



Manual For Therapists

GRADED EXERCISE THERAPY FOR CFS/ME

**Bavinton J, Darbishire L, White PD
On behalf of the PACE trial management group**

FINAL TRIAL VERSION: Version 7 (MREC Version 2)

NB This manual was used in the PACE trial by healthcare professionals to support Graded Exercise Therapy (GET) and is available free of charge for down-loading at www.pacetrial.org, so long as no changes are made. Any use of this manual should acknowledge the PACE trial (www.pacetrial.org). This treatment should only be delivered by appropriately qualified healthcare professionals, who have received appropriate training and continued supervision in the use of GET. The treatment described was not designed to be a stand-alone self-help approach. No responsibility is accepted by the authors for the application of GET described in this manual outside of the PACE trial. The PACE trial team are unable to respond to queries or comments regarding the use of this manual or the treatment described.

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DOCUMENTS TO ACCOMPANY THIS MANUAL

- PACE protocol
- GET Participant's manual
- SSMC Manual
- APT Manuals
- CBT Manuals
- Patient Clinic Leaflet (PCL)
- Participant Information Sheet (PIS)

ABBREVIATIONS

APT	Adaptive Pacing Therapy
CBT	Cognitive behaviour therapy
CFS	Chronic Fatigue Syndrome
RN	Research Nurse
DNA	Did not attend
EBV	Epstein-Barr virus
HRM/s	Heart Rate Monitor/s
ME	Myalgic encephalomyelitis/encephalopathy
PACE	Pacing, graded Activity, Cognitive behaviour therapy: a randomised Evaluation
RPE	Rating of Perceived Exertion
UTA	Unable to attend

INTRODUCING THE GET MANUAL

- This manual contains the information necessary to allow you to confidently apply Graded Exercise Therapy (GET) for participants with Chronic Fatigue Syndrome (CFS) / Myalgic Encephalitis/ encephalopathy (ME). The treatment that you will give is based on the GET procedure as outlined in a number of randomised controlled trials of GET,^{1, 2,} as well as the guidance published since,³ and the experience of clinicians involved in GET for CFS/ME.
- Supervision sessions will allow you to gain further confidence in your treatment and to overcome any challenges.
- This manual also contains a copy of all of the records that both the therapist and the participant will need to complete during GET, as well as additional information that is therapeutically useful.
- A manual has also been written for the participants of this trial. It contains all of the information that you will be covering with them during their course of GET, as well as copies of all of the relevant worksheets.
- As you read this manual, you are encouraged to make notes; to aid your understanding and to consolidate important points.
- This manual is now the final version that will be used in the PACE trial. 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 West Midlands Multi-centre Research Ethics Committee.
- This manual and the accompanying participant's manual are copyrighted and must not be reproduced without the permission of all three Principal Investigators and the GET treatment leader.

INTRODUCING THE PACE TRIAL

The study is designed to compare the efficacy, adverse effects, and cost-effectiveness of standardised specialist medical care (SSMC) versus SSMD with three supplementary treatments for CFS/ME.

Two established treatments, Graded Exercise Therapy (GET) and Cognitive Behaviour Therapy (CBT) will be undertaken, alongside Adaptive Pacing Therapy (APT). APT is strongly advocated by patient organisations and some therapists, but has never been tested in a randomised trial.

The trial is also designed to better understand the process by which participants improve and the factors that predict a positive outcome. Supplementary research, running alongside the trial, may also result in a deepening of our knowledge of CFS/ME.

You will gain a better understanding of the process of the PACE trial by reading the trial protocol, supplied separately.

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, headache, 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 the family.

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. 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 stress and viral infection 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 compared in PACE Trial

Pacing, graded Activity and Cognitive behaviour therapy: a randomised Evaluation

Short title of trial:

Pacing, graded Activity, and Cognitive behaviour therapy; a randomised Evaluation

Long title of trial:

A randomised trial of adaptive pacing, cognitive behaviour therapy, and graded exercise, as supplements to standardised specialist medical care versus standardised specialist medical care alone for patients with the chronic fatigue syndrome / myalgic encephalomyelitis or encephalopathy

The aim of this trial is to compare four forms of management, all of which may be regarded as forms of pacing; standardised specialist medical care alone and standardised specialist medical care plus one of three forms of supplementary therapies that all involve activity management in patients with CFS/ME.

All three supplementary therapies and specialist medical care have been variously described. We have standardised each of them for the purpose of the trial by focussing on what are the theoretical basis and core features of each intervention. The aim is to make them both optimal treatments and clearly distinct

Standardised specialist medical care

Essence

The essence of SSMC is good quality medical care. SSMC does not involve advocacy of a particular form of management or therapy and advice given will be compatible with any therapy that the participant is receiving (APT, CBT, GET or SSMC alone). SSMC alone does not involve seeing the participant on a frequent basis to deliver a version of one of the therapies in the trial (APT, CBT and GET).

All participants will receive this treatment.

Aim

The aim of SSMC is to provide an optimal supportive medical relationship, to offer advice regarding symptom relieving medication, to support basic self-management and co-ordination of care.

Theoretical Model

The assumption of SSMC is agnostic to the nature of the cause and best treatment of CFS/ME. It assumes that participants are able to improve with a combination of validation of their illness experience, simple advice, prescribed medications and time (with or without an additional supplementary therapy).

Procedure

There is a manual to guide the doctors in the provision of SSMC. The participant is given a diagnosis, accurate information and advice (within the limits of our knowledge) symptomatic medication and a therapeutic relationship with an empathic understanding doctor. A positive diagnosis of CFS/ME is made and an explanation of the condition that is consistent with the Patient Clinic Leaflet. The participant is given general advice on managing activity, stress and coping with the illness that is consistent with the Patient Clinic Leaflet:

- *Avoid extremes of activity.* Many people with CFS/ME get into a pattern of being very active and then very inactive. It is better to give yourself a pattern of activity that you can keep going. This may be a lower level of activity than you are used to.
- *Set a daily level of activity.* It will help to set a simple level of activity that you do every day. For example, stretching exercises may help to minimise the weakening effects that creep up if you don't use your muscles for a time.
- *Make only gradual changes to your activity level.* If you feel you can increase your level of activity, and not everyone does, make changes carefully and gradually. A sudden increase in activity may make your symptoms worse.
- *Try to reduce stress in your life.* When we are ill, stresses such as excessive work

demands don't help us. If you can reduce these stresses, it will help you recover.

Should a participant ask for advice on how to manage their day to day activities in a particular way that is consistent with one of the supplementary therapies, and they are receiving SSMC alone, then the doctor can use the Patient Clinic Leaflet as a means to provide an overview of the general principles of such an approach, and can mention that there are self-help books and guides available. If they are already receiving a supplementary therapy arm of the trial, they should be advised to discuss this with their therapist, so long as they have not completed their therapy.

Medication may be prescribed for specific symptoms (such as simple analgesia, hypnotics and antidepressants) if agreed and indicated. Whilst SSMC may include referral to other doctors or healthcare professionals (such as a dietician for weight reduction or an orthopaedic surgeon for back pain) if there is a clear clinical need. It does not include the referral of the participant to other therapists for treatment of the CFS/ME itself, including those delivering therapies similar to those being evaluated in the trial (APT, CBT and GET).

Delivery

The administration of SSMC in this trial will be by a trained doctor who has had training in the SSMC manual and specific experience and training in treating patients with CFS/ME.

Simple, non-incremental pacing / Adaptive Pacing Therapy (APT)

This is a strategy widely used and described for patients with pain and advocated for patients with fatigue. It has however been subject to little systematic evaluation. Many patients report it to be helpful, however, and it has been recommended by a recent Government working party as one of the treatments of choice for CFS/ ME.

Essence

The essence of simple pacing is the monitoring and planning of activity with the aim of balancing rest and activity in order to avoid exacerbations of fatigue and other symptoms.

Aim

To stabilise the symptoms and activity with the anticipated benefit of: (a) maximising what can be achieved within a limited amount of energy; (b) preventing exacerbation of symptoms and disability; (c) enabling participants to plan activities; (d) providing the best environment for the body to naturally recover; (e) allowing gradual increases in activity as the participant feels able.

Theoretical Model

The assumptions of simple pacing are that it is beneficial to stabilise activity and to balance rest with activity. An analogy of balancing the energy “account” to avoid overdrawing it is often used. Symptoms are regarded as warning signs to be “listened to”. It is assumed that the symptoms reflect a pathological disturbance, which is not reversed by undertaking increases in activity. Rather the assumption is that ignoring fatigue and other symptoms risks activity induced exacerbations of the illness and consequently impeding natural recovery, whereas good pacing will maximize the chance of natural recovery and hence improve function in the long term. Activity is therefore planned so as to balance activity and rest. The aim is to do what can be done on the one hand, within the limits set by the illness, but to limit activity related exacerbations of symptoms on the other.

Procedure

The manual includes the following components: (a) The participant is helped to monitor their activity and their energy using simple self-ratings. (b) By learning about the relationship between what they do and how they feel, the participant is more able to plan their pattern of rest and activity; (c) The process is an iterative one whereby level of energy and other symptoms and activity are monitored; activity is planned and then modified in the light of its effect on symptoms. (d) The participant is encouraged to do as much as they are able within the limits imposed by their knowledge of what risks exacerbating symptoms.

Delivery

The administration of adaptive pacing therapy in this trial will be done by occupational therapists, who will have had training in the therapy manual and specific experience and training in applying the therapy to patients with CFS/ME.

Complex Incremental Pacing /Cognitive Behavioural Therapy (CBT)

This is the most complex treatment. It involves elements of simple pacing to stabilise activity, graded increases in activity, as with simple incremental pacing, and also directly addresses the participant's beliefs and fears about their symptoms and functioning. CBT differs from GET by directly targeting cognitions and related behaviours and it differs from APT by encouraging the participant to extend their physical functioning beyond their current ability.

Essence

The essence of CBT is helping the participant to change their interpretation of symptoms and associated fear, symptom focusing and avoidance. Participants are encouraged to see symptoms as temporary and reversible and not as signs of harm or evidence of fixed disease pathology. In this way it is anticipated that they will gain more control of their lives, as they, and not their symptoms, dictate what they do.

Aim

The aim of this treatment is to change the behavioural and cognitive factors, which are assumed to be partially responsible for perpetuating the participant's symptoms and disability, and to help the participants to develop strategies for dealing with other factors, physical, emotional, social or financial, that may also be impacting on their illness.

Theoretical Model

The model emphasises the importance of the participant's understanding of their illness and their interpretation of symptoms. For example, they may interpret symptoms as a warning sign to reduce activity. Fear of symptoms and consequent avoidance of activity associated with symptoms is central. This model also acknowledges that the participant's beliefs and behaviours are influenced by available information and attitudes of families and friends and that these may also need to be addressed. The model assumes that physiological (fatigue), cognitive (fear of engaging in activity) and behavioural responses (avoidance of activity), are linked. Therefore by modifying one response it is anticipated that changes occur in the other responses. For example, increasing activity (behaviour) may gradually reduce the fear (cognitions) that activity leads to worsening of symptoms.

Procedure

The manual has the following components: Initial stabilisation of activity and rest, establishing a regular sleep pattern and then graded increases or changes in activity to work towards planned goals. CBT also actively addresses the participant's understanding of their illness which may involve challenging unhelpful beliefs, e.g., about symptoms or activity that may be preventing recovery.

Delivery

The administration of CBT in this trial will be by a trained therapist, usually a mental health professional, who has had training in CBT and specific experience and training in applying CBT to patients with CFS/ME.

Simple Incremental Pacing /Graded Exercise Therapy/ (GET)

GET involves the basic element of simple pacing to stabilise the participant's physical activity, 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 differs from CBT by not directly targeting cognitive factors and from APT by encouraging the participant to extend their physical functioning beyond their current ability.

Essence

The essence of GET is to help the participant to gradually engage and participate in physical activity and aerobic exercise. It involves a careful assessment of the participant's current physical capacity, and mutual negotiation of meaningful functional, physical goals. A baseline of physical activity is agreed and commenced, at a manageable low level of intensity. The duration of the physical activity/exercise is then increased slowly and carefully, at the right time for each participant. Once managing 30 minutes of low intensity activity/exercise, e.g. walking, they will be assisted in gradually increasing the intensity of their activity/exercise, by keeping a careful record of their activity/exercise and monitoring their heart rate. It is their planned physical activity, and not their symptoms, that determine what they are asked to do, although activity is mutually reviewed on a regular basis and plans may be adjusted depending on general health and symptoms.

Aim

The aim of this treatment is to reverse the physical inactivity that helps to maintain CFS/ME, and to re-engage the participant in physical activity. The overall objective is to help a participant to become independent in the integration of physical activity and exercise into their every day lives.

Theoretical model

GET assumes that CFS/ME is perpetuated by deconditioning (lack of fitness), reduced physical strength and altered perception of effort consequent upon reduced physical activity. A normal process of adaptive change in the body is assumed to occur as a consequence of rest or a reduction in physical functioning, i.e. weakening of muscles, reduction in fitness, ('use it or lose it') and altered perception of effort. Activity can then produce symptoms as a result of these negative changes, as the body is attempting a physical activity beyond its current capacity. These changes are thought to be reversible, and thus improving fitness and physical functioning will alter perception of effort, enable the body to gain fitness and strength, leading to a reduction in symptoms and an increase in activity capacity ('use it and gain it'). Preliminary research suggests that reduced symptoms arise from simply doing a GET programme, rather than necessarily getting fitter, whereas improved function is related to getting fitter and stronger. Participants are encouraged to see symptoms as temporary and reversible, as a result of their current physical weakness, 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.

There may be other mechanisms involved in the success of GET apart from 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 by the treatment.

Procedure

The manual includes the following components: A baseline of physical activity is agreed and commenced, at a manageable and low level of intensity. The duration of the physical exercise is then increased slowly and carefully, at the right time for each participant. Once managing 30 minutes of low intensity exercise a day, e.g. walking, they will be assisted in increasing the intensity of their exercise, by keeping a careful record of their exercise and not exceeding their target heart rate. Planned physical activity and not symptoms are used to determine what the participant does. The level of activity is mutually reviewed on a regular basis and plans adjusted depending on the participant's current health and symptoms.

Delivery

The administration of GET in this trial will be by a trained exercise therapist, usually a physiotherapist, who has had training in the GET manual and specific experience and training in applying it to patients with CFS/ME.

SUMMARY of THERAPIES TABLE

	SIMPLE ADAPTIVE PACING (APT)	INCREMENTAL PACING (GET)	COMPLEX INCREMENTAL PACING (CBT)
Model	Pathology	Physiology + behaviour	Physiology + behaviour + cognition
Ingredients of therapy	Balance activity and symptoms	Planned increases in activity on basis of physiological tolerance	Planned increases in activity with challenging of understanding of symptoms
Stabilise activity	Y	Y	Y
Planned increases in activity	N	Y	Y
Direct challenge of cognitions	N	N	Y
Specific encouragement of aerobic exercise	N	Y	N

MODEL AND RATIONALE BEHIND GET

GET has been shown to improve muscle strength, cardiovascular endurance, and symptoms in a wide variety of illnesses,⁴ including fibromyalgia, a painful fatiguing illness related to CFS/ME.⁵ Three systematic reviews have concluded that GET is a promising treatment for outpatients with CFS/ME.⁶⁻⁸ Five randomised controlled trials (RCTs) have found improved fatigue and disability with differing graded exercise programmes compared to no treatment or control treatments.^{1,2,9-11} Three randomised controlled trials of graded exercise suggest that GET improves symptoms or disability more than relaxation or supportive therapy.^{1,10,11}

The rationale behind GET stems from both 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.^{1,2,11} Exercise also has a role to play in improving the sleep disturbance, mood, and cognitive problems found in people with CFS/ME.¹⁰

The most prominent symptom of CFS/ME is post-exertional fatigue, resulting in avoidance of exercise, exercise intolerance, and reduced aerobic capacity.¹²⁻¹⁴ One study has also shown significantly lower isometric quadriceps strength.¹⁴ Prolonged inactivity can perpetuate or worsen fatigue and its associated symptoms in both healthy volunteers¹³ and in people recovering from a viral illness.¹⁵

Physical deconditioning is characterised by reduced muscle strength and aerobic capacity.¹³ 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.^{14,16,17,18,19} A further small study found nearly two minutes difference in an exercise test compared to controls.²⁰ A seventh study also concluded that exercise tolerance was reduced, although time spent exercising was not given.²¹ 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^{14,16-20}. Only two studies found no significant differences from healthy controls,^{22,23} although both patients and controls were less fit than predicted.²² 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,²² suggesting that deconditioning was important even in these apparently negative studies.^{22,23}

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.^{11,14} The latter may be related to reduced left ventricular mass found in CFS/ME.²⁴ A graded exercise programme produced a 13 per cent increase in peak VO₂ and a 26 per cent increase in quadriceps muscle strength.^{1,14} Improved exercise capacity was also correlated with reduced heart-rate response to sub-maximal exercise.¹⁴

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 Chief Medical Officer (2004) is 30-45 minute sessions of moderate intensity physical activity at least five times a week.²⁵

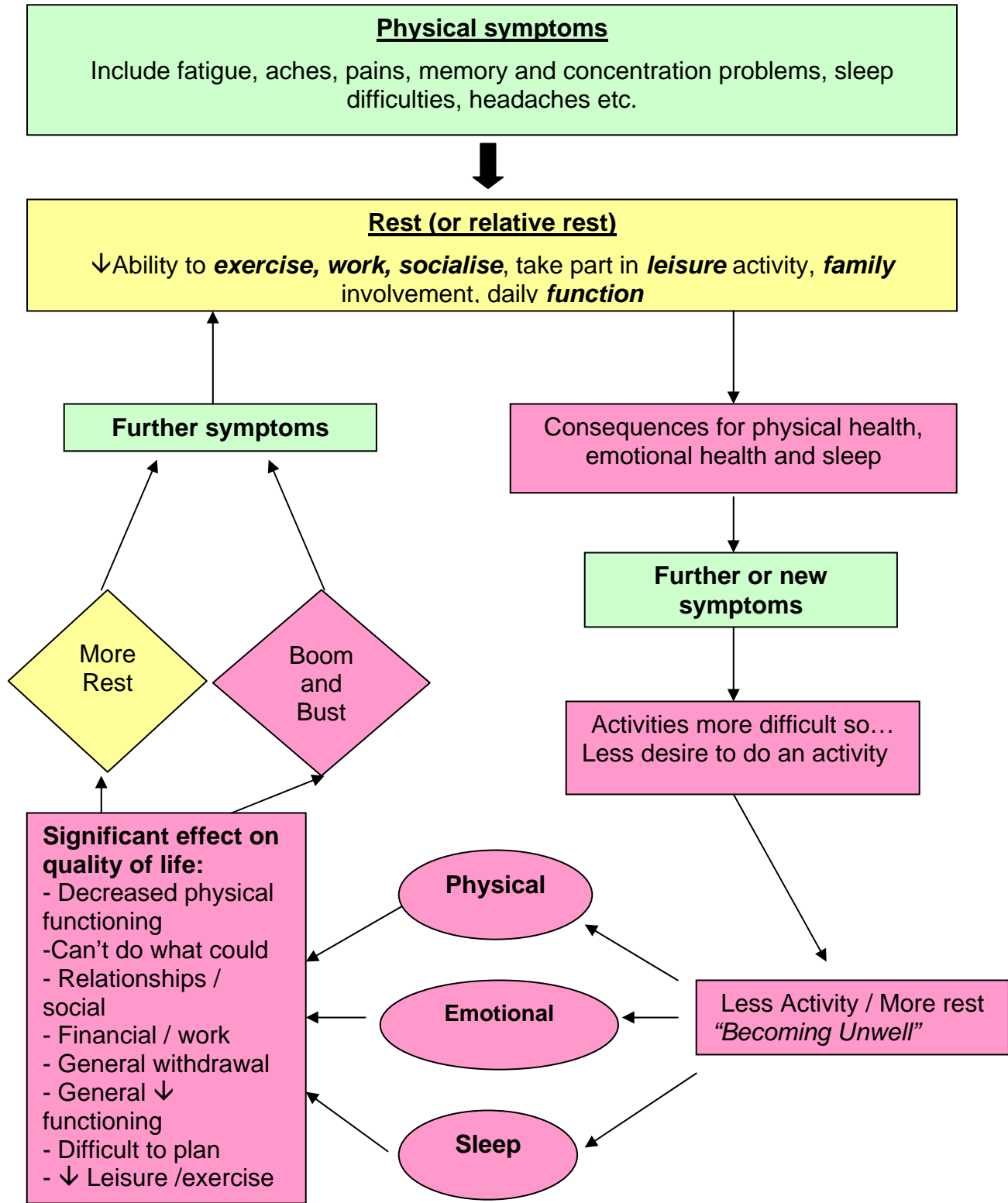
As well as direct impact upon CFS/ME, exercise has also shown to have a strong role in the prevention of various diseases such as coronary heart disease, stroke, cancer, and type II diabetes, as well as reducing the risk of premature death by 20-30%²⁵. Exercise is also well known to also have positive affects upon psychological wellbeing, sleep and the maintenance of a healthy musculoskeletal system.²⁵

ADVERSE EFFECTS OF GRADED EXERCISE THERAPY (GET)

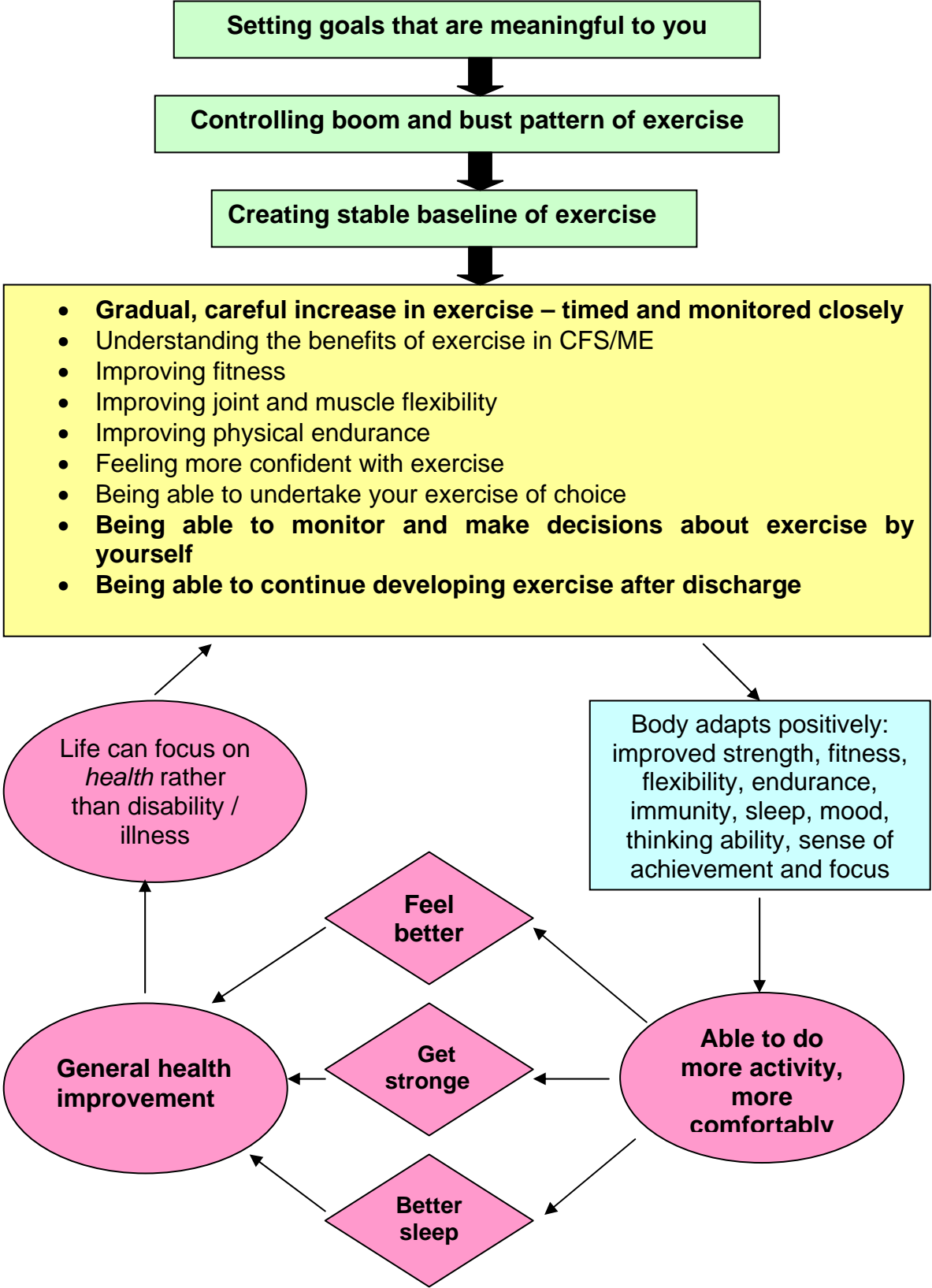
Surveys by patient groups of their members have suggested that GET may be harmful to some people with CFS/ME.²⁶⁻²⁸ It is now believed this finding was due to inappropriately planned or progressed exercise programmes, possibly undertaken independently or under supervision from a person without appropriate experience.²⁸

This manual will show you how you can develop an exercise programme for people with CFS/ME in a carefully controlled and supervised manner, thus reducing the chances of adverse effects.

Explaining CFS/ME: The deconditioning model



FEELING BETTER WITH EXERCISE: THE CYCLE OF RECONDITIONING



THERAPIST PREPARATION

This section aims to prepare you as much as possible for GET sessions with trial participants. It contains the following:

- An overview of treatment sessions,
- A summary of GET sessions,
- Engaging the participant in treatment,
- How to structure treatment sessions,
- Discussing what is required of the participant,
- Explaining the GET model to participants.

OUTLINE OF TREATMENT

Number of sessions

Participants will be offered up to fifteen sessions: sessions may be omitted if therapy is going well and the next session is agreed by both therapist and participant not to be necessary. If a participant is unable to attend a session in person for any reason, and the session cannot be re-arranged within five working days, this session may be held over the telephone.

It should be noted that it may not be possible for the participant to receive all 15 sessions during the 9 months, 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.

Frequency of sessions

- The first 4 sessions will usually occur weekly.
- Sessions 5 - 14 will usually occur fortnightly, the last session being in the 23rd week after randomisation.
- Session 15 will occur in the 39th week after randomisation.

Duration of sessions

The first session will be up to 90 minutes in duration, the remaining sessions will be up to 50 minutes.

Treatment phases

Treatment can be divided into three main phases, plus a booster session:

1. Phase 1: Assessment, engagement and treatment planning (sessions 1-3)
2. Phase 2: Active treatment (sessions 4-12)
3. Phase 3: Preparation for discharge (sessions 13-14)
4. Booster session (session 15)

Notice the colour coding of the phases: this will help you to navigate your way around this manual.

If possible, sessions should be arranged on the same day of the week and the same time of day. It will be useful for both of you to plan some sessions in advance.

Audiorecording of therapy sessions

This is a necessary part of the trial and participants have all consented to have this occur. You will need to confirm that consent has been given. You will need to set up the recording equipment before the session starts, remember to turn it on, reminding the participant that you are doing this, and turn it off at the end. 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.

SUMMARY OF GET SESSIONS

Session Number	Week No	Time (mins)	Summary	Homework
1	1	90	- Subjective assessment - Engagement in GET model - Education - Start to investigate exercise goals	Activity diary + exercise questionnaire + goal setting
2	2	50	- Goal setting - Education - Review physical activity diary - Negotiate baseline activity - Demonstrate stretches	Baseline physical activity + stretches
3	3	50	- Mutually agreed and prioritised goals - Exercise baseline negotiation	Start exercise baseline + activity baseline + stretches
4	4	50	GET - Active treatment - Demonstrate heart rate monitors - Sleep advice for exercise - HR/Borg comparisons - Reviewing exercise record - Planning next session of exercise - Written setback plan - Assessing motivation - Reviewing goals - Preventing/managing setbacks - Muscle relaxation - Maintaining changes - Adding strengthening exercises	Exercise
5	6	50		
6	8	50		
7	10	50		
8	12	50		
9	14	50		
10	16	50		
11	18	50		
12	20	50		
13	22	50	- HR/Borg comparisons	Exercise + variety + independence
14	24	50	- Tail off HRM - Encouraging variety / independence - Plan ongoing exercise	
15	36	50	Treatment booster session: - Maintenance of changes - Future goal setting and planning - Discharge	Ongoing exercise + goal setting

KEY:

- Phase 1: Assessment, engagement and treatment planning
- Phase 2: Active treatment
- Phase 3: Ending treatment and preparing for future
- Treatment booster session

ENGAGING PARTICIPANTS IN TREATMENT

Engaging participants in GET and encouraging them to undertake their exercise plans are cornerstones to your therapy. The following suggestions are likely to improve engagement and compliance with the programme:

- Ask what the participant would like to be called when you first meet.
- 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 during the assessment process (and thereafter).
- Tell the participant that you look forward to working with them over the coming months.
- Use language that participants will understand.
- Give a clear explanation of the GET model using visual aids; re-visit model frequently.
- Don't be tempted to start exercise too high or progress too quickly: stay on the side of caution: start low, progress steadily.
- ALWAYS ensure the process is collaborative and that every stage is jointly negotiated.
- Ensure goals set are agreed and achievable: explain 1-10 motivation technique.
- Always recognise achievements and congratulate participants on efforts to engage with GET.
- Give participants the opportunity to discuss any fears or worries in relation to GET.
- Work with the participant's partner, friends or family as appropriate and encourage participants to share their programme and progress with the people important to them.
- Photocopy all relevant sheets for the participant to keep: a record of previous weeks' exercise and goals can be very motivating.

KNOWLEDGE AND SKILLS REQUIRED

As well as a sound knowledge of the aetiology, epidemiology, consequences and available treatments of CFS/ME, a range of skills will also be necessary in order to help you to engage and work collaboratively.

Engagement

In order to engage the participant in therapy, it is important that the therapist conveys to the participant their belief in the reality of their symptoms, distress and disability. The therapist should be able to demonstrate a sound knowledge of CFS/ME 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 problems seriously. People with CFS/ME are often sensitive to the over-emphasis of psychological factors. It is therefore important right from the start that an integrative model that incorporates biological factors, e.g. initiating infection, is used. It is important that you show respect for their beliefs on the cause(s) of their illness and avoid challenging them as this is likely to provoke strong emotion and will reduce the likelihood of a good therapeutic relationship being established. In order to maintain participant’s engagement throughout treatment, it will be important that you continue to use an integrative model and avoid promoting a rigidly dichotomous view of physical and psychological illness.

Warmth and Empathy

Empathy is something that we will hopefully tend to do with all patients without thinking about it. However, with this client group it is particularly important. Often they have had their health problems for a long time. Many of them 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 at your first meeting. The assessment provides a wonderful opportunity for participants to tell their story. Often it is the first time that they will have been able to go into detail about their problems. Allowing participants to elaborate on their illness often gives them the feeling that their illness is being taken seriously, often for the first time. Acknowledging the difficulties they have encountered along the way in terms of their illness, whether related to its impact on their life or response from other health professionals, etc., is important.

Throughout your treatment sessions, it will be important that you continue to show warmth and empathise with your participant. There is no doubt that getting people to change previous routines can be difficult in a number of ways. The participant may be very fearful

of changing the way they do things, fearing worsening of the symptoms. They may find that their symptoms initially worsen when starting their GET programme. Acknowledging the challenges associated with the programme is important if you are to win their trust.

Sensitivity

Participants may not have had their illness taken seriously by previous professionals and may be concerned that you will be no different. They may think that you will be another “professional” who will tell them “to pull themselves together” etc. 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*. Although you cannot forever be thinking about whether or not you are going to offend them, it is worthwhile listening to and trying to use language that is not going to be alienating. In general, it is best to use the language that the participant does to describe their symptoms.

Collaboration

Collaboration is an essential skill in working with people with CFS/ME. Up to the point of meeting you, many participants will not have been included in the management of their illness. They may not have been asked their opinion about what is wrong with them and may feel rather helpless and out of control. Collaborating throughout treatment will help participants to feel more involved in their treatment and will help them to regain some sense of control.

You will be demonstrating a collaborative style at your first meeting when you individualise the GET model to their illness. By this we mean drawing a model together, examining factors they think have been responsible for triggering as well as maintaining the illness. Agreeing an agenda for each treatment session, asking for their input in making suggestions for their activity programme and evaluating previous sessions will help participants to feel valued and included in the treatment process.

Positive reinforcement

It is essential that you demonstrate positive reinforcement when you work with people with CFS/ME. Often, they will be very good at pointing out what they haven’t achieved. 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, however small they may seem, whether it is managing to walk for a minute longer than the previous session, read for 5 minutes longer or get up 5 minutes earlier.

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. One cautionary note, 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, rather than trying to answer it in a muddled way.

Encouraging optimism

Although it is important that you are realistic about the treatment targets that you set with participants, it is important that you encourage optimism about the progress that they may make with this approach. You can explain the previous positive research findings of GET and show in the way you discuss goals and use language that you believe they can get better.

HOW TO STRUCTURE TREATMENT SESSIONS

The following guidelines will help you to structure treatment:

- Read your previous session notes before the participant comes into the session.
- Use session checklists, and add any agenda items not covered in previous sessions.
- After greeting the participant, discuss the agenda with the participant, suggesting your own ideas and asking for theirs.
- Remind the participant of the length of the session (50 minutes).
- Work through the agenda.
- Remind the participant when you have 5-10 minutes left, if necessary.
- Write down on your therapist session record anything that you have not managed to discuss in the session, so that it can be prioritised for the next session.
- 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 (e.g. bringing forward the introduction of upper limb strengthening exercises in a mother with a young child).

Every session should contain the following:

- A review of homework and the exercise record.
- Exercise sessions achieved and not achieved should be reviewed; feedback and encouragement given.
- Motivational assessment.
- Review of GET model.
- The opportunity to discuss any difficulties with adherence to the programme.
- Adapting programme as necessary.
- Exercise for the following two weeks negotiated and planned.
- Thorough written records and reflective practice sheet completed.

EXPLAINING THE GET MODEL TO PARTICIPANTS

Participants can be shown the visual aids in their manual in order to explain the influence that physical strength and fitness can have on their CFS/ME. Explaining the benefits of exercise, especially in relation to their particular symptoms and experience, is an important starting point. You can then explain that 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.

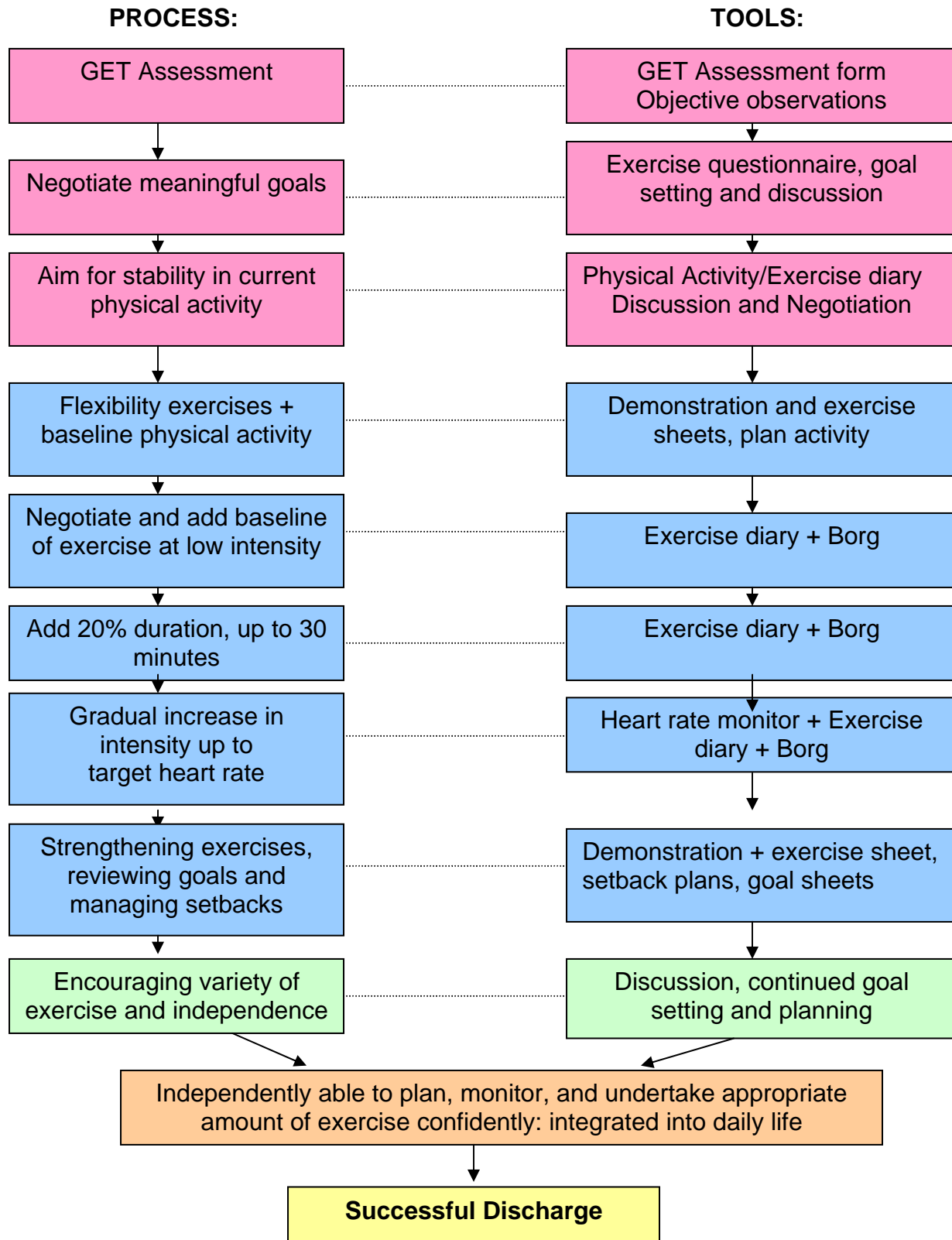
You can explain the ‘use it or lose it’ theory of physical strength, by using examples in their lives. Try to illustrate this using specific hobbies they have, or experiences they have been through: For example, if working with a musician, draw parallels with GET theory with learning to play to a high 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.

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.

You can share with them the research that shows reduced numbers of mitochondria in muscles of people with CFS/ME and how this is related to reduced energy capacity in their muscles as a consequence of too much inactivity.

THE GET PROCESS



PHASE 1: ENGAGEMENT, ASSESSMENT & TREATMENT PLANNING

Sessions 1-3: Initial assessment (90 minutes) and session 2 and 3 (50 mins)

Purpose of Phase 1:

1. To explain what is required of the participant
2. To undertake a subjective assessment, including function and exercise
3. To undertake a brief physical assessment
4. To engage the participant in GET model and explain reversibility
5. To discuss implications of activity cycling / 'boom/bust' patterns
6. To set goals
7. To agree a baseline of physical activity
8. Emphasise the importance of homework tasks
9. Teaching a stretching routine
10. Assessment of motivation to exercise

1. What is required of the participant

It is important right from the beginning that you discuss with the participant ways in which they can help themselves to get the most out of GET. You may try to cover the following points in the first couple of sessions.

- To complete all records, e.g. exercise records: explain that the purpose is to help them monitor their exercise, to see their achievements and to help you understand their levels and patterns of exercise.
- To do as much of the homework as possible – to give themselves the best chance of making progress.
- 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, or arrange to do the session over the telephone.
- To keep you informed of any changes in medication, other treatments etc.
- To participate in setting an agenda each session - so that all of their needs and requirements are met.
- To feel able to tell you if they are not clear on any aspect of the treatment programme.
- To attend appointments on time (wherever possible) as you may have an appointment straight afterwards and would therefore be unable to offer extra time.

- To bring in their participant manual and all of the worksheets completed to sessions to get the best out of their appointment.

2. *Subjective assessment, including function and exercise*

a) *Review the clinical letter*

Make note of relevant information on the GET assessment form, paying special attention to mention of physical capacity and exercise.

b) *Undertake a subjective assessment*

- Listen to the participant, recognise and believe his or her individual experience.
- Note that it may not be necessary to review all symptoms and history in detail, depending upon details received in initial referral. You will receive information regarding the participant from the doctor and Research Nurse (RN), including results from their step test²⁹ and estimated VO_{2max} ³⁰ and it will be frustrating for the participant to go through this again.
- Special attention should be made to previous levels and experience of exercise.
- Assess the participant's activities of daily living in order to estimate current level of function.

Please note that the participant will have been screened for suitability to participate in exercise: see protocol for exclusions. It will be the clinic doctor's responsibility to undertake this screening and to alert you to any precautions for exercise. Those who are contraindicated to exercise are excluded from the trial.

3. *Brief physical assessment*

You are not required to undertake a full objective assessment: objective measures and fitness assessments will already have been conducted prior to your assessment, and this data passed on to you. This information will include the results of the step test, walk test and Borg scale. You will not receive actigraphy data.

Participants will also already have undertaken a thorough physical assessment during the diagnosis phase: you will not be expected to assess symptoms individually or to make diagnoses.

The purpose of the physical assessment is therefore to:

- 1) To rule out gross loss of range of movement or strength;
- 2) To establish a physical baseline;
- 3) To assess specific sites of concern if they are relevant to the participant undertaking a GET programme, e.g. previously fractured ankle, knee instability. It will usually not therefore be appropriate to undertake a full neck or back

assessment, or to undertake neurological testing that may usually be an aspect of your assessment.

You may need to refer significant musculoskeletal problems to another physiotherapist separately, although you will need to take co-morbid conditions into account throughout your GET programme, e.g. osteoarthritis, previous injuries etc. This should only be done after discussion with the SSMC doctor, or centre leader if necessary, since referral for other treatments during the trial is discouraged.

The following range of movement and strength tests will need to be performed around session 2. They should be done in the order stated so as to avoid unnecessary physical exertion.

Range of movement tests

Order	Starting position of participant	Instructions	Purpose
1	Sat in chair	'Look over your right shoulder. Repeat to the other side'	To test range of cervical spine rotation.
2	Sat in chair	'Reach as far up your back as you can with both hands'	To test ROM at the shoulder joint
3	Sat in chair	'Reach up above your head'	To test ROM at the shoulder joint
4	Sat in chair, arms across chest	'Turn as far as you can to your left. Then repeat to the right'	To test trunk rotation
5	Sat in chair	'Rise up on toes. Then rise up on heels'	To test ROM at the ankle joint
7	Sat in chair	'Lift your right leg up to hug your knee. Repeat with your left leg'	To test ROM at the hip and knee joints
9	In standing, hands on hips	'Lean your trunk backwards' Replace with extension in prone if poor balance	To test range of lumbar spine extension
10	In standing, holding on to back of chair	'Keeping your trunk upright, extend your right leg behind you as far as you can. Repeat with your left leg'	To test range of hip extension

Functional muscle strength tests

Order	Starting position of participant	Instructions	Purpose
8	Sat in chair	'Stand up'	To test strength of quads, gluts & hamstrings in a functional way
6	Sat in chair	'Straighten your left knee. Repeat with your right knee.'	To test strength of quads
11	In standing, holding on to back of chair	'Rise up on toes'	To test strength of gastrocnemius & soleus
12	In standing	'Pretend you are going to sit down on a low chair by bending at your hip'	To test strength of lower limb muscles in a functional way

Objective test of physical function

A walk test and step test will be performed by the RN. However, it may also be useful for you to conduct a brief physical measure of physical capacity, as you would normally do in physiotherapy practice. The following tests are recommended, and you should choose one that best suits your participant:

- 1) Sit-stand test (count number in one minute + Borg rating).
- 2) Timed Up and Go (Timed: from chair – stand – walk 3 meters – turn – walk back and sit down + Borg rating).
- 3) 2 minute walk test (distance covered + Borg).

The test you choose can be repeated at sessions 7 and 13, or whenever therapeutically useful.

4. GET model and reversibility

Explaining the deconditioning and exercise intolerance model to participants has been explained in detail previously. The main purpose of engaging the participant in the model is to allow the participant to understand the multifactorial influences exercise can have on their health and CFS/ME 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.

5. Activity cycling / 'boom/bust' patterns

Over Activity and Under Activity Cycle

Establish whether the participant identifies with the over activity/under activity ('boom or bust') cycle. These terms describe physical activity levels fluctuating over time. It is common for people with CFS/ME 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. It is therefore important to establish with the participant a baseline for every day physical exercise and activity before starting the GET. Many people with CFS/ME find that when they exercise more than their body is comfortable with at the time, 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 minutes, rather than 30 minutes twice a week that leads to feeling unwell the next day. Diagrams can be helpful to illustrate this point.

The purpose of the *Physical activity and exercise diary*, to be used in the first two weeks, will be to establish whether the participant is currently showing signs of a boom/bust pattern, and to help correct this. This is important in order to provide a stable baseline of physical activity and exercise to work from.

6. Set goals

Setting meaningful objectives is an essential component of GET, in order to help motivate the participant and help them appreciate the functional context of exercise in their own lives. Not only do they provide a clear, functional focus for treatment, but also lead to a measurable outcome. Specific, behavioural goals that focus upon regular, realistic, functional and enjoyable exercise should be encouraged.

Participant worksheets will help with setting goals: 'Guidelines for choosing exercise', 'Setting goals' and the 'Exercise questionnaire'. These should be given to read and complete as a homework task. The exercise questionnaire can then be discussed at the next appointment, and goals can be negotiated from this discussion. The 'Mutually Negotiated Goals' sheet should then be filled in and copied to ensure both participant and therapist has a copy.

A goal for GET should be a clearly observable, behavioural change, not a reduction or absence of a symptoms e.g. "Walking every day for 20 minutes", not "no longer feeling fatigued."

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 a therapist chooses to give a goal a timeframe, they should do so carefully, being careful to 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 in three months time. This goal can then be broken down further into weekly or fortnightly 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. The 'Setting Goals: Breaking goals down into manageable sections' worksheet will help to set short term goals.

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 on the *Mutually Agreed Goals* sheet. 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, mid-therapy provides a formal opportunity to reconsider goals.

7. *Baseline of physical activity or exercise*

The purpose of setting a baseline for every day activity is to establish a consistent and sustainable level of physical activity. A baseline of everyday physical activity is the amount of physical activity that is manageable without the participant's symptoms being made significantly worse. It is useful to review the first week's physical activity diary to establish and negotiate this baseline.

8. *Homework tasks*

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

Homework will include:

- Reading participant information sheets: Guidelines for choosing exercise, Benefits of exercise, and Goal Setting, Explaining CFS/ME; The deconditioning model and Feeling better with Exercise.
- Thinking about the GET model and observing the 'use it or lose it' principle in other areas of their lives.
- Completing the activity diary for one week.
- Completing the Exercise Questionnaire.

9. *Stretching routine*

You should start by teaching participants stretching exercises; you will give participants appropriate written instructions and diagrams. Stretching exercises should be demonstrated and performed accurately by the participant before undertaking these independently at home. Initially participants may not be able to sustain a stretch for more than a few seconds, which is the level they should commence at. The duration of the stretch can then be gradually increased to around 10 seconds.

Type of stretch

As exaggerated guarding and increased myotatic stretch reflexes have been identified in those with painful muscles,^{31,32} static/sustained stretching will be used.

Adapting stretches

The exercises in the participant handout outline a range of stretches specifically compiled for CFS/ME (see p 137). However, a therapist should use their clinical reasoning to eliminate certain stretches or replace these with stretches more appropriate to the participant (e.g. those with a musculoskeletal disorder). Changes to this standardised sheet must be justified and recorded.

Determining the balance of stretches and aerobic exercise

Use clinical judgment to ascertain the appropriate stage for adding cardiovascular exercise: for most participants, the first homework session should be stretches only, alongside the negotiated level of physical activity. By week 4, most participants will be able to commence aerobic exercise.

However, if the participant is physically very disabled, fearful of exercise, or has an extremely low exercise tolerance, it may be more appropriate to begin with two weeks of stretching alone with no prescribed aerobic activity. 'Stretch days' can then be alternated with 'aerobic days' to start with. This will inevitably lead to fewer aerobic sessions than is desirable, and so should be discouraged as soon as possible in order to increase to five or six aerobic sessions per week.

It is important to calculate exercise capacity conservatively to start with, as well as to ensure that the participant agrees readily to try that which is proposed. At this stage in the programme the participant will be building up their confidence in both you and the exercise, and early difficulties may affect the future of their programme.

10. Assessing motivation to exercise

It can help participants and you to assess the likelihood that the participant will undertake the exercise prescription decided upon. This is done by asking the participant to use a simple scale from 1 to 10. 1 represents "very unlikely" to undertake the prescribed exercise, up to 10, which represents "very likely" to undertake the exercise in the next week/fortnight. If the participant scores themselves at 6 or under, you may need to discuss adjusting the exercise prescription so that they can score 7 or more, which we know from previous research with this scale is consistent with their being more likely than not to succeed in doing the exercise.

PHASE 2: ACTIVE TREATMENT

Purpose of Phase 2:

After setting meaningful goals, establishing a baseline of physical activity and starting stretches, the exercise programme process for GET follows 5 main stages:

1. Negotiating a sustainable baseline of exercise
2. Increasing exercise duration at low intensity
3. Increasing the intensity of the exercise to target HR
4. Developing strengthening routine
5. Encouraging variety, flexibility and community/social integration of exercise
6. Successful GET will also include:
 - Encouraging an appropriate warm-up and cool-down
 - Planning and managing setbacks
 - Encouraging a good night's sleep

Graded exercise prescription

Graded exercise treatment follows the basic principles of exercise prescription for healthy individuals, but adapted to the participant's current capacity.³³ The exercise therapy should have two components: stretching to increase soft tissue length and joint mobility, and aerobic conditioning to increase fitness. Strengthening exercises should be introduced very gradually, if the aerobic exercise programme is going well.

Aerobic Exercise

Concepts of aerobic exercise planning and progression:

Whilst reading the following GET process, notice the following components of aerobic exercise prescription:

1. Frequency: Starts and remains at 5-6 days out of 7
2. Duration: Starts at a comfortable baseline, then increases carefully to 30 mins per day
3. Intensity: Starts low, then progresses carefully to target heart rate

The GET programme

1. Negotiating a sustainable baseline of aerobic exercise

The importance of this stage cannot be overestimated. Finding a level of aerobic exercise the participant can do comfortably, even when they are not feeling at their best (including their 'bad days'), is the first point of negotiation and planning. 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/ME symptoms. It should be negotiated carefully: the participant should be asked what level they feel they could achieve regularly. The baseline should be renegotiated if, after subjective assessment or review of the *Physical activity/exercise diary*, the therapist feels this level is inappropriate.

You should explain that participants should expect a mild increase in fatigue or muscle stiffness/soreness as a normal response to exercise³⁴, 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 make dinner etc). The information sheet *Normal response to exercise* can be shown and explained.

You should encourage the participant to undertake this baseline for 5 or 6 days out of 7, 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 very carefully using a digital watch or stopwatch ("there is a significant difference between 5 and 7 minutes"), and to monitor their Borg rating and average heart rate (HR) using their exercise record.

At this stage, they can be given their target heart rate, not initially as a rate to achieve, but as a rate not to exceed. It is unlikely that this heart rate will be reached in the initial stages of the programme, and this should not be encouraged to start with. **Emphasise that the first part of the programme is about increasing duration only, and the heart rate is not a target at this stage.** However, if this heart rate is exceeded, the participant should be encouraged to slow down or stop temporarily and then resume, keeping within their target zone.

It will be worth considering whether variety is necessary at this stage to account for poor weather affecting outdoor exercise or whether other factors are likely to make it difficult for a participant to undertake the planned levels of exercise, e.g. childcare responsibilities. For example, if a participant will not enjoy going outside in wet weather,

even with protective clothing/umbrella etc, then this will affect regularity and mixing with indoor exercise will need to be considered.

2. Increasing exercise duration at low intensity

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

Once a baseline can be achieved comfortably, often leading to a reduction in Borg scale ratings, the participant should be encouraged to increase the duration of the exercise. The incremental increases should not be any more than around 20%. E.g. A 5-minute walk becomes 6 minutes; a 2-minute bounce on a rebounder might become at most 2.5 mins.

The **duration** of exercise should then be slowly increased, without an increase in HR / intensity, to around 30 minutes. Once the participant is able to achieve 30 minutes of exercise, 5 or 6 days out of 7, and is managing this without exacerbating symptoms, only then should the intensity be increased.

Sometimes it is helpful to break up the exercise into two or three separate sessions in the day. This can be useful in someone who finds it difficult to find 30 minutes for exercise, or someone who finds it difficult to exercise for 30 minutes non-stop.

3. Increasing the intensity of the exercise to target HR

Once the participant is able to do 30 minutes of low intensity exercise without exacerbating their symptoms, you can now consider increasing the intensity of the exercise in order to work towards the target heart rate. Firstly, the HR of their current 30 mins of exercise is recorded. The HR can then increase by 10-20% in incremental stages in order to achieve their ultimate target HR, stabilising in between stages when appropriate.

This might mean encouraging a participant to speed up the pace of their walk, increase the resistance on exercise machines or do an activity faster, using their heart rate monitor (HRM) as a guide. 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.

4. Developing a strengthening programme

If the participant is progressing well, or is particularly motivated by strengthening exercises, these can be added to the routine. This is usually considered at around session 10, although may vary significantly between participants. This can take the form of local muscle conditioning exercises using a participant's own body weight. Hand-held weights can be added if appropriate (e.g. using tins or bottles). Some participants may prefer to choose their own strengthening exercises, perhaps those they have done before in a gym or at an exercise class.

It should be noted that some participants may not be motivated by a specific strengthening programme, and can be encouraged instead to participate in functional strengthening activities, e.g. cleaning high cupboards or painting to improve upper limb strength, or participating in more physically demanding daily tasks such as cleaning floors, gardening, or hanging out washing.

It may be also be clinically unnecessary for the participant to undertake strengthening at all, especially if they are progressing well without any clinical need identified.

5. Encouraging variety, flexibility and community/social integration

The final stage of GET is to encourage the participant to find sustainable methods of maintaining exercise, and to solve any 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. joining local gyms, exercise classes, walking with friends, or participating in team sports. 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 consider how the participant will exercise during the winter, when they may be less likely to walk outside, or how they might tackle a significant increase in gradient (e.g. a day trip to the town of Bristol, notorious for its hills).

6. Encouraging an appropriate warm-up and cool-down

Encourage a warm - up before aerobic activity: this may be a combination of gentle stretches and/or the aerobic activity at a lower intensity. The participant should then maintain the exercise intensity as planned, and then gradually decrease the intensity of the workout. They will then be encouraged to stretch after the exercise during a cool-down period. The exact duration of the warm-up, aerobic exercise and cool-down

periods will need to be considered individually and altered according to current capacities.

Preventing and managing setbacks

CFS/ME setbacks usually involve an exacerbation of their 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 which may have attributed towards their setback. Sometimes setbacks also appear to be caused by sleep disturbance, a new active infection or emotional distress. It is normal, and likely, that participants will suffer setbacks throughout the GET programme.

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

A central concept of GET 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 despite 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 difficult symptoms, 'hurt does not equal harm' (as you would do with somebody with chronic low back pain).

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 maintain as much as they are able to, and work towards building up the activity/exercise as soon as possible. Additional support may be required at this time.

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. It is therefore useful to discuss and review a written setback plan, outlining useful information to follow in the event of a setback.

Encouraging a good night's sleep

A good night's sleep is especially important for people exercising with CFS/ME. Severe insomnia has been found anecdotally to be one of the barriers to successful GET¹ whilst sleep deprivation has been found to increase the perceived effort felt during exercise³⁵.

All cells divide and grow most during sleep, mediated by the release of growth hormone, among other hormones, which only occurs during sleep.³⁶ We also know that poor sleep is associated with fibromyalgia (chronic widespread pain) and the general inability to repair tissues adequately. One study showed that depriving men of slow wave sleep, but not REM sleep, led to muscle pain and tenderness, especially in untrained men.³⁷ We also know that physically unfit people sleep less well than fit people,³⁸ and that exercise improves sleep.^{39,40}

Purpose of sleep advice in GET:

1. To allow the participant to feel subjectively refreshed and therefore more able to conduct GET.
2. To allow physiological processes of growth and repair to occur, and hence allow GET to continue comfortably.
3. To prevent the possibility when working with those with insomnia, of developing delayed onset muscle soreness.

Sleep advice for GET

The following should be encouraged:

A wind-down routine and hot bath

A general slowing down of physical activities towards the end of the day aims to prepare the body for sleep. The last hour of the day can be dedicated to a warm bath (20 minutes) followed by a gentle muscle stretching routine. The bath is likely to relax muscles and increase blood flow: this may reduce lactic acid symptoms and help prepare muscles for a gentle stretching routine at night.

You can teach a muscle relaxation technique (see p 149) to use whilst in bed to further relax muscles and aid sleep.

Encouraging sleep normalisation/regulation

If a participant has an abnormal sleep pattern, then it is useful to encourage a gradual normalisation of the pattern. The main abnormalities are as described in the following paragraphs.

a) Daytime sleeping/napping

You may find that participants sleep during the morning or day, or sometimes after work or early evening. Sleeping during the day has been found to affect the quality of the sleep at night: poor quality night-time sleep has been linked to muscle pain and fibromyalgia symptoms; likely to impact upon the participant's ability to undertake exercise. It is important to gradually discourage daytime sleeping. A 4-hour sleep in the afternoon could be gradually reduced by 30 minutes each week, or as appropriate. For example, you might ask the participant to try relaxing in an upright chair instead of sleeping.

b) Sleeping for too long

If a participant has longer sleep hours than normal (hypersomnia) then it is useful to gradually reduce these hours. Encouraging a morning routine to provide multi-sensory waking stimuli can be helpful, i.e. Use of musical or TV alarm clock, opening curtains, gentle stretches in bed etc.

NB: Amongst other disorders, hypersomnia can sometimes be a sign of depression: although other disorders will have been ruled out by medical assessment, if you suspect that a participant's mood is low or the hypersomnia is a new problem, report this to their clinic doctor.

c) Not sleeping enough

A participant who is not sleeping enough may have difficulties in the first part of sleep (initial insomnia) and/or in the middle of the night (middle insomnia). You can encourage muscle relaxation techniques for both types of insomnia, and tell the participant that exercise has been shown to increase the depth of sleep so is likely to also be helping their sleep problem.

NB: As with hypersomnia, insomnia can often signify an underlying problem, often related to anxiety or depression. Again, if you suspect this is a new or developing problem, report this to the clinic doctor.

PHASE 3: ENDING OF TREATMENT, PREPARING AND PLANNING FOR FUTURE SELF-MANAGEMENT

Purpose of Phase 3:

1. To aim towards self management and independence with exercise programme
2. To re-examine the Borg-HR relationship
3. To examine how to maintain exercise after discharge

1. Self-management and independence with exercise programme

The therapy should be reviewed, and progress highlighted. Encouragement and instructions to continue the exercise programme should be given, reviewing the principles of graded exercise therapy. Participants should be taught how to continue GET without supervision, with a view to joining local community exercise groups or leisure centres, depending on their interests.

At this stage in the programme, it is important that the participant can come to their own decisions regarding their exercise type, intensity, frequency and duration. You can discuss with them theoretical questions to demonstrate their understanding and ability to be adaptable. E.g. If you decided to take up badminton, what might be the steps involved?

People with CFS/ME often report seasonal changes: some appear to prefer warmer weather and struggle to go out in the winter, while others find their symptoms are worse in summer. It will be useful to discuss seasonal differences with the participant so that they can plan a strategy that will work for them at all times of year.

The participant should be encouraged to try different types of exercise, and to have confidence in planning new activities. For example, it will be useful to be able to work out how to manage a situation that may arise in future, e.g. playing Frisbee in the park with friends or playing football with a nephew.

2. Re-examining HR and Borg relationship

The relationship between HR and Borg should now be examined: if the participant has a consistent perception of effort for their target HR (hopefully around Borg 11-13) they can be encouraged to reduce reliance on the Heart Rate Monitor (HRM). If this has occurred, the participants can be shown that their perception of effort for work done has been reduced, and this should be encouraged as a positive sign that they are feeling

more comfortable with exercise. They should now be encouraged to rely on their subjective Borg perception as an indicator of exercise intensity, rather than the HRM.

If their Borg and HR seem inconsistent, or if their Borg scores are particularly high, then the participant can be encouraged to continue using the HRM for a little longer, to provide an objective measure for exercise intensity. Ultimately, it is more useful for the participant to gradually reduce the use of their reliance upon the HRM, so that they do not need to apply the device whenever they wish to exercise.

3. Maintaining exercise

It should be explained that in order for the body to continue strengthening, and for changes to be maintained, that 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}

BOOSTER SESSION: NUMBER 15 AT 36 WEEKS

Purpose of booster session:

1. To review the exercise programme and congratulate participant on achievements
2. To encourage the participant to continue exercise after discharge
3. To review setback management
4. To clarify any areas of concern and to answer last questions

This session should be used to review GET and health status in the previous 13 weeks, paying particular attention to the frequency, duration and content of exercise sessions. You will also have the results of the independent assessment of walking capacity and step test data from the Research Nurse's assessment at 24 weeks. This can be used to explore physical changes and progress.

A review of any setbacks and how they were managed is important. The ways in which a participant was able to maintain their programme or be creative about new ideas should be congratulated, and any difficulties and their solutions discussed.

The therapist can use this session to explore ways in which the participant has been adaptable, flexible, and has integrated exercise into their lives. The participant's future objectives for exercise can be examined, and any barriers to achieving these explored. The importance of maintaining exercise can be further emphasised, and the therapist can use this opportunity to give the participant another goal sheet that will help focus them on the plans after discharge.

EXERCISING SAFELY

You should be aware of the following precautions:

If you discuss the use of participant-owned home exercise equipment, you must explain 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 in doubt, watch the DVD/video yourself and make decisions together.

Rowing machines should only be recommended with caution, and should not be recommended for those with back pain or significant generalized weakness. Explanation regarding safe usage, and preferably demonstration, should be offered.

If you discourage from using a certain piece of equipment or an exercise, you will need to document this.

Ask the participant to consider safety at all times when considering heavy, movable exercise equipment: explain manual handling if necessary.

Discussing any other safety considerations with regards to:

7. Asthma and inhalers,
7. Appropriate footwear,
7. Avoiding outdoor activity in icy conditions,
7. Appropriate hydration, especially in hot weather,
7. Other appropriate precautions relating to specific medical conditions.

Always consider safety first.

CALCULATING TARGET HEART RATE

Exercise target heart rates are calculated for each individual. Two different methods for the calculation of heart rate intensity are available. See table to follow.

The main difference between method 1 and method 2 lies in the resting heart rate (RHR). RHR is measured and accounted for in method 2, and hence may be more appropriate for those with a significantly high RHR, while method 1 does not take RHR into account and is simpler to use.

It is therefore advisable to use method 1 to start with. However, if the participant is found to be reaching this lower HR very quickly, and without much effort or challenge, it will be useful to take their resting HR and ascertain whether method 2 may be more appropriate.

Method 1: Using a calculation known to therapists/gymnasiums, and aiming for a normal heart rate target

The participant's target HR zone is calculated from a universally accepted and understood method; a method used for normal, healthy people: $220 - \text{age} \times 0.6-0.9$.⁴⁶ Note that the intensity of exercise can go up to 0.9 (90%) of Maximum HR. However, as a lower intensity workout for a longer duration is both more comfortable and is recommended for improving overall fitness,⁴⁶ 60-75% of Max HR can be used as a guide. 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.

Method 2: As used in previous CFS/ME research

You will estimate the maximum heart rate response to exercise from the formula $210 - (\text{age} \times 0.65)$.⁴⁵ By measuring the heart rate after 10 minutes of sitting; the heart rate reserve can be calculated (maximum estimated heart rate with exercise minus resting heart rate).

Most participants can begin at an intensity of 40 per cent of their maximum aerobic capacity, which approximately equates to 50 per cent of their estimated individual heart rate reserve added to their resting heart rate. E.g. if the maximum HR = 180 beats per minute (bpm) and the resting HR is 80 bpm, the HR reserve is 100 bpm and the exercise target HR is $80 + (0.5 \times 100) = 130$ bpm. The method is shown clearly with examples in the following table.

Max HRR = Max HR response to exercise = $210 - (\text{age} \times 0.65)$
40% of max aerobic capacity = 50% heart rate reserve (HRR) + rest HR
HRR = max estimated HR – (minus) resting HR
Rest HR = HR after 10 minutes sitting and relaxing (to be measured)

Measuring resting HR

Resting heart rate is ideally performed with the participant lying for 10 minutes: however, the constraints upon the therapy session may necessitate this being measured after sitting for 10 minutes.

A note on using HR calculations

At first, the participant is asked to monitor their heart rate during their periods of baseline exercise. At this stage 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 the therapist exercise baseline information. Most people will not be near this target intensity at the beginning of the programme: it could even take a number of months to achieve this.

Once they have achieved 30 minutes of exercise, they can record a week of their HR, which is then compared to their target. If the HR was higher than their target, and the participant is significantly symptomatic with exercise, the participant is encouraged to slow the pace/reduce the intensity of the exercise. However, if a participant is managing well at a higher intensity without significant symptoms, despite perhaps having achieved this more suddenly than expected, then it may not be appropriate to reduce the HR. In this situation, it may be more useful to stabilise at this stage without adding any further intensity to ensure that the body has adapted to this level. Sometimes stabilising can take time, usually around 2-4 weeks. Exercising beyond 80-85% of their maximum HR is not generally recommended, even for those without a medical condition.

If the HR is considerably less, the participant is encouraged to aim for a slightly higher intensity (around 10-20% increments) then accustomise to this, and then raise the HR further until the target is reached.

Avoiding stimulants

Stimulants will have a direct physiological relationship with heart rate (as well as impacting adversely upon sleep). Therefore, participants should be advised to avoid all stimulants such as caffeine, chocolate. Although nicotine is a stimulant in high doses, you should not encourage participants to give up smoking at the same time as doing GET.

A TABLE TO COMPARE THE TWO METHODS OF HR CALCULATION

	Method 1	Method 2
Rationale	Method known to gyms etc.	Previously used in CFS/ME research
Information required	Age	Age Resting HR
Method	<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. Take resting heart rate 2. Calculate the Max HR response: <ol style="list-style-type: none"> a) multiply age by 0.65 b) subtract this figure (a) from 210 3. Calculate heart rate response (HRR): Take the figure you obtained in 2b), and then minus the resting HR (RHR) 4. Multiply this number by 0.5 5. Work out target HR: Add resting HR to the figure obtained in 4. 6. Target zone = 10 bpm either side
<p>Example 1</p> <p>Age: 27</p> <p>Rest HR: 86</p>	<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. <ol style="list-style-type: none"> a) $27 \times 0.65 = 17.55$ b) $210 - 17.55 = 192.45$ 2. $192.45 - 86 = 106.45$ 3. $106.45 \times 0.5 = 53.225$ 4. $86 + 53.225 = 139.225$ (approx 140) 5. Target exercise zone = 130-150
<p>Example 2</p> <p>Age: 51</p> <p>Rest HR: 74</p>	<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 	<ol style="list-style-type: none"> 1. <ol style="list-style-type: none"> a) $51 \times 0.65 = 33.15$ b) $210 - 33.15 = 176.85$ 2. $176.85 - 74 = 102.85$ 3. $102 \times 0.5 = 51.425$ 4. $51.425 + 74 = 125.425$ 5. Target exercise zone: 115 - 135

USING HEART RATE MONITORS (HRMS)

Each participant will be lent an ambulatory heart rate monitor so that they can measure the intensity of their exercise. During the first stage of the programme this can be used to ensure that they do not exceed their target heart rate during exercise, or to help objectify their progress if they have an abnormal Borg/HR relationship. Some participants may not need to use the HRM early in the programme, especially if their Borg/HR relationship is normal.

Once the duration of exercise is 30 minutes, the purpose of the HRM is to allow careful monitoring of an increase in intensity, to work up to their target HR zone. You may choose to monitor the HR at the very first stage of the programme, but then discontinue the heart rate facility while with programme duration is increased at a low intensity. Some participants, however, will find the HRM motivational whilst others may find it a hindrance and may affect adherence: you will need to use your clinical judgment as appropriate.

You will need to set the participants target heart rate zone for them. At first, they may not even have a zone to aim for, but simply be measuring their baseline.

You can explain the different HRM facilities, e.g. stopwatch, split timing etc, and encourage them to use these if they are helpful or motivational. However, some people will not feel comfortable with the technology and may feel overwhelmed by the different functions: if this is the case, then you will need to be more cautious and encourage basic monitoring only.

Considerations for using HRMs:

- It is important to moisten the electrodes on the skin side of the monitor and to ensure that it is tightly but comfortably attached to ensure correct function.
- It will be useful to teach a participant to take their own pulse rate so that they can estimate a heart rate should the HRM malfunction. This should be demonstrated and practised.
- The participant should put on the HRM immediately before the aerobic component of their programme, in order to ensure that the HR recorded is an accurate measure of the exercise, and not the stretching period beforehand.
- Participants should be told 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.

USING PEDOMETERS

Pedometers may be used where appropriate, as per the manufacturer's instructions. Walking is highly functional, and pedometry will allow you to monitor 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 you may choose to use this as an adjunct to GET.

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.

Pedometry could be especially useful for those who are less mobile, or for those who struggle to utilise the stopwatch or HRM during exercise.

However, as with HRMs, it is useful to discourage excessive attention to the figures displayed, and to encourage its use only for a set daily purpose.

ACTIVITY DIARY, EXERCISE RECORD AND BORG SCALE

Using an Exercise diary

There are three types of activity and exercise records, serving different purposes. The *Physical activity/exercise diary*, to be completed for the first two weeks, 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.

The other two, *Exercise Record 1* and *Exercise Record 2*, serve to record exercise only, and are the main records after session 3. These records will note the type and duration of exercise, Borg scale, and average HR achieved. This will also be used to plan the participant's exercise, as well as functioning as a motivational tool for the participant. There are minor differences between the two exercise records, and which one you use will be negotiated according to the preference of the participant.

Using the Borg Scale

It is normal for CFS/ME patients to have higher Rating of Perceived Exertion (RPE) or Borg Scale number than normal subjects^{1,20,47} (This may be related to sleep disturbance, deconditioning, enhanced interoception (increased awareness of body sensations), or mood disturbance among others.¹) The RPE cannot therefore be used as an objective measure of intensity for this patient group, although it can be a useful tool alongside HR measurements. After an exercise programme, research has shown that the RPE in CFS patients is normalized, and can at that stage usually be reliable as a measure of intensity.¹

The participant should be shown the Borg scale and it should be explained how this is used this to help monitor their exercise.⁴⁸ Exercise should not feel too hard and should be reduced if it does. You can tell them that it is normal to expect their ratings to be a little higher as they start or progress to a new level, and reduce as they accustomise to this new level. It can therefore be a useful method to determine when to increase a further stage.

The Borg scale can be used or introduced at any appropriate time.

Using heart rate measurements in early stages of the programme

You will be given the information from the RN from the participant's physical tests. This includes their Borg scale rating and heart rate on exercise.

Most people with CFS/ME have a higher Borg rating than normal subjects for the same HR, so they cannot rely on their subjective Borg ratings to determine optimal exercise

intensity. However, some people with CFS/ME do have a normal Borg/HR relationship, and therefore may not need to monitor the objective HR measurements so closely.

You can use the data gained from both the RN and your own objective tests to determine whether your participant has a normal Borg/HR relationship, and then ascertain whether they would benefit from using a HRM earlier in the programme to objectify their progress. Those with a normal Borg/HR relationship can rely on their Borg and may therefore not need to be introduced to heart rate monitors until later in the programme when they are increasing intensity.

Reducing reliance upon Borg towards the end of the programme

The use of the Borg scale can then be reduced towards the end of the exercise programme, since they can rely on their normal sensations of effort as they did before they were ill. However, a participant who does not achieve their target HR relatively comfortably may need extra support or assessment.

IMPORTANT GET CONSIDERATIONS

There are a number of clinically important considerations when working with GET and CFS:

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 HR, rather than a sense of effort
7. The importance of maintaining exercise levels
8. Strategies for planning exercise
9. Exercise and rest
- 10 The importance of achieving a healthy balance of exercise

1. Individualising treatment

- Progress is determined by individual ability. A physiotherapist should use their clinical reasoning to determine the rate of progress, within GET guidelines.
- Participants will respond differently; some will take a lot longer to adapt to each new level, whereas others will have to be held back, particularly those who have been active sports participants in the past. Participants inclined to over-exert themselves to speed up the recovery process should be monitored carefully, as this can be a contributing factor in non-recovery or relapse.

2. Flexible exercise prescription

- Sometimes it can help to break up the exercise sessions during the day, so that a participant may do two sessions of 15 minutes each rather than one of 30 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 should 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. 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 the same 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.

Scheduling 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 do not exceed 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 HR, 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 the HR 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 as a response to a new level of exercise, they should be encouraged to remain at the same level for an extra week or more. 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. The use of the Borg scale can be particularly helpful at this time, for the participant will be able to see their Borg ratings decrease as they maintain the exercise. They can then increase the exercise when the symptoms or Borg scale decreases.

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? Using written reminders and rewards for exercising can also be helpful. You can also use a technique known to motivational interviewing: ask the participant 'What is the likelihood of you undertaking this plan?' (scale 1-10). If they respond under 7, it is unlikely that they will do the activity being discussed, so it will need re-negotiating.

9. Rest and exercise

In order to adapt to an exercise programme, it is important to allow the body time to rest appropriately after exercise. Rest after exercise is particularly important at the start of GET, preferably for not longer than 30 minutes, to allow the neuro-musculo-skeletal and cardiovascular systems to adjust. If a participant needs to rest for more than around 30 minutes after exercise, then the GET therapist will need to consider whether the exercise duration or intensity is too high for the participant, as an increase in overall rest periods in a day is not desirable. The participant can be encouraged to have a physical rest (not sleep) for around 30 minutes after exercise: this could involve reading a book, relaxing, or watching TV whilst replenishing themselves with water.

10. 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. Participants such as this can be encouraged to stabilise at a

certain level for a while, e.g. 2-3 weeks, to ensure their body is comfortable before the next incremental increase.

ENSURING YOUR TREATMENT IS NOT CBT OR APT

GET is not CBT

It is essential that the three supplementary therapies are as different as possible, within the confines of keeping the therapies consistent with their models. In contrast to CBT, it is important that you do not consciously provide cognitive interventions or interpretations, e.g. suggest that being able to exercise more may mean that there cannot be a persistent viral infection in their body. Should a participant speculate in this way you should remain non-committal and explain that the study does not allow you to respond to the suggestion. This is not the same as responding to a participant's questions and queries about the therapy and providing educational explanations as to how and why GET works and how it should be applied. This is allowed and is in fact imperative.

GET is not APT

In contrast to APT, it is important that the “envelope theory” of pacing is not adhered to. APT is underpinned by an organic disease model, which encourages a person to stay within the limitations set by their illness, and being directed by their symptoms as guides to what they can do. The rationale behind APT involves the ability of the body to heal itself by not provoking symptoms. In significant contrast, GET encourages the participant to stretch the limits of physical capacity in order to improve them.

A main difference between APT and GET is that GET plans for incremental increases in activity while APT does not.

There will be extensive training on how to differentiate your treatment, including role plays, observation and written exercises to help separate the three therapies more clearly.

The Therapies Integrity Rating Scale

The Therapies Integrity Scale (in Appendix) outlines the core elements of each therapy, and will be used by independent evaluators to ascertain whether the treatment you are giving is consistent with your model. They will listen to a random selection of therapy tapes and will mark them according to this scale.

You will note that the first part of the scale is concerned with core areas, considered important for APT, CBT, and GET (covering aspects such as therapeutic alliance, rapport, generic therapy skills), while the treatment-specific sections outline the cornerstones of the individual treatments. This scale is also likely to be used throughout supervision as an aid to training.

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 GET programme, there will be occasions when you will need to use your clinical judgment and clinical reasoning skills to alter your therapy sessions as appropriate.

There may be times when it may be appropriate to engage a participant in strengthening before looking at aerobic fitness (e.g. if working with a body-builder whose strength is of primary motivational importance). Our body-builder can focus on aerobic exercise later in the programme. However, it is important that all participants receive the same general treatment at some time in the 15 sessions, and receive all of the essential elements relating to the GET model.

Another 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 exercise sooner, or perhaps to assess his ability to undertake a variety of physical exercise rather than to add **more** exercise to his day.

When dealing with someone in distress, it may not be appropriate to bring the topic of conversation back onto GET. You will need to use your own judgment and therapy skills to comfort the participant, perhaps comment on how exercise helps us to cope emotionally with our lives, and then record the incident and discuss with your therapy leader if necessary.

Checklists are present as a reminder, and do not need to be strictly adhered to if not appropriate, e.g. if you notice a participant is getting very tired by 30 minutes and you cannot complete your checklist, or if certain checklist items are not relevant. However, you will need to ensure that items not covered are covered in subsequent sessions, and only omitted under clear clinical circumstances – e.g. if a participant already attends a gym and follows a gym-based programme, they will not need to undertake the PACE strength exercises. You **MUST** record any diversions from the manual clearly in your written notes and they must be justified clearly.

SUPERVISION AND REFLECTIVE PRACTICE

Clinical supervision will be provided no more than once a week via telephone contact and a minimum of once per month. Face-to-face supervision will take place no more than once a month and a minimum of once every three months at St Bartholomew's Hospital, London.

Supervision will provide you with the opportunity to discuss all of your participants and iron out any difficulties that you may be experiencing. Supervision will be given in a peer support group and individually.

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

- Plan in advance what you hope to get out of supervision,
- Audio record all clinical sessions and bring records to supervision,
- Bring clinical notes to supervision,
- Actively reflect on your experience, and make daily notes,
- Keep a record of what has been discussed in supervision.

You will be encouraged to actively reflect on your sessions and make suggestions for improvements in your own delivery of the therapy, or the way in which you handle any challenges. You will be encouraged to use a Reflective Practice sheet after each session.

You will also be encouraged to maintain good contact with your GET, CBT and APT peers, to provide mutual support and to ensure that all therapists benefit from your ideas and learning. You will also be encouraged to make good use of email contact. Peer coaching, whereby therapists support one another's learning, will be encouraged where appropriate.

DOCUMENTATION

Trial session records should be used to record details of each contact that you have with the participant, e.g. phone appointments, outpatient appointments or brief phone calls between sessions. Please remember that non-session contacts with the participant are not encouraged.

Outline of paperwork:

The paperwork can be divided into 3 categories:

1. Therapy records
2. Participant records and worksheets
3. Participant information

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, space to write additional SOAP notes and plans, an assessment form, an attendance record, an unplanned phone call record, and a mutually agreed goals sheet. (**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 – see appendix and checklists for details).

You will also find exercise records and activity diaries upon which to write plans and record achievements or comments. 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 PACE 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:

- Clinical Global Impression change scale (therapist rated),
- 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).

A letter will already have been sent to the participant's GP informing them of their involvement in the PACE trial. However, as per normal physiotherapy practice, You will need to write a letter to the GP and referring doctor stating that you have commenced

GET (see appendix), and will then to write progress reports for the referring doctors when appropriate.

Important note: Reflective Practice Sheet (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

Participant records and worksheets (ON YELLOW PAPER)

This section includes the worksheets that the participant will be expected to fill in at home, including an activity diary and exercise record. An exercise questionnaire will also be utilised to explore the participant's relationship with exercise, and to help them to formulate goals. This forms part of the participant's manual.

Participant information

This section includes educational tools and information sheets to familiarise the participant with the GET model, to help them use the worksheets effectively, to help them choose exercise, and to make them aware of normal and abnormal responses to exercise. The stretching and strengthening exercise sheets also form part of this section.

These sheets are copied, along with additional information and tools, in the Participant's manual. A copy of the Participant's manual should be given to the participant in session 1.

How to complete the session paperwork

- 1) After you have discussed and jointly negotiated the plans for the forthcoming session of homework, you will encourage the participant to complete the top section of the *GET Plans and Progress* sheet (in their file), you can then check it to ensure the correct information is recorded. This information roughly equates to the '*Participant Homework discussed*' section within the O section of your SOAP notes, which you may wish to complete at the same time.
- 2) When the participant returns for their next session, their homework is reviewed – and they are encouraged to complete the bottom part of the *GET Plans and Progress sheet* by summarising how they have got on with the plan in the section above. This may include comments such as '*Able to walk for 20 minutes 4 days out of 7 despite my setback, HR 125 average; able to refer to setback plan successfully*' or '*Difficulty completing plan as finding walking boring: tried cycling*

but not sure about intensity'. This section roughly equates to the 'Subjective' (S) part of Physiotherapy SOAP notes.

- 3) You will then use another *GET Plans and Progress* sheet to record the next plans as discussed, and so on.
- 4) You will collect the participant's *Exercise Record* from the previous homework session and include this in your therapy notes.
- 5) During the session, you may wish to check that you have completed the session checklist, or will have decided not to include any items based on clinical judgment.
- 6) After the session, you will record the duration of the session at the bottom of the checklist.
- 7) You will also need to record your SOAP notes on the reverse, using the P section for any plans for the next session, including any agenda items that have not been covered.
- 8) You will need to sign and date each page, and print your name beside your signature.
- 9) If more space is required, a blank sheet can be added in chronological order.

Therapy record colour-coding system

The paperwork should be colour-coded to assist navigation of the paperwork during sessions. This will also be helpful for auditors or anyone needing to access and utilise notes for trial purposes.

Therefore, notes should be printed on different coloured paper as follows, and should be filed as listed in the table below.

Therapy records	Number of copies needed per participant
Title sheet	1
Attendance record	1
GET Assessment form	1
Discussing what is required of the participant (checklist)	1
Exercise questionnaire (yellow)	1
Physical activity and exercise diary	1
Mutually negotiated goals	1
Goal Setting: Breaking goals down into manageable sections	3 (1 of each 3 goals)
SOAP notes, with session checklist on reverse (white)	1 of each session
Exercise record	13
Unplanned phone call record	5 (average)

TROUBLESHOOTING

Also refer to PACE protocol to answer frequently asked questions and to gain better understanding of the trial procedures.

1. Adherence or compliance problems

a) Participant wishes to terminate therapy or trial

In the first instance, you will contact the participant by telephone to ascertain the reason for drop-out, to clarify any misunderstandings, and establish whether any concerns can be resolved. You will then try to ascertain whether the participant would be willing to continue with the treatment. This information should then be discussed with both the SSMC doctor and the centre leader. If the participant does not wish to talk to the physiotherapist or SSMC doctor, the centre leader or nominee should contact them themselves.

b) Participant has not completed exercise diary/ undertaken the agreed exercise plan

Try to ascertain why and encourage its use, explaining that the information it contains is very helpful for you to plan exercise effectively. Encourage the participant to keep their records in their participant's manual. It may be useful for them to write a reminder to themselves before their appointment to bring their manual.

c) Participant asks you not to record the session

If a participant asks you not to record a session, ask them the reason why and remind him/her why you are recording. If necessary switch the tape off for a five minute period, but record content in writing and try to get permission to switch on again as soon as permissible.

2. Attendance issues

a) Participant is unable to attend a session

If it is unclear as to why a participant has not attended, the therapist should attempt to contact them in order to ascertain any reasons for this, and to encourage attendance at the next arranged session. If for any reason the participant is not able to attend a session, try to replace the missed appointment with another one within five working days (for a part-time therapist, 5 working days may equate to more than 5 days). This could be by telephone if the participant is unable to attend at the hospital. The number of sessions not attended and reasons for non-attendance must be recorded in the participant's therapy record.

b) It seems appropriate to alter the session timings or intervals

Both the number of sessions, and the intervals between them, can be altered with mutual agreement. The reasoning behind the changes needs to be recorded in therapy records. If both the participant and therapist agree that the next session is redundant and unnecessary, then that session may be omitted. This may occur if the participant is doing

particularly well, and is applying principles independently to good effect. If a participant is completely and consistently recovered before the end of GET, the remaining sessions, apart from the 15th booster session at 35 weeks, may be omitted.

c) The participant is having difficulty travelling in to the hospital

Telephone contact between sessions should be handled on an individual basis and is not banned, but should not be encouraged. It is a better alternative than dropping the therapy session altogether.

3. CBT/APT conflicts

a) Therapist realises they have mistakenly given a CBT or APT intervention

It is perhaps inevitable that therapists will find that they have mistakenly given a cognitive interpretation, or encouraged a form of pacing, especially with the first few of their participants in the trial.

A therapist should not be worried about admitting these problems; in fact, difficulties should be shared with the team to allow all to learn from this. This will allow difficulties to be resolved, and strategies devised for next time.

Action: Continue the session but discuss with GET leader after session.

b) Participant asks advice on other management strategies e.g. diet / stress management

Explain that the trial does not allow you to give any advice on these issues, but, if necessary the therapist can ask the clinic doctor to review the participant.

4. Setback issues

a) Therapist is not sure if this is a CFS/ME setback

Discuss with GET leader or centre leader.

b) Participant has a cold/cough/other new or active infection

As CFS/ME symptoms can be sometimes be similar to symptoms of a cold/cough/new or active infection, it is important to obtain information as to the nature of the symptoms. A raised objective temperature (using a thermometer, not relying on subjective assessment), sneezing, sputum production may be clearer indicators of infection, rather than common CFS/ME symptoms such as sore throat, fatigue, body aches, dizziness etc.

If the participant appears to have a new or active infection, then they should be encouraged to rest and build up their activity and exercise gradually as soon as they are feeling better. If they are able to continue gentle walking / other low intensity exercise without exacerbation, this should be encouraged.

5. Unforeseen or new medical issues

Any serious concerns or worries about the participant such as deliberate self-harm, significant and prolonged illness progression, or severe adverse events should be discussed with the centre leader immediately, so that the relevant course of action can take place.

a) Therapist identifies a need that cannot be managed in GET sessions

- e.g. anxiety, panic attack, medical concern etc.
- It will be important to ascertain whether this need will interfere with GET e.g. – clearly, new angina pain will be an issue that will need urgent attention and postponement of GET, whereas developing of panic attacks may be compatible with a continuation in GET.
- Discuss with clinic doctor, centre leader or GET therapy leader.

b) Participant develops a musculoskeletal injury

- Advice for management should be given, e.g. RICE.
- Exercise programme should be adapted as appropriate.
- If likely to affect GET longer term, or if requires frequent physiotherapy treatment, discuss with centre leader / GET leader.
- Referral to local physiotherapy services can be considered and discussed with the centre leader.

c) Another Physiotherapy need becomes apparent, e.g. longstanding back problem, frozen shoulder etc

- Give some initial Physiotherapy advice if appropriate and refer to participant's GP/local Physiotherapy service, following the consent of the centre leader.

d) Participant becomes unwell during treatment session

- Treat any severe distress or medical problem fully without constraint
- Discuss with clinic doctor or centre leader
- Document session clearly
- Consider whether the event is related to treatment or independent causation
- Incident reporting should continue as per your Trust policy

e. Co-morbid condition limits exercise

If a co-morbid condition limits exercise, e.g. arthritis, pre-existing musculoskeletal problem, encourage maximum exercise potential to be achieved within the limits imposed by their problem.

6. Technical difficulties

a) HRM malfunctions

- Preventative teaching of pulse monitoring

- Replace ASAP

b) *Audiotape recorder malfunctions*

- Continue with session
- Try to resolve problem after session
- Record in notes
- Replace by next session if possible

7. Difficult questions relating to trial

a) *Participant asks for opinion on issues read in press etc*

- Can give factual info re: GET only.
- Cannot ask participant what they think (CBT), but can suggest they discuss with clinic doctor.

b) *Participant expresses doubt over GET as result of reading press/other*

- Can give factual info re: GET only.
- Cannot ask participant what they think (CBT) but can suggest they discuss with clinic doctor.

c) *Participant has been advised not to continue GET by an outside influence*

- Contact centre leader and discuss with GET lead.

8. Other issues

Participant asks whether they can bring someone to therapy (e.g. partner)

- Yes they can. You must ensure that you have the participant's consent, without the family member/friend with them, before they can attend.

Participant asks for further references or suggested websites

- Explain that there are no particular references you can recommend for GET, but that you would be happy to make comment on anything they find. You should explain that there is a significant amount of inaccurate information on the internet, and in other publications, and that they need to approach this with caution.

Participant is following a very restricted diet or requests assistance with their eating plan

- Referral to dietician is appropriate as it is classified as SSMC: a referral can be made in the normal way.

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This patient has agreed to participate in the PACE research trial and has been entered into the Graded Exercise Therapy arm of the trial.

Trial Number: ISRCTN54285094

Graded Exercise Therapy

Participant Identification Number: _____

ATTENDANCE AND PHONE CALL RECORD

PIN _____ INITIALS _____

Example: participant did not attend their 1st session (face to face appt) due to a setback, so appt was re-arranged for 10/06/04 to be conducted on the telephone

Session Number	Attendance*		Outcome	Comments
	Date	Appt Type**		
<i>E.g. 1</i>	<i>7/06/04</i>	<i>FF</i>	<i>X+</i>	<i>SB</i>
<i>1</i>	<i>10/06/04</i>	<i>PPC</i>		

***Outcome Key**

✓ Attended appt as planned
 X Did not attend appt as planned
 + Another appt made
 - Another appt not made

****Appt type**

FF – Face to face
 PPC – Planned Phone call
 UPC- Unplanned Phone call

Reasons for non-attendance:

SB – CFS setback
 UW- unwell (other reason)
 WC – work commitment
 FC – family commitment
 TR – transport problem
 UK – unknown
 SS – Staff sickness
 SL – Staff leave (e.g. hols)
 OT – other, please record

LETTER TO GP AND REFERRING CLINIC DOCTOR

(PACE letterhead, include physiotherapy contact details)

(GP address)

Date

Dear Dr

RE: Patient name, DOB and address

You will already be aware from previous correspondence that your patient as named above has received a diagnosis of Chronic Fatigue Syndrome/ Myalgic Encephalomyelitis / encapalopathy (CFS/ME), and has consented to participate in the PACE trial.

Your patient will be receiving Graded Exercise Therapy (GET), in addition to Standardised Specialist Medical Care (SSMC). GET has been shown in research to improve functioning, disability and symptoms via carefully monitored graded increases in physical activity and exercise.

A goal-focused physical activity and exercise programme will now be negotiated and conducted over the next 6 months.

After initial assessment, the main areas of focus will be:
(add main goals/any area of concern).

I will keep you informed of your patient's progress as necessary, and will send you a discharge report.

I will conduct an assessment to ensure suitability to undertake exercise therapy: however, I would appreciate if you could let me know any medical information, either currently on record or as a result of future consultations that may affect the exercise programme.

If you have any questions about your patient's care, please do not hesitate to contact me.

Yours sincerely

Physiotherapist
Cc Clinic doctor/other clinicians involved in care

GET ASSESSMENT

PIN _____

Initials _____

Date _____

<p>HISTORY OF PRESENT COMPLAINT</p> 	<p>CURRENT SYMPTOM PRESENTATION</p> <p style="text-align: right;"> Fatigue Physical <input type="checkbox"/> Fatigue Mental <input type="checkbox"/> Headache <input type="checkbox"/> Sore throat <input type="checkbox"/> Generalised pain <input type="checkbox"/> Sleep problems <input type="checkbox"/> Concentration <input type="checkbox"/> Dizziness <input type="checkbox"/> Other symptoms/comments: </p>
<p>EXERCISE – LIMITING CONDITIONS</p> 	
<p>PAST MEDICAL/SURGICAL HISTORY</p> 	
<p>DRUG HISTORY</p> 	<p>Activity patterns:</p>
<p>CURRENT FUNCTIONAL CAPACITY</p>	
<p>Able to:</p> 	<p>Unable to:</p>

PIN _____

Initials _____

Date _____

TARGET HEART RATE/ZONE		
CURRENT EXERCISE PARTICIPATION	PREMORBID EXERCISE PARTICIPATION	
ATTITUDE TOWARDS EXERCISE		
EXPLORING EXERCISE OPTIONS (tick)		
	EXERCISE INTERESTED IN	EXERCISE NOT INTERESTED IN
Specific Sports		
Walking		
Jogging		
Swimming		
Cycling		
Circuits		
Attending gym		
Social/family involvement		
Outdoors		
Functional exercise (DIY/garden etc)		
Other 1:		
Other 2:		
Possible exercise options:		

PIN _____

Initials _____

Date _____

SOCIAL HISTORY	
Leisure interests	
Work/vocation:	
Hours:	
Social / family support	Smoker Caffeine Alcohol
SLEEP	Other assessment information:
Initial insomnia Middle insomnia Early morning waking Daytime naps Refreshed?	

PIN _____

Initials _____

Date _____

OBJECTIVE OBSERVATIONS			
Posture	Gait	Walking aids	
RANGE OF MOVEMENT			
UL:	LL:	Trunk/Neck:	
STRENGTH			
UL:	LL:	Trunk/ neck:	
Specific tests indicated:			
Objective measure:	TUAG	Sit - Stand	2 min walk
1st Ax	Time: Borg: End HR:	Number: Borg: End HR:	Distance: Borg: End HR:
Mid Ax	Time: Borg: End HR:	Number: Borg: End HR:	Distance: Borg: End HR:
Final Ax	Time: Borg: End HR:	Number: Borg: End HR:	Distance: Borg: End HR:
Other:			

MUTUALLY NEGOTIATED GOALS

PIN _____

Initials _____

Date _____

The following goals are thought to be the main priorities, and will form the focus for the GET programme:

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:

GOAL SETTING: BREAKING GOALS DOWN INTO MANAGEABLE SECTIONS

PIN _____

Initials _____

Date _____

Goal 2: _____

Step 1:

Step 2:

Step 3:

Step 4:

Step 5:

Step 6:

Step 7:

End goal:

GOAL SETTING: BREAKING GOALS DOWN INTO MANAGEABLE SECTIONS

PIN _____

Initials _____

Date _____

Goal 2: _____

Step 1:

Step 2:

Step 3:

Step 4:

Step 5:

Step 6:

Step 7:

End goal:

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:

- To complete all records, e.g. exercise records: explain that the purpose is to help them monitor their exercise, to see their achievements and to help you understand their levels and patterns of exercise.
- To do as much of the homework as agreed – to give themselves the best chance of making progress
- To let you know if they are struggling to maintain the paperwork, travel to the clinic or are having any difficulties with the programme.
- 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 keep you informed of any changes in medication, other treatments etc.
- To not participate in additional forms of therapy throughout the trial
- To openly ask questions - so that all of their needs and requirements are met
- To feel able to tell you if they are not clear on any aspect of the treatment programme.
- To attend appointments on time (wherever possible) as you may have an appointment straight afterwards and would therefore be unable to offer extra time
- To bring in their participant manual and all of the worksheets completed to sessions to get the best out of their appointment, and to use a folder to keep paperwork together
- Explain that the trial offers a **maximum** of 15 sessions: it may be that not all are completed (i.e. due to sickness, holidays etc).

Signed _____

Date/s _____

PHASE 1: ENGAGEMENT, ASSESSMENT AND TREATMENT PLANNING

PIN _____

Initials _____

Date _____

Session 1

Session content

- Discuss length and content of session
- Outline number of sessions and treatment plan
- Listen to the participant, recognise and believe their individual experience
- Give participant their manual
- To conduct a subjective assessment
- Explain role of fitness and exercise, using *Explaining CFS*;
The deconditioning model and *Feeling better with Exercise* sheets
- Start to investigate with participant a possible exercise programme
- Explain what is expected of participant (checklist) (see checklist)

Discuss homework and write plan on *GET plans and progress sheet*:

- Complete 1 week activity diary
- Read pages in manual as discussed

Encourage participant to read the following:

- Explaining CFS; The deconditioning model
- Feeling better with exercise
- Guidelines for choosing exercise
- Benefits of exercise
- Goal Setting

Paper work to complete after session:

- Complete *GET assessment* sheet
- 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
- Send letter to referring doctor, GP, and anyone else involved in care
- Any adverse events?

Y/N

Session duration _____ mins

Signed _____

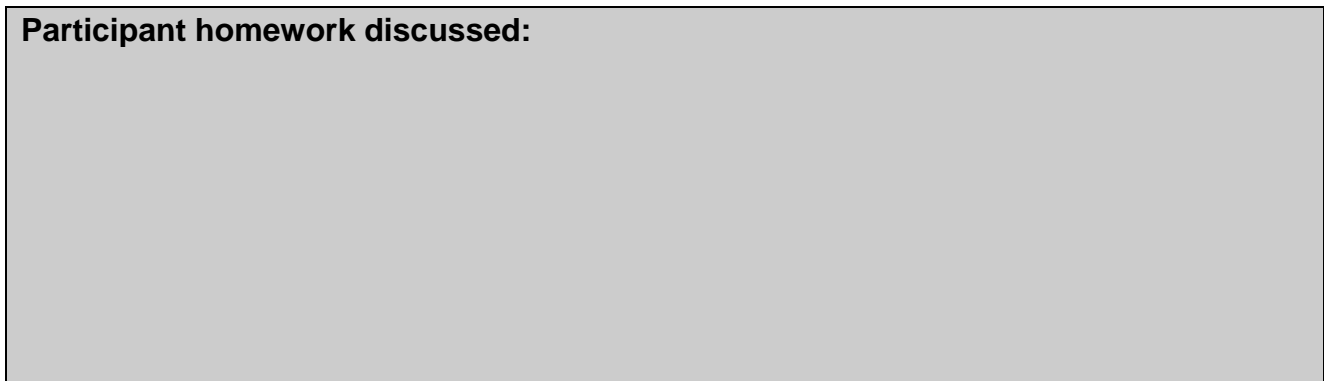
Date _____

Session 1
S: (subjective information)

Participant name _____ DOB _____

O: (objective information and treatment discussed)

Participant homework discussed:



A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

PIN _____

PIN _____

Initials _____

Date _____

Session 2

Session content

- Discuss length and content of session
- Review *Physical activity and exercise diary*
- Discuss and negotiate baseline of physical activity: stabilising not adding
- Review GET model of CFS
- Undertake objective assessment
- Undertake baseline objective measure
- Demonstrate and practise stretching exercises
- Explain what is expected of participant (checklist) (see checklist)
- Hand out an exercise questionnaire

Discuss progress of previous session's plans:

- Take in *Physical activity and exercise diary*
- Complete bottom section of GET plans and progress sheet

Discuss homework and write plan on GET plans and progress sheet:

- Try out stretching exercises
- Undertake baseline of physical activity + stretches
- Complete 1 week *Physical activity and exercise diary*
- Complete exercise questionnaire
- Read pages in manual as discussed

Encourage participant to read the following:

- Stretching sheets

Paper work to complete after session:

- Complete *GET assessment* sheet
- 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? Y/N

Session duration _____ mins

Signed _____

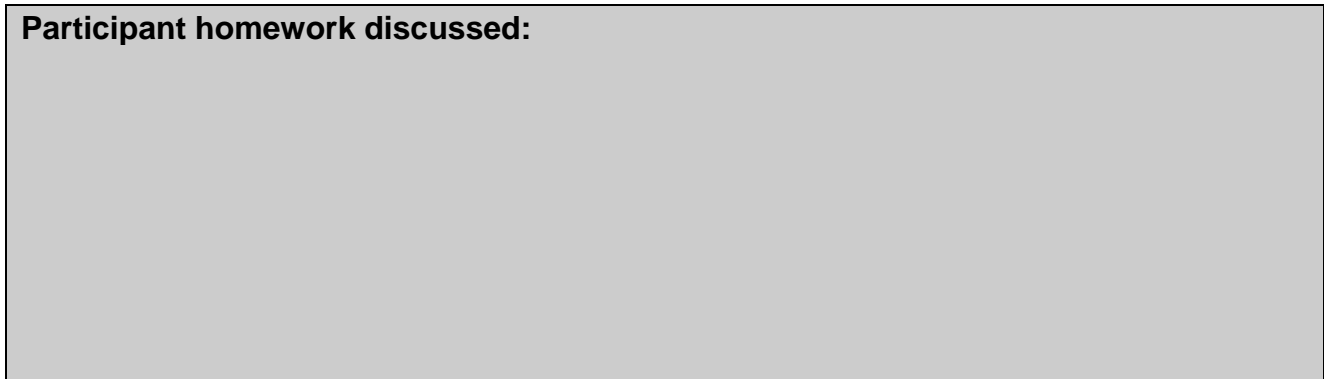
Date _____

Session 2:
S: (subjective information)

Participant name _____ DOB _____

O: (objective information and treatment discussed)

Participant homework discussed:



A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

PIN _____

PIN _____

Initials _____

Date _____

Session 3

Session content

- Discuss length and content of session
- Review *Physical activity and exercise diary*
- Review exercise questionnaire
- Review stretches
- Undertake any objective assessment not covered last session
- Set mutually agreed goals (+copy to participant)
- Prioritise goals and break down into manageable sections
(Write on *Goal Setting: breaking down goals* sheets)
- Negotiate baseline of exercise

Discuss progress of previous session's plans:

- Take in *Physical activity and exercise diary*
- Complete bottom section of GET plans and progress sheet
- Take in Exercise questionnaire

Discuss homework and write plan on *GET plans and progress sheet*:

- Exercise addition
- Undertake baseline of physical activity + stretches
- Complete 1 week *Exercise Record*
- Read pages in manual as discussed

Encourage participant to read the following:

- Stretching sheets
- General advice for exercise
- Normal response to exercise

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? Y/N

Session duration _____ mins

Signed _____

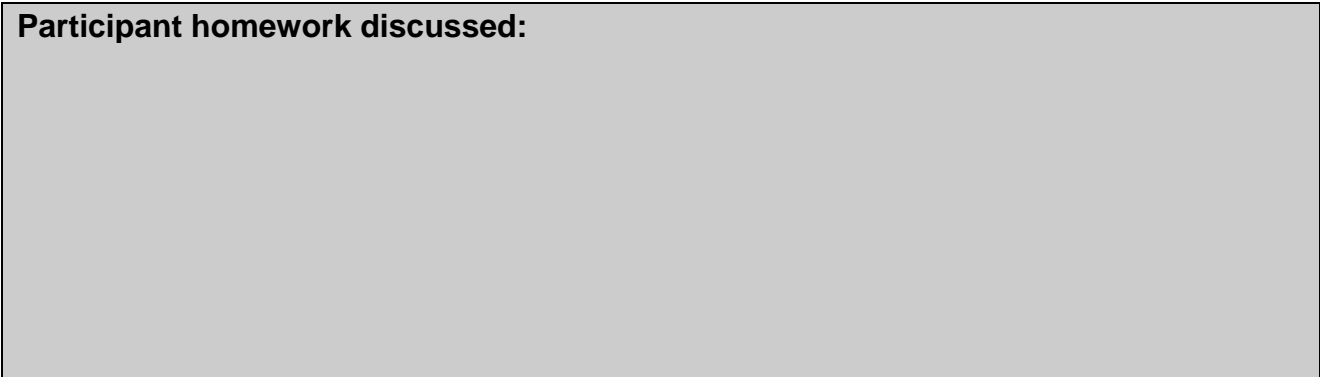
Date _____

Session 3
S: (subjective information)

Participant name _____ DOB _____

O: (objective information and treatment discussed)

Participant homework discussed:



A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

PIN _____

PHASE 2: ACTIVE TREATMENT

PIN _____

Initials _____

Date _____

Session 4

Session content

- Discuss length and content of session
- Review *Exercise Record*
- Review exercise: congratulate achievements and overcome difficulties
- Discuss Borg/HR relationship and consider HRM usage
- If appropriate, demonstrate use of HRM and practice use with participant
- If appropriate, teach participant how to take pulse without HRM
- Explain use of Borg scale
- Plan following fortnight in view of previous week
- Give participant 2 weeks exercise record

Discuss progress of previous session's plans:

- Take in *Exercise Record*
- Complete bottom section of GET plans and progress sheet

Discuss homework and write plan on *GET plans and progress sheet*:

- Exercise as plan
- Complete *Exercise Record*
- Read pages in manual as discussed

Encourage participant to read the following:

- Any parts of the manual as appropriate

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? Y/N

Session duration _____ mins

Signed _____

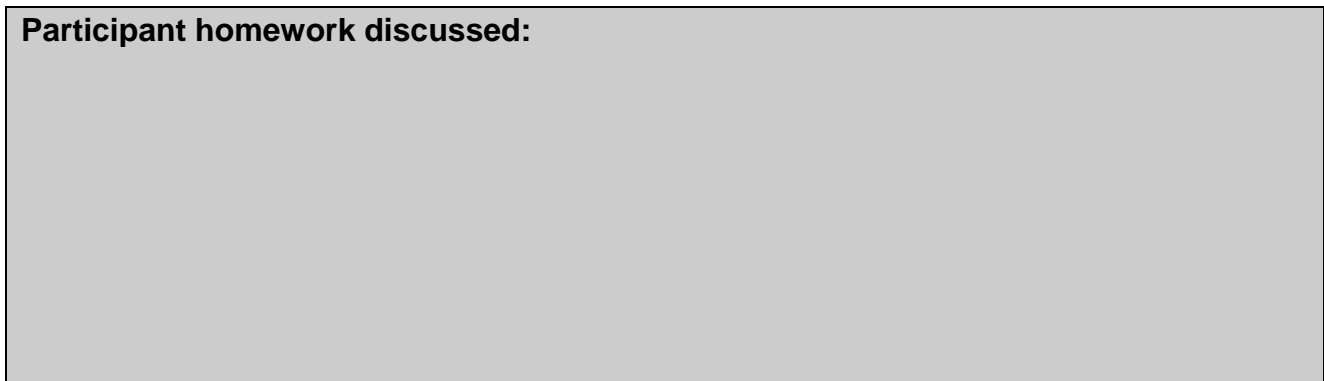
Date _____

Session 4
S: (subjective information)

Participant name _____ DOB _____

O: (objective information and treatment discussed)

Participant homework discussed:



A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

PIN _____

PIN _____

Initials _____

Date _____

Session 5

Session content

- Discuss length and content of session
- Review *Exercise Record*
- Review exercise: congratulate achievements and overcome difficulties
- Discuss sleep management advice
- Plan following fortnight in view of previous week
- Give participant 2 weeks exercise record

Discuss progress of previous session's plans:

- Take in *Exercise Record*
- Complete bottom section of GET plans and progress sheet

Discuss homework and write plan on *GET plans and progress sheet*:

- Exercise as plan
- Amendments to sleep hygiene as appropriate
- Complete *Exercise Record*
- Read pages in manual as discussed

Encourage participant to read the following:

- Sleep hygiene section

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? Y/N

Session duration _____ mins

Signed _____

Date _____

Session 5
S: (subjective information)

Participant name _____ DOB _____

O: (objective information and treatment discussed)

Participant homework discussed:

A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

PIN _____

Session 6

Session content

- Discuss length and content of session
- Review *Exercise Record*
- Review exercise: congratulate achievements and overcome difficulties
- Review sleep management advice
- Discuss written setbacks and setback plan
- Plan following fortnight in view of previous week
- Give participant 2 weeks exercise record

Discuss progress of previous session's plans:

- Take in *Exercise Record*
- Complete bottom section of GET plans and progress sheet

Discuss homework and write plan on *GET plans and progress sheet*:

- Write a setback plan
- Exercise as plan
- Complete *Exercise Record*
- Read pages in manual as discussed

Encourage participant to read the following:

- Writing a setback plan and setback information

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? Y/N

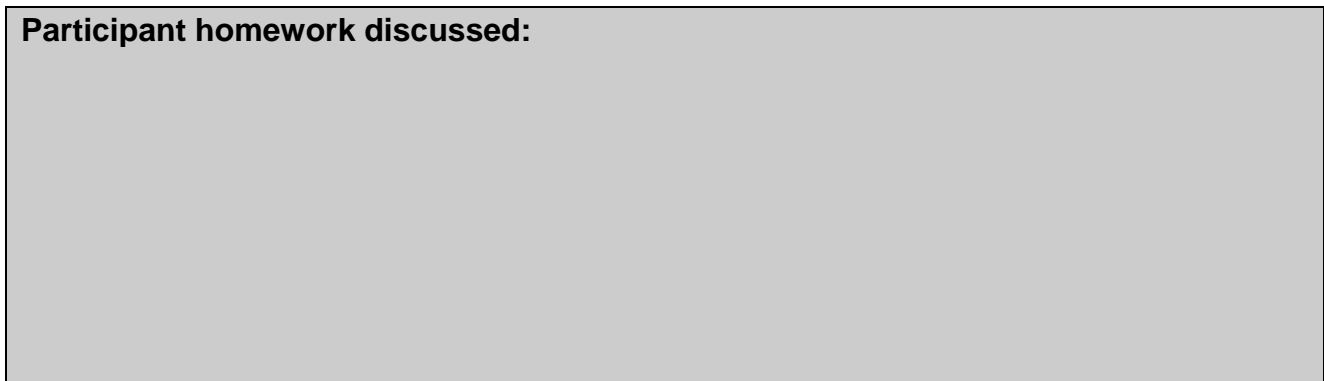
Session duration _____ mins
Signed _____
Date _____
PIN _____

Session 6
S: (subjective information)

Participant name _____ DOB _____

O: (objective information and treatment discussed)

Participant homework discussed:



A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

PIN _____

PIN _____

Initials _____

Date _____

Session 7

Session content

- Discuss length and content of session
- Review *Exercise Record*
- Review exercise: congratulate achievements and overcome difficulties
- Review setback plan
- Plan following fortnight in view of previous week
- Go through muscle relaxation technique
- Give participant 2 weeks exercise record
- Review objective measures if appropriate

Discuss progress of previous session's plans:

- Take in *Exercise Record*
- Complete bottom section of GET plans and progress sheet
- Photocopy setback plan

Discuss homework and write plan on *GET plans and progress sheet*:

- Exercise as plan
- Complete *Exercise Record*
- Read pages in manual as discussed

Encourage participant to read the following:

- Any appropriate section

Paper work to complete after session:

- Write progress letter to all clinicians involved
- 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? Y/N

Session duration _____ mins

Signed _____

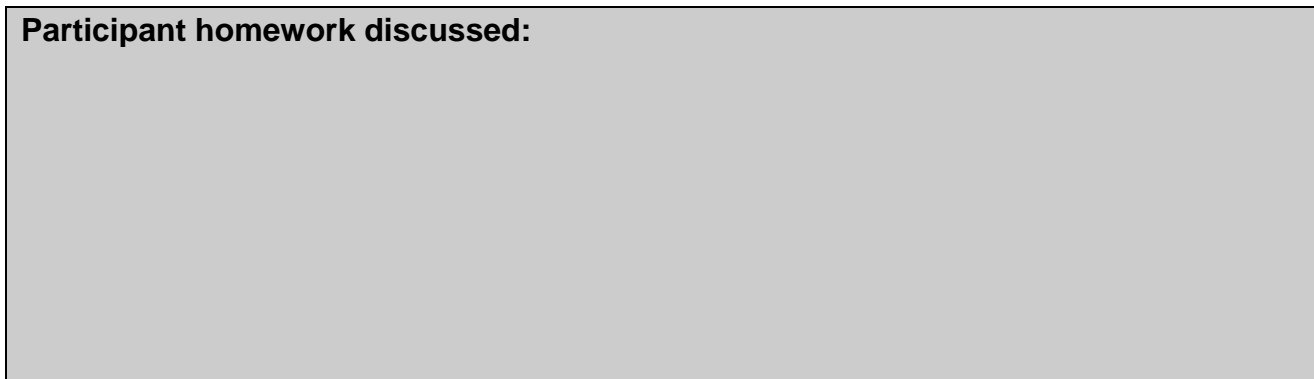
Date _____

Session 7
S: (subjective information)

Participant name _____ DOB _____

O: (objective information and treatment discussed)

Participant homework discussed:



A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

PIN _____

PIN _____

Initials _____

Date _____

Session 8

Session content

- Discuss length and content of session
- Review *Exercise Record*
- Review exercise: congratulate achievements and overcome difficulties
- Plan following fortnight in view of previous week
- Give participant 2 weeks exercise record

Discuss progress of previous session's plans:

- Take in *Exercise Record*
- Complete bottom section of GET plans and progress sheet

Discuss homework and write plan on *GET plans and progress sheet*:

- Exercise as plan
- Complete *Exercise Record*
- Read pages in manual as discussed

Encourage participant to read the following:

- Any appropriate section

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? Y/N

Session duration _____ mins

Signed _____

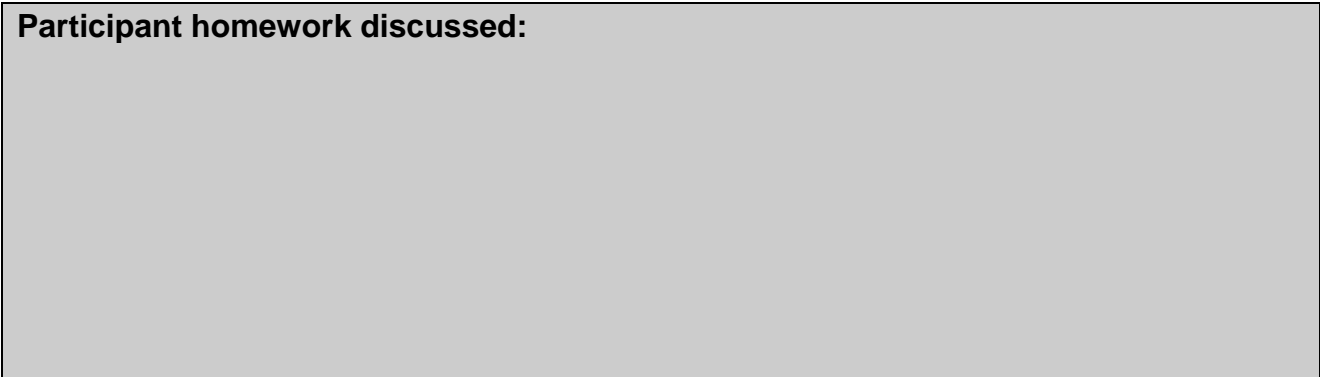
Date _____

Session 8
S: (subjective information)

Participant name _____ DOB _____

O: (objective information and treatment discussed)

Participant homework discussed:



A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

PIN _____

PIN _____

Initials _____

Date _____

Session 9

Session content

- Discuss length and content of session
- Review *Exercise Record*
- Review exercise: congratulate achievements and overcome difficulties
- Review goals and exercise relationships to goal
- Add new/altered goals if necessary
- Plan following fortnight in view of previous week
- Give participant 2 weeks exercise record

Discuss progress of previous session's plans:

- Take in *Exercise Record*
- Complete bottom section of GET plans and progress sheet

Discuss homework and write plan on *GET plans and progress sheet*:

- Exercise as plan
- Complete *Exercise Record*
- Read pages in manual as discussed

Encourage participant to read the following:

- Strengthening exercises + information
- Any appropriate section

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? Y/N

Session duration _____ mins

Signed _____

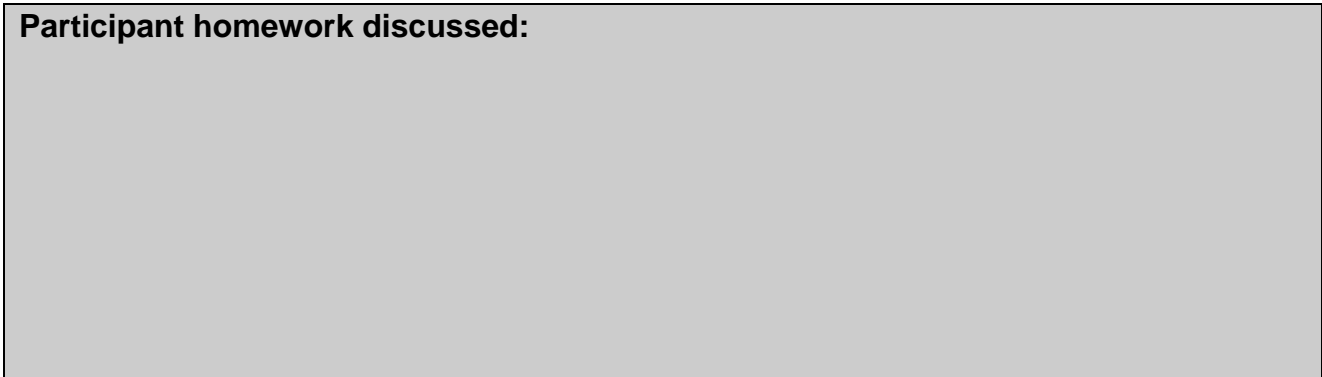
Date _____

Session 9
S: (subjective information)

Participant name _____ DOB _____

O: (objective information and treatment discussed)

Participant homework discussed:



A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

PIN _____

PIN _____

Initials _____

Date _____

Session 10

Session content

- Discuss length and content of session
- Review *Exercise Record*
- Review exercise: congratulate achievements and overcome difficulties
- Plan following fortnight in view of previous week
- Give participant 2 weeks exercise record
- Start to discuss independence and variety
- Start to consider adding strengthening exercises

Discuss progress of previous session's plans:

- Take in *Exercise Record*
- Complete bottom section of GET plans and progress sheet

Discuss homework and write plan on *GET plans and progress sheet*:

- Exercise as plan
- Complete *Exercise Record*
- Read pages in manual as discussed

Encourage participant to read the following:

- Sections re: independence and variety
- Strengthening exercises + information

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? Y/N

Session duration _____ mins

Signed _____

Date _____

Session 10
S: (subjective information)

Participant name _____ DOB _____

O: (objective information and treatment discussed)

Participant homework discussed:

A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

PIN _____

PIN _____

Initials _____

Date _____

Session 11

Session content

- Discuss length and content of session
- Review *Exercise Record*
- Review exercise: congratulate achievements and overcome difficulties
- Plan following fortnight in view of previous week
- Give participant 2 weeks exercise record
- Start to discuss independence and variety
- Think about reducing reliance upon Borg
- Start to consider adding strengthening exercises
- Review strength exercises if already started

Discuss progress of previous session's plans:

- Take in *Exercise Record*
- Complete bottom section of GET plans and progress sheet

Discuss homework and write plan on *GET plans and progress sheet*:

- Exercise as plan
- Complete *Exercise Record*
- Read pages in manual as discussed

Encourage participant to read the following:

- Sections re: independence and variety
- Strengthening exercises + information

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? Y/N

Session duration _____ mins

Signed _____

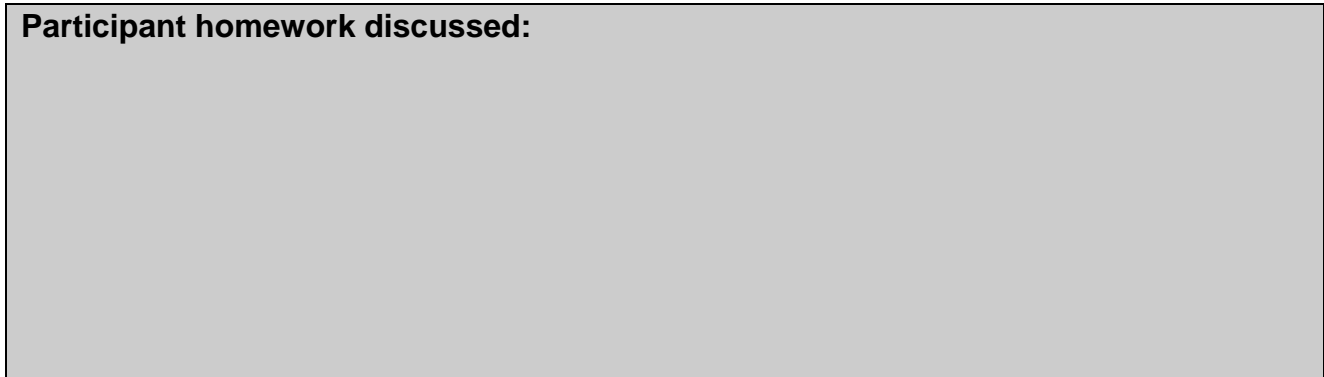
Date _____

Session 11
S: (subjective information)

Participant name _____ DOB _____

O: (objective information and treatment discussed)

Participant homework discussed:



A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

PIN _____

PIN _____

Initials _____

Date _____

Session 12

Session content

- Discuss length and content of session
- Review *Exercise Record*
- Review exercise: congratulate achievements and overcome difficulties
- Plan following fortnight in view of previous week
- Give participant 2 weeks exercise record
- Start to discuss independence and variety
- Reducing reliance on Borg if appropriate

Discuss progress of previous session's plans:

- Take in *Exercise Record*
- Complete bottom section of GET plans and progress sheet

Discuss homework and write plan on *GET plans and progress sheet*:

- Exercise as plan
- Complete *Exercise Record*
- Read pages in manual as discussed

Encourage participant to read the following:

- Sections re: independence and variety

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? Y/N

Session duration _____ mins

Signed _____

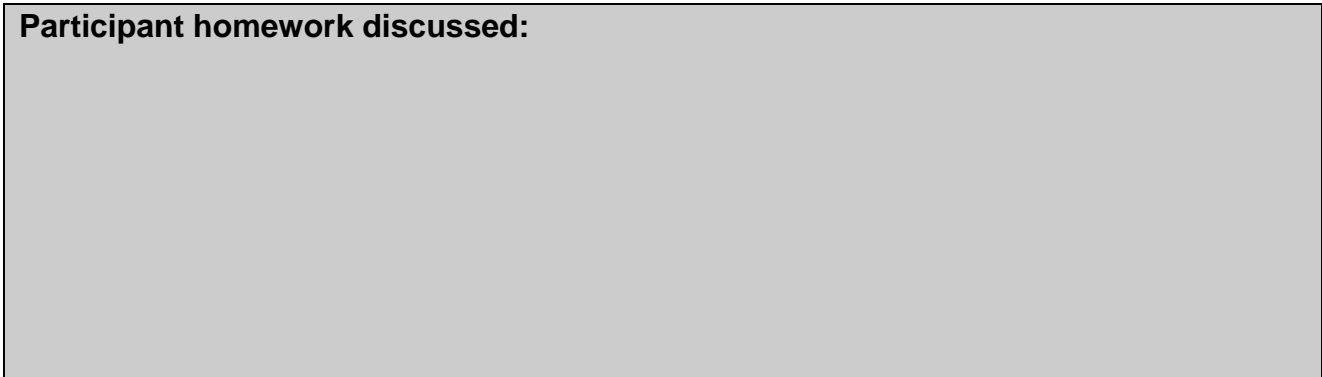
Date _____

Session 12
S: (subjective information)

Participant name _____ DOB _____

O: (objective information and treatment discussed)

Participant homework discussed:



A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

PIN _____

PHASE 3: PREPARATION FOR DISCHARGE

PIN _____ Initials _____ Date _____

Session 13

Session content

- Discuss length and content of session
- Review *Exercise Record*
- Review exercise: congratulate achievements and overcome difficulties
- Plan following fortnight in view of previous week
- Give participant 2 weeks exercise record
- Focus upon independence and variety
- Discuss how to be flexible with exercise (e.g. weather, season)
- Reassess objective measures

Discuss progress of previous session's plans:

- Take in *Exercise Record*
- Complete bottom section of GET plans and progress sheet

Discuss homework and write plan on *GET plans and progress sheet*:

- Exercise as plan
- Complete *Exercise Record*
- Read pages in manual as discussed
- Think about future goals and plans after discharge

Encourage participant to read the following:

- Sections re: independence and variety

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? Y/N

Session duration _____ mins

Signed _____

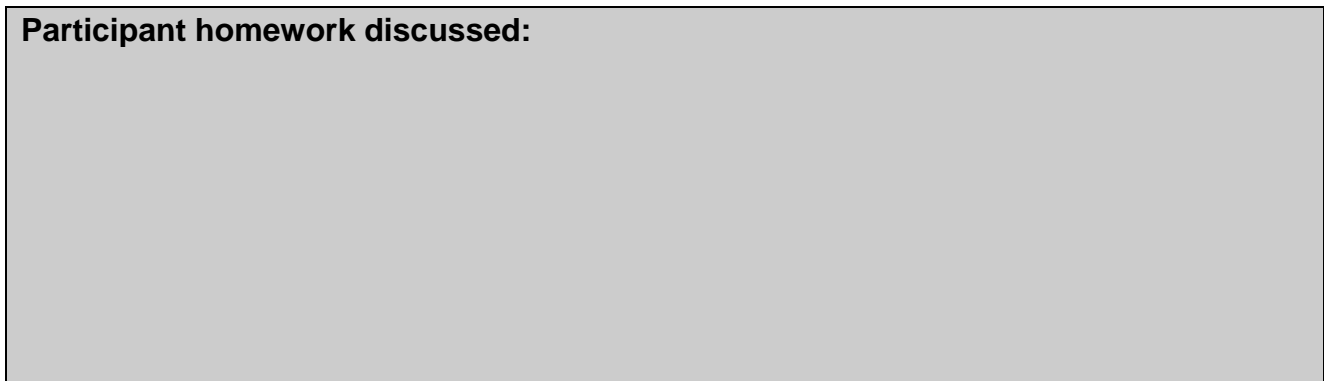
Date _____

Session 13
S: (subjective information)

Participant name _____ DOB _____

O: (objective information and treatment discussed)

Participant homework discussed:



A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

PIN _____

PIN _____

Initials _____

Date _____

Session 14

Session content

- Discuss length and content of session
- Review *Exercise Record*
- Review exercise: congratulate achievements and overcome difficulties
- Plan following 3 months
- Give participant 2 weeks exercise record
- Focus upon independence and variety
- Discuss how to be flexible with exercise (e.g. weather, season)
- Discuss how to maintain exercise after discharge
- Reassess objective measures
- Review goals
- Review setback plan

Discuss progress of previous session's plans:

- Take in *Exercise Record*
- Complete bottom section of GET plans and progress sheet

Discuss homework and write plan on *GET plans and progress sheet*:

- Exercise as plan
- Complete *Exercise Record*
- Read pages in manual as discussed
- Complete another goal sheet for post-discharge plans

Encourage participant to read the following:

- Sections re: independence and variety
- Any other appropriate sections

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 Clinical Global Impression
- Any adverse events? Y/N

Session duration _____ mins

Signed _____

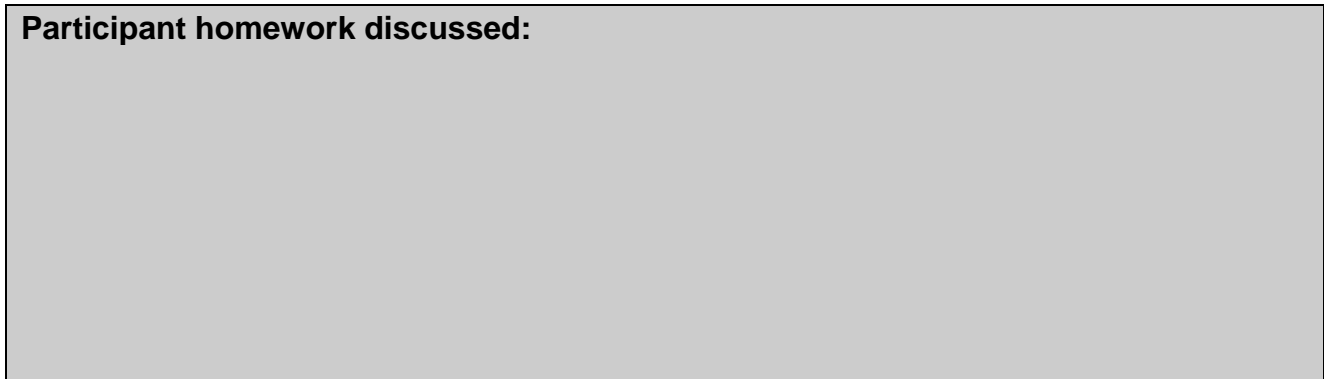
Date _____

Session 14
S: (subjective information)

Participant name _____ DOB _____

O: (objective information and treatment discussed)

Participant homework discussed:



A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

PIN _____

GET BOOSTER SESSION

PIN _____

Initials _____

Date _____

Session 15

Session content

- Discuss length and content of session
- Review *Exercise Record*
- Review exercise: congratulate achievements and overcome difficulties
- Make discharge plans according to new goals
- Give participant any helpful paperwork, exercise records etc.
- Discuss how to maintain exercise after discharge
- Reassess objective measures
- Answer any questions or concerns

Discuss progress of previous session's plans:

- Take in *Exercise Record*
- Complete bottom section of GET plans and progress sheet

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
- Discharge report to clinicians involved
- Any adverse events? Y/N

Session duration _____ mins

Signed _____

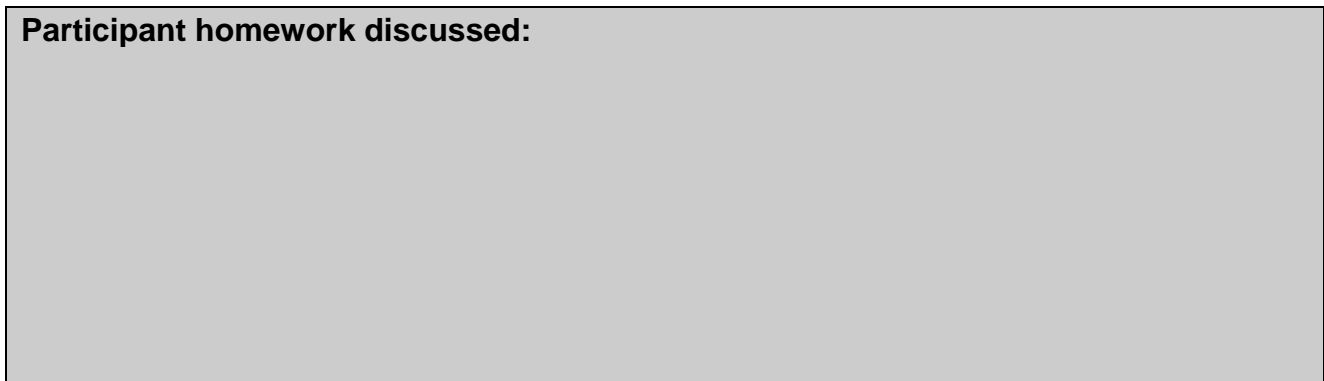
Date _____

Session 15
S: (subjective information)

Participant name _____ DOB _____

O: (objective information and treatment discussed)

Participant homework discussed:



A: (Analysis and clinical reasoning)

Plan:

Signed _____

Date _____

PIN _____

UNPLANNED PHONE CALL RECORD

PIN _____

Initials _____

Date _____

Phone calls between sessions should be avoided; mostly, you will be able to cover questions and concerns in the next session. However, if the nature of the call is urgent or important, then you will need to record the conversation in as much detail as possible on this sheet.

If this call is to replace a GET session, then record it on the normal SOAP documentation. This sheet is only to record supernumerary telephone conversations.

WHO CALLED WHO?

- PARTICIPANT CALLED, AND SPOKE TO, THERAPIST
- THERAPIST CALLED, AND SPOKE TO, PARTICIPANT
- PARTICIPANT LEFT MESSAGE ON ANSWERPHONE/ RECEPTIONIST
- THERAPIST LEFT MESSAGE ON ANSWERPHONE/ WITH ANOTHER

PURPOSE OF CALL:

(tick all appropriate boxes and add further comments if necessary)

- 1. To rearrange an appointment (write new date in attendance record)
- 2. Is this within 5 days?
 - a. Yes
 - b. No
- 3. To explain a DNA/UTA (add to attendance record)
- 4. To request advice (add clear notes below)
- 5. To follow up a DNA
- 6. Was any therapeutic advice given?
 - a. Yes (write full notes below)
 - b. No

Discussion summary + therapeutic advice given (PTO if necessary)

Signed _____ Date _____

REFLECTIVE REVIEW OF PACE SESSION

PIN _____

Initials _____

Date _____

Therapist name	Date	Session Number
What went well?	What did not go so well?	
Were there any CBT/APT conflicts?	What would be done next time to avoid CBT/APT conflicts?	

Would you do anything different next time?	Were there any other difficulties encountered or questions you need to ask?
Amendments to paperwork to improve clarity or usage?	

Action plan and questions to clarify for next time:

A large, solid purple rectangular area that occupies most of the page below the header. It is intended for users to write their action plans and questions for the next time.

CLINICAL GLOBAL IMPRESSION: THERAPIST RATING

PIN	Participant Initials	Date completed			
<input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/> <input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/>	<input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/> <input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/> <input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/>	<input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/> <input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/>	<input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/> <input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/>	<input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/> <input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/> <input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/> <input style="width: 20px; height: 20px; border: 1px solid black;" type="text"/>	
Centre	Participant	Fore. Midd. Sur.	Day	Month	Year

The following is a global impression of change scale. Please rate this scale including all of the various therapeutic factors.

1. Overall, how much has the participant changed since the start of the study (please tick only one box)?

Very much better	
Much better	
A little better	
No change	
A little worse	
Much Worse	
Very much worse	

2. How well has the participant adhered to the treatment – did the participant actually implement what had been negotiated in the therapy sessions (please tick only one box)?

Completely	Very well	Moderately well	Slightly	Not at all
------------	-----------	-----------------	----------	------------

3. To what extent did the participant accept the model of therapy? (Please tick only one box).

Completely	Very well	Moderately well	Slightly	Not at all
------------	-----------	-----------------	----------	------------

4. Sessions received

a. How many therapy sessions with you **in total** has the participant received (include face-to-face sessions and telephone sessions, but not administrative calls i.e. to re-arrange appointments)?

--	--

- b. Of these, how many were conducted over the telephone (do not include administrative calls)?

- c. How many hours and minutes in total of treatment were given (do not include administrative calls)?

 Hours minutes

5. How many planned sessions did NOT occur?

Of these:

- a. How many were cancelled because of your being unable to attend?

- b. How many cancellations or DNAs were instigated by the participant (e.g. travel problems, sickness, family commitments)?

- c. How many therapy sessions were cancelled by mutual consent (i.e. both you and the participant *agreed that the session was unnecessary*)?

6. How many unplanned phone calls took place (phone calls regarding treatment issues, do not include administrative calls)?

7. How many sessions were attended by a relative (not partner) of the participant?

8. How many sessions were attended by a friend of the participant?

9. How many sessions were attended by the participant's partner?

EXERCISE QUESTIONNAIRE

There are different types of exercise: this worksheet aims to help work out what type of exercise is important to you, and which exercise you are not so keen on. Read 'Guidelines for Choosing exercise' in your manual, and then complete this sheet to help work out what exercise might form a part of your Graded Exercise Therapy programme.

1. *'Every-day changes' Exercise*

This category reflects exercise that you could add to your daily routine, it is not an extra 'sport' type exercise, these are extra activities such as getting off the bus the stop before, making use of the stairs instead of a lift, taking a detour on the way back from shopping, walking to the shop daily for milk instead of having it delivered etc.

Could any of these, or other similar activities, be appropriate for you? (please list)

- a)
- b)
- c)
- d)
- e)

2. *'Sports-type' Exercise*

Are you interested in any sports, or in attending exercise classes? Would you like to be able to join a local gym? Would you like to join a walking or cycling group near you? How about getting back into an exercise video or DVD you once enjoyed? Would you like to get back to playing football with friends or playing tennis with children?

Could any of these or other similar activities, be appropriate for you? (please list)

- a)
- b)
- c)
- d)
- e)

3. 'Around the home' Exercise

Do you have any physically demanding tasks around the home; tasks that might make you feel breathless when you do them? E.g. Gardening, Do-It-Yourself projects, housework? Do simple tasks like getting dressed or washed have this effect?

Would you like to work towards any of these activities? (Please list)

- a)
- b)
- c)
- d)
- e)

4. Is there any exercise that you would prefer NOT to do? (Please state)

5. How confident do you feel about undertaking exercise? (Please mark on line)

Not at all confident 0----1-----2-----3-----4-----5-----6-----7-----8-----9-----10 Very confident

6. Do you have any concerns about undertaking exercise? (Please explain)

7. Apart from improving your chronic fatigue and symptoms, what other benefits of exercise interest you?

- a) Improved sleep
- b) Improved ability to do more activity
- c) Improved immune system
- d) Weight loss/ control
- e) Prevention of osteoporosis
- f) A healthier heart
- g) Improved breathing / less breathlessness
- h) Improved body image and confidence
- i) Ability to exercise with children/ family
- j) Ability to exercise socially
- k) Feeling better in spirits
- l) Greater stamina
- m) Greater energy
- n) Greater strength

Please bring this completed sheet with you to your next physiotherapy appointment

Week Commencing _____ **PHYSICAL ACTIVITY AND EXERCISE DIARY 1** PIN _____

	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
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-							

Week Commencing __ **PHYSICAL ACTIVITY AND EXERCISE DIARY 2**

PIN _____

	MONDAY	TUESDAY	WEDNESDAY	THURSDAY	FRIDAY	SATURDAY	SUNDAY
Exercise 1: Stretching							
Exercise 2:							
Exercise 3:							
Exercise 4:							
Comments:							

GET Plans and Progress

Date:

Session Number:

GET Plan:

Signed _____

Date:

Session Number:

Review of previous session plans: *(To be completed at the next appointment)*

Signed _____

PIN _____

Initials _____

Date _____

Exercise Record					
Date	Type of Exercise	Time (exactly)	Average Heart Rate	Borg	Comments

SETTING GOALS

Setting goals can help you to focus upon what you want to achieve by using exercise. Goals can also help your physiotherapist understand what is important to you, and thereby ensures that your programme is individually designed and appropriate for you.

In order to set goals, it can be useful to explore how you feel about exercise – what exercise are you keen on? What exercise do you NOT want to undertake? The exercise questionnaire asks some questions about your relationship with exercise, and will help you to set your goals.

Guidelines for Ideas

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

Try to

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

What to do next

- i. Read 'Guidelines for Choosing Exercise' information sheet
- ii. Read 'Benefits of Exercise' information sheet
- iii. Complete the exercise questionnaire

The exercise questionnaire will help you to formulate goals that are important to you: these will be discussed at your next appointment, so please be sure to bring in your completed questionnaire.

NOTES FOR USING THE ACTIVITY DIARY

The information gathered in this activity diary will help the physiotherapist work out how much physical activity you are doing. This will help plan your exercise, and you can use the information gathered to help stabilise your activity. The first step is to write down details of your activity on the weekly chart (Physical activity and exercise diary).

It can be tempting to change the way you do things when you are being asked to record details. However, please note that the objective of this diary is to record your **NORMAL** activity patterns, and not what you feel you **SHOULD** do. Your therapist will only be able to help if the record accurately reflects your daily activity patterns and your responses to them.

Write down your daily activity for a week, including the following

- **Sleep:** Time went to bed, woke up, got up, and any sleep during the day.
- **Activity:** A log of your activity during the day (e.g. got dressed, walked 4 mins x 2 to shop, rest – sat down 10 mins, made lunch etc).
- **Symptoms:** At relevant times, make a note of any important symptoms on a scale of 1-10 (10 being worst), e.g. fatigue 7/10 after going to shop, 2/10 when enjoying lunch with friend.
- **Rest:** When, for how long, and how?
- **Exercise:** Do you do any exercise? If so, how much, how often?

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.

GUIDELINES FOR CHOOSING EXERCISE

Exercise should be

- | | |
|-------------------|---|
| 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. |
| 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’ |
| Realistic: | 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. |
| Enjoyable: | What do you really enjoy doing? Sometimes exercising in a group/ with your friends/ family can be more enjoyable |

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.

GENERAL ADVICE FOR STRETCHING

Why is stretching helpful?

Regular stretching will help to keep your muscles, ligaments and joints flexible and supple. They need to be supple in order to let you move freely, without pulling uncomfortably. They can 'stiffen up' if you have been in a position for a long period of time, or if you have been generally less active than normal. As muscles and ligaments can actually shrink in length, they may be uncomfortable or painful when they are pulled as part of normal every-day activity. Stretching allows you to gradually increase the flexibility of your muscles.

However, the good news is, that with regular stretching, you can feel much more supple and this can make your muscles feel more comfortable. Many people with CFS/ME report how much better they feel when stretching regularly.

If you are used to doing particular stretches, e.g. Yoga, discuss this with your physiotherapist as you might be able to do some of these as well/instead of those given.

When should I stretch?

You will see improvements only if you stretch regularly. You might start by stretching just once a day, but 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 your muscles and mean you can stretch a bit further and more comfortably
2. If you 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 you 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 you are actively lengthening muscles that may be tightened, 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 with you for a long time after the stretch. If you find this, please consult your physiotherapist who can help to alter the stretch for you.

Where should I start?

When you first start to stretch, stretch gently, slowly and smoothly. As your body gets more supple you will find you will be able to stretch further.

Start by holding your stretches for as long as feels comfortable (maybe 2-5 seconds), with the view of eventually working up towards 10 seconds. You might start by just doing one stretch each side, but will then work this up gradually.

Over time you will find these stretches will become easier as your flexibility increases. Your physiotherapist will advise you how to progress your stretching programme.

Caution

Never “bounce” when stretching. Stretches should be slow, smooth and sustained at all times.

If you are unsure how to perform a particular stretch, please don't hesitate to ask our physiotherapist. It is important to adopt the right position when stretching and do it correctly.

Add in stretching exercises here

GENERAL ADVICE FOR EXERCISE

- ❖ ALWAYS do a **warm-up** and **warm down**: (a more gentle form of your exercise and stretches) **before** you start and **after** your exercise. Start your aerobic session gradually then build up the intensity, slowing down at the end.
- ❖ **Take care not to 'over train' i.e. exercise for longer/harder than your 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.**
- ❖ Drink plenty of water or 'isotonic' drink (e.g. *Lucozade Sport, Gatorade, Isostar*) BEFORE, DURING AND AFTER exercise; **don't wait to feel thirsty.**
- ❖ Wear comfortable clothes, e.g. tracksuit, and wear trainers that will support your feet. Ask your physiotherapist for advice if you are not sure.
- ❖ If you use an inhaler, be sure to have it with you and use it appropriately.
- ❖ Be aware of 'normal' and '(rare) abnormal' responses to exercise. Exercise can cause many normal responses; these feelings are all positive and show that you are working well and making positive changes in your body (CBT?).
- ❖ Avoid exercising after a large meal.
- ❖ If you have a temperature (tested using a thermometer), stop exercising but **be sure to seek advice from your physiotherapist regarding how and when to re-start.**
- ❖ Avoid exercising late in the evening as it has a tendency to 'stimulate' your body and therefore not give you a 'wind down' before sleep; however, exercise early evening/afternoon can help prepare you for sleep later in the evening.
- ❖ Avoid exercising very first thing in the morning; your muscles/joints will usually need to 'get going' for a while. If this is the only time you can exercise, be sure to warm up and stretch sufficiently beforehand.

Your physiotherapist will be able to clarify any of the advice above; please feel free to ask questions if you have any queries or concerns

THE NORMAL RESPONSE TO EXERCISE

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

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.

- ❖ **Moderate or Intense stiffness – these feelings do not indicate harm to your body, but as they are uncomfortable, you may need to adjust your programme; ask your physiotherapist**

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.

RARE ADVERSE REACTIONS TO EXERCISE

IF YOU GET ANY OF THESE SIGNS, STOP EXERCISING AND DISCUSS WITH YOUR PHYSIOTHERAPIST OR GP.

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

If you feel anything else that is making you feel uncomfortable during exercise, be sure to discuss this with your physiotherapist or GP.

NOTES FOR USING THE EXERCISE RECORD

Why keep an exercise record?

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

1. It can be very motivating for you to see how you progress: it can really help to see your achievements on paper to recognise how well you are doing.
2. To help you and your physiotherapist negotiate the next level of exercise.
3. To help you and your physiotherapist establish whether there are any difficulties with your exercise plans and progress.

Important note

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



Using the Exercise Record, write down your exercise. Include the following:

Duration

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

Heart Rate

Record your average heart rate during the exercise, using your heart rate monitor.

Borg Scale of Perceived Exertion

Using the Borg Scale record the how hard you felt you were working at the most strenuous point of your exercise. Read the instructions carefully.

Comments

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

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

E.g. for a 7 minute walk, this means walking 3.5 minutes then turning around and walking back.

THE BORG SCALE

Instructions for Borg Rating of Perceived Exertion (RPE) Scale

While doing physical activity, we want you to rate your perception of exertion. This feeling should reflect how heavy and strenuous the exercise feels to you, combining all sensations and feelings of physical stress, effort, and fatigue. Do not concern yourself with any one factor such as leg pain or shortness of breath, but try to focus on your total feeling of exertion.

Look at the rating scale below while you are engaging in an activity; it ranges from 6 to 20, where 6 means "no exertion at all" and 20 means "maximal exertion." Choose the number from below that best describes your level of exertion. This will give you a good idea of the intensity level of your activity, and you can use this information to speed up or slow down your movements to reach your desired range.

Try to appraise your feeling of exertion as honestly as possible, without thinking about what the actual physical load is. Your own feeling of effort and exertion is important, not how it compares to other people. Look at the scales and the expressions and then give a number.

THE BORG SCALE

PIN Initials Date completed

Day Month Year

Read the instructions over the page and then rate the exertion you felt during exercise on the following scale:

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

ADVICE FOR STRENGTHENING EXERCISES

Why do strengthening exercises?

As well as your body being generally physically fitter, muscles also need to be strong to enable you to do physical activities during the day. For example, it takes muscle strength to climb the stairs, to wash your hair, to hang out washing, to undertake artwork, or to engage in Do-It-Yourself or gardening tasks in the home. It is also important to strengthen muscles if you are re-starting to exercise or trying a new physical activity or sport, so that you are strong enough to be able to do it. In essence: a stronger muscle will let you do more of the things you want to do.

How often should I do strengthening exercises?

It is best to try to work up to doing strengthening exercises daily if you can. However, you might start by doing them every second day to start with. It is better to do fewer repetitions more regularly than to do a long session all at once.

Where should I start?

Your physiotherapist will advise you where to start and how to progress. You will probably start with a low number of repetitions and then build up slowly, in the same way as you have increased your aerobic exercise.

When should I do strengthening exercises?

You can choose whether you would like to do them either all in one session, with maybe some rest breaks in between, or spread out throughout the day. Discuss this with your physiotherapist.

Recording your exercise

It can be very useful and motivating to keep a good record of the number of repetitions you are doing for each exercise, and how often you are doing them. This record will also be useful for your physiotherapist so please bring it along each time you visit. As you get stronger, you can notice how much you have progressed.

What should muscle strengthening feel like?

At the time, a strengthening exercise is likely to feel quite hard, and you may feel a burning sensation at the time. It is important that you reach this stage, because it is at this stage that the muscle can get a message to the brain to build more muscle and make you stronger. You may also feel heaviness in your muscles and maybe a bit of a 'jelly' feeling in them. These feelings are quite normal after a muscle has been exercised. As with stretches, although strengthening exercises may feel uncomfortable at the time, they should not give you sharp pain, or pain that gets worse over time. If you are not sure about whether your reaction is normal, speak to your physiotherapist.

ADD STRENGTH EXERCISES IN PLACE OF THIS PAGE

MUSCLE RELAXATION TECHNIQUE

Muscle relaxation

CFS/ME can be associated with muscle soreness. Some people describe this as a pain, or as a heavy or stiff feeling, or a muscle tension. Some people notice that their muscles feel tighter or firmer: these symptoms can be very uncomfortable. Some people notice that these symptoms can be related to physical activity.

There has been interest into why people with CFS/ME have muscle soreness, and it appears to be related to either a hypersensitive response to physical activity or due to delayed muscle soreness after unaccustomed exercise. Athletes tell us that when they exercise hard, they also get muscle soreness as a result of challenging their muscles. We believe that this symptom of CFS/ME is a normal response to increased exercise or physical activity, and that it can even be seen as a positive sign that our body is being challenged and is strengthening.

However, there may be times when these muscle symptoms can be uncomfortable, making it more difficult to manage physical activity. The good news is that our muscles respond well to techniques that make them feel less tension and more relaxed, improving the body's ability to heal and feel more comfortable.

When to use the muscle relaxation technique

You can practice this technique anytime that works for you. Some people choose to use relaxation when their symptoms are particularly uncomfortable, while others enjoy the ability to feel more comfortable before bedtime. Others will use relaxation after a period of exercise or physical exertion, to give the body time to switch off and gain real benefit from the period of rest. Others choose to use this technique in a warm bath, whilst winding down before bedtime; sometimes followed by some gentle stretching exercises. Other people find they can use this technique whilst on a bus, or even whilst sitting on a park bench. You can try different places and work out what works best for you.

Relaxation is a skill: it does not come naturally for most people, and to gain real benefit you will need to practise it frequently. It is recommended that you build up to using this technique for 20 minutes each day.

Instructions

Find yourself a comfortable place to sit or lie: using pillows to support you if this makes you more comfortable.

If you have other people living with you, it can be useful to tell them that you are relaxing and not to interrupt you: some people even find taking the 'phone off the hook can also be useful to gain maximum benefit from not being disturbed.

Relaxation script

“Relaxation is used by wise people in many different cultures in different ways, and has been shown over thousands of years to have significant healing effects. This particular form of relaxation will focus upon helping your **muscles** to feel more relaxed.

We know that as you really take the time to feel more relaxed, muscle tension can reduce and make you feel much more comfortable.

The first part of this technique will focus upon your breathing. As you sit, or lie in the position that is comfortable for you, just take a moment to become aware of your breathing pattern. There is no need to try to breathe in a particular way, just become aware of your own pattern.

You may notice the air as it comes in through your nose, and maybe even the feelings in your chest as you breathe that air in. Some people become aware of their abdomen rising and falling, or notice where exactly the air seems to end up in their chest. Just become aware of the sensations and feelings as you breathe in..... and out.... noticing the whole journey that the air takes from outside....to inside...to outside again.

Now some people notice that they breathe slightly higher in their chest, whilst their abdomen does not move as much, whilst others notice perhaps that their shoulders rise as they breathe. Others notice that their breath travels further down into their chest towards their abdomen – just notice what it feels like to breathe for you.

Now think about the rhythm of your breathing: it might be that your out- breath is longer than your in-breath, or maybe that your in- breath is longer than your out- breath, or maybe even that your in-breath and out -breath are about the same length. It really doesn't matter right now.

As you become aware of what is normal for you, you can now become more aware of a particular breathing pattern that will help you to feel better. It might be that you are breathing like this anyway, or it could be something new to you, but just take a moment to notice how the location of the breath and the timing of your breathing can have impact upon your health as we work through a techniques known as 'diaphragmatic breathing'. This breathing really makes use of our diaphragm – a large, flat muscle located at the bottom of our lungs: but sometimes we are not very good at using it to its maximum benefit. Sometimes we breathe more towards the upper part of our chest, or even use our shoulder or neck muscles in the process: muscles that are not well designed for this task. Diaphragmatic breathing is much more efficient than other types of breathing, and uses less energy to do. So it is well worth finding a way to practise it regularly.

When we really use our diaphragm to breathe, the breath is taken to a lower place in the chest... just notice that now as you start to feel that bit more comfortable... Try to direct the breath towards your abdomen allowing it to gently lift and fall.... Being aware that this is a comfortable breath that is more efficient and calming. Some people like to place a hand on their abdomen, just below the rib cage so they can feel the action of the diaphragm really working. You can either use your hand yourself, or simply be aware of your abdomen rising and falling...maybe you can feel your clothes against your skin as you breathe in and out. You might like to imagine a little balloon just under your ribcage filling and letting go gently as they do this. You can try this for a while, being aware that this type of breathing really helps your whole body system to relax.... (pause).

As one part of your mind concentrates on breathing to that lower place, another part of your mind can think about the timing of your breathing. We know that breathing longer on your out breath can be very relaxing ... just now direct your attention to the rhythm of your breath now and see whether you can make breathing out last a little longer. Some people find this difficult at first, and if so, don't worry, just try this for a while and gradually you can find it becomes easier and easier with time.

Some people like to count their in and out-breath, to help them get into a pattern: for you, it could be breathing in for 2 and out for 3 for 4, or perhaps counting a little faster you may find that the right pattern for you could be in for 7 and out for 11. Everyone is different, and you can now think about finding what works for you as you practise now.

As you feel more comfortably relaxed with each breath you take, you can become more aware of your body and the way it feels right now. It could be that your muscles are feeling relaxed already, or maybe that they feel a little uncomfortable. Either way, just find a way to accept how they feel right now, knowing that in the next few minutes and every time you do this technique, that they can feel more and more comfortable, and more and more relaxed.

You may notice that there are muscles that feel a little tighter: this could be around your jaw, neck or shoulders. Or it could be your tummy muscles or your scalp that feels slightly tighter. Wherever it might be for you, just notice how you can slowly let go of the tension within them: this might mean becoming aware of more space between your teeth, or perhaps just dropping your shoulders a little. Let go of the tension in these muscles, if you feel it wants to go.

It might be that you enjoy imagining your muscles melting slightly, or else softening gently in their place. An image that can be particularly helpful in muscle relaxation is imagining a cloud floating gently across your muscles, gradually absorbing tension from them, changing to a deeper colour as it goes: when you have finished, this cloud, full of the muscle tension from the day, can float away and disintegrate in the distance. Or you might like to think about your muscles feeling heavier or lighter, warmer, or floating or sinking comfortably. You can even create your own techniques...this is about working out what works for you, and as we work through your different muscles, you can choose and practise different things as you go along.

As we now take a journey around the muscles in your body, you may wish to concentrate for longer on some muscles than others: it may be that spending a shorter time on some may be appropriate: it's up to you.

It can be useful to concentrate first on your feet, and now just becoming aware of how they feel... it might be that you can feel your feet in your shoes, or maybe you are not wearing shoes and you can feel your heels on the floor or another surface. Whatever it is for you, just become aware of the position your feet are in, and allow them to be comfortable. You can now think about your cloud, absorbing tension from the day's physical activity, or perhaps concentrate on a light or sinking feeling in your muscles: whatever feels good.

Then you can take your attention further up your legs to below your knees, where you can allow your calf muscles at the back of your legs to relax more comfortably....(pause)... And now you can focus on your thigh muscles at the front of your legs... use whatever images or thoughts help you to feel more relaxed, as you allow your muscles to release their tension and instead be filled with a sense of comfort and warmth.

You can now take your attention to your buttocks and then your tummy, where you can allow yourself to soften into the chair or bed and let go of tension you might find.

As you let go, you can think about the muscles a little higher up in your tummy, and you may even find that you can become more aware of the muscles around your diaphragm, again focusing upon the rising and falling as you breathe in and out gently.

Now you've covered nearly half of your body, you can notice that feeling of relaxation travelling further up towards your chest - again feeling the rising and falling of your breathing. You can notice that as you feel more relaxed, your shoulders may have dropped, making the muscles around your neck and upper arms feel heavier, softer, warmer or even lighter.

You can then allow this feeling to float now towards your arms and your. Your hands can open now as they lie gently on your lap, or wherever they are comfortable. You may notice how much better they can feel in this opened position, where the muscles have chance to really rest.

You can take this feeling with you up your arms again and now direct it towards your neck – it might be that you enjoy the thought of gentle kneading at your neck muscles, or a feeling that the deeper muscles in your neck can gently unwind as you focus upon them.

You may find that there is more space now between your teeth as your jaw muscles relax and allow your face to feel more comfortable. This release can now be linked to smoothing out your forehead and allowing any tension to dissolve away.

Your head also has some tiny muscles that can do with some attention, and just focus upon these now, letting the top and back of your head feel warm and rested.

Now that you have given attention to every part of your body, just notice how simple it can be for your muscles to feel better. As your muscles feel better, they can get the rest they

need to restore themselves and allow you to feel more comfortable during the night and day.”

If you are using this session to help your muscles feel more comfortable for sleep, then you can go through the process again, noticing how more relaxed you feel as you go through a second, or maybe third time... allowing yourself to drift comfortably into a good night's sleep.

If you are using this during the day, then you might like to now just become slowly more aware of the room that you are in and when you are ready you can open your eyes and gently start to move your arms and legs, knowing that what you have just done will help you to be more comfortable and active during the day.

PROBLEM SOLVING TECHNIQUE

Sometimes things happen in life which will get in the way of your GET. There may be unexpected happenings, which distract you, affect your energy levels, or leave you with insufficient time to do your GET. Problem solving is one strategy which can be utilised in relation to this issue.

Problem solving is something we all do on a daily basis in relation to the activities we need to do. All that is being suggested here is a strategy that may generate alternative and more workable solutions. When involved in this process it is helpful to be as clear and concise as you possibly can as this in itself can provide an immediate solution to the problem as it avoids ambiguity, prevents misunderstandings and helps resolve any misconceptions.

Identify the problem

What is your problem? Try to define it as clearly and objectively as possible. In what way is it interfering with your GET?

What are the available solutions?

- Brainstorm possible solutions (what has previously worked). Revisit solutions you may have previously written off as impossible. Use your imagination and be creative. For example, if you have been asked to travel to attend something, can this be broken down into easier steps, as you would do with your exercise programme? Can it be incorporated into your GET programme?
- Can any of these potential solutions be modified in any way? Use your knowledge of your graded approach to activity to think about possible solutions.

Prioritise

- Prioritise solutions according to the time, resources and help available.
- Discuss possible solutions with others so they know what you can and cannot do, within the limits of your GET programme and illness. Sometimes saying “no” can be the best solution, to prevent this affecting your GET programme.

Select the most acceptable and workable solution

- Try it out. Does it allow you to adhere to your graded approach to activity?
- Review and re-select as necessary. The right solution on one occasion may be the wrong solution at another time.
- Summarise the problem and solution you have chosen.

Evaluate the effective strategy and re-visit the problem cycle

Remember to tackle one problem at a time

THERAPY INTEGRITY RATING SCALE

A) Alliance and facilitative conditions scale:

1. Supportive encouragement:

Was the therapist supportive of the client by acknowledging the client's gains during therapy, or by reassuring the client that gains will be forthcoming?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

2. Convey expertise:

Did the therapist convey that she/he understood the client's problems and is able to help the client?

1	2	3	4	5	6	7
not at all		some		considerably		very much

3. Therapist's communication style:

How interesting is the therapist's style of communication? (Consider (1) the vividness of her/his language; (2) the originality of her/his ideas; (3) the liveliness of her/his manner of speaking).

1	2	3	4	5	6	7
dull, uninteresting		less interesting		more interesting		very interesting
		than average		than average		

4. Involvement:

How involved was the therapist?

1	2	3	4	5	6	7
very detached		somewhat detached		mainly involved		very involved

5. Warmth:

Did the therapist convey warmth?

1	2	3	4	5	6	7
not at all or very little		some		a lot		very much

6. Rapport:

How much rapport was there between therapist and client (i.e. how well did the therapist and client get along?)

1	2	3	4	5	6	7
total	absences	some		considerable	excellent	
of	rapport	rapport		rapport	rapport	

7. Empathy:

Was the therapist empathic towards the client (i.e. did she/he convey an intimate understanding of and sensitivity to the client's experiences and feelings)?

1	2	3	4	5	6	7
not	at	some		considerably	extensively	
at	all					

8. Patient self-discloses thoughts and feelings:

1	2	3	4	5	6	7
not	at	somewhat		quite a bit		very much so
at	all					

9. Patient expresses strong emotions:

1	2	3	4	5	6	7
not	at	somewhat		quite a bit		very much so
at	all					

10. Patient works actively with therapist's comments:

1	2	3	4	5	6	7
not	at	somewhat		quite a bit		very much so
at	all					

11. Patient shows confidence in therapy and therapist:

1	2	3	4	5	6	7
not	at	somewhat		quite a bit		very much so
at	all					

12. Patient and therapist agree on the kind of changes to make:

1	2	3	4	5	6	7
not	at	somewhat		quite a bit		very much so
at	all					

13. Patient and therapist share same sense about how to proceed:

1 2 3 4 5 6 7
not at all somewhat quite a bit very much so

14. Patient and therapist agree on salient themes:

1 2 3 4 5 6 7
not at all somewhat quite a bit very much so

B) Therapy scales

CBT scale

1. Rationale for behavioural procedures:

Did the therapist provide a rationale which emphasised the importance for the client of undertaking specific activities in order to alleviate the client's symptoms?

1 2 3 4 5 6 7
not at all some considerable extensive
discussion discussion discussion

2. Practising/planning alternative behaviours:

Did the therapist work with the client to plan, or to practice alternative overt behaviours for the client to utilise outside of therapy?

1 2 3 4 5 6 7
not at all some considerably extensively

3. Rationale for cognitive procedures:

Did the therapist provide a rationale which emphasised the importance of evaluating the accuracy of the client's beliefs and changing inaccurate beliefs in order to alleviate the client's fatigue?

1 2 3 4 5 6 7
not at all some considerable extensive
discussion discussion discussion

4. Recognising cognitive errors:

Did the therapist help the client to identify specific types of cognitive distortions or errors (e.g. all-or-nothing thinking, over-generalisation) that were present in the client's thinking ?

1 2 3 4 5 6 7
not at all some considerably extensively

5. Searching for alternative explanations:

Did the therapist help the client to consider alternative explanations for events besides the client's initial explanations for those events?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

6. Maintaining gains:

Did the therapist encourage the continued use after the end of therapy, of the skills the client had acquired during therapy?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

Adaptive Pacing Therapy Scale

1. Rationale for balancing activity:

Did the therapist provide a rationale which emphasised the importance for the client of balancing activity?

1	2	3	4	5	6	7
not at all		some discussion		considerable discussion		extensive discussion

2. Practising alternating physical and mental activities:

Did the therapist work with the client to plan and or practice alternating physical and mental activities outside of therapy?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

3. Rationale for energy conservation and expenditure:

Did the therapist provide a rationale which emphasised the importance of energy conservation and expenditure?

1	2	3	4	5	6	7
not at all		some discussion		considerable discussion		extensive discussion

4. Discussion about the importance of prioritising certain activity:

Did the therapist discuss with the client the importance of prioritising activity?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

5. Discussion about the importance of activity analysis and modification:

Did the therapist help the client to analyse and/or modify specific activities?

1 2 3 4 5 6 7
not at all some considerably extensively

6. Importance of rest and relaxation

Did the therapist teach and practice rest and relaxation techniques with the client?

1 2 3 4 5 6 7
not at all some considerably extensively

Graded Exercise Therapy Scale

1. Rationale for use of exercise or physical activity:

Did the therapist provide a rationale which emphasised the importance and benefits of exercise or physical activity?

1 2 3 4 5 6 7
not at all some considerably extensively

2. Discussion about the content of a physical exercise programme:

Did the therapist discuss the content of a physical activity or exercise programme with the participant?

1 2 3 4 5 6 7
not at all some considerably extensively

3. Monitoring the physiological effects of exercise:

Did the therapist discuss ways of monitoring the physiological effects of exertion (heart rate/Borg rating scale) with the participant?

1 2 3 4 5 6 7
not at all some considerably extensively

2. Incremental Changes

Did the therapist emphasis the importance of incremental, progressive changes in physical activity or exercise?

1 2 3 4 5 6 7
not at all some considerably extensively

3. Adapting programme

Did the therapist discuss how the participant could adapt their exercise or physical activity according to their changing circumstances or goals?

1 2 3 4 5 6 7
not at all some considerably extensively

4. Physical goals

Did the therapist discuss, review or refer to the patient's physical goals?

1	2	3	4	5	6	7
not at all		some		considerably		extensively

C) Finally

Homework assigned/reviewed: (same for all therapies)

Did the therapist or client develop one or more specific assignments for the client to engage in between sessions?

1	2	3	4	5	6	7
did not		some attempt		considerable		extensive
	to develop		attempt to		attempt to	
	homework		develop		develop	
			homework		homework	

Overall, how would you rate the therapeutic alliance?

1	2	3	4	5	6	7
very poor		fair		good		excellent

Was this therapy session:

- Adaptive Pacing Therapy** 1
- CBT** 2
- Graded Exercise Therapy** 3

SELF PACED SUB MAXIMAL 2 MINUTE WALK TEST⁴⁶

Background

Functional walking tests measure functional status or capacity that can be used to help determine current physical capacity and change over time.

The participant is instructed to walk a 10 m level course (e.g. corridor/gym space) covering as much ground as possible in the two minutes. Distance walked, Borg and HR are recorded.

The self paced two minute walk test (2MWT) assesses the sub maximal level of a patients' functional capacity. The majority of patients do not achieve maximal exercise capacity during the two minute walk test. Instead they choose their own intensity of exercise, stopping for rests as required.

This test has been demonstrated to have good validity and reliability in amputee populations and cardiorespiratory domains.

Indications

Most people with CFS/ME who attend on an out-patients basis will be able to conduct this test: rests are allowed for those who need to. The TUAG or 1 minute sit-to-stand may be more appropriate for those who are severely impaired, e.g. those who are predominantly wheelchair users.

Location

Carried out in an enclosed quiet corridor or gym space.

Required equipment

2 cones / markers	2 Chairs: placed at each end of the course
10m course on level ground	Heart rate monitor
Stopwatch	Borg scale + instructions
Recording sheet	

Participant preparation

The heart rate monitor will be attached. The participant will have the aims of the test explained to them, and will be seated until they are ready to start. Water will be provided as required.

“The aim of this test is to give us an idea of your current walking ability. We can then do this test again later in the programme to work out what changes there have been. This particular test simply involves walking over a 2 minute period, while I take down measurements of your heart rate and gather an idea of how hard you feel the walking is for you.”

The resting HR is recorded.

At the beginning of the exercise test the Borg Scale should be shown, and the participant is asked:

“Based upon your activity today, please look at this scale and tell me how hard you feel your physical activities have been today. For example, you might report that you have not been very busy and that your overall exertion has been quite low, or else you may have already been quite physically active today.” (Read out Borg scale instructions and show Borg scale).

Instructions

“The object of this test is to walk as far as you can comfortably go in 2 minutes. You may stop and rest as needed. You will walk back and forth along the course set out for you. You can slow down, stop and to rest as necessary, sitting on the chairs if you need to. The time will continue to lapse during any rests that you take.

You will be walking back and forth around the cones/markers. You should pivot around the cones/markers and continue back the other way without hesitation.

Meanwhile I am going to keep track of the number of laps you complete. Remember that the object is to walk as far as possible, as fast as you are comfortably able to in 2 minutes but don't run or jog.

Start now or whenever you are ready”.

The participant should use any aids that they would do normally.

At the end of the test the Borg scale and end HR is again recorded, and then again after one minute recovery.

Measurement

Heart rate will be recorded to objectify effort and fitness at the beginning, end, and at recovery. The number of laps completed will be recorded. The number of stops used or any subjective data will be recorded. From this information an average speed can be calculated if required.

Baseline and recovery measures will be recorded immediately before the test and one minute after the end of the test.

SELF PACED 2 MINUTE WALK TEST RECORD

Name.....**PIN**.....

Physiotherapist..... **Date**.....

Time	HR	Borg	Distance (metres)	Stops required	Duration of rest	Speed (m/sec)	Comments
1st Assessment: Date –							
Pre test (sitting)							
Post test (sitting)							
1 min recovery							
Mid-way assessment: Date –							
Pre test (sitting)							
Post test (sitting)							
1 min recovery							
Final assessment: Date –							
Pre test (sitting)							
Post test (sitting)							
1 min recovery							

TIMED UP AND GO TEST^{50, 51}

Background

This test has proven to be a valid and reliable test for quantifying functional mobility. It is simple to carry out, requires little equipment, is repeatable and allows physiotherapeutic analysis of movement if required. It has previously been used and validated in frail elderly populations, but clinically proves a useful objective for patients with lower functional mobility levels.

The timed up and go (TUAG) test measures a participant's functional muscle strength as well as balance, and locomotor patterning.

Indications

The TUAG will only be relevant for those with CFS/ME with a significantly lower level of activity, e.g. those who are mostly wheelchair-users or those who have significant difficulty walking.

Location

This test can be carried out in any space that allows a distance of at least 3 meters to be covered with no obstacles. It is preferably situated in a gym or corridor location, although many clinic rooms will allow it to be carried out without having to move location.

Required equipment

Chair (standard height, non mobile with arms)	Borg scale + instructions
3 meter course (marked out)	Recording sheet
Stopwatch	Heart rate monitor

Participant preparation

The participant is seated in the chair with their back against the back of the chair. Arms may rest on the arms of the chair and any usual walking aid may be used.

Instruction

A heart rate monitor is applied to the participant. An explanation of the test is then given:

“The aim of the test is to give us a measure of both the current strength in your legs and your walking ability. We can then do this test again later in the programme to work out what changes there have been. The test measures the time taken to rise from the chair, walk along the set course towards a marker and then back, aiming to return to the chair and sit down”

At the beginning of the test the Borg Scale should be shown, and the participant is asked:

“Based upon your activity today, please look at this scale and tell me how hard you feel your physical activities have been today. You might, for example, report that you have not

been very busy and that your overall exertion has been quite low, or else you may have already been quite physically active today.” (Read out Borg scale instructions and show Borg scale).

The resting HR is recorded.

You will then give instructions for the test:

“When I ask you to start, you will stand up from this chair and walk at a comfortable and safe pace to the marker (or chair/cone etc) which is located 3 meters away. You will walk around the cone/marker and return to the chair and sit down again.”

The test is begun, the stopwatch started, and the time taken is recorded from the participant's back leaving the back of the chair to final sitting. After the test, the participant's HR is recorded and the Borg scale is repeated. After one minute of recovery time, the HR and Borg are again repeated.

TIMED UP AND GO (TUAG) TEST RECORD

Name.....PIN.....

Physiotherapist..... Date.....

	HR	Borg	Time to complete (seconds)	Comments
1st Assessment: Date –				
Pre test (sitting)				
Post test (sitting)				
1 min recovery				
Mid-way assessment: Date –				
Pre test (sitting)				
Post test (sitting)				
1 min recovery				
Final Assessment: Date –				
Pre test (sitting)				
Post test (sitting)				
1 min recovery				

ONE MINUTE SIT-TO-STAND TEST

Background

Sit- to- stand is a functional activity that requires a complex interaction between lower limb muscle groups. By carrying out a 1 minute sit to stand test, the functional strength as well as the endurance of lower limb muscle groups can be assessed and compared on different occasions.

Indications

Most people with CFS/ME will be able to conduct this test, even if they are significantly impaired. In CFS/ME patient populations it is useful to have a measure of not only general exercise tolerance and muscle strength, but the functional ability and response to repeating a task as may occur in daily life and function. It is particularly relevant as it gives a functional measure of quadriceps strength, which has shown to be reduced in CFS/ME populations.

Location

The test is extremely versatile and can be carried out in any area where there is access to a standard height chair. The test requires little other equipment. It should be noted that an identical chair should be used on repeating the measure.

Equipment

Chair (standard height, non mobile with arms) Stopwatch
Heart rate monitor Borg scale+ instructions
Recording sheet

Participant preparation

The participant is seated in the chair comfortably with arms resting on the arms if required. Aids can be used as would be in a normal situation.

Instructions

The heart rate monitor will be attached and the Borg scale will be explained. The resting HR is recorded.

At the beginning of the exercise test the Borg Scale should be shown, and the participant is asked:

“Based upon your activity today, please look at this scale and tell me how hard you feel your physical activities have been today. For example, you might report that you have not been very busy and that your overall exertion has been quite low, or else you may have already been quite physically active today.” (Read out Borg scale instructions and show Borg scale).

The test will then be explained.

“The aim of this test is to evaluate how many times you can stand and sit back on the chair in one minute. We can then do this test again later in the programme to work out what changes there have been. The aim is to stand up and sit down as many as you can comfortably. You must ensure your bottom comes all the way off the chair on each occasion. You can slow down, to stop and to rest as necessary, however the time will continue to lapse”

The participant is instructed to start when ready. The stopwatch is started as soon as movement begins.

Measures

Measures of heart rate and Borg scale rating are then taken directly after the test and then again after a final minute.

1 MINUTE SIT TO STAND TEST RECORD

Name.....**PIN**.....

Physiotherapist..... **Date**.....

	HR	Borg	Number of completed sit-stands	Comments
1st Assessment: Date –				
Pre test (sitting)				
Post test (sitting)				
1 min recovery				
Mid-way assessment: Date –				
Pre test (sitting)				
Post test (sitting)				
1 min recovery				
Final Assessment: Date –				
Pre test (sitting)				
Post test (sitting)				
1 min recovery				

Note for repeatability: What chair was used?

APPENDIX 1: GENERAL THERAPY SKILLS

Knowledge and skills required

As well as a sound knowledge of the aetiology, epidemiology, consequences and available treatments of CFS/ME, a range of skills will also be necessary in order to help you to engage and work collaboratively with these people.

Engagement

In order to engage the participant in treatment, it is important that the doctor conveys belief in the reality of their symptoms, distress and limitations. The therapist should be able to demonstrate a sound knowledge of CFS/ME 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 problems seriously. People with CFS/ME are often sensitive to the over-emphasis of psychological factors. In order to maintain participant’s engagement throughout treatment, it will be important that you continue to use a medical approach and do not imply that the illness is non-biological, purely psychological or all in the mind.

Warmth and Empathy

Empathy is something that we will hopefully tend to do with all patients without thinking about it. However, with this patient group it is particularly important. Often they have had their health problems for a long time. Many of them 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. They may 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 at your first meeting. The assessment provides a wonderful opportunity for participants to tell their story. Often it is the first time that they will have been able to go into detail about their problems. Allowing participants to elaborate on their illness often gives them the feeling that their illness is being taken seriously, often for the first time. Acknowledging the difficulties they have encountered along the way in terms of their illness, whether related to its impact on their life or response from other health professionals, etc, is important.

Sensitivity

Participants may not have had their illness taken seriously by previous professionals and may be concerned that you will be no different. They may think that you will be another “professional” who will tell them “to pull themselves together” etc. 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*. Although you cannot forever be thinking about whether or not you are going to offend them, it is worthwhile listening to and trying to use language that is not going to be

alienating. In general, it is best to use the language that the participant does to describe their symptoms. For example if a participant called their illness ME don't attempt to challenge this, ME or CFS is an appropriate term to use.

Collaboration

Collaboration is an essential skill in working with people with CFS/ME. Up to the point of meeting you, many participants will not have been included in the management of their illness. They may not have been asked their opinion about what is wrong with them and may feel rather helpless and out of control. Collaborating throughout treatment will help participants to feel more involved in their treatment and will help them to regain some sense of control.

Positive reinforcement

It is essential that you demonstrate positive reinforcement when you work with people with CFS/ME. Often, they will be very good at pointing out what they haven't achieved. 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, however small they may seem.

Establishing confidence in you as a Specialist

Establishing the participant's confidence in you as a therapist is important. This is likely to occur if you have knowledge of research into CFS/ME and use 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, rather than trying to answer it in a muddled way.

Encouraging optimism

Although it is important that you are realistic about the prognosis for participants, it is important that you encourage optimism about the progress that they may make. Although this has not been scientifically tested (to our knowledge), they are more likely to succeed if you encourage a positive expectation of therapeutic outcome.

Engaging Participants in SSMC

Do's:

- Ask what the participant what they would like to be called when you first meet
- Discuss the agenda for the appointment and ask the participant whether there is anything that they would like to add to it.
- Show empathy, warmth, sensitivity and understanding
- Give a clear explanation of the diagnosis using the participant's own words where possible.
- Be very positive about participant's attempts to help themselves to overcome their CFS/ME.

- Give participants the opportunity to discuss any fears or worries in relation to treatment.
- Tell the participant that you will look forward to seeing them over the coming year.
- Use language that participants will understand

Don'ts

- Get into an argument with the participant about their beliefs about the illness
- Minimize symptoms by saying something like 'we all get tired'
- Imply that the symptoms are imaginary

APPENDIX 2: MANAGING POTENTIAL DIFFICULTIES

The participant has a fixed physical attribution of illness

If participants are insistent that there is an ongoing “physical” problem, it is rarely helpful to directly challenge them on this point. It is important that you acknowledge that their illness is real but its effects can be reduced by the way they manage it.

The participant feels that a cause has been missed and wants further investigations

Some participants may feel that despite adequate investigations, something has been missed. The value and limitation of investigations may be explained. It may also be explained that whilst we can never guarantee that the participant does not have an alternative explanation for their symptoms it is very unlikely. . Clinical judgement is required in deciding to carry out any further tests. In general they should be done for a clinical indication rather than in response to a participant’s request

Participant deterioration

If you have a concern that a participant (in which ever therapy group) is deteriorating or there is evidence of suicide risk, deliberate self-harm, significant and prolonged illness progression, a severe adverse event this should be discussed with the centre leader immediately, so that the relevant course of action can take place. Please do this before the participant is given advice on what to do (whether continuing in or withdrawing from their therapy or from the trial).

Participant requests to withdraw from the trial

If a participant says that they no longer want to participate in the trial, i.e., they withdraw their consent, the centre leader should be informed on the same day, if possible. The centre leader or research nurse will then contact the participant to find out whether consent is withdrawn from further trial treatment only or further trial treatment and follow-up. The reason for drop-out should be ascertained if possible and passed on to the research nurse. The date of drop-out and reason (if known) should be recorded in the participant’s medical notes.

Cancellations, DNA s and missed appointments

If a participant does not attend it is worth considering a telephone appointment as an alternative. This will be done in the supplementary therapies. Cancellations or DNA’s should be rearranged within five working days if possible.

Telephone calls from participants

Telephone contact between sessions should be handled on an individual basis. It is not banned, but should be discouraged.

IMPORTANT CONTACTS AND PHONE NUMBERS

All public PACE trial enquiries should go to:

pace@qmul.ac.uk

Please do not give out any personal information to anyone not associated with the PACE trial: if in doubt, go through PACE management

Serious adverse events

In case of a serious adverse event (SAE), **immediately contact the clinic doctor, the RN or the centre leader:**

Local hospital cardiac arrest number:

GET CONTACTS

GET Therapy Leader:

GET Therapist at Royal Free:

GET Therapist at Bart's (1):

GET Therapist at Oxford:

GET Therapist at Bart's (2):

GET Therapist at Kings:

GET Therapist at Edinburgh:

CONTACTS FOR APT and CBT THERAPISTS

OT at Bart's (1):

OT at Kings :

OT at Edinburgh:

OT at Bart's (2):

OT at Royal Free:

OT at Oxford:

CBT Therapist at Bart's (1):

CBT Therapist at Kings :

CBT Therapist at Edinburgh:

CBT Therapist at Bart's (2):

CBT Therapist at Royal Free:

CBT Therapist at Oxford:

My centre leader is:

My Research Nurse is:

Trial Manager: Julia DeCesare

Principal Investigators: Prof Peter White, Prof Trudie Chalder, Prof Michael Sharpe