



GUIDED GRADED EXERCISE SELF-HELP (GES) FOR CFS/ME

Therapist Manual

This is the manual used by the physiotherapists delivering GES in the GETSET Trial. We recommend that it should only be used by physiotherapists who are trained in delivering graded exercise programmes to patients with CFS/ME.

Clark LV, Tims E, White PD

On behalf of the GETSET Trial Management Group

This manual is copyrighted to the GETSET Trial Management Group. This manual is available free of charge for downloading so long as no changes are made. Any use of this manual should acknowledge the [GETSET trial](#). This intervention should only be delivered by appropriately qualified healthcare professionals, who have received appropriate training and continued supervision in the use of GET. The information in this manual is not designed to be a stand-alone self-help approach, and should be used alongside the [GET booklet](#). No responsibility is accepted by the authors for the application of GES described in this manual outside of the GETSET trial. The GETSET trial team are unable to respond to queries or comments regarding the use of this manual or the intervention described.

ACKNOWLEDGEMENTS

We would like to thank other people have contributed indirectly towards this manual through their involvement in the development of the [PACE trial GET manuals](#) for therapists and participants, from which some of the information in this manual has been adapted. We would specifically like to thank Jess Bavinton and Helen Chubb.

ABBREVIATIONS

CFS	Chronic Fatigue Syndrome
DNA	Did Not Attend
GES	Guided graded exercise self-help
GET	Graded exercise therapy
ME	Myalgic Encephalomyelitis/Encephalopathy
RPE	Rating of Perceived Exertion
TM	Trial Manager
UTA	Unable To Attend

INTRODUCING THE GES MANUAL

1. This manual contains the information necessary to allow you to confidently guide and support patients with CFS/ME through a guided graded exercise self-help (GES) programme as part of a randomised controlled trial (GETSET). The guided support that you will provide is based on the **GET booklet**¹ which has been written as a self-help guide by physiotherapists with experience of delivering graded exercise therapy (GET) programmes to patients with CFS/ME. The booklet was developed following evidence from the PACE trial² as well as from published guidance on GET for people with CFS^{3,4} and for the healthy population^{5,6}. Advice from clinicians with experience of GET for CFS/ME has also been considered.
2. Appendix 1 contains additional information about graded exercise therapy in general, which might help you when you are delivering GES sessions.
3. Telephone and face-to-face supervision sessions with the GES therapy leader will allow you to gain further confidence in the guided support you are providing to participants and help you to overcome any challenges. Face-to-face supervision (either in a group or individually) will be up to one hour every two weeks. A recording of a GES session will be reviewed in supervision at least quarterly after competency has been attained, but more frequently prior to that.
4. This manual is the final version that was used in the GETSET trial, although the appendices were not originally a part of the manual but provided separately. The manual must not be altered in any way, and **must be adhered to in detail**, unless formally changed by the Trial Management Group (TMG), with the approval of both the independent Trial Steering Committee and the Research Ethics Committee.
5. This manual is copyrighted and must not be altered without the permission of the Principal Investigator and the Treatment Leader of the GETSET trial. It is freely available for downloading.

DOCUMENTS TO ACCOMPANY THIS MANUAL FOR PHYSIOTHERAPISTS

- GETSET trial protocol⁷
- GET Booklet¹

INTRODUCING THE GETSET TRIAL

Title of trial: Graded Exercise Therapy guided Self-hElp versus specialist medical care for patients with chronic fatigue syndrome (GETSET): a randomised controlled trial

The main aim of this pragmatic two arm trial is to determine the acceptability, efficacy and safety of specialist medical care (SMC) supplemented by Guided graded Exercise Self-help (GES), compared to SMC alone, for patients diagnosed with CFS/ME attending secondary care specialist CFS/ME clinics in the UK. You will gain a better understanding of the process of the GETSET trial by reading the trial protocol.⁷

INTRODUCING CHRONIC FATIGUE SYNDROME (CFS) AND MYALGIC ENCEPHALOMYELITIS / ENCEPHALOPATHY (ME)

Chronic Fatigue Syndrome (CFS), Post Viral Fatigue Syndrome, and Myalgic Encephalomyelitis/Encephalopathy (ME) have all been used to describe similar illnesses. There is controversy about whether these are similar or identical conditions. For brevity we will consider them together here as CFS/ME.

What are the symptoms?

Common to these illnesses are the symptoms of physical and mental fatigue, usually made worse by exertion. Other symptoms may include difficulty with memory and concentration, muscular and joint pain, unrefreshing sleep, headaches, tender lymph glands, and sore throats. Some patients also suffer from other health problems, such as irritable bowel syndrome, depression, and anxiety. There are often day-to-day fluctuations in the symptoms, some people have to give up work or studying, greatly reduce their social and leisure activities and/ or restrict what they can do at home or with their family. Some patients are at worse, bedbound by their condition.

How is the diagnosis made?

At present there is no clinical or blood test for CFS/ME and the diagnosis is made from the symptoms and associated disability, which are ascertained by a clinician taking a careful history from the patient. Fatigue may be a symptom of many illnesses (such as diabetes, anaemia and severe depression) and medical and psychiatric assessments are required to exclude these other conditions. The term CFS/ME has been reserved for patients in whom characteristic fatigue and other symptoms cannot be explained by other diagnoses.

What is the cause?

No specific cause for CFS/ME has been identified. There is some evidence for viral infection and stress as triggers. There is also evidence of changes in the immune, nervous and hormonal systems in patients with CFS/ME. It is possible that different factors apply to different patients.

TREATMENT TO BE TESTED IN THE TRIAL

The treatment to be tested in this trial is Guided graded Exercise Self-help (GES) for patients diagnosed with CFS/ME waiting for face-to-face appointments with a therapist at secondary care specialist CFS/ME clinics. Trial participants allocated to GES will receive a paper copy of the **GET booklet**¹ and four guided support face-to-face, telephone and/or Skype® contacts from you. In addition to guiding the participant, you will also provide a level of encouragement for participants to complete the programme of guided self-help.

The GET booklet in GETSET

The **GET booklet** describes a graded exercise programme for people to read and apply at home. It involves them stabilising their physical activity to prevent cycles of boom-bust, followed by gradual and planned increases in physical activity or exercise, leading towards an increase in the ability to undertake physical exercise and activity. GET as described in the **GET booklet** is a rehabilitation therapy in that it encourages an extension of physical functioning beyond current ability.

How is GET different from GES

This treatment is called Guided graded Exercise Self-hElp (GES) because it combines a graded exercise programme, designed as a self-help intervention, supported by guidance provided by a suitably trained physiotherapist. The principles of the treatment are based on graded exercise therapy (GET), but it is not GET because GET is a therapy delivered by a physiotherapist face-to-face in a clinic setting. The title of the booklet, used in GES, is 'GET booklet', and we have consistently referred to it as this throughout.

The theoretical model within GET booklet

It is not fully understood why GET helps many people with CFS/ME. Several theories have been suggested and it is thought to be due to multiple factors which may vary from person to person.

One theory which can be used to explain GET, as outlined in the **GET booklet** is based on deconditioning which is the gradual decline in physical fitness and strength in the body as a consequence of a reduction in physical functioning. Another theory points to an altered perception of effort (this may be more significant than deconditioning). Researchers have noticed that some people with CFS/ME may experience changes in how they interpret the messages that the body gives them during physical activity.

These changes in both conditioning and perception of effort are thought to be reversible. Therefore, by gradually increasing physical activity, this may enable the body to gain fitness and strength as well as making changes to the perception of effort.

Preliminary research suggests that reduced symptoms (including fatigue) are related to simply participating in a GET programme, rather than necessarily getting fitter, whereas improved functioning is related to getting fitter and stronger. Participants are encouraged to see symptoms as temporary and reversible, as a result of their current relative physical inactivity, and not as signs of progressive pathology.

A mild and transient increase in symptoms is explained as a normal response to an increase in physical activity. Apart from the behavioural and perceptual effects of graded exposure to

previously avoided physical activities, there may be other mechanisms involved in the success of GET such as reversing deconditioning, including elements of habituation, and positive effects of re-engagement with important activities. GET has also been shown to improve sleep, cognition, and mood; factors that are also likely to perpetuate the condition, although these are not directly addressed in the **GET booklet** or GES itself.

Existing evidence base for GET

GET has been shown to improve muscle strength, cardiovascular endurance, and symptoms in a wide variety of illnesses⁸. Three systematic reviews have concluded that GET is a promising treatment for outpatients with CFS/ME.⁹⁻¹¹ Six randomised controlled trials (RCTs) have found improved fatigue and disability with differing graded exercise programmes compared to no treatment or control treatments.¹²⁻¹⁷ Three randomised controlled trials of graded exercise suggest that GET improves symptoms or disability more than relaxation or supportive therapy.^{12,15,16} In the most recent research, the PACE trial (www.pacetrial.org), graded exercise therapy was shown to be more effective in reducing fatigue and improving functioning than specialist medical care alone and adaptive pacing therapy.¹⁷

Guided graded exercise self-help (GES) in GETSET

In guided graded exercise self-help (GES), participants will receive guided support from you with the aim of enhancing any benefits they gain from the **GET booklet**. Each participant allocated to receive GES will be offered an initial 30 minute face-to-face session with you in the clinic (but can opt for a Skype® or telephone consultation), and up to a further three 20 minute telephone or Skype® calls. These 4 guided support sessions take place over approximately 9 weeks. The aim of this guided support is to advise patients on the proper and effective use of the **GET booklet**, without providing additional therapy in its own right. Your role is to encourage and motivate people - so as to facilitate their use and application of the principles they are learning about in the **GET booklet**.

The essence of GES

The essence of GES is that the physiotherapist-led telephone/Skype® sessions support participants as they engage and participate in increasing physical activity and aerobic exercise duration and then intensity. It is participant-led; they will be expected to read the **GET booklet** themselves and follow the programme described with guidance from their physiotherapist. The programme has six steps: stabilise routine, start doing regular stretching, decide on a goal and choose an exercise/physical activity, set an exercise/physical activity baseline, and increase the duration and then the intensity of the exercise/physical activity.

Aim of your role in supporting participants undertaking GES

The aim of your role is to provide guidance and support to participants as they engage in exercise/physical activity through self-help, without providing any additional therapy. That means your focus is always on helping the participant apply the knowledge they have obtained from the **GET booklet** themselves.

USING YOUR CLINICAL JUDGMENT

Following a manual should not affect your clinical judgment as a physiotherapist or your compassion when dealing with someone in distress. There may be times when it will be difficult to adhere strictly to the session checklists, and some occasions when it may well be appropriate not to do so.

Although this manual outlines the ideal GES guided support programme, there will be occasions when you will need to use your clinical judgment and clinical reasoning skills to alter your support sessions as appropriate.

An example of when it may be appropriate to alter the programme may be a high functioning participant who is already walking for 30 minutes daily: it may be appropriate to work on the intensity of his/her exercise sooner, or perhaps to review his/her ability to undertake a variety of physical exercise rather than to add **more** exercise to his/her day.

When helping someone who is distressed, it may not be appropriate to bring the topic of conversation back onto **GES**, *at least not immediately*. You will need to use your own judgment and therapy skills to comfort the participant or acknowledge their distress, perhaps commenting on how exercise can sometimes help us to distract ourselves to better cope emotionally with our lives or help us to relieve stressful feelings, and then record the incident and discuss with your therapy leader if necessary.

Checklists are present as a reminder to cover the key areas, and can be used with some flexibility if, on occasion they are not appropriate, e.g. if you notice a participant is getting very tired by 10 minutes and you cannot complete your checklist, or if certain checklist items are not relevant then you can focus on key points/areas. However, you will need to ensure that items not covered are covered in subsequent sessions, and only omitted under clear clinical circumstances. You **MUST** record any diversions from the manual clearly in your written notes and they must be justified clearly.

OUTLINE OF THE GES GUIDED SUPPORT SESSIONS

Number of guided support sessions

Participants will be offered one face-to-face session of 30 minutes (which can, if easier for the patient, be via Skype® or telephone), and up to three further telephone/Skype® sessions of up to 20 minutes each. Reasonable effort will be made to ensure that the participant receives all 4 sessions however it should be noted that it may not be possible for the participant to receive all 4 sessions during the 9 weeks due to UTAs or DNAs that cannot be rearranged, holidays, festive periods or staff absence. This should be made clear to the participant so that they do not have an unrealistic expectation of the session numbers and contents.

Appointments can be up to five working days (Mon-Fri) outside of the appointment window either before or after the proposed dates, but the remaining sessions should be based upon the original timeline which is set from session 1.

A record should be made of when the sessions have occurred and if participants contact you by telephone, email or text between sessions.

Frequency of sessions

- Session 1 will occur within 5 working days of the **GET booklet** being sent to the participant.
- Session 2 will occur 7 to 14 days (1-2 weeks) after session 1.
- Session 3 will occur 28 to 35 days (4-5 weeks) after session 1.
- Session 4 will occur 49 to 56 days (7-8 weeks) after session 1.

Duration of sessions

- The first session will be up to 30 minutes in duration and will ideally be face-to-face, but by telephone/Skype® as an alternative. A face to face initial appointment may be preferable as it is known to help establish a better relationship therefore it should be encouraged. However if the patient prefers not to do this, then the telephone/ Skype® can be used.
- The remaining 3 sessions will be up to 20 minutes in duration and can be by telephone or Skype®.
- If possible, sessions should be arranged on the same day of the week and a similar time of day. It will be useful to plan all sessions in advance, and this is recommended.

Audio recording of therapy sessions

All patient contacts will be recorded (if consent is given) as a necessary part of the trial. We understand that sometimes people get concerned about being recorded, however it is an important part of the trial for us to understand what the content of the support is, and to make sure the focus is on helping people apply the information they obtain from the **GET booklet**. After a few sessions hopefully any concerns will diminish and participants will become confident in being recorded.

It is important, for the patient's confidentiality that, at the start of the session, you enquire whether they are sitting down in a quiet room with their **GET booklet**, out of earshot of others, and that they will not be distracted (as if they are in a clinic room).

Participants must each have provided written consent to have recordings made as part of their agreement to participate. If in any doubt, you will need to confirm with the TM that written consent has been completed. Some participants may have asked for the sessions not to be recorded; you will be informed by the TM if this is the case before you see the participant. A copy of their consent form will be in their research notes. If they do not wish to consent, do not record but please make written notes of how you covered the session checklists.

When you are recording a session you will need to set up the recording equipment before the session starts, remember to turn it on, reminding the participant that you are recording the session, and turn it off at the end. Check the battery levels are sufficient. You can remind the participant, if necessary, that you are doing this for the purposes of supervision, assessment of competence, assessment of therapy differences and other research purposes. If the participant refuses to have a particular session audio recorded, you can continue with the session, but you will need to complete a *'File-note form'*.

All recordings will need to be downloaded into the secure container that is on the network and all other copies of session recordings should be deleted, but only once the trial manager has confirmed the relevant sessions have been saved. Please download recordings from the recording device as soon as possible and delete from the device. Treat recordings as if they were clinical notes - they are confidential and personal. Be careful with the recordings and keep the recorder in a locked office/filing cabinet when not in use.

TRAINING, SUPERVISION AND REFLECTIVE PRACTICE

Training

Research training is provided by the Treatment Leader. It is estimated that approximately 24 hours of research training is required, but it is individually determined based upon each therapist's knowledge of GET as a treatment for chronic illness at the start. It includes the following (see log book in Appendix 2):

Supervision

Research supervision is provided in a fortnightly group meeting of 30-60 minutes. This time provides the opportunity for you to discuss participants and work through any difficulties or challenges being experienced, and is delivered in a peer support group and/or individually. Supervision also includes a review of written patient records to ensure that they are compliant with The Chartered Society of Physiotherapy's record keeping guidance.

In order for you to get the most out of your research supervision it would be helpful for each therapist to do the following:

- Plan in advance what you hope to get out of a particular supervision session.
- Audio record all clinical sessions and let the supervisor know the name of the recording(s) you would like to discuss in advance, so that she can prepare.
- Bring relevant clinical notes to supervision.
- Actively reflect on your experience after each session. Keep a record of all supervision dates, times and what was discussed.

You are encouraged to actively reflect on your guided support sessions and make suggestions for improvements in your own delivery of the therapy, or the way in which you handle any challenges. You are encouraged to use a reflective review sheet after each session and keep it in your records. You are also encouraged to use other therapists and the therapy lead as support as needed between supervision sessions. Peer coaching, whereby therapists support one another's learning, is encouraged where available.

A selection of recorded sessions will be rated using the *guided support for GET rating scale* (adapted from the GRCS – Williams 2009). This will be to ensure quality and fidelity of treatment throughout the trial.

SUMMARY OF GES GUIDED SUPPORT SESSIONS

Session	Week	Time (mins)	Your role	What participant should be doing
1	1	30	<p>Ensure participant has received a copy of the GET booklet and Activity Diary</p> <p>Explain what is required of the participant</p> <p>Engage with participant</p> <p>Encourage participant to read the opening sections of the GET booklet (pages 1-6)</p> <p>Encourage participant to read and apply steps 1-4 of the GET booklet</p> <p>Explain GET model and rationale as required</p> <p>Reassure participant as required using knowledge of evidence for GET.</p>	Have received booklet prior to session
2	2-3	20	<p>Enquire about progress with steps 1-4 and review activity diary</p> <p>Encourage participant to move to step 5 and answer questions or concerns</p> <p>Recognise achievements and congratulate efforts</p> <p>Problem-solve where difficulties have arisen or where the approach has not been implemented.</p> <p>Encourage participant to read about setbacks.</p> <p>Revisit GET model if required.</p>	Have read and applied steps 1-4 of the GET booklet
3	5-6	20	<p>Enquire about progress with Step 5</p> <p>Answer any questions or concerns about moving forward to Step 6</p> <p>Remind participants to continue with stretches</p> <p>Recognise achievements and congratulate efforts</p> <p>Problem-solve where difficulties have arisen or where the approach has not been implemented.</p> <p>Enquire about understanding of setbacks</p>	Have read and applied step 5 of the GET booklet and read about setbacks
4	8-9	20	<p>Enquire about progress with all relevant steps</p> <p>Recognise achievements and congratulate efforts</p> <p>Problem-solve where difficulties have arisen or where the approach has not been implemented</p> <p>Review goals</p> <p>End support, prepare and plan for self-management, including review of setback plan</p>	Have read and applied step 6 of the GET booklet

ENGAGING PARTICIPANTS IN TREATMENT

Engaging participants in GES and encouraging them to read and apply the information in the **GET booklet** is your main role. The following suggestions are likely to improve your participant's engagement and compliance with the programme:

- Introduce yourself to them and tell them something relevant about your knowledge/experience. They should have received your profile when they received their GET booklet in the post.
- Ask what the participant would like to be called when you first speak with them.
- Discuss the agenda for the first session and ask the participant whether there is anything that they would like to add to it.
- Show empathy, warmth, sensitivity and understanding about their illness.
- Tell the participant that you look forward to working with them over the coming weeks.
- Use language that participants will understand.
- When asked to explain something, be as clear as possible and check understanding.
- Always recognise achievements and congratulate participants on their efforts to engage with GES.
- Acknowledge and give participants the opportunity to discuss any fears or worries in relation to GES.
- Ask participants if they could position themselves in a quiet room with no distractions for the sessions on the phone/Skype (as if they were in a clinic room). Ideally they should not be outside (walking the dog, for example) or doing something else (such as ironing) whilst having a session with you.

KNOWLEDGE AND SKILLS REQUIRED

As well as a sound knowledge of the aetiology, epidemiology, consequences and available treatments for CFS/ME, a range of skills and experience are also necessary in order to help you to engage and support participants.

Engagement

In order to engage the participant in therapy, it is important that you convey to the participant your belief in the reality of their symptoms, distress and disability. You should be able to demonstrate a sound knowledge of CFS/ME should you need to, as participants will generally be well informed about their illness and may have had difficult experiences with other professionals who may have not taken their illness seriously. It is important that you show respect for your patient's beliefs about the cause(s) of their illness and avoid challenging them as this may sometimes provoke strong emotion and could reduce the likelihood of a good professional relationship being established.

Warmth and Empathy

Empathy is the ability to both understand and acknowledge how someone is feeling (e.g. being able to imagine oneself being in someone else's situation and understanding it). Empathy is something that is hopefully provided to all patients without thinking about it. Often patients have had their health problems for a long time and many will report at least one upsetting incident relating to a health professional, whether it is not being believed, not being taken seriously or being told it is all in their mind. Often participants will have been given conflicting advice about how to deal with their problems, leading them to a state of confusion and frustration. Some participants will feel guilty about being ill and blame themselves for their predicament. Some participants will have had trauma in their background that may still provoke emotion.

It is therefore very important that you convey warmth and empathy in your first contact and throughout the sessions. There is no doubt that helping people to change previous routines can be difficult in a number of ways: the participant may be very fearful of worsening their symptoms by changing the way they do things. They may find that their symptoms initially slightly worsen when starting their GES programme. Acknowledging the challenges associated with the programme is important if you are to gain their trust.

Sensitivity

Participants may feel sensitive about the use of particular words, such as asking them how often they feel *tired* which can provoke anger in someone who differentiates strongly between the word *fatigue* and *tiredness*. Be aware of how your language will affect your message and rapport with patients. In general, it is best to use the same words that the participant themselves use to describe their illness and symptoms.

Collaboration

Collaboration is an essential skill in working with patients. Up to the point of talking with you, many participants will not have been included in the management of their illness. They may feel rather helpless and out of control. Mutual collaboration with your patient throughout your support sessions will help them to feel more involved in their treatment and may help them to regain some sense of control. This treatment should be led by the participant; you are just guiding and providing support.

You will be demonstrating a collaborative style in your contacts when you agree an agenda for each support session and evaluate how they are progressing. These aspects aim to help participants to feel valued and included.

Positive reinforcement

It is essential that you demonstrate positive reinforcement when you work with patients. Often, patients may be more inclined to focus on what they have not achieved rather than what they have. It is therefore important that you emphasise and are very positive about what they have achieved. Every session you should positively reinforce all of their achievements.

Establishing confidence in you as a therapist

Establishing the participant's confidence in you as a therapist is important. This is likely to occur if you utilise the skills in the sections listed above. If you do not know the answer to a question, you are more likely to be respected for saying that you don't know the answer (but will find out if the answer exists), rather than trying to answer it in a muddled way.

Encouraging optimism

Although it is important that you are realistic about the benefits of GES, it is important that you encourage optimism about the progress participants may make with this approach. You can explain the previous positive research findings of GET and that you believe they too can improve.

HOW TO STRUCTURE GUIDED SUPPORT SESSIONS

The following guidelines will help you to structure your support sessions:

- Read your previous session notes before seeing/contacting the participant.
- Use session checklists, and add any agenda items not covered in previous sessions.
- Greet the participant and ask them if they have their **GET booklet** with them and are in a quiet space and unlikely to be disturbed.
- After greeting the participant, firstly discuss the agenda.
- Remind the participant of the length of the session (up to 20 or 30 minutes).
- Keep a track of time and remind the participant when you have 5 minutes left, if necessary.
- Book the next appointment.
- If you and the participant agree it would be useful, you may be flexible in what you discuss in any one particular session as long as it is within the guided support being offered.

Every session should contain the following:

- A collaborative agenda: agree what will be discussed in the session.
- Explore how easy it has been, or not, to use the **GET booklet** between sessions.
- Review their experience of using the **GET booklet**:
 - What has gone well/not so well?
 - What have they learned?
 - Has it been helpful/unhelpful?
- Refer to the section of the guide of most relevance to the issue in hand.
- Encourage them to set their own homework task (the section of the booklet they need to read and apply for the next period, negotiated and planned).
- Thorough written records including SOAP notes.
- Book the next session.

After every session

- Complete checklist.
- Complete reflective practice sheet.
- Write and send any letters required (GP, specialist).
- Record/report adverse health events.
- Complete attendance record.

SESSION 1

Engage with participant and encourage them to undertake GES using the *GET booklet*

Purpose of session 1: *Initial face-to-face, telephone or Skype® call (30 minutes)*

1. Ensure the participant has received a copy of the GET booklet and Activity Diary
2. Explain what is required of the participant
3. Engage with the participant
4. Encourage participant to read the opening sections of the GET booklet including 'what is GET' and 'the theory behind GET'
5. Encourage participant to read and apply steps 1-4 of the GET booklet.
 - Encourage participant to stabilise their routine (Step 1) by completing an activity diary for the next 7-days and then review that diary themselves before setting their own physical activity baseline, with your guidance.
6. Explain the GET model, rationale and a normal response to exercise as required
7. Reassure participant as required, using knowledge of evidence for GET

1. *Has the participant received a copy of the GET booklet*

It is important that before you can provide support that the participant has received a copy of the GET booklet and Activity Diary (see Appendix 3) on paper through the post. You will need to then know if they have read any of the GET booklet before the session as this will influence how you proceed.

2. *What is required of the participant*

You will need to discuss with the participant ways in which they can help themselves to get the most out of the GES programme. Go through the checklist in Appendix 4 that lists what is expected of them.

Tasks to do between sessions

Explain the importance of undertaking tasks between sessions, both written and physical exercise, and explain that it is what they do at home that makes the difference.

These tasks will include:

- Reading the opening sections of the GET booklet including ‘what is GET’, ‘will GET do me harm’, ‘previous experience with exercise’, ‘evidence for the benefits of GET’ and ‘the theory behind GET’.
- Reading and applying steps 1-4 of the GET booklet:
 - 1) Completing the activity diary for one week using p10-11 in GET booklet as a guide (see appendix 3 – activity diary). Reviewing that diary themselves to try to develop a more stable routine.
 - 2) Starting regular stretches (as explained p25-32 of GET booklet).
 - 3) Deciding on an appropriate goal and choosing an exercise/physical activity that is relevant, enjoyable, can be done regularly and is achievable.
 - 4) Setting a physical activity baseline.

3. Engage with participant

You can use your knowledge and skills (page 14-15 of this manual) to engage with the participant so as to maximise their chance of success with the GET booklet and your support.

4. Encourage participant to read the opening sections of the GET booklet (pages 1-6)

Be ready to explain any parts of the theory and models of GET (including reversibility and boom-bust patterns) that participants may ask about and direct them to the appropriate pages of the **GET booklet** to read before their next session (pages 1-6).

The main purpose of ensuring the participant understands and is engaging with the GET model is to thereby ensure they understand the multiple ways that exercise can help improve their health and CFS recovery.

The positive influence of exercise upon physical strength, endurance, cardiovascular fitness, mood, cognition, sleep, body image and confidence, immunity, weight loss, and disease prevention can all be emphasised with particular reference to any of these aspects found in the participant’s own presentation. The benefits are explained on page 3 of the GET booklet.

An over activity/under activity (‘boom or bust’) cycle, the terms used to describe physical activity levels fluctuating over time, is regularly observed in people with CFS. Patients tend to be over-active on their better days which may lead to an increase in symptoms and hence being functionally more restricted in the days/week following. Over activity may lead to an increase in rest and a decrease in fitness and function if prolonged.

5. Encourage participant to read and apply steps 1-4 of the GET booklet

The information below is to help you as you support participants through these sections of the **GET booklet**. It is possible that participants may have read some of these sections prior to session 1, although not expected to have done so, which is why the information is here. Basically, in session 1 you should be encouraging participants to read and apply the following steps. They will not require all the additional information below.

You could refer them to the diagram on page 7 of their GET booklet to see the steps.

Step 1: Stabilise routine

It is important that the participant establishes a baseline for everyday physical exercise and activity as a starting point. Ideally they need to do this in the seven days after their first telephone contact with you. Many people with CFS/ME find that when they exercise more than their body is comfortable with, there is a significant post-exertional response including muscle soreness, fatigue and stiffness. These post-exertional difficulties inevitably lead to a reduction in function, and an inability to sustain exercise. You can explain to the participant that this boom/bust pattern of exercise is unhelpful as it leads to inconsistency: consistent, regular exercise is essential for the body to adapt. It is far better, therefore, to encourage a regular daily walk of 5-8 minutes that is achievable without exacerbating symptoms, rather than 30 minutes twice a week that leads to feeling unwell the next day.

The purpose of completing an *activity diary* (see Appendix 3) is for the participant to establish whether they are currently showing signs of a boom/bust pattern or activity avoidance, and to assist them to correct it. This is important in order to provide a stable baseline of physical activity and exercise to work from. They will need to assess this themselves (and reflect on this with you at their next session) and then adapt their routine during the following 7-days.

The examples of diaries (boom-bust; page 10 and stabilised; page 11) in the GET booklet are rather complex and difficult to interpret. It may be that you will need to spend a little time explaining to them how they can best complete and make use of the activity diary sheets.

Step 2 – Start doing regular stretches

Participants need to be directed to the stretching exercises on page 26-32 in the GET booklet. They should use the guidance (GET booklet p25) about how to stretch, how many stretches to do, and how long to hold each one. Stretches should not replace aerobic exercise, but should be completed alongside it. Stretches do not, however, need to be done at the same time of the day as the aerobic activity. Stretches should be started immediately and progressions should start within one week.

Step 3: Decide on a goal and choose exercise/physical activity

Setting meaningful goals is an essential component of GES, in order to help motivate participants and help them appreciate the functional context of exercise in their own lives. Not only do goals provide a clear, functional focus for treatment, but they also lead to a measurable outcome. Specific, behavioural goals that focus upon regular, realistic, functional and enjoyable exercise should be encouraged. A goal for GES should be a clearly observable, behavioural change, not a reduction or absence of symptoms. For example “walking every day for 20 minutes” and “walking outside every day for 2 minutes to and from the bus stop” are measurable, but “no longer feeling fatigued” is not.

You will need to guide participants to set themselves at least one short and one longer-term goal. To guide participants as to how to set goals, refer them to their GET booklet.

Step 4: Set exercise/physical activity baseline

Setting an exercise/physical activity baseline will have to be done after Step 1 has been completed and the participant has a stable routine. The importance of finding a level of exercise or physical activity the participant can do comfortably, even when they are not feeling at their best (including their 'bad days'), cannot be underestimated. This baseline should be a level of exercise that is achievable on a regular basis (5 or 6 days per week) without leading to unmanageable exercise-related / CFS symptoms. It should be developed carefully, and may need to be adapted after support in session 2.

You may need to explain that a mild increase in fatigue or muscle stiffness/soreness is a normal response to unaccustomed exercise, but that this response should not be so severe as to interfere with their sleep pattern or function. (i.e. they should not need to have a sleep afterwards, and should still be able to carry out their normal level of activity e.g. making dinner etc).

You should encourage the participant to undertake this baseline for at least 5-6 days a week and NOT to increase beyond this level if they are feeling better, or on a 'good day'. It must be emphasised that extending beyond their baseline may lead to uncomfortable exercise-related symptoms, and may cause difficulty maintaining the necessary frequency. (e.g. "If you do too much on one day, you may not be able to achieve your baseline the next day, and then you have lost the regularity required to make progress").

Carrying out the baseline will form the next homework task of the exercise programme. Participants should be encouraged to time the exercise, using a digital watch or stopwatch ("there is a significant difference between 5 and 7 minutes"). It may be helpful to ask the patient to plan the time and location they will perform the exercise.

Emphasise that the first part of the programme is about increasing frequency and then duration; increasing intensity is not a target at this stage.

6. Explain the GET model and rationale and a normal response to exercise

The *GET model and rationale* are described on page 6-7 of this manual. It is important that you understand the model well enough to explain it to participants and answer questions when asked. You may want to include in your discussion what the normal response to exercise is. It is not unexpected that fatigue might increase a bit after an incremental increase in exercise/physical activity. As long as the increase in fatigue is manageable, participants should be encouraged to continue with their exercise as planned but not increase it until symptoms return to their previous level (if needed, refer to the section in the GET booklet: '*Managing a set-back*').

7. Reassure participant as required using knowledge of evidence for GET

SESSION 1 – Checklist

PIN _____

Initials _____

Date _____

Face to face Telephone Skype® (check appropriate box)

Start of session

- Introduce yourself
- Remind participant you will be recording the session
- Set agenda for the session
- Check participant has a copy of the guide and are in a quiet space
- Discuss length and content of session
- Outline number of sessions and guided support plan
- Explain what is required of participant (Appendix 4)
(including tasks to do between sessions)

Encourage participant to read pages 1-6 of guide:

- Explaining CFS; the perceptual and deconditioning models
- Feeling better with exercise
- Guidelines for choosing exercise
- Benefits of exercise
- Goal Setting
- Read and apply pages 7-15 of the manual

Encourage participants to complete an *activity diary*

- Reassure participant as required
- Arrange further appointments

Paper work to complete after session:

- Complete session checklist (this page)
- Complete *Discussing what is required of the participant* checklist
- Complete SOAP notes, including plans for next session
- Complete attendance record and book sessions if appropriate
- Complete reflective review of session
- Transfer recording to CD and password protect it
- Send letter to referring doctor, GP, and anyone else involved in care
- Any adverse events (*Adverse Event Reporting Form*)? Y/N

Session duration _____ mins

Signed _____

Date _____

SESSION 1: SOAP NOTES

PIN _____

Initials _____

Date _____

S /O: (Guided support discussed. Subjective and Objective information.)

Tasks to do for next session

A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

SESSION 2

Provide guided support

Purpose of session 2: Telephone/Skype call (20 minutes)

1. Enquire about progress with steps 1-4 and review activity diary.
2. Encourage participant to move to step 5 and answer any questions or concerns.
3. Recognise achievements and congratulate efforts.
4. Problem-solve where difficulties have arisen or where the approach has not been implemented.
5. Encourage participant to read about setbacks.
6. Revisit GET model if required.

1. Enquire about progress with steps 1-4

Participants will vary in their progress between sessions 1 and 2. It is your role to provide support and answer any queries they have about steps 1-4. There was a lot for participants to do in the 2-3 weeks from session 1, and they are likely to need some encouragement to continue to progress and any concerns need to be addressed. You will need to briefly review how they managed with completing their activity diary to stabilise their routine (step 1) and how they are managing with setting their exercise/physical activity baseline (step 4). You should also ask how they are getting along with their stretches and provide support with their choice of goals, ensuring they meet the guidelines (relevant, enjoyable, regular & achievable).

You should include in your notes information about the participant's goals. Try to ensure they have a timescale for each goal and a way they will measure if it has been achieved.

2. Encourage participant to move to step 5 and answer any questions or concerns

Before an increase in aerobic exercise **intensity** is considered, the first stage of GES involves an increase in exercise **duration** at low/moderate intensity. This is to improve the participant's confidence with the programme, and minimises the risk of symptom exacerbation.

Once a daily baseline duration of physical activity can be achieved comfortably (often leading to a reduction in perceived effort), the participant should be encouraged to increase the duration of their daily (5 days per week) exercise. The incremental increases should not be any more than 20%, but the increase should occur at each exercise session that occurs in that week. E.g. a 5-minute walk 5 days per week becomes 6 minutes on all 5 days; a 2-

minute bounce on a rebounder 5 days a week becomes a 2.5 mins bounce on 5 days each week, 10 sit-to-stands become 12, 1 minute on the exercise bike becomes 72 seconds.

The **duration** of exercise should then be incrementally increased, without an increase in intensity, to 30 minutes. Once the participant is able to achieve 30 minutes of exercise on 5 days out of 7 (even if they are doing some on other days) and is managing this without exacerbating their symptoms, **only then should the intensity be increased**.

Sometimes it is helpful to suggest the exercise is broken up into two separate sessions in the day. This can be useful for someone who finds it difficult to exercise for 20 minutes non-stop. However, each session should not be less than 10 minutes, as 10 minutes is required to make progress.

3. *Recognise achievements and congratulate efforts*

It is essential that you demonstrate positive reinforcement, emphasising and being very positive about what they have achieved and the effort made. At every session you should positively reinforce all of their achievements, however small.

4. *Problem-solve where difficulties have arisen or where the approach has not been implemented.*

It is impossible to determine what difficulties might arise. When the approach has not been implemented you will need to explore this with the participant and assist them in overcoming their barriers or difficulties to implementing the programme, by referring to the appropriate section of the guide and talking it through with them.

5. *Encourage participant to read about setbacks on page 19 of the GET booklet.*

Participants have a short description of what a setback is in their GET booklet. They also have a diagram to help them understand what a setback is. You need to understand setbacks in enough detail to be able to advise them on how to manage a setback, using the guide. It is helpful to explain the theory behind maintaining exercise during a setback to participants **before** they have a setback if possible, as while they are symptomatic it may be more difficult to encourage them. It is therefore useful to encourage them to consider writing a **setback plan**, referring to the relevant section of the guide, outlining useful information to follow in the event of a setback.

CFS/ME setbacks usually involve an exacerbation of symptoms, leading to a significantly reduced functional capacity. Participants may describe these as a 'relapse', or 'crash'. People with CFS/ME can usually identify an increase in physical activity or activities of daily living which may have attributed towards their setback. Sometimes setbacks also appear to be caused by sleep disturbance, an intercurrent infection or emotional distress. It is normal, and likely, that participants will suffer a setback at some point during their GES programme, for whatever reason.

If the plan has been undertaken carefully, with a low baseline and small increments as planned, it is very unlikely to be the exercise programme that is responsible for their setback. However, it is important to ascertain whether any components of the GES programme may have contributed towards setbacks, and to adapt the plan immediately to avoid difficulties.

A central concept of GET and GES is to ***maintain*** exercise as much as possible during a CFS/ME setback. This is to reduce the many negative consequences of rest, and to allow the body to habituate to the increase in activity. If activity and exercise is reduced at this time, the boom/bust cycle continues, and the body is not able to desensitise to the increase in activity: which is, of course, an essential component of a graded increase in exercise and activity.

Although it can be difficult to encourage maintenance of exercise during an increase in symptoms, participants usually are able to understand the reasoning behind this and are often pleased they were able to maintain activity during this time. It is important to explain that although they have an increase in symptoms, 'hurt does not equal harm'.

Some participants may be resistant to this approach, and will wish to reduce both activity and exercise during this time. If they cannot be encouraged to maintain their previous level of exercise, then encourage them to maintain as much as they are able to, and work towards building up the activity/exercise as soon as possible.

6. Revisit GET model if required

SESSION 2 – Checklist

PIN _____

Initials _____

Date _____

Telephone Skype® (check appropriate box)

Start of session

- Set agenda
- Remind participant you will be recording the session
- Check participant has a copy of the guide and are in a quiet space
- Discuss length and content of session
- Explain what is expected of participant (if not finished last session)
- List questions/concerns

Discuss progress:

- Review physical activity diary (if completed)
- Review experience of reading and applying the GET booklet
- e.g. stabilising routine, regular stretches, deciding on a goal, set baseline*
- What has gone well and not so well }
- What have you learned? }
- Has it been helpful/unhelpful? }
- Answer questions/concerns

Encourage participant to:

- Encourage participant to read and apply step 5 (p16 & 17)
- Encourage participant to read about setbacks (p19-23)

Paper work to complete after session:

- Complete session checklist (this page)
- Complete *Discussing what is required of the participant* checklist
- Complete SOAP notes, including plans for next session
- Complete attendance record and book sessions if appropriate
- Complete reflective review of session
- Any adverse events (*Adverse Event Reporting Form*)? Y/N

Session duration _____ mins

Signed _____

Date _____

SESSION 2: SOAP NOTES

PIN _____

Initials _____

Date _____

S /O: (Guided support discussed. Subjective and Objective information.)

Tasks to do for next session

A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

SESSION 3

Provide guided support

Purpose of session 3: Telephone/Skype call (20 minutes)

1. Enquire about progress with step 5
2. Encourage participant to move to step 6 and answer any questions or concerns
3. Remind participants to continue to progress with stretches
4. Recognise achievements and congratulate efforts
5. Problem-solve where difficulties have arisen or where the approach has not been implemented.
6. Enquire about participant's understanding of a setback and guide them appropriately.

1. Enquire about progress with step 5

Participants will vary in their progress between sessions 2 and 3. It is your role to provide support and answer any queries they have about step 5. There is a lot for participants to do, and some may still be getting to grips with steps 1-4, let alone 5. Participants are likely to need your support and guidance to continue to progress from where they are at. You will need to briefly review how they managed with increasing the duration of their physical activity aiming for 30 minutes 5 days per week. You may also ask how they are getting along with previous steps, depending upon their progress.

2. Encourage participant to move to step 6 and answer any questions or concerns

Once the participant is able to do 30 minutes of exercise at their own intensity 5 days per week without exacerbating their symptoms, they can consider increasing the intensity of the exercise.

It would be useful to explain to participants that increasing intensity can be measured by the time taken to walk from A to B. The duration of their current exercise is recorded. Participants can be encouraged to speed up the pace of their walk, increase the resistance or level on aerobic exercise machines (e.g. exercise bike) or do an activity faster. However, it is important that this increase in intensity is also done with care and is likely to be done in stages. E.g. there are a number of stages between walking at a strolling pace and jogging. It can be useful to build up the intensity by adding in shorter bursts of higher intensity activity to start with, e.g. one minute of fast walking interspersed with two minutes of normal pace.

Participants may ask about the appropriateness of using their heart rate to measure the intensity of their exercise. If they have access to a heart rate monitor and are comfortable to use their heart rate as a measure of intensity, this is fine. However, you are unlikely to have

time to give much advice on this and so, if possible, it is best to provide participants with alternative ways of measuring intensity as described in the previous paragraph.

3. Remind participants to continue to progress with stretches

Participants need to be reminded to continue to perform the stretching exercises from page 26 in the **GET booklet**. They should be increasing the number of different stretches they do by at least one each week, or increase the number of each stretch they are currently doing, and be holding them for up to 20 seconds as described in the guidelines on page 25 of the **GET booklet**. Stretches should not replace aerobic exercise, but should be completed alongside it. They do not, however, need to be done at the same time of the day.

4. Recognise achievements and congratulate efforts

It is essential that you demonstrate positive reinforcement, emphasising and being very positive about what they have achieved and the effort they have made. During every session you should positively reinforce all achievements.

5. Problem-solve where difficulties have arisen or where the approach has not been implemented.

It is not possible to determine exactly what difficulties might arise. When the approach has not been implemented you will need to explore this with the participant and assist them in overcoming their obstacles or difficulties to implementing the programme.

It is important to encourage the participant to find sustainable methods of maintaining exercise, and to support them in solving difficulties they have had in establishing a regular exercise programme. Integrating their exercise into a social or community setting may also be important, e.g. walking with friends, participating in a team sport, joining a local gym or doing an exercise class. If they are keen to aim towards a goal that is beyond their current capability, discuss how they could increase their physical exercise to achieve their plan. For example, if the participant wishes to attend a local kick-boxing class, they will need to build up their aerobic capacity, flexibility and physical strength to be able to achieve an hour of a high intensity activity. You might want to highlight that they should consider how they will exercise during the winter, when they may be less likely to walk outside, or how they might tackle a significant increase in gradient.

6. Enquire about participant's understanding of a setback and guide appropriately.

Participants should have read the short description of what a setback is in their GET booklet. They should also have studied the diagram that is there to help them understand the concept. You could enquire as to their understanding of managing a setback and whether they have written a **setback plan**. You may need to refer them back to the relevant sections of the **GET booklet**, outlining useful information to follow in the event of a setback.

You could enquire about their understanding that a central concept of GET and GES is to **maintain** exercise as much as possible during a CFS/ME setback. This is to reduce the many

negative consequences of rest, and to allow the body to habituate to the increase in activity. This may need to be emphasised. Although it can be difficult to encourage maintenance of exercise during an increase in symptoms, participants usually are able to understand the reasoning behind this and are often pleased they were able to maintain activity during this time. It is important to explain that although they have an increase in symptoms, 'hurt does not equal harm'.

Some participants may be resistant to this approach, and will wish to reduce both activity and exercise during this time. If they cannot be encouraged to maintain their previous level of exercise, then encourage them to maintain as much as they are able to rather than stopping altogether, and work towards building up the activity/exercise, as they had done previously, as soon as possible.

SESSION 3 – Checklist

PIN _____

Initials _____

Date _____

Telephone Skype® (check appropriate box)

Start of session

- Set agenda
- Remind participant you will be recording session
- Check participant has a copy of the guide and are in a quiet space
- Discuss length and content of session
- List questions/concerns

Discuss progress:

- Review experience of reading and applying the GET booklet
e.g. increasing duration of exercise
- What has gone well and not so well
- What has been learned?
- Has it been helpful/unhelpful?
- Remind participants to continue to progress with stretches
- Review participants understanding of setbacks (p19-23)
- Discuss forming a setback plan
- Answer questions/concerns

Encourage participant to:

- Read and apply step 6 (p18)

Paper work to complete after session:

- Complete session checklist (this page)
- Complete SOAP notes, including plans for next session
- Complete attendance record and book sessions if appropriate
- Complete reflective review of session
- Any adverse events (*Adverse Event Reporting Form*)? Y/N

Session duration _____ mins

Signed _____

Date _____

SESSION 3: SOAP NOTES

PIN_____

Initials_____

Date _____

S /O: (Guided support discussed. Subjective and Objective information.)

Tasks to do for next session

A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

SESSION 4

Ending support, preparing and planning for self-management

Purpose of session 4: Telephone/Skype call (20 minutes)

1. Enquire about progress with all relevant steps.
2. Recognise achievements and congratulate efforts.
3. Problem-solve where difficulties have arisen or where the approach has not been implemented.
4. Review goal(s).
5. Ending of support, preparing and planning for self-management, including a review of set-back plan.

1. Enquire about progress with relevant steps

Participants will vary in their progress between sessions 3 and 4. It is your role to provide support and answer any queries they have about the steps relevant to them. There is a lot for participants to do, and some may still be getting to grips with steps 1 and 2, let alone 6. Participants are likely to need your support and guidance to continue to progress from where they are currently at. You will need to briefly review how they managed with increasing the duration and/or intensity of their physical activity, if they have reached this stage. They may need some individualised and specific guidance about how to increase the intensity of their chosen physical activity.

2. Recognise achievements and congratulate efforts

It is essential that you demonstrate positive reinforcement, emphasising and being very positive about what they have achieved and the effort they have made. Every session you should positively reinforce all of their achievements, however small.

3. Problem-solve where difficulties have arisen or where the approach has not been implemented.

It is not possible to determine exactly what difficulties might arise. When the approach has not been implemented by the participant you may need to explore this with them and assist them in overcoming their obstacles or difficulties to implementing the programme.

You may need to encourage the participant to find sustainable methods of maintaining exercise, and to support them in solving difficulties they have had in establishing a regular exercise programme. Integrating their exercise into a social or community setting may also be important, e.g. walking with friends, or participating in a team sport, joining a local gym or doing an exercise class. If they are keen to aim towards a goal that is beyond their current

capability, help them to break it down and discuss how they could increase their physical exercise to achieve their plan. For example, if the participant wishes to attend a local kick-boxing class, they will need to build up their aerobic capacity, flexibility and physical strength to be able to achieve an hour of a high intensity activity. You might want to highlight that they should consider how they will exercise during the winter, when they may be less likely to walk outside, or how they might tackle a significant increase in gradient.

4. Review goal(s)

You should review the participant's goals they set earlier in the programme. Are the goals specific, behavioural goals that focus upon regular, realistic, functional and enjoyable exercise? A goal for GES should be a clearly observable, behavioural change, not a reduction or absence of a symptoms e.g. "Cycling every day for 20 minutes", not "no longer feeling fatigued." At this point they may want to think about longer-term goals.

5. Ending of support, preparing and planning for self-management

Self-management and independence with stretches and exercise programme

The support given should be reviewed, and progress highlighted. Encouragement and instructions to continue the GES programme should be given, reviewing the principles of graded exercise therapy if necessary.

Participants should be taught how to continue GES without supervision, with a view to, depending on their interests, joining a local community exercise group, leisure centre, dance class, walking group or cycling group.

The participant should be encouraged to continue with the stretches in the manual and their physical activity programme, but also to try different types of exercise, and to have confidence in planning new activities.

Maintaining exercise

It can be explained that in order for the body to continue strengthening, and for changes to be maintained, exercise should form a regular part of their lives from here onwards. The long-term benefits of exercise for prevention of CFS/ME specifically,^{41,42} and other diseases in general can be emphasised.^{43,44}

Review setback plan

You should ask the participant if they have completed their setback plan and feel that if they should need to they would understand how to follow it. If relevant you could review the information on setbacks with them on pages 19-21 of the GET booklet.

SESSION 4 – Checklist

PIN _____

Initials _____

Date _____

Telephone Skype® (check appropriate box)

Start of session

- Set agenda
- Remind participant you will be recording session
- Check participant has a copy of the guide and are in a quiet space
- Discuss length and content of session
- List questions/concerns

Discuss progress:

- Review experience of reading and applying the GET booklet
 - What has gone well and not so well
 - What have you learned?
 - Has it been helpful/unhelpful?
- Answer questions/concerns

Encourage participant to:

- Continue to apply steps 1-6 of the GET booklet
- Continue stretches
- Continue to review setback plan
- Continue to review goal(s)

Paper work to complete after session:

- Complete session checklist (this page)
- Complete SOAP notes, including plans for next session
- Complete attendance record and book sessions if appropriate
- Complete reflective review of session
- Complete *measure of adherence & record of sessions attended*
- Send letter to referring doctor, GP, and anyone else involved in care
- Any adverse events (*Adverse Event Reporting Form*)? Y/N
- Let the trial manager know you have completed guided support

Session duration _____ mins

Signed _____

Date _____

SESSION 4: SOAP NOTES

PIN _____

Initials _____

Date _____

S /O: (Guided support discussed. Subjective and Objective information.)

Tasks to do for next session



A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

DOCUMENTATION

Trial session records should be used to record details of each contact that you have with the participant, e.g. phone/Skype® appointments or brief phone calls, texts and e-mails between sessions. Please remember that non-session contacts with the participant are not encouraged. The paperwork can be categorised into 2 sections:

Therapy records (ON BLUE PAPER)

The therapy records include all of the documentation you will need to maintain your participant notes: these include checklists for each session, SOAP notes, space to write additional SOAP notes and plans, an attendance record and an unplanned contacts record (**SOAP** notes, as used in normal physiotherapy practice as recommended by the Chartered Society of Physiotherapy, will incorporate **S**ubjective and **O**bjective data, **A**nalysis/clinical reasoning and will record therapy **P**lans).

Normal Chartered Society of Physiotherapy standards for note keeping will be expected, including dates, signatures, page numbers etc. Participants will be identified by their unique 'Participant Identification Number' (PIN) and initials of their name, given upon referral, which is to be added to all pages of GETSET paperwork alongside the participant's name. The only exception to this is NOT writing the participant's name on the following documents, as they will be needed by the trial data collection anonymously:

- Measure of adherence & record of sessions attended,
- Attendance record,
- Any Unplanned Phone Records that include therapy advice (i.e. those that do not result in advice can be filed into the therapy notes).
- File notes

A letter will already have been sent to the participant's GP informing them of their involvement in the GETSET trial, and that they have been randomised to GES.

Reflective Practice Sheet (ON GREEN PAPER)

After each treatment session, you will be expected to fill in a reflective practice sheet – this is to a) learn from achievements and challenges in the session, b) to share in supervision c) to share with colleagues (if appropriate) so they may benefit from your learning d) to make plans to change practice if necessary for the next session.

LIST OF APPENDICES

- APPENDIX 1:** Further information about exercise and graded exercise therapy
- APPENDIX 2:** Training logbook
- APPENDIX 3:** Activity diary
- APPENDIX 4:** Discussing what is required of the participant checklist
- APPENDIX 5:** References

APPENDIX 1

FURTHER INFORMATION ABOUT EXERCISE AND GRADED EXERCISE THERAPY (GET)

This information is for therapists to refer to enable them to provide informed advice to participants.

This appendix includes the following:

- 1 Benefits of exercise**
- 2 General advice for safe and effective exercise**
- 3 Normal responses to exercise**
- 4 Unusual adverse reactions to exercise**
- 5 Explaining the principles of graded exercise therapy to participants**
- 6 Model and rationale behind the GET booklet**
- 7 Adverse effects of GET**
- 8 Important GET considerations**
- 9 Using an exercise/physical activity diary**
- 10 Using ratings of perceived exertion**
- 11 Using heart rate measurements**
- 12 Using pedometers**
- 13 Setting goals and participant goals sheets**
- 14 Guidelines for choosing exercise**
- 15 General advice for stretching**

1. BENEFITS OF EXERCISE

Regular exercise has many known benefits to people of all ages and with many differing medical conditions. Exercise of an appropriate duration, intensity, and regularity is known to affect the following in a positive way:

Cardiovascular System

Your heart, lungs, and circulation system work more efficiently, making your body more able to deal with the demands of daily activities. The improvements in the cardiovascular system can reduce your risks of certain diseases e.g. heart disease.

Strength

Exercises that challenge your muscles improve the strength of individual muscles and muscle groups, making some daily tasks easier, e.g. climbing stairs, hanging out the washing.

Endurance

Exercises that are prolonged enable you to do more than you could previously, e.g. walk further, swim further, do the housework for longer.

Flexibility

Many exercises, especially those involving stretches (e.g. Yoga), can improve the flexibility of your joints, ligaments, and muscles helping you to move easier with less stiffness.

Balance

Certain exercises can improve your balance, e.g. dancing, standing on one foot.

Immune system

The right amount of exercise maintains and improves your immune system, essential for fighting viruses and infections.

Sleep

A good night's sleep is essential in order to feel refreshed and wake up feeling better. Exercise improves slow wave sleep, during which hormones are released to repair your muscles.

Increase in Bone Density

Exercises that involve putting weight through your legs (known as *weight bearing exercises*) help increase and maintain bone density, reducing your risk of broken bones and osteoporosis (*'brittle bones'*).

Thinking ability (cognition)

Graded Exercise Therapy for CFS/ME has been shown to improve thinking ability, or cognition.

Well – being and mood

Exercise releases your own natural hormones in your body that can make you feel more relaxed and happier. It can therefore be of particular help for people affected by depression or anxiety.

Putting stress hormones to good use

Various natural substances are released into your bloodstream at times of stress, in order to prepare your body and muscles for physical action. Sometimes we are not physically active at times of stress, which can lead to certain symptoms, e.g. dizziness, muscle tension. Exercise can be an effective and positive way of utilising the physical preparation and helping to control certain physical symptoms.

Weight loss

If you are overweight, aerobic exercise is an essential component to successful weight loss.

Body Image

Exercise can make you feel better about your body.

Confidence

Participating in exercise can improve your confidence, especially if you are learning something new and challenging, or returning back to an activity you previously enjoyed. A sense of achievement is important to everyone.

Social Contact

Exercise can be a good way of establishing or re-establishing social contact.

2. GENERAL ADVICE FOR SAFE AND EFFECTIVE EXERCISE

- Participants should take care not to 'over train' i.e. exercise for longer/harder than their body can deal with; this may seem like a step forward but is often two steps back. A manageable starting point and gradual progression is the key.
- Participants should be encouraged to drink water BEFORE, DURING AND AFTER exercise and not to wait until they **feel thirsty**.
- Participants should be encouraged to wear comfortable clothes, e.g. tracksuit, and supportive trainers.
- If the participant uses an inhaler, they should have it with them whilst exercising and use it appropriately.
- Participants may need guidance on the 'normal' and '(rare) abnormal' responses to exercise. Exercise can cause many normal responses; these feelings are all positive and show that they are working well and making positive changes in their body.
- Participants should stop exercising if they have a temperature (tested using a thermometer), but **be sure to seek** advice from the GET booklet, their GP or specialist regarding how and when to re-start.
- If participants report having trouble sleeping, they can be advised to avoid exercising late in the evening as it has a tendency to 'stimulate' the body making any 'wind down' before sleep longer. However, exercising early evening/ afternoon can help prepare them for sleep later in the evening.
- If you discuss the use of participant-owned home exercise equipment, the participant needs to be aware that they are responsible for the choice, safe usage and maintenance of any such equipment.
- Participants may ask you for advice on exercise equipment, which you may give as long as the participant is aware that you will not be able to ensure its safe or effective use.

- If a participant joins a gym, they should be advised to seek advice from the gym instructors on the safe use of equipment.
- If a participant uses an exercise video or DVD, they should be aware that it is often not appropriate to copy the exact exercise as shown: they are likely to need to conduct fewer repetitions at a lower range and lower duration than shown.
- If you discourage a participant from using a certain piece of equipment or an exercise, you will need to document this in your participant notes. For example rowing might not be suitable for someone with a back injury.
- You can discuss other practical safety considerations with regards to, for example, wearing appropriate footwear, avoiding icy conditions and being appropriately hydrated.
- You should suggest the participant discusses any medical safety issue with their GP or specialist doctor. This could include asthma and inhaler use and any other appropriate precautions relating to specific medical conditions.

3. NORMAL RESPONSES TO EXERCISE

The following signs and feelings are *normal* reactions during exercise; they show that the participant is working at the right level to make real positive changes to their body. If they do not feel any of these when exercising, they will not be making any positive changes to their body.

Increased breathing rate

Your breathing will become faster than normal, to a rate that you are able to control. This is to supply your muscles with more oxygen because they are working harder than usual.

Increased heart rate

You may feel your heart rate increasing: Your heart will beat faster in order to pump the extra oxygen around your body to provide for your muscles.

Body parts turning red in colour

Your face, arms, legs, or other body parts may turn red in colour during and after exercise. This is because there is more blood being supplied to the muscles beneath the surface of your skin. It is also because your blood vessels move towards the surface when you are warm to help keep you cool.

Sweating

Sweating is your way of helping to control your body temperature: as you become warmer on exercise, the sweat evaporates and it cools you down.

Increased temperature

You will feel warmer all over your body as your muscles are working harder and giving off more heat.

'Jelly feeling', especially in arms and legs.

You may feel like your arms or legs are a little shaky or feel like jelly. When you stop exercise and rest this feeling should gradually reduce and stop. This is a normal response to exercise.

Normal response after exercise

After exercise, your heart and breathing rate will gradually slow down to their normal resting rates. You may also feel the following as part of a normal reaction after exercise:

Heaviness feeling: After your muscles have worked hard, they are likely to feel heavy.

Stiffness feelings in muscles: These come in varying degrees; a mild stiffness is normal and is associated with positive changes. Stiffness should gradually improve and should not last long. A good warm up and warm down will help reduce these feelings.

Stiffness feelings are associated with a build up of a normal by-product of exercise, known as lactic acid. Lactic acid gradually gets washed out of your muscles after exercise by your bloodstream. You can help this process and feel more comfortable by having a long, warm bath followed by gentle stretching exercises. Gentle movement, e.g. walking, can also help.

Natural tiredness: Exercise will make you feel a normal and natural tiredness and will help improve sleep. This tiredness may feel more than usual in somebody with CFS/ME.

4. UNUSUAL ADVERSE REACTIONS TO EXERCISE

IF PARTICIPANTS GET ANY OF THESE SIGNS, THEY SHOULD STOP EXERCISING AND BE ADVISED TO DISCUSS WITH THEIR GP OR SPECIALIST.

- ❖ **Breathing becoming out of control**
- ❖ **Wheezing**
- ❖ **Chest pains**
- ❖ **Collapse or faintness**
- ❖ **Injuries**

If they mention to you that anything else is making them feel uncomfortable during exercise, be sure to recommend they discuss it with their GP or specialist if you are concerned.

5. EXPLAINING THE PRINCIPLES OF GRADED EXERCISE THERAPY TO PARTICIPANTS

The principles behind graded exercise therapy as a treatment for CFS are described in the main part of your manual. However, explaining them in a way that people understand can be challenging.

In relation to your role in guiding people through the GET booklet, explaining what graded exercise therapy is and its benefits, especially in relation to a patient's particular symptoms and experience, is a good starting point. You can direct them to pages 1&3 of their **GET booklet**. They may be worried that it will harm them in some way or make them worse. You can reassure them, using the information in your manual about safe and effective exercise, and also normal responses to exercise in this appendix.

Explaining the theory of GET can be complicated, but you can explain the 'use it or lose it' theory of physical fitness by using examples in their lives. Try to illustrate this using specific hobbies they have, or experiences they have been through: For example, if working with a musician, draw parallels with GET theory with learning to play to a high level. You might explain how a beginner will need to start with practising musical scales, learning to read music and learning where to place their fingers on their instrument. They can then learn music to grade 1 level, practise at this level for a while before feeling comfortable trying grade 2. A beginner cannot automatically play in an orchestra. Equally, someone who has not played their instrument since childhood may need to start by reminding themselves how to read music, and to start at a lower playing ability. Such metaphors can be very powerful in getting a participant to understand the theory of deconditioning and reconditioning, and should be tailored to their own interests. Learning a foreign language

or learning to walk or ride a bike can also be useful explanatory concepts. These should be used as a support to **GES**.

You can then explain that GES can be broken down into a 6-step programme. By carefully establishing a baseline of physical activity/exercise that they can do regularly will form the first part of the programme, followed by mutually agreed gradual increments in the duration of exercise at the same level of intensity. You can then tell them that once this can be done comfortably, an increase in intensity will help further strengthen the body. This is all in their **GET booklet**, but may need additional brief explanation.

You can explain that research that shows significant reductions in physical capacity after periods of rest, or relative rest, and how this can equate to their situation. Even if they have not had periods of full bed-rest, participants can usually relate to a relative reduction in exercise, activity or physical functioning as a result of their CFS/ME.

You can give them information on previous research trials of GET for CFS/ME that show increases in physical strength, fitness, and functional capacity, sleep, mood and cognition. The role of exercise in general health and the prevention of major chronic diseases, such as stroke, obesity, coronary heart disease, type II diabetes and cancers can also be explained.

6. MODEL AND RATIONALE BEHIND GRADED EXERCISE THERAPY (GET)

GET has been shown to improve muscle strength, cardiovascular endurance, and symptoms in a wide variety of illnesses⁸. Three systematic reviews have concluded that GET is a promising treatment for outpatients with CFS/ME.⁹⁻¹¹ Six randomised controlled trials (RCTs) have found improved fatigue and disability with differing graded exercise programmes compared to no treatment or control treatments.¹²⁻¹⁷ Three randomised controlled trials of graded exercise suggest that GET improves symptoms or disability more than relaxation or supportive therapy.^{12,15,16} In the most recent research, the PACE trial (www.pacetrials.org), graded exercise therapy was shown to be more effective in reducing fatigue and improving functioning than specialist medical care alone and adaptive pacing therapy.¹⁷

The rationale behind GET stems from both a physical and behavioural understanding of CFS/ME. Physical deconditioning, exercise intolerance and avoidance caused by relative inactivity are reversed by gradually and carefully re-introducing regular physical exercise, aiming to return a patient to normal health and ability. This model has been used in previous trials.^{12,13,16} Exercise also has a role to play in improving the sleep disturbance, mood, and cognitive problems found in people with CFS/ME.¹⁵

The most prominent symptom of CFS/ME is post-exertional fatigue, resulting in avoidance of exercise, exercise intolerance, and reduced aerobic capacity.¹⁸⁻²⁰ One study has also shown significantly lower isometric quadriceps strength.²⁰ Prolonged inactivity can perpetuate or worsen fatigue and its associated symptoms in both healthy volunteers¹⁹ and in people recovering from a viral illness.²¹

Physical deconditioning is characterised by reduced muscle strength and aerobic capacity.¹⁹ This has been supported by a number of exercise studies that have shown reduced exercise tolerance in CFS/ME patients compared to controls. Five case-control studies have found that exercise tolerance was significantly reduced in CFS/ME participants.^{20,22-25} A further small study found nearly two minutes difference in an exercise test compared to controls.²⁶ A seventh study also concluded that exercise tolerance was reduced, although time spent exercising was not given.²⁷ Six of these studies also found that people with CFS/ME were either more deconditioned than healthy controls or at least as deconditioned as sedentary healthy controls^{20,22-26}. Only two studies found no significant differences from healthy controls,²⁸⁻⁹ although both patients and controls

were less fit than predicted.²⁸ However, CFS/ME participants in these two studies had significant correlations between deconditioning and both fatigue and functional impairment, and a negative correlation with physical activity,²⁸ suggesting that deconditioning was important even in these apparently negative studies.²⁸⁻⁹

Studies also show exercise incapacity was significantly correlated with reduced muscle strength and/or higher heart-rate response to sub-maximal exercise in people with CFS/ME.^{17,20} The latter may be related to reduced left ventricular mass found in CFS/ME.³⁰ A graded exercise programme produced a 13 per cent increase in peak VO₂ and a 26 per cent increase in quadriceps muscle strength.^{12,20} Improved exercise capacity was also correlated with reduced heart-rate response to sub-maximal exercise.²⁰

The more severely disabled group of CFS/ME patients were excluded from previous studies as the studies involved an exercise test that may have been too challenging. However due to greater levels of inactivity in the more severely disabled group, the deconditioning model should apply equally if not more to these patients.

Apart from improvements in CFS/ME and function, a major objective for GET is to undertake the amount of exercise recommended for full health and prevention of disease. The quantity of exercise recommended by the British Association of Sport and Exercise Sciences (2010) and the American College of Sports Medicine (2011) is 30 minute sessions of moderate intensity physical activity at least five times a week.^{5,6}

As well as direct impact upon CFS/ME, exercise has also shown to have a strong role in the prevention of various diseases such as coronary heart disease, stroke, cancer, and type II diabetes, as well as reducing the risk of premature death by 20-30%³¹. Exercise is also well known to also have positive affects upon psychological wellbeing, sleep and the maintenance of a healthy musculoskeletal system.³¹

7. ADVERSE EFFECTS OF GRADED EXERCISE THERAPY (GET)

Surveys by patient groups of their members have suggested that GET may be harmful to some people with CFS/ME.³²⁻³⁴ It is now believed this finding is due to inappropriately planned or progressed exercise programmes, possibly undertaken independently or under supervision from a person without appropriate experience.³⁴

This manual will show you how to deliver safe telephone/Skype® support, using the GET booklet, for people with CFS/ME undertaking an exercise programme. The telephone support is planned in a carefully controlled and supervised manner, with the aim of minimising the chance of adverse effects.

8. IMPORTANT GET CONSIDERATIONS

There are a number of clinically important considerations we would usually recommend when planning and delivering a more intensive GET programme for someone with CFS. They will be described here, although you will be limited for time to cover all these considerations in as much detail as is described here:

1. Individualising treatment
2. Flexible exercise prescription
3. Encouraging variety
4. Encouraging exercise routines
5. The importance of not exceeding the planned level of exercise
6. The importance of relying on distance covered, rather than a sense of effort
7. The importance of maintaining exercise levels
8. Strategies for planning exercise
9. The importance of achieving a healthy balance of exercise

1. Individualising treatment

Progress is recommended as 20% increases in duration or intensity once a baseline has been set. You should use your clinical reasoning to determine if the rate of progress is working. Participants will respond differently; some will take a lot longer to adapt to each new level, whereas others will benefit from being guided to hold back a little (particularly those who have been active sports participants in the past).

2. Flexible exercise prescription

Sometimes it can help to break up the exercise sessions during the day, so that a participant may be advised to do two sessions of 10 minutes each rather than one of 20 minutes. An interval training approach can be useful to increase intensity or duration, so that a participant can break up the exercise period into 1 - 2 minutes of target pace activity, interspersed with 1 minute at a slower pace. They can then gradually increase the duration of the faster bursts and decrease the slower periods.

3. Encouraging variety

Participants can be encouraged to use other modes of exercise at home, such as stationary and outdoor cycling, swimming, a home exercise circuit or going to the gym. Physical activity with children/grandchildren can also be introduced, e.g. going to the park to play football. Guiding the participant into having a 'wet weather plan' can be useful if the participant is unlikely to exercise in the rain.

4. Encouraging exercise routines

Especially at the beginning of the programme, encourage participants to schedule their exercise session into a similar time of day, being particularly aware of the best time of day for that participant to exercise. However, it can also be useful to allow some flexibility, e.g. poor weather, or an engagement that occurs at their usual exercise time. Suggesting that the participant schedules their exercise around a regular daily event or functional need can be particularly successful, e.g. taking a detour on the way back from a school run, or walking to the shops to get a newspaper instead of having it delivered, or walking at lunchtime with a friend.

5. The importance of not exceeding the planned level of exercise

It is important that participants are aware they should not exceed the planned exercise during a good phase. This ensures that the participant remains symptomatically comfortable, as well as retaining their confidence

in exercise: Exceeding the agreed amount is likely to lead to symptom exacerbation, and possibly a decreased exercise capacity the following day. If the level is decreased the next day, the regularity is lost and confidence can be reduced, and hence further gains can be difficult to make. It is also discouraging a 'boom/bust' exercise pattern so often found in people with CFS/ME, and hence providing an increase in activity stability.

6. The importance of relying on distance covered, rather than a sense of effort

The sense of effort is not a reliable indication of physiological effort in a patient with CFS/ME. So distance covered in a specific time can replace this, and should be used at the stage of gradually increasing the intensity of exercise/activity.

7. The importance of maintaining exercise levels

If the participant reports an increase in fatigue or other symptoms of CFS/ME as a response to a new level of exercise, they should be encouraged to remain at the same level for an extra few days. They should be reminded that each new level will initially feel harder until the body adapts: they are doing an activity they have not done for a while.

8. Strategies for planning exercise

When planning the next session of exercise, various means may be used to improve the likelihood of the participant undertaking the next phase of the programme. Motivational techniques commonly used by physiotherapists to improve compliance are considered appropriate, as long as the techniques do not involve CBT. E.g. Motivational interviewing and precise planning, as well as encouraging participation from partners, family and colleagues can be used. E.g. when are you going for a walk? Who with? What time?

9. The importance of achieving a healthy balance of exercise

Some participants may have a tendency to do more exercise than discussed, perhaps in the hope that this may lead to more rapid gains. Others may find exercise so helpful that they focus much of their daily attention upon it, sometimes to the detriment of other important aspects of their lives. Participants should be encouraged to participate in a healthy amount of exercise, whilst keeping other important aspects of their lives in balance, e.g. social or vocational functioning. A participant who is trying to progress too quickly can be warned that a rapid increase can lead to an accumulative effect and an increase in symptoms.

9. USING AN EXERCISE/PHYSICAL ACTIVITY DIARY

The *Physical activity/exercise diary*, to be completed at the start of the guided support, serves to help identify boom/bust patterns of exercise or physical activity, and to get an idea of the participant's daily routines and patterns. This can be helpful when negotiating baselines or timings of exercise sessions.

It is recognised that the diaries shown on pages 10-11 of the **GET booklet** are rather complicated for participants to understand. They may require some explanation, breaking them down into sections. Further to this, some participants will not be working and therefore their days will not resemble the examples in any way, making it difficult for participants to relate them to their own patterns of activities.

Why keep an exercise record?

It is very useful for participants to write down the exact details of the exercise they are doing. This acts in the following ways:

1. It can be very motivating for them to see how they progress: it can really help them to see their achievements on paper to recognise how well they are doing.

2. To help them (with you for support) negotiate the next level of exercise.
3. To help them (with you for support) establish whether there are any difficulties with their exercise plans and progress.

Important note

It is essential that they record ACCURATE details of the exercise they are doing. If they are unable to reach a plan or maintain an exercise, they need to be encouraged to write this on their record and explain to you when you meet. It is a normal part of GET to need to change or adapt a programme, but this can only be done if the feedback they give accurately represents their situation. Failing to report difficulties may result in detrimental effects on their support programme.

Using the Exercise Record, they will need to write down the following:

Duration

Record EXACTLY for how long they are exercising (the difference between 7 mins and 10 mins is important)

Comments

Any further comments they may have? Feeling better during exercise? Different symptoms? Any changes noticed? Any problems to discuss?

IT IS ESSENTIAL THAT THEY RECORD THE LENGTH OF TIME THEY ARE EXERCISING PRECISELY USING A CLOCK, AND THAT THEY DO NOT GO OVER OR UNDER THIS TIME.

10. USING RATINGS OF PERCEIVED EXERTION (RPE)

While doing physical activity, participants will have a perception of how hard that exercise feels. This is called a rating of perceived exertion. This feeling reflects how heavy and strenuous the exercise feels to them, combining all sensations and feelings of physical stress, effort, and fatigue. They are supposed to not concern themselves with any one factor such as leg pain or shortness of breath, but try to focus on their total feeling of exertion.

The rating of perceived exertion (RPE) (measured using the Borg Scale below³⁵) is not discussed in the **GET booklet** and therefore is not something you need to discuss with the participant unless they mention it. It is a concept that is important to the participant in their overall success with GES because it is usual for CFS/ME patients to have higher Rating of Perceived Exertion (RPE) than those who do not have CFS.^{12,26,36} This may be related to sleep disturbance, deconditioning, enhanced interoception (increased awareness of body sensations), or mood disturbance among other reasons.¹²

The RPE cannot therefore be used as an objective measure of intensity for this patient group, although it can be a useful tool alongside heart rate measurements in face-to-face therapy. After an exercise programme, research has shown that the RPE in CFS patients is normalised, and can at that stage usually be reliable as a measure of intensity.¹²

Intensity	Please circle one number
	6
Very, Very Light	7
	8
Very Light	9
	10
Fairly Light	11
	12
Somewhat Hard	13
	14
Hard	15
	16
Very Hard	17
	18
Very, Very Hard	19
	20

11. USING HEART RATE MEASUREMENTS

Most people with CFS/ME have a higher RPE score than normal subjects for the same heart rate, so they cannot rely on their subjective RPE ratings to determine optimal exercise intensity. However, in the **GET booklet** heart rate is not used to measure exercise intensity, but distance covered. If a participant is particularly interested in using a heart rate monitor to determine their exercise intensity, you can provide advice within the time you have, but will need to inform the participant that you do not have much time to dwell on it.

You could provide them with the following information: once participating in 30 minutes of physical activity or exercise on at least 5 days of the week, they should aim to be working between 60 and 75% of their predicted heart rate maximum.

Participants may decide to use heart rates to measure the intensity of their exercise. So this information is for your general knowledge, but does not need to be used with participants unless they require this information so that they are exercising safely.

The participant's target HR zone is calculated from a universally accepted and understood method; a method used for normal, healthy people ($220 - \text{age}, \times 0.6-0.75$).³⁷ Where 0.6 to 0.75 correspond to 60% and 75% of predicted maximum heart rate. This intensity is recommended for improving overall fitness.³⁷ As this figure is

used for normal, healthy people and is not adjusted for CFS/ME, the objective is to work up to this figure gradually as the participant recovers, and is unlikely to be a starting point. See examples in box below.

If the participant is monitoring their heart rate during their periods of baseline exercise, they are not aiming for a heart rate target, they are simply observing the rate they are able to do comfortably, and using the 'target' as a figure not to exceed. The purpose of this first HR measurement is mainly to ensure that the participant is not exceeding their target HR, and to give them baseline information. Most people will not be near this target intensity at the beginning of the programme.

Considerations for using HRMs:

- Participants should be advised to wear the HRM only for exercising, and not at other times during the day.
- You should be aware that HR measurements can concern some people, and participants may worry about the implications of a low/high HR. It is therefore important to reassure them that the HRM is being used a 'rough guide' only, and to let them know what their age adjusted maximum HR is.

Examples of Exercising Heart Rate Zones

Information required	Method	Example 1 Age: 27 Rest HR: 86	Example 2 Age: 51 Rest HR: 74
Age	<p>$220 - \text{age} \times 0.6 - 0.75$</p> <ol style="list-style-type: none"> 1. Minus age from 220 2. Multiply this by 0.6 to obtain the lower exercise figure 3. Multiply figure obtained in 1. by 0.75 to obtain outer exercise figure 4. The target zone is between 2. and 3. 	<ol style="list-style-type: none"> 1. $220 - 27 = 193$ 2. $193 \times 0.6 = 115.8$ 3. $193 \times 0.75 = 144.75$ 4. Target exercise zone: 115 - 145 	<ol style="list-style-type: none"> 1. $220 - 51 = 169$ 2. $169 \times 0.6 = 101$ 3. $169 \times 0.75 = 126.75$ 4. Target exercise zone = 100 - 125

12. USING PEDOMETERS

Pedometers may be used where appropriate, as per the manufacturer's instructions.

Walking is highly functional, and a pedometer will allow participants to monitor their walking effectively, either independently of exercise duration or in addition.

You may find that a participant will be motivated by seeing the distance they are walking daily, or during a set time period, and they may choose to use this as an adjunct to GES.

This could be especially useful in the first stages of the exercise programme, whereby the participant is establishing activity stability and increasing exercise duration (and hence, also distance). They may be able to recognise boom/bust patterns of physical activity by comparing daily figures if appropriate.

A pedometer could be especially useful for those who are less mobile, however, as with HRMs, it is useful to discourage excessive attention to the figures displayed, and to encourage its use only if mentioned by the participant and for a set daily purpose.

13. SETTING GOALS

Setting goals can help participants to focus on what they would like to achieve by using exercise. Goals can also help anyone supporting them to understand what is important to them, and thereby ensure that their programme is individually designed and appropriate for them.

In order to set goals, it can be useful for participants to explore how they feel about exercise – what exercise are they keen on? What exercise do they NOT want to undertake?

Guidelines for ideas:

- Is there something they want to get back to doing?
- Is there something they have always wanted to try?
- Is there a physical activity they are struggling with?

They should try to:

- Be Specific: try to get them to pinpoint what it is they really want to achieve.
- Try to be realistic: it is far better for them to aim for something they know they can achieve, and then work on more difficult aims once these are achieved.

What to do next

- i. Read 'decide on a goal and choose your exercise/physical activity' section of the GET booklet (page 13)
- ii. Re-read 'evidence for the benefits of GET' section of the GET booklet (page 3)

SMART Goals

Goals should also follow the following 5 key points (SMART):

Specific - exactly what, how much, when, where and with whom

Measurable - how far, how long for and how often?

Achievable - are the goals realistic?

Relevant - relevant to the participant's life and interests?

Time-related - the goals have a specific time-frame?*

* It should be noted clearly with a participant that giving goals specific time frames is not always helpful for CFS/ME, as setbacks may occur and prolong a goal unpredictably. If you choose to give a goal a timeframe, you should overestimate the timeframe so as not to set a participant up to fail.

Long term goals (six months or longer)

These may be functional activities, hobbies, or an exercise that the participant would like to do. It may be an activity they used to enjoy, or a new activity.

For example:

- Walking to the shops three times a week.

- Riding an exercise bike for twenty minutes every day.
- Weeding the garden for an hour at a time.
- Managing to vacuum the home all in one go.
- Swimming 20 lengths three times a week.

Short-term goals

It is helpful to break these long-term goals into smaller components, e.g. walking to the shops could be broken down into walking half-way to the shops by a particular time-frame. This goal can then be broken down further into weekly exercise goals. Goals with more complex components, such as returning to play badminton, may require a number of individual goals corresponding to flexibility, strength, and endurance.

NB: Participants may be tempted to set unrealistic goals for themselves. Ensure that goals set with participants are realistic and balanced: e.g. it would not be recommended to set goals that involve working 80 hours a week, playing football 5 times a week and staying out until 4 in the morning at weekends.

A participant may have various goals they would like to work on: if there are more than three goals, these should be prioritised and written in order of priority. Goals for GET should have relevance to exercise, physical activity or physical functioning.

Goals should be reviewed alongside the participant's general progress at every session and can be altered at any time: however, the final session provides a formal opportunity to reconsider goals.

Choose your activity: exercise should be:

<p>Relevant: Exercise should relate to an activity you enjoy (e.g. visiting museums / enjoying social outings) or an activity you need to do in your daily life e.g. housework, walking to the tube.</p> <p>Regular: To make changes and maintain them, exercise needs to be done regularly and fit into your everyday life; it is a long-term lifestyle change – not a 'quick fix'</p> <p>Achievable: Be sure that you are not aiming too high and attempting to do exercise that is beyond your current capacity. However, you may well be able to work up to your 'goal exercise' (e.g. joining a fitness class/playing football with friends) if you follow the concepts of Graded Exercise Therapy carefully.</p> <p>Enjoyable: What do you really enjoy doing? Sometimes exercising in a group/ with your friends/ family can be more enjoyable</p>

PARTICIPANT GOALS

PIN _____

Initials _____

Date _____

The following goals are thought to be the main priorities as described by the participant. These are just for your own records

Goal No/	Goal	Time Scale	Measure	Outcome

GOAL SETTING: BREAKING GOALS DOWN INTO MANAGEABLE SECTIONS

PIN _____

Initials _____

Date _____

Goal 1: _____

Step 1:

Step 2:

Step 3:

Step 4:

Step 5:

Step 6:

Step 7:

End goal:

14. GUIDELINES FOR CHOOSING EXERCISE

Exercise can be about 'sporting activities'

- ❖ Walking or cycling; for pleasure, to the bus stop, shops etc.
- ❖ Sporting activities e.g. football, swimming, cycling
- ❖ Home-based exercise programmes or going to the gym

Exercise can also include

- ❖ Housework: e.g. Cleaning / vacuuming / putting on a duvet cover!
- ❖ Gardening
- ❖ DIY; decorating and home maintenance
- ❖ Climbing stairs
- ❖ Playing with children/ grandchildren, e.g. playing 'catch' or football
- ❖ Yoga , Pilates, Tai Chi

The activities can be classified as 'aerobic exercise' if they make you feel breathless and are raising your heart rate.

15. GENERAL ADVICE FOR STRETCHING

Why is stretching helpful?

Regular stretching helps keep muscles, ligaments and joints flexible and supple. They need to be supple in order to allow free movement, without pulling uncomfortably. They can 'stiffen up' if one position is maintained for a long period of time, or during periods of less activity than normal. As muscles and ligaments can actually shrink in length during long periods of inactivity, they may be uncomfortable or painful when they are pulled as part of an increase in normal every-day activity. Stretching allows a gradual increase in muscle flexibility.

However, the good news is, that with regular stretching, muscles will become much more supple and this can make them feel more comfortable. Many people with CFS/ME report how much better they feel when stretching regularly. If a participant is used to doing particular stretches, e.g. Yoga, they might prefer to do some of these as well/instead of those given in the **GET booklet**. This is acceptable, as long as they have a way of monitoring their own progression.

When should stretching take place?

Improvements will only be seen if stretching becomes regular. A participant might start by stretching just once a day, but they should work up to stretching frequently. It is useful to stretch at the following times:

1. After a warm bath in the evenings: the warm water will soften muscles and mean they can stretch a bit further and more comfortably
2. If they are in one position for a long time, e.g. at a computer, lying down, or sitting. It is important to stretch every half an hour or so if they are in one position for a long time.
3. At regular opportunities during the day, e.g. waiting for the kettle to boil, watching TV etc.
4. Before and after any aerobic exercise or difficult physical activities, e.g. DIY, gardening.

What should stretches feel like?

Many people report that they feel more comfortable and flexible after they have stretched, and often people feel more relaxed. However, as tight muscles are being actively lengthened, stretching may feel uncomfortable at the time of the exercise. Stretches should not lead to an increase in pain, or to a pain that stays for a long time after the stretch. If a participant finds this, they should consult their GP or specialist who can help to alter the stretch for them.

Where should they start?

When a participant first starts to stretch, they should stretch gently, slowly and smoothly. As their body gets more supple they will find they will be able to stretch further. They should start by holding each stretch for as long as feels comfortable (maybe 2-5 seconds), with the view of eventually working up towards 10 seconds. They might start by just doing one stretch each side, but will then work this up gradually. Over time they will find these stretches will become easier as their flexibility increases.

APPENDIX 4

Training Log Book

Overall Training Received

To be completed by all therapists working on the GETSET trial. Please document all training undertaken whilst working on the GETSET trial. Include training specific to GETSET as well as any other training days, courses or conferences that you attend. Please keep this form regularly updated.

Name: _____ Post (for GETSET trial): _____

Date dd/mm/yy	Training provider	Type of training	Training covered (Brief Description)	GETET related?

APPENDIX 3

ACTIVITY DIARY

(just one copy is sent to participant at the start of their guided support)

Week Commencing _____

PIN _____

Write in below the days of the week, starting on the day you start your diary							
07.00-							
08.00-							
09.00-							
10.00-							
11.00-							
12.00-							
13.00-							
14.00-							
15.00-							
16.00-							
17.00-							
18.00-							
19.00-							
20.00-							
21.00-							
22.00-							
23.00-							

NOTES FOR USING THE ACTIVITY DIARY

The information gathered in this activity diary will help the participant work out how much activity/ they are doing and when they are doing it. This will help them work out their baseline and progression, and they can use the information gathered to help stabilise their own activity. The first step is to write down details of their activity/ on the weekly chart (activity diary).

They should write down their daily activity for a week, including the following

- **Activity:** A log of all physical activity during the day (e.g. got dressed, walked 4 mins x 2 to shop, rest – sat down 10 mins, made lunch etc).
- Participants shade activities according to whether they think this activity level is low, moderate or high.
- **Rest:** When, for how long, and how (lying/sitting)?
- **Exercise:** Do they do any exercise? If so, how much, how often?

APPENDIX 4

DISCUSSING WHAT IS REQUIRED OF THE PARTICIPANT: CHECKLIST

PIN _____

Initials _____

Date _____

The following checklist explains essential points that you will need to discuss with each participant over the first one or two sessions. Please tick the item when it has been discussed with the participant:

- They will need to be available for 3 further telephone/Skype® sessions over the next 9 weeks.
- The trial offers a maximum of 4 sessions: it may be that not all are completed (i.e. due to sickness, holidays).
- To participate in setting an agenda each session - so that all of their needs and requirements are met.
- To do as much of the programme as possible, including the work to do between sessions, to give themselves the best chance of making progress.
- To complete their own records, e.g. exercise records: explain that the purpose is to help them monitor their exercise, to see their achievements and to help them remember what they have done when you speak.
- To have their GET booklet with them for sessions to get the best out of their appointment, and to use a folder to keep any additional paperwork together.
- To be available for appointments on time and without distractions, as you may have an appointment straight afterwards and would therefore be unable to offer extra time.
- To keep you informed of any changes in medication or any other treatments.
- To not participate in additional forms of therapy throughout the trial
- To contact you as soon as possible if they are not going to be able to attend an appointment - so that you can rearrange one for them within the time specifications of the trial protocol.
- To let you know if they are struggling to maintain the programme.
- To feel able to tell you if they are not clear on any aspect of the GET booklet

Signed _____

Date/s _____

APPENDIX 5 REFERENCES

1. Clark LV (ed.) Graded Exercise Therapy: A self-help guide for those with chronic fatigue syndrome/myalgic encephalomyelitis. Bart's and the London NHS Trust, 2011. <https://www.elft.nhs.uk/uploads/files/1/Services/Chronic%20Fatigue/GETSET%20Leaflet.pdf>
2. White PD, Goldsmith KA, Johnson AL, Potts L, Walwyn R, DeCesare JC, Baber HL, Burgess M, Clark LV, Cox DL, Bavinton J, Angus BJ, Murphy G, Murphy M, O'Dowd H, Wilks D, McCrone P, Chalder T, Sharpe M and on behalf of the PACE trial management group. Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. *The Lancet* 2011; 377:823-36.
3. Fulcher KY & White PD. Chronic fatigue syndrome: a description of graded exercise treatment. *Physiotherapy* 1998;84:223-6.
4. National Institute for Health and Clinical Excellence. Clinical Guideline CG53 (2007). Chronic fatigue syndrome/myalgic encephalomyelitis (or encephalopathy): diagnosis and management. <http://guidance.nice.org.uk/CG53> (accessed 7th February 2011).
5. The ABC of Physical Activity for Health: A consensus statement from the British Association of Sport and Exercise Sciences. *Journal of Sports Sciences*, 2011. DOI: 10.1080/02640411003671212. URL: <http://dx.doi.org/10.1080/02640411003671212>.
6. Quantity and Quality of Exercise for Developing and Maintaining Cardiorespiratory, Musculoskeletal, and Neuromotor Fitness in Apparently Healthy Adults: Guidance for Prescribing Exercise. *Medicine and Science in sport and Exercise*, 2011. DOI: 10.1249/MSS.0b013e318213febf. URL: http://journals.lww.com/acsm-msse/Fulltext/2011/07000/Quantity_and_Quality_of_Exercise_for_Developing.26.aspx.
7. Clark LV, McCrone P, Ridge D, Cheshire A, Vergara-Williamson M, Pesola F, White PD. Graded Exercise Therapy Guided Self-Help Trial for Patients with Chronic Fatigue Syndrome (GETSET): Protocol for a Randomized Controlled Trial and Interview Study. *JMIR Res Protoc* 2016; 5: e70
8. Basmajian JV & Wolf SL. *Therapeutic Exercise*. Baltimore, Williams & Wilkins, 1990.
9. Whiting P, Bagnall A, Sowden A, Cornell J, Mulrow C, Ramirez G. Interventions for the treatment and management of chronic fatigue syndrome: a systematic review. *JAMA* 2001;286:1360-8.
10. Bagnall AM et al. *A systematic review of interventions for the treatment and management of chronic fatigue syndrome and/or myalgic encephalomyelitis*. www.york.ac.uk/inst/crd/cfs.htm 2001.
11. Edmonds M, McGuire H, Price J. Exercise therapy for chronic fatigue syndrome. *Cochrane Database Syst Rev*. 2004(3):CD003200.
12. Fulcher KY & White PD. Randomised controlled trial of graded exercise in patients with the chronic fatigue syndrome. *BMJ* 1997; 314: 1647-52.
13. Powell P et al. A randomised controlled trial of patient education to encourage graded exercise in chronic fatigue syndrome. *BMJ* 1997; 314: 1647-52.
14. Wearden AJ et al. A randomised, double-blind, placebo-controlled trial of fluoxetine and graded exercise for chronic fatigue syndrome. *Br J Psychiatry* 1998;172:485-90.

15. Wallman K, Morton A, Goodman C, et al. Randomised controlled trial of graded exercise therapy for chronic fatigue syndrome. *Med J Australia* 2004;180:444-8.
16. Moss-Morris R, Wash C, Tobin R, Baldi JC. A randomised controlled graded exercise trial for chronic fatigue syndrome: outcomes and mechanisms of change. *J Health Psychol* (in press).
17. White PD, Goldsmith KA, Johnson AL, Potts L, Walwyn R, DeCesare JC, Baber HL, Burgess M, Clark LV, Cox DL, Bavinton J, Angus BJ, Murphy G, Murphy M, O'Dowd H, Wilks D, McCrone P, Chalder T, Sharpe M and on behalf of the PACE trial management group. Comparison of adaptive pacing therapy, cognitive behaviour therapy, graded exercise therapy, and specialist medical care for chronic fatigue syndrome (PACE): a randomised trial. *The Lancet* 2011;377:823-36.
18. Royal Colleges. *Chronic Fatigue Syndrome; Report of a joint working group of the Royal Colleges of Physicians, Psychiatrists and General Practitioners*. London, Royal College of Physicians, CR54, 1996.
19. Sandler H, Vernikos J. *Inactivity: physiological effects*. London: Academic Press, 1986.
20. Fulcher KY & White PD. Strength and physiological response to exercise in patients with the chronic fatigue syndrome. *J Neurol Neurosurg Psychiatry* 2000;69:302-7.
21. Dalrymple W. Infectious mononucleosis: 2. Relation of bed rest and activity to prognosis. *Postgrad Med* 1961;35:345-349.
22. DeBecker P et al. Exercise capacity in chronic fatigue syndrome. *Arch Intern Med* 2000;160:3270-7.
23. Fischler, B, Dendale P, Michiels V, Cluydts R, Kaufman L, De Meirleir K. Physical fatigability and exercise capacity in chronic fatigue syndrome: association with disability, somatisation and psychopathology. *J Psychosom Res* 1997;42:369-78.
24. Riley MS, O'Brien CJ, McCluskey DR, Bell NP, Nicholls DP. Aerobic work capacity in patients with chronic fatigue syndrome. *BMJ* 1990;301:953-6.
25. Sisto SA, Lamanca J, Cordero DL et al. Metabolic and cardiovascular effects of a progressive exercise test in patients with chronic fatigue syndrome. *Am J Med*; 1996: 100: 634-40.
26. Gibson J, Carroll N, Clague JE, Edwards RHT. Exercise performance in fatiguability in patients with chronic fatigue syndrome. *J Neurol Neurosurg Psychiatry* 1993;56:993-8.
27. Inbar O, Dlin R, Rootstein A, Whipp BJ. Physiological responses to incremental exercise in patients with chronic fatigue syndrome. *Med Sci Sports Exerc* 2001;33:1463-70.
28. Bazelmans E, Bleijenberg G, Van Der Meer JWM, Folgering H. Is physical deconditioning a perpetuating factor in chronic fatigue syndrome? A control study on maximal exercise performance and relations with fatigue, impairment and physical activity. *Psychol Med* 2001;31:107-14.
29. Sargent C, Scroop GC, Nemeth BN, Burnet RB, Buckley JD. Maximal oxygen uptake and lactate metabolism are normal in chronic fatigue syndrome. *Med Sci Sports Exerc* 2002;34:51-6.
30. De Lorenzo F, Xiao H, Mukherjee M et al. Chronic fatigue syndrome: physical and cardiovascular deconditioning. *Q J Med* 1998;91:475-81.
31. Department of Health *At least five a week: evidence on the impact of physical activity and its relationship to health, a report from the Chief Medical Officer*, Department of Health, London, 2004.
http://www.dh.gov.uk/PublicationsAndStatistics/Publications/PublicationsPolicyAndGuidance/PublicationsPolicyAndGuidanceArticle/fs/en?CONTENT_ID=4080994&chk=1Ft1Of

32. Action for M.E.. *Severely neglected ME in the UK*. London: Action for M.E., 2001.
<http://www.afme.org.uk/res/img/resources/Severely%20Neglected.pdf>
33. Cooper L. *Report on survey of members of local ME groups*. London: Action for ME and the ME association, 2000.
<http://www.afme.org.uk/res/img/resources/Group%20Survey%20Lesley%20Cooper.pdf>
34. Action for M.E. Membership Survey 'your experiences' questionnaire. Wells: Action for M.E., 2003.
35. Borg, GA. Perceived exertion as an indicator of somatic stress. *Scand J Rehabil Med* 1970;2:92-8.
36. [Paul LM](#), [Wood L](#), [Maclaren W](#). The effect of exercise on gait and balance in patients with chronic fatigue syndrome. *Gait & Posture* 2001;14:19-27.
37. American College of Sports Medicine, www.acsm.org