Much of the evidence received echoes what we already know from previous surveys and feedback received by charities over a number of years.

The full report follows this executive summary. We set out below the key findings that we have drawn from it. We acknowledge that there may be some bias in the results of the survey due to its promotion by ME charities rather than NHS organisations. There are also limitations in self-reported data however we feel the scale of the response demonstrates the strength of feeling and harm on the issue.

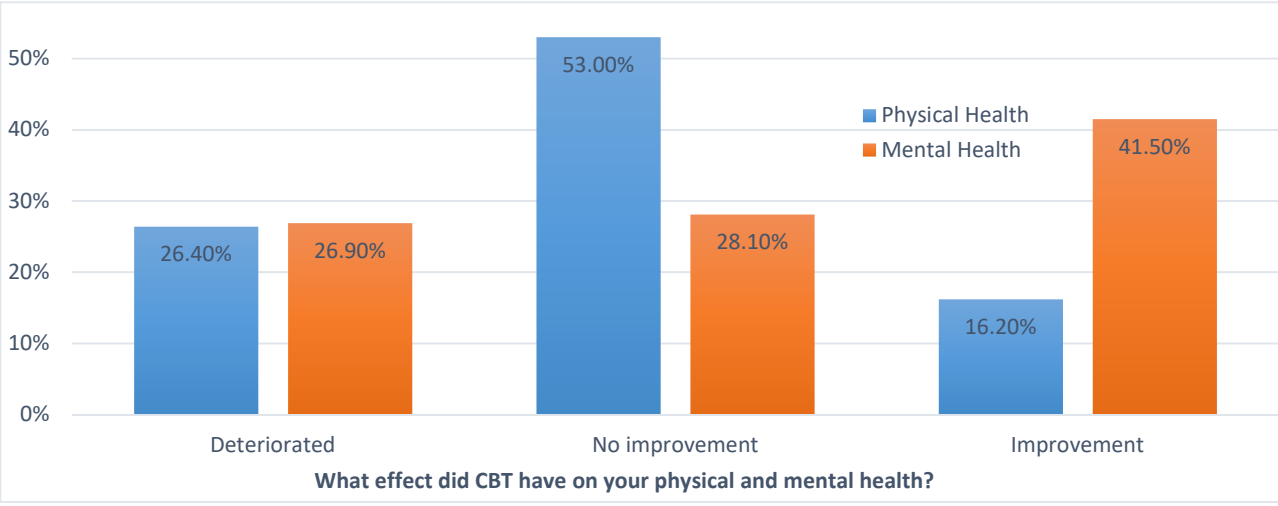
Demographics

- 2,274 survey responses were received for the survey. Of these, 80.4% identified as female and 16.0% as male, with the remaining choosing 'non-binary' or 'prefer not to say'.
- 98.5% said they experience post-exertional malaise. This is shown on the table to the side.
- 8% were aged 18 or under and the age band with the highest responses rate was 41-50 at 26.6%.



Just CBT

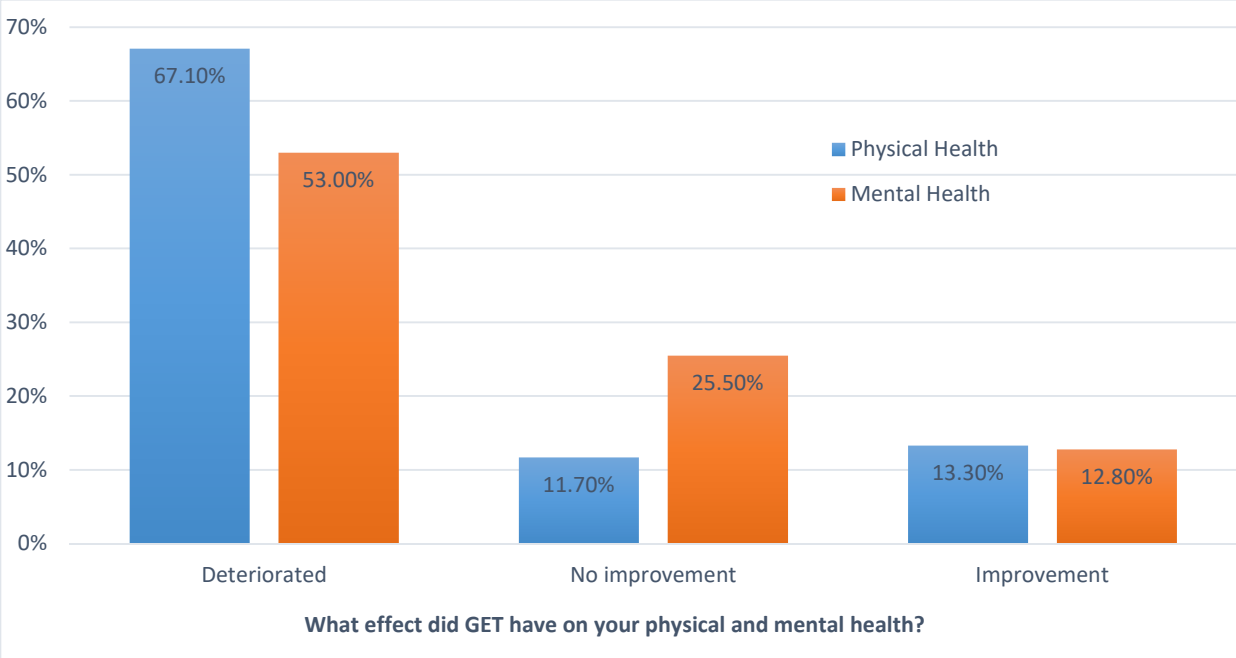
- 789 people said they were offered a course of CBT with 84.9% starting the course.
- We asked whether any symptoms worsened because of the treatment. 46.6% said yes and 48.5% said no. The most common symptoms mentioned were fatigue and pain. 21.6% also developed new symptoms.
- We asked people *''what severity is their condition both before and after treatment?*'. The percentage of people describing their condition as severe before treatment was 10.9% and this increased to 19.1% after treatment.
- Of those who started the course, we asked *'what impact did CBT have on their physical and mental*



health?'. The results are below.

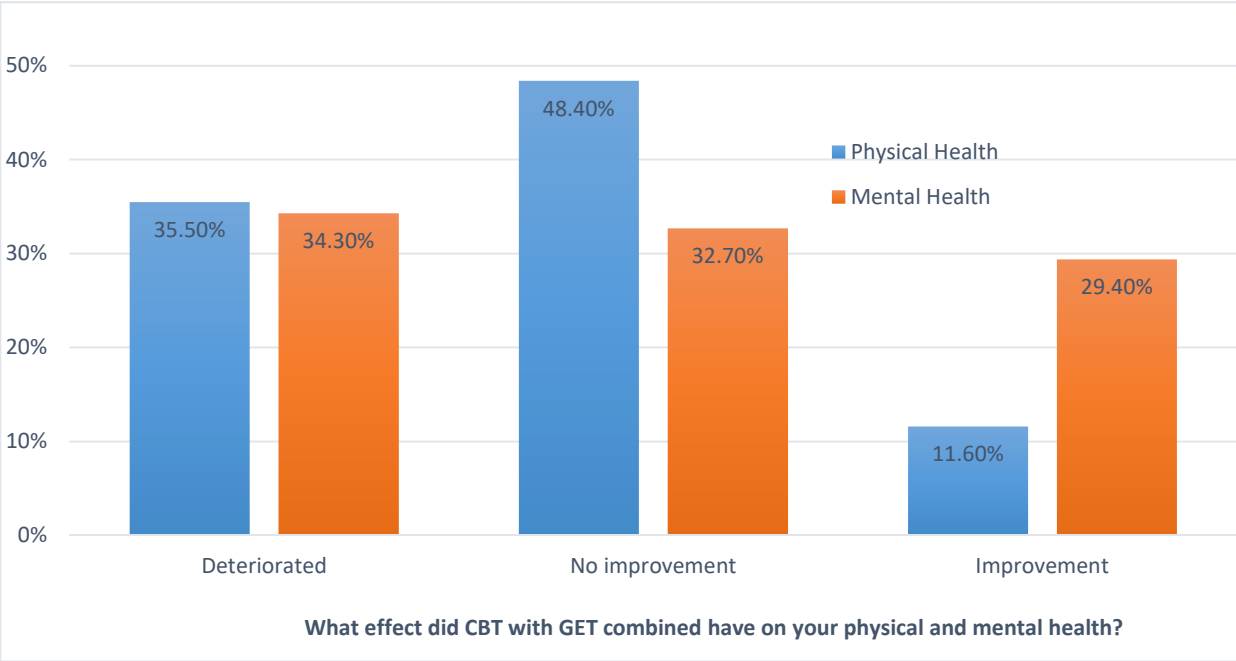
GET

- 542 people said they were offered a course of GET with 79% starting the course.
- We asked whether any symptoms worsened because of the treatment. 81.1% said yes and 13.3% said no. The most common symptoms mentioned were fatigue and pain. 36.7% also developed new symptoms.
- We asked people *''what severity is their condition both before and after treatment?'*. The percentage of people describing their condition as severe before treatment was 12.9% and this increased to 35.3% after treatment.
- Of those who started the course, we asked *'what impact did GET have on their physical and mental health?'*. The results are below.



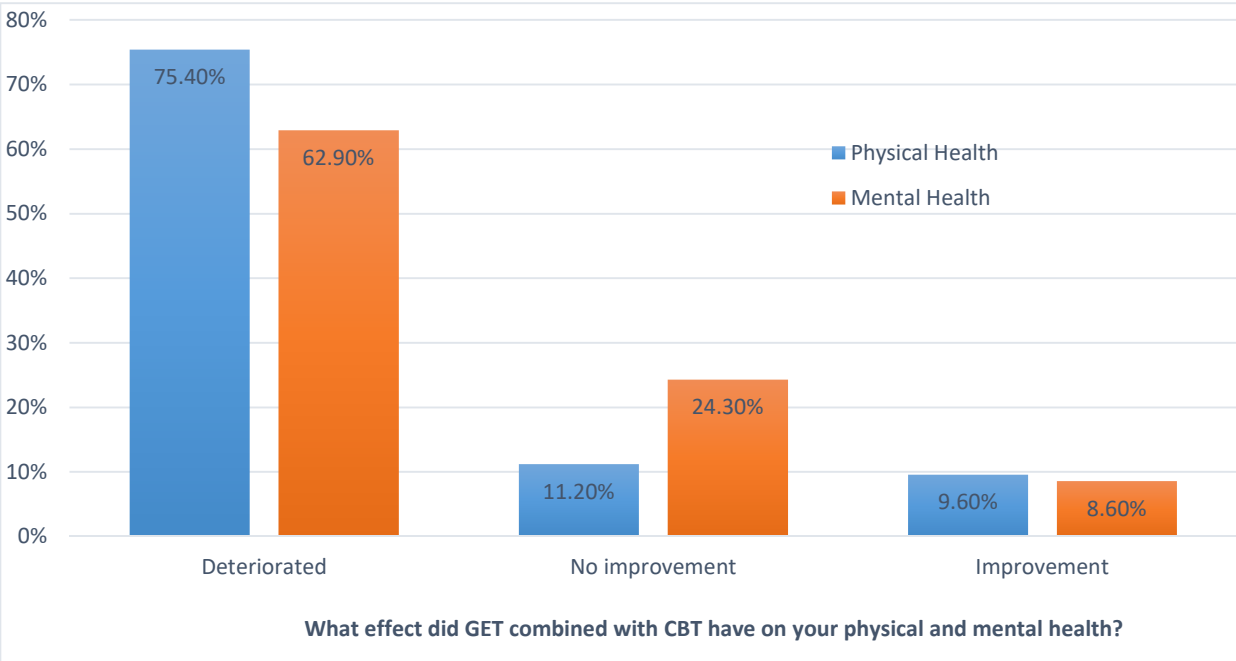
CBT with GET combined

- 943 people said they were offered a course of CBT with GET combined with 76.9% starting the course.
- We asked whether any symptoms worsened because of the treatment. 58.3% said yes and 37.7% said no. The most common symptoms mentioned were fatigue and pain. 29% also developed new symptoms.
- We asked people *''what severity is their condition both before and after treatment?'*. The percentage of people describing their condition as severe before treatment was 12.6% and this increased to 26.6% after treatment.
- Of those who started the course, we asked *'what impact did CBT with GET combined have on their physical and mental health?'*. The results are below.



GET combined with CBT

- 943 people said they were offered a course of GET with CBT with 75% starting the course.
- We asked whether any symptoms worsened because of the treatment. 85.9% said yes and 10.3% said no. The most common symptoms mentioned were fatigue and pain. 44.4% also developed new symptoms.
- We asked people *''what severity is their condition both before and after treatment?*'. The percentage of people describing their condition as severe before treatment was 13.2% and this increased to 41.9% after treatment.
- Of those who started the course, we asked *'what impact did GET combined with CBT have on their physical and mental health?'*. The results are below.



Conclusions

The results show clearly that cognitive behavioural therapy and graded exercise therapy are unsuitable treatments or management approaches for ME/CFS. The changes in severity and the worsening of symptoms are clear indications that the therapies being offered are having adverse effects on the health of individuals.

CBT, while may be effective for a minority in helping with mental health challenges such as depression or anxiety, is shown to be ineffective in a considerable proportion of people and even led to almost half of respondents reporting worse symptoms.

GET is shown to cause considerable deterioration in physical and mental health. It has led to people becoming more severe and the open questions have given us insight into the worsening symptoms that have developed when patients have increased their activity beyond their capabilities.

The results show that although NICE might not recommend GET for the severely affected, they are clearly being given GET at the clinical level. This could be because clinics are not tailoring their management advice to the individual (as NICE recommends) or are simply not aware of the unsuitability of aerobic/exercise for people with ME/CFS.

Alongside this the analysis of the survey provided by Oxford Brookes University show that people with ME/CFS have experienced negative effects with regard to welfare and benefits when choosing whether or not participate in these treatments. Results also show that the adverse effects of the treatment has had a considerable impact on the employment and education capabilities of individuals.

We acknowledge that there may be some bias in the results of the survey due to the promotion of the survey being organised by ME charities rather than NHS organisations. There are also limitations in self-reported data. However, we feel the scale of the response demonstrates the strength of feeling and harm on this issue.

As there is a commitment that this new guideline be 'patient led' we believe that the responses should carry considerable weight in the consideration of effective treatment or management approaches. There is also an ethical question[1] whether the current management recommendations relating to CBT and GET can continue while the development is underway when their unsuitability is evident.

Our collective recommendation is that GET and CBT be removed from the NICE guideline for ME/CFS.

Information about Forward ME

Forward-ME consists of a fairly broad spectrum of charities and voluntary organisations invited by the Countess of Mar to meet from time to time. The Aim of Forward-ME is to promote effective joint working by ME and CFS organisations to maximise impact on behalf of all people with ME and CFS in the UK.

Forward-ME has no formal constitution. It exists to improve recognition, understanding, research, management, support and information for everyone whose life is affected by ME and CFS.

The linked organisations and associates are:

Countess of Mar (Chair), Carol Monaghan MP (vice chair), Dr Nigel Speight, Dr William Weir, Dr Nina Muirhead, ME Association, ME Research UK, Action for ME, TYMES Trust, reMEmberCFS, BRAME, ME Trust, BRAME, 25% ME Group, #MEAction.

[1] http://forward-me.org.uk/Reports/10%20year%20surveillance%20(2017).pdf

Evaluation of a survey exploring the experiences of adults and children with ME/CFS who have participated in CBT and GET interventional programmes

FINAL REPORT

Submitted by Oxford Clinical Allied Technology and Trials Services Unit (OxCATTS), Oxford Brookes University, 27th February 2019

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Appendices 1-6 (these are provided as separate documents)

1. Executive Summary

In total 2,274 responses were received for the survey. The majority of (87%) responses were self-reported, with (62.4%, 1419 people) reporting their condition was moderate before treatment. In this survey, individuals were asked if they started cognitive behaviour therapy (CBT), graded exercise therapy (GET), or both CBT and GET treatment courses. Where they reported combined treatment, they were asked to comment on CBT and GET components separately. Approximately 35% were offered CBT, 23.8% GET and 41.5% combined CBT and GET.

Overall, respondents to the survey who started CBT alone or as a component of CBT/GET were more likely to complete the course than those who started GET alone. Those who ceased CBT alone or in combination with GET most commonly cited being too ill to continue and/or the practitioner recommending cessation of treatment. For GET the most common reason for stopping treatment was worsening symptoms. The impact of treatment was evaluated through patient-reported improvement or deterioration of physical and mental health following treatment. For participants receiving CBT alone or combined with GET, approximately 70% of respondents reported completing the course. With CBT on its own, approximately seventy nine percent of participants reported either no change (53%) or deterioration (26.4%) in physical health after CBT treatment, whereas 41.5% reported an improvement in mental health with 55% reporting no improvement (28.1%) or deterioration (26.9%). Overall, responders reported that CBT was more helpful than harmful for mental health outcomes.

With GET on its own, the majority of responders reported not completing the course (61%), of those that started the course 81% reporting worsening of symptoms. Approximately seventy nine percent of people reported no improvement (11.7%) or deterioration (67.1%) in physical health. Seventy nine percent of people reported that GET led to no change (25.5%) or worsening (53%) of mental health after GET.

When reporting on the CBT component of a combined CBT/GET course responders predominantly (84%) reported no effect (48.4) or worsening (35.5%) of physical health with 67% reported no effect (32.7%) or worsening (34.4%) of mental health. Responders were also asked whether any symptoms had worsened with CBT in combination with GET. Over half of responders (58.3%) reported that CBT, when undertaken with GET, worsened their symptoms. CBT when combined with GET appears to have a less positive effect than when delivered on its own.

When reporting on the GET component of a combined CBT/GET course, 48.4% completed the course with approximately 87% reporting no effect (11.2%) or deterioration (75%) in physical health, and 87% reporting no effect (24.3%) or deterioration (62.9%) in mental health. Eighty six percent of responders reported that GET, when combined with CBT, had worsened their symptoms.

The effect of treatment was further evaluated through reported ability to resume or carry out employment or education, as well as a reported effect on claiming Department of Work and

Pensions (DWP) benefits. For both treatments, whether alone or combined most respondents (78.8% or more) reported the treatment did not affect their claiming DWP benefits.

CBT alone did not affect returning to work or school for most individuals, 77% of respondents reported no change, 21.8% reported a change. However, GET alone and CBT and GET treatments in combination had more of an effect on the ability to return to work or school, with a range of 44.4-47.2% of respondents reporting a change.

In summary, the majority of individuals reported deterioration or no change in symptoms and health over the course of all treatment approaches.

2. Background

The 'Forward ME' group of patient support and research funding charities has been asked by the 'ME/CFS Guideline Development Group' (appointed by NICE) to collect some new 'patient evidence' on the acceptability, safety and harms relating to the use of Cognitive Behavioural Therapy (CBT) and Graded Exercise Therapy (GET).

A Qualtrics survey prepared by a sub-group consisting of Action for ME (AfME), ME Association (MEA), #MEAction and ME Research UK (MERUK) was made available via social media and online sources to the public for completion during the period 11th January 2019 -31st January 2019.

This report is a summary of findings, intended to contribute to the preparation of the new National Institute for Health and Care Excellence (NICE) guideline on ME/Chronic Fatigue Syndrome.

Objectives for Oxford Clinical Allied Technology and Trials Services Unit (OxCATTS) utilising responses from the survey were to:

- Describe the experiences of adults and children with ME/CFS who have participated in CBT and GET interventions
- Describe the experiences within subgroups of modifiable and non-modifiable variables

3. Methodology

The survey data was exported from the Qualtrics platform (Qualtrics, Provo, UT) and converted to a SPSS (IBM, SPSS Statistics, Version 25) data file. The data was cleaned to verify respondent eligibility and highlight any anomalies. From the 2508 responses, 198 had been routed out of the survey having been ineligible by date offered treatment. A further 36 people were excluded across the three treatment categories responding with offered dates that were pre 2007. 11 respondents who selected 'Both CBT and GET' as treatment expressed they had either started CBT or GET before 2007, therefore these were reclassified to CBT or GET treatment only. Statistical descriptives and frequencies were run to analyse the frequency of response to the close ended questions e.g. Yes or No.

The open ended questions were analysed through NVivo 12 Plus qualitative data analysis Software (QSR International Pty Ltd. Version 12). The software automatically coded themes by sentence, indexed words using a word frequency count and coded responses into sentiment, highlighting negative or positive responses. Each open-ended question has been reported primarily by theme and word frequency. Sentiment categorisation has been applied mainly to the survey end questions.

The survey data has been reported to show the demographics for all respondents (those eligible), then split according to treatment group: CBT, GET, CBT combined with GET and GET combined with CBT. Appendices have been provided for demographics and each treatment group. All respondent quotes appear italicised within the report and appendices.

The survey and evaluation of collected data received institutional research ethics approval.

Inclusion criteria for participation in the survey was:

1. To have been offered or received CBT and/or GET since 2007 – even if the course was not completed **AND**
2. To have a diagnosis of ME, ME/CFS, CFS or PVFS confirmed by a clinician **AND**
3. To have received treatment within the UK

4. Demographics

In total 2,274 responses were received for the survey. Most (87%) responses were self-reported, 8.1% of responses were completed on behalf of a child and 4% were completed by a carer on behalf of an individual with ME. Survey responses spanned from 12 and under (0.7%/17 people) through to 71+ (1.1%/25 people) (See Figure 1).

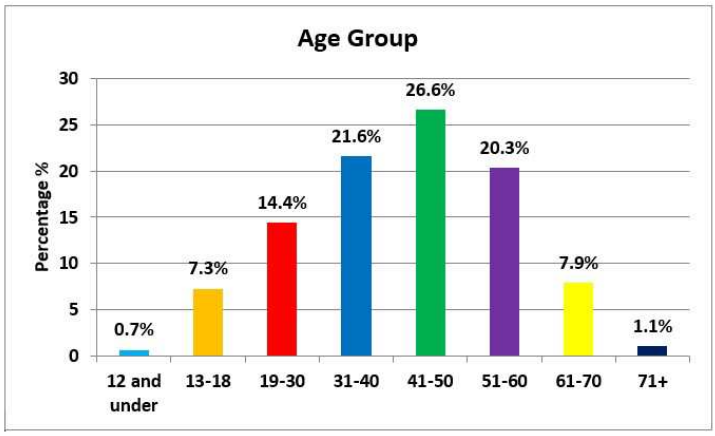


Figure 1. Age group

Of the 2,274 participants, 1829 (80.4%) identified as female and 384 (16.9%) identified as male. The remaining participants identified as 'non-binary', 'other' or preferred not to say.

The majority of the respondents were from areas within postcode regions of Sheffield, followed by Oxfordshire, Edinburgh, Manchester, Bristol, Newcastle-upon-Tyne, Gloucester, Glasgow, Nottingham and Bath.

The survey asked participants to rate the severity of their condition before treatment using a scale of 'mild', 'moderate' and 'severe' (see Figure 2). Most people (62.4%/1419 people) said their condition was moderate before treatment. Participants were also asked if they experienced any post-exertional malaise (PEM), with 2,239 (98.5%) responding 'yes'.

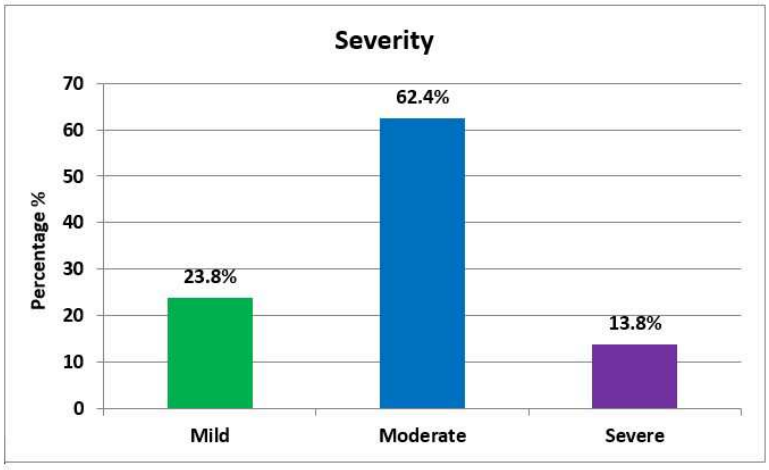


Figure 2. Severity of symptoms before treatment

Participants were asked what treatment they had been offered (Figure 3). Of all the participants who completed the survey, more individuals (943) were offered combined cognitive behavioural therapy (CBT) and graded exercise therapy (GET) than either CBT or GET alone.

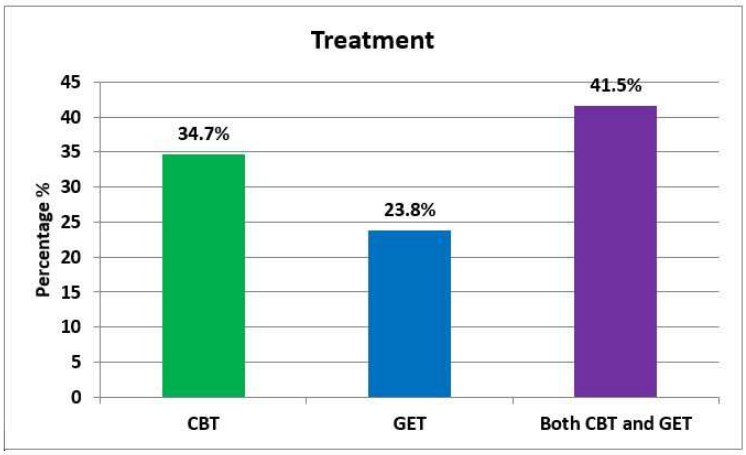


Figure 3. Type of treatment offered

5. Cognitive Behavioural Therapy (CBT)

5.1 Details of treatment

The 789 respondents who answered that they had been offered a course of CBT were asked whether the course was offered through the NHS or through the private medical sector. 93.3% (736) were offered CBT through the NHS. They were also asked if they started the course and 84.9% (670) responded 'yes'. Those people who responded 'no' were asked an open question to explain why they had not started the course.

Respondents mentioned being too ill to attend, issues surrounding travel, waiting lists and previous experience of CBT not being beneficial to be barriers to starting the course.

'It meant travelling to the hospital for too many sessions which was unrealistic'

'Was too ill to attend'

'I have done CBT before, for anxiety, and found it useless'

'I had a home assessment by CBT therapist and she said I was mentally stable and because [sic] had a plan of action to improve my life so didn't require therapy'

'Having done CBT before, the therapist and I decided it wasn't helpful for ME/CFS'

Participants were then asked if they completed the course (see Figure 4). 70% (469) said 'yes', 21.6% (145) said 'no' and 8.4% (56) respondents were still participating in a course of CBT.

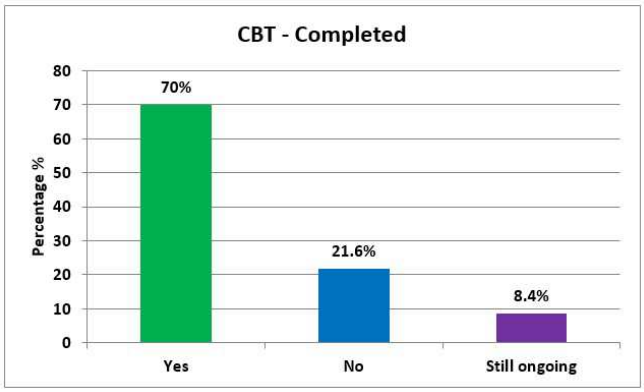


Figure 4. Completion of CBT treatment course

Those people who responded 'no' were asked an open question to explain why they had stopped.

Respondents mentioned they were too ill to continue, including worsening of symptoms of post exertional malaise (PEM), stress and anxiety. In addition, many respondents quoted treatment being stopped by the practitioner due to detrimental effects or CBT being unnecessary for the individual.

'After 5 sessions was told I was too ill for them to proceed further'

'The sessions were too long and I suffered PEM after each one and [sic] took me two weeks to cover to previous level'

'It was mutually agreed between the CBT therapist and myself that CBT was having a detrimental effect on me physically and psychologically therefore we ceased treatment'

'The counsellor identified that I was already able to do the processes that constitute CBT and did not feel I would benefit from further practice'

The participants who started a CBT course (670) were asked how many sessions were/are involved. The number of reported sessions ranged from 1 through to 180, with 197 respondents stating the number of sessions was unknown and 5 failing to respond to the question. The most common answer was six sessions (19.4%/130).

CBT courses were reported to have been delivered through a range of clinicians. A cognitive behavioural therapist was the most common answer, at 49.9% (334) of respondents. 11.9% (80) of the respondents chose 'other'. In addition, frequency word count also highlighted services offered online (see Appendix 2 for more detail). Most respondents (83%/556) reported that courses involved individual treatment (see Figure 6).

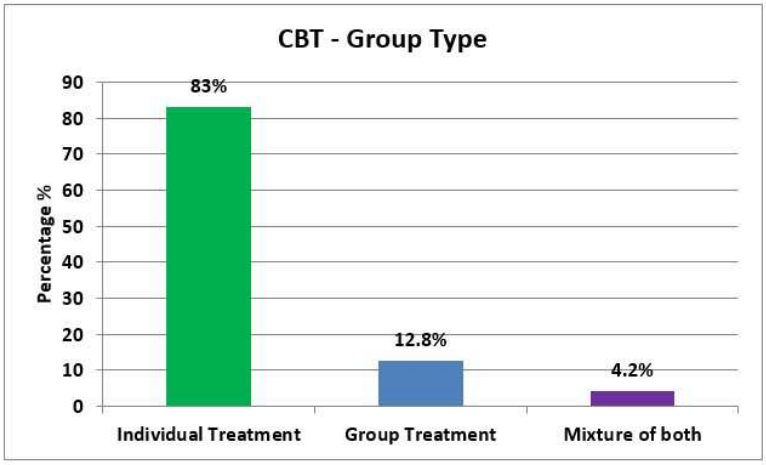


Figure 6. CBT treatment type

5.2 Impact of treatment

Respondents were asked about their physical and mental health following treatment (see Figure 7).

Most people with ME (53%) reported no change in physical health after CBT treatment. However, more experienced deterioration (26.4%) than improvement (16.2%).

People with ME most often reported an improvement in mental health after CBT (41.5%), but 28.1% experienced no change in mental health, and 26.9% reported worsened mental health after CBT.

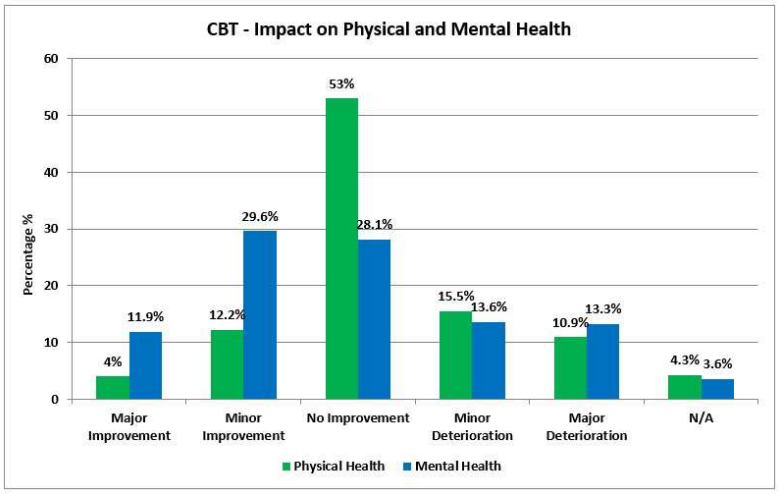


Figure 7. Impact of CBT treatment on physical and mental health

From those who started the CBT course, 46.6% (312 people) reported worsening of symptoms (Figure 8). These respondents were asked to describe how their symptoms had worsened. Common themes in responses included fatigue, cognitive issues, pain, and activity levels.

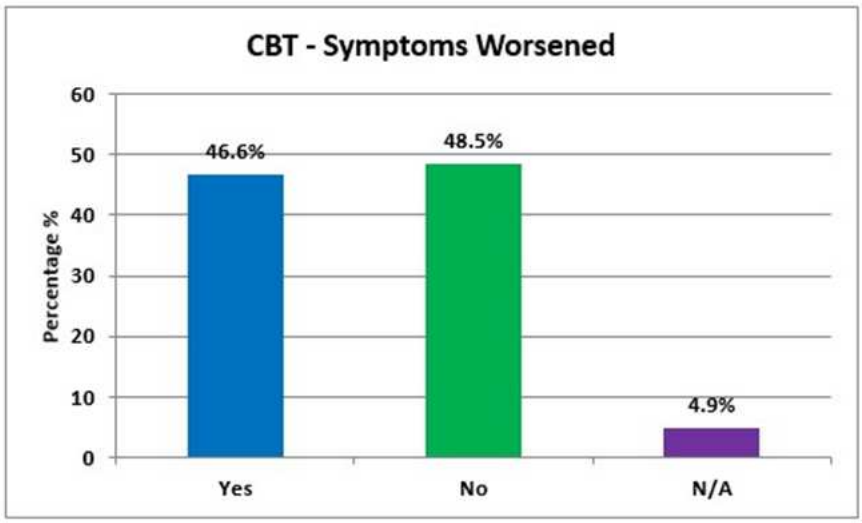


Figure 8: Symptoms worsening after CBT

'The advice to ignore symptoms caused all symptoms to increase and progressively caused [sic] condition to become worse whereby I couldn't then return to a functioning level'

'All her symptoms worsened – cognitive issues, pain levels, fatigue levels, sleep deteriorated'

'The efforts made in physically going out had a strenuous impact, increasing some symptoms'

'CBT sessions are very exhausting but worthwhile. Processing the information and skills learned takes time and is very tiring'

Respondents were also asked if they developed any new symptoms with most responding 'no' (71.8%/481 people).

Of those who started CBT, most respondents reported that before any treatment the severity of their condition was rated as 'moderate' – 66% (442 people). When asked to rate their condition after treatment with CBT most responded again as 'moderate' – 59.9% (401 people). Those rating their condition as severe went from 10.9% (73) before treatment to 19.1% (128) after treatment.

65.2% (437) of respondents were not offered other treatments in addition to GET. 33.7% (226 people) were offered other treatments. The top coded themes included management, therapy, exercise, activity and pacing. Word frequencies highlighted GET, pacing, pain management and mindfulness.

5.3 Effect of treatment

The survey asked respondents who started, if the course of CBT resulted in any change in the ability to carry out or resume employment or education. 77% (516 people) said 'no' and 21.8% (146 people) stated 'yes'.

'Her condition deteriorated so much that she has been bed bound since and is unable to resume her studies at the University or get an employment [sic]'

'Yes it greatly delayed any chance of resuming employment if at all. I may have gone back to work years earlier if I hadn't received CBT. It made my health much worse for many years¨

'Improved symptoms in order to increase very limited work hours and duties'

'Helped me plan my energy expenditure so I could return to work in a controlled way'

'I found it a little easier to manage my fatigue and so I was able to study more and carry out ad hoc [sic]'

All respondents who were offered CBT were asked if the course (completed or non-completed) had an effect on any Department for Work and Pensions (DWP) benefits (i.e. Employment and Support Allowance (ESA), Personal Independence Payment (PIP), Disability Living Allowance (DLA)) that were claimed.

Of the 670 who started CBT, most (88.7%/594 people) reported no effect on DWP benefits. Those who said 'yes' (10.7%/72) were asked to provide further detail (see Appendix 2).

Respondent quotes include:

'Helped to qualify me for benefits, I was not believed by the DWP with only my own testimony'

'My CBT therapist wrote a letter to go along with my ESA application and I think it helped me get ESA'

'Not continuing to attend fatigue clinic means no medical evidence'

'Assessor viewed attendance at CBT as a way of being able to get out of the house and reduced award'

Out of the 119 who did not start CBT, 87.4% (104) reported no effect on DWP benefits, 8.4% (10) responded 'yes' and 4.2% (5) did not answer.

The people who started CBT were asked if they had any additional comments regarding their course of treatment.

Respondent's quotes included:

'*Only thing on offer from my GP referral. The only benefit was being in a room with others sharing the condition'. Later on I realised it had been a waste of time. Also, it is an insult to suggest that ME is all in the mind. It is a physical condition not dealt with by CBT*'

'CBT helped me to accept my diagnosis and my limitations. I was able to feel more in control and understand the condition more by using pacing techniques, but the improvement in my physical health was minimal'

'I found the physical effect of attending hospital for CBT caused PEM and anxiety as I felt so dizzy and weak that I found it hard getting up the stairs to the therapist's office. If sessions could be on skype or by telephone this would reduce payback suffered by attending treatment'

'The CBT course was not long enough. I was only just beginning to grasp the concept and be able to put some of it into practice when my sessions ended'

6. Graded Exercise Therapy (GET)

6.1 Details of treatment

The 542 respondents who answered that they had been offered a course of GET were asked whether the course was offered through the NHS or through the private medical sector. 95.2% (516) were offered through the NHS. They were also asked if they started the course and 79% (428) responded 'yes'. Those people who responded 'no' were asked an open question to explain why they had not started the course.

'Refused treatments as had [sic] done GET previously and made him worse. Explained he used functional activity when possible and pacing'

'Was too ill and unable to walk from pain'

'I was too unwell to deal with an increase in pain levels brought on by exercise. The physio said it was the only option but agreed that it would be difficult for me'

'I was advised but was not well enough to do GET at all due to PEM'

The majority of responders did not complete the course of graded exercise therapy (over 60%/260). 29.7% (127) did finish, and 9.6% (41) of respondents were still participating in a course of GET.

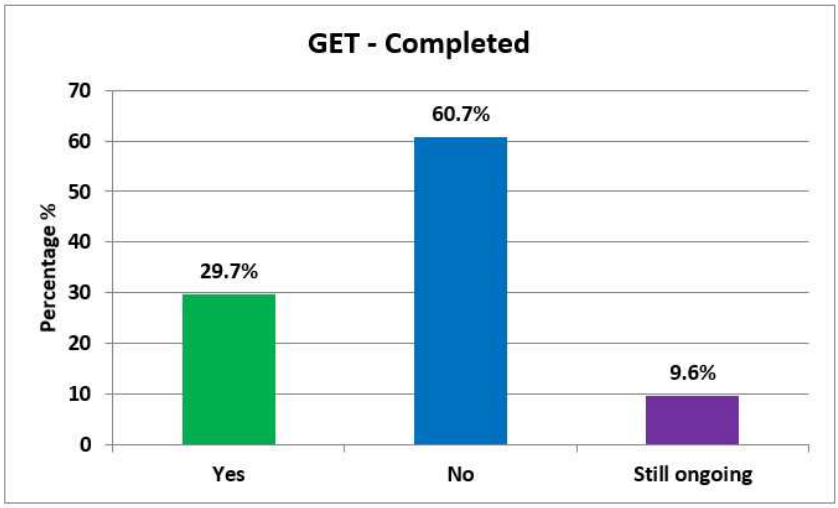


Figure 10. Completion of GET treatment course

Those people who responded 'no' were asked an open question to explain why they had stopped. Respondents mentioned an increase of symptoms, pain, discomfort, deterioration and relapse for stopping GET.

'The treatment was actually making my conditions worse, causing more pain, discomfort and exhaustion'

'Symptoms became much worse, more exhaustion and PEM'

'My condition deteriorated and I was unable to complete'

'Too difficult to maintain consistently alongside having a job and being a parent to a toddler'

'After one session I was so exhausted and in so much pain that I was confined to bed for three weeks'

'Could not establish a base point starting point ME was worse after the basic exertion also even getting to the physio Dept. caused PEM and I missed too many appointments it was cancelled'

Figure 11. Frequency count for non-completion of GET

The participants who started a GET course (428) were asked how many sessions were/are involved. The number of reported sessions ranged from 1 through to 2100, with 204 respondents stating the number of sessions was unknown and 2 failing to respond to the question. The most common answer was six sessions (10%/43).

GET courses were reported to have been delivered through a range of clinicians, the most common being a physiotherapist, reported by 48.4% (207 respondents). 19.2% (82) of the respondents chose 'other', with therapist, occupational therapist, nurse, specialist, and psychologist mentioned.

In addition, respondents also quoted GET to have been delivered by: *'A trained sports therapist'*, *'Local gym'*, *'Personal trainer'*, and an *'ME paediatric specialist'*.

Most respondents (78.5%/336) reported that GET courses involved individual treatment (see Figure 12).

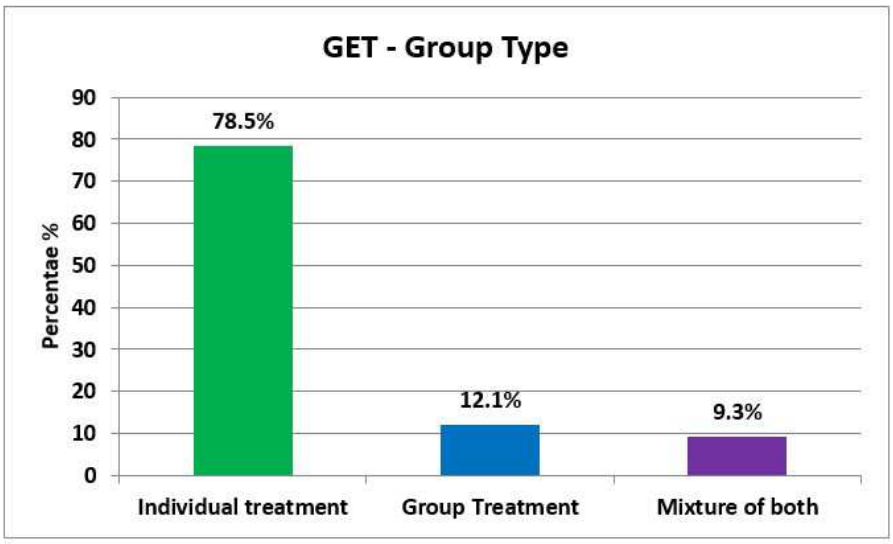


Figure 12. GET treatment type

6.2 Impact of treatment

Respondents were asked to report the impact of treatment on physical and mental health (see Figure 13). 67.1% (287) of people with ME reported deterioration in physical health after graded exercise therapy. 13.3% (57) reported an improvement in physical health, and 11.7% (50) reported no improvement (no change).

People with ME reported that GET led to deterioration in mental health as well, with 53% (227 people) reporting a worsening of mental health after GET. 25.5% (109) reported no improvement in mental health (no change), and 12.8% (55) reported improvement.

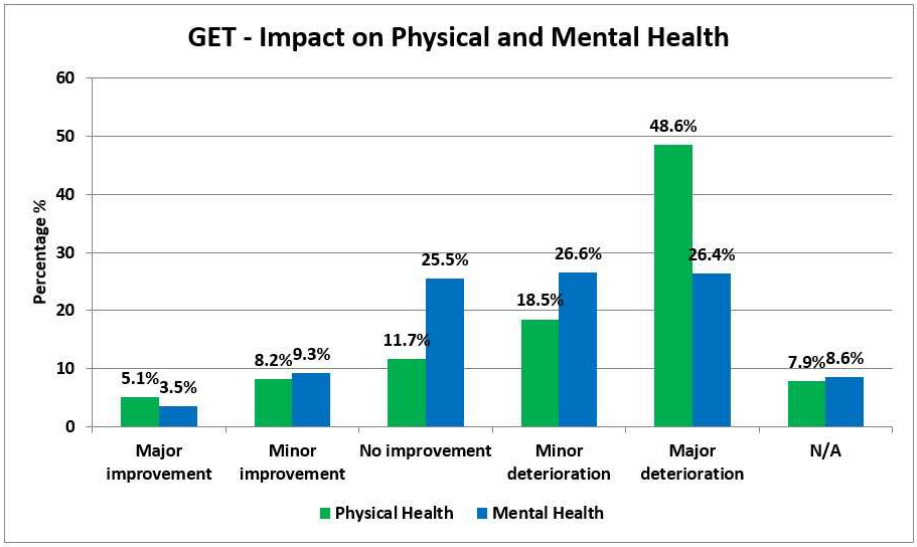


Figure 13. Impact of GET treatment on physical and mental health

From those who started the GET course, 81.1% (347) reported worsening of any symptoms (see Figure 14). These respondents were asked to describe how their symptoms had worsened. Top coded themes included pain, fatigue, muscular symptoms, cognitive issues, malaise, brain fog, and mental well-being.

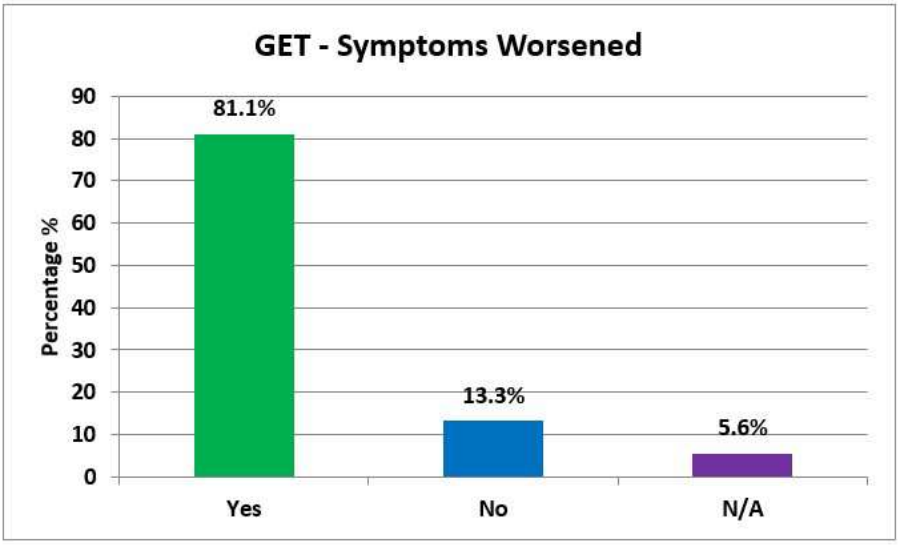


Figure 14. Worsening of symptoms post-GET treatment

'Worse fatigue, pain, mobility, sensitivities to noise and light'

'Pain was worse, exhaustion was worse. Brain fog worse, walking was too difficult'

Muscle pain, cognitive function, fatigue, dizziness, all worsened considerably'

'When I tried to increase my activity my symptoms all got worse as PEM. Over time my condition continued to worsen'

'Immediately after doing exercise, it would feel great. Then I would slowly crash and it would make me feel worse. Trying to

push through and keep going with GET encouraged the energy crashes'

Figure 15. Frequency word count for worsening symptoms after GET

Respondents were also asked if they developed any new symptoms with the majority responding 'no', 54.4% (233 people), and 36.7% (157) as 'yes'. The people who responded 'yes' were asked an open question to describe. The top coded themes included pain, sensitivity, muscular symptoms, joints, and brain. In addition, the word frequency count highlighted ideas related to disease/symptom severity and ability to walk.

'A lot more pain and fatigue was worse for a couple of months'

'Pain wasn't really a problem before GET'

'Severe neurological symptoms, including muscle spasms from stimuli, and severe stabbing headaches'

'Periodic paralysis, loss of fine motor control, breathing problems, passing out, memory loss, extreme sensitivity to light, sound and touch'

Of those who started GET, most respondents reported that before treatment the severity of their condition was rated as 'moderate' – 62.1% (226 people). When asked to rate their condition after treatment with GET most responded again as 'moderate' – 49.5% (212 people). Those who rated their severity as 'severe' before GET was 12.9% (55), which increased to 35.3% (151) after GET. See Appendix 3 for more detail.

55.1% (236 people) were not offered other treatments in addition to GET. 43.7% (187 people) were offered other treatments. The top coded themes included management, pain, activity management, sessions, therapy, sleep, exercises, psychological, pacing and medication. The word frequency count highlighted CBT, offered, help and mindfulness (see Appendix 3 for more detail).

In addition, respondents mentioned:

'Stretching exercises for pain relief. Advice on pacing and proper resting', 'Relaxation and sleep techniques, diet', 'Nutrition advice', 'Pacing and good sleep hygiene'

6.3 Effect of treatment

The survey asked respondents who started if the course of GET resulted in any change in the ability to carry out or resume employment or education. Most respondents - 53.7% (230 people) said 'no' and 44.6% (191) stated 'yes'. The top coded themes included time, time, full time, part time, school, ill health, hours, home, education and work. The word frequency count highlighted similar with the addition of able, unable, return, week and years (see Appendix 3 for more detail).

Notably 191 individuals (44.6%) reported changes in their employment after GET, and a very similar number (230, 53.7%) also reported a major change in their physical health.

Respondent quotes included:

'My condition deteriorated so I was unable to return to work'

'Yes, because my symptoms were worse I had to quit school entirely'

'After the course, I was left almost totally bed/housebound & the minor tasks I had previously been able to complete were no longer possible.'

'I was able to start back at university'

'Has speeded up recovery rate so ultimately yes'

'It meant I could mobilize for longer and gave me confidence in being more independent'

'Returned to school full time'

All respondents who were offered GET were asked if the course (completed or non-completed) had an effect on any Department for Work and Pensions (DWP) benefits (i.e. ESA, PIP, DLA) that were being claimed.

Of the 428 who started GET, most (83.6%/358 people) reported no effect on DWP benefits. Those who said 'yes' (62/14.5%) were asked to provide further detail. See Appendix 3 for more.

Respondent quotes highlighted:

'Once I had tried GET my application for DLA was finally accepted. Before GET I had applied twice and was refused twice. Tribunals for these two applications were also unsuccessful'

'Yes, as they thought I was getting exercise they thought I wasn't poorly'

'Taking part almost certainly in their eyes is meaning you're able to go back to work. Now going [sic] to lose my mobility car. As deemed fit'

'Led them to think am capable of more than actually [sic] am'

Out of the 114 who did not start GET, 84.2% (96) reported no effect on DWP benefits, 15.8% (18) responded that there was an effect.

The people who started GET were asked if they had any additional comments regarding their course of treatment. See Appendix 3 for more detail.

Respondents quoted:

'GET significantly worsened quality of life'

'I felt that all that was accomplished by either treatment was to make me feel guilty and like I wasn't trying hard enough. I was also very conflicted as my symptoms worsened following GET but stabilised somewhat following the use of simple pacing strategies'

'I got more unwell from doing GET and I have struggled to recover from that experience'

'It increased my stamina in the sense that I was able to walk further for example but still experienced the same fatigue post exercise'

'GET is the only intervention where we have seen consistent and measurable improvements. It has also helped my wife understand how to manage her energy and activity levels'

7. CBT with GET Combined

Where individuals started both CBT and GET treatment courses, they were asked to comment on CBT and GET components separately. Responses for the CBT component are in the section below.

7.1 Details of treatment

The 943 respondents who answered that they had been offered a course of CBT (combined with GET) were asked whether the course was offered through the NHS or through the private medical sector. 93% (877) of courses were offered through the NHS. They were also asked if they started the course and 76.9% (725) responded 'yes'. Those people who responded 'no' were asked an open question to explain why they had not started the course.

Respondents mentioned declining treatment, CBT being inappropriate for physical symptoms, and issues with travel and energy.

'It will not help me deal with my physical symptoms. Personally I also suffer with emotional fatigue so bringing up past issues will cause me to crash'

'I wasn't well enough to attend appointments and they were 20 miles away so getting there was difficult'

'Therapy was too far away and CBT [sic] therapist felt it would do more harm than good for me to travel there. Therapist asked questions over the phone and concluded that I wouldn't benefit from any CBT as [sic] sounded like I had the right mindset and coping strategies regarding my ill health'

'My energy levels where [sic] next to none, I simply could not attempt this'

Participants were then asked if they completed the course (see Figure 16). 70.3% (510) said 'yes', 24.8% (180) said 'no' and 4.8% (35) respondents were still partaking in a course of CBT.

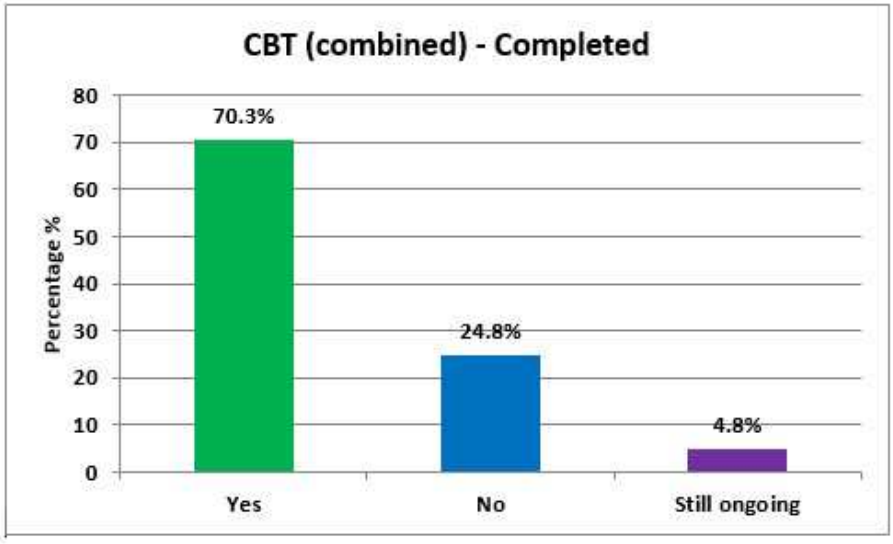


Figure 16. Completion of CBT (combined with GET) treatment course

Those people who responded 'no' were asked an open question to explain why they had stopped. Respondents mentioned they were too ill to continue with worsening of symptoms, inability to keep up with attendance, and being discharged from the service.

'Too ill to attend last few sessions'

'Too difficult to attend caused worsening of symptoms'

'The CBT therapist said CBT would be of no benefit to me as I already had a good attitude with regards to dealing with my illness'

'The CBT instructor said I was "too happy for CBT to work" and removed me from the service'

Figure 17. Frequency count for non-completion of CBT (combined with GET)

The participants who started a CBT course (725) were asked how many sessions were/are involved. The number of reported sessions ranged from 1 through to 200, with 246 respondents stating the number of sessions was unknown and 4 failing to respond to the question. The most common response (15.9%/115) was that six sessions were involved.

CBT courses were reported to have been delivered through a range of clinicians, the most common being a cognitive behavioural therapist as reported by 32.8% of respondents (238). 15.7% (114) of the respondents chose 'other', with therapist, occupational therapist, clinical, psychologist and nurse mentioned. See Appendix 4 for more detail.

Most respondents 68.7% (498) reported that courses involved individual treatment (see Figure 18).

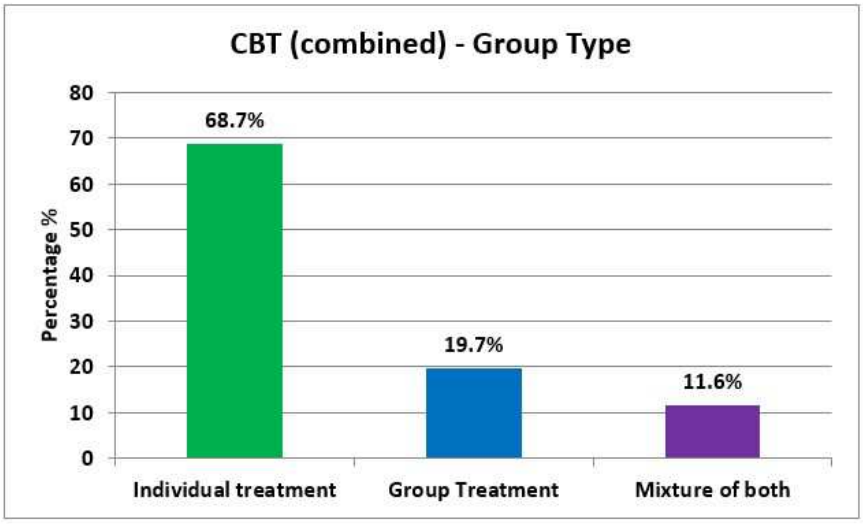


Figure 18. CBT (combined with GET) treatment type

7.2 Impact of treatment

Respondents were asked to report the impact of treatment on physical and mental health (see Figure 19). The most common response was that CBT did not improve physical health (48.4%/351 people). 11.6% (84) of respondents reported an improvement in physical health, while 35.5% (258) reported deterioration in physical health with CBT. Responses to the impact on mental health were mixed, with 34.3% (249) respondents reporting deterioration, 32.7% (237) reporting no improvement and 29.4% (213) reporting an improvement in mental health with CBT in combination with GET.

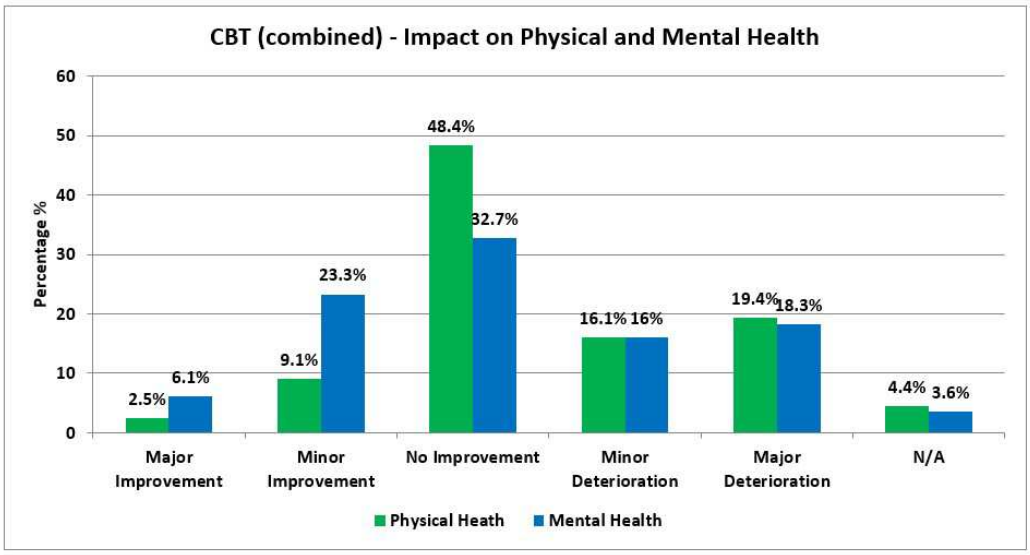


Figure 19. Impact of CBT (combined with GET) on physical and mental health

From those who started the CBT course (combined with GET), 58.3% (423) reported worsening of any symptoms (see Figure 20). These respondents were asked to describe how their symptoms had worsened. Top coded themes included brain, mental, pain, health, symptoms, cognitive, function, energy and malaise.

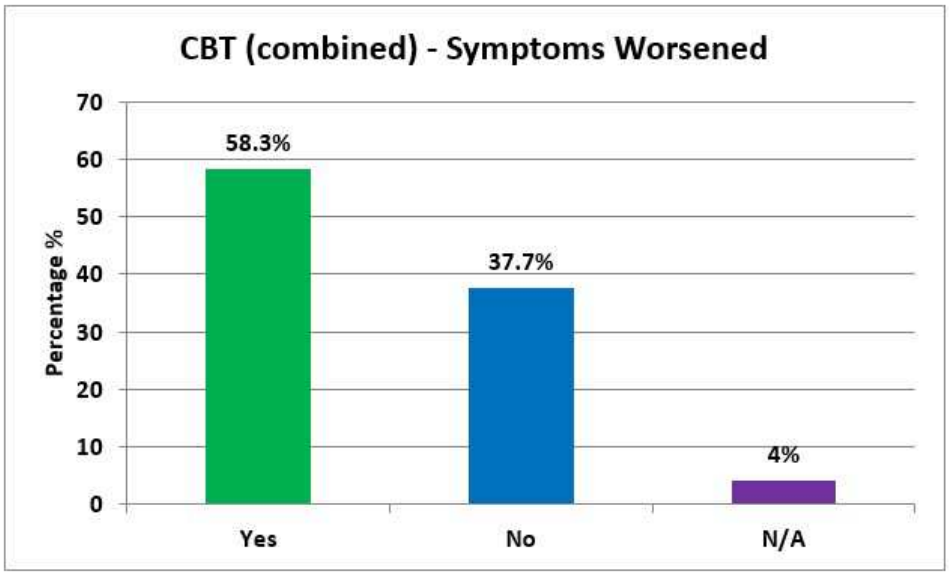


Figure 20. Worsening of symptoms post-CBT (combined with GET) treatment

'Energy and pain all got worse.

'I got PEM from the activities that were suggested that I try. Symptoms included loss of sleep, worse mood, rhinitis and fatigue.

'Pretty much all as [sic] was using too much energy on the CBT had none left for anything else'

Figure 21. Frequency count for worsening of symptoms following CBT (combined with GET)

'Complete [sic] exhausted and severe pain'

Respondents were also asked if they developed any new symptoms with most (64.6%/468) responding 'no', and 29% (210) 'yes'. The people who responded 'yes' were asked an open question to describe.

'It worsened and brought on panic and anxiety attacks'

'By allowing myself to think more of [sic] condition and impact I feel I started to experience more of over thinking without answers so it impacted on my mental health greatly'

'When I increased my activity, I went from periods of being able to be active to being on forced bed rest and I had new sensory sensitivity, muscle pain and painful glands'

'I found focusing on symptoms made me see worse. I went backwards quite quickly and became photosensitive and weak'

Of those who started CBT, most respondents -- 63.3%, or 459 people -- reported that before any treatment the severity of their condition was rated as 'moderate'. When asked to rate their condition after treatment with CBT most responded again as 'moderate' – 57.4% (416 people). The mild group reduced from 24.1% (175) before to 16% (116) after treatment. The severe group increased from 12.6%/(91) to 26.6% (193) after treatment.

63.9% (463) of respondents were offered other treatments in addition to CBT. The top coded themes included exercise, graded, therapy, management and sessions. Word frequencies highlighted GET, pacing and mindfulness (see Appendix 4 for more detail).

In addition, respondent quotes included the following:

'Sleep clinic, GET, pain management'
'Dietary, meditation, mindfulness, pain management, graded exercise'
'Advice on sleep and managing energy levels was most useful'

7.3 Effect of treatment

The survey asked the 725 respondents who started if the course of CBT resulted in any change in the ability to carry out or resume employment or education. 54.5% (395 people) said 'no' and 44.4% (322) stated 'yes'. Given that these responses are not value coded (a respondent may have improved and replied that there was no change if their employment remained the same; a respondent may have worsened, and reported the same answer.)

'Made [sic] even less likely to go back to Uni or get work'

'I had to give up a job I loved and move back in with my parents. I couldn't work for over a year'

'Loss of career, unable to return to work'

'The CBT has made it go from impossible to highly likely that I will go back to university this year (2019)'

'I now work 10 hours a week, however it took 6 months to recover from GET, and another 6 months after of slow improvement, to get to this point'

'I was able to return back to work where I had been off previously for 3 years. Changed my life!'

All respondents who were offered CBT were asked if the course (completed or non-completed) had an effect on any Department for Work and Pensions (DWP) benefits (i.e. ESA, PIP, DLA) that were being claimed.

Of the 725 who started CBT most (80.3%/582 people) reported no effect on DWP benefits. Those who said 'yes' (18.8%/136) were asked to provide further detail (see Appendix 4).

Respondent quotes highlighted:

'Both CBT and GET were compulsory to attend and a condition of my incapacity benefit as it was at the time'

'I was deemed fit for work for attending GET/CBT which also added to deterioration of [sic] condition'

'I was told I wouldn't get letters to support benefits if I didn't do the course'

'Because I completed the course the DWP claimed I must be cured and no longer sick. I was refused benefits for CFS'

'Hard to say for sure, but [sic] seemed to make my reassessment for ESA easier and got some PIP, I think because I had better evidence'

'It had [sic] positive effect in the respect that I was shown to be in receipt of treatment even though it did not improve or help symptoms had I not attended then benefits would not have been awarded'

'I believe the reports from the GET and CBT contributed to me being awarded ESA as they confirmed that, despite treatment, my condition has been progressively worsening'

'Got a job and came off benefits'

Out of the 218 who did not start CBT, 166 (76.1%) reported no effect on DWP benefits, 46 (21.1%) responded 'yes' and 6 (2.8%) did not answer.

8. GET combined with CBT

Where individuals started both CBT and GET treatment courses and were asked to comment on CBT and GET components separately. Responses for the GET component are in the section below.

8.1 Details of treatment

The 943 respondents who answered that they had been offered a course of GET (combined with CBT) were asked whether the course was offered through the NHS or through the private medical sector. 94.3% (889) of courses were offered through the NHS. They were also asked if they started the course and 75% (707) responded 'yes'. Those people who responded 'no' (25%/236) were asked an open question to explain why they had not started the course. Top coded themes included exercise, activity, pain, time, course, treatment, levels, illness, and symptoms. See appendix 5 for more detail.

'ME [sic] too severe ill to attend group therapy offered'

'My therapist felt I was too ill for GET as I had cognitive and sensory symptoms too. We started with graded activity trying to sit up to eat or brush teeth'

'I knew the dangers of GET and my health wasn't stable enough to start. The OT agreed and we used Activity pacing instead'

'The physiotherapist refused saying I was too debilitated and offered acupuncture instead'

Participants were then asked if they completed the course (see Figure 22). 48.4% (342) said 'yes', 45.3% (320) said 'no' and 6.4% (45) respondents were still partaking in a course of GET. In this combination, CBT seems to have an impact on compliance with GET treatment.

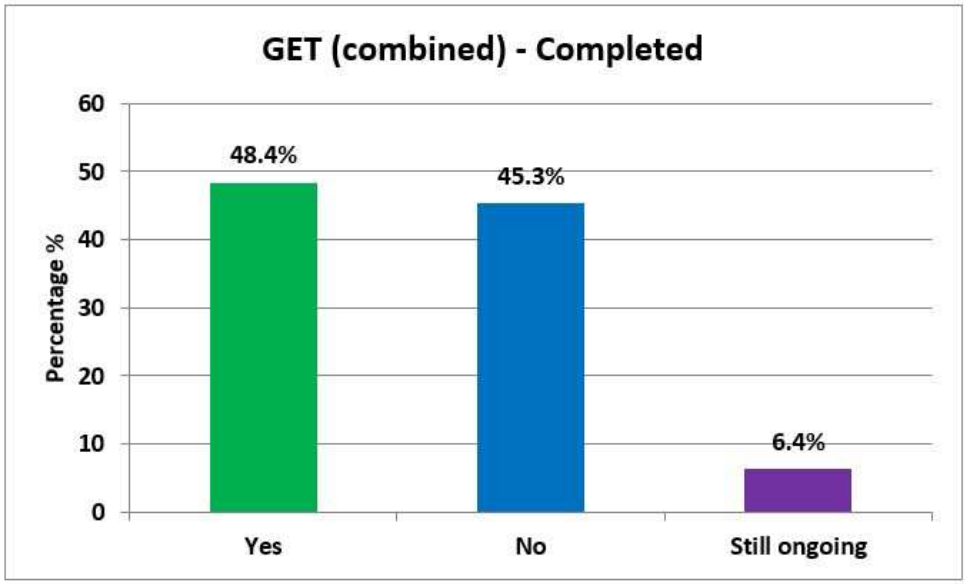


Figure 22. Completion of GET (combined with CBT) treatment

Those people who responded 'no' were asked an open question to explain why they had stopped. Top themes included exercise, activity, symptoms, pain, malaise, session, health, worsening, and illness. Word frequency counts highlighted GET, worse, made, much, and start (see Figure 23). Many respondents mentioned an increase of symptoms, pain, deterioration and worsening as reasons they stopped GET.

'Made me so ill couldn't finish the course'

'I was assessed as physically unable to, went from moderate to severe'

'I was unable to complete as my symptoms deteriorated and I became too unwell to attend or practice the information given. I also had cognitive issues and struggled to understand as I deteriorated'

'My ME specialist said it was making me worse and had to stop'

Figure 23. Frequency count for non-completion of GET (combined with CBT)

The participants who started a GET course (707) were asked how many sessions were/are involved. The number of reported sessions ranged from 1 through to 365, with 320 respondents stating the number of sessions was unknown and 8 failing to respond to the question. The most common answer (11.5%/81) was that six sessions were involved.

GET courses were reported to have been delivered through a range of clinicians, the most common being a physiotherapist as reported by 46.1% (326 respondents). 17.8% (126) of the respondents chose 'other', with therapist, occupational therapist, gym, clinical, instructor and specialist being the top coded themes amongst this group.

In addition, respondents also quoted GET to have been delivered by: *'Team of physiotherapists and occupational therapists'*, *'Gym instructor'* , *'Sports trainer'*, *'Specialist nurse'*, *'Specialist Nurse/Physiotherapist'*. Most respondents 68.3% (483) reported that GET courses involved individual treatment (see Figure 24).

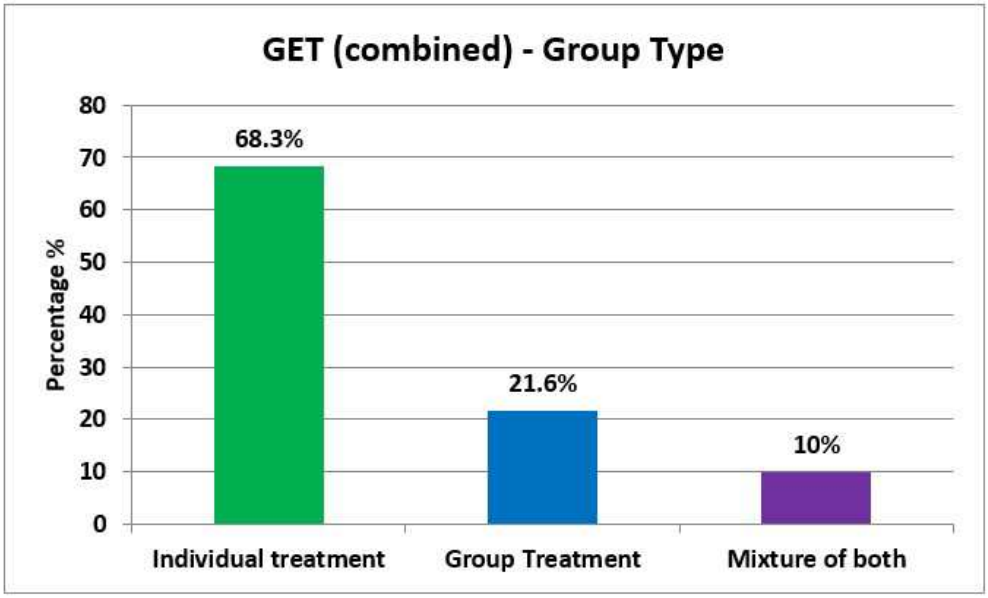


Figure 24. GET (combined with CBT) treatment type

8.2 Impact of treatment

Respondents were asked to report the impact of treatment on physical and mental health (see Figure 25). 75.4% (533) of respondents reported deterioration in physical health, while 9.6%/68 reported an improvement in physical health with GET and 11.2%/79 reported no improvement.

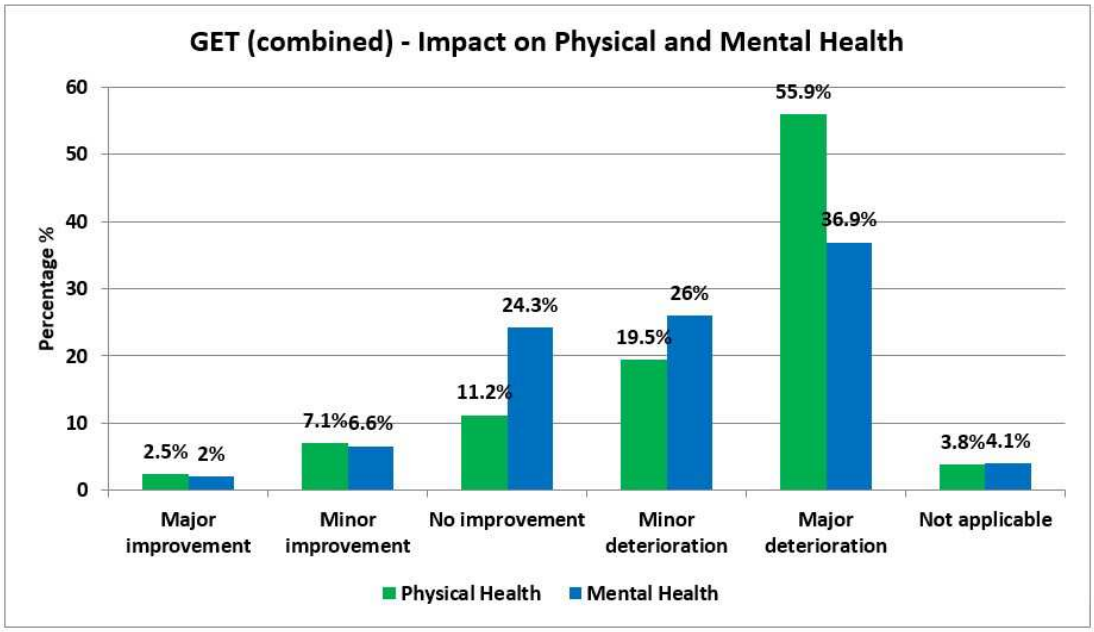


Figure 25. Impact of GET (combined with CBT) treatment on physical and mental health

GET was reported to cause deterioration in mental health in most respondents – 62.9% (445) people, 24.3% (172) reported no improvement in mental health and 8.6% (61) reported improvement.

From those who started the GET course, 85.9% (607) reported worsening of any symptoms (see Figure 26). These respondents were asked to describe how their symptoms had worsened. Top coded themes included pain, muscle, brain fog, health, mental health, levels, symptoms, cognitive, malaise and fatigue.

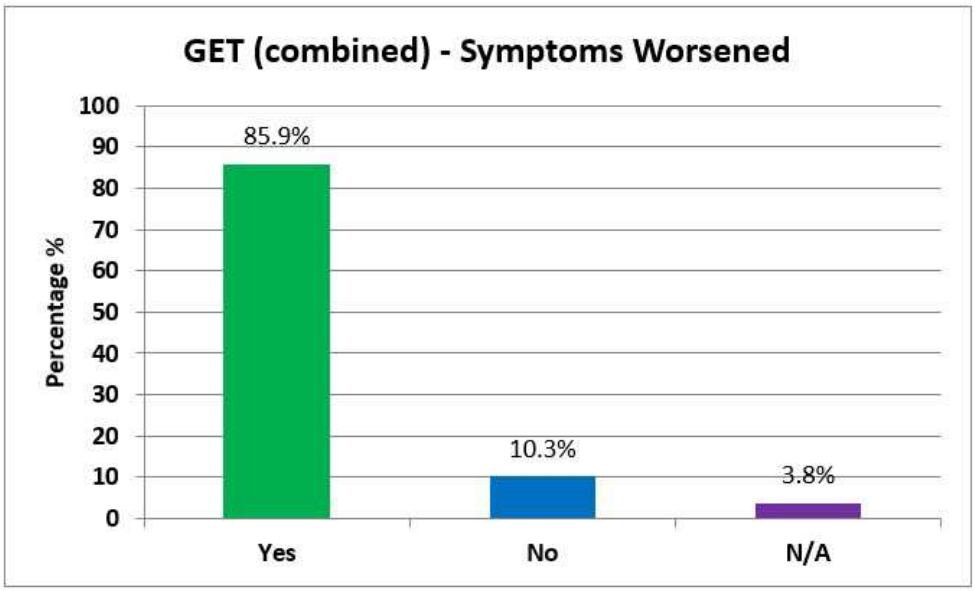
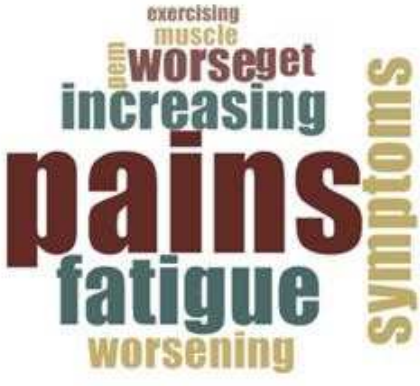


Figure 26. Worsening of symptoms post-GET (combined with CBT) treatment

In addition, frequency word count also highlighted the words increasing, worse, worsening, GET and PEM (figure 27).

'Baseline fatigue worsened. Severe PEM. Physical capabilities declined'



'My condition deteriorated during the course and continued to decline afterwards. I have never felt as well as I was at the start since, for even a day. I was not at all well beforehand'.

'I became much more fatigued and had much more pain in my joints'

'Temporary PEM following each session, but probably due to the travel effort, rather than the gentle exercises'

Figure 27. Frequency count for worsening of symptoms following GET (combined with CBT)

Respondents were also asked if they developed any new symptoms with 48.4% (342) responding 'no' and 44.4% (314) responding 'yes'. The people who responded 'yes' were asked an open question to describe. The top coded themes included pain, problems, muscle, joint, symptoms, issues and cognitive. In addition, the word frequency count highlighted severe, GET, became, unable, and walking.

'Sensory overload. More cognitive impact'

'Weakness of muscles, horrendous pain in joints and muscles'

'Ever since GET I have suffered from muscle pain all over body, very heavy painful legs and episodes of paralysis below the waist, I had none of these symptoms pre GET'

'I experienced a great deal of post exertional malaise and joint pain. My cognitive function worsened and I have never recovered to the level I was at before the commencement of GET'

Of those who started GET, most respondents (61.7%/436 people) reported that before treatment the severity of their condition was rated as 'moderate'. When asked to rate their condition after treatment with GET the most common response was still 'moderate', but it no longer represented the majority of responders, at 46% (325). The number of severe patients more than tripled after GET treatment was delivered, rising from 93 to 296 individuals (13.2% to 41.9%).

59% (417) of respondents were not offered other treatments in addition to GET, while 38.8% (274) people were offered other treatments. The top coded themes included group, pain, advice, management, course, pacing, clinic, treatment and occupational therapist. The word frequency count highlighted CBT, mindfulness, help and managing.

In addition, respondents mentioned:

'Pain management course', 'Psychotherapy', 'Painkillers and different anti-depressants', 'Acupuncture', 'Sleep hygiene', 'Meditation, yoga, counselling, nutrition awareness'

8.3 Effect of treatment

The survey asked respondents who started if the course of GET resulted in any change in the ability to carry out or resume employment or education. 51.6% (365 people) said 'no' and 47.2% (334) stated 'yes'. The top coded themes included time, full time, work, school and health. The word frequency count highlighted similar with the addition of able, unable, worse, back and hours.

Respondents quoted:

'Find it extremely difficult to go to school some days, have very little energy. I am missing the best years of my life and this illness is not in my head'

'It pushed my levels of activity back so far that I don't know if I will ever be able to work again. My confidence in myself was shattered'

'My symptoms were worsening and I went from being in full time employment to being off sick for several months and then having to give work up completely'

'The symptoms made it harder to work as many hours'

'As my condition is worse I am finding it harder to do my job and spend more time recovering in the evening and weekend'

'I have now started to start [sic] school work again but all from home'

'They helped me bet [sic] back into school faster than I would have without CBT and GET'

All respondents who were offered GET were asked if the course (completed or non-completed) had an effect on any Department for Work and Pensions (DWP) benefits (i.e. ESA, PIP, DLA) that were being claimed.

Of the 707 who started GET most (78.8%/557 people) reported 'no effect' on DWP benefits. Those who said 'yes' (20.1%/142) were asked to provide further detail. Respondent quotes highlighted:

'Was told if I didn't do it, it would affect my claim. I had to go to a tribunal and the people that did the course wrote [sic] incorrect report on my condition and what happened to me when I was there'

'I went from claiming no benefits and earning my own living to unable to work on [sic] highest rate DLA (awarded indefinitely) and ESA'

'I was able to access social security because I had medical evidence to support my case'

Out of the 236 who did not start GET, 80.9% (191) reported no effect on DWP benefits, 16.9% (40) responded 'yes'.

Both CBT and GET respondents

The final question asked all respondents who started treatment to provide any additional comments on their course of CBT and/or GET.

Coded themes included mental, health, illness, treatment, symptoms, people, activity, exercise, levels and pain. Additionally, word frequency counted getting, CBT, helps, course, made and feel as most mentioned words.

Respondents quoted:

'It didn't not [sic] work .was made to fill [sic] like u [sic] had to feel better at the end of the course. Lots of people drop out .I never got over the graded exercise I've been in severe pain with my legs ever since trying to do it'

'Totally inappropriate, coercive, abusive and harmful. New symptoms arose, existing symptoms permanently worsened, and my confidence [sic] severely knocked. Cannot trust doctors again'

'I imagine CBT can be helpful for some, particularly with co-morbid mental health issues but the distances patients have to travel to access ME/CFS services are prohibitive for patients who are already struggling with everyday activities'

'I think GET is very dangerous for people with M.E. as we push ourselves to try and follow medical advice and yet GET negatively affected me both physically and mentally as I thought that the medical advice would help me not make my condition worse'

'ME/CFS is a serious medical condition and CBT and GET are not appropriate forms of treatment. You cannot talk yourself out of this and gradually increasing your activity has long term negative effects. Please stop offering them to patients; it will ruin their already restricted lives'

'CBT had little or no effect apart from the distress and upheaval of making it to the appointments and causing brain fog and tiredness. GET completely exacerbated my symptoms and left me nearly bedbound for several months'

'CBT helped me listen to my system and learn how little I could do and how to try to not overdo it. It changed nothing about the nature of the illness itself. GET ignored all that and caused a major crash'

'It helped a great deal with understanding and coming to terms with my condition'

'Everybody should have CBT, although I still have CFS I feel better equipped to cope with it'

'CBT only helped me accept that I have to learn to live with CFS/ME [sic] didn't help to get me better'

'Did make a positive improvement over all [sic] increasing self-confidence. I was very pleased with the service I was delivered and my therapists were always easy to contact'

'Really changed my life even though my symptoms only slightly improved. It taught me to understand the condition so now I'm able to manage it much better and live an almost normal life. This has improved my mental health too. I was taught skills that I'll use for life and it was great to find someone that understood the condition'

'They had an amazing difference on my son; don't know what we would have done without this support'

Appendix 1 – Demographics for survey participants

Age group

Age group	Count	Percentage (%)
12 and under	17	0.7
13-18	167	7.3
19-30	328	14.4
31-40	491	21.6
41-50	604	26.6
51-60	462	20.3
61-70	180	7.9
71+	25	1.1
Total	2274	100

Gender

Gender	Number	Percentage (%)
Male	384	16.9
Female	1829	80.4
Non-binary	28	1.2
I would prefer not to say	30	1.3
Other	3	0.1
Total	2274	100

ME/CFS Appendix 1

Postcode sector

Postcode	Count	Weighted Percentage (%)
S - Sheffield	64	2.88
OX – Oxfordshire	60	2.70
EH - Edinburgh	57	2.56
M – Manchester	51	2.29
BS – Bristol	50	2.25
NE – Newcastle-upon-Tyne	50	2.25
GL - Gloucester	47	2.11
G – Glasgow	43	1.93
NG - Nottingham	43	1.93
BA – Bath	39	1.75
PE - Peterborough	38	1.71
PO - Portsmouth	36	1.62
SW – South West London	36	1.62
B - Birmingham	35	1.57
BN – Brighton	34	1.53
EX – Exeter	34	1.53
SE – South East London	33	1.48
CB - Cambridge	31	1.39
DE – Derby	30	1.35
CH – Chester	29	1.30
GU - Guildford	29	1.30
LE – Leicester	28	1.26
KT – Kingston-upon-Thames	27	1.21
CA – Carlisle	26	1.17
MK – Milton Keynes	26	1.17
SK – Stockport	26	1.17
BT – Belfast	25	1.12
CM - Chelmsford	25	1.12
CV – Coventry	25	1.12
HU - Hull	25	1.12

Who completed the survey?

Participant	Number	Percentage (%)
I am completing this myself (for myself)	1979	87
I am a parent completing it on behalf of my child	185	8.1
I am a carer completing it on behalf of someone I care for	92	4
Other (please specify)	17	0.7
*missing response	1	0
Total	2274	100

ME/CFS Appendix 1

Severity of condition before treatment

Severity Before Treatment	Number	Percentage (%)
Mild	542	23.8
Moderate	1419	62.4
Severe	313	13.8
Total	2274	100

Which treatment course was offered?

Treatment	Number	Percentage (%)
CBT	789	34.7
GET	542	23.8
Both CBT and GET	943	41.5
Total	2274	100

Self-reporting of post exercise malaise

PEM	Number	Percentage (%)
Yes	2239	98.5
No	35	1.5
Total	2274	100

Appendix 2 CBT treatment participants

What year were you offered a course of CBT treatment?

CBT year offered	Number	Percentage (%)
2007	34	4.3
2008	39	4.9
2009	37	4.7
2010	34	4.3
2011	27	3.4
2012	54	6.8
2013	54	6.8
2014	57	7.2
2015	64	8.1
2016	106	13.4
2017	130	16.5
2018	143	18.1
2019	10	1.3
Total	789	100

*Total = all those who were offered CBT

Was the CBT treatment offered on the NHS or through the private medical sector?

CBT Sector	Number	Percentage (%)
NHS	736	93.3
Private Medical Sector	43	5.4
*missing responses	10	1.3
Total	789	100

*Total = all those who were offered CBT

Appendix 2 – CBT treatment

Did you start the CBT course? (*answer required)

CBT started	**Number**	**Percentage (%)**
Yes	670	84.9
No	119	15.1
Total	789	100

*Total = all those who were offered CBT

If yes, please state the year or approximate year

CBT year started	**Number**	**Percentage (%)**
2007	21	3.1
2008	30	4.5
2009	26	3.9
2010	26	3.9
2011	20	3
2012	39	5.8
2013	41	6.1
2014	43	6.4
2015	45	6.7
2016	89	13.3
2017	84	12.5
2018	101	15.1
2019	11	1.6
missing responses/unknown	94	14
Total*	670	100

*Total number = those who started only

No (please explain why)

Word	Count	Weighted Percentage (%)	Similar Words
CBT	64	3.96	CBT, 'CBT'
help	27	1.67	help, help', helped, helpful, helps
illness	27	1.67	ill, ill', illness
offered	25	1.55	offer, offered, offering, offerings
appointment	19	1.17	appointment, appointments
course	17	1.05	course, courses
get	16	0.99	get, getting
treatment	16	0.99	Treatment
attend	13	0.80	attend, attended
feel	13	0.80	feel, feelings

Theme	Count	Associations
Psychological	22	Psychological treatment, psychological therapy, psychological therapies, psychological illness, psychological problems, psychology background, psychological techniques, psychological help, psychological approaches
Illness	21	Physical illness, psychological illness, mentally ill, mental illness
Treatment	18	Treatment option, psychological treatment, mental health treatment, appropriate treatment, right treatment, psychiatric treatment, physiological treatment
Health	13	Mental health treatment, mental health, physical health, private health, mental health conditions, health status
Physical illness	12	
Symptoms	7	Physical symptoms, neurological symptoms, improving symptoms, emotional symptoms
Issues	7	Mental health issues, memory issues, massive issues, main issues, capacity issues, behavioural issues
Waiting	6	Waiting list, waiting room
Option	6	Treatment option, viable option
Course	4	Previous course, online course, level course, audio course

Participant quotes:

"It meant travelling to the hospital for too many sessions which was unrealistic."

"Was too ill to attend."

"They did not seem to accept that I was not able to travel to them."

"I have done CBT before, for anxiety, and found it useless."

"Assessment by CBT lead at Bart's ME/CFS centre concurred with a previous (private health) assessment a few years earlier that "no evidence of faulty thinking patterns " and so CBT would not be beneficial."

"I had a home assessment by CBT therapist and she said I was mentally stable and because had a plan of action to improve my life so didn't require therapy."

"Having done CBT before, the therapist and I decided it wasn't helpful for ME/CFS."

"I have been on a waiting list for a few months."

Appendix 2 – CBT treatment

"I had previously tried sessions of CBT a few years before I was offered more of the same. I found that CBT just made me aware that I had an illness and I had limitations, but didn't actually go anywhere in improving the condition. If anything I think CBT made me feel more depressed because it reinforced the fact I was stuck with an illness."

"My main issue is probably that I have tried to do too much. I am currently unsure what benefit CBT will be to me because of this. My reason to take it would be to help with feelings of guilt - in my head I feel bad for not doing enough, or equally for doing too much. Motivation is not a problem at all for me. What I feel I need is information not necessarily CBT but I am open to what the clinic have to say."

Did you complete the CBT course?

CBT completed	**Number**	**Percentage (%)**
Yes	469	70
No	145	21.6
Still ongoing	56	8.4
Total	670	100

*Total number = those who started only

If you answered No to the previous questions, why did you stop?

Word	**Count**	**Weighted Percentage (%)**	**Similar Words**
sessions	55	2.67	session, sessions
illness	34	1.65	ill, illness
CBT	27	1.31	CBT
helping	27	1.31	help, 'help', helped, helpful, helping
symptoms	26	1.26	Symptoms
attend	20	0.97	attend, attended, attending
worse	20	0.97	Worse
course	19	0.92	Course
made	19	0.92	Made
therapist	18	0.87	Therapist

Theme	**Count**	**Associations**
Session	29	Group session, hour session, intense session, 4 hour sessions, 3 group sessions, 2nd session, 2hr group session, third session, last session, disjointed sessions, counselling session
Group	24	Group sessions, negative group, group leaders
Hour	15	Hour session, lasted hours, 2 hours travel, 4 hour sessions, good hour
Symptoms	13	Worsening symptoms, worsened symptoms, physiological symptoms, dismissing symptoms, physical symptoms
Ill	12	Ill health, severely ill, physical illness, ill health pension, moderately ill, illness effects
Level	10	Stress levels, pain levels, energy levels, intense level, previous levels, anxiety level
Health	8	Ill health, ill health pension, poor health, mental health
Treatment	5	Private treatment, failing treatments, ceased treatment, audio treatment hypnotherapy
Pain	5	Pain levels, severe pain, much pain, incredible pain
Activities	5	Daily activities, outdoor activities, mental activity, activity sheets

Appendix 2 – CBT treatment

"I had 6 sessions at home. Saw 4 different lady's and had to keep starting over each time. The last 2 sessions with same lady, I informed her how I missed working and she suggested when I had the odd good hour I started an Open University course on line. Then realised she didn't understand the extent of illness. Which made me feel so deflated so I stopped the sessions."

"It was mutually agreed between the CBT therapist and myself that CBT was having a detrimental effect on me physically and psychologically therefore we ceased treatment."

"Became unable to attend clinic due to PEM. Had a couple of sessions at home. Therapist from CAMHS stated 'we cannot treat ME' so CBT was stopped."

"After 5 sessions was told I was too ill for them to proceed further."

"The sessions were too long and I suffered PEM after each one and took me two weeks to cover to previous level. The sessions were weekly so I missed alternative ones and did not make last one. They were part of condition management programme but were basically CBT."

"The therapist stated after 2 sessions that the answers to the questions and my thoughts and feelings that I had no need for any further sessions."

"The counsellor identified that I was already able to do the processes that constitute CBT and did not feel I would benefit from further practice."

"It made my condition worse as it concentrated my mind on my poor health."

"No difference in symptoms."

"CBT practitioner decided I shouldn't complete, it was not helping and he was worried it was making my mental health worse."

"6 sessions were a waste of my energy getting to and from the meeting. I man just sat there and waited for me to speak."
"He promised to send several pieces of info via email but did not fulfil his promises. He seemed totally disinterested in me and my case. Highly disappointing."

"At assessment the professional reported that as it was only my health that affected my mental well-being it was not appropriate as generally I did not suffer with anxiety or depression unless my ME had worsened."

"I attended approximately six sessions but found them increasingly stressful. My anxiety level increased significantly before each session to the point when I became highly distressed and had to cancel further appointments."

"It was too general, what I really needed was help to deal with the fact my life had drastically changed due to ME\CFS, CBT didn't offer that, it was mainly about day to day depression not adjusting to a new way of life."

"The therapist left. I realised that the CBT was targeted to depression. I was not depressed."

"Therapist moved away, was offered the chance to meet a new therapist but declined due to lack of any improvement."

Appendix 2 – CBT treatment

Appendix 2 – CBT treatment

How many CBT sessions were/are involved?

CBT sessions	Number	Percentage (%)
0	2	0.3
1	6	0.9
2	16	2.4
3	9	1.3
4	24	3.6
5	16	2.4
6	130	19.4
7	5	0.7
8	79	11.8
9	5	0.7
10	43	6.4
11	1	0.1
12	72	10.7
13	2	0.3
14	3	0.4
15	7	1
16	8	1.2
18	3	0.4
20	13	1.9
22	1	0.1
24	8	1.2
25	2	0.3
26	4	0.6
29	1	0.1
30	5	0.7
40	1	0.1
50	1	0.1
180	1	0.1
unknown	197	29.4
*missing responses	5	0.7
Total	670	100

*Total number = those who started only

Appendix 2 – CBT treatment

Who delivered the CBT treatment?

CBT Clinician	**Number**	**Percentage (%)**
Cognitive Behavioural Therapist	334	49.9
Physiotherapist	18	2.7
Occupational Therapist	85	12.7
Clinical Psychologist	128	19.1
Other	80	11.9
Neurologist	1	0.1
GP	1	0.1
Psychiatrist	23	3.4
Total	670	100

*Total number = those who started only

Other (please specify)

Word	**Count**	**Weighted Percentage (%)**	**Similar Words**
nurse	14	6.48	nurse
therapist	9	4.17	therapist, 'therapist', therapists
clinic	9	4.17	clinic, clinical
CFS	7	3.24	CFS
health	6	2.78	health
psychologist	6	2.78	psychologist
specialist	6	2.78	specialist
mental	5	2.31	mental
online	4	1.85	online
service	4	1.85	service

Appendix 2 – CBT treatment

Theme	Count	Associations
Nurse	11	Mental health nurse, specialist nurse, psychiatric nurse, mental health nurse counsellor
Mental health	9	Mental health nurse, mental health team, mental health nurse counsellor
Clinic	9	Clinical psychologist, clinic specialist, CFS clinic, management clinic
Therapist	5	Talking Space therapist, qualified therapist, occupational therapist, intensity therapist
Specialist	5	Specialist nurse, clinic specialist, non-specialist
Counselling	5	Mental health nurse counsellor, counselling psychologist
Psychologist	4	Counselling psychologist, clinical psychologist
Symptoms		Symptoms clinic, physical symptoms
CFS	3	CFS clinic, local CFS service
Wellbeing practitioner	2	Wellbeing practitioner

'Other' answers provided:

Mental health nurse

Nurse at CFS Clinic

Online programme

CFS/M.E Specialist

Physio and an OT

I don't know.

I'm not sure what she was. I was never told

I'm unsure. Probably a CB therapist

Were/are you being seen individually or as part of a group?

CBT group type	Number	Percentage (%)
Individual treatment	556	83
Group Treatment	86	12.8
Mixture of both	28	4.2
Total	670	100

*Total number = those who started only

Appendix 2 – CBT treatment

What impact did CBT have on your physical health?

CBT Physical Health	Number	Percentage (%)
Major improvement	27	4
Minor improvement	82	12.2
No improvement	355	53
Minor deterioration	104	15.5
Major deterioration	73	10.9
Not applicable	29	4.3
Total	670	100

*Total number = those who started only

What impact did CBT have on your mental health?

CBT Mental Health	Number	Percentage (%)
Major improvement	80	11.9
Minor improvement	198	29.6
No improvement	188	28.1
Minor deterioration	91	13.6
Major deterioration	89	13.3
Not applicable	24	3.6
Total	670	100

*Total number = those who started only

Did any of your symptoms worsen? (*answer required)

CBT symptoms worsened	Number	Percentage (%)
Yes	312	46.6
No	325	48.5
Not applicable	33	4.9
Total	670	100

*Total number = those who started only

Yes, please describe

Word	Count	Weighted Percentage (%)	Similar Words
fatigue	86	2.40	fatigue, fatigued
sessions	73	2.03	session, sessions
symptoms	62	1.73	symptom, symptoms
pain	61	1.70	pain, painful, pains
worsening	54	1.51	worsen, worsened, worsening
worse	50	1.39	worse
increased	47	1.31	increase, increased, increases, increasing, increasingly
physical	47	1.31	physical, physically
time	47	1.31	time, times
CBT	45	1.25	CBT

Theme	Count	Associations
Sessions	35	Phone sessions, informal group sessions, hour long sessions, fortnightly sessions, session time, previous sessions, post sessions, online session, offering telephone sessions, fatigue sessions, double sessions, weekly sessions, telephone sessions, space sessions, sessions sensitivities, past sessions, next session, hour session, following session, attending sessions
Symptoms	27	Physical symptoms, cognitive symptoms, nervous system type symptoms, fatigue symptoms, flu type symptoms, cardiovascular symptoms, symptom range, symptoms change, related symptoms, PEM symptoms, original symptoms, muscular symptoms, fibromyalgia symptoms, actual symptoms
Fatigue	26	Fatigue levels, fatigue symptoms, travelling fatigue, fatigue sessions, extreme fatigue, extra fatigue, overall fatigue, mental fatigue, increased fatigue, severe fatigue issues, severe fatigue, fatigued afterwards, fatigue nausea, exertional fatigue
Time	20	Took time, taking time, session time, little time, considerable time, time afterwards, similar time period, resting time, regular time, full time employment, full time, bed time, appointment time
Levels	20	Pain levels, fatigue levels, energy levels, stress levels, functioning levels
Cognitive	20	Cognitive issues, cognitive symptoms, cognitive function, cognitive dysfunction, cognitive difficulties, cognitive skills, cognitive side, cognitive problems, cognitive deterioration, cognitive abilities
Pain	18	Pain levels, pain crash days, joint pain, physical pain, increased pain, full body pain, extreme pain, chronic pain condition, chest pain, body pain
Activity	17	Physical activity, day activities, daily activities, pacing activities, mental activity, activity plan, activity management
Brain fog	12	Brain fog
Health	11	Mental health, physical health

PEM from mental exertion caused extra fatigue, pain and flu like symptoms for 2 or 3 days after each on-line session

Less Mobility. More Pain and fatigue

Pain, fatigue, mood, hopelessness. I felt more misunderstood and isolated and that my symptoms were not believed.

All her symptoms worsened - cognitive issues, pain levels, fatigue levels, sleep deteriorated

Muscle weakness, post-exertional malaise, fatigue, cognitive symptoms (due to pushing beyond limits)

I felt more anxious attending the courses, I was told that I should pretend my CFS didn't exist or inhibit my life and should ignore it. I tried to do this; I felt I was over exerting myself and getting more unwell.

Post exertional fatigue, lowered mood and frustration at ineffective therapy offered. Impacted negatively on my routine and therefore ability to pace

I was initially moderate, but weekly outings for CBT (public transport, walking along busy roads, hour-long sessions having to sit up and then face the trip all the way back home and still have to get dressed, fix dinner, etc.) caused deterioration, we had to switch to fortnightly sessions, then phone sessions as I couldn't go out anymore, then once monthly half-sessions as phone calls were too much for me too. I was close to 100% bedridden by the time it was finished and my sister had moved in to be my full time carer. So general deterioration and worsening of all my symptoms. Became severely affected. Have not recovered from it to this day.

The advice to ignore symptoms caused all symptoms to increase and progressively caused condition to become worse whereby I couldn't then return to a functioning level.

Can't remember exactly just that the condition was worse

Did a double session fortnightly visit to reduce the travel impact which caused extreme fatigue

The efforts made in physically going out had a strenuous impact, increasing some symptoms

I had so much hope that someone could teach my how I could do something to help myself. To realise yet another person doesn't understand the extent of M.E. was crushing.

You make an assumption I am mentally ill or have depression. I occasionally get frustrated like any human - but soon feel happier once I have expressed myself. My symptoms worsened due the 100 miles round trip to hospital. I went as both GP & I were frustrated with neurologists and rheumatologists saying CBT was a magic answer. I understood GET as previously had been a cyclist and swimmer (40mls & 6mls per week).

I started the therapy able to sit upright for half an hour, by the end I couldn't. My pain levels had significantly increased. I stopped going outside entirely, and my walking had severely deteriorated. I was increasingly noise sensitive leaving me extremely isolated. Beyond this, I blamed myself for no longer being well enough to contact my friends, as my therapist had told me I should be able to do this. The CBT left me worse off, and with no tools to manage the grief of losing so much of my life

I was worried about attending the sessions I found it stressful and it made me anxious but I felt I should carry on as I was given this opportunity to reduce my symptoms.

CBT sessions are very exhausting but worthwhile. Processing the information and skills learned takes time and is very tiring

Getting to the sessions was physically demanding and the sessions were emotionally exhausting so I would lose an entire day, which impacts my entire week. But this is very minor, and was no more exhausting then a social or work activity.

Appendix 2 – CBT treatment

Did you develop any new symptoms? (*answer required)

CBT symptoms new	Number	Percentage (%)
Yes	145	21.6
No	481	71.8
Not applicable	44	6.6
Total	670	100

*Total number = those who started only

Yes, please describe

Word	Count	Weighted Percentage (%)	Similar Words
pain	27	2.01	pain, pains
symptoms	22	1.63	symptom, symptoms
anxiety	21	1.56	anxiety
CBT	14	1.04	CBT
severe	13	0.97	several, severe, severely
became	12	0.89	became
problems	12	0.89	problem, problems
increased	11	0.82	increased, increasingly
worsening	11	0.82	worsen, worsened, worsening
bed	10	0.74	bed

Theme	Count	Associations
Pain	33	Severe pain, nerve pain, arm pains, knee pain, joint pain, continual head pain, ankle pain, excruciating pain, severe muscle pains, physical pain, pain clinic, neuropathic pain, jaw pain
Symptoms	23	Flu symptoms, gastrointestinal symptoms, fever symptoms, neurological symptoms, severe symptoms, prominent anxiety symptoms, physical symptoms, recording symptoms, developing POTS symptoms
Problems	14	Teeth problems, mobility problems, mental health problems, digestion problems, constructive problem
Time	9	Day time, wrong time, time delay, night time
Orthostatic	8	Orthostatic intolerance, movement intolerance, postural orthostatic
Mobility	7	Mobility problems, mobility scooter, mobility deterioration
Levels	7	Anxiety levels, low level, energy level, activity levels
Cognitive	7	Cognitive dysfunction, cognitive impairment, extreme cognitive impairment
Anxiety	7	Prominent anxiety symptoms, anxiety levels, slight anxiety, severe anxiety, anxiety score
Bed	3	Largely bed, hospital bed, bed numbness

Anxiety. Later became PTSD from not being listened too by medical staff, started with this psychologist

My disability get much worse as I needed to quit my job which I was able to work two days a week before GET/CBT treatment

By noting patterns and recording symptoms I became increasingly anxious

Appendix 2 – CBT treatment

My physical symptoms worsened. My mobility decreased and I am in more pain. I think my energy levels being pushed made everything worse.

Increased anxiety and exhaustion

Anxiety. Later became PTSD from not being listened too by medical staff, started with this psychologist

After some time, I developed more symptoms.

Not as such, but as a result of the reading done as part of the CBT, I learnt I should not read more than a few pages/for half hour max at a time, otherwise I'd be bed ridden the following day

Stronger mind-set

Not 100%sure as it's a fluctuating condition but my movement is much worse now

It made me doubt myself.

Just wanted to add that CBT was changed to acceptance therapy due to my very positive outlook. It was changed from the 2nd session and really helped.

Over the course of the therapy, yes. As a result of the therapy, I cannot say. But I certainly became more severely ill in spite of the CBT and the adjustments made.

More pain, fatigue, exhaustion, sickness, and feeling down, useless and worthless as every goal we set I fail to achieve because it's just unrealistic!!

My mental health worsened I felt it made me more stressed and more confused

With more acceptance of my condition came psychological grieving

Felt alone and deflated, disappointed. What's the point in things when no one gets ME so my family rallied round to bring my spirits back up mentally.

CBT severity <u>before</u> treatment (all)	**Number**	**Percentage (%)**
Mild	183	23.2
Moderate	510	64.6
Severe	96	12.2
Total	789	100

Appendix 2 – CBT treatment

CBT severity <u>after</u> treatment (all)	**Number**	**Percentage (%)**
Mild	141	17.9
Moderate	401	50.8
Severe	128	16.2
*missing responses	119	15.1
Total	789	100

How severe was your condition **before** treatment with CBT and/or GET was offered/undertaken?

CBT severity <u>before</u> treatment (those started)	**Number**	**Percentage (%)**
Mild	155	23.1
Moderate	442	66
Severe	73	10.9
Total	670	100

*Total number = those who started only

How severe was your condition **after** treatment with CBT?

CBT severity <u>after</u> treatment (those started)	**Number**	**Percentage (%)**
Mild	141	21
Moderate	401	59.9
Severe	128	19.1
Total	670	100

*Total number = those who started only

Appendix 2 – CBT treatment

Were other treatments offered in addition to CBT?

CBT other treatments	Number	Percentage (%)
Yes	226	33.7
No	437	65.2
*missing responses	7	1
Total	670	100

*Total number = those who started only

Word	Count	Weighted Percentage (%)	Similar Words
get	64	4.31	get, getting
pacing	35	2.36	pace, pacing
therapy	29	1.95	Therapy
offered	28	1.88	offer, offered
pain	28	1.88	Pain
exercise	26	1.75	exercise, exercises, exercising
management	23	1.55	manage, management, management', managing
CBT	22	1.48	CBT
graded	22	1.48	Graded
mindfulness	19	1.28	minded, mindful, mindfulness, minds

Theme	Count	Associations
Management	48	Pain management course, management, graded activity management, activity management, weight management, sleep management, pain management clinic, self-management course, life style management course, condition management advice
Therapy	38	Graded exercise therapy, occupational therapy, physio therapy, pacing therapy, hydro therapy, exercise therapy, 8 sessions group therapy, supportive therapy, neuro physio therapy, acceptance therapy
Pain	38	Pain management course, pain management, pain clinic, pain management, pain medication, pain killers, pain control, pain class, joint pain, constant nerve pain
Exercise	37	Graded exercise, graded exercise therapy, graded exercise programme, exercise therapy, gentle exercise, exercise plan, exercise classes, cardio exercise
Course	32	Pain management course, 6 week course, sleep management course, 4 session course, self-management course, self-esteem course, pacing course, mindfulness course, life style management course, 8 week course
Graded exercise	30	Graded exercise, graded exercise therapy, graded exercise programme
Pain management	26	Pain management course, pain management, pain management clinic
Activity	17	Graded activity management, activity management, graded activity, usual activity, stage activity, activity levels
Sessions	15	4 session course, 30 min session, individual sessions, 8 session group therapy, six advice sessions, group sessions, group session, relaxation sessions, 6 psychologist sessions
Pacing	11	Pacing therapy, pacing programme, pacing course, pacing advice, life pacing

Appendix 2 – CBT treatment

Medication, antidepressants and pain killers increased

Amitriptyline for pain. Pacing and condition management advice

I was given six weeks of counselling before having CBT. I was also advised to exercise and push through my symptoms and pain - all of which led to a severe worsening of my condition. I then attended a six week fatigue clinic at the RUH - the effort of attending, on top of the damage done by exercising led to a severe crash that left me bed bound for over a year. I am still housebound years later and I still haven't recovered from all the damage done from incorrect medical advice.

Refused GET as exercise makes me worse not better

I attended a physiotherapist shortly before, the physiotherapist made an exercise plan for me (I don't know if it was GED as I was around the age of 12), she agreed that she seen no improvements and we stopped the therapy

Mindfulness. I gave it a go but found the whole experience demoralising and degrading and then I crashed as the journey there was physically too much.

Oxygen chamber

Gentle exercise and counselling

Group relaxation sessions

Wellbeing/Mindfulness Therapy

Activity management, Mindfulness

Acupuncture

Dietician & Physio

"Group Sessions" were (later) offered by local NHS CFS Service. I don't remember what they involved (major brain-fog at time) but I do remember rejecting them as I knew that sitting around, talking to people, would not cure my physical symptoms and expending the energy required to get to the clinic was detrimental to my health.

I had already seen a consultant who prescribed sertraline, propranolol and weekly B12 injections. These had improved the severity of the condition. Unfortunately, I lived too far away to be offered a place in his group meetings and the NHS has since banned ME consultants from prescribing B12 injections for their patients - a huge blow as he said it greatly helped 60% of the people he treated.
Physio therapy was offered after I moved to a new area and my CBT therapist referred me to a local service. But I was too ill to make it out to any of the appointments so they discharged me.

Once the therapist had assessed my situation she stopped CBT and offered me supportive therapy.

GET was talked about however it was up to me to implement independently.

After CBT graded activity management was offered as a choice alongside graded exercise therapy. Due to my worsening whilst having CBT I opted to take graded activity management which was essentially more CBT around pacing and organising and acceptance yet positivity. The sessions in total, CBT and GAM came to approx. 10.

Did the course of CBT and/or GET result in any change in your ability to carry out or resume employment or education?

Appendix 2 – CBT treatment

CBT employment/education (those started)	Number	Percentage (%)
Yes	146	21.8
No	516	77
*missing responses	8	1.2
Total	670	100

*Total number = those who started only

Further answers for Yes

Word	Count	Weighted Percentage (%)	Similar Words
work	87	5.98	work, worked, working
CBT	32	2.20	CBT
time	28	1.92	time, times
able	25	1.72	Able
helped	23	1.58	help, helped, helpful, helping
hours	22	1.51	hour, hours
day	20	1.37	day, days
employment	19	1.31	employed, employer, employers, employment
course	19	1.31	course, courses
job	18	1.24	job, jobs

Theme	Count	Associations
Time	36	Full time, full time work, full time employment, worked part time, part time university course, part time jobs, part time, wait time, taking time, part time home
Full time	25	Full time, full time work, full time employment
Work	17	Full time work, working days, worked part time, voluntary work, limited work hours, course work, working hours, work load, work environment, considering work
Days	16	Daily goals, working days, sort days, rest days, daily diaries, sick days, full days, daily living, crash days, 3 day week
Course	9	Part time university course, course work, university course, learning course, college, CBY courses, CBT course
Symptoms	7	Physical symptoms, making symptoms, improved symptoms, fluctuating symptoms
Health	8	Ill health retirement, early retirement, mental health, medical retirement, ill health retirement process, 18 months health
Employment	6	Full time employment, resuming employment, resumed employment, reduced employment prospect

Too Ill to work

I was unable to finish my school life and struggled to home schooled myself

The CBT did not help, and I eventually had to quit the volunteer position I had been doing for only 5 hours a week.

On long term sick. Made me feel even less able to cope with a return to work.

Made it even more difficult to cope with any form of study as used up all her limited energy.

Yes it greatly delayed any chance of resuming employment if at all. I may have gone back to work years earlier if I hadn't received CBT. It made my health much worse for many years.

Had to quit job

Her condition deteriorated so much that she has been bed bound since and is unable to resume her studies at the University or get an employment.

Became housebound - home tutored but sometimes too ill to have this

The treatment allowed me to feel more relaxed in my work environment, with the reduction in stress I had more energy to focus on the work at hand.

I was working 2 hours a day I increased this to 4 hours a day

Improved symptoms in order to increase very limited work hours and duties

Helped me plan my energy expenditure so I could return to work in a controlled way.

I was advised to reduce my hours which I did

I managed to keep on working, albeit on reduced hours by understanding cause & effect

Understood pacing left my career and changed job but condition remains same

It enabled me to finish my university course by helping me to reduce my stress, anxiety and depression a little bit. Only just enough to complete the course, not enough to rid me of said afflictions. It has since helped me keep at a steady, controllable level which has enabled me to get two part time jobs. However I am physically and mentally still unable to work full time.

It helped me pace in my old job, unfortunately I cannot do this is my new job and I have to work as I have a mortgage and no one will help me and provide pip

I had this course of CBT after I was able to claw my way back to work with reasonable adjustments after a relapse made me housebound for 8 months. The effects of the NHS CBT made it more difficult to carry on working, but using the knowledge and skills I'd learnt from previous consultants and private CBT with a clinical psychologist, I just about made it.

I was diagnosed with ME/CFS in June 2010 - luckily my doctor and company doctor suspected it straight away and I was put on reduced working hours. I got a lot of company support and the company paid for my CBT after the CBT I returned to work full time. (I'd been down to a 3 day week which slowly got increased).

(Course still ongoing) Helped me plan my energy expenditure so I could return to work in a controlled way.

I found it a little easier to manage my fatigue and so I was able to study more and carry out ad hoc work.

Appendix 2 – CBT treatment

Did the course (or completion / non-completion of the course) have an effect on any DWP benefits (i.e. ESA, PIP, DLA) that you were claiming?

CBT DWP benefits (those started)	Number	Percentage (%)
Yes	72	10.7
No	594	88.7
missing responses	4	0.6
Total	670	100

*Total number = those who started only

Further answers for Yes

Word	Count	Weighted Percentage (%)	Similar Words
claim	22	3.09	claim, claimed, claiming, claims
pip	16	2.25	pip
benefit	15	2.11	benefit, benefits
work	15	2.11	work, working
ESA	14	1.97	ESA
helped	14	1.97	help, helped, helping
course	12	1.69	course, 'course', courses
get	12	1.69	get, getting
support	12	1.69	support, supported, supporting, supports
evidence	10	1.40	evidence

Theme	Count	Associations
Benefit	18	Benefit claims, PIP benefits, benefit decision, benefit application
Claims	17	Benefit claims, PIP claim, claiming anything
Benefit claims	10	Benefit claims
PIP	9	PIP claim, PIP benefits, PIP assessment, full PIP
Letter	8	Supporting letter, medical letters
health	8	Worsened health, health assessments, ill health pension, health professional
Stress	5	Extra stress, added stress
ESA	4	ESA payments, illness disability payment, ESA application
Treatment	3	Offered treatments, getting treatment, following treatment
Appointment	3	Stress appointment, attending appointments

I was refused PIP despite the support of ME North east with my application and assessment.

Not continuing to attend fatigue clinic means no medical evidence

I claimed pip initially for ME without stating I was getting CBT and was turned down. I later claimed for ME and stated I was getting CBT and the assessor assumed I had depression and anxiety, this was detailed in their report and I was awarded pip. I do not have depression and anxiety.

Health insurance for illness disability payment only made after CBT completion

Since I was declared fit to work, the commitment condition for receiving Universal Credit was that I follow

recommended course of treatment through doctors and specialists

The worsening of my ME/CFS following the course of CBT has meant that I required much more support and am now in receipt of the higher rates of both PIP components

My CBT therapist wrote a letter to go along with my ESA application and I think it helped me get ESA.

Assessor viewed attendance at CBT as a way of being able to get out of the house and reduced award.

Yes, it allowed me to continue receiving them as this is evidence for my PIP claim.

Helped to qualify me for benefits. I was not believed by the DWP with only my own testimony

They claimed I had "completed" treatment and should be cured.

I am not certain but I suspect that attending the course helped my claim because it showed I was willing to take the advice given by medical professionals.

It made it harder to get DLA as they insisted it should have cured me but weirdly made getting ESS easier and I went into the Support Group on paper without a WCA.

Did the course (or completion / non-completion of the course) have an effect on any DWP benefits (i.e. ESA, PIP, DLA) that you were claiming?

CBT DWP benefits (not started)	**Number**	**Percentage (%)**
Yes	10	8.4
No	104	87.4
*missing responses	5	4.2
Total	119	100

Further answers for Yes

Word	**Count**	**Weighted Percentage (%)**	**Similar Words**
refused	3	2.97	refusal, refused
affected	2	1.98	affected, affects
appeal	2	1.98	appeal
benefit	2	1.98	benefit, benefits
CBT	2	1.98	CBT
declared	2	1.98	declared
due	2	1.98	due
ESA	2	1.98	ESA
fit	2	1.98	fit
help	2	1.98	help, helped

Appendix 2 – CBT treatment

Theme	Count	Associations
Unable to generate themes, not enough data		

I have been refused my Ill Health retirement because I haven't done CBT.

I had to have it or risk losing my ESA

I am led to believe that PIP will be affected... not sure about ESA or UC

well not sure but I have been waiting 6 months to be medically assessed and only give £103 a month to live off in universal credit so maybe

I was declared fit for work before this so saw no point in triggering another two years of depression due to being told I'm not sick. I survive due to the kindness of family and my v limited self-employment and my partner's job seekers. He has anxiety and was also declared fit for work. He volunteers to get his confidence back

They wrote a letter about how my ME affects me and I used this as evidence in my benefits claims and have been successful.

Are there any other comments on your course of CBT and/or GET? (those who started CBT treatment)

Word	Count	Weighted Percentage (%)	Similar Words
CBT	285	2.81	CBT
help	233	2.30	help, helped, helpful, helping, helps
illnesses	132	1.30	ill, illness, illnesses
symptoms	118	1.16	symptom, 'symptom, symptoms
get	108	1.06	get, getting
course	96	0.95	course, courses
conditions	84	0.83	condition, conditioning, conditions, 'conditions'
health	82	0.81	health
mental	82	0.81	mental, mentally
CFS	81	0.80	CFS

Appendix 2 – CBT treatment

Theme	Count	Associations
Physical	96	Physical symptoms, physical health, physical illness, physical condition, physical activity, physical problems, physical disability, physical improvements, physical behaviours, physical aspects, significant physical disability, physically unwell, physical strength, physical situation, physical root cause, physical pain, physical effect, physical difference, physical bio
Health	85	Physical health, mental health, mental health support, mental health issues, mental health conditions, term health condition, mental health services, mental health problems, mental health fallout, mental health aspect, previous health level, mental health team, mental health impacts, ill health, ill health retirement, health symptoms, health deterioration occupational health, health restrictions, general health
Activity	69	Activity levels, day activities, daily activities, increasing activity levels, physical activity, baseline activity levels, daily living activities, increasing activity, essential activities, suggested activities, graded activity therapy, different activities
Illness	61	Physical illness, chronic illness, mental illness, changing illness, physiological illness, illness beliefs, false illness beliefs, constant illness, psychological illness, moderately ill, immune illness, illness online, illness effects, ill mother, ill effects, complicated illness, chronic illness patients, brutal illness, actually ill
Symptoms	50	Physical symptoms, worsening symptoms, symptom management, difficult symptoms, health symptoms, cognitive symptoms, varying symptoms, symptom flare up, neurological symptoms, mental symptoms, making symptoms, immune symptoms, core symptoms, CFS symptoms
Daily	49	Day activities, daily activities, daily living activities, normal day, good days, bad days, particular day, daily living sleeping, daily living, daily diary, day basis, daily challenges, several days recovery, 4 days recovery
Levels	39	Activity levels, increasing activity level, baseline activity levels, stress levels, previous health level, fatigue levels, cellular level, residual energy levels, baseline level
Condition	27	Physical condition, mental health condition, long term health condition, underlying condition, psychological conditions, mental condition, manageable conditions, immune condition, fatigue conditions, difficult condition, depressing condition, debilitating condition, complex condition, changing condition
Course	26	CBT course, several courses, pain management course, course handbook, actual course, whole course, useful course, short course, school courses, ridiculous course, led group course, group course, generic course, courses fault
Sessions	19	Group sessions, swimming sessions, next session, therapy session, psychological rehabilitation sessions, online group sessions, limited sessions, last session, individual assessment sessions, difficult sessions, counselling sessions, 3 hour session, 2hr session, 15min sessions

Only thing on offer from my GP referral. The only benefit was being in a room with others sharing the condition. Later on I realised it had been a waste of time. Also, it is an insult to suggest that ME is all in the mind. It is a physical condition not dealt with by CBT.

I found it very damaging. It made me obsessive about my condition and how I might be able to gain back some form of control in my situation. It made me physically and mentally worse.

It meant that my child got inadequate medical care. So she suffered dreadful pain but the psychologist tried to use mindfulness to manage this. An 11 year old with severe nerve pain, it was torture and meant we had to keep attending A&E for morphine in the middle of the night. Psychologist not communicating with consultant to maintain proper care.

I did my CBT course via the phone as I was unable to drive to the venue. Skype wasn't available. The same therapist wasn't always available so no continuity. Overall very disappointing.

I found it very damaging. It made me obsessive about my condition and how I might be able to gain back some form of control in my situation. It made me physically and mentally worse

Appendix 2 – CBT treatment

CBT gave me false hope; I really believed that it was going to improve my condition so when it made no difference it left me feeling very depressed.

I found the physical effect of attending hospital for CBT caused PEM and anxiety as I felt so dizzy and weak that I found it hard getting up the stairs to therapist's office. If sessions could be on skype or by telephone this would reduce payback suffered by attending treatment.

I'm someone who always tried hard. So I tried hard and did everything they told me. I wish I hadn't.

Apart from highlighting how beneficial mindfulness could be I thought it was not what I needed. More one to one CBT would have been more help to me at the time.

I was very open about how the course was affecting me, when this was reported back to the neurologist who had implemented it there was no concern for my worsening symptoms. Although I would not say my CFS became severe I would describe the new episodes I had been having as severe. I believe if this had lasted longer my condition would have permanently worsened

Helped me to deal with being unwell

The Clinical Psychologist was caring and understood ME.

The only benefit was meeting others with the same condition who understood what we were all going through

It was just talking to help me come to terms with life change

Helped me see things were not my fault and helped me cope with specific issues I was facing a hat time.

Talking helps. I need to like myself and be kinder to myself

The CBT course was not long enough. I was only just beginning to grasp the concept and be able to put some of it into practice when my sessions ended

CBT is too generic; my ME wasn't spoken about all during the course

It has given me some coping methods but does not take away all my symptoms.

It was useful for me & got me to look at how I see things from a different perspective- didn't really do anything for my ME although I do try to not react to situations like I used to in order to conserve energy

It was helpful to talk to somebody about managing my symptoms and adapting my life to fit my disease. However, it did not alter or improve my disease in any way, and often the specialist administering the CBT was teaching out-of-date ideas compared to current research.

Friendly therapist who was very sympathetic and understanding. Followed to the letter but saw no improvement.

CBT helped me accept the condition but certainly made no physical difference. It was invaluable in me coming to terms with my now total lack of exercise and huge reduction in my hobbies

At the time, as a newly diagnosed ME sufferer who still had it all to learn, I thought that CBT did at least help me come to terms with the diagnosis, and the reality of having ME, but now I'm not so sure even that was a good thing. It just made me believe that I was responsible for my illness and that my thought patterns had caused it. I was very confused by it, and still am.

Please use the funding that is wasted on CBT on research or something that will actually help people like us, CBT is just a reinforcement of the idea that ME is very mild and can be fixed by a simple change in mind-set, my

mind is not making up this pain it's real and I wish that those who don't believe us could walk in our shoes for a day.

The CBT has greatly helped with pain management and depression it has helped me cope holistically and physically with my health and mental wellbeing definitely recommend it for others.

The most benefit was talking to someone who really understood the condition and could explain symptoms

It was great to have an unbiased opinion and to have someone who could listen and help somewhat with my mental state

CBT helped me to accept my diagnosis and my limitations. I was able to feel more in control and understand the condition more by using pacing techniques, but the improvement in my physical health was minimal.

I was already familiar with the principles of CBT so it didn't add much to my knowledge, but it did validate my knowledge and my approach to trying to manage my condition. It was also useful to undertake the CBT programme in a group, as the support of the group was beneficial more generally (and we kept in touch after the programme ended, so that informal support - of people who understand the challenges of living with CFS/ME - continued)

My CBT was fantastic and the therapist literally changed my life and brought back the old me. I was in a very dark place before CBT as I didn't understand the illness. Through being taught more I have learnt to control my CFS and understand it better.

Glad have received it. And have the skills now and knowledge to understand condition and what makes me worse/crash

Although CBT was good as it was nice to talk to someone understanding, I don't think it targets the underlying condition. Coping strategies are useful but the health symptoms still stand.

For me I found it really helpful, knowing and understanding my limitations and how to prioritise was key. Positive outlook really helped too
Although my physical health has remained the same, I found mentally I feel more positive. Gaining an understanding of what's happening to my body has helped me greatly with looking ahead.

I found CBT extremely helpful in teaching me ways to deal with my M.E.

Appendix 3 – GET treatment participants

What year were you offered a course of GET treatment?

GET year offered	Number	Percentage (%)
2007	22	4.1
2008	19	3.5
2009	24	4.4
2010	20	3.7
2011	21	3.9
2012	30	5.5
2013	35	6.5
2014	48	8.9
2015	61	11.3
2016	62	11.4
2017	92	17
2018	102	18.8
2019	6	1.1
Total*	542	100

*Total = all those who were offered GET

Was the GET treatment offered on the NHS or through the private medical sector?

GET Sector	Number	Percentage (%)
NHS	516	95.2
Private Medical Sector	23	4.2
*missing responses	3	0.6
Total	542	100

*Total = all those who were offered GET

Appendix 3 – GET treatment

Did you start the GET course? (*answer required)

GET started	Number	Percentage (%)
Yes	428	79
No	114	21
Total	542	100

*Total = all those who were offered GET

Yes, please state the year or approximate year

GET year started	Number	Percentage (%)
2007	15	3.5
2008	14	3.3
2009	15	3.5
2010	12	3.3
2011	16	3.7
2012	19	4.4
2013	23	5.4
2014	34	7.9
2015	44	10.3
2016	43	10
2017	64	15
2018	69	16.1
2019	2	0.5
*missing responses/unknown	56	13.1
Total	428	100

*Total = those who started GET

No, please explain why

Word	Count	Weighted Percentage (%)	Similar Words
get	53	2.93	get, getting
exercise	27	1.49	exercise, exercises, exercising
day	23	1.27	day, days
worse	23	1.27	worse
walk	21	1.16	walk, walked, walking, walks
trying	18	1.00	tried, try, trying
activity	16	0.88	active, activities, activity
knew	15	0.83	knew
make	15	0.83	make, making
offering	15	0.83	offer, offered, offering

Theme	Count	Associations
Exercise	21	Increasing exercise, mild exercise, graded exercise, couple exercise, stretching exercises, prescribed exercise routine, ongoing exercise, light exercise, exercise plan, exercise classes
Increase	4	Increase exercise, staged increase approach, marked increase
Appointment		1-2-1 afternoon appointment, initial appointment, fortnightly appointment, follow- up appointment, assessment appointment, afternoon appointment
Session	6	Group session, support group, preliminary sessions
Treatment	5	Refusing treatment, refused treatments, appropriate treatment
Specialist	5	Couple exercise specialist, non-specialist health professionals, local specialist service, awaiting specialist confirmation
Activity	5	Physical activity, graded activity therapy, functional activity
Pain	4	Attending pain management clinics, pain levels, neck pain
Heart rate	4	Monitoring heart rate, heart rate monitor, heart rate
Energy	4	Much energy, limited energy, little energy

Refused treatments as had done Get previously and made him worse. Explained he used functional activity when possible and pacing.

My daughter was told by the hospital at her appointment that all she needed to do to get better was to take a walk each day and increase upon this daily. She was so desperate to get better she carried this out..... resulting in her becoming bedridden for 9 months.

Was too ill and unable to walk from pain

Was encouraged to push through by every medic throughout illness. Until it was impossible to do this anymore

I find courses impossible to attend due to my ME!

Because I knew it would make me suffer 'payback' of fatigue and pain for some days afterward which is very debilitating

I was too unwell to deal with an increase in pain levels brought on by exercise. The physio said it was the only option but agreed that it would be difficult for me

As a preteen/teen, I followed doctors' advice to exercise, stay out of bed, and push past my pain. It made my condition deteriorate rapidly. Now I am bedbound and traumatised from being forced to exert myself.
IT WAS NOTED THAT I WAS NOT RESPONDING WELL AND GOING DOWN HILL FAST DURING THE ME/CFS NHS COURSE OFFERED. THE OT WHO WAS LEAD IN THE SESSIONS ACTUALLY PUT ME ON 0% ACTIVITY AS A RESULT

OF SEEING ME AFTER THE FIRST COUPLE OF WEEKS TRYING TO DO WHAT THEY WERE SUGGESTING IN THE MEETINGS.

Matthew had done a previous course of GET and CBT in Huddersfield before 2007 and ended up worse afterwards so declined to try GET this time

Local sports facility was unable to supply treatment/therapy, as no one had any experience of GET, nor any possibility of learning it. Referral lapsed because of this

Saw physio and she gave different form of exercise

The physiotherapist said she was unhappy doing GET with people with ME because in her experience it made them worse.

I would have had to make up the time at work if I travelled to the hospital for GET. Hospital was too far away.

I was advised but was not well enough to do GET at all due to PEM

The clinic felt I wasn't well enough to attend to weekly GET meeting

Physio & OT are delivering a programme of GET for our son. We encourage him to do some stretching exercises (when he feels able) as the programme recommends - however we will not be pushing him to do any more than he feels capable of due to severe PEM.

Because I had and continue to keep pushing myself to increase my mobility and health always with the same result so far and that is to relapse. So no point in starting something I know is not only not going to work but is likely to have an adverse effect on my health .

The physiotherapist offering GET required me to find my baseline and to work up (increase exercise) from there. At the time it was impossible for me to even find my baseline as I was already doing much more than my ME allowed (I.e. Working full time, raising my two children alone, running a household). I was totally stuck in a 'boom and bust' cycle, so I felt that increasing my exercise at that time was only going to do further damage and be detrimental to my ME. Four years on I still believe this to be true.

Did you complete the GET course?

GET completed	**Number**	**Percentage (%)**
Yes	127	29.7
No	260	60.7
Still ongoing	41	9.6
Total	428	100

*Total = those who started GET

Appendix 3 – GET treatment

If you answered No to the previous questions, why did you stop?

Word	Count	Weighted Percentage (%)	Similar Words
worse	87	2.91	worse
get	69	2.31	get, getting
symptoms	67	2.24	symptoms
made	58	1.94	made
exercise	40	1.34	exercise, exercises
increase	38	1.27	increase, increased, increases, increasing
became	34	1.14	became
activity	33	1.11	active, activities, activity
day	32	1.07	day, days
illness	30	1.00	ill, illness, illnesses

Theme	Count	Associations
Activity	23	Increasing activity, daily activities, physical activity, required activities, pacing activities, pace activity, limited activity, home graded activity, additional activities, activity periods
Daily	19	Daily activities, bad days, increasing days, daily walk, daily living, days plus, daily headaches, consecutive days
Exercise	15	Graded exercise, complete exercise, exercise levels, suggested exercise, stretching exercises, much exercise, gentle exercise movements, exercise treatment, exercise plan
Increasing	14	Increasing activity, increasing exercise, increasing days, increase program
Symptoms	12	Worsening symptoms, exertion symptoms, severe symptoms, making symptoms, exacerbating symptoms
Worsening	11	Worsening symptoms, severe worsening, extreme worsening, subsequent worsening, profound worsening
Pain	9	Pain levels, much pain, severe pain, knee pain, joint pain
Health	8	Shocking health, mental health issues, health care professionals, health care people, good health, deteriorating health, daughters health
Session	6	Group session, routine session, remaining session, next session, lone session
Appointments	6	Telephone appointments, psychological appointments, next appointment, hospital appointments, doctors' appointments, bimonthly appointments

Deteriorating health

Severe worsening of fatigue made bedridden now in a wheelchair

Suffered PEM immediately tried to increase activity, symptoms became worse and before could complete the course became severely affected by ME and have been 90+% housebound ever since

The Treatment was actually making my conditions worse, causing more pain, discomfort and exhaustion.

No improvement then subsequent worsening of all symptoms and had to stay off school

Discharged from Alderhey as there was no improvement. Appointments and PEM recovery were causing worsening of symptoms

My son crashed and never recovered!!

Symptoms became much worse, more exhaustion and PEM

It made my symptoms worse, became too ill to complete any more sessions

Appendix 3 – GET treatment

My condition deteriorated and I was unable to complete

It made me worse and pushed me into a 3 month relapse I never fully recovered from.

Too difficult to maintain consistently alongside having a job and being a parent to a toddler

Pain became worse and was involuntarily discharged

After one session I was so exhausted and in so much pain that I was confined to bed for three weeks.

Exacerbated symptoms from beginning & during (age 15) took own decision to cease & decision supported by other medical professionals

Unachievable

The physio stopped the therapy and ended her work with me, because I was unable to reach my targets.

Increase in symptoms despite following suggestions to the book

Could not establish a base point starting point ME was worse after the basic exertion also even getting to the physio Dept. caused PEM and I missed too many appointments it was cancelled

The course change to fatigue management

At reaching a certain level of activity (around 20 minutes walking) my daughter suffered severe PEM/relapse. She was then advised by hospital team to start back at lower level of activity and gradually increase again, but again reached a level at which she would relapse. None the less the hospital team continued to promote this approach over the 3 years we were under them.
She has only been able to achieve more educationally and feel better emotionally by keeping her physical activity low

I started to decline around half way through the program after initially making improvements. To try and keep the improvements we decided to move to home graded activity via community physio instead. I continue but worsened to such a degree that all agreed to terminate program including the professionals.

I couldn't make the sessions. I get ill very easily & common Illnesses such as cough, cold & viral infection means I am able to do very little. I tried to attend 3 sets of sessions. The most I made it was 3 sessions

Appendix 3 – GET treatment

How many GET sessions were/are involved?

GET sessions	**Number**	**Percentage (%)**
1	14	3.3
2	15	3.5
3	25	5.8
4	27	6.3
5	23	5.4
6	43	10
7	3	0.7
8	13	3
10	16	3.7
11	1	0.2
12	17	4
13	4	0.9
14	2	0.5
15	8	1.9
16	2	0.5
20	2	0.5
25	3	0.7
28	1	0.2
30	1	0.2
52	1	0.2
2100	1	0.2
unknown	204	47.7
*missing responses	2	0.5
Total	428	100

*Total = those who started GET

Appendix 3 – GET treatment

Who delivered the GET treatment?

GET Clinician	Number	Percentage (%)
Cognitive Behavioural Therapist	12	2.8
Physiotherapist	207	48.4
Occupational Therapist	98	22.9
Clinical Psychologist	14	3.3
Other	82	19.2
GP	9	2.1
Immunologist	2	0.5
Psychiatrist	4	0.9
Total	428	100

*Total = those who started GET

Other (please specify)

Word	Count	Weighted Percentage (%)	Similar Words
specialist	15	5.32	specialist
nurse	13	4.61	nurse, nurses
therapist	13	4.61	therapist
occupational	10	3.55	occupational
clinic	9	3.19	clinic, clinical
psychologist	9	3.19	psychologist
physiotherapist	8	2.84	physiotherapist
CFS	7	2.48	CFS
hospital	6	2.13	hospital
physio	6	2.13	physio

Theme	Count	Associations
Therapist	23	Occupational Therapist, trained sports therapist, nurse therapist
Occupational Therapist	19	Occupational Therapist
Nurse	15	Specialist nurse, pain management nurse, specialist consultant nurse, nurse therapist, nurse practitioners, consultant nurse
Specialist	11	Specialist nurse, specialist consultant nurse, specialist physiotherapist, specialist paediatric, specialist experience
Trained	6	Trained sports therapist, trained gym worker, physical trainer, occupational therapy training, local trainer
Psychologist	5	Trainee psychologist, clinical psychologist
Hospital	3	Homeopathic hospital, Glenfield hospital, Frenchay hospital

Appendix 3 – GET treatment

Delivered by an occupational therapist.

I believe it was a physiotherapist with specialist experience of GET

Consultant nurse

ME nurse

ME paediatric specialist

Clinical Psychologist and Physio Therapist

Personal trainer Local gym

Combination of physio and OT

A trained sports therapist

Team including physiotherapist, occupational therapist, and pain-management nurse

Were/are you being seen individually or as part of a group?

GET group type	**Number**	**Percentage (%)**
Individual treatment	336	78.5
Group Treatment	52	12.1
Mixture of both	40	9.3
Total	428	100

*Total = those who started GET

What impact did GET have on your physical health?

GET Physical Health	**Number**	**Percentage (%)**
Major improvement	22	5.1
Minor improvement	35	8.2
No improvement	50	11.7
Minor deterioration	79	18.5
Major deterioration	208	48.6
Not applicable	34	7.9
Total	428	100

*Total = those who started GET

Appendix 3 – GET treatment

What impact did GET have on your mental health?

GET Mental Health	Number	Percentage (%)
Major improvement	15	3.5
Minor improvement	40	9.3
No improvement	109	25.5
Minor deterioration	114	26.6
Major deterioration	113	26.4
Not applicable	37	8.6
Total	428	100

*Total = those who started GET

Did any of your symptoms worsen? (*answer required)

GET symptoms worsened	Number	Percentage (%)
Yes	347	81.1
No	57	13.3
Not applicable	24	5.6
Total	428	100

*Total = those who started GET

Yes, please describe

Word	Count	Weighted Percentage (%)	Similar Words
pains	165	4.41	pain, painful, pains
fatigue	125	3.34	fatigue, fatigued
increased	104	2.78	increase, increased, increases, increasing
worsening	74	1.98	worsen, worsened, worsening, worsens
worse	69	1.85	worse
symptoms	64	1.71	symptom, symptoms
muscle	52	1.39	muscle, muscles
get	49	1.31	get, getting
became	43	1.15	became
PEM	42	1.12	PEM

Appendix 3 – GET treatment

Theme	Count	Associations
Pain	56	Physical pain, joint pain, muscle pain, extreme pain, constant pain, extra pain, general pain
Fatigue	61	Worsened fatigue, post exertion fatigue, overall fatigue, physical fatigue, fatigue increased, extreme fatigue, cognitive fatigue
increased	65	Increased pain, increasing activity, increased muscle pain, increased headaches, increased fatigue, increased exhaustion, increased aches
Muscle	104	Muscle weakness, muscle twitching, severe muscle weakness, muscle pain, increased muscle pain, muscle aches, leg muscle pain
Symptoms	28	Worsening symptoms, worsening cognitive problems, flu-like symptoms, physical symptoms, PEM symptoms, horrendous symptoms
Cognitive	46	Worsening cognitive symptoms, worsening cognitive abilities, cognitive weakness, cognitive problems, dysfunction, issues, impairment, difficulties
Levels	41	Tolerance levels, significant levels, pain levels, fatigue levels, energy levels, general fatigue levels
Malaise	41	PEM, malaise worsens, exhaustion malaise, general malaise
Brain fog	55	Sever brain fog, increased brain fog, constant brain fog, brain fog nerve pain, brain fog mental health
Mental	19	Mental welfare, mental symptoms, mental health crash, mental distress, mental capacity

Worse fatigue, pain, mobility, sensitivities to noise and light

Pain was worse, exhaustion was worse. Brain fog worse, walking was too difficult

Went from mild end of moderate to severe. Could not attend school. Housebound. Severe pain. Severe brain fog

All symptoms worsened - in particular increased fatigue, severe headaches, eye strain / pain. Became primarily housebound and bed bound.

All symptoms increased - joint pain, severe headaches, poorer cognitive function, flu like feelings, more tiredness.

PEM and fatigue increased, felt more ill, increased pain, increased headaches, more sore throats

My ME got worse; I was in bed for almost 2 years, awful fatigue, bad stomach problems, nausea, PEM

Muscle pain, cognitive function, fatigue, dizziness, all worsened considerably

All symptoms worsened both cognitive and physical.

Taking a lot longer to recover from each activity

Tiredness, unable to concentrate for extended time, school attendance fell
When I tried to increase my activity my symptoms all got worse as PEM. Over time my condition continued to worsen.

Over the first few sessions, I noticed little change but gradually started to "pace" myself and found some improvement before relapsing and then struggling to get back to where I was before.

Continued experiencing debilitating PEM despite enjoying moving. Later deteriorated again, but I think that was multifactorial, rather than specifically due to GET

Appendix 3 – GET treatment

Initially both physical and mental symptoms greatly improved but then suddenly hit that wall and everything was a lot worse with no improvement for over a year

All of them. I found the baseline helpful, plus viewing the illness with positivity. But, trying to make each day the same intensity extremely hard and not achievable. It still rules me with its complexity.

Immediately after doing exercise, it would feel great. Then I would slowly crash and it would make me feel worse. Trying to push through and keep going with GET encouraged the energy crashes.

Keep trying and not improving so struggling to stay positive. I'm a naturally active woman and want to improve

Fatigue did mildly but long term has improved. Although if I overdid it was detrimental as I was left to monitor myself

Did you develop any new symptoms? (*answer required)

GET symptoms new	**Number**	**Percentage (%)**
Yes	157	36.7
No	233	54.4
Not applicable	38	8.9
Total	428	100

*Total = those who started GET

Yes, please describe

Word	**Count**	**Weighted Percentage (%)**	**Similar Words**
pains	57	4.11	pain, painful, pains
muscle	18	1.30	muscle, muscles
severe	18	1.30	several, severe, severely
symptoms	17	1.23	symptoms
get	16	1.15	get, getting
legs	15	1.08	leg, legs
sensitivity	15	1.08	sensitive, sensitivity
walk	15	1.08	walk, walked, walking
able	14	1.01	able
unable	14	1.01	unable

Appendix 3 – GET treatment

Theme	Count	Associations
Pain	34	Joint pain, increased pain, nerve pain, minor knee pain, severe pain, severe muscle pain, joint pain headaches, sever leg pain, worsening body pain
Sensitivity	24	Light sensitivity, sound sensitivity, temperature sensitivity, noise sensitivity, sensory sensitivity, extreme sensitivity
Symptoms	15	Neurological symptoms, cognitive symptoms brain fog, secondary symptoms, existing symptoms, possible symptoms
Muscle	15	Eye muscles, sever muscle pain, poor body muscle strength, muscle wastage, muscle pain, muscle spasms, muscle tremors, muscle contractions
Health	15	Mental health issues, existing health issues, overall health, mental health deterioration
Issues	13	Mental health issues, existing health issues, mobility issues, developed issues, cardio issues, balance issues
Time	10	Night time vision, employment part time, full time e employment, whole time, time bedbound, increased recovery times
Joint	10	Joint pain, joint pain headaches, joint aches, aching joints
Loss	8	Struggled hair loss, periodic voice loss, memory loss, complete loss
Brain	8	Brain fog, cognitive symptoms, worsened brain

Over the years with: no successful treatment; worsening of symptoms; the illness has progressed and I have joined the many sufferers with the long list of symptoms this illness causes. The debilitating nature of ME over time has caused secondary symptoms connected with long term, chronic illness.

Pain wasn't really a problem before GET

Developed issues with balance, speech, facial twitches, head jerks, headaches and tinnitus. Became freezing cold all of the time. Constant fevers. Heart palpitations. Severe hypersomnia and insomnia. Increased dizziness/feeling faint.

IBS symptoms, sensitivity to light, noise, movement and smells. Inability to hold conversations for long periods. Palpitations, rapid heartbeat, feeling feverish, hot and cold sweats, nerve pain, dry eyes and mouth, poor memory, poor balance, poor coordination, inability to tolerate sitting in an upright position, dizziness, nausea, brain fog, breathlessness.

A lot more pain and fatigue was worse for a couple of months

Now a wheelchair user, bed bound, housebound, with deterioration of mental health to include panic attacks, constant anxiety and agoraphobia

Severe neurological symptoms, including muscle spasms from stimuli, and severe stabbing headaches

Periodic paralysis, loss of fine motor control, breathing problems, passing out, memory loss, extreme sensitivity to light, sound and touch.

Much higher fatigue & PEM - spent even more time bedbound.

The whole condition worsened and I have almost all possible symptoms. I don't remember if any of the symptoms developed after GET

I had symptoms which I thought had healed return, e.g. pots, thrumming, tingling, sugar crashing, low cortisol

Less mobile than before

Increased body aches pains. Less mobile. Back pains. Tearful the whole time. active ability declined. Can barely

lift items. Not washing herself and putting on a brave face to GET pretending she is achieving what is asked as doesn't want to let them down and get kicked out CFS system. Wants to stay in in hope something new will come as took 2 years to get any support

Added Feeling of disappointment, sadness, more pain to deal with on top of what I already had. Frustration that I knew it wasn't working but I didn't dare give up for a long time

I developed migraines, much later found to be greatly linked to overexertion, as detailed above. About 1 1/2 years after I started GET my migraines are still present and only just beginning to improve. It is very probable that my period of GET is not the sole cause, however I think it may have contributed to their appearance/continuation.

How severe was your condition **before** treatment with CBT and/or GET was offered/undertaken? (completed or not)

GET severity <u>before</u> treatment (all)	**Number**	**Percentage (%)**
Mild	130	24
Moderate	332	61.3
Severe	80	14.8
Total	542	100

How severe was your condition **before** treatment with CBT and/or GET was offered/undertaken? (completed or not)

GET severity <u>after</u> treatment (all)	**Number**	**Percentage (%)**
Mild	65	12
Moderate	214	39.5
Severe	153	28.2
*missing responses	110	20.3
Total	542	100

Appendix 3 – GET treatment

How severe was your condition **before** treatment with CBT and/or GET was offered/undertaken?

GET severity <u>before</u> treatment (those started)	**Number**	**Percentage (%)**
Mild	107	25
Moderate	226	62.1
Severe	55	12.9
Total	428	100

*Total = those who started GET

How severe was your condition **after** treatment with GET?

GET severity <u>after</u> treatment (those started)	**Number**	**Percentage (%)**
Mild	65	15.2
Moderate	212	49.5
Severe	151	35.3
Total	428	100

*Total = those who started GET

Were other treatments offered in addition to GET?

GET other treatments	**Number**	**Percentage (%)**
Yes	187	43.7
No	236	55.1
*missing responses	5	1.2
Total	428	100

*Total = those who started GET

Appendix 3 – GET treatment

Further answers for Yes

Word	Count	Weighted Percentage (%)	Similar Words
CBT	105	7.58	CBT
offered	30	2.17	offer, offered
pacing	27	1.95	pace, pacing
get	24	1.73	get, getting
help	22	1.59	help, helped, helpful
management	20	1.44	management, managing
sessions	18	1.30	session, sessions
course	17	1.23	course, courses
pain	17	1.23	pain
mindfulness	15	1.08	mind, mindfulness

Theme	Count	Associations
Management	37	Activity management, pain management, activity management group, patient management course, self-management
Pain	24	Pain management, pain clinic, pain relief, pain killers
Activity management	15	Activity management group
Sessions	19	Relaxation sessions, education sessions, open sessions, group sessions, exercise sessions, 30 min group sessions, phone sessions, last session, 10 group sessions
Therapy	12	Hobby therapy, physical therapy, therapy group, occupational therapy, group therapy, acceptance therapy
Sleep	12	Sleep hygiene, addressing sleep, sleep techniques, sleep pattern, good sleep hygiene
Exercises	11	Stretching exercises, minor physio exercises, exercise sessions, exercise programme, mindfulness exercises, graded sexercise, breathing exercises
Psychological	10	Psychological impact, psychological support, psychological appointments, psychological treatments, psychological input
Pacing	4	Positive pacing, discussed pacing, adaptive pacing
Medication	4	Relief medication, medication review, medication advice

Gabapentin prescribed but side effects severe

CBT was discussed as an alternative post the failure of GET to help. However it was not accessible as I was too ill to access this.

Pain management

Pain clinic. Pain killers. Anti-depressants.

Stretching exercises for pain relief. Advice on pacing and proper resting.

CBT

Sleep management ideas

Relaxation and sleep techniques, diet

Psychological support

Pacing and good sleep hygiene

Appendix 3 – GET treatment

Mindfulness course

Nutrition advice

Ongoing hydrotherapy which I was not well enough to attend

They suggested CBT but referred me back to my GP & she didn't agree it was suitable for me

Please note the exercise sessions were part of an ME course including nutrition, general info, relaxation. A couple of medical practitioners were okay and understanding and some sessions were not unhelpful though didn't tell me anything didn't already know. The exercises however were led by a physiotherapist who didn't really 'get it' and felt pushed way too hard too quickly and giving the impression if you exercised more you'd recover.

Yes, but only after I started GET. They were a condition of GET not an alternative. Most useful was mindfulness, run by the pain clinic

Pain relief medication. A new community physio helped me to mobilise in my own time and did not push me beyond my limitations

I was offered CBT but already have a working knowledge having an interest prior to my ME.
Rehabilitation programme addressing sleep, diet, pacing, psychological impact, activity management
This was very helpful

Did the course of CBT and/or GET result in any change in your ability to carry out or resume employment or education?

GET employment/education (those started)	**Number**	**Percentage (%)**
Yes	191	44.6
No	230	53.7
*missing responses	7	1.6
Total	428	100

*Total = those who started GET

Further answers for Yes

Word	**Count**	**Weighted Percentage (%)**	**Similar Words**
work	98	4.90	work, worked, working
school	52	2.60	school, schooled, schooling
get	49	2.45	get, getting
time	46	2.30	time
able	38	1.90	able
hours	33	1.65	hour, hours
unable	32	1.60	unable
return	30	1.50	return, returned
week	26	1.30	week, weekly, weeks
years	26	1.30	year, years

Appendix 3 – GET treatment

Theme	Count	Associations
Time	60	Full time, part time, part time school, managing part time, full time education, part time job, part time basis, sick time, full time employment, reduced school time, extremely part time, needed time
Full time	30	Full time hours, full time education, full time employment
Part time	24	part time school, managing part time school, part time job, part time basis, extremely part time
School	20	Part time school, managing part time school, home school educator, special school, school hours, reduced school time, home school, online schooling, complete schooling
Ill health	13	Worsening illness, Physical health, ill health retirement, ill health grounds
Hours	13	Full time hours, school hours, work hours, unsocial hours, half hour classes, college hours, 3 hour sessions, 1 hour sessions
Home	13	Home education, home school educator, home tutor, home school, home tuition
Education	13	Home education, full time education, home school educator, education service, attending education
Work	8	Work hours, voluntary work couple, voluntary work, work days, started work, longer work

I was able to discuss my hours of work with my employer as to what and when I find it difficult to work. The course discussed this.

After the course I was left almost totally bed/house bound & the minor tasks I had previously been able to complete were no longer possible. At the start of the course I was able to attend in person, although always with payback. This deteriorated until all sessions were telephone consultations

My condition deteriorated so I was unable to return to work

Yes, because my symptoms were worse I had to quit school entirely.

It delayed my daughter's return to education by having her spend too much energy on her physical goals. Once we accepted her level of activity, used a wheelchair to go out (which we had been advised not to do, thereby further isolating my daughter), and began online schooling my daughter was able to participate in education at a level she had not been able to do for 3-4 years.

While I had been improving and starting to return to education, the severe decline in my health following GET made this impossible.

My aim was to try and go back to university on a part time basis (which was encouraged by my physiotherapist) but I started to relapse before I started my course again and I only managed 6 weeks before becoming very ill - as a result I spent the next 6 years bedbound or housebound

Returned to school full time

I have had to cut down work as a result. I tried 3 days I can now not even do one. I have not left the house apart from my Monday pa job and had to be helped home after that by my partner

Off work as a teacher and education manager for 18 month. Fully resumed my job.

Missed 3 months of part-time school

I had to apply for ill health retirement with no prospect of ever being able to return to work. I lost a very good career

I had previously worked full time but had to move to work part time for two and a half years.

Appendix 3 – GET treatment

I was able to start back at university

Started voluntary work couple of hours a weeks
Unsure, but suspect that due to an increase in fatigue and a number of other symptoms from the GET (which is why I decided to stop doing it), I found it took a much longer period to get back to work than I anticipated, and my return to a number of hours of work that meant I could be financially stable.

It allowed me to fix my work days and hours and take me off all unsocial hours and on call duties. The work stayed the same and so did the negativity from employer/supervisors.

Has speeded up recovery rate so ultimately yes

It meant I could mobilize for longer, and have me confidence in being more independent

My health gradually, very slowly, improved and is still improving. As I improved I can add more hour of work to my week (At one point I was working 10 hours a month).

Did the course of CBT and/or GET result in any change in your ability to carry out or resume employment or education?

GET employment/education (those not started)	**Number**	**Percentage (%)**
Yes	3	2.6
No	1	0.9
*missing responses	110	96.5
Total	114	100

Word	**Length**	**Weighted Percentage (%)**	**Similar Words**
made	4	4.76	made
make	4	4.76	make
related	7	4.76	related
school	6	4.76	school, schooled
therapies	9	4.76	therapies, therapy
worsened	8	4.76	worsened, worsening
aches	5	2.38	aches
activities	10	2.38	activities
afraid	6	2.38	afraid
CBT	3	2.38	CBT

Theme	**Count**	**Associations**
Unable to generate themes – limited data		

My illness was worsened & I was unable to make it into school due to extreme aches and pains. Resulted in my being home schooled.

No counselling or CBT or exercise related therapy has ever made any difference. You can make small inroads with therapies and they offer support but I'm afraid they have made no impact to my overall worsening picture

as the tears have gone on - and I've tried them all and still do.

Yes. Had to stop activities social and work related

Did the course (or completion / non-completion of the course) have an effect on any DWP benefits (i.e. ESA, PIP, DLA) that you were claiming?

GET DWP benefits (those started)	**Number**	**Percentage (%)**
Yes	62	14.5
No	358	83.6
*missing responses	8	1.9
Total	428	100

*Total = those who started GET
Further answers for Yes

Word	**Count**	**Weighted Percentage (%)**	**Similar Words**
get	21	2.77	get, getting
benefits	19	2.51	benefit, benefits
pip	17	2.25	pip
claim	14	1.85	claim, claimed, claiming, claims
ESA	11	1.45	ESA
time	9	1.19	time
work	9	1.19	work
applied	8	1.06	applied, apply
support	8	1.06	support
refused	8	1.06	refused, refusing

Themes	**Count**	**Associations**
ESA	5	ESA claims, ESA renewals, ESA application, ESA entitlement
Claiming	5	ESA claims, claiming benefits, proper benefits
Support	4	Wrote letter support, support group, support system, additional support
Question	4	Original question
Struggles	4	Hard struggle, daily struggle
Things	4	Small things, certain things
PIP	2	PIP form, enhanced PIP

I was rejected in benefits when I first became ill and was unable to do my job. . I had to leave my post, After not being able to work. I applied for DLA and was refused.

I have never successfully been able to claim benefits for my M.E. I claimed after I did GET because I had been made redundant during the course and was too ill to work but I was denied benefits and failed my appeal and tribunal.

I was refused PIP as they didn't believe what I told them about my condition. Awarded at Tribunal a year later. Was refused I'll health retirement because I was undergoing GET treatment "which could make you better".

DWP believed well enough to walk so denied PIP on the first application

Therapist saw deterioration of health. So therapist wrote letter support for more care for me

I was accepted into the DWP Support Group due to the severity of my CFSME prior to undertaking GET. The evidence from the clinic was important to validating my ESA application and appeal. I have not been called for re-assessment since.

led them to think am capable of more than actually am

I had to tell the DWP the "treatments" I was undergoing/due to undergo otherwise you get marked down as refusing treatment which you can be penalised for.

Being on the course definitely helped with both PIP and ESA claims which is why I did it despite having reservations

PIP award was short due to the DWP interpreting the treatment as a cure.

Taking part almost certainly in their eyes is meaning you're able to go back to work. Now going to lose my mobility car. As deemed fit
Once I had tried GET my application for DLA was finally accepted. Before GET I had applied twice and was refused twice. Tribunals for these two applications were also unsuccessful.

Yes, I was too scared to leave the course in case I then couldn't get my ESA entitlement so for the last few years I've had to put up with forcing my body to do things it wasn't capable of doing by following my specialists GET advice. This isn't right and shouldn't be like this but the doctors have no understanding of ME so I have literally no one else to give as a name for my ESA renewals and that really scares me.

I felt that I needed to engage with the sessions in order to satisfy criteria for the WRAG component of ESA

Yes, as they thought I was getting exercise they thought I wasn't poorly

Did the course (or completion / non-completion of the course) have an effect on any DWP benefits (i.e. ESA, PIP, DLA) that you were claiming?

GET DWP benefits (those not started)	**Number**	**Percentage (%)**
Yes	18	15.8
No	96	84.2
Total	114	100

Appendix 3 – GET treatment

Further answers for Yes

Word	Count	Weighted Percentage (%)	Similar Words
benefits	7	3.03	benefit, benefits
get	5	2.16	get
like	4	1.73	like, likely
refusing	4	1.73	refusal, refused, refusing
told	4	1.73	told
clinic	3	1.30	clinic
depression	3	1.30	depressed, depression
ESA	3	1.30	ESA
made	3	1.30	made
pip	3	1.30	pip

Themes	Count	Associations
Support	2	Specialist support, ongoing support

DWP took the fact that I wasn't currently in treatment as an indication that I had recovered. In fact, the NHS told me they don't offer any ongoing support for ME sufferers, and none at all for those in the moderate-to-severe category.

Indirectly. GP initially refused to sign forms as he thought my daughter was able to work and not trying

Yes, it went hand in hand with all departments of the government. Treated like a fraud

I was asked if I was doing it at my interview and I said no. I was told I was not for work and received no benefits. I have received nothing since then.

As my GP's 'advice' made my condition considerably worse it made me eligible for DLA.

My notes from the clinic were used against me at my PIP assessment
Lost DLA in 2008 when ATOS assessment introduced but after that with appeals and building other science based med evidence in USA via Dr Klimas and others including in Belgium and New castle from Prof Newton's as part of her studies I can no longer be denied benefit

Are there any other comments on your course of CBT and/or GET? (those started)

Word	Count	Weighted Percentage (%)	Similar Words
getting	241	3.00	get, getting
help	107	1.33	help, helped, helpful, helping, helps
time	76	0.95	time, timed, times, timing, timings
exercise	71	0.88	exercise, exercised, exercises, exercising
works	66	0.82	work, worked, working, works
treatments	65	0.81	treatment, 'treatment', treatments
activity	62	0.77	active, activities, activity
symptoms	61	0.76	symptom, symptoms
feel	59	0.73	feel, feeling, feelings, feels
told	58	0.72	told

Appendix 3 – GET treatment

Theme	Count	Associations
Exercise	49	Gentle exercise, exercise levels, supine exercises, graded exercise, exercise programme, commencing exercise, much exercise, graded exercise sessions, daily exercise, used exercise bike, taking exercise, structured exercise therapy, lying exercises, increasing exercise, giving exercise, following exercise, fatigue post exercise, dangerous exercises, cardiopulmonary exercise test
Activity	47	Activity levels, normal activities, increasing activity, physical activity, patients baseline activity level, extra activity, daily activity level, current activity level, school activities, activity times, activity level diary, 1 hour activity, mental activity, activity tracker, activity management
Levels	32	Activity levels, exercise levels, daily activity levels, current activity levels, activity level diary, ridiculous level, mineral levels, level sport, good level, fitness level, energy levels, available energy levels
Time	18	Full time, part time, activity times, work times, serious time, horrific time, hellish time, unspecified time, right time, multiple times, full time care, enough time
Health	18	Mental health, term health, mental health therapy, mental health illness, poor health, health retirement, health professional, worsening health, sufferers health, health declines, full health, daughters health
Daily	18	Daily walk, daily activity levels, daily routine, daily living, part-time days, daily exercise, full day, day effects, daily tasks
Treatment	15	Poor treatment, diverse treatment, treating something, refusing treatment, recommended treatment, proper treatment, possible treatments, inappropriate treatment, harmful treatment, effective treatment, appropriate treatment
Symptoms	13	Worsening symptoms, physical symptoms, system symptoms, son's symptoms, moderate symptoms, mild symptoms, cardiac symptoms
Illness	13	Physically ill, mental health illness, chronically ill, weird illness, true illness, terrible illness, term illness group, mental illness, simply ill, ill child
Support	13	Supportive relationship, medical support, fantastic support, telephone support, supporting patients, professional support teams, peer support, local support group, moral support, carer support

Get is not suitable for ME/CFS sufferers it really makes the condition deteriorate

GET is nothing short of abuse, it has made my daughter much, MUCH worse, no help and social services are abhorrent!

I felt that whichever professional I spoke to about issues with GET all put it down to the fact I was scared, de-motivated or lazy. As an ex GB athlete, I can safely say all I want is to be back training and I'd do anything to make that happen.

My experience I'd GET is that is caused major deterioration

I feel health professionals in the vacuum of treatments and cures hang on these therapies as the industry standards and they are defiantly not for all are detrimental to healing and health and dangerous in many cases

GET was the worse treatment I had and I would not advocate it for this illness

A totally inappropriate treatment for neurological ME and I sincerely hope it is removed from the NICE guidelines asap

I find exercise extremely debilitating, culmination me being bedbound for a period. Pacing normal activities with regular breaks is the only way to maintain my current activity levels.

I felt that all that was accomplished by either treatment was to make me feel guilty and like I wasn't trying hard enough. I was also very conflicted as my symptoms worsened following GET but stabilised somewhat following the use of simple pacing strategies.

Appendix 3 – GET treatment

I was sure that what I was told that I was de conditioned was right so I pushed myself to get fit again. It was a disaster for me.

I got more unwell from doing GET and I have struggled to recover from that experience

It was patronising, common-sense rubbish that did not seem to have much clinical basis. It's the same thing I was told to do by physios in the past BEFORE being diagnosed with ME/CFS so it seems rather stupid to prescribe the same thing to people with and without ME when the latter group have such a deteriorated energy capacity.

I think GET is extremely damaging. Your being told to push your body past what it's capable of and if you struggle it's insinuated that you're not trying hard enough. I push myself to breaking point all under the guidance of professionals. It added years to me being unwell and I've only just got back to how the level of my illness was before the GET made me much worse.

It is clear to me that these treatments are completely useless. I am a very educated individual who has studied CBT in my past work and delivered aspects of our to clients. GET is simply another name for how I've approached any exercise in my life. I was running 40min 3x week when ME really knocked me over.

Despite being 18 months ago child still has not got health back to the same baseline as when GET started.

GET significantly worsened quality of life

GET set me back years. Don't allow for PEM and pushes too much physically. I felt like a failure as I couldn't keep up with the exercises and actually felt worse, which lasted three years.

This was the most harmful thing that I was ever prescribed. It ruined my life. I was managing my symptoms before this, and undertook it because I was told it would help me recover. Instead I was left disabled and had to leave my job and studies. I needed full time care from my family.

My concerns were continually ignored & goals set despite deterioration

From 1987 had always exercised within my capabilities. The exercise regime suggested by my GP left me unable to even swim without knee and elbow locking. Now Restorative Yoga is helping

I have reduced my working hours since I did the course to 13 a week which has helped me manage it better.

GET is the only intervention where we have seen consistent and measurable improvements. It has also helped my wife understand how to manage her energy and activity levels

My child has been fortunate in that he has been encouraged to pull back activity when symptoms increase. Doing the increases just does not work. He can now do less than when he started the course.

The graduated walking allowed me to do more & more

Once baseline found then minimal daily exercise incorporated into pacing to avoid de conditioning helped. Pushing through worsening symptoms did not help at all and only when my daughter stopped pushing and listened to her body did she start to improve

I was clear from the onset that any exercise therapy needed to be carefully carried out and that M.E. is not due to deconditioning.
GET-if you could not fit/do the treatment suggested for you, you were encouraged to ignore your body and continue. If you did not continue were made to feel that you were preventing a recovery.

GET and CBT should be offered however pacing is more important.

Physio, first person to help understand illness and help to understand not going mental

Appendix 3 – GET treatment

The sessions were valuable to test capability, given by a highly empathetic person, done very well. The morale support was valuable too. However, I'm still experiencing much reduced mobility and pain. I'd say that in the 3 years since I had the GET I have improved a bit from more severe ME to moderate.

It increased my stamina in the sense that I was able to walk further for example but still experienced the same fatigue post exercise.

I didn't finish it but I tried it and made little progress over a year. Previously I had been able to regularly do some level of exercise and I had been walking, cycling, canoeing and climbing. I think it is harmful and had a clear correlation - exercise exacerbates ME. I really wanted it to work as I would have been an active person who enjoyed the outdoors but it was harmful.

GET has made my sons symptoms worse. If he had rested, not pushed in the beginning of this illness I don't think that he would be so poorly still now. GET does harm and it you do not follow what the hospital prescribe as a parent you are scared that you will be accused of refusing treatment and the social service implication that may bring. All we want is to help our children to feel better and lead more normal lives but there is no help at all to achieve this.

At first GET seems to work - I gradually increase my activity and for a few weeks I am able to continue doing so. But every time this then results in a major crash and I end up as bad as I was before I started the GET.

The whole thing was completely pointless. While I was doing it I did not experience any improvement in my condition at all. I only started to improve once I stopped.

My GET experience from West Sussex ME/CFS service was completely different from any other GET experience I have heard of. It was entirely personalised to me and the expected increase in activity and approach was much more gradual, and therefore effective and mentally positive

I used to love exercise more than anything. If GET could have worked then I would have been very happy but this is not the answer for not people with ME. Myself and many others I know only got worse not better from following these guidelines. Alternative treatments need proper funding.

Would have been good to have more supervision or more sessions. Or structured exercise therapy with a therapist in a gym or something

I embraced planning and pacing. I looked at stress and triggers. I am not back at work yet but feel I may be able to in the future - a big step forward for me.

I have only done 5 sessions but have found it extremely useful and my fitness levels have improved.

Appendix 4 – CBT (combined with GET)

What year were you offered a course of CBT treatment? (*answer required)

CBT_both year offered	Number	Percentage (%)
2007	49	5.2
2008	52	5.5
2009	58	6.2
2010	51	5.4
2011	46	4.9
2012	69	7.3
2013	65	6.9
2014	87	9.2
2015	93	9.9
2016	111	11.8
2017	116	12.3
2018	139	14.7
2019	7	0.7
Total	943	100

*Total = all those who were offered CBT (combined with GET)

Was the CBT treatment offered on the NHS or through the private medical sector?

CBT_both Sector	Number	Percentage (%)
NHS	877	93
Private Medical Sector	62	6.6
missing responses	4	0.4
Total	943	100

*Total = all those who were offered CBT (combined with GET)

Appendix 4 – CBT (combined with GET)

Did you start the CBT course?

CBT_both started	Number	Percentage (%)
Yes	725	76.9
No	218	23.1
Total	943	100

*Total = all those who were offered CBT (combined with GET)

Yes, please state the year or approximate year

CBT_both year started	Number	Percentage (%)
2007	32	4.4
2008	37	5.1
2009	30	4.1
2010	36	5
2011	33	4.6
2012	46	6.3
2013	53	7.3
2014	61	8.4
2015	63	8.7
2016	87	12
2017	77	10.6
2018	76	10.5
2019	4	0.6
missing responses/unknown	90	12.4
Total	725	100

*Total = all those who started CBT (combined with GET)

No (please explain why)

Word	Count	Weighted Percentage (%)	Similar Words
CBT	112	3.18	CBT
help	55	1.56	help, helped, helpful, helping
get	42	1.19	get, getting
ill	41	1.16	ill, illness
offered	37	1.05	offer, offered, offering
attend	32	0.91	attend, attendance, attended, attending
symptoms	31	0.88	symptoms, symptoms'
treatment	30	0.85	treatment, treatments
years	30	0.85	year, years
course	29	0.82	course, courses

Theme	Count	Associations
Treatment	22	Psychological treatment, appropriate treatment, treatment options, private treatment, treatment approach, specialist treatment, proposed treatment, proper treatment, private treatment, outdated treatment, inappropriate treatment, helpful treatment, effective treatment, beneficial treatment
Symptoms	22	Physical symptoms, unexplained symptoms, worsening symptoms, worsened symptoms, severe symptoms, psychological symptoms
Physical symptoms	16	
Illness	16	Psychological illness, physiological illness, physical illness, ill health, critically ill, chronic illness, incorrect illness beliefs, false illness beliefs, abnormal illness beliefs
Disorder	16	Neurological disorder, somatisation disorder, somatic disorder, personality disorder, anxiety disorder
Therapy	14	Talking therapy, psychodynamic therapy, group therapy, group therapy session, receiving play therapy, daily cognitive therapies
Sessions	14	Taster sessions, missing sessions, group therapy session, group sessions, multiple sessions, hospital session
Course	13	6 week course, similar course, previous course, different course, counselling skills course, CBT course, alone course, 8 week course, 3 week course
Mental health	11	Mental health, ill health, mental health issues, mental health team
Energy	6	Limited energy, precious energy, enough energy, energy levels

Too sick

Some years ago I had CBT during an extreme depressive episode, for that it had been a beneficial treatment. My GP stated that NICE guidelines suggested CBT for ME/CFS. We then had a lengthy discussion pro/cons of this treatment for this condition and we BOTH concluded that CBT would probably be of no benefit given my symptoms and other aspects of my wellbeing

I declined. My personal experience of PEM and my ME triggered by virus means this approach is likely to do more harm than good. Also, the scientific evidence doesn't support GET/CBT theories & I don't trust findings of the PACE trial. Also know many others made much worse from GET/CBT

It will not help me deal with my physical symptoms. Personally I also suffer with emotional fatigue so bringing up past issues will cause me to crash.

Previously had CBT 5 years ago. Completely ineffective and significantly worsened my condition. Traveling to & from appointments and sitting through appointments caused more harm than good and again significantly

worsened my condition.

Didn't feel it was necessary as I had attended psychology in past for CFS for help with strategies. Strategies and techniques such as CBT helped me to accept my illness and reduced working hours but no effect on CFS.

Therapy was too far away and CBT therapist felt it would do more harm than good for me to travel there. Therapist asked questions over the phone and concluded that I wouldn't benefit from any CBT as sounded like I had the right mind set and coping strategies regarding my ill health.

Too ill to take part

I wasn't well enough to attend appointments and they were 20 miles away so getting there was difficult.

The M.E specialist told me it would likely do no good as I already had M.E for 8 years at that point

Offered 1.5 hours away from home and travel too much

Too ill to attend sessions, and previous course had failed to help

Already had both back in 2009 both made me worse 100% worse so reluctant to do the same again and astounded at the offer

I tried GET first, which dramatically worsened my condition. I was then too ill to attend any CBT sessions

I was given CBT in the past and did not find it helpful.

Already doing private CBT

Sessions too long. Group sessions not appropriate.

My energy levels where next to none, I simply could not attempt this

The therapist, after two sessions, said they couldn't help me as I already had healthy coping mechanisms

No, as I didn't think it would be appropriate or beneficial as a treatment

I decided to try activity management instead

After hearing about what it entails from other M.E sufferers, I knew it would not help my condition. Luckily, the psychologist at the CFS Clinic felt I was mentally managing my M.E myself fine

I'd had it before but rather than making me improve it made me more ill and led to months of being housebound. I'd have been mental to put myself through that again.

I have participated in a previous course of CBT and accept that I am ill and have limitations but try to have as positive attitude as possible and do as much as I am able within my daily envelope of energy

I have only just been offered some CBT. It is probably going to be 3 sessions but there is an ongoing discussion about whether the practitioner thinks mindfulness will be more helpful

I have a close support network and can talk easily and often about my feelings towards my ME

My son is very intelligent, reviewed the "evidence" himself and decided it wasn't worth the energy

Was offered a choice of CBT or GET by ME clinic. Opted for GET, but also signed up for, and completed 6-week separate CBT-type IAPT course, as recommended.

Appendix 4 – CBT (combined with GET)

Did you complete the CBT course?

CBT_both completed	Number	Percentage (%)
Yes	510	70.3
No	180	24.8
Still ongoing	35	4.8
Total	725	100

*Total = all those who started CBT (combined with GET)

If you answered No to the previous questions, why did you stop?

Word	Count	Weighted Percentage (%)	Similar Words
ill	38	1.63	ill, illness
made	34	1.45	made
CBT	32	1.37	CBT
sessions	31	1.33	session, sessions
get	28	1.20	get, getting
symptoms	28	1.20	symptom, symptoms
worse	28	1.20	worse
course	24	1.03	course
help	24	1.03	help, helped, helpful, helping
attend	22	0.94	attend, attendance, attended, attending

Theme	Count	Associations
Mental	13	Mentally ill, mental illness, mental health issues, mental activity, mental issues, mental health, mental exhaustion
Illness	13	Mentally ill, mental illness, false illness beliefs, chronic illness, unhealthy illness beliefs, suddenly ill, psychological illness, ill children, false illness beliefs approach
Group	11	Group environment, group facilitator, group course, 2 group sessions
Sessions	10	Several sessions, 2 group sessions, last session, counselling sessions, 3rd session, 2 hour sessions
Activity	9	Mental activity, little activity, social activity, physical activity, gradual activity management, activity diary
Energy	8	Much energy, little energy, limited energy, finite energy, valuable energy, available energy
Symptoms	7	Worsening symptoms, managing symptoms, making symptoms, symptoms management, CFS symptoms
Course	7	Group course, course years, course delivery, separate course, initial course, 6 week course
Process	7	Thinking process, natural process, thought process, grieving process, disease process
Therapist	5	Occupational therapist, student therapist, ironically therapist

Too ill to attend last few sessions

Was completely wrecked mentally after every session and then took a bad flu and did not recover from it.

I was too unwell to attend for several sessions and told had to commit to all to benefit, it was decided with group facilitator /counsellor as had struggled to do so and that being in a group environment reached decision

to leave as I struggled to attend, when did so, to concentrate and remain focused. I also had one to one therapy at Pain clinic.

It was too much and was making me worse

Too ill to complete .could not get to appointment and ended in hospital
It was far too much for my daughter to cope with, she struggles with concentration and she didn't believe it would

It was ineffective - caused more harm, because of the energy required to attend, than good (none)

Too difficult to attend caused worsening of symptoms

Mutual agreement between me and counsellor who said she 'felt like she was torturing me'

Made me worse and increased anxiety and depression
The CBT therapist said CBT would be of no benefit to me as I already had a good attitude with regards to dealing with my illness.

Just couldn't. Increased symptoms, pain, anxiety

I was too ill to attend sessions

Could not keep up attendance - time and frequency inappropriate for me

It was extremely detrimental to both my physical and mental health.

Was discharged after 2 sessions

Was told I already thought the way CBT was supposed to make you think so there was no point going back after the first session

It was frustrating. Not practical. Therapist was patronising and did not understand ME

I had 2 sessions because the doctor didn't think I needed it. I had already altered my thoughts myself as it took 2-3 years to diagnose.

Therapist decided I didn't need it

The CBT instructor said I was "too happy for CBT to work" and removed me from the service.

The person offering the service just stopped after admitting she felt it wasn't appropriate for me.

I didn't agree with being told that my problem was listening to my body too much and if I was motivated enough and just pushed on through I would get better

Was having no positive effect, I was using up valuable energy to get to the sessions and back, It took me 4/5 days to recover from the exertion and the attitude of the therapist was I am not trying hard enough!

Totally redundant use of finite energy. I am not depressed or anxious. I couldn't be any less mentally ill than I am at the moment. I am bizarrely content, giving my situation

I went to the sessions, and told by the practitioner it couldn't help me as I already had very strong control of my thought processes - the practitioner discharged me after the second session

Had originally agreed to CBT hoping it would help with sleep problems. Agreed with practitioner that there was no point in carrying on. She couldn't identify any 'unhealthy illness beliefs' that she could 'cure'.

Appendix 4 – CBT (combined with GET)

How many CBT sessions were/are involved?

CBT_both sessions	Number	Percentage (%)
1	13	1.8
2	13	1.8
3	26	3.6
4	13	1.8
5	11	1.5
6	115	15.9
7	11	1.5
8	64	8.8
9	5	0.7
10	67	9.2
11	3	0.4
12	66	9.1
13	8	1.1
14	5	0.7
15	8	1.1
16	12	1.7
17	2	0.3
18	3	0.4
20	11	1.5
21	2	0.3
24	2	0.3
30	6	0.8
32	1	0.1
33	1	0.1
36	1	0.1
40	1	0.1
60	1	0.1
75	1	0.1
100	1	0.1
112	1	0.1
200	1	0.1
unknown	246	33.9
missing responses	4	0.6
Total	725	100

*Total = all those who started CBT (combined with GET)

Appendix 4 – CBT (combined with GET)

Who delivered the CBT treatment?

CBT_both Clinician	**Number**	**Percentage (%)**
Cognitive Behavioural Therapist	238	32.8
Physiotherapist	36	5
Occupational Therapist	121	16.7
Clinical Psychologist	180	24.8
Other	114	15.7
Neurologist	1	0.1
GP	2	0.3
Psychiatrist	33	4.6
Total	725	100

*Total = all those who started CBT (combined with GET)

Other (please specify)

Word	**Count**	**Weighted Percentage (%)**	**Similar Words**
psychologist	22	5.56	psychologist, psychologists
therapist	22	5.56	therapist, therapists
clinical	17	4.29	clinic, clinical
nurse	16	4.04	nurse, nurses
occupational	12	3.03	occupational
CBT	9	2.27	CBT
CFS	8	2.02	CFS
sessions	8	2.02	session, sessions
specialist	8	2.02	specialist
course	7	1.77	course, courses

Appendix 4 – CBT (combined with GET)

Theme	Count	Associations
Therapist	56	Occupational therapist, psychological therapist, CBT therapist, clinic therapist, trainee therapist
Occupational therapist	37	Occupational therapist
Clinical	30	Clinical psychologist, clinical psychology student, clinical therapist, private clinic, pain clinic, clinical practitioner
Psychologist	24	Clinical psychologist, trainee psychologist, student psychologist, counselling psychologist
Clinical psychologist	21	Clinical psychologist
Psychological	12	Psychological therapist, clinical psychology student
Sessions	9	15 minute session, physiotherapy sessions, 5 group sessions, mixed group, group sessions
Nurse	8	Nurse practitioner, specialist nurse, psychiatrist nurse, psychiatric nurse, psych nurse, mental health nurse
Course	4	Short course, intensive course, mindfulness course, course leader

Psychologist OT and physiotherapist were involved

CFS service physio

I'm not sure; it was an NHS partnership with a rehabilitation charity

Specialist nurse (trained in CBT)

CFS/ME clinic therapist

Occupational therapist and clinical psychologist

OT with CBT and mindfulness specialities

OT & Psychiatrist

Psychological therapist

Online course

Were/are you being seen individually or as part of a group?

CBT_both group type	Number	Percentage (%)
Individual treatment	498	68.7
Group Treatment	143	19.7
Mixture of both	84	11.6
Total	725	100

*Total = all those who started CBT (combined with GET)

Appendix 4 – CBT (combined with GET)

What overall impact did the CBT course have on your physical health?

CBT_both Physical Health	Number	Percentage (%)
Major improvement	18	2.5
Minor improvement	66	9.1
No improvement	351	48.4
Minor deterioration	117	16.1
Major deterioration	141	19.4
Not applicable	32	4.4
Total	725	100

*Total = all those who started CBT (combined with GET)

What impact did CBT have on your mental health?

CBT_both Mental Health	Number	Percentage (%)
Major improvement	44	6.1
Minor improvement	169	23.3
No improvement	237	32.7
Minor deterioration	116	16
Major deterioration	133	18.3
Not applicable	26	3.6
Total	725	100

*Total = all those who started CBT (combined with GET)

Did any of your symptoms worsen? (*answer required)

CBT_both symptoms worsened	Number	Percentage (%)
Yes	423	58.3
No	273	37.7
Not applicable	29	4
Total	725	100

*Total = all those who started CBT (combined with GET)

Yes, please describe

Word	Count	Weighted Percentage (%)	Similar Words
symptoms	112	2.23	symptoms
fatigue	101	2.01	fatigue, fatigued
pain	91	1.81	pain, painful, pains
worse	88	1.75	worse
worsening	80	1.59	worsen, worsened, worsening
physical	65	1.29	physical, physically
sessions	64	1.27	session, sessions
CBT	51	1.01	CBT
get	51	1.01	get, gets, getting
mental	51	1.01	mental, mentally

Theme	Count	Associations
Brain	63	Brain fog, brain fatigue, brain function, brain fog anxiety
Mental	60	Mental health, mental exhaustion, mental wellbeing, mental health issues, mental strategies, mental exhaustion, mental decline, mental block, mental abuse
Pain	55	Nerve pain, joint pain, severe pain, muscle pain, pain levels, severe stomach pains, extreme pain, body pain, worsening pain, stomach pain, permanent pain, pain confusion, pain clinic, much pain, increasing pain
Health	50	Mental health, physical health, mental health issues
Symptoms	48	Physical symptoms, cognitive symptoms, bowel symptoms, bladder symptoms, severe symptoms, physical fatigue symptoms, POTS symptoms, neurological symptoms, worsening symptoms, whole symptoms, viral symptoms, flu-like symptoms, flu symptoms, exertional symptoms, depressive symptoms, debilitating symptoms, anxiety symptoms
Cognitive	46	Cognitive function, cognitive symptoms, cognitive ability, poor cognitive function, mental cognitive, cognitive function decline, extreme cognitive, cognitive problems, cognitive issues, cognitive dysfunction, cognitive decline
Function	34	Cognitive function, poor cognitive function, physical function, mitochondrial function, cognitive function decline, brain function
Energy	17	Energy levels, energy exertion, fatigue energy level, planning concentration energy, much energy, managing energy levels, energy results
Malaise	16	Exertional malaise, malaise exertion, post-exertional malaise, physical exhaustion, exertional malaise

Struggled with severe symptoms after attendance of sessions, I felt more anxious and depressed at the reality of trying to cope, trying to incorporate what had learnt as brain fog and poor cognitive function made it all very difficult at times impossible to change.

Energy and pain all got worse.

My mental health deteriorated rapidly due to feeling so hopeless and bullied by such a patronising approach. When I did not show improvement it was automatically put down to me not trying hard enough and threats of all support being taken away if I did not show improvement were common. This on turn affected my energy and stress levels that then exacerbate every other symptom of M.E. like a vicious circle.

I got PEM from the activities that were suggested that I try. Symptoms included loss of sleep, worse mood, rhinitis and fatigue.

Got a lot more tired, unable to walk now full time in a wheelchair.

Appendix 4 – CBT (combined with GET)

Overall feeling of fatigue, greater Post-external malaise, cognitive symptoms, greater patterns of 'boom and bust', reduced ability to carry out tasks.

Just attending made everything worse (pain, fatigue, concentration, brain fog, mood, etc...)

Complete exhausted and severe pain

Cognitive function declined .brain fog mentally exhausted .depression after course

Muscles became more painful after a session. Terrible head. Fatigued.

Pain and Fatigue and Exhausted

Brain fog got bad because of more over-thinking

Severe pain and fatigue for days or weeks afterwards

Pretty much all as was using too much energy on the CBT had none left for anything else

Fatigue and muscle pain increased. Dizziness and poor sleep. Digestive issues. Anxiety.

Exercise meant I relapsed back to bed for months after being told to ignore the symptoms

Went from being able to do some things to not being able to get out of bed mental health got so bad

If I had followed the advice then yes but I did not listen as I knew my body.

Trying to attend the CBT sessions whilst working did make the symptoms worse in the short-term

My physical symptoms worsened due to trying to keep going.

Ability to concentrate and brain fog got worse after sessions

Was put under a lot of pressure to complete

Had to revert to telephone appointments as I was unable to get to the clinic.

Yes, they worsen at first due to the effort of having to think about different positive thoughts in order to replace my negative thoughts. CBT has helped me to control my mind and therefore my emotions preventing my health of being deteriorated by negative emotions. However CBT didn't cure me and it doesn't cure anybody with ME. It only helps to prevent the worsening of symptoms due to negative thoughts and emotions.

I have been managing M.E. since 1991. However, my concentration and emotional state worsened after the course. I felt that I was being told to 'think' myself better - as I would love to be better I followed all the instructions, but to my detriment,

Brought me face to face with my limitations, so undermined my main coping mechanism of trying to live within my capabilities in a reasonably happy state of mind and acceptance of how my life has been destroyed by the illness

I have tried not to focus on how debilitating my illness was and to concentrate on other more positive things. The repeated addressing of the impact of my ME made my depression worse, as did the fact that the therapist really didn't understand the Illness at all. She was constantly trying to increase my motivation to go out, exercise and work. I was previously a dance and fitness instructor, and was very depressed because I had lost that part of my life. To be assumed to lack motivation do the thing that I most desperately want to do is soul-destroying. I also felt more hopeless because it didn't help me, just made it all worse, and that was the only treatment besides GET. It became clear to me that the NHS did not understand to illness at all. My physical

health also deteriorated because I was repeatedly pushing myself to go to the appointments even when I was crashing, and doing more than was safe physically because I had been encouraged to do so by the therapist. Both made my ME worsen permanently

Tiredness increased as I became more active but this was part of the recovery

Did you develop any new symptoms?

CBT_both symptoms new	Number	Percentage (%)
Yes	210	29
No	468	64.6
Not applicable	40	5.5
missing responses	7	1
Total	725	100

*Total = all those who started CBT (combined with GET)

Yes, please describe

Word	Count	Weighted Percentage (%)	Similar Words
symptoms	39	2.11	symptom, symptoms
pain	35	1.90	pain, painful, pains
anxiety	32	1.73	anxiety
depression	30	1.63	depressed, depressing, depression
worsening	23	1.25	worsen, worsened, worsening
became	20	1.08	became
severe	20	1.08	sever, several, severe
time	19	1.03	time, times
feel	18	0.98	feel, feeling, feelings, feels
CBT	15	0.81	CBT

Theme	Count	Associations
Pain	23	Unbearable nerve pain, shooting pains, pain level, muscle pain, pain management, intolerable pain, hip pain, fatigue pain, facial pain, excruciating pain, chest pain, regular pain medication, pain mobility, bone pain, body pain
Symptoms	17	Physical symptoms, bowel symptoms, regular symptoms, current symptoms, underlying symptoms, previous symptoms, parkinsonian symptoms, major symptoms
Sensitivity	17	Light sensitivity, touch sensitivity, noise sensitivity, sensory sensitivity, sound sensitivity
Anxiety	17	Pervasive anxiety, anxiety issues, paranoia anxiety, associated anxiety, temporary anxiety, severe anxiety, increased anxiety, anxiety attacks, hyper anxiety, experienced anxiety
Health	17	Mental health, mental health treatment, health service, health condition
Mental health	12	Mental health, mental health treatment
Treatment	11	Mental health treatment, actual treatment, medical treatment
Brain	11	Brain fog, severe brain fog, brain burning
Attacks	8	Panic attacks, anxiety attacks, adrenaline attacks
Issues	7	Anxiety issues, vision issues, swallowing issues, cognitive issues, anger issues

Appendix 4 – CBT (combined with GET)

Before treatment I suffered from no pervasive anxiety but stressful logistics of having to travel to appointments and arrange already limited occupational and social activities around treatment caused new anxiety issues and increased sleep difficulties

It worsened and brought on panic and anxiety attacks

Anxiety - which had never been an aspect of my life either with or previous to ME

I found focusing on symptoms made me see worse. I went backwards quite quickly and became photosensitive and weak.

When I increased my activity, I went from periods of being able to be active to being on forced bed rest and I had new sensory sensitivity, muscle pain and painful glands.

New bladder and bowel symptoms - different kinds of pain, new intolerances, severe light sensitivity, noise sensitivity, touch sensitivity, unable to read much

Relapse in symptoms. More aches and pains. And extreme fatigue

While I was attending the course I began to experience increased pain that was no longer manageable via regular pain medication. I also experienced a general setback at the same time.

The opposite of hoped for.

Depression has come on over last 2 years due to worsening of health and situation as I can no longer work

Became anxious because I felt that I wasn't getting any better

I just needed to rest. The effect of having to prepare and go through these sessions triggered light sensitivity, tinnitus and extreme exhaustion and worsening of headaches

I've developed a few new symptoms since treatment, but I can't say if they are a direct result of treatment.

Self-doubt/loathing thanks to limitations of condition. Realisation that health professionals have no idea what life with ME really entails. Increased daytime naps, reduced ability to power through as fatigue, dizziness and nausea worsened dramatically.

Can't remember. Great feeling of disappointment as I believed it would make things better

I did not develop new symptoms per se, but I became very low and upset as CBT was taught to me in a way that I could 'control' my physical symptoms, which was not true. I was made to feel they weren't real and easily cured by using CBT methods.

By allowing myself to think more of condition and impact I feel I started to experience more of over thinking without answers so it impacted on my mental health greatly

This is an odd question, I feel perhaps after going through major symptoms and discussing what was happening to the body I took more notice of how I felt and what was happening than before. This included arthritis and myalgia, nausea etc. whereas before I only focused on fatigue. This was really helpful for me, however because I could understand why I was feeling this symptoms and what to do for them.

Appendix 4 – CBT (combined with GET)

CBT_both severity before treatment (all)	**Number**	**Percentage (%)**
Mild	229	24.3
Moderate	577	61.2
Severe	137	14.5
Total	943	100

CBT_both severity after treatment (all)	**Number**	**Percentage (%)**
Mild	116	12.3
Moderate	416	44.1
Severe	193	20.5
missing responses	218	23.1
Total	943	100

How severe was your condition **before** treatment with CBT and/or GET was offered/undertaken?

CBT_both severity before treatment (those started)	**Number**	**Percentage (%)**
Mild	175	24.1
Moderate	459	63.3
Severe	91	12.6
Total	725	100

*Total = all those who started CBT (combined with GET)

How severe was your condition **after** treatment with CBT?

CBT_both severity after treatment (those started)	**Number**	**Percentage (%)**
Mild	116	16
Moderate	416	57.4
Severe	193	26.6
Total	725	100

*Total = all those who started CBT (combined with GET)

Appendix 4 – CBT (combined with GET)

Were other treatments offered in addition to CBT?

CBT_both other treatments	Number	Percentage (%)
Yes	463	63.9
No	247	34.1
missing responses	15	2.1
Total	725	100

*Total = all those who started CBT (combined with GET)

Further answers for Yes

Word	Count	Weighted Percentage (%)	Similar Words
get	283	15.53	get, gets, getting
therapy	58	3.18	therapies, therapy, therapy'
exercise	57	3.13	exercise, exercises
graded	48	2.63	graded, grading
pacing	37	2.03	pace, pacing
mindfulness	30	1.65	mindfulness, 'mindfulness'
CBT	28	1.54	CBT
managing	25	1.37	manage, managed, management, managing
sessions	23	1.26	session, sessions
course	19	1.04	course

Theme	Count	Associations
Exercise	106	Graded exercise, graded exercise therapy, graded exercise therapy pacing, physical exercises, physical exercise, breathing exercises, graduated exercise, gradient exercises, Chi type exercises
Graded	103	Graded exercise, graded exercise therapy, graded exercise therapy pacing, occupational therapy grading, management grading, graded therapy, graded activity
Therapy	77	Exercise therapy, art therapy, occupational therapy, graded exercise therapy pacing, therapy sessions, occupational therapy grading, normal therapy, graded therapy, talking therapy referral, talking therapy, talking therapies, suggested family therapy, focussed therapy, sleep therapy, mindfulness therapy, adaptive pacing therapy, therapy program, behavioural therapy, activity therapy
Management	20	Pain management, sleep management, management grading, activity management, managing finances, management energy levels, management strategy, lifestyle management course, fatigue management, activity management mindfulness
Sessions	12	Therapy sessions, information sessions, group sessions, weekly gym sessions, ten minute sessions, started sessions, regular sessions, clinic sessions10 group sessions

Sleep clinic, GET, pain management.

Dietitian for restricted diet

Referral to pain management to look for other potential underlying issues that could be causing problems

Pacing methods, pain management, mindfulness, very low level yoga

Appendix 4 – CBT (combined with GET)

Ongoing psychotherapy, some type of group work (not started) and dietary changes, medication and GET.

Dietary, meditation, mindfulness, pain management, graded exercise

Group information sessions about M.E.

Employment with chronic illness course

Mindfulness

GET

Activity pacing

Mindfulness meditation

Get, nutrition and lifestyle planning, pacing

Antidepressants

Advice on sleep and managing energy levels was most useful.

Did the course of CBT and/or GET result in any change in your ability to carry out or resume employment or education?

CBT_both employment/education (those started)	**Number**	**Percentage (%)**
Yes	322	44.4
No	395	54.5
missing responses	8	1.1
Total	725	100

*Total = all those who started CBT (combined with GET)

Answers for Yes

Word	**Count**	**Weighted Percentage (%)**	**Similar Words**
work	179	5.39	work, worked, working
get	92	2.77	get, getting
time	74	2.23	time, times
able	58	1.75	able
made	42	1.27	made
unable	40	1.21	unable
return	38	1.15	return, returned, returning
CBT	37	1.12	CBT
worse	37	1.12	worse, worsening
years	36	1.08	year, years

Appendix 4 – CBT (combined with GET)

Theme	Count	Associations
Time	91	Full time, part time, part time work, full time work, full time employment, part time job, full time university course, part time study, part time school, full time education, part time university course, part time hours, part time education, increasingly part time
Full time	42	Full time, full time work, full time employment, full time university, full time education
Work	34	**Part time work, full** time work, working hours, work plan, voluntary work, social work, resumed work, left work completely, decreased work hour
Health	15	Ill health, occupational health unit, mental health, occupational health, mental health professional, ill health retirement, health issues, health improvements

Made even less likely to go back to Uni or get work

Worked for first 3 years of illness while undiagnosed and managing symptoms myself through pacing. After treatment lost ability to work and have been dependent on benefits for over a decade.

It pushed my levels of activity back so far that I don't know if I will ever be able to work again. My confidence in myself was shattered.

Before I began the "treatments" my ME was slowly improving, to the point that I thought I'd soon be able to return to work, but I declined so much that this has never happened.

I had to give up a job I loved and move back in with my parents. I couldn't work for over a year.

Completely crippled me. I have never been able to resume work/study. I never recovered, instead faced a steady daily decline - and still do.

Loss of career, unable to return to work

No longer able to concentrate or retain information so had to give up my university course

I was too fatigued to go to school, more so than if I'd been resting at home for the day

Made part time work more difficult. Had to take sick leave.

I subsequently became too ill to work. I lost my job of (after being in employment all of my adult life) and have been unable to work since.

Lost job due to relapse after GET and had to drop out of university course

The recovery from both made any resumption of work or education impossible or maybe just helped me reach the stark reality of there is no treatment for ME except total rest in a dark quiet environment

Working part time instead of full time

Improvement in ability to attend education

Made it worse cannot work now before was working part time having gone down from full time

Had to cut back on home tuition from 30mins 4 times a week to 10 mins 4 times a week

Unable to attend school. Currently hospital educated.

The doctor wrote a letter to my manager explaining about ME, symptoms and treatment. As a result I managed to get changed to permanent day shifts whereas before I worked early shifts, day shifts and late shifts. This change improved my symptoms and made work more manageable

Appendix 4 – CBT (combined with GET)

I was struggling to even work part time already but after GET I had to give up working and have been told it is highly likely that I will not work again

The CBT was helpful for me personally as I had some issues with anxiety and overthinking. The CBT really helped with that so I could learn techniques so I was not wasting energy I did not have on things I could not control. It has helped me personally and professionally.

The CBT has made it go from impossible to highly likely that I will go back to university this year (2019).

I now work 10 hours a week, however it took 6 months to recover from GET, and another 6 months after of slow improvement, to get to this point

I had two different courses of CBT and the first course had little impact at all. The second course from iTalk (who I went to for depression from having ME) was amazing and I did see a huge improvement in my ability to pace and in my mood.

I was able to return back to work where I had been off previously for 3 years. Changed my life!

Increased ability to carry out employment by writing report to occupational health and helping gradual increase of hours approach.

Did the course of CBT and/or GET result in any change in your ability to carry out or resume employment or education?

CBT_both employment/education (not started)	**Number**	**Percentage (%)**
Yes	36	16.5
No	33	15.1
missing responses	149	68.3
Total	218	100

Further answers for Yes

Word	**Count**	**Weighted Percentage (%)**	**Similar Words**
work	23	6.35	work, working
able	11	3.04	able
get	9	2.49	get, getting
education	7	1.93	education
school	6	1.66	school
severe	6	1.66	several, severe, severely
continue	5	1.38	continue, continued, continuing
hours	5	1.38	hour, hours
leave	5	1.38	leave, leaving
back	5	1.38	back

Appendix 4 – CBT (combined with GET)

Theme	Count	Associations
Work	5	Volunteering work, school work, left work
School	4	School work, secondary school, school age
Health	3	Worsening health, ill health
Term	2	Short term memory problems, medium term future
Part time	2	Part time

My deterioration continued until I was so severe I had to give up work. I'm retired on ill health. There have been no improvements since

I was school aged when I had GET because of my deterioration in health from GET I was no longer able to continue in my education. Ever since G.E.T I have remained too unwell to work or study

I had to give up my 1 day a week volunteering work due to worsening health

Yes, it delayed my recovery and delayed my return to work/employment. It set me back months!

I have had to reduce my hours at work from 26 to 20 hours a week due to severe brain fog, inability to focus, short term memory problems and fatigue.

By continuing to keep pushing myself in the belief this would make me better, I got so unwell that I was no longer able to hold down employment.

I have now started to start school work again but all from home

Made it less possible

Despite reasonable adjustments to work my symptoms were too severe to continue.

I missed more lessons of secondary school, as I was not able to concentrate

Difficult to judge but it certainly worsened my health.

Did the course (or completion / non-completion of the course) have an effect on any DWP benefits (i.e. ESA, PIP, DLA) that you were claiming?

CBT_both DWP benefits (those started)	Number	Percentage (%)
Yes	136	18.8
No	582	80.3
missing responses	7	1
Total	725	100

*Total = all those who started CBT (combined with GET)

Appendix 4 – CBT (combined with GET)

Further answers to Yes

Word	Count	Weighted Percentage (%)	Similar Words
benefits	50	2.46	benefit, 'benefit', benefits
get	45	2.22	get, getting
works	39	1.92	work, work', worked, working, works
pip	39	1.92	pip
claiming	37	1.82	claim, claimed, claiming
time	29	1.43	time, times
CBT	28	1.38	CBT
course	28	1.38	course, courses
DWP	23	1.13	DWP
ESA	20	0.99	ESA

Theme	Count	Associations
Benefits	27	Claiming benefits, incapacity benefit, needed benefits, benefits applications, benefit award
Claiming	22	Claiming benefits, disability claim, claim years, actual claim
Claiming benefits	16	**Claiming benefits**
Time	13	Part time, part time work, full time full time university lecturer, bad time
Work	12	Work sessions, part time work, working lives, work capability assessment, finished work
Part time	9	Part time, part time work
Illness	9	Terminal illness diagnosis, term illness, ill health retirement, psychosocial illness, physical illness, chronic illness
Assessments	9	PIP assessments, health assessments, difficult assessment interview, work capability assessment, future assessment, assessments procedure
Evidence	8	Supporting evidence, medical evidence, believing evidence
Health	7	Ill health retirement, health assessment, health retirement, health professional, full health

DWP thought I wasn't trying hard enough

Was refused DLA despite using a wheelchair to go outside and mainly housebound

PIP was allowed. Now no treatment and no specialists, symptoms much worse, now, my PIP been stopped. Awaiting tribunal

Both CBT and GET were compulsory to attend and a condition of my incapacity benefit as it was at the time.

I was told that if I was well enough to attend I was well enough to work. Declined for ESA was stopped for 8 months

My decision to stop CBT (and to not continue GET at the end of the course) was used against me in my PIP tribunal.

PIP was taken away

PIP stopped my claim

I was deemed fit for work for attending GET/CBT which also added to deterioration of condition,

Appendix 4 – CBT (combined with GET)

I was told I wouldn't get letters to support benefits if I didn't do the course

I was advised by my GP that not attending the course would suggest that I didn't want to get well and that I wasn't taking up all opportunities to get help to get better

Because I completed the course the DWP claimed I must be cured and no longer sick. I was refused benefits for CFS

My condition was so much worse that I now qualify for the higher rate of PIP. I did not before.

I have not got the energy to deal with the DWP hence me forcing myself back to work. The DWP do not understand this condition, I know this through their withdrawal of my SSP and the false reasoning behind it even though at the assessment they did not complete the fully because the doctor said she could see I was getting tired. I'd rather protect my health and livelihood than deal with those people.

During my ESA interview I was told that I should do more to try and get well, and was questioned as to why I refused to continue with CBT/GET. When I told her of my worsening symptoms she actually snorted with laughter and told me I was being over dramatic. She told me I was rude and lazy. I cried for about a week after, which of course worsened all my symptoms again.

Hard to say for sure, but seemed to make my reassessment for ESA easier and got some PIP, I think because I had better evidence.

It had positive effect in the respect that I was shown to be in receipt of treatment even though it did not improve or help symptoms had I not attended then benefits would not have been awarded

The only positive outcome was that the CBT therapist providing the course was happy to write letters in support of my DLA application.

I believe the reports from the GET and CBT contributed to me being awarded ESA as they confirmed that, despite treatment, my condition has been progressively worsening.

Got a job and came off benefits

Did the course (or completion / non-completion of the course) have an effect on any DWP benefits (i.e. ESA, PIP, DLA) that you were claiming?

CBT_both DWP benefits (not started)	**Number**	**Percentage (%)**
Yes	46	21.1
No	166	76.1
missing responses	6	2.8
Total	218	100

Appendix 4 – CBT (combined with GET)

Further answers to Yes

Word	Count	Weighted Percentage (%)	Similar Words
get	24	3.03	get, gets
benefits	15	1.90	benefit, benefits
support	14	1.77	support, supported, supporting, supportive
CBT	13	1.64	CBT
refused	12	1.52	refusal, refuse, refused, refuses, refusing
pip	11	1.39	pip
ill	10	1.26	ill, illness
clinic	8	1.01	clinic, clinical, clinics, clinics'
course	7	0.88	course, courses
DWP	7	0.88	DWP

Theme	Count	Associations
Support	8	Supporting evidence, medical support, wouldn't support, accurate reference support
Illness	6	Ill health grounds, severely ill, physical illness
Evidence	6	Supporting evidence, medical evidence
Health	5	Ill health grounds, mental health, health condition
Retirement	4	Early retirement, medical retirement
Letter	3	Wrote letter, refusal letter, assessment letter
Clinical	3	Particular clinic, clinical nurse
Benefits	3	Claiming benefits, ESA benefit
Amount	3	Possible amount, fair amount
Help	2	Wanting help, didn't help

Other doctors have questioned the reasoning my GP who knew me well before I fell ill had for not making me complete the course. The attitude is that if you don't complete it then you are responsible for staying ill or want to be ill. It's a hostile environment that is very unfair and often leads to a poor attitude towards further care.

I am claiming PIP and this proved really difficult to get. Even with supporting evidence from my doctors I had to go to mandatory reconsideration before being awarded standard but nothing for mobility.

I was unable to apply for PIP because the GP who I am registered with refused to supply me with supporting evidence

I got PIP as my OT did an assessment letter

Non completion was taken as me 'not wanting help/ not wanting to get better

I am constantly harassed by DWP & GP to attend a course; I am unable to leave my bed

No. But refusing the course made me extremely anxious that benefits would be withdrawn. I felt coerced into doing both the CBT and GET courses, which were repeatedly mentioned over several years.

I am not sure, but was asked what I was doing in order to help myself with recovery.

Appendix 4 – CBT (combined with GET)

Are there any other comments on your course of CBT and GET? (Those started)

Word	Count	Weighted Percentage (%)	Similar Words
getting	394	2.52	get, 'get, gets, getting
CBT	286	1.83	CBT
helps	232	1.49	help, helped, helpful, helping, helps
illness	175	1.12	ill, illness, 'illness', illnesses
treatments	173	1.11	treatment, 'treatment, 'treatment', treatment', treatments, 'treatments', treatments'
symptoms	136	0.87	symptom, symptoms
course	129	0.83	course, courses
made	127	0.81	made
health	120	0.77	health
feel	119	0.76	feel, feeling, feelings, feels

Appendix 4 – CBT (combined with GET)

Theme	Count	Associations
Mental	150	Mental health, mental health issues, mental health problems, mental illness, mental health treatment, mental health therapy, mental health nurse, mental health disorder, mental health condition, mental health symptoms, mental wellbeing, mental symptoms, mental strength, mental state, mental problems, mental health services, mental health perspective, mental health effects, mentally unwell, mental tiredness
Health	150	mental health, physical health, health care professionals, poor health, health levels, health improvements, chronic health condition, worsening health, trusting health professionals, health system, full health, fluctuating health, emotional health, disabling health condition, deteriorating health
Illness	64	Physical illness, mental illness, chronic illness, long term illness, serious illness, much iller, moderately ill, ill people, severely ill, ill body, really ill, real illness, psychological illness, negative illness beliefs, biological illness, varying illness, term illness, mistaken illness beliefs, incorrect illness beliefs, illness behaviour, false illness beliefs, destroying illness, debilitating illness, extremely ill
Treatment	62	Effective treatment, mental health treatment, treating people, private treatment, harmful treatment, ineffective treatment, ethical treatment, enough treatment, early treatments, treatment plans, treatment options, resuming treatment, adequate treatment, treatment path, standard treatment, psychological treatments, proper treatment, practical treatment, physical treatment, ongoing treatments, NHS treatment, medical treatment, inpatient treatment, horrendous treatment, forcing treatment, dangerous treatment, current treatment, core treatment, coping treatment, controversial treatment, beneficial treatment, appropriate treatment
Symptoms	51	Physical symptoms, symptom control, mental health symptoms, managing symptoms, fatigue symptoms, existing symptoms, mental symptoms, improving symptoms, horrendous symptoms, diagnostic symptoms, depressive symptoms, similar symptoms, severe symptoms, raised symptoms, preventing symptoms, POTS symptoms, patients symptoms, ongoing milder symptoms, individual symptoms, included symptoms, disregarded symptoms, direct symptoms, condition symptoms, caused symptoms
People	50	Treating people, ill, people, helping people, course people, medical people, nice people, negative comments people, lazy people, awful people, active people
Activity	46	Physical activity, physical activity levels, standing activity, seat activity, everyday activities, overall activity levels, graded activity, activity levels, social activities, tailor activity, normal activity, daily activity,
Exercise	44	Graded exercise, aerobic exercise, graded exercise class, exercise therapy, strengthening exercises, gentle exercise, trying exercise, traditional exercise, standing exercise, exercise levels, exercise intolerance, physical exercise, loved exercise, inappropriate exercise, gradual exercise, exercise regimes, exercise bike, enjoyed exercise, dangerous exercise
Levels	42	Physical activity levels, energy levels, low levels, different levels, base level, activity levels, health levels, exercise levels, assessing recovery levels, Victorian levels, reliable levels, managing energy levels, existing energy levels, certain level, cellular level, basic level, at base level
Pain	25	Physical pain, nerve pain, severe pain, immense pain, pain management, pain clinic consultant, much pain, real pain, pain relief, pain management course, pain history, pain clinic consultant, great pain, extra pain, emotional pain, constant pain, chronic pain patients, chronic cramp pains

It didn't not work .was made to fill like u had to feel better at the end of the course. Lots of people drop out .I never got over the graded exercise I've been in severe pain with my legs ever since trying to do it.

Certainly helps to accept long term condition also helps put things into perspective. i.e.: condition doesn't change just helps you to manage yourself better by incorporating rest periods as and when required. Still have moderate/severe.

It was extremely harmful, had zero patient care, thought of impacts and left me isolated and alone with no hope for health improvements or even try and managing symptoms. Consequently I ended up suicidally

depressed and tried to commit suicide. None of this would have happened if I hadn't been forced that these dangerous treatment roots, as I was in a poorly but stable place prior to treatment.

Totally inappropriate, coercive, abusive and harmful. New symptoms arose, existing symptoms permanently worsened, and my confidence severely knocked. Cannot trust doctors again.

I imagine CBT can be helpful for some, particularly with co-morbid mental health issues but the distances patients have to travel to access ME/CFS services are prohibitive for patients who are already struggling with everyday activities.

CBT offered help to cope with grief of lost normal life, Support and encouragement. Strategies to cope with it was devastating to hear an implication that I was unwell because I was deconditioned and have false illness beliefs. I was a dance instructor before I became ill, and I also went to the gym about three times per week. The ME happened as a slow deterioration over months and years. How did deconditioning happen in that time?? I got much worse and seven years later I am still unable to work. CBT is useless for people with ME. Our problem isn't that we are trapped into being negative and believing ourselves to be ill, it is that we are disbelieved, ignored and held in contempt. People with ME want to work. Please stop trying to treat us with methods that don't work or make us worse. Put money into biomedical research and find a way to help us so that we can go back to work and live a normal life.

CBT was tailored to my thought processes as a starter finisher to try and stop me attempting too much on good days. Otherwise, no benefit at all. GET was a complete waste of time as I do not have a consistent baseline

I think GET is very dangerous for people with M.E. as we push ourselves to try and follow medical advice and yet GET negatively affected me both physically and mentally as I thought that the medical advice would help me not make my condition worse.

ME/CFS is a serious medical condition and CBT and GET are not appropriate forms of treatment. You cannot talk yourself out of this and gradually increasing your activity has long term negative effects. Please stop offering them to patients; it will ruin their already restricted lives.

CBT/GET are not miracle cures. They're not cures at all. Most (if not all) ME/CFS sufferers are well aware of their own limits and abilities. I find it frustrating that these treatments are invariably led by people who have no personal experience of this majorly debilitating illness. We can't overcome its' effects by sheer willpower (would that we could)

CBT had little or no effect apart from the distress and upheaval of making it to the appointments and causing brain fog and tiredness.
GET completely exacerbated my symptoms and left me nearly bedbound for several months.

The CBT was helpful in that we focused on a trauma and I was encouraged to seek more help. The Get side was harmful and I realised I couldn't fulfil the goals.

She felt so let down, feeling like others thought it was in her head due to the CBT. The GET absolutely ruined any living she had. She was left in bed, in pain not being able to do anything. This affected her to the point of suicide!

I felt both inappropriate as they both used more brain and muscle power than my body could cope with. There was a feeling that if I didn't achieve what was given to me I was a failure.

CBT helped me listen to my system and learn how little I could do and how to try to not overdo it. It changed nothing about the nature of the illness itself. GET ignored all that and caused a major crash.

No long term improvement

Terrible to end up worse off. Had such high hopes and spent a good bit.

Found both experiences of both although tried my very best to commit to, overwhelming and distressing. Naively believed in both praying would help, bring around changed and help improve my quality of life. Individual counselling, listening therapies have been most beneficial in offering an outlet to help me cope with emotional health, low moods and anxiety attributed to my ME.

CBT helped me to accept my illness without guilt and shame. GET did the opposite and contradicted the CBT planning I had done previously

I cannot understand why health professionals will recommend exercise therapy for an illness that is known to be exercise intolerant.

I had a lot of hope before I attended the CFS/ME service. I really believed that they would be able to do something to help me manage my condition and that they would understand how physically unwell I am. I tried very hard improving my health but these interventions just made me more ill and feeling more alone.

I felt as though the courses were too prescriptive in the sense that they try to offer a 'one size fits all' approach. Neither were applicable or helpful to me at that time of my illness and hence I didn't finish either course.

CBT made no different to me as I was already where they would expect someone to be but the get I feel has made me now severely ill with no improvements since, only a decline in my health

I find that the CBT is a useful tool in the box at times if I feel negative and despondent about my situation which is a very normal feeling being housebound & dependent on others for most things. It can be a good supportive measure but it does not improve my symptoms and is certainly not a treatment or a cure.

I was surprised that the courses were more beneficial than I expected, particularly for the newest sufferers in our group, one of whom had fully recovered 6 months after completion.

I have on average and will continue to be positive in mind set (luckily for me) though it has been a struggle at the low points. I got some useful coping strategies so far from CBT for the lows but GET is a disaster for this condition. I refuse to accept any more GET.

It only offered me a minor improvement; much of it is common sense such as not being hypervigilant to symptoms and not predicting the worst. Many of us appear to do this already and the therapy is only of use to individuals who have developed bad coping habits in my opinion. However, for me, it only led to a very slight improvement.

It was pretty basic and then I was discharged from the service. I have had no treatment or anything since. I'm just left outside of the system with no support

CBT seems useful, although no improvement. GET caused symptoms to worsen

It helped a great deal with understanding and coming to terms with my condition.

Although group was useful to meet others with ME (and this was possibly the most useful thing to get from it) we were at such different levels and stages of illness things really weren't tailored enough to our needs.

I went to GP to ask about exercise referral scheme at local gym. It's low impact therapy. I did this after finding a massive improvement with gentle stretching each day

I would like to make it clear that I was not forced to take part in GET; The CBT was delivered in a way that was designed to help us to come to terms with our condition and improve our mental health. When it became apparent that GET wasn't working for me I was not forced to continue,

CBT only helped me accept that I have to learn to live with CFS/ME didn't help to get me better

Appendix 4 – CBT (combined with GET)

It's useful to talk and get an understanding of how to help myself

Everybody should have CBT, although I still have CFS I feel better equipped to cope with it.

CBT/GET didn't help. Coaching on managing energy levels and coping with symptoms did.

They had an amazing difference on my son; don't know what we would have done without this support

Did make a positive improvement over all increasing self confidence
I was very pleased with the service I was delivered and my therapists were always easy to contact.

I found CBT very helpful in accepting my condition and being able to accept using a wheelchair as well as teaching me the importance of breathing and meditating.

Really changed my life even though my symptoms only slightly improved. It taught me to understand the condition so now I'm able to manage it much better and live an almost normal life. This has improved my mental health too. I was taught skills that I'll use for life and it was great to find someone that understood the condition.

I was very lucky to be treated at the Maudsley Clinic, London and have an excellent therapist.
I didn't always listen to his GET instructions, I listened to my body, and he understood this.
There was never any hurry and I am to continue with my therapy, which includes counselling, until I am greatly improved as I also have dissociative seizures.

It was nice to be able to talk to someone who was supportive and had some understanding of what I was experiencing

Both of these treatments were personally life changing for me. Although there were ups and downs, the overall difference in both my physical and mental health from start to finish was astonishing. Both courses where of course made easier with amazing specialists throughout (psychologist, physiotherapist and consultant). I feel very lucky to have been offered treatment as I know it is not the case for everybody.

Appendix 5 - Both GET

What year were you offered a course of GET treatment?

GET_both year offered	Number	Percentage (%)
2007	50	5.3
2008	46	4.9
2009	59	6.3
2010	51	5.4
2011	46	4.9
2012	64	6.8
2013	58	6.2
2014	76	8.1
2015	90	9.5
2016	125	13.3
2017	129	13.7
2018	141	15
2019	8	0.8
Total	943	100

*Total = all those who were offered GET (combined with CBT)

Was the GET treatment offered on the NHS or through the private medical sector?

GET_both Sector	Number	Percentage (%)
NHS	889	94.3
Private Medical Sector	51	5.4
*missing responses	3	0.3
Total	943	100

*Total = all those who were offered GET (combined with CBT)

Did you start the GET course? (*answer required)

GET_both started	Number	Percentage (%)
Yes	707	75
No	236	25
Total	943	100

*Total = all those who were offered GET (combined with CBT)

Appendix 5 – GET (combined with CBT)

Yes, please state the year or approximate year

GET_both year started	Number	Percentage (%)
2007	28	4
2008	19	2.7
2009	31	4.4
2010	28	4
2011	31	4.4
2012	44	6.2
2013	43	6.1
2014	44	6.2
2015	59	8.3
2016	74	10.5
2017	76	10.7
2018	72	10.2
2019	5	0.7
*missing responses/unknown	153	21.6
Total	707	100

*Total = all those who started GET (combined with CBT)

No, please explain why

Word	Count	Weighted Percentage (%)	Similar Words
get	125	2.76	get, getting
symptoms	50	1.10	symptom, symptoms
worse	50	1.10	worse
exercise	48	1.06	exercise, exercised, exercises, exercising
activity	46	1.02	active, activities, activity, 'activity'
time	45	0.99	time, times, timing
ill	42	0.93	ill, illness
offered	39	0.86	offer, offered, 'offered', offering, offers
make	36	0.80	make, making
years	35	0.77	year, years

Appendix 5 – GET (combined with CBT)

Theme	Count	Associations
Exercise	22	Several exercise, graded exercise, exercise levels, exercise duration, exercise bike, anaerobic exercise, aerobic exercise, increased exercise, gentle exercise, exercise routines, exercise regimes, exercise programme, bad post exercise fatigue
Activity	21	Physical activity, activity levels, extra activity, used activity pacing, strenuous activity, mental activity, increasing activity, graded activity, everyday activities, daily self-care activities
Pain	20	Chest pain, nerve pains, constant pain, much pain, experiencing pain
Time	12	Waiting time, scarce time, working part time, precious time, part time work, false hopes time, explained time
Course	12	Prescription courses, structured course, sixteen week course, similar course, previous courses, pacing course, mindfulness course, half day course, advisable course, CBT course, actual course
Treatment	11	Treatment option, suggested treatments, correct treatment, treatment model, private treatment, possible treatments
Levels	10	Activity levels, exercise levels, good level, energy levels fluctuate, energy levels
Illness	10	Mental illness, initial illness, illness mode, severely ill, really ill, ongoing illness
Thing	9	Sensible thing, last thing people, terrifying things, poor things, organic things, negative things, effective thing
Symptoms	7	Making symptoms, severe symptoms, sensory symptoms, main symptoms, horrendous symptoms, CFS symptoms

I suffer with extreme PEM. My GP stated that NICE guidelines suggest GET as an ME/CFS treatment option. We had lengthy discussion pro/cons of this treatment for my condition, taking my PEM into consideration. We BOTH concluded that GET would not be an advisable course of action for me. So although I was offered GET, it was not taken up on medical advice.

I have had severe ME for 26 years. I thought GET was completely inappropriate and potentially harmful

I knew from many years of experience that increased exercise would be harmful, plus I was too ill to attend in any case.

Same answer as before: Agreed travel distances to CFS clinic would do more harm than good.

ME too severe ill to attend group therapy offered

I have tried unsuccessfully myself to gradually increase my levels of activity

I was offered CBT a few months before & I was struggling with that & didn't want to start anything else. I was struggling to work part time at the time & I didn't want to add anything else in to my day.

Too ill to stay in the town where it was offered. Had to give up studies and move back to parents because of the effects of CBT

Previously had GET 5 years ago. Completely ineffective and significantly worsened my condition. Traveling to & from appointments and sitting through appointments caused more harm than good and again significantly worsened my condition. The advice given and activities prescribed were extremely harmful to me and led me to having severe M.E.

My therapist felt I was too ill for GET as I had cognitive and sensory symptoms too. We started with graded activity trying to sit up to eat or brush teeth.

I was already attending a mindfulness course for fatigue and pain. I couldn't manage attending both courses.

The occupational therapist explained the principles; she seemed wary of it and advised me to very slowly and gently apply the techniques myself

Appendix 5 – GET (combined with CBT)

The physiotherapist refused saying I was too debilitated and offered acupuncture instead

Refused it after advice from other, well researched sufferers

Due to being in too much pain and bed bound

Too ill to attend

My physical capacity and/or response to anaerobic exercise had not been tested so it was impossible to know if it was the correct treatment for my symptoms or if it would cause harm.

Because I had suffered with ME for years before and I knew how my body reacted even after a small amount of exercise and was not prepared to make myself feel worse

I knew the dangers of GET and my health wasn't stable enough to start. The OT agreed and we used Activity pacing instead.

It was eventually deemed that I wasn't well enough to start the course. Though, I was encouraged to exercise when I felt able.

It was far and GP thought it would negate benefits to travel

I was previously an exercise professional and it was during this time that I realised the destructive nature of exercise on my body. The more I pushed the worse I got. Eventually having to leave employment

Waiting list of over a year and could only choose one of three options (CBT, get or a support workshop which only had a few months waiting list)

Had to choose between CBT and GET. Was still supposed to have 2 GET sessions, but these ended up being physio for an urgent issue instead.

My condition is too severe, the physio demonstrated little empathy or understanding of more severe cases and I had already been warned of the dangers of GET and the damage it has done to countless numbers of people.

I knew from previous experience that graded exercise is guaranteed to make me worse. I didn't want to risk my health further

My fatigue and post exertional fatigue was too severe for me to engage in GET. I was told to start with 30 seconds - 1 minute on my exercise bike and gradually build up the amount of time I exercised. However I could not go beyond 1 minute without experiencing pain and an increase in fatigue.

Agreed to keep an 'activity' chart with realistic goals for each day. These comprised of everyday activities which he might be able to complete (i.e.) going up and down the stairs.

My NHS neurologist offered to arrange for me to attend CBT/GET sessions but advised that he did not feel they would be of benefit. I agreed and no arrangements were made.

The physio told me the basics and because I'd previously been an international swimmer he trusted me to follow his recommendations by myself

Appendix 5 – GET (combined with CBT)

Did you complete the GET course?

GET_both completed	Number	Percentage (%)
Yes	342	48.4
No	320	45.3
Still ongoing	45	6.4
Total	707	100

*Total = all those who started GET (combined with CBT)

If you answered No to the previous questions, why did you stop?

Word	Count	Weighted Percentage (%)	Similar Words
get	115	2.33	get, getting
worse	102	2.07	worse
symptoms	98	1.99	symptoms
made	69	1.40	made
illness	55	1.12	ill, illness, illnesses
much	55	1.12	much
worsening	54	1.10	worsen, worsened, worsening
exercise	52	1.06	exercise, exercise', exercises
session	48	0.97	session, sessions
start	48	0.97	start, started, starting

Theme	Count	Associations
Exercise	30	Exercise malaise, weekly group exercise sessions, pain management exercise, horrific post exercise malaise, graded exercise therapy, graded exercise, exercise bike, breathing exercises, regular exercise, physical exercise, much exercise, loved exercise, gentle exercise, exercise targets, exercise plan, exercise period, basic exercises, base level exercise
Activity	23	Increasing activity, physical activity, past activity management stage, energy requiring activities, normal activity, graded activity, extra activity, extra activities, different activities, completing activities, basic activities, basic activity, aerobic activity, additional activity, activity management, activity levels, activity level
Symptoms	22	Worsening symptoms, numerous symptoms, making symptoms, physical symptoms, managing symptoms course, mad symptoms, fluey symptoms, experiencing symptoms, CFS symptoms, caused symptoms
Pain	20	Much pain, severe pain, pain management, exercise, increased pain, constant pain, terrible pain, regarding pain, pain exhaustion, immense pain, aggravated pain, adverse pains
Malaise	18	Post exertional malaise, exercise malaise, horrific post exercise malaise, exertion malaise, exertional malaise
Session	17	Weekly group exercise sessions, group session, actual session, third session, several session, previous sessions, next sessions, last session, destroying sessions, CBT sessions, 2hr sessions
Health	16	Mental , physical health breakdown, physical health, immune health, ill health, general health
Worsening	14	Worsening symptoms, considerable worsening, massive worsening, drastic worsening, distinct worsening
Illness	11	Much iller, physical illness, ill health, really ill, incorrect illness beliefs, illness mode beliefs, extremely ill
Daily	11	Daily tasks, subsequent days, good days, daily walk, daily living, daily life, bad days, 2nd day

Appendix 5 – GET (combined with CBT)

Made me so ill couldn't finish the course.

Too ill. It was too much for me. Pushing beyond what I could manage. And it made me more ill

I was getting worse and was being told it was my fault: lack of motivation and listening to my body too much when I should be pushing through

It made me much much iller resulting in a physical health breakdown.

I became very ill during the session. My blood pressure dropped and I had to lie down for half an hour before I could leave afterwards I suffered severe PEM and was incapacitated for a long time.

Physically unable to .went from moderate to severe

I was assessed as being too ill to cope physically or cognitively

Physical, cardiac exacerbation of symptoms, decline

Too ill. Made it worse

I didn't start it, I refused to do it

I was unable to complete as my symptoms deteriorated and I became too unwell to attend or practice the information given. I also had cognitive issues and struggled to understand as I deteriorated

Because the rate of increase asked was too much to sustain, and I began to feel very unwell trying to complete the therapists walking requirements

Discharged as became too ill. Never made it past activity management stage, or trying to increase the amount of more energy-requiring activities during the day, let alone increasing no. of minutes doing an aerobic activity! Heck, I was struggling with the more complicated record keeping!!!

I did not want to make my symptoms worse

Didn't start as not well enough. My condition is now far worse than it was.

The first session knocked the stuffing out me. The PEM lasted for two months.

Symptoms not stable enough to carry on. Need to establish a consistent baseline first. Regular exercise was flooring me.

Made condition much worse, unable to attend sessions

Unable to sustain planned increases in exercise period.

My ME specialist said it was making me worse and had to stop

Pacing was outlined and left to manage this myself

Because the therapist and myself agreed it was making me worse!!

It was never formal, very ad hoc. The OT advised but never devised what I should do, basically I was told to just increase my activity slowly. However the OT stated my base line was higher than I was saying it was, therefore what he expected me to do was too much

It was attempted for 6months but her health deteriorated - that's when she was discharged from Bath hospital Child ME/CFS clinic and referred to her local CAMHS for CBT

Appendix 5 – GET (combined with CBT)

Because it caused relapses - I deteriorated and haven't reacheived the level of health I had at the start.

The course was tailor made by a peripatetic OT but I have never been able to extend my baseline of 30 minutes of 'normal activity' in any 24 hours to achieve the goal set by the course. The goal was to walk to my local library and back.

Daughter's energy focussed on studying for her GCSE's this summer so she cannot do both. Graded Exercise has not improved her condition as the symptoms of PEM still exist and the fundamental issues of the physiological problems of this illness not being addressed. Daughter did manage to get up to 30 minutes of gentle walking a day but her symptoms were still the same, extreme brain fog, fatigue and PEM being the top three

It was going very well until I caught a cold and couldn't exercise, when I went back to GET less fit than before it was implied that it was my fault!

Physio has relation with ME. She didn't believe in GET. Spent 90 mins talking about pacing and life with ME. Very good. Told me to contact her if I needed. I have with a couple of questions about stretches etc.

How many GET sessions were/are involved?

GET_both sessions	**Number**	**Percentage (%)**
0	1	0.1
1	22	3.1
2	23	3.3
3	22	3.1
4	22	3.1
5	20	2.8
6	81	11.5
7	5	0.7
8	51	7.2
9	2	0.3
10	47	6.6
11	1	0.1
12	43	6.1
13	4	0.6
14	2	0.3
15	5	0.7
16	6	0.8
17	1	0.1
18	1	0.1
20	8	1.1
21	1	0.1
24	2	0.3
25	1	0.1
30	1	0.1
40	1	0.1
60	2	0.3
100	3	0.4
365	1	0.1
Unknown	320	45.3
*missing responses	8	1.1
Total	707	100

*Total = all those who started GET (combined with CBT)

Appendix 5 – GET (combined with CBT)

Who delivered the GET treatment?

GET_both Clinician	Number	Percentage (%)
Cognitive Behavioural Therapist	33	4.7
Physiotherapist	326	46.1
Immunologist	3	0.4
Other	126	17.8
Occupational Therapist	160	22.6
Clinical Psychologist	38	5.4
Neurologist	1	0.1
GP	11	1.6
Psychiatrist	9	1.3
Total	707	100

*Total = all those who started GET (combined with CBT)

Other responses:

Word	Count	Weighted Percentage (%)	Similar Words
clinic	23	4.58	clinic, clinical
nurse	19	3.78	nurse, nurses
therapist	19	3.78	therapist, therapists
specialist	17	3.39	specialist, specialists
CFS	14	2.79	CFS
occupational	12	2.39	occupational
know	11	2.19	know
gym	10	1.99	gym
physio	10	1.99	physio
physiotherapist	10	1.99	physiotherapist, physiotherapists

Theme	Count	Associations
Therapist	36	Occupational therapist, physiotherapist, physical therapist
Occupational therapist	28	Occupational therapist
Gym	16	Gym instructor, local gym, medical gym referral, gym trainers, gym programme, gym pool
Clinical	14	Clinical psychologists, specialist clinic, private clinic, pain clinic, paediatric clinic, clinical practitioner, clinical psych, clinical physiotherapy
Instructor	11	Gym instructor, rehabilitation instructor, fitness instructor
Specialist	10	Specialist nurse, specialist, specialist physiotherapist, mindfulness specialist, lead specialist, breathworks specialists
Psychologists	10	Clinical psychologists, missed psychologists
Nurse	10	Specialist nurse, psychiatric nurse, nurse practitioner, psych nurse
Team	8	Multi-disciplinary team, tiredness team, support team, chronic fatigue team
Centre	4	Sports centre, rehabilitation centre, local leisure centre, chronic fatigue centre

Occupational therapist, psychotherapist for CFS

Nurse - pain clinic

Unsure. As team of staff.

It was part of sessions run by psychologist, OT and physiotherapist

Appendix 5 – GET (combined with CBT)

Physiotherapist Occupational Therapist
Team of physiotherapists and occupational therapists

Gym instructor Sports trainer

Specialist nurse

Specialist Nurse/Physiotherapist

Myself

Were/are you being seen individually or as part of a group?

GET_both group type	Number	Percentage (%)
Individual treatment	483	68.3
Group Treatment	153	21.6
Mixture of both	71	10
Total	707	100

*Total = all those who started GET (combined with CBT)

What impact did GET have on your physical health?

GET_both Physical Health	Number	Percentage (%)
Major improvement	18	2.5
Minor improvement	50	7.1
No improvement	79	11.2
Minor deterioration	138	19.5
Major deterioration	395	55.9
Not applicable	27	3.8
Total	707	100

*Total = all those who started GET (combined with CBT)

What impact did GET have on your mental health?

GET_both Mental Health	Number	Percentage (%)
Major improvement	14	2
Minor improvement	47	6.6
No improvement	172	24.3
Minor deterioration	184	26
Major deterioration	261	36.9
Not applicable	29	4.1
Total	707	100

*Total = all those who started GET (combined with CBT)

Did any of your symptoms worsen? (*answer required)

GET_both symptoms worsened	Number	Percentage (%)
Yes	607	85.9
No	73	10.3
Not applicable	27	3.8
Total	707	100

*Total = all those who started GET (combined with CBT)

Yes, please describe

Word	Count	Weighted Percentage (%)	Similar Words
pains	299	3.78	pain, painful, pains
fatigue	188	2.37	fatigue, fatigued
symptoms	151	1.91	symptom, symptoms
increasing	138	1.74	increase, increased, increases, increasing
worse	124	1.57	worse
worsening	118	1.49	worsen, worsened, worsening
get	114	1.44	get, getting
muscle	86	1.09	muscle, muscles
PEM	84	1.06	PEM
exercising	75	0.95	exercise, 'exercise', exercisers, exercises, exercising

Theme	Count	Associations
Pain	196	Joint pain, muscle pain, pain levels, increased pain, physical pain, nerve pain, joint pain headaches, pain fatigue, pain legs, shoulder pain, severe muscle pain, pain clinic, much pain, excruciating pain, cognitive difficulties nerve pain, chronic pain, body pain, severe pain, neck pain, muscular pain, permanent muscle pain, pain spasm, pain killer treatment, pain headache sensitivities, pain exhaustion, intense burning pain, ice pick pain, extreme pain fatigue, pain knee pain, body wide pain, worsening pain, suffered pain, stomach pains, serious pain, intense pain,
Muscle	105	Muscle pain, muscle weakness, muscle spasms, muscle aches, dysregulation muscle weakness, activity level muscle, muscle fatigue, severe muscle pain, worsening muscle fatigue, permanent muscle pain, speech muscle, particularly muscle, including muscle, calf muscle, aching muscle, muscle cramps, muscle strength,
Brain fog	88	Brain fog, thinking brain fog, severe brain fog, including brain fog, horrendous brain fog, energy mind fog, disability brain fog, causing brain fog, caused brain fog
Health	74	Mental health, mental health issues, physical health improvement, physical health, mental health symptoms, overall health, ill health requirements, general health benefits, general health
Mental health	64	Mental health, mental health issues, mental health symptoms
Levels	63	Pain levels, fatigue levels, energy levels, activity level muscle, activity levels, certain level, increased level, stable level, stress levels, previous level, pre-GET level, appropriate exercise level, useful levels, overall levels, original levels, low levels
Symptoms	62	Physical symptoms, following symptoms, pre-existing symptoms, cognitive symptoms, POTS symptoms, mental health symptoms, main symptoms, existing symptoms, vital symptoms, virus symptoms, underlying symptoms, symptoms exacerbate, single symptom, severe symptom, serious symptom increase, primary symptoms, exertional symptoms, gastro symptoms, additional symptoms
Cognitive	53	Cognitive function, cognitive issues, cognitive dysfunction, cognitive symptoms, cognitive problems, cognitive ability, cognitive impairment, cognitive function impairment, cognitive difficulties, cognitive function decline, cognitive task
Malaise	51	Exertional malaise, post-exertional malaise, exertion malaise, temporary malaise, general malaise, exercise malaise, exceptional malaise
Fatigue	50	Fatigue levels, pain fatigue, muscle fatigue, overall fatigue, extreme fatigue, worsening muscle fatigue, worsening fatigue, increased fatigue, overall fatigue, general fatigue, mental fatigue, extreme pain fatigue, unmanageable fatigue, severe fatigue, fatigue aches, exhaustion fatigue flu, exertional fatigue, especially fatigue, debilitating fatigue, baseline fatigue

Appendix 5 – GET (combined with CBT)

Baseline fatigue worsened. Severe PEM. Physical capabilities declined

Post exertional - fatigue and pain, emotionally very low, low confidence the realisation cannot do this no matter how much wanted to.

My condition deteriorated during the course and continued to decline afterwards. I have never felt as well as I was at the start since, for even a day. I was not at all well beforehand.

No longer mobile now full time in a wheelchair. Completely physically and mentally tired all the time

I started to have really long relapses as I pushed myself more and then blamed myself and tried to push through

Severe PEM and ill for about 2 weeks after the session

Post exertional malaise got worse, as did cognitive dysfunction.

Had to give full time work up to part time but still struggling

I became much more fatigued and had much more pain in my joints

All ...pain headaches sensitivities cognitive and baseline dropped not recovered fully since

When following the course instructions I was unable to attend work due to fatigue
Work was a priority so didn't increase activity as instructed

I had to stop doing other things in order to just get to the appointment so was only doing session and then resting until the next session resulting in no social or quality of life

Sometimes PEM would be worse after doing the exercise recommended

Found I needed to sleep after each exercise session.

Occasionally I overdid it and had an energy crash - but was temporary

Took a long time trialling different exercises which sometimes made my symptoms worse

Exercise made my symptoms worse which had an effect on my mental status. The only thing that helped physically was to rest and over time I got stronger

Exhaustion and pain increased dramatically. So much so it took several months of being bed bound to get back to my original levels of pain and energy.

All symptoms deteriorated. Debilitating fatigue, flu like symptoms and a multitude of CFS symptoms. I did not suffer from any mental health issues.

It mentally made me feel useless. I had been a very fit and active sporty person previously and I was sold an idea that graduated exercise would increase my range and tolerance. Instead I lost the ability to function in between sessions, where I was so tired that what I could do before became disabled and actually my tolerance became much worse per session. My physical and mental body didn't become stronger it became weaker and weaker

Temporary PEM following each session, but probably due to the travel effort, rather than the gentle exercises.

Almost of all my symptoms got worse after GET. But have improved a little since I stopped.

Initially home visiting/phone service. After effects of any exercise, increased activity or hospital visits or targets.

Appendix 5 – GET (combined with CBT)

But built up strength & stamina very very gradually.

Did you develop any new symptoms? (*answer required)

GET_both symptoms new	Number	Percentage (%)
Yes	314	44.4
No	342	48.4
Not applicable	51	7.2
Total	707	100

*Total = all those who started GET (combined with CBT)

Yes, please describe

Word	Count	Weighted Percentage (%)	Similar Words
pain	112	3.79	pain, painful, pains
symptoms	57	1.93	symptom, symptoms, symptoms'
severe	45	1.52	several, severe, severely, severity
get	42	1.42	get, gets, getting
muscle	38	1.29	muscle, muscles
became	29	0.98	became
problems	27	0.91	problem, problems
unable	27	0.91	unable
fatigue	25	0.85	fatigue, fatigued
walking	24	0.81	walk, walking

Theme	Count	Associations
Pain	87	Joint pain, extreme pain, severe pain, muscle pain, chest pain, pain levels, increased pain, excruciating pain, chronic pain, severe muscle pain, searing pain, worsening pain, stomach pains, shoulder pain, neuropathic pain, knee pain, horrendous pain, facial pain, nerve pain, muscular pain, leg pain, different pains, constant pain, complex pain, bone pain, body pain, additional pain
Problems	45	Respiratory problems, nervous system problems, mobility problems, joint problems, bladder problems, balance problems, stomach problems, speech problems, major problem, developed problems, swallowing problems, gastronomical problems, sound sensitivity problems, sleep problems, significant problems, severe heart problems, depression problems, arm problems
Muscle	36	Muscle weakness, muscle pain, severe muscle, muscle weakness spread, developed muscle tremors, severe muscle pain, muscle spasms, constant muscle pain, severe muscle loss, neuralgia muscle weakness, muscle twitching, muscle energy, muscle aches, lose muscle, arm muscles
Joint	33	Joint pain, joint knee pain, joint hip pain, painful joints, joint problems, joint issues, aching joints
Symptoms	28	POTS symptoms, fibromyalgia symptoms, significant digestive symptoms, physical symptoms, major symptoms, cognitive symptoms, symptoms list, specific symptoms, severe symptoms, reversal symptoms, possible symptoms, neurological symptoms, mental symptoms, managing symptoms, managed symptoms, gastro symptoms, blaming symptoms, autonomic symptoms
Issues	27	Cognitive issues, cardiac issues, joint issues, gastrointestinal issues, stomach issues, psychological issues, neurological issues, mobility issues, hip issues, digestive issues
Cognitive	25	Cognitive issues, cognitive impairment, significant cognitive dysfunction, severe cognitive dysfunction, cognitive symptoms, cognitive function, cognitive dysfunction, cognitive decline, cognitive malfunction, cognitive impact

Appendix 5 – GET (combined with CBT)

Lots more pain and severe fatigue

Additional pain and exhaustion

Sensory overload. More cognitive impact
Seizures, gastrointestinal issues, extreme light and sound sensitivities, severe cognitive dysfunction. For several years lost independent use of limbs and ability to chew or swallow solid food.

The pain spread, I developed muscle tremors, the muscle weakness spread and I developed peripheral neuropathy and in turn, balance and mobility problems.

New areas of pain. Loss of speech and digestive and bladders issues and swallowing difficulties

Weakness of muscles, horrendous pain in joints and muscles

I developed severe insomnia, chest pain, inability to move for long periods. Gastrointestinal issues. Psychological issues that now mean I don't trust doctors. I developed POTS.

Ever since G.E.T I have suffered from muscle pain all over body, very heavy painful legs and episodes of paralysis below the waist, I had none of these symptoms pre G.E.T.

Chronic pain, fibromyalgia symptoms, POTs symptoms

Constant muscle pain, especially in my legs.

Increase in pain. Almost complete loss of already very limited mobility.

I developed problems with balance, coordination, weakness and increased pain.

I experienced a great deal of post exertional malaise and joint pain. My cognitive function worsened and I have never recovered to the level I was at before the commencement of GET

My mobility declined, I can't walk far, get pain from walking, can't stay upright anymore, ache and pains, exhaustion and cognitive decline

Respiratory problems and bad allergies, cognitive issues, cardiac issues, autonomic nervous system problems, muscle weakness and shaking, extreme pain

A whole new level of exhaustion. Headaches. Digestive issues and horrendous nausea. Pain in my legs and hips

My inability to follow the program made me more depressed about my situation.

I felt more frustration and depression at my situation

Symptoms returned that I thought were gone. This was due to focusing on my weaknesses and trying to stop activities that were actually helping me to manage my ME

Again, I have many new symptoms but I cannot say if they are a direct result of GET

Anxiety started as I never knew fully how bad the consequences of the "treatment" would affect me

Slightly depressed as they kept saying I should try harder or it was all in my mind, and look at these examples and testimonies, if they can do it then you can, but I couldn't. And even worse that it not helping make me any better, just getting there and trying made it all worse. So I got pretty down, and angry and frustrated and that's unusual for me as I'm usually a cheery wee soul.

Appendix 5 – GET (combined with CBT)

Before treatment my only major symptoms were fatigue and PEM, but during and after treatment my pain levels skyrocketed, my fatigue and PEM became completely debilitating, and I developed a whole host of other symptoms such as IBS and sensitivity to light and sound, and I went from being just-about-functional to needing a wheelchair to leave the house and often being bedridden

Not as a direct result of GET but the condition progressed.

GET_both severity before treatment (all)	**Number**	**Percentage (%)**
Mild	229	24.3
Moderate	577	61.2
Severe	137	14.5
Total	943	100

GET_both severity after treatment (all)	**Number**	**Percentage (%)**
Mild	101	10.7
Moderate	373	39.6
Severe	321	34
*missing responses	148	15.7
Total	943	100

How severe was your condition **before** treatment with CBT and/or GET was offered/undertaken?

GET_both severity before treatment (those started)	**Number**	**Percentage (%)**
Mild	178	25.2
Moderate	436	61.7
Severe	93	13.2
Total	707	100

*Total = all those who started GET (combined with CBT)

How severe was your condition **after** treatment with GET?

GET_both severity after treatment (those started)	**Number**	**Percentage (%)**
Mild	86	12.2
Moderate	325	46
Severe	296	41.9
Total	707	100

*Total = all those who started GET (combined with CBT)

Were other treatments offered in addition to GET?

GET_both other treatments	**Number**	**Percentage (%)**
Yes	274	38.8
No	417	59
*missing responses	16	2.3
Total	707	100

*Total = all those who started GET (combined with CBT)

Appendix 5 – GET (combined with CBT)

Further answers to Yes

Word	Count	Weighted Percentage (%)	Similar Words
CBT	187	13.24	CBT
pacing	28	1.98	pace, pacing, pacing
get	22	1.56	get
mindfulness	22	1.56	mind, mindfulness, 'mindfulness'
course	21	1.49	course, courses
pain	20	1.42	pain, pains
managing	19	1.35	manage, management, managing
help	17	1.20	help, helped, helpful, helping, helps
group	15	1.06	group
therapy	15	1.06	therapies, therapy

Theme	Count	Associations
Group	24	Support group, patient self-help group, nature therapy group, cancer group, group course
Therapy	20	Occupational therapy, nature therapy group, talking therapy group, phone therapy, therapy sessions, sleep therapy, occupational therapy activity, drug therapy, behaviour therapy, activity therapy
Pain	20	Pain management, pain management course, pain psychology, pain relief techniques, pain clinic, chronic pain clinic, pain injections
Advice	15	Pacing advice, dietary advice, health advice, useful advice, sleep advice, nutritional advice, diet advice, career advice
Management	14	Pain management, pain management course, lifestyle management, completed anxiety management course, self-management, management strategies, activity management
Course	13	Group course, pain management course, anxiety management course, mindfulness course, 12 week course, 12 week lifestyle course
Pacing	11	Pacing advice, talking therapy pacing, pacing etc., activity pacing
Clinic	9	Clinic interventions, pain clinic, chronic pain clinic, CFS clinic
Treatment	8	Supportive treatment, main treatment, ongoing treatment program, MDT treatment, inpatient psychology treatment, actual treatment
Occupational Therapist	8	Occupational Therapist, Occupational Therapist review

Pain management course

Psychotherapy

Painkillers and different anti-depressants

CBT & Mindfulness

Pain medication

Anxiety management course and also mindfulness

Pacing, pain management, CBT, mindfulness, yoga

Yes pain management, relaxation, holistic physio approach

CBT and psychotherapy, pacing advice.

Appendix 5 – GET (combined with CBT)

Medication

CBT and activity management/pacing

Mindfulness

Acupuncture

Sleep hygiene

Meditation, yoga, counselling, nutrition awareness

Hydrotherapy

Activity Management

Lifestyle Management Course

Nutritional advice

Did the course of CBT and/or GET result in any change in your ability to carry out or resume employment or education?

GET_both employment/education (those started)	**Number**	**Percentage (%)**
Yes	334	47.2
No	365	51.6
*missing responses	8	1.1
Total	707	100

*Total = all those who started GET (combined with CBT)

Further answers to Yes

Word	**Count**	**Weighted Percentage (%)**	**Similar Words**
work	189	5.43	work, worked, working
get	101	2.90	get, getting
time	76	2.18	time, times
able	68	1.95	able
made	45	1.29	made
school	41	1.18	school, schooling
unable	39	1.12	unable
worse	38	1.09	worse, worsening
back	37	1.06	back
hours	37	1.06	hour, hours

Appendix 5 – GET (combined with CBT)

Theme	Count	Associations
Time	97	Full time, part time, part time work, full time work , full time employment, part time school, part time job, full time university, part time study, full time education, part time university course, part time hours, part time education, increasingly part time
Full time	43	Full time, full time work, full time employment, full time university course, full time education
Work	37	Part time work, full time work, working hours, work plan, volunteering work, school work, voluntary work, social worker, social work, resumed work, left work, left work completely, decreased work hours
School	17	Attended school, part time school, school work, school hours, stopped school, secondary school education, secondary school, school age
Health	16	Ill health, worsening health, occupational health unit, mental health, occupational health, mental health professional, ill health retirement, health issues, health improvements

Find it extremely difficult to go to school some days, have very little energy. I am missing the best years of my life and this illness is "not in my head"

As I said previously, after 9 months of pursuing these protocols my condition deteriorated to the point I had to retire from teaching. Both CFS and Fibromyalgia were regarded as waxing and waning conditions so I was offered the minimum early retirement package. As I've said, my condition continues to worsen.

Made even less likely to go back to Uni or get work

Worked for first 3 years of illness while undiagnosed and managing symptoms myself through pacing. After treatment lost ability to work and have been dependent on benefits for over a decade.

It pushed my levels of activity back so far that I don't know if I will ever be able to work again. My confidence in myself was shattered.

Before I began the "treatments" my ME was slowly improving, to the point that I thought I'd soon be able to return to work, but I declined so much that this has never happened.

My symptoms were worsening and I went from being in full time employment to being off sick for several months and then having to give work up completely

No longer able to concentrate or retain information so had to give up my university course

I was too fatigued to go to school, more so than if I'd been resting at home for the day

Not able to concentrate enough to work, or study, absolutely debilitating fatigue on minimal excursion

I had a scholarship to start some studies as part of my rehabilitation. The GET made me so poorly I had to delay it 2 years.

Lost job due to relapse after GET and had to drop out of university course

The symptoms made it harder to work as many hours.

Unable to work any more

As my condition is worse I am finding it harder to do my job and spend more time recovering in the evening and weekend

Working part time instead of full time

During the sessions I went to, my symptoms worsened and I had to have time off work.

Appendix 5 – GET (combined with CBT)

Took longer to recover enough to go back in to employment

I have now started to start school work again but all from home

Since then I have reduced from full time work to part time (20 hours per week)

I was struggling to even work part time already but after GET I had to give up working and have been told it is highly likely that I will not work again

It made me even worse; who thought that was possible... I eventually lost my beloved job as my sick leave ran out.

The CBT was helpful for me personally as I had some issues with anxiety and overthinking. The CBT really helped with that so I could learn techniques so I was not wasting energy I did not have on things I could not control. It has helped me personally and professionally.

The CBT has made it go from impossible to highly likely that I will go back to university this year (2019).

Increased ability to carry out employment by writing report to occupational health and helping gradual increase of hours approach.

They helped me bet back into school faster than I would have without CBT and GET.

It enabled me to maintain university study and get the support needed. And then last year it helped me tackle some of the issues that were affecting physical and mental health, and get through a phased return to work.

Did the course of CBT and/or GET result in any change in your ability to carry out or resume employment or education?

GET_both employment/education (not started)	**Number**	**Percentage (%)**
Yes	24	10.2
No	63	26.7
*missing responses	149	63.1
Total	236	100

Further answers to Yes

Word	**Count**	**Weighted Percentage (%)**	**Similar Words**
work	13	6.57	work, working
week	6	3.03	week, weeks
resulted	5	2.53	result, resulted
unable	5	2.53	unable
CBT	4	2.02	CBT
ability	3	1.52	abilities, ability
completing	3	1.52	completing, completely, completing
employment	3	1.52	employment
feel	3	1.52	feel, feeling
focus	3	1.52	focus

Appendix 5 – GET (combined with CBT)

Theme	Count	Associations
Work	2	Work hours, part time work

Felt too tired after group sessions to focus on studies

CBT made me feel I could pace and return to work. I returned to work for 1 hour a week twice a week. I managed 3 weeks then relapsed to a serious state which remains.

It caused her to have to drop out of her studies.

It resulted in me having to give up employment and training

It ended my career which ironically I only excepted CBT as a last ditch attempt to save my career. Due to being told to ignore my symptoms and push on It made me move from being a mild/moderate sufferer to a fully moderate\Severe
I had to take a break from studying as it severely affected my ability to attend lectures, retain information, read and focus attention, and even leave the flat most days.

Signed off sick from work shortly after completing CBT sessions - could not go on anymore. This was Aug 2018 and so far have been unable to return (Jan 2018)

Yes I had to make the decision to stop the education I was in and focus on my health.

I realised I couldn't cope with work and had to retire

During this period I became unable to continue working.

I have been unable since 2017 to carry on the part-time work (of only 16hours per week) I had previously managed and in 2018 have since had to leave employment completely through ill health

I was able to increase my work hours gradually

Did the course (or completion / non-completion of the course) have an effect on any DWP benefits (i.e. ESA, PIP, DLA) that you were claiming?

GET_both DWP benefits (those started)	Number	Percentage (%)
Yes	142	20.1
No	557	78.8
*missing responses	8	1.1
Total	707	100

*Total = all those who started GET (combined with CBT)

Appendix 5 – GET (combined with CBT)

Further answers to Yes

Word	Count	Weighted Percentage (%)	Similar Words
get	54	2.50	get, gets, getting
benefits	50	2.31	benefit, 'benefit', benefits
pip	43	1.99	pip
works	37	1.71	work, work', worked, working, works
claiming	36	1.66	claim, claimed, claiming
CBT	33	1.52	CBT, CBT'
time	29	1.34	time, times
course	28	1.29	course, courses
DWP	24	1.11	DWP
ESA	24	1.11	ESA

Theme	Count	Associations
Benefits	25	Claiming benefits, incapacity benefit, needed benefits, benefits applications, benefits award
Claiming	20	Claiming benefits, disability claim, claim years, actual claim
Illness	13	Ill health retirement, ill health grounds, terminal illness diagnosis, term illness, psychosocial illness, physical illness, chronic illness
Health	13	Ill health retirement, ill health grounds, health retirement process, health professional, health assessment, full health
Time	12	Part time, part time work, full time, full time university lecturer, bad time
Retirement	10	Early retirement, ill health retirement, health retirement processes, medical retirement
Part time	8	Part time, part time work
Assessments	8	health assessment, difficult assessment interview, work capability assessment, PIP assessments, future assessment, assessment procedure
Evidence	7	Supporting evidence, medical evidence, believing evidence
Professional	6	Health professional, professional involvement, medical professional

Was told if I didn't do it, it would affect my claim. I had to go to a tribunal and the people that did the course wrote incorrect report on my condition and what happened to me when I was there.

I went from claiming no benefits and earning my own living to unable to work on highest rate DLA (awarded indefinitely) and ESA.

I was able to access social security because I had medical evidence to support my case.

It initially effected the length of ESA, which is unfair as that indicated that CBT and get is a cure

It helped to be able to say I had tried it as before that they thought I didn't want to get better and wasn't trying.

My condition was so much worse that I now qualify for the higher rate of PIP. I did not before.

None of the above but I was required to demonstrate that I'd taken part in both CBT and GET to the DWP and my employers Occupational Health, Human Resource and pension committee..

MY ESA was stopped after a year (even though I completed the course), because it was deemed I was well enough to work and I had completed the NHS course

Being seen by a specialist for ME/CFS meant I had appropriate paperwork for benefits applications. Now I am no longer under a consultant & I am not able to submit previous paperwork because the DWP no longer accepts medical papers over 2 years old.

Appendix 5 – GET (combined with CBT)

Was told I had to have these interventions as they had been proven to cure people with ME, I was getting incapacity benefit on life term sick note but have continually been told by an unqualified person that the decision made by 3 GPs and two consultant experts in the field don't matter I have to work, so I get no aid whatsoever.

During my ESA interview I was told that I should do more to try and get well, and was questioned as to why I refused to continue with CBT/GET. When I told her of my worsening symptoms she actually snorted with laughter and told me I was being over dramatic. She told me I was rude and lazy. I cried for about a week after, which of course worsened all my symptoms again.

I had hoped to return to work (I was off sick during the course), but the deterioration in my symptoms has meant this has been impossible, so I had to start claiming benefits.

Because I completed the course the DWP claimed I must be cured and no longer sick. I was refused benefits for CFS.

Hard to say for sure, but seemed to make my reassessment for ESA easier and got some PIP, I think because I had better evidence.

It had positive effect in the respect that I was shown to be in receipt of treatment even though it did not improve or help symptoms had I not attended then benefits would not have been awarded

The only positive outcome was that the CBT therapist providing the course was happy to write letters in support of my DLA application

Did the course (or completion / non-completion of the course) have an effect on any DWP benefits (i.e. ESA, PIP, DLA) that you were claiming?

GET_both DWP benefits (not started)	Number	Percentage (%)
Yes	40	16.9
No	191	80.9
*missing responses	5	2.1
Total	236	100

Further answers to Yes

Word	Count	Weighted Percentage (%)	Similar Words
benefits	15	2.29	benefit, benefits
get	15	2.29	get
support	9	1.37	support, supporting
CBT	8	1.22	CBT
pip	7	1.07	pip
claim	7	1.07	claim, claimed, claiming
course	7	1.07	course, courses
ill	7	1.07	ill, illness
refused	7	1.07	refusal, refuse, refused, refuses, refusing
several	7	1.07	several, severe, severe', severely

Appendix 5 – GET (combined with CBT)

Theme	Count	Associations
Evidence	12	Supporting evidence, medical evidence, massive evidence
Support	10	Supporting evidence, medical support, accurate reference support
Supporting evidence	6	Supporting evidence
Illness	4	Severely ill, physical illness
Hospital	4	Hospital appointments, hospital treatment
Medical evidence	5	Medical evidence
Biopsychosocial model	4	Biopsychosocial model
Health	2	Mental health, health condition

Possibly not sure the Consultant wasn't impressed and kept on trying to get me to do it despite me telling him I have severe ME & bedbound now 10 yrs. and previous CBT & GET made me worse so quite possibly was passed onto DWP for non-compliance of recommended therapy

I was unable to apply for PIP because the GP who I am registered with refused to supply me with supporting evidence.

Was constantly asked if I had undertaken CBT or GET as this is what the NICE guidelines regard as treatment. Constantly having to explain the effect GET in particular has on moderate/ severe M.E. And what it would do to me.

My GP wouldn't support my application for benefits unless I was referred for treatment

Didn't receive benefit as I didn't attempt the course.

Yes I was told it was all in my head I had to control It was told that they would report to DWP and say that I wasn't willing to help myself so all my benefits was stripped from me.

Non completion was taken as me 'not wanting help/ not wanting to get better
I am constantly harassed by DWP & GP to attend a course; I am unable to leave my bed

No. But refusing the course made me extremely anxious that benefits would be withdrawn. I felt coerced into doing both the CBT and GET courses, which were repeatedly mentioned over several years.

Appendix 6 – Survey

Forward ME Survey

Start of Block: Introduction

This is a questionnaire for adults and children with a diagnosis of ME (Myalgic Encephalomyelitis)/ CFS (Chronic Fatigue Syndrome)/ PVFS (Post Viral Fatigue Syndrome), who received or were offered CBT and/or GET in the UK since 2007. The questionnaire will be asking you about the most recent course you attended.
You may fill out this questionnaire on behalf of someone else, please ensure all questions are answered in relation to the person you are filling out the form for.

The deadline to complete this survey is 31st January 2019.

Start of Block: Def and confirmation

As part of the process for gathering patient evidence for the National Institute for Health and Care Excellence (NICE) guideline committee, Forward ME has prepared this questionnaire on the use of cognitive behavioural therapy (CBT) and graded exercise therapy (GET). According to NICE if you have mild or moderate ME/CFS, you should be offered CBT and/or GET.

Forward ME consists of a broad spectrum of charities and voluntary organisations, invited by the Countess of Mar to meet from time to time. The aim of Forward ME is to promote effective joint working by ME and CFS organisations to maximise impact on behalf of all people with ME and CFS in the UK.

As Forward ME has been asked by NICE to conduct this survey, we have copied in their definitions of CBT and GET below. Please note, these definitions are not a reflection of the views of the members of Forward ME, for these, please go to their respective websites or contact them directly.

Cognitive behavioural therapy (CBT)

"An evidence-based psychological therapy that is used in many health settings, including cardiac rehabilitation and diabetes management. It is a collaborative treatment approach. When it is used for CFS/ME, the aim is to reduce the levels of symptoms, disability and distress associated with the condition. A course of CBT is usually 12–16 sessions. The use of CBT does not assume or imply that symptoms are psychological or 'made up".

Graded exercise therapy (GET)

"An evidence-based approach to CFS/ME that involves physical assessment, mutually negotiated goal-setting and education. The first step is to set a sustainable baseline of physical activity, then the duration of the activity is gradually increased in a planned way that is tailored to the person. This is followed by an increase in intensity, when the person is able, taking into account their preferences and objectives, current activity and sleep patterns, setbacks/relapses and emotional factors. The objective is to improve the person's CFS/ME".

Eligibility Please confirm whether you have received or were offered CBT or GET or both in the UK since 2007.

- ○ Yes (1)
- ○ No (2)

Start of Block: Ineligible

Thank you for your interest in the survey. Unfortunately you are not eligible to take part as you have not been offered a course of CBT or GET in the UK since 2007.

Start of Block: Demographics

All responses collected within this survey will be anonymous. By completing this survey you agree to the following:

1. Your responses to be recorded via the Qualtrics website and stored on a secure database

2. Your data only being used by Forward ME/ Action for ME/ #MEAction/ ME Research UK/ ME Association/ Oxford Brookes University to compile a subsequent report/publication

3. Any responses or quotes included in this survey to be used in any subsequent report/publication

Please be aware some questions with text boxes are mandatory and will require a response to proceed. These are highlighted throughout with (*answer required).

Please note this questionnaire will take approximately 10 minutes to complete.

Page Break

Who is filling out the questionnaire?

- ○ I am completing this myself (for myself) (1)
- ○ I am a parent completing it on behalf of my child (2)
- ○ I am a carer completing it on behalf of someone I care for (3)
- ○ Other (please specify) (4) _____

What age are you? (Please provide the age of the person this questionnaire relates to)

- ○ 12 and under (1)
- ○ 13-18 (2)
- ○ 19-30 (3)
- ○ 31-40 (4)
- ○ 41-50 (5)
- ○ 51-60 (6)
- ○ 61-70 (7)
- ○ 71+ (8)

What gender do you identify as? (Please provide the gender of the person this questionnaire relates to)

- ○ Male (1)
- ○ Female (2)
- ○ Non-binary (3)
- ○ I would prefer not to say (4)
- ○ Other (5)

What is the first part of your postcode? (*answer required)

_____

Page Break

Do you experience Post Exertional Malaise (PEM)? (a worsening of symptoms, which may be delayed in onset following activity)

- ○ Yes (1)
- ○ No (2)

Page Break

Severity-Before How severe was your condition **before** treatment with CBT and/or GET was offered/undertaken? (Please note the following are definitions created by NICE, these are not necessarily those accepted by the members of Forward ME)

- ○ **Mild** - People with mild CFS/ME are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week. (1)

- ○ **Moderate** - People with moderate CFS/ME have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work, school or college and need rest periods, often sleeping in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed. (2)

- ○ **Severe** - People with severe CFS/ME are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed, and are often extremely sensitive to light and noise. (3)

Page Break

This survey has been split into two sections, CBT and GET.

Please select the most recent treatment you have been offered:

- ○ CBT (Cognitive Behavioural Therapy) (1)
- ○ GET (Graded Exercise Therapy) (2)
- ○ Both CBT and GET (3)

Page Break

Start of Block: CBT1

What year were you offered a course of CBT treatment? (*answer required)

(If unsure please enter the approximate year)

_____

Was the CBT treatment offered on the NHS or through the private medical sector?

- ○ NHS (1)
- ○ Private Medical Sector (2)

Did you start the CBT course? (*answer required)

- ○ Yes (please state the year or approximate year) (1)

_____

- ○ No (please explain why below) (2)

_____

Start of Block: End1

Did the course (or completion / non-completion of the course) have an effect on any DWP benefits (i.e. ESA, PIP, DLA) that you were claiming?

- ○ Yes (please describe below) (1)

_____

- ○ No (2)

Start of Block: CBT2

Did you complete the CBT course?

- ○ Yes (1)
- ○ No (2)
- ○ Still ongoing (3)

If you answered No to the previous questions, why did you stop?

_____

_____

_____

_____

_____

How many sessions were/are involved?

- ○ (Please state the number of sessions) (0)

_____

- ○ Don't know (999)

Who delivered the CBT treatment?

- ○ Cognitive Behavioural Therapist (1)
- ○ Physiotherapist (2)
- ○ Occupational Therapist (3)
- ○ Psychiatrist (12)
- ○ Clinical Psychologist (4)
- ○ Neurologist (8)
- ○ GP (9)
- ○ Immunologist (11)
- ○ Other (please specify) (5) _____

Were/are you being seen individually or as part of a group?

- ○ Individual (1)
- ○ Group (2)
- ○ Mixture of both (3)

Page Break

What impact did CBT have on your physical health?

- ○ Major improvement (1)
- ○ Minor improvement (2)
- ○ No improvement (3)
- ○ Minor deterioration (4)
- ○ Major deterioration (5)
- ○ Not applicable - did not complete course (999)

What impact did CBT have on your mental health?

- ○ Major improvement (1)
- ○ Minor improvement (2)
- ○ No improvement (3)
- ○ Minor deterioration (4)
- ○ Major deterioration (5)
- ○ Not applicable - did not complete course (999)

Page Break

Did any of your symptoms worsen? (*answer required)

- ○ Yes (please describe below) (1)

_____

- ○ No (2)
- ○ Not applicable - did not complete the course (999)

Did you develop any new symptoms? (*answer required)

- ○ Yes (please describe below) (1)

_____

- ○ No (2)
- ○ Not applicable - did not complete the course (999)

Page Break

How severe was your condition **after** treatment with CBT? (Please note the following are definitions created by NICE, these are not necessarily those accepted by the members of Forward ME)

- ○ **Mild** - People with mild CFS/ME are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week. (1)
- ○ **Moderate** - People with moderate CFS/ME have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work, school or college and need rest periods, often sleeping in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed. (2)
- ○ **Severe** - People with severe CFS/ME are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed, and are often extremely sensitive to light and noise. (3)

Were other treatments offered in addition to CBT?

- ○ Yes (please describe below) (1)

_____

- ○ No (2)

Are there any other comments on your course of CBT and/or GET?

- ○ Yes (please describe below) (4)

_____

- ○ No (19)

Start of Block: End1

Did the course (or completion / non-completion of the course) have an effect on any DWP benefits (i.e. ESA, PIP, DLA) that you were claiming?

- ○ Yes (please describe below) (1)

_____

- ○ No (2)

Start of Block: End2

Did the course of CBT and/or GET result in any change in your ability to carry out or resume employment or education?

- ○ Yes (please describe below) (1)

_____

- ○ No (2)

Start of Block: GET1

What year were you offered a course of GET treatment? (*answer required)
(If unsure please enter the approximate year)

_____

Was the GET treatment offered on the NHS or through the private medical sector?

- NHS (1)
- Private Medical Sector (2)

Did you start the GET course? (*answer required)

- Yes (please state the year or approximate year) (1)

_____

- No (please explain why below) (2)

_____

Start of Block: GET2

Did you complete the GET course?

- Yes (1)
- No (2)
- Still ongoing (3)

If you answered No to the previous questions, why did you stop?

_____

_____

_____

How many GET sessions were/are involved?

- ○ (Please state the number of sessions) (0) _____
- ○ Don't know (999)

Who delivered the GET treatment?

- ○ Cognitive Behavioural Therapist (1)
- ○ Physiotherapist (2)
- ○ Occupational Therapist (3)
- ○ Psychiatrist (10)
- ○ Clinical Psychologist (5)
- ○ Neurologist (7)
- ○ GP (8)
- ○ Immunologist (9)
- ○ Other (please specify) (6) _____

Were/are you being seen individually or as part of a group?

- ○ Individual (1)
- ○ Group (2)
- ○ Mixture of both (3)

Page Break

What impact did GET have on your physical health?

- Major improvement (1)
- Minor improvement (2)
- No improvement (3)
- Minor deterioration (4)
- Major deterioration (5)
- Not applicable - did not complete course (999)

What impact did GET have on your mental health?

- Major improvement (1)
- Minor improvement (2)
- No improvement (3)
- Minor deterioration (4)
- Major deterioration (5)
- Not applicable - did not complete course (999)

Page Break

Did any of your symptoms worsen? (*answer required)

- ○ Yes (please describe below) (4)

_____

- ○ No (7)
- ○ Not applicable, did not complete the course (9)

Did you develop any new symptoms? (*answer required)

- ○ Yes (please describe below) (4)

_____

- ○ No (7)
- ○ Not applicable, did not complete the course (9)

Page Break

How severe was your condition **after** treatment with GET? (Please note the following are definitions created by NICE, these are not necessarily those accepted by the members of Forward ME)

- ○ **Mild** - People with mild CFS/ME are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week. (1)

- ○ **Moderate** - People with moderate CFS/ME have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work, school or college and need rest periods, often sleeping in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed. (2)

- ○ **Severe** - People with severe CFS/ME are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed, and are often extremely sensitive to light and noise. (3)

Were other treatments offered in addition to GET?

- ○ Yes (please describe below) (1)

_____

- ○ No (2)

Are there any other comments on your course of CBT and/or GET?

- ○ Yes (please describe below) (4)

_____

- ○ No (19)

Start of Block: End1

Did the course (or completion / non-completion of the course) have an effect on any DWP benefits (ie ESA, PIP, DLA) that you were claiming?

- ○ Yes (please describe below) (1)

_____

- ○ No (2)

Start of Block: End2

Did the course of CBT and/or GET result in any change in your ability to carry out or resume employment or education?

- ○ Yes (please describe below) (1)

_____

- ○ No (2)

Start of Block: CBT-Both1

This is the section for individuals who have been offered both CBT and GET. The first section will focus on **CBT**. Questions regarding GET will be in the following section.

What year were you offered a course of CBT treatment? (*answer required)

(If unsure please enter the approximate year)

_____

Was the CBT treatment offered on the NHS or through the private medical sector?

- ○ NHS (1)
- ○ Private Medical Sector (2)

Did you start the CBT course? (*answer required)

- ○ Yes (please state the year or approximate year) (1)

_____

- ○ No (please explain why below) (2)

_____

End of Block: CBT-Both1

Start of Block: GET-Both1

This is the section for individuals who have been offered both CBT and GET. This section will focus on **GET**.

What year were you offered a course of GET treatment? (*answer required)

(If unsure please enter the approximate year)

_____

Was the GET treatment offered on the NHS or through the private medical sector?

- ○ NHS (1)
- ○ Private Medical Sector (2)

Did you start the GET course? (*answer required)

- ○ Yes (please state the year or approximate year) (1)

_____

- ○ No (please explain why below) (2)

_____

End of Block: GET-Both1

Start of Block: GET-Both2

Did you complete the GET course?

- ○ Yes (1)
- ○ No (2)
- ○ Still ongoing (3)

If you answered No to the previous questions, why did you stop?

_____

_____

_____

_____

_____

How many GET sessions were/are involved?

- ○ (Please state the number of sessions) (0)

_____

- ○ Don't Know (999)

Who delivered the GET treatment?

- ○ Cognitive Behavioural Therapist (1)
- ○ Physiotherapist (2)
- ○ Occupational Therapist (7)
- ○ Psychiatrist (11)
- ○ Clinical Psychologist (8)
- ○ Neurologist (9)
- ○ GP (10)
- ○ Immunologist (3)
- ○ Other (please specify) (6) _____

Were/are you being seen individually or as part of a group?

- Individual (1)
- Group (2)
- Mixture of both (3)

What impact did GET have on your physical health?

- Major improvement (1)
- Minor improvement (2)
- No improvement (3)
- Minor deterioration (4)
- Major deterioration (5)
- Not applicable - did not complete course (999)

What impact did GET have on your mental health?

- Major improvement (1)
- Minor improvement (2)
- No improvement (3)
- Minor deterioration (4)
- Major deterioration (5)
- Not applicable - did not complete course (999)

Page Break

Did any of your symptoms worsen? (*answer required)

- ○ Yes (please detail below) (4)

_____

- ○ No (7)
- ○ Not applicable, did not complete the course (9)

Did you develop any new symptoms? (*answer required)

- ○ Yes (please detail below) (4)

_____

- ○ No (7)
- ○ Not applicable, did not complete the course (9)

Page Break

How severe was your condition **after** treatment with GET? (Please note the following are definitions created by NICE, these are not necessarily those accepted by the members of Forward ME)

- ○ **Mild** - People with mild CFS/ME are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week. (1)
- ○ **Moderate** - People with moderate CFS/ME have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work, school or college and need rest periods, often sleeping in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed. (2)
- ○ **Severe** - People with severe CFS/ME are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed, and are often extremely sensitive to light and noise. (3)

Were other treatments offered in addition to GET?

- ○ Yes (please detail below) (1)

  _____
- ○ No (2)

Start of Block: CBT Both2

Did you complete the CBT course?

- ○ Yes (1)
- ○ No (2)
- ○ Still ongoing (3)

If you answered No to the previous questions, why did you stop?

_____

_____

_____

How many sessions were/are involved?

- ○ (Please state the number of sessions) (0)

_____

- ○ Don't Know (999)

Who delivered the CBT treatment?

- ○ Cognitive Behavioural Therapist (1)
- ○ Physiotherapist (2)
- ○ Occupational Therapist (3)
- ○ Psychiatrist (9)
- ○ Clinical Psychologist (4)
- ○ Neurologist (6)
- ○ GP (7)
- ○ Immunologist (8)
- ○ Other (please specify) (5) _____

Were/are you being seen individually or as part of a group?

- ○ Individual (1)
- ○ Group (2)
- ○ Mixture of both (3)

Page Break

What overall impact did the CBT course have on your physical health?

- ○ Major improvement (1)
- ○ Minor improvement (2)
- ○ No improvement (3)
- ○ Minor deterioration (4)
- ○ Major deterioration (5)
- ○ Not applicable - did not complete course (999)

What impact did CBT have on your mental health?

- ○ Major improvement (1)
- ○ Minor improvement (2)
- ○ No improvement (3)
- ○ Minor deterioration (4)
- ○ Major deterioration (5)
- ○ Not applicable - did not complete course (999)

Page Break

Did any of your symptoms worsen? (*answer required)

- ○ Yes (please describe below) (1)

_____

- ○ No (2)
- ○ Not applicable - did not complete the course (999)

Did you develop any new symptoms? (*answer required)

- ○ Yes (please describe below) (1)

_____

- ○ No (2)
- ○ Not applicable - did not complete the course (999)

Page Break

How severe was your condition **after** treatment with CBT? (Please note the following are definitions created by NICE, these are not necessarily those accepted by the members of Forward ME)

- ○ **Mild** - People with mild CFS/ME are mobile, can care for themselves and can do light domestic tasks with difficulty. Most are still working or in education, but to do this they have probably stopped all leisure and social pursuits. They often take days off, or use the weekend to cope with the rest of the week. (1)

- ○ **Moderate** - People with moderate CFS/ME have reduced mobility and are restricted in all activities of daily living, although they may have peaks and troughs in their level of symptoms and ability to do activities. They have usually stopped work, school or college and need rest periods, often sleeping in the afternoon for 1 or 2 hours. Their sleep at night is generally poor quality and disturbed. (2)

- ○ **Severe** - People with severe CFS/ME are unable to do any activity for themselves, or can carry out minimal daily tasks only (such as face washing, cleaning teeth). They have severe cognitive difficulties and depend on a wheelchair for mobility. They are often unable to leave the house or have a severe and prolonged after-effect if they do so. They may also spend most of their time in bed, and are often extremely sensitive to light and noise. (3)

Were other treatments offered in addition to CBT?

- ○ Yes (please describe below) (1)

_____

- ○ No (2)

End of Block: CBT Both2

Are there any other comments on your course of CBT and/or GET?

- ○ Yes (please describe below) (4)

_____

- ○ No (19)

Start of Block: End1

Did the course (or completion / non-completion of the course) have an effect on any DWP benefits (i.e. ESA, PIP, DLA) that you were claiming?

- ○ Yes (please describe below) (1)

_____

- ○ No (2)

Start of Block: End2

Did the course of CBT and/or GET result in any change in your ability to carry out or resume employment or education?

- ○ Yes (please describe below) (1)

_____

- ○ No (2)