

**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, 27<sup>th</sup> 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 11<sup>th</sup> January 2019 -31<sup>st</sup> 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).

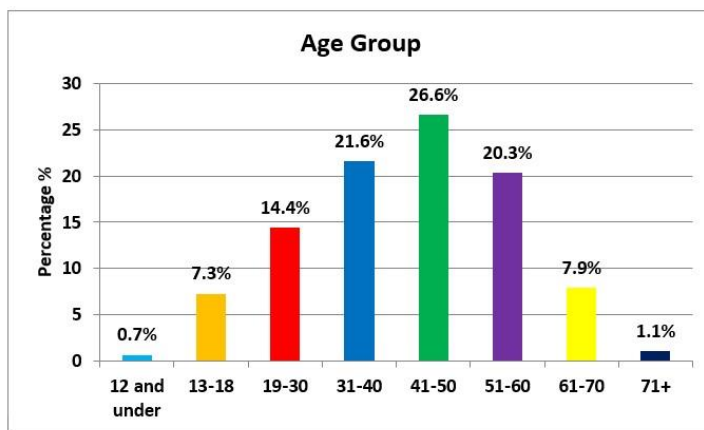


Figure 1. Age group

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'.

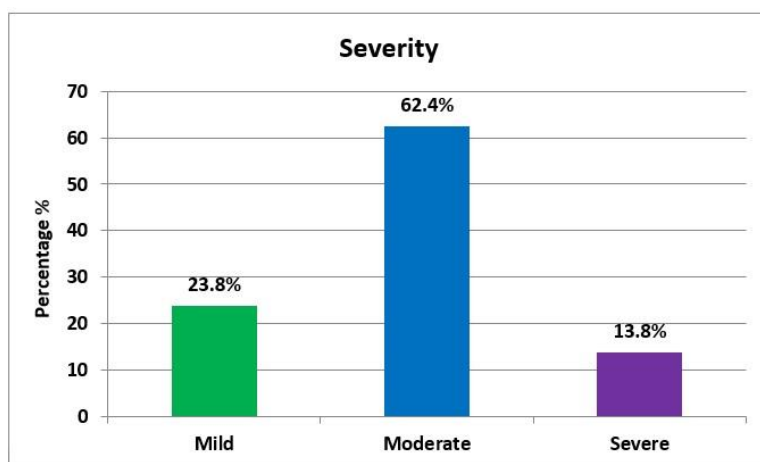


Figure 2. Severity of symptoms before treatment

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.

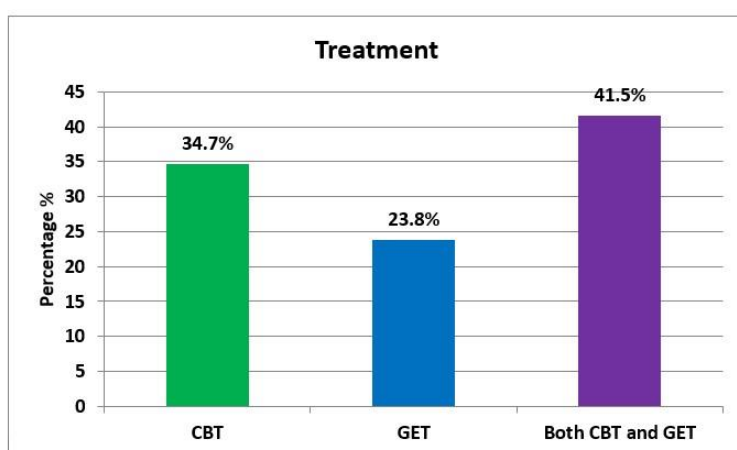


Figure 3. Type of treatment offered

## 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.

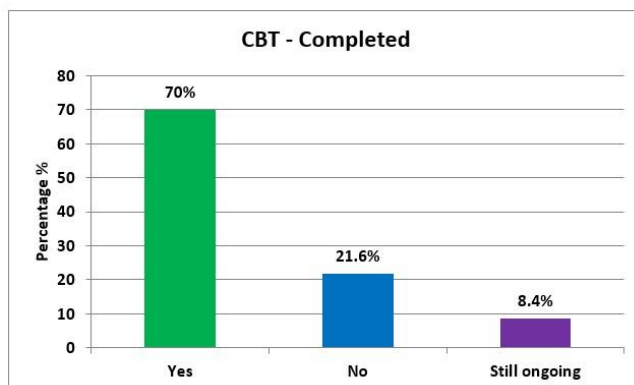


Figure 4. Completion of CBT treatment course

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).

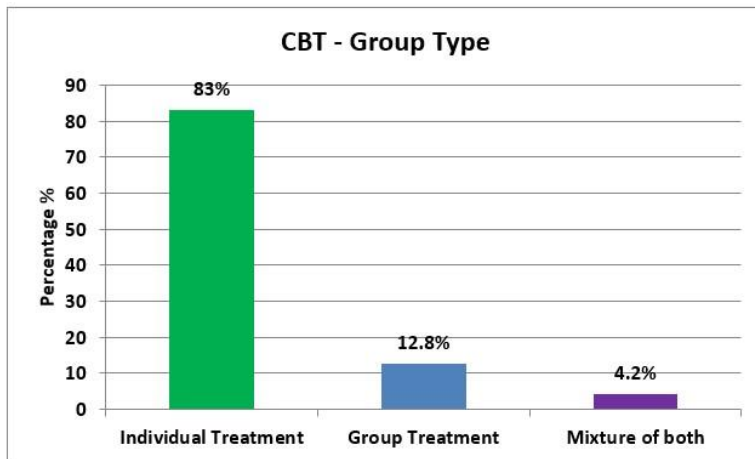


Figure 6. CBT treatment type

## 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.

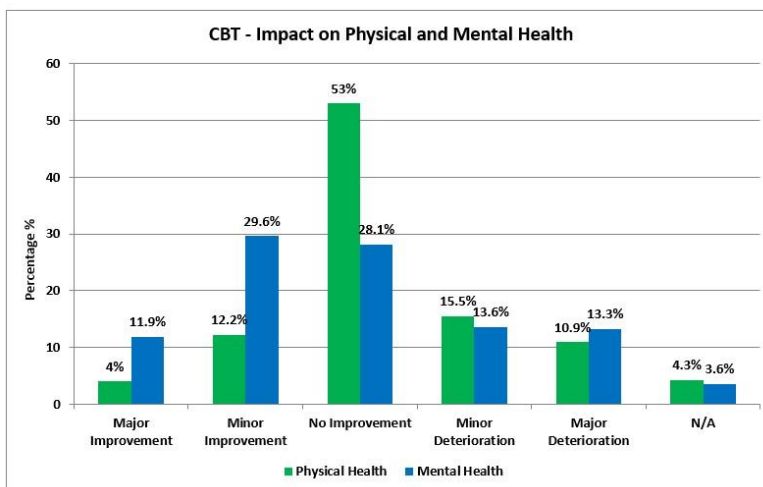


Figure 7. Impact of CBT treatment on physical and mental health

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.

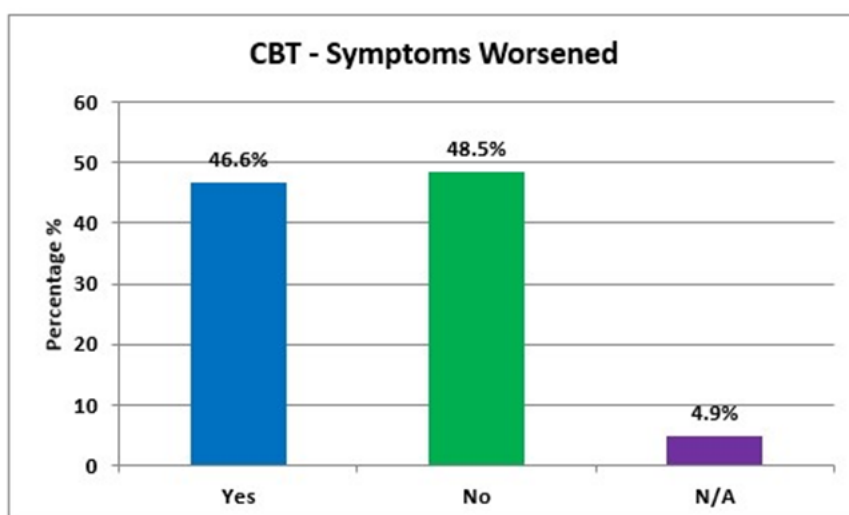


Figure 8: Symptoms worsening after CBT

*'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.

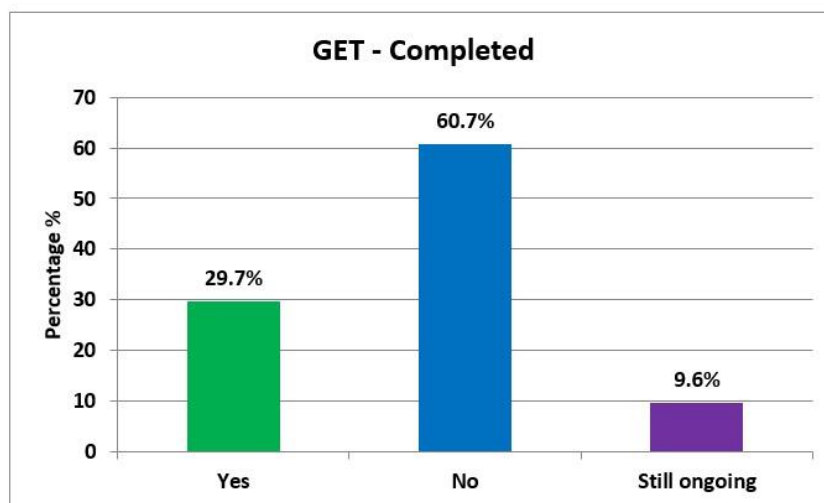


Figure 10. Completion of GET treatment course

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'*

exercise  
get  
activity  
became  
increase  
day  
worse  
symptoms  
made

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).

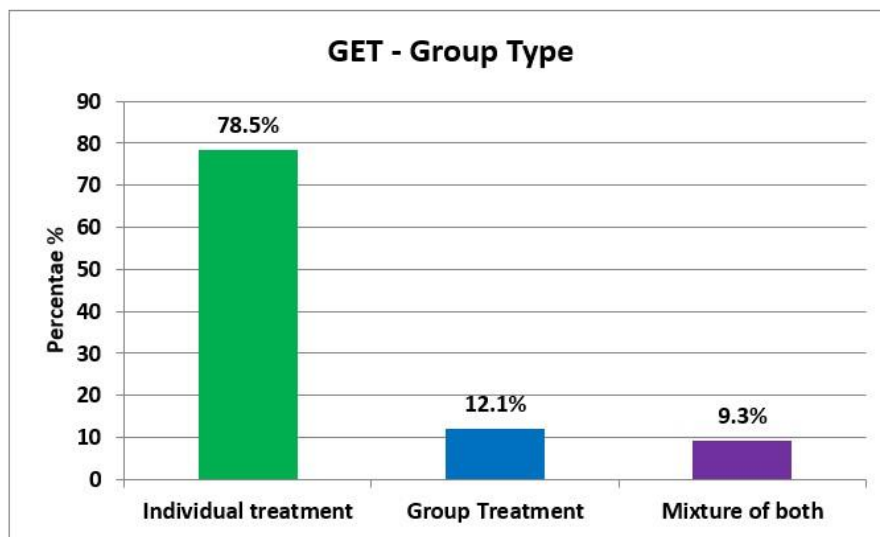


Figure 12. GET treatment type

## 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.

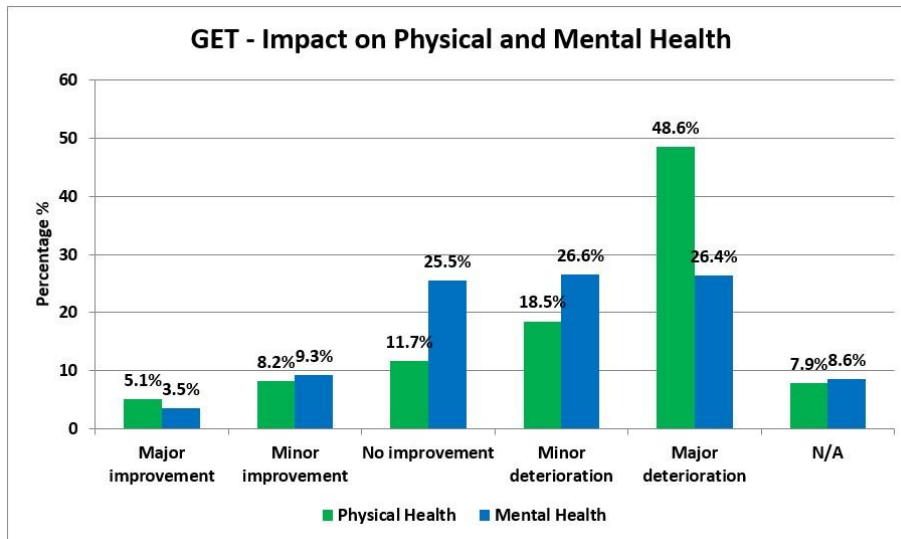


Figure 13. Impact of GET treatment on physical and mental health

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.

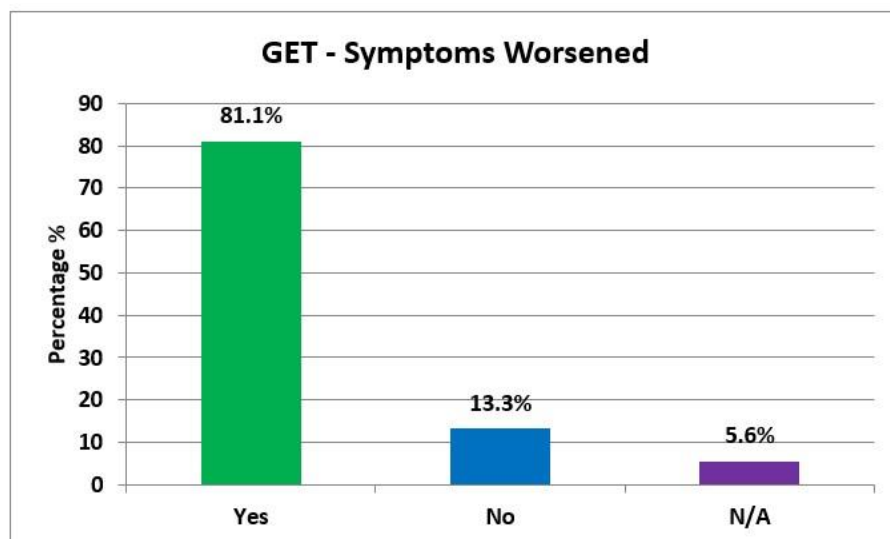


Figure 14. Worsening of symptoms post-GET treatment

*‘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.

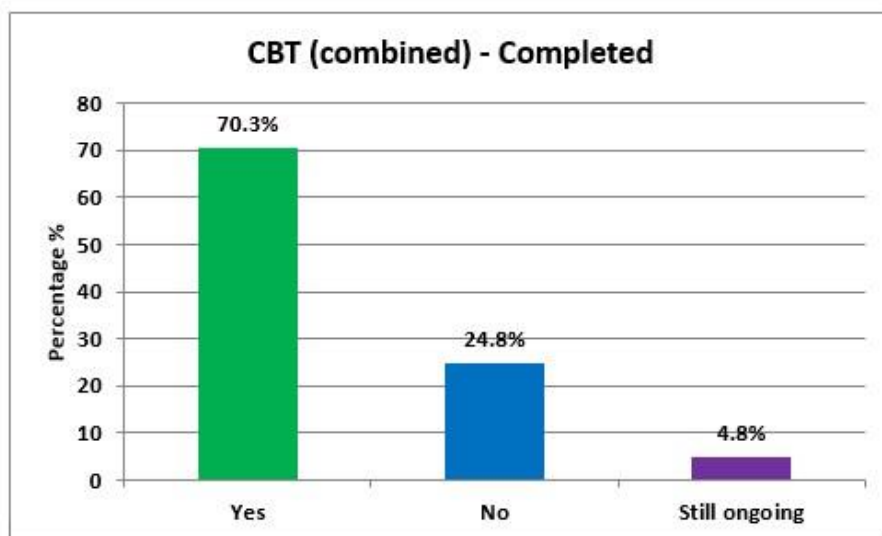


Figure 16. Completion of CBT (combined with GET) treatment course

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).

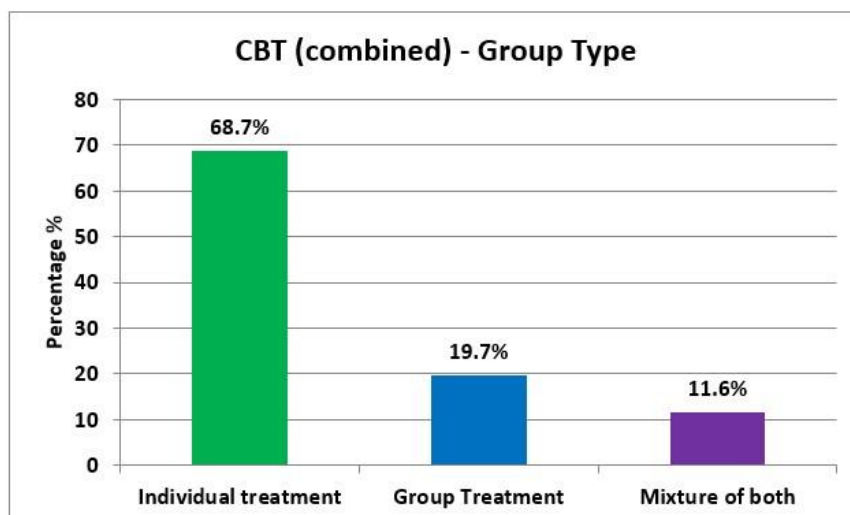


Figure 18. CBT (combined with GET) treatment type

## 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.

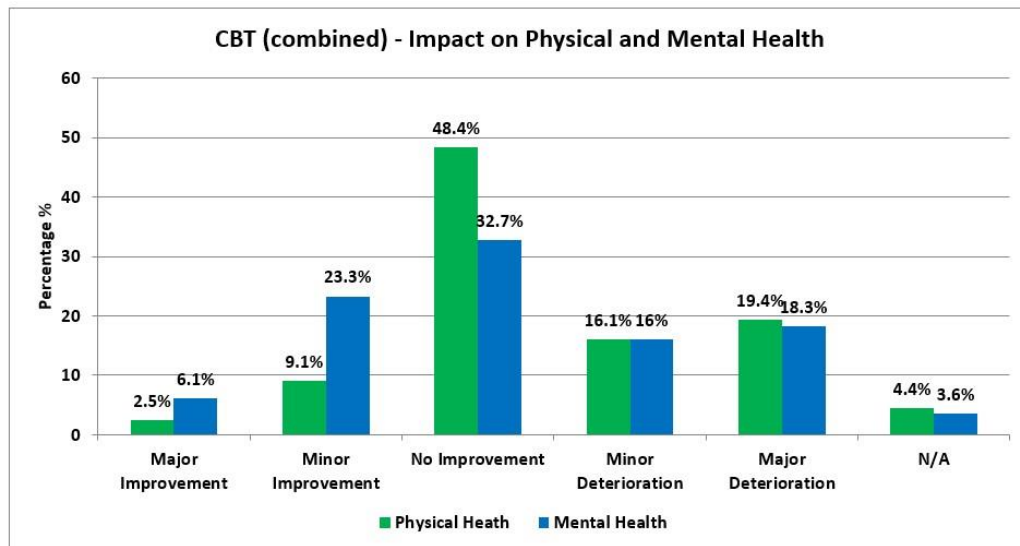


Figure 19. Impact of CBT (combined with GET) on physical and mental health

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.

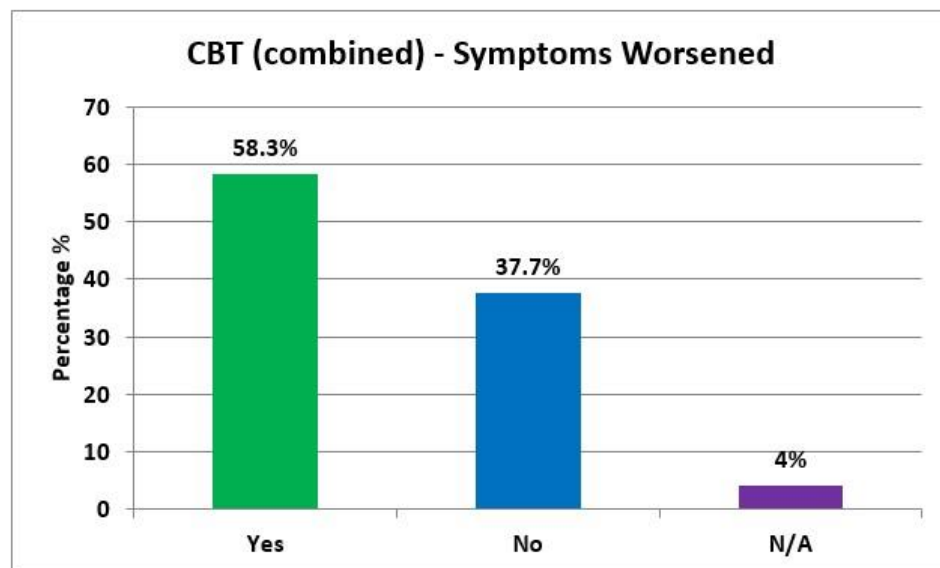


Figure 20. Worsening of symptoms post-CBT (combined with GET) treatment



*'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.

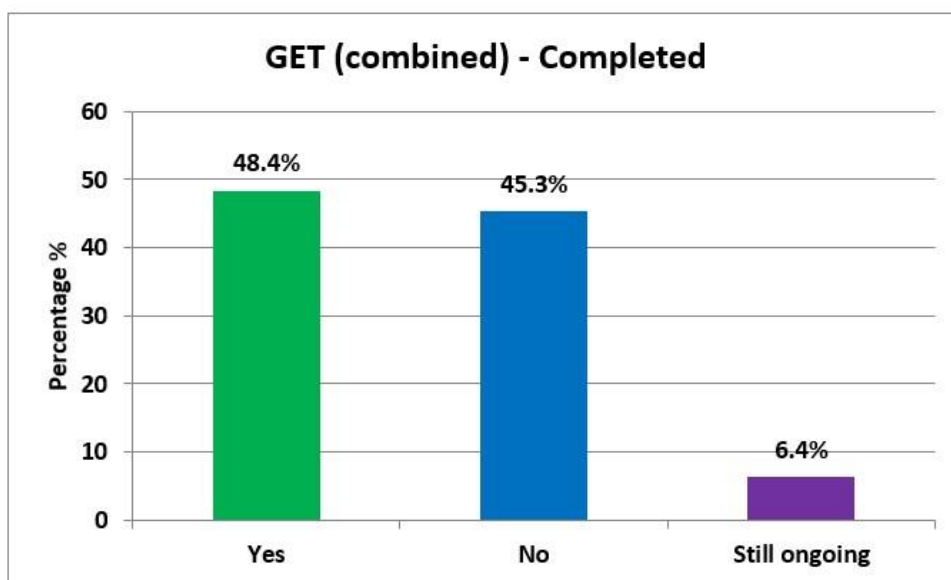


Figure 22. Completion of GET (combined with CBT) treatment

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).

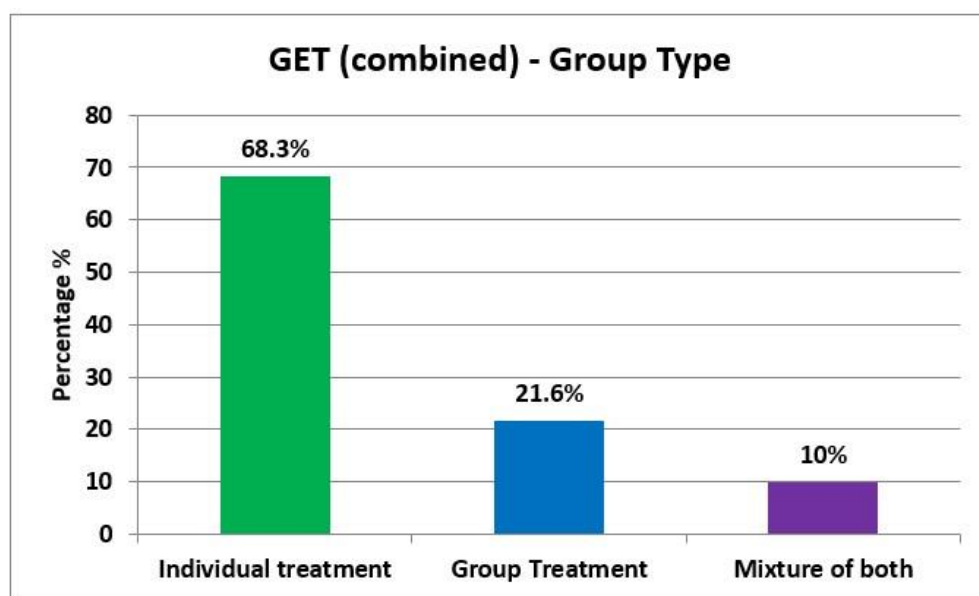


Figure 24. GET (combined with CBT) treatment type

## 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.

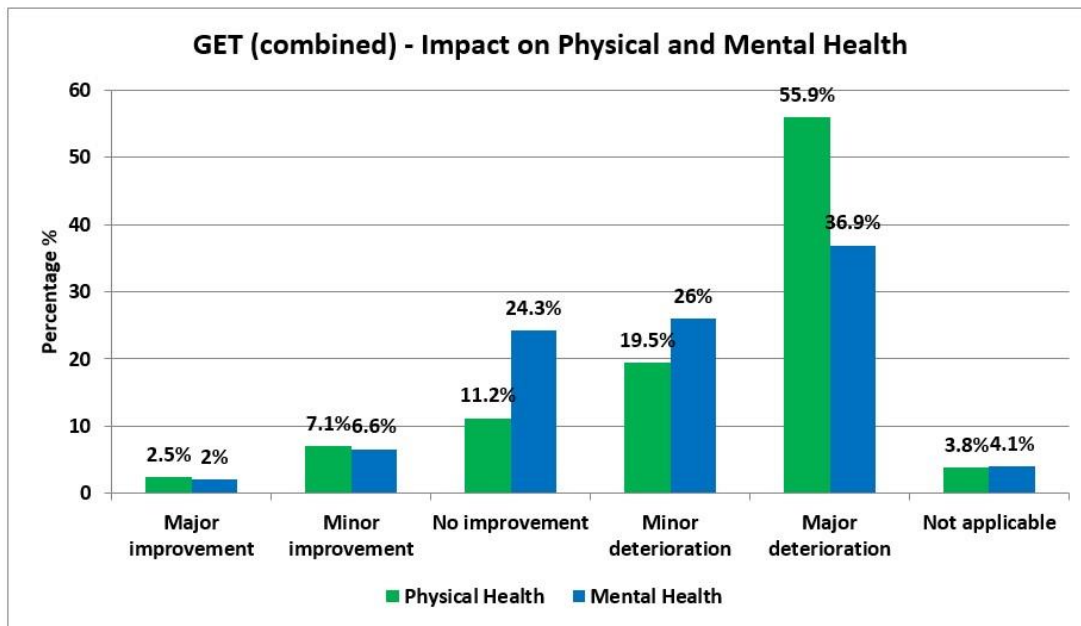


Figure 25. Impact of GET (combined with CBT) treatment on physical and mental health

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.

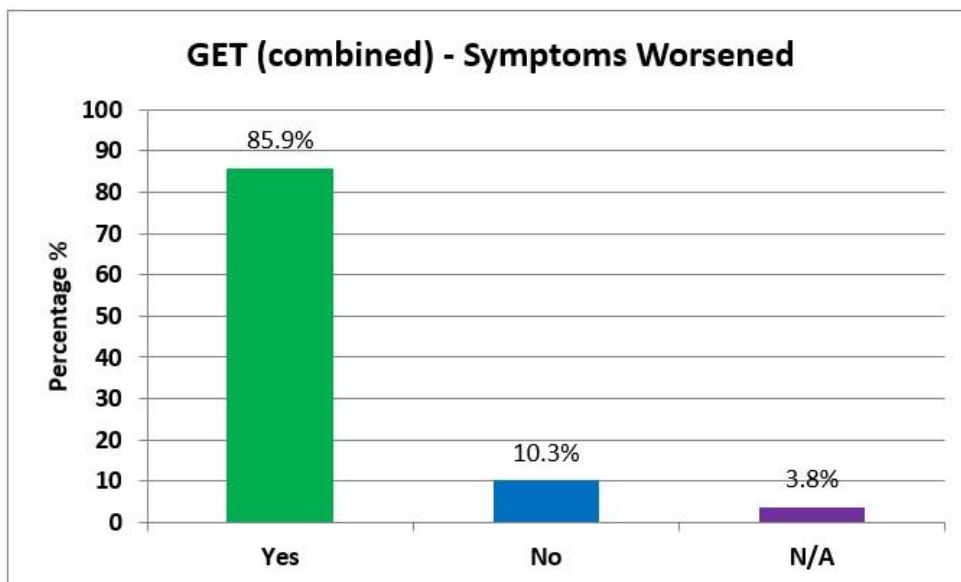


Figure 26. Worsening of symptoms post-GET (combined with CBT) treatment

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 get [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'*