

# **Lessening the Impact of Fatigue trial**

in Inflammatory Rheumatic Diseases: a randomised clinical

## **The Personalised Exercise Programme Manual For Therapists**

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On behalf of the LIFT trial management group

This manual was developed for use by trained therapists in the LIFT trial. It describes a personalised exercise programme to managing fatigue in Inflammatory Rheumatic Disease (IRD) that can be delivered after brief training by physiotherapists who have experience of working with participants with IRD. The therapy has been tailored for delivery by internet-based calls or telephone. The manual is not a self-help manual and is not intended for use by untrained therapists.

## INTRODUCING THE PEP MANUAL

- This manual contains the information necessary to allow you to confidently apply the Personalised Exercise Programme (PEP) for participants with Inflammatory Rheumatic Disease (IRD).
- 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 the PEP, as well as additional information that is therapeutically useful.
- Additional information about study specific logistic and procedures, e.g. summary of protocol, Standard Operating Procedure for reporting of adverse events are located in the Appendix Logistics and Procedures at the end of the manual.
- 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 PEP, as well as examples and copies of all of the relevant worksheets.
- All work sheets and forms for therapists and participants are available for download from the study database <https://w3.abdn.ac.uk/hsru/lift>. Alternatively, more paper copies are available on request from the Trial Office Aberdeen via the study coordinator (01224 437228 or [lift@abdn.ac.uk](mailto:lift@abdn.ac.uk)).
- 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 LIFT 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 relevant Research Ethics Committee.
- This manual and the accompanying participant's manual are copyrighted and must not be reproduced without the permission.

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## **WHAT IS INFLAMMATORY RHEUMATIC DISEASE (IRD)?**

“Inflammatory rheumatic diseases” is an umbrella term to describe a number of related conditions in which the body’s immune system, designed to defend the body against foreign organisms and substances, instead attacks the body’s own cells.

They are characterised by pain and a consequent reduction in the range of motion and function in one or more areas of the musculoskeletal system; in some diseases there are signs of inflammation: swelling, redness, warmth in the affected areas. IRD can also affect internal organs;

IRD encompasses more than 200 different diseases which span from various types of arthritis to osteoporosis to systemic connective tissue diseases. Some of the most common IRDs are rheumatoid arthritis (RA), ankylosing spondylitis (AxSpA) systemic lupus erythematosus (SLE), all of which are included in the present study.

IRDs affect more individuals than any other disease group. In fact a third of people are affected at some point during their lifetime. They affect all ages and both genders, although women are more frequently affected than men.

### **What are the symptoms?**

There are different symptoms to IRD which include the following:

- Persistent joint pain
- Tenderness
- Inflammation indicated by joint swelling, stiffness, redness, and/or warmth
- Joint deformity
- Loss of range of motion or flexibility in a joint
- Extreme fatigue, lack of energy, weakness, or a feeling of malaise.

### **Diagnosis and treatment**

A definitive diagnosis of rheumatic diseases can be made by assessing the medical history, by performing a physical examination or ordering specific laboratory tests, and undertaking imaging investigations.

There is no single medication or treatment which is optimal for everyone. There are treatment options which help manage pain and control arthritis symptoms, many IRDs are treated with so-called disease modifying drugs (e.g. methotrexate) which have a more profound impact than drugs which reduce disease symptoms only; new biologic therapies are among these more effective agents, e.g. tumour necrosis factor alpha (TNF- $\alpha$ ) inhibitors Infliximab.

Medications are the traditional treatment for arthritis. But there are also: injections into a joint or the soft tissues, natural treatment (acupuncture, chiropractic ...), alternative medicines and surgical options. Patients vary in their response to treatments for arthritis.

*Source: based on 10 things you should know about rheumatic diseases [www.EULAR.org](http://www.EULAR.org)*

## WHAT IS FATIGUE?

Fatigue can be described as the lack of energy and motivation (both physical and mental). This is different than drowsiness, a term that describes the need to sleep. Often a person complains of feeling tired and it is up to the health care professional to distinguish between fatigue and drowsiness, though both can occur at the same time.

Aside from drowsiness, other symptoms can be confused with fatigue including shortness of breath with activity and muscle weakness. Again, all these symptoms can occur at the same time. Also, fatigue can be a normal response to physical and mental activity; in most normal individuals it is quickly relieved (usually in hours to about a day, depending on the intensity of the activity) by reducing the activity.

Fatigue is a very common complaint and it is important to remember that it is a symptom and not a disease. Many physical and/or psychological illnesses can result in the complaint of fatigue.

Often, the symptom of fatigue has a gradual onset and the person may not be aware of how much energy they have lost until they try to compare their ability to complete tasks from one time frame to another. They may presume that their fatigue is due to aging and ignore the symptom. This may lead to a delay in seeking care.

While it is true that depression and other psychiatric issues may be the reason for fatigue, it is reasonable to make certain that there is not an underlying physical illness that is the root cause

People with fatigue may have three primary complaints; however, fatigue is very individualised.

1. The person lacks the motivation or the ability to begin an activity;
2. The person tires easily once the activity has begun; and
3. The person has mental fatigue or difficulty with concentration and memory to start or complete an activity.

*Source: based on [http://www.medicinenet.com/fatigue/article.htm#fatigue\\_facts](http://www.medicinenet.com/fatigue/article.htm#fatigue_facts) by Benjamin Wedro, MD, FACEP, FAAEM*

## **FATIGUE IN INFLAMMATORY RHEUMATIC DISEASE (IRD)**

Many patients cite fatigue as their principal problem; sometimes even more disabling and distressing than pain. For example, as many as 80% of RA patients report significant fatigue, and over 70% consider fatigue to be equal to pain in terms of burden. Studies in AxSpA and SLE have found similarly high rates of fatigue (65-85%). Fatigue in IRD has a profound impact on quality of life and ability to work, yet the symptom of fatigue is often overlooked in routine management.

Fatigue is in fact a very common symptom across long-term health conditions, and in the general population. It may be because we have all experienced tiredness, and because tiredness commonly occurs in healthy people (e.g. after strenuous activity or unremitting work) that the symptom can sometimes be overlooked. Fatigue in IRDs differs from “normal” tiredness in its severity, the extent to which it impairs people’s daily activities, its persistence (that is, it is not susceptible to normal management) and its unpredictability.

For such a common experience, fatigue has proved troublesome to define and measure. Patients have argued that the term “fatigue” should be reserved for the subjective experience of feeling exhausted, weak, or wiped-out from their IRD; as such, it can only be measured by self-report. On the other hand, it is recognised that fatigue is often associated with loss of performance, such as inability or failure to carry out various actions, which can be measured by self-report or observational means.

While IRD-related fatigue may reasonably be attributed to the person’s IRD and while there are times when levels of experienced fatigue correlate with markers of disease activity, IRD-related fatigue can occur when the disease is less severe, and it can persist. In other words, the correlation between disease activity and fatigue is not always strong. We know that, in the general population, and in most long-term conditions, the presence of persistent fatigue is associated with distress and often with depression (indeed fatigue is a symptom of depression), and this can also be the case in RA related fatigue.

However, the nature of the relationship between fatigue and depression is not entirely clear, and it is also possible for people to be fatigued and not be depressed. Similarly, fatigue is often associated with poor sleep and sleep disorders. Fatigue is not necessarily synonymous with sleepiness, but may be exacerbated by poor sleep. Establishing more regular and better quality sleep patterns may be a goal of self-management. Equally, doing too much without a break may be related to fatigue in IRD, and this is often a cornerstone of self-management approaches.

IRD-related fatigue may have special features which therapists should be aware of. For example, there may be diurnal variations in fatigue – although these seem to follow a very individual pattern. Another potentially important feature of IRDs which may be associated with fatigue is a tendency to reduced aerobic fitness, probably resulting from lower activity levels, which may themselves be related to fatigue, pain and other symptoms. There is evidence that activity levels and fatigue are inversely correlated in the general population, and the same appears to be true in people with IRD.

*Source: The cognitive behavioural approach Manual for therapists by Karina Lovell, Sarah Hewlett, Alison Wearden, Emma Dures, Neil Basu.*

## **PROVIDING THERAPY BY TELEPHONE/INTERNET-BASED CALLS – GENERAL POINTS**

- Delivering PEP by telephone is similar to face to face but there are a few things that are different which we have found from patient and therapist experience. We will be covering it in the training but just as a reminder:
- Provide your credentials – ie name, role, part of LIFT study, where you are located and some details about yourself (ie 'I have been working as a rheumatology health professional for a number of years and work with both children and adults')
- Determine if client has any concerns re telephone therapy
- Explain that if there is a silence then this is because you are writing or thinking about what they have said (remember that silences face to face area sign of active listening but on the phone they are seen as a dysfluency or being cut off.
- Therapists who are not used to telephone sometimes think that the lack of visual cues lead to a reduction in the therapeutic alliance but our work has suggested that there is no difference in therapeutic alliance or engagement between face to face or telephone.

*Adapted from: The cognitive behavioural approach Manual for therapists by Karina Lovell, Sarah Hewlett, Alison Wearden, Emma Dures, Neil Basu*



## **PERSONALISED EXERCISE PROGRAMME (PEP)**

PEP 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. PEP differs from CBT by not specifically targeting cognitive factors.

### ***Essence***

The essence of PEP is to help the participant to gradually increase their physical activity and aerobic exercise. It involves a careful assessment of the participant's current physical capacity, and mutual negotiation of meaningful exercise and physical activity goals.

### ***Aim***

The aim is to gradually increase the level and intensity of the participants exercise and physical activity to, at least, the levels recommended by national guidelines. The overall objective is to help a participant to become independent in the integration of physical activity and exercise into their everyday lives.

### ***Theoretical model***

PEP assumes that IRDs are associated with deconditioning, reduced physical strength and altered perception of effort consequent upon reduced physical activity. Activity can 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'). 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 PEP apart from reversing deconditioning, including elements of habituation, and positive effects of re-engagement with important activities. PEP has also been shown to improve sleep, cognition, and mood, although these are not directly addressed by the treatment.

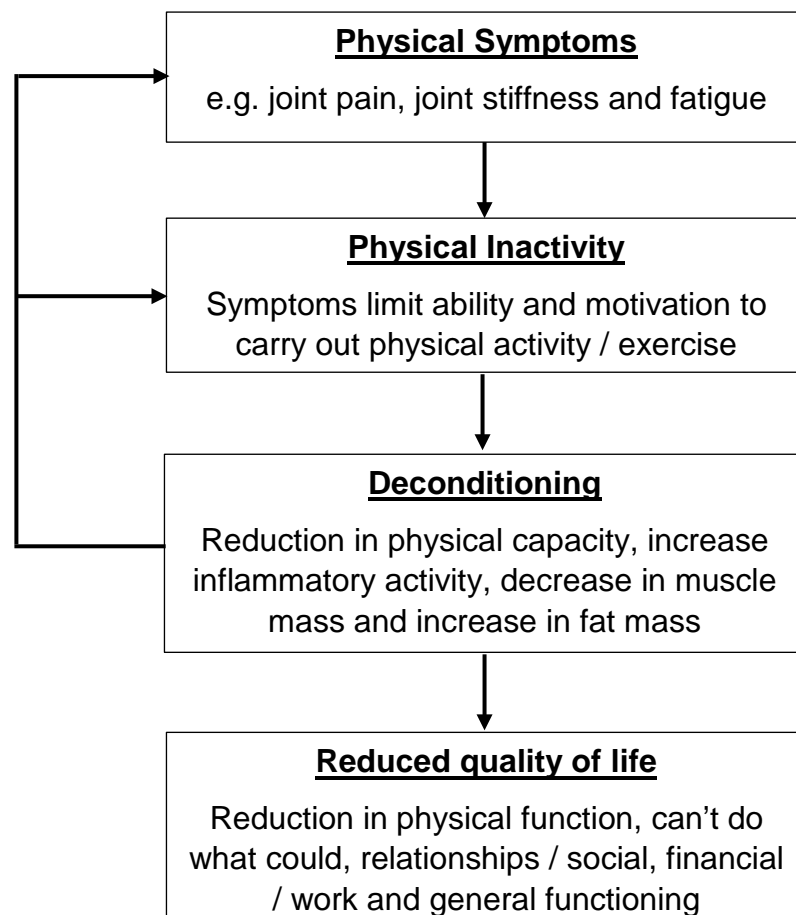
### ***Procedure***

Baseline physical activity is assessed and the duration of physical activity/exercise is then increased slowly and carefully 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. Activity is mutually reviewed on a regular basis and plans adjusted depending on general health and symptoms.

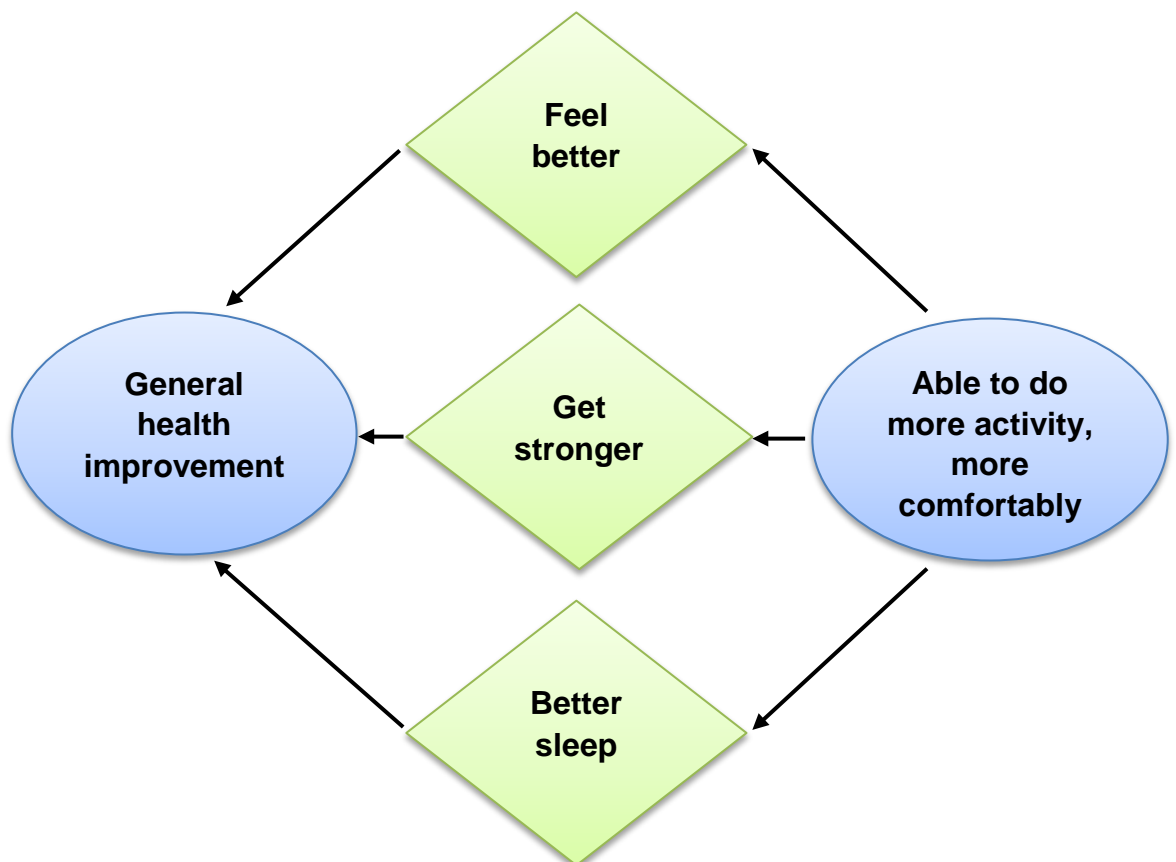
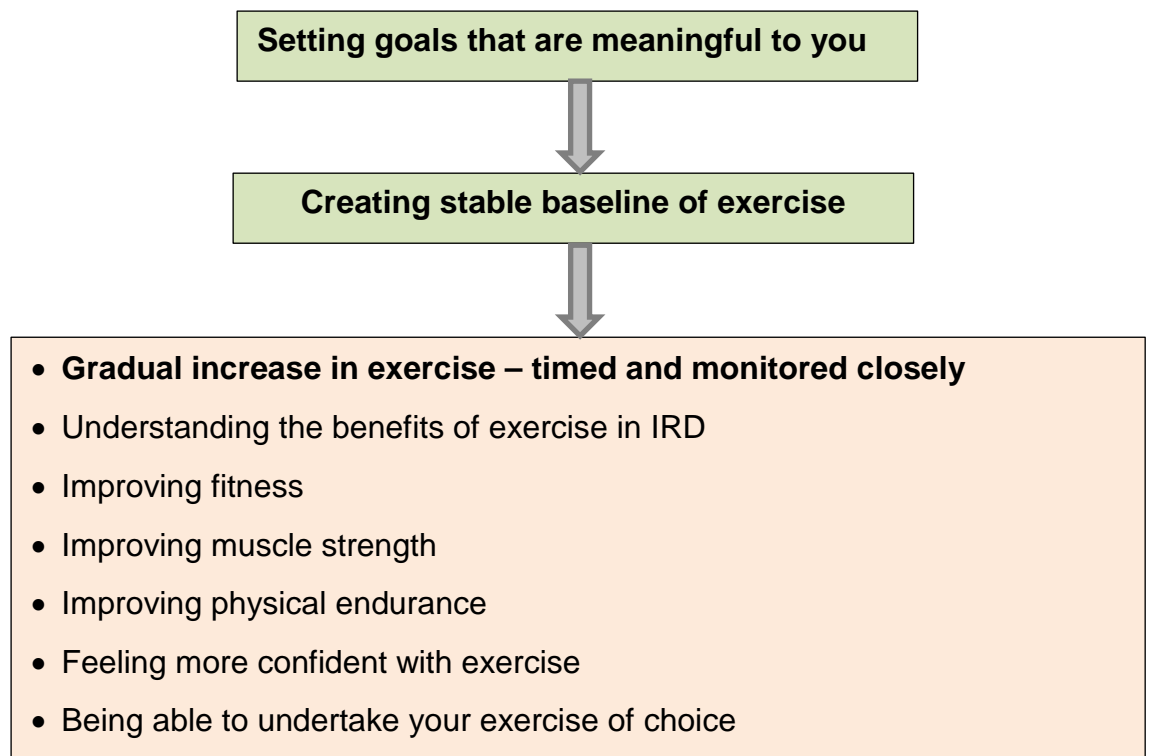
### ***Delivery***

The administration of PEP in this trial will be by a trained physiotherapist.

**Figure 1 - Explaining Inflammatory Rheumatic Disease: The Deconditioning Model**



**Figure 2 - Feeling Better With Exercise**





## IMPORTANT PEP CONSIDERATIONS

**There are a number of clinically important considerations for this programme**

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 increasing and sustaining exercise
9. The importance of achieving a healthy balance of exercise

### ***1. Individualising treatment***

Progress is determined by individual ability and symptoms. A physiotherapist should use their clinical reasoning to determine the rate of progress, within PEP guidelines.

Participants will respond differently; some will take a lot longer to adapt to each new level.

### ***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 different modes of exercise, such as cycling, swimming, a home exercise circuit or going to the gym. It is important to focus on activities which the participant enjoys.

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 at the best time of day for that participant to exercise. Some people with IRDs have more stiffness and pain early in the morning and therefore would benefit from exercising at another time. However, it is useful to allow some flexibility,

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

#### ***6. The importance of relying on HR, rather than a sense of effort***

The sense of effort is often not a reliable indication of physiological effort so where possible participants should use their heart rate response at the stage of gradually increasing the intensity of exercise/activity.

**However, due to the blunted heart rate response, participants taking beta blockers should use the Borg scale rather than HR.**

#### ***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 increasing and maintaining exercise***

It is important that therapists focus on the behaviour change techniques which evidence suggests are beneficial in terms of increasing and sustaining exercise behaviour.

In particular, the behaviour change techniques of goal setting, action planning and

feedback are integral to the programme however social facilitation and relapse prevention are also included.

### ***9. The importance of achieving a healthy balance of exercise***

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.

## **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 PEP 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. However, it is important that all participants receive the same general treatment at some time in the 8 sessions, and receive all of the essential elements relating to the PEP 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 exercise rather than to add **more** exercise to his day.

Checklists are present as a reminder, and do not need to be strictly adhered to if not appropriate. However, you will need to ensure that items not covered in one session are covered in subsequent sessions, and only omitted under clear clinical circumstances – e.g. if a participant already regularly attends a gym, they will not need to undertake the strength exercises. You **MUST** record any diversions from the manual clearly in your written notes and they must be justified clearly.

During the course of the PEP sessions you may identify additional needs or concerns relating to the participant, for example:

- a) *Participant has an active infection or flare of their condition*
- b) *Participant develops a musculoskeletal injury*
- c) *Another Physiotherapy need becomes apparent, e.g. longstanding back problem, frozen shoulder etc.*
- d) *Co-morbid condition limits exercise*
- e) *Therapist identifies a medical need that cannot be managed in PEP sessions*

**Any serious concerns or worries about the participant such significant and prolonged illness progression, or severe adverse events should be reported immediately (see Appendix Logistic and Procedures, so that the relevant course of action can take place.**

*a) Participant has an active infection or flare of their condition*

If the participant appears to have an active infection, 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.

If participants report a local or more generalised flare in their condition they should be encouraged to rest and to contact their GP or medical team if required. Participants may have their own definition of flare but it can be defined as an increase in symptoms which interferes with normal activities of daily living.

*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 PEP longer term, or if requires frequent physiotherapy treatment, discuss with centre leader / PEP 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.



*d) Co-morbid condition limits exercise*

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

*e) Therapist identifies a medical need that cannot be managed in PEP sessions*

If a separate medical need becomes apparent during one of the sessions, you are encouraged to use your own clinical judgment on in which direction to point the participant to receive additional care. Should you need further assistance regarding this participant, please use the notification system incorporated in the database (see Appendix Logistics and Procedures) to request additional support outside your regular supervision sessions.

## ENGAGING PARTICIPANTS IN TREATMENT

Engaging participants in PEP 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 PEP model; re-visit model frequently.
- Don't be tempted to start exercise too high or progress too quickly: start low, progress steadily.
- ALWAYS ensure the process is collaborative and that every stage is jointly negotiated.
- Ensure goals set are agreed and achievable.
- Always recognise achievements and congratulate participants on efforts to engage with PEP.
- Give participants the opportunity to discuss any fears or worries in relation to their PEP.
- Encourage participants to discuss and share their programme with their partner, friends or family as appropriate

## **EXERCISING SAFELY**

In addition to the normal health and safety aspects of exercise prescription of patients you should be aware of the following precautions:

If you discuss the use of participant-owned home exercise equipment or mobile phone apps 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.

Participants with axial spondyloarthritis should be advised to avoid contact or high impact exercise.

Discussing any other safety considerations with regards to:

- Asthma and inhalers,
- Appropriate footwear,
- Appropriate hydration, especially in hot weather,
- Other appropriate precautions relating to specific medical conditions.

**Always consider safety first.**

## CALCULATING EXERCISE INTENSITY

Exercise intensity is calculated for each individual. In this first instance this should be calculated using heart rate (HR).

### ***Calculating intensity via HR***

The participant's target HR zone is calculated from a universally accepted and understood method; a method used for normal, healthy people:  $(220 - \text{age}) \times 0.6-0.75$  to correspond to a desired HR range of 60-75% of each individual's maximum HR. As this figure is used for normal, healthy people, the objective is to work up to this figure gradually, and is unlikely to be a starting point.

**However, due to the blunted heart rate response, participants taking beta blockers should use the Borg scale rather than HR.**

### ***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.

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, 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. 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.

### **Examples of HR calculation**

<b>Information required</b>	Age
<b>Method</b>	220-age, x 0.6-0.75  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.
<b>Example 1</b> <b>Age: 27</b> <b>Rest HR: 86</b>	1. $220 - 27 = 193$ 2. $193 \times 0.6 = 115.8$ 3. $193 \times 0.75 = 144.75$ 4. Target exercise zone: 115 – 145 beats/min
<b>Example 2</b> <b>Age: 51</b> <b>Rest HR: 74</b>	1. $220 - 51 = 169$ 2. $169 \times 0.6 = 101$ 3. $169 \times 0.75 = 126.75$ 4. Target exercise zone = 100 – 125 beats/min

### **Calculating intensity via RPE**

If the use of a HR monitor is not possible then the Borg RPE scale can be used. For participants the target range would be RPE 11-13. Again with HR the expectation would be that participants would build up to the required intensity.

## **SELF-MONITORING OF EXERCISE**

It is important that participants self-monitor the type, duration and intensity of the exercise they undertake. This information will help them reflect on their current levels of activity, review progress made and also plan for future exercise progression.

If participants already own or use physical activity devices such as Fitbits, Jawbone, or apps on their smart phone such as myfitnesspal or S Health they will be encouraged to use those devices or apps. However, Fitbits and similar devices are not to be used to record the intensity. Where participants do not have these devices/apps the therapist will provide them with either a heart rate monitor or a pedometer (discussed previously). In addition, all participants will be taught how to take their pulse and how to use the Borg Scale to monitor the effort made during exercise as a measure of exercise intensity.

Exercise diaries (described below) will be used to record participant's physical activity and the information in the diaries will form the basis of the discussion during the telephone/internet-based call appointments.

### **USING THE BORG SCALE**

The participant should be shown the Borg scale and it should be explained how this is used this to help monitor their exercise. The target range is an RPE between 11 and 13. 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.

### **USING HEART RATE MONITORS (HRMS)**

Some participants will be given an ambulatory heart rate monitor so they can measure the intensity of their exercise (discussed previously). 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 early stages of the programme but then discontinue if the participant is coping well. Some participants 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

### **MEASURING HEART RATE MANUALLY VIA THE PULSE**

Due to an altered perception of effort some participants may 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. Participants should measure their pulse in the carotid or radial artery for 15s and multiply that figure by four to calculate their heart rate per minute.

## EXERCISE DIARY

### *Using an Exercise diary*

There are two types of Physical Activity and exercise Diaries. The Week 1- *Physical activity and Exercise diary* helps identify the participants level and pattern of physical activity. (see page 51 for an example). This can be helpful when negotiating the PEP programme.

For the rest of the trial participants complete weekly Physical Activity and Exercise Diaries, these records will note the type and duration of exercise, Borg scale, and average HR achieved (see page 60 for an example). This will also be used to plan the participant's exercise, as well as functioning as a motivational tool for the participant.

## **DOCUMENTATION**

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

### ***Therapy records***

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 RAP (Review, Analysis and Plan) notes and plans and an attendance record (Health Economics Therapist Log).

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 ID' given upon referral, which is to be added to all pages of LIFT paperwork.

There is an additional form for unplanned Phone Calls which may also include therapy advice.

You have the option to keep your records as hard copies with only minimal recording required in the database **or** record everything online in the study database (more information in the Appendix Logistics and Procedures).

### ***Reflective Practice Sheet***

After each treatment session, you will be expected to fill in a reflective practice sheet (example on next page, template see Appendix Logistics and Procedures) – this is to a) learn from achievements and challenges in the session, b) to share in supervision c) to make plans to change practice if necessary for the next session

### **How to complete the session paperwork**

- 1) 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.
- 2) After the session, you will record the duration of the session at the bottom of the checklist.
- 3) You will also need to record your RAP notes on the reverse, using the final section for any plans for the next session, including any agenda items that have not been covered.
- 4) You will need to sign and date each page, and print your name beside your signature.

If more space is required, a blank sheet can be added in chronological order.



## REFLECTIVE REVIEW OF LIFT SESSION - Example

Therapist name	Date	Session No
<i>Jane Bloggs</i>	0   9   M   a   y   2   0   1   7	1

### What went well?

*Instant connection with the participant, very engaged and interested in PEP*

### What did not go so well?

*Got a bit carried away and lost track of time, so had to rush to get through all the assessments*

### Would you do anything different next time?

*Set a reminder to the last 10 min*

### Were there any other difficulties encountered or questions you need to ask?

*Participant had difficulties to find clinic*

### Action plan and questions to clarify for next time:

*Check if participant has HRM, wanted to borrow from son  
Contact study coordinator to provide more details or map how to find clinic*



## **OUTLINE OF TREATMENT**

### **Number of sessions**

Participants will be offered up to eight sessions. The first session will be held face to face with the therapist and thereafter sessions will be either by telephone or internet-based calls depending on the preference of the participant.

It should be noted that it may not be possible for the participant to receive all 8 sessions, due to being unable to attend (UTA) or did not attend (DNA) that cannot be rearranged, holidays, festive periods or staff absence.

### **Frequency of sessions**

The sessions will initially be weekly and then less frequently as the participant becomes more independent.

Session 1	Week 0
Session 2	Week 1 (1 week later)
Session 3	Week 2 (1 week later)
Session 4	Week 4 (2 weeks later)
Session 5	Week 6 (2 weeks later)
Session 6	Week 10 (4 weeks later)
Session 7	Week 14 (4 weeks later)
Session 8	Week 22 booster (8 weeks later)

### **Duration of sessions**

All sessions will last up to 45 minutes.

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.

### **Audio-recording of therapy sessions**

Some of the sessions will be audio-recorded, this is a necessary part of the trial and participants will have consented to this. You find more information in the Appendix Logistics and Procedures.

## SUMMARY OF PEP SESSIONS

Session No	Week No	Time (min)	Summary	Homework
<b>PHASE 1: ENGAGEMENT, ASSESSMENT &amp; TREATMENT PLANNING</b>				
1 Face to face	0	45	<ul style="list-style-type: none"> <li>• Initial assessment</li> <li>• Overview of the PEP programme</li> <li>• Discussion of exercise goals</li> </ul> <p><u>Education</u></p> <ul style="list-style-type: none"> <li>• Use of pedometers</li> <li>• Use of exercise diaries</li> <li>• How to measure HR</li> </ul>	<ul style="list-style-type: none"> <li>• Monitor exercise/ physical activity for one week</li> <li>• Complete exercise diary and upload/ return to physio</li> <li>• Complete Exercise questionnaire</li> </ul>
2	1	45	<ul style="list-style-type: none"> <li>• Review exercise diary</li> <li>• Break down main exercise goal to smaller goals</li> <li>• Negotiate exercise goal for the next week</li> </ul> <p><u>Education</u></p> <ul style="list-style-type: none"> <li>• Setting SMART goals</li> <li>• Action Planning</li> </ul>	<ul style="list-style-type: none"> <li>• Complete exercise diary and upload/return to physio</li> <li>• Consider your SMART exercise goals</li> <li>• Write an action plan to achieve these goals</li> <li>• Return copy of goals and action plan to physio</li> </ul>
<b>PHASE 2: ACTIVE TREATMENT</b>				
3	2	45	<ul style="list-style-type: none"> <li>• Review exercise diary</li> <li>• Review SMART goals and action plan and revise as appropriate</li> <li>• Negotiate exercise goal for the next 2 weeks</li> </ul> <p><u>Education</u></p> <ul style="list-style-type: none"> <li>• Monitoring your heart rate and/or rating of perceived exertion for intensity</li> <li>• Importance of Social Support</li> </ul>	<ul style="list-style-type: none"> <li>• Complete exercise diary and upload/return to physio</li> <li>• Revise SMART goals and action plan if needed</li> <li>• Identify sources of social support and add to the action plan</li> </ul>

Session No	Week No	Time (min)	Summary	Homework
4	4	45	<ul style="list-style-type: none"> <li>Review exercise diary</li> <li>Negotiate exercise goal for the next 2 weeks</li> </ul> <p><u>Education</u></p> <ul style="list-style-type: none"> <li>Strengthening exercise</li> </ul>	<ul style="list-style-type: none"> <li>Complete exercise diary (including strengthening exercise) and upload/ return to physio</li> </ul>
5	6	45	<ul style="list-style-type: none"> <li>Review exercise diary</li> <li>Negotiate exercise goal for the next 4 weeks</li> </ul> <p><u>Education</u></p> <ul style="list-style-type: none"> <li>Identify activity barriers</li> <li>Relapse prevention</li> <li>How to manage a relapse</li> </ul>	<ul style="list-style-type: none"> <li>Complete exercise diary and upload/return to physio</li> <li>Identify barriers to exercise and how these can be overcome</li> <li>Record strategies for returning to exercise after a relapse.</li> </ul>
6	10	45	<ul style="list-style-type: none"> <li>Review exercise diary</li> <li>Negotiate exercise goal for the next 4 weeks</li> </ul> <p><u>Education</u></p> <ul style="list-style-type: none"> <li>The importance of sleep</li> </ul>	<ul style="list-style-type: none"> <li>Complete exercise diary and upload/return to physio</li> <li>Read material on sleep</li> <li>Prepare any questions/ areas for discussion during final session</li> </ul>
<b>PHASE 3: ENDING OF TREATMENT, PREPARING AND PLANNING FOR FUTURE SELF-MANAGEMENT</b>				
7	14	45	<ul style="list-style-type: none"> <li>Review physical activity diary</li> <li>Review programme to date</li> <li>Discuss future goal setting, action planning and managing relapse</li> </ul>	
8 Booster session	22	45	<ul style="list-style-type: none"> <li>Reflect on previous 8 weeks</li> <li>Discuss progress and activity barriers</li> <li>Discuss future activity goals including maintenance as appropriate</li> </ul>	

## HOW TO STRUCTURE TREATMENT SESSIONS

The following guidelines will help you to structure treatment:

- Read your previous session notes before the appointment with the participant.
- 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 (no more than 45 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 however this must be recorded.

Every session should contain the following:

- A review of homework and the exercise/physical activity diary.
- Exercise sessions achieved and not achieved should be reviewed; feedback and encouragement given.
- Motivational assessment.
- The opportunity to discuss any difficulties with adherence to the programme.
- Adapting the programme as necessary.
- Discussion of the educational component of the session
- Exercise for the period up to the next session negotiated and planned.
- Thorough written records and reflective practice sheet completed.

## **Sessions 1-2: Initial assessment (45 mins) and session 2 (45 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 PEP model
5. To discuss implications of activity cycling / 'boom/bust' patterns
6. To establish a baseline level of physical activity/exercise
7. To discuss SMART goals
8. To explain action planning
9. To explain the role of the exercise diary
10. To demonstrate how to monitor heart rate
11. To discuss the use of pedometers, smart phone apps and devices for self-monitoring
12. Emphasise the importance of homework tasks
13. 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 their PEP. You may try to cover the following points.

- 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 keep an appointment - so that you can rearrange one for them if possible.
- 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 be available on the phone or online at the appointment time (wherever possible) as you may have an appointment straight afterwards and would therefore be unable to

offer extra time.

- To have their participant manual and all of the worksheets completed to refer to during the phone/online appointments.

## **2. Subjective assessment, including function and exercise**

### *a) Review the clinical information on the study website (CHaRT)*

You will receive all available information regarding the participant from the study database, including results from the step test and estimated VO<sub>2</sub>max. Make a note on the PEP assessment form. In particular check the physical activity data (from the activPAL) and the step test results.

### *b) Undertake a subjective assessment*

- Note that it may not be necessary to review all symptoms and history in detail, depending upon details received in initial referral.
- 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.**

**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 associated Borg scale and objectively measured physical activity.

### **The purpose of the physical assessment is therefore:**

- 1) To establish general range of movement and muscle strength;
- 2) To establish the irritability of the participants joints and how likely they are to 'flare'
- 3) To assess specific sites of concern if they are relevant to the participant undertaking a PEP programme, e.g. spinal pain and range of movement for people with AxSpA, any areas of active joint inflammation



**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 PEP programme, e.g. osteoarthritis, previous injuries etc.**

#### **4. PEP model and reversibility**

Explain to participants that due to symptoms people often reduce their physical activity which leads to a cycle of deconditioning and an increase in symptoms. The PEP programme aims to reduce that cycle. The positive influence of exercise upon physical strength, endurance, cardiovascular fitness, fatigue, 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. Establishing exercise behaviours and avoiding 'boom/bust' patterns**

##### *Over Activity and Under Activity Cycle*

There are two main exercise behaviours with which people with IRD may present.

The first is a general low level of physical activity/exercise with possible fear avoidance behaviour. A combination of factors including aging, pain, habit may have led to low levels of physical activity and exercise. People with this pattern of activity should be supported to incrementally increase their levels of activity without significantly increasing their symptoms.

The second is the '**boom or bust**' cycle where physical activity levels fluctuate over time with people being 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. For people with this pattern of activity it is important to establish a baseline for every day physical exercise and activity before starting to progress the exercise. 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.

One of the purposes of the *Physical activity and exercise diary week 1*, is to establish whether the participant is currently showing signs of a boom/bust pattern or general low levels of physical activity and to help correct this.

## 6. Establish baseline level 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 on a regular basis (5 or 6 days a week), even on a 'bad day' without the participant's symptoms being made significantly worse. It is useful to review the objective physical activity data from the activPAL and the participant's physical activity diary from the first session to establish and negotiate this baseline.

You should explain that participants may experience a mild increase in fatigue, muscle stiffness/soreness or joint pain as a normal response to exercise, but that this response should not be so severe as to interfere with the normal daily activity.

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 (see also section 10 below). **Emphasise that the first part of the programme is about increasing duration only, and the heart rate is not a target at this stage.**

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.

## 7. To discuss SMART goals

Setting meaningful objectives is an essential component of PEP, 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.

Information within the participant manual will help with setting goals '**Smart goals and action plans**' and the '**Exercise questionnaire**'. These should be given to read and complete as a homework task if necessary. The exercise questionnaire can then be discussed at the next appointment. The '**Mutually Negotiated Goals**' sheet should be filled in and copied to ensure both participant and therapist have a copy.

A goal for PEP 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?

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

**Achievable** - are the goals realistic?

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

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

### 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:*

- a. Walking to the shops three times a week.
- b. Riding an exercise bike for twenty minutes every day.
- c. Weeding the garden for an hour at a time.
- d. Managing to vacuum the home all in one go.
- e. 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 '**Goal Setting: Breaking goals down into manageable steps**' worksheet will help to set short term goals.

**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 or playing football 5 times a week.**

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 PEP 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.

## **8. Action Planning**

Once the participant has determined the short term goal(s) they should be supported to plan how they will reach their goal using the '**Smart goals and action plans**' worksheet.

Participants may need help and advice to ensure that their action plans are appropriate, achievable and relevant to the goal(s) set.

## **9. Use of the exercise diary**

There are two exercise diaries for this trial. The **Physical Activity and Exercise Diary – Week 1** is used to provide detail on the participant's level and pattern of daily activity. This information can be used to help with goal setting and exercise planning.

From Week 2 onwards participants are given a different **Physical Activity and Exercise Diary** for each week to record the type, time and any comments in relation to the planned activity they are undertaking as part of the LIFT trial. Again, the information in the diaries should be used to discuss progress and to plan exercise for subsequent weeks.

## **10. Demonstration of measuring Heart Rate**

### **a) USING HEART RATE MONITORS (HRMs)**

Where appropriate participants will be lent an ambulatory heart rate monitor so they can measure the intensity of their exercise. 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.

Participants should be shown how to apply the HRM to their chest and how to read their HR.

### *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.
- 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 as a 'rough guide' only, and to let them know what their age adjusted maximum HR is.

### **b) MEASURING HEART RATE MANUALLY VIA THE PULSE**

Those with a normal Borg/HR relationship can rely on their Borg (described later) however it is useful to demonstrate to all participants, even those issued with HRMs, how to measure their pulse.

The pulse can be taken either via the carotid artery, in the neck, or the radial artery at the wrist. Participants should measure their pulse for 15s and multiply that figure by four to calculate their heart rate per minute.

### **11. Discussion on the use of pedometers/ physical activity apps and devices for self-monitoring**

Pedometers may be used where appropriate. Participants may have pedometers on their own smart phones or other devices which measure physical activity such as Fitbits or Jawbones which they should use. Pedometers are available for those participants who do not have devices. The study pedometers should be worn on the waistband or belt.

The main limitation of pedometers is that they primarily measure the number of steps taken and are therefore only useful for participants for whom walking is their main exercise activity. You may find that a participant will be motivated by seeing the number of steps they have taken or the distance they are walking daily.

Pedometers are useful in the early stages of the exercise programme when the participant is increasing their exercise duration by taking more steps (and hence, also increasing the distance walked). In the later stages exercise intensity is increased by walking faster i.e. taking more steps in the same time period or taking the same number of steps over a shorter time period. Thirty minutes of walking is approximately equivalent to taking 3000 steps. When 30 minutes of walking has been achieved it is important to try and increase the intensity of the exercise e.g. by taking 3000 steps but in a shorter time.

## **12. 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:**

- a. Reading participant information sheets e.g. Benefits of exercise, Smart goals and Action Plans.
- b. Completing the activity diary each week.
- c. Completing the Exercise Questionnaire.

## **13. 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 etc. If the participant scores themselves at 6 or under, you may need to discuss adjusting the exercise prescription so it is more achievable.

Participant ID

Date: ddmmmyyyy

## Session 1

### Session content

- Discuss length and content of session
- Outline number of sessions and treatment plan
- Give participant their manual
- Explain the rationale of the study and the potential effect of exercise on fatigue (pages 6 and 7 in the participant manual)
  
- Conduct a subjective/objective assessment
- Explore if the participant has an activity monitor e.g. smart phone app
- Give participants HRM/pedometers if they need one
- Demonstrate how to measure HR
- Explain the Borg scale
- Discuss how to complete and return/upload *Physical activity and exercise diary* Week 1
- Discuss and complete *What is Expected of the Participant* (checklist)

### Discuss homework:

- Complete *Physical activity and exercise diary* Week 1
- Read pages in manual as discussed
- Complete *Exercise Questionnaire*

### Encourage participant to read the following:

- What is the difference between exercise and physical activity*
- Benefits of exercise*
- How to monitor your exercise: Use of heart rate and Borg Scale*

### Paper work to complete after session:

- Complete *PEP assessment* form
- Complete session checklist (this page)
- Complete *What is required of the participant* checklist
- Complete RAP notes, including plans for next session
- Complete attendance record and book sessions if appropriate
- Complete reflective review of session
- Any adverse events? (*Please tick only one*) Yes  No

Session duration (minutes) \_\_\_\_\_

Signature \_\_\_\_\_

Date

ddmmmyyyy

Participant ID

Date:

## PEP ASSESSMENT FORM

<b>CURRENT STATUS</b>	
<b>DIAGNOSIS</b>	<b>CURRENT SYMPTOM PRESENTATION</b> (including pain, stiffness, fatigue)
<b>CURRENT MEDICATION, e.g. beta blocker</b>	
<b>SLEEP</b>	Other relevant information:
Initial insomnia Middle insomnia Early morning waking Daytime naps Refreshed?	
<b>CURRENT FUNCTIONAL CAPACITY</b>	
<b>Able to:</b>	<b>Unable to:</b>
<b>Target heart rate/zone (bpm)</b>	
<b>Activity patterns: (activPAL)</b>	
<b>VO<sub>2max</sub> from Step test</b>	



Participant ID

Date:

<b>HISTORY</b>	
<b>HISTORY OF PRESENT COMPLAINT</b>	<b>PAST MEDICAL/SURGICAL HISTORY</b>
<b>DRUG HISTORY</b>	<b>BALANCE/FALLS HISTORY</b>
<b>CURRENT EXERCISE</b>	<b>PREVIOUS/PREMORBID EXERCISE</b>
<b>SOCIAL HISTORY</b>	
<b>Leisure interests</b>	<b>Housing</b>
<b>Work/study:</b>	
<b>Hours:</b>	
<b>Social / family support</b>	<b>Lifestyle (Smoking/Alcohol/Diet)</b>

Participant ID

Date:

**OBJECTIVE OBSERVATIONS**

Gait	Walking aids / Orthotic insoles

**RANGE OF MOVEMENT / Relevant joint limitations**

UL:	LL:	Trunk/Neck:

**STRENGTH**

UL:	LL:	Trunk/Neck:

**Other:/Behaviour**

--

Participant ID 

--	--	--	--	--	--

Date: 

d	d	m	m	m	y	y	y	y
---	---	---	---	---	---	---	---	---

**A: Analysis and clinical reasoning**

**P: Plan:**

Signature

---

Date

d	d	m	m	m	y	y	y	y
---	---	---	---	---	---	---	---	---

Participant ID

Date:

## WHAT IS REQUIRED OF THE PARTICIPANT: CHECKLIST

The following checklist explains essential points that you will need to discuss with the participant during the first session.

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, uploading documents or are having any difficulties with the programme.

To contact you as soon as possible if they are unable 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 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 have the relevant sections of participant manual completed for each session to get the best out of their appointment.

Signature

---

Date

## Session 1 - Participant material

### WHAT IS THE DIFFERENCE BETWEEN PHYSICAL ACTIVITY AND EXERCISE?

**Physical activity** is defined as any movement that involves contraction of your muscles. Any of the activities we do throughout the day that involve movement: housework, gardening, walking, climbing stairs are all examples of being physically active.

**Exercise** is a specific form of physical activity - planned, physical activity performed with the intention of acquiring fitness, for example swimming and yoga.

All forms of exercise contain physical activity but not all physical activity is exercise.

In this trial we are really asking you to do **exercise**, because it's planned with the aim of improving fitness and reducing fatigue. As you will see from the definitions above the exercise in the LIFT trial isn't about going to the gym or taking up a new sport – unless of course you want to do that – it is about finding an activity you like which could be walking, and doing it a bit more or a bit harder and faster so that your heart rate goes up a bit.

## **Session 1 - Participant material**

### **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 and diabetes.

#### **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. Improvements in strength have also been linked to reductions in the risk of certain diseases e.g. heart disease and diabetes

#### **Endurance**

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

#### **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, and alongside increases in muscle strength may reduce the risk of falling.

#### **Immune System**

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

## **Session 1 - Participant material**

### **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)**

For some people regular exercise 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.

### **Weight Loss**

If you are overweight, aerobic exercise, when in combination with modification of your diet, 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.

## **Session 1 - Participant material**

### **HOW TO MONITOR YOUR EXERCISE (1): 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 hard the exercise feels, 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 alter your activity (for example by going faster or slower) to reach your desired range.

Try to appraise your feeling of exertion as honestly as possible, without thinking about the actual physical task. Look at the scales and the expressions and then give a number.

#### **The BORG SCALE**

### **HOW TO MONITOR YOUR EXERCISE (2): MEASURING YOUR HEART RATE**

#### **a) Measuring your heart rate manually i.e. taking your pulse**

The pulse can be taken either via the carotid artery, in the neck, or the radial artery at the wrist.

- Use the pads of the fingers of the index and middle fingers to find your pulse.
- Using a stopwatch or the second hand on your watch, measure your pulse for 15 seconds and multiply that figure by four to calculate your heart rate in beats per minute.

A normal heart rate is often quoted as 72 beats per minute but in fact 'normal' can be anything between 60 and 100 beats per minute.

#### **b) Measuring your heart rate using a heart rate monitor**

You may be given a loan of a heart rate monitor so that you can measure the how hard you are working during your exercise. This involves a strap that fits under your shirt that picks up the beat of your heart, and transmits this signal to a receiver on a watch.

The heart rate monitor will help you and your physiotherapist to measure the effects of your exercise programme, and ensure that your programme is progressed at the rate that is right for you.



## **Session 1 - Participant material**

### **Instructions for using heart rate monitors**

- It is essential that you wet the electrodes on the skin side of the monitor to ensure correct function.
- Place the heart rate monitor directly on your skin around your chest. For women, this is just underneath the bottom line of your bra.
- The heart rate monitor should be a snug but comfortable fit
- Wear the heart rate monitor only for exercising, not at any other times during the day.
- Be aware that the heart rate monitor can give incorrect readings if you are in close proximity to other people wearing heart rate monitors.
- Please let your physiotherapist know if your heart rate monitor isn't working.

## Session 1 - Participant material

### NOTES FOR USING THE PHYSICAL ACTIVITY AND EXERCISE DIARY – WEEK 1

The information gathered in this Physical Activity and Exercise diary will help you and your physiotherapist work out how much physical activity you are doing. This will help plan and progress your exercise.

Please note that the objective of this diary is to record your ACTUAL 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 and your responses to that activity.



**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 activity/exercise you did during the day, what you did and for how long
- **Symptoms:** Make a note of any important changes in your symptoms
- **Rest:** When, for how long, and how?

**You may also find it helpful to colour each block of time in terms of your feelings of fatigue. Periods of significant fatigue should be shaded in red, moderate fatigue yellow and minimal or no fatigue green.**

You find an example of a completed diary on the following page. A blank diary is located at the end of the manual (poly pocket) or you can download a word file from the database <https://w3.abdn.ac.uk/hsru/lift>.

You can also complete your diary directly in the database using your log-in card or send a paper copy via post to your therapist but please make sure that you keep a record for yourself.

Participant ID Start date: **PHYSICAL ACTIVITY AND EXERCISE DIARY – WEEK 1 Example**

	Time	Monday 8.5	Tuesday 9.5	Wednesday	Thursday
Morning	06:00				
	07:00	7.30 woke up, got up	7.15 woke up, 7.45 got up		
	08:00	15 min stretching	Rushed to get ready		
	09:00	30 min walk to work,	Took bus to work,		
	10:00	work 9.30 till 12pm; desk work	work 9.30 till 12pm; desk work		
	11:00				
Lunch	12:00				
	13:00	45 min lunch break	30 min lunch break		
	14:00	Desk work till 4pm	Desk work till 3pm		
Afternoon	15:00		Left early for GP appointment, take bus		
	16:00	20 min walk to shop, 15 min shopping	GP appointment, waiting for 45 min		
	17:00	Take bus home, 30 min rest (chair)	Take bus home, 45 min rest (chair)		
Evening	18:00	Prepare, eating dinner	Prepare and eat dinner		
	19:00	Watched TV	Do household chores		
	20:00				
	21:00	21.30 went to bed + read book	21.30 went to bed + read book		
Night	22:00	22.20 fell asleep	10pm asleep		
	23:00				
	24:00				

Participant ID

Start date:

**PHYSICAL ACTIVITY AND EXERCISE DIARY – WEEK 1 Template**

	Time	Monday	Tuesday	Wednesday	Thursday
<b>Morning</b>	06:00				
	07:00				
	08:00				
	09:00				
	10:00				
	11:00				
<b>Lunch</b>	12:00				
	13:00				
	14:00				
<b>Afternoon</b>	15:00				
	16:00				
	17:00				
<b>Evening</b>	18:00				
	19:00				
	20:00				
	21:00				
<b>Night</b>	22:00				
	23:00				
	24:00				

Participant ID

Start date:

	Time	Friday	Saturday	Sunday
<b>Morning</b>	06:00			
	07:00			
	08:00			
	09:00			
	10:00			
	11:00			
<b>Lunch</b>	12:00			
	13:00			
	14:00			
<b>Afternoon</b>	15:00			
	16:00			
	17:00			
<b>Evening</b>	18:00			
	19:00			
	20:00			
	21:00			
<b>Night</b>	22:00			
	23:00			
	24:00			

## Session 1 - Participant material

### 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.

Complete this sheet to help work out what exercise might form a part of your PEP 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)	

**Session 1 - Participant material**

**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*)**

a)	
b)	
c)	
d)	
e)	

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

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

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

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## Session 1 - Participant material

### 7. Apart from improving your symptoms, what other benefits of exercise interest you? *(Please tick all that apply)*

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



Participant ID

Date: ddmmmyyyy

## Session 2

### Session content

Discuss length and content of session

Review Week 1-*Physical activity and exercise diary* and establish baseline activity

Discuss SMART goals and set mutually agreed goals (max 3)

Explain Action Planning

Negotiate Physical activity and exercise goals for the next week

### Discuss homework:

Complete week 2 *Physical activity and exercise diary*

Record SMART exercise goals (3 maximum) and prioritise

Chose one goal and break down into manageable sections

(*Goal Setting: breaking down goals into manageable steps*)

Write an action plan

Return copies of Diary, SMART goals and Action Plan to the physio

### Encourage participant to read the following:

*Smart goals and action plans*

### Paper work to complete after session:

Complete session checklist (this page)

Complete RAP notes, including plans for next session

Complete attendance record and book sessions if appropriate

Complete reflective review of session

Any adverse events since last session? (*Please tick only one*) **Yes**  **No**

*If yes, please confirm with participant if this has been recorded previously and complete the report form, if required*

Session duration (minutes) \_\_\_\_\_

Signature \_\_\_\_\_

Date

ddmmmyyyy

Participant ID 

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Date: 

d	d	m	m	m	y	y	y	y
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**RAP notes Session 2**

<b>R: Review of returned documents and participant homework discussed</b>
<b>A: Analysis and clinical reasoning</b>
<b>P: Plan:</b>

Signature

Date

d	d	m	m	m	y	y	y	y
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Participant ID 

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Date: 

d	d	m	m	m	y	y	y	y
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## NOTES FOR USING THE PHYSICAL ACTIVITY AND EXERCISE DIARY

### 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
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 PEP to need to change or adapt a programme, but this can only be done if the feedback you give accurately represents your situation.



**Using the Physical activity and Exercise diary, write down your exercise.**

Include the following:

- **Duration**

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

- **Heart Rate**

Record your average heart rate during the exercise, using your heart rate monitor or by taking your pulse.

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

Participant ID Week: Start date: **PHYSICAL ACTIVITY AND EXERCISE DIARY - Example**

Date	Type of exercise	Duration (exactly)	Average Heart Rate	Borg	Comment
15.5.2017	<i>Stretching</i>	<i>13.5 min</i>	76	11	<i>Manual heart rate, was really stiff so had to stop earlier</i>
16.5.2017	<i>Stretching</i>	<i>15 min</i>		10	<i>Had good night sleep, quite awake</i>
16.5.2017	<i>Walking to work half way</i>	<i>8 min</i>		13	<i>Had to get bus half way as getting too tired</i>
18.5.2017	<i>Stretching</i>	<i>10 min</i>		12	<i>Running late for work so had to stop early</i>
19.5.2017	<i>Walk the dog with neighbour</i>	<i>20 min</i>		14	<i>Forgot the time chatting away and walked longer than planned</i>
20.5.2017	<i>Vacuuming carpet</i>	<i>5 min</i>		15	<i>Exhausted from yesterday</i>

Participant ID

Week:

Start date:

**PHYSICAL ACTIVITY AND EXERCISE DIARY - Template**

Date	Type of exercise	Duration (exactly)	Average Heart Rate	Borg	Comment

## **SMART GOALS AND ACTION PLANS**

### **Why is goal setting important?**

Goal setting is a major component to long-term success. The steps you take to achieve your goal are like the road map that helps you get to your destination. When you have a certain end point in mind you stay focused towards the goal.

Goal setting allows you to define where you want to go and how you are going to get there. It helps you focus and allocate your time and resources efficiently

Goal setting allows you to measure progress and also help you believe in yourself, and can keep you motivated

### **What is meant by a SMART goal?**

You should try and set SMART goals. This can take a bit of time but it is time well spent. SMART stands for -

**S** – Specific (precise, clear and simple)

**M** – Measurable (can I measure in some way if I have achieved the goal?)

**A** – Achievable (is it possible?)

**R** – Relevant-realistic (to provide the purpose)

**T** – Time bound (when should this be done by?).

Participant ID 

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### MUTUALLY NEGOTIATED GOALS - Example

Date: 

d	d	m	m	m	y	y	y	y
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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.

 **Chose three main goals, these will form the focus for the PEP programme**

Goal number	Goal	Time scale	Measure	Outcome
1	<i>Being able to swim two lengths twice a week</i>	6 weeks	<i>Number of lengths, number of days per week</i>	
2	<i>Going out with friends</i>	4 weeks		<i>Enjoy social time</i>

Participant ID

### MUTUALLY NEGOTIATED GOALS - Template

Date:

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.

 **Chose three main goals, these will form the focus for the PEP programme**

Goal number	Goal	Time scale	Measure	Outcome



Participant ID

**GOAL SETTING: BREAKING GOALS DOWN INTO MANAGEABLE STEPS - Example**

Date:

Goal number:   1   *Being able to swim two lengths twice a week*

	Description of step
<b>Step 1</b>	<i>Find out about the times and prices of the swimming pool</i>
<b>Step 2</b>	<i>Schedule a good day into my diary</i>
<b>Step 3</b>	<i>Go to the swimming pool and swim across and back</i>
<b>Step 4</b>	<i>Go to the swimming pool and swim across and back (twice per week)</i>
<b>Step 5</b>	<i>Go to the swimming pool and swim one length (once per week)</i>
<b>Step 6</b>	<i>Go to the swimming pool and swim one length (one way) and one across and back (once per week)</i>
<b>Step 7</b>	<i>Go to the swimming pool and swim one length (one way) and one across and back (twice per week)</i>
<b>Step 8</b>	<i>Go to the swimming pool and swim two lengths once per week</i>
<b>Step 9</b>	
<b>End goal</b>	<i>Being able to swim two lengths twice a week</i>

Participant ID

**GOAL SETTING: BREAKING GOALS DOWN INTO MANAGEABLE STEPS - Template**

Date:

Goal number: \_\_\_\_\_

	Description of step
Step 1	
Step 2	
Step 3	
Step 4	
Step 5	
Step 6	
Step 7	
Step 8	
Step 9	
End goal	

Participant ID 

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### Action planning - Example

Once you have set your goals it is important to plan how you are going to meet those goals. This may involve breaking the SMART goals into smaller steps and working through these steps helps you reach your goal.

The table below gives you examples of some questions you might ask yourself as you are planning how you will achieve your goal or step towards that goal.

<b>What is my SMART goal or Step towards my SMART goal?</b>	<i>Go to the swimming pool and swim across and back (twice per week)</i>
<b>My planning</b>	
<b>How I will do it?</b>	
<b>When?</b>	<i>Monday and Thursday afternoon</i>
<b>Where?</b>	<i>The swimming pool</i>
<b>Who with?</b>	<i>My friend Barbara</i>
<b>What difficulties could I face?</b>	<i>Too tired from work</i>
<b>How I will overcome them?</b>	<i>Take a lunch break</i>
<b>How I will know I have achieved my goal?</b>	<i>Went to the pool and swam, did laundry of wet swimming clothes afterwards</i>

Participant ID 

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### Action planning - Template

Once you have set your goals it is important to plan how you are going to meet those goals. This may involve breaking the SMART goals into smaller steps and working through these steps helps you reach your goal.

The table below gives you examples of some questions you might ask yourself as you are planning how you will achieve your goal or step towards that goal.

<b>What is my SMART goal or Step towards my SMART goal?</b>	
<b>My planning</b>	
<b>How I will do it?</b>	
<b>When?</b>	
<b>Where?</b>	
<b>Who with?</b>	
<b>What difficulties could I face?</b>	
<b>How I will overcome them?</b>	
<b>How I will know I have achieved my goal?</b>	

## Sessions 3-6 – Each lasting no longer than 45 mins

### Purpose of Phase 2:

After setting meaningful goals and establishing a baseline level of physical activity, process for PEP has 6 main components:

1. Increasing exercise duration at low intensity
2. Increasing the intensity of the exercise to target HR
3. Developing strengthening routine
4. Encouraging variety, flexibility and social integration and support
5. Planning for, and managing, setbacks (relapses)

Successful PEP will also include:

6. Encouraging an appropriate warm-up and cool-down
7. Encouraging a good night's sleep

### Personalised Exercise Programme - prescription

The PEP is a graded programme of exercise which follows the basic principles of exercise prescription for healthy individuals, based on the Department of Health guidelines for physical activity but adapted to the participant's current capacity.

The PEP has two components exercise/physical activity of 150 minutes week at moderate intensity to increase fitness and strengthening exercises for the major muscle groups performed twice a week. Participants should continue with any stretching programme they may have been prescribed from their physiotherapist or other health care professional.

### Aerobic Exercise

#### Concepts of aerobic exercise planning and progression:

1. **Frequency:** Starts and remains at 5-6 days out of 7
2. **Duration:** Starts at a comfortable baseline, then increases gradually to 30 mins per day (up to 150 minutes week)
3. **Intensity:** Starts low, then progresses gradually to target heart rate/RPE

#### 1. Increasing exercise duration at low intensity

Before an increase in aerobic exercise **intensity** is considered, the first stage of PEP 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 of exercise/physical activity has been established 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.

The **duration** of exercise should then be slowly increased, without an increase in HR / intensity, to around 30 minutes. Thirty minutes of walking per day is equivalent to around 3,000 steps. 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 has difficulty finding 30 minutes for exercise, or someone who finds it difficult to exercise continuously for 30 minutes.

## **2. 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 (or RPE) of their current 30 mins of exercise is recorded. The HR can then increase by 10-20% (or the RPE by 1-2 points) in incremental stages in order to achieve their ultimate target HR (or RPE), 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 (HRMs) 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.

## **3. Developing a strengthening programme**

Strengthening exercises should be undertaken twice per week according to physical activity guidelines. This is usually considered at in Session 4. The participant should be encouraged to undertake strengthening exercises of the major muscle groups of the limbs and trunk twice per week. Resistance can be provided by the participant's own body weight or 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.

If a participant has joint pain they may have to begin with isometric exercise before progressing to resistance exercise. Any change in symptoms should be noted in the exercise diary and the programme amended if the strengthening programme leads to a

significant local or systemic increase in symptoms or flare.

#### **4. Encouraging variety, flexibility and social integration and support**

The final stage of PEP 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.

Evidence shows that social support is an important factor in improving physical activity and exercise. Social support can be provided by family, friends, work colleagues, on-line forums and can involve practical, physical support i.e. exercising with the participant or psychological support i.e. providing verbal encouragement and reinforcement. Participants should be encouraged to identify people who can provide social support and use that support to facilitate positive behaviour change.

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.

You might want to consider how the participant will exercise during the winter, when they may be less likely to walk or exercise outside.

#### **5. Preventing and managing setbacks**

Setbacks, also called relapses, are common for anyone undertaking an exercise programme. Relapses can occur due to an exacerbation of their symptoms or due to another unrelated health issue such as a chest infection. Other causes of relapses may be emotional distress and/or other personal circumstances such as family issues, bereavement, employment issues or holidays. It is normal, and likely, that participants will suffer setbacks throughout the PEP 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 PEP programme may have contributed towards the relapse, and to adapt the plan if necessary

**Session 5** will encourage the participant to consider their activity barriers and also to discuss strategies a) for relapse prevention and b) for managing a relapse should it occur.

Where possible participants should try and maintain some level of exercise during their relapse however it is also important that participants return to their programme following the relapse. When they return to their programme they should be aware they may have to reduce the intensity and/or duration of their exercise programme and gradually progress again as discussed above.

## **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.

## **7. Encouraging a good night's sleep**

A good night's sleep is especially important. Severe insomnia has been found anecdotally to be one of the barriers to successful PEP whilst sleep deprivation has been found to increase the perceived effort felt during exercise. Sleep advice is given in **Session 6**.

### **Purpose of sleep advice in PEP:**

1. To allow the participant to feel subjectively refreshed and therefore more able to conduct PEP.
2. To allow physiological processes of growth and repair to occur, and hence allow PEP to continue comfortably.



Participant ID

Date:

### Session 3

#### Session content

Discuss length and content of session

Review *Week 2 Physical activity and exercise diary*

Review and Revise Goals and action plan as appropriate

Discuss possible barriers to exercise

Discuss the importance and forms of social support

Negotiate Physical activity and exercise goals for the next 2 weeks

#### Discuss homework and write plan in notes:

Complete weeks 3 and 4 *Physical activity and exercise diary*

Add sources of social support to the action plan if appropriate

Revise Goals and action plan as appropriate

Complete the Barriers to Exercise and Social Support Activities

#### Encourage participant to read the following:

*General advice for exercise*

*Normal response to exercise*

#### Paper work to complete after session:

Complete session checklist (this page)

Complete RAP notes, including plans for next session

Complete attendance record and book sessions if appropriate

Complete reflective review of session

Any adverse events since last session? (*Please tick only one*)

*If yes, please confirm with participant if this has been recorded previously and complete the report form, if required*

Yes

No

Session duration (minutes) \_\_\_\_\_

Signature

Date

Participant ID

Date:

**RAP notes Session 3**

**R: Review of returned documents and participant homework discussed**

**A: Analysis and clinical reasoning**

**P: Plan:**

Signature

Date

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## Session 3 - Participant material

### GENERAL ADVICE FOR EXERCISE

These instructions are generally for 'sport type activity' rather than walking or other forms of 'normal' activity

- ALWAYS do a **warm-up** and **warm down**: (a gentler 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.
- If your joints get more painful or swollen stop the exercise and take advice from your physiotherapist. A bit more pain might be expected when you start an exercise you haven't done for a while but this should not be severe or prolonged.
- **Take care not to do too much 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
- 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
- Avoid exercising after a large meal.
- If you have a temperature or infection, 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**

## Session 3 - Participant material

### THE NORMAL AND ABNORMAL 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. 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 fuel 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 widen when you are warm to help keep you cool.

#### **Sweating**

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

#### **Increased temperature**

You will feel warmer 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.

#### **Slight increase in joint pain**

Starting a new exercise programme often leads to some aches and pains. These should not be too painful nor long lasting.

## Session 3 - Participant material

### 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 and sometimes tender. This response can last for a day or two but normally only occurs the first couple of times you perform exercise.

**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.

## ***RARE ADVERSE REACTIONS TO EXERCISE***

***IF YOU GET ANY OF THESE SIGNS, STOP EXERCISING AND DISCUSS WITH YOUR PHYSIOTHERAPIST / GP OR if you feel it is more serious call 111 / 999 if out of hours***

- **Breathing becoming out of control**
- **Wheezing**
- **Chest pains**
- **Collapse or faintness**
- **Injuries**
- **Severe joint pain**

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

## Session 3 - Participant material

### BARRIERS TO EXERCISE

**Exercise barriers** are barriers that prevent you from doing physical activity or exercise.

- Common barriers to doing exercise include:
- Do not have enough time to walk
- The weather – e.g. 'it's raining', 'it's too cold'
- Lack of motivation, can't be bothered, 'I don't feel like it'
- Don't enjoy exercise
- Lack confidence to exercise,
- Lack encouragement, support, or companionship from family and friends
- Don't have anywhere convenient to go to exercise eg. Safe parks, walking paths, sport or leisure centres
- Lack of childcare
- Cost

#### How can we overcome these barriers?

**Problem solving** is a process that includes identifying the problem, generating a number of possible solutions, then selecting the most appropriate solution for you and finally evaluating if that solution works.

#### Here are some barriers and suggestions to overcome these barriers

**a) Too tired** - Everyone feels tired at times; so its common barrier to exercise.

- ✓ Break your activity into smaller bursts into your daily life; take the stairs instead of the lift.

**b) The Weather** - It's too cold', 'it's raining'.

- ✓ Dress appropriately.
- ✓ Have a variety of indoor and outdoor activities to choose from so that weather can't interfere with your exercise plans (walk indoors at your local shopping centre, swimming etc.)

### Session 3 - Participant material

#### Activity

Think of your own circumstances and the exercise barriers you might face.



**Write them in the box below and then try and 'problem solve' i.e. identify solutions to the barriers you have identified.**

Exercise Barrier	Possible Solutions

## Session 3 - Participant material

### SOCIAL SUPPORT

**Social networks** are very important in encouraging and motivating us to be active.

**Social support** could come from family, friends, work colleagues, neighbours or new people who share the same goal, interests or activities.

In terms of exercise people from your social support network may exercise with you. We all know it's more enjoyable and motivating to exercise with someone than on your own.

However, social support can also take the form of general encouragement. So if you are planning to go for a walk at lunchtime at work, a colleague could provide positive social support and reinforcement by coming with you or by showing interest and asking about walk, the programme and how you are getting on.

Conversely people around us can also be a barrier to physical activity. In the example above the work colleague might try and discourage you from your lunchtime walk so they can sit with you in the canteen and eat lunch.

It is important that you identify those in your social network who would provide good social support for your exercise programme and similarly to identify those who might be less than supportive.



**You might find it useful to make a note of these people below and talk to them about your PEP.**

<b>People, who might provide social support</b>	<b>What support might they provide?</b>



Participant ID

Date: d d m m m y y y y

## Session 4

### Session content

Discuss length and content of session

Review *Physical activity and exercise diary* of previous 2 weeks

Review exercise: congratulate achievements and overcome difficulties

Introduce programme of strengthening exercises

Negotiate Physical activity and exercise goals for the next 2 weeks

Give participant Exercise diaries for the next 2 weeks

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

### Discuss homework and write plan in notes:

Complete strengthening exercises twice per week

Complete weeks 5 and 6 *Physical activity and exercise diary*

<input type="checkbox"/>
<input type="checkbox"/>

### Encourage participant to read the following:

*Strengthening exercises*

<input type="checkbox"/>
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### Paper work to complete after session:

Complete session checklist (this page)

Complete RAP notes, including plans for next session

Complete attendance record and book sessions if appropriate

Complete reflective review of session

Any adverse events since last session? (*Please tick only one*)

*If yes, please confirm with participant if this has been recorded previously and complete the report form, if required*

Yes

No

<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

Session duration (minutes) \_\_\_\_\_

Signature

Date

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Participant ID 

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**RAP notes Session 4**

<b>R: Review of returned documents and participant homework discussed</b>
<b>A: Analysis and clinical reasoning</b>
<b>Plan:</b>

Signature

Date

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## Session 4 – Participant material

### 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. It is also important to strengthen muscles if you are starting to exercise or trying a new physical activity or sport. In essence: a stronger muscle will let you do more of the things you want to do.

#### Strengthening exercise also helps:

- **Support your joints** – Strengthening the muscles around your joints provides extra support for your joints.
- **Strengthen bone** -Strength training improves the structure of bone and helps prevent osteoporosis.
- **Burn Calories**

#### How often should I do strengthening exercises?

Physical activity guidelines state that people should undertake strengthening exercises twice per week.

#### Where should I start?

Strength exercises for the major muscles of the legs, arms and trunk will be performed at home, twice a week, with each exercise repeated 8-12 times. 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. The strength training component of the PEP will be reviewed by your physiotherapist and progressed as appropriate.

#### 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 of each exercise, and how often you are doing them. This record will also be useful for your physiotherapist. It also lets you see how much you have progressed.

## Session 4 – Participant material

### What should muscle strengthening feel like?

At the time, a strengthening exercise is likely to feel quite hard, and you may feel a burning, heaviness or jelly like sensation. These feelings are quite normal after a muscle has been exercised. 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.

### Is strengthening exercise safe for people with sore joints?

There is no evidence that strengthening exercise is harmful to people with arthritis however it is important that you follow the physiotherapist's advice and do not overload the muscle or joint.

**1. Biceps curls** - Start in a standing position with your feet shoulder width apart and your knees relaxed or sit in a chair.

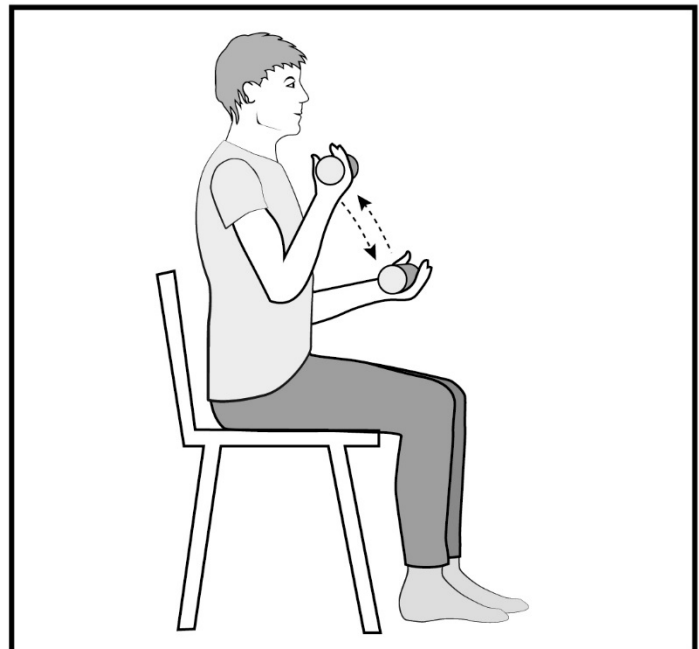
Grasp a weight with your hands. This could be a tin or a full water bottle. Your grip should be underhand (palms facing upwards) and let the weight hang next to your thighs.

Bend at your elbows to curl the bar to shoulder level.

Hold for five seconds, then slowly lower the weight back to the starting position.

Relax and repeat 10 times.

Date agreed	Number of Repetitions	Number of Sets



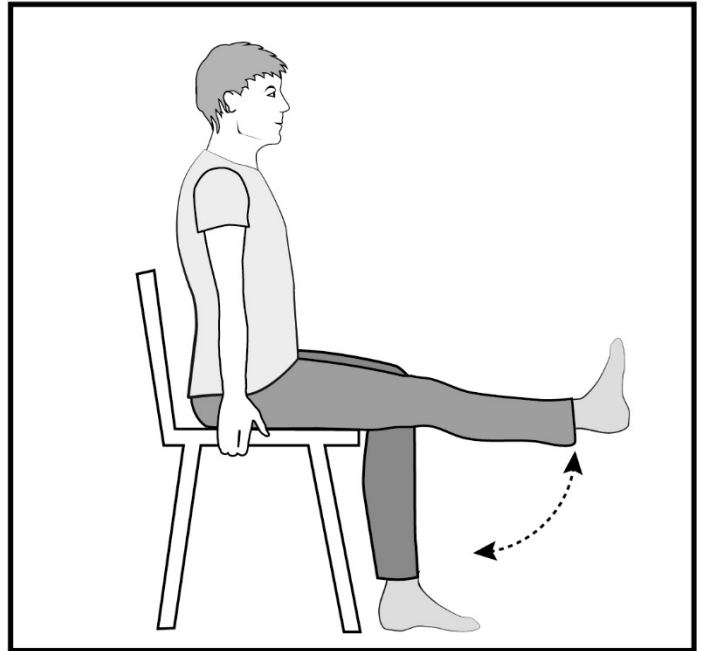
## Session 4 – Participant material

**2. Leg extension** – While sitting in a chair, slowly straighten one leg and hold while you slowly count to 5 then bring it back to the floor. Be sure you don't lock your knee.

Alternate left and right legs. Repeat 8 to 12 times. Rest for a minute and repeat the exercise.

If this exercise becomes easy, you can add a light weight around your ankle or tie an elastic resistance band to a chair leg and one ankle.

Date agreed	Number of Repetitions	Number of Sets

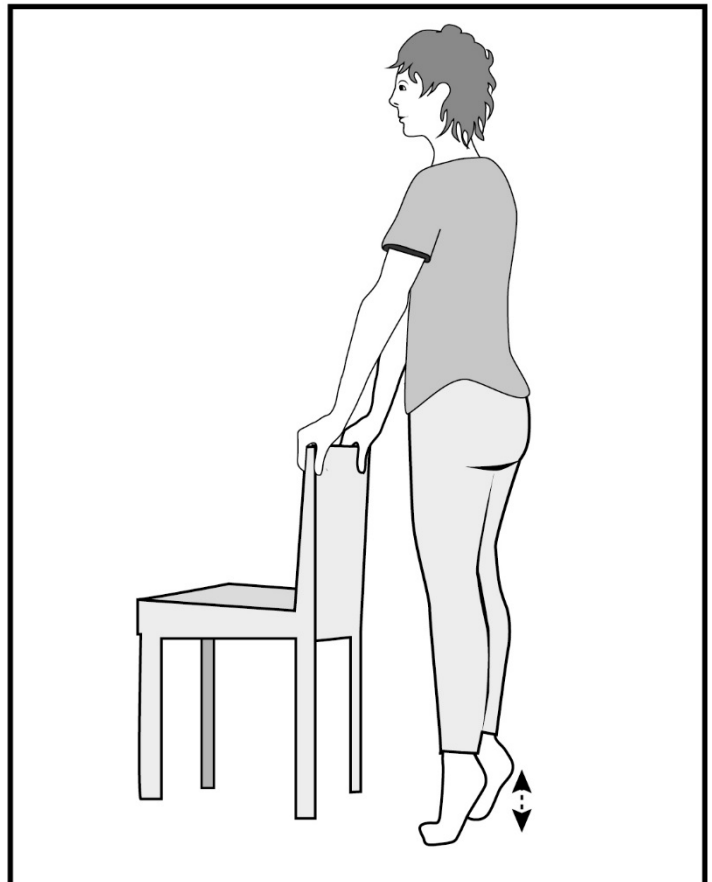


**3. Calf raises** hold on to a chair, stand up straight, rise up on to your toes and back down, repeat until your calf feels tired.

When this gets too easy do the exercise standing on one leg at a time.

If you want to make it harder still then wear a loaded backpack/ rucksack.

Date agreed	Number of Repetitions	Number of Sets



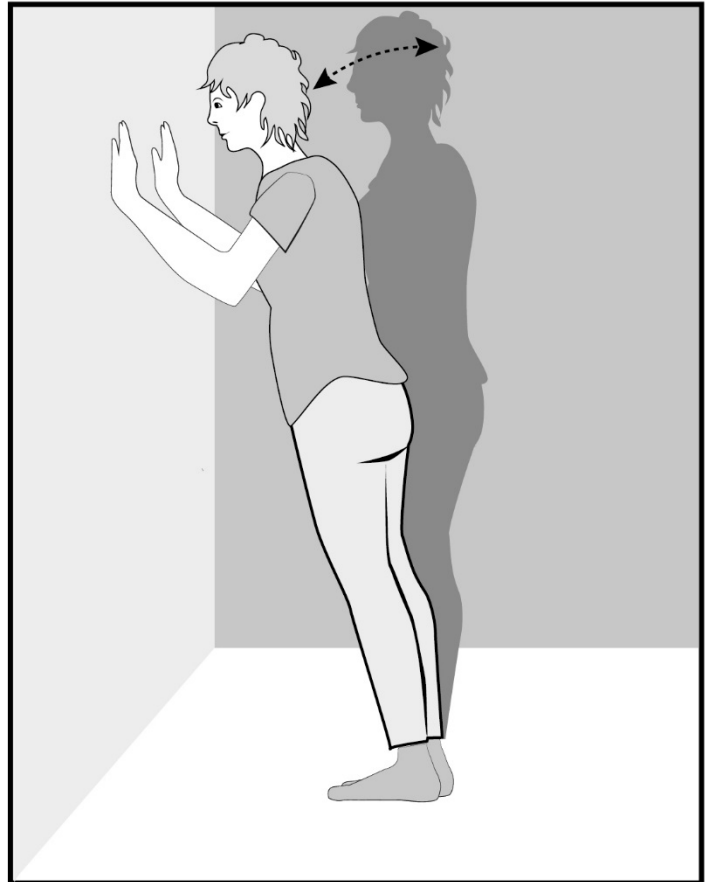
## Session 4 – Participant material

**4. Wall press-up-** Stand facing a wall, about 30 to 45 cm away and place your hands on the wall at shoulder height. Slowly bend your elbows and bring your face toward the wall, moving your hips and shoulders forward together. Push slowly back to the starting position.

When you can do this exercise against a wall comfortably you can move your feet a bit further back from the wall or try it against a table. Make sure the table is fixed/solid and won't move.

You can then slowly progress to the end of a couch or a sturdy chair, and finally to the floor.

Date agreed	Number of Repetitions	Number of Sets



Participant ID

Date: d d m m m y y y y

## Session 5

### Session content

Discuss length and content of session

Review *Physical activity and exercise diary* of previous 2 weeks

Review exercise: congratulate achievements and overcome difficulties

Discuss possible setbacks, how to avoid them or how to deal with them

Negotiate Physical activity and exercise goals for the next 4 weeks

Give participant Exercise diaries for the next 4 weeks

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<input type="checkbox"/>
<input type="checkbox"/>

### Discuss homework and write plan in notes:

Complete Physical activity and exercise diaries for weeks 7-10

Complete the Dealing with Setbacks exercise

<input type="checkbox"/>
<input type="checkbox"/>

### Paper work to complete after session:

Complete session checklist (this page)

Complete RAP notes, including plans for next session

Complete attendance record and book sessions if appropriate

Complete reflective review of session

Any adverse events since last session? (*Please tick only one*)

*If yes, please confirm with participant if this has been recorded previously and complete the report form, if required*

Yes  No

<input type="checkbox"/>
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Session duration (minutes) \_\_\_\_\_

Signature

Date

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Participant ID

Date:

**RAP notes Session 5**

**R: Review of returned documents and participant homework discussed**

**A: Analysis and clinical reasoning**

**P: Plan:**

Signature

Date

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## Session 5 – Participant material

### DEALING WITH SETBACKS

Starting an exercise programme is one thing, maintaining it can be even harder.

From time to time most people experience problems and sometimes these can lead to a setback, so that, for whatever reason, you can't do some, or all, of your programme.

#### Common triggers for setbacks:

- A period of illness
- Stressful situations at home or work.
- You are on holiday and out of your normal routine.
- Looking for an excuse to stop walking, such as, poor weather
- You get disappointed because you haven't done as much exercise as you had hoped.
- Your arthritic condition is fine and so you don't not want to take part anymore.
- Feeling that the goals which have been set are unrealistic, or that they take too much time and/or effort to obtain

#### What can you do to avoid a setback?

Everyone has setbacks along the way, the important thing is not to get disheartened;

Don't give up! Try not to get downhearted- if you feel this way talk it over with someone close or your therapist who will be happy to help.

Stay focused on your goals – not your emotions.

To avoid setbacks and to back on track after a setback make sure you

1. Are clear about **what** you want to achieve
2. Are clear about **why** you want to achieve it
3. Keep a record of your progress
4. Let people know how well you are doing
5. Review your SMART goals regularly

When you experience a setback, you might experience feelings of failure, disappointment, and frustration. The key to success is to not let these setbacks undermine your self-confidence.

If you lapse back to an old behaviour, think about why it happened. What triggered the relapse? What can you do to avoid these triggers in the future?

## Session 5 – Participant material

It is even more helpful to anticipate difficult situations you might encounter, that would stop you doing your exercise programme and to plan in advance how you would deal with them to avoid them triggering a setback if they do happen.

### Getting back to exercise after a setback.

During a setback, especially if its related to illness or a flare of your condition, it is natural to rest for a while but it is also important to do some activity as you are able.

Something is better than nothing! This might involve going out for a short walk try to go out for a short walk every day. Then, build up your physical activity/exercise as soon as you can, in a gradual way.

### Writing a setback plan

Because setbacks are common during exercise programmes it is useful to think about possible situations which might trigger a setback and plan in advance how to a) reduce the setback if possible or b) return gradually to your PEP after the setback.



**What setbacks do you anticipate in the next month?**

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**What can you do to avoid or minimise the setback(s)?**

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Participant ID

Date: d d m m m y y y y

## Session 6

### Session content

Discuss length and content of session

Review *Physical activity and exercise diary* of previous 4 weeks

Review exercise: congratulate achievements and overcome difficulties

Review goals and add new/alter goals if necessary

Review sleep management advice

Negotiate Physical activity and exercise goals for the next 4 weeks

Give participant Exercise diaries for the next 4 weeks

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### Discuss homework and write plan in notes:

Complete Physical activity and exercise diaries for weeks 11-14

Consider any final areas for discussion/questions for Session 7

<input type="checkbox"/>
<input type="checkbox"/>

### Encourage participant to read the following:

*General Advice on Improving your Sleep*

<input type="checkbox"/>
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### Paper work to complete after session:

Complete session checklist (this page)

Complete RAP notes, including plans for next session

Complete attendance record and book sessions if appropriate

Complete reflective review of session

Any adverse events since last session? (*Please tick only one*)

*If yes, please confirm with participant if this has been recorded previously and complete the report form, if required*

Yes

No

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Session duration (minutes) \_\_\_\_\_

Signature \_\_\_\_\_

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Participant ID

Date:

**RAP notes Session 6**

**R: Review of returned documents and participant homework discussed**

**A: Analysis and clinical reasoning**

**P: Plan:**

Signature

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Date

## Session 6 - Participant material

### GENERAL ADVICE FOR IMPROVING YOUR SLEEP

Difficulty with sleep and sleeping patterns can contribute to feelings of fatigue. Sleep problems include: taking a long time to go to sleep at night; frequent or prolonged awakenings during the night; waking early; or sleeping too much. The quality of sleep is often poor and people will often report waking up feeling exhausted.

To improve your sleep and sleep pattern you might try the following:

#### 1. Establish an optimal sleep pattern

##### a) *Efficient sleeping*

Your sleep pattern is *optimal* when it is both *efficient* and *regular*. By efficient, we mean that the more time you are asleep when in bed, the more efficient your sleep is. To establish your optimal sleep pattern, you may need to reduce the amount of time you are in bed, in order to increase the amount of time that you are asleep.

Calculate your *total* time asleep on an “average” night. Stay in bed for the time that you are usually asleep only. For example, if you are usually in bed for 10 hours a night, but are only asleep for 6 hours in total, you should only stay in bed for 6 hours. This change should be made gradually.

##### b) *Daytime sleeping/napping*

You may find that you 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, so it is important to gradually reduce and eliminate day time napping.

##### c) *Not sleeping enough*

If you are not sleeping enough, you may have difficulties in the first part of sleep (initial insomnia) and/or in the middle of the night (middle insomnia). Relaxation techniques may help both types of insomnia. Exercise will also be helping you sleep deeper.

#### 2. Sleeping too long

If you feel you are sleeping for too long cut down your sleep time gradually – either by going to bed 1/2 hour later, or getting up 1/2 hour earlier. Also establish a routine with a set waking up time and going to bed-time.

## Session 6 - Participant material

### 3. Sleep Hygiene

Sleep hygiene refers to lifestyle and environmental factors that may be beneficial or detrimental to sleep.

The following guidelines may help to promote an improved sleep pattern:

- ✓ *Exercise:* Avoid exercise within 1 hour of bed-time, as this may potentially waken you up. Exercise in the late afternoon may deepen sleep.
- ✓ *Diet:* A light snack before bed-time may be sleep inducing, but a heavy meal too close to bed-time will interfere with sleep. Fluid intake should be limited just before bed.
- ✓ *Caffeine:* is a central nervous system stimulant and is associated with delaying sleep onset and it can cause wakefulness. Substances containing caffeine, e.g. coffee, tea, chocolate should be avoided 4-6 hours before bed-time or during the night if you wake up.
- ✓ *Nicotine:* is also a central nervous system stimulant therefore smoking should be avoided near bed-time and during night time waking.
- ✓ *Alcohol:* is a central nervous system depressant, although it may speed up sleep onset, it often causes disrupted sleep later in the night as it is metabolised. A milky drink before bed can help you to feel sleepy and will not cause you to waken in the night.
- ✓ *Environment:* Your bed and mattress should be comfortable. Minimise light, noise and excessive temperature during your sleep period. Avoid using your phone/tablet in your bedroom. Your room temperature should be around 18° C. Use blinds if necessary or an eye mask; ear plugs if you live in a particularly noisy place and are unable to get used to it and use a fan/heating to control temperature.
- ✓ *Electronic Devices:* Avoid using electronic devices such as smart phones and tablets in the bedroom.

### 4. Preparing for sleep

Establishing a routine will help you to prepare mentally and physically for going to sleep.

- ✓ Try to wind down in the hour or so before you go to bed.
- ✓ Include relaxing activities such as watching television, having a warm bath, listening to music in your schedule.
- ✓ Avoid stimulating activities which will keep you alert, for example work, studying, decision making.
- ✓ Develop a regular order of doing things, e.g. locking up the house, turning out the lights, brushing teeth etc. This will act as a signal to your body that it is preparing for sleep.

## **Session 6 - Participant material**

### **5. Waking up**

Establish a routine on walking up

Try to get up at the same time each day

On waking open your curtains to access daylight





## ***Final session (Session 7)***

### **Purpose of Session 7:**

1. To aim towards self-management and independence with exercise programme
2. To re-examine the Borg-HR relationship
3. To clarify any areas of concern and to answer any questions

### **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. It should be explained that in order for the body to continue strengthening, and for changes to be maintained, exercise should form a regular part of their lives from here onwards. The long-term benefits of exercise for people with IRDs and the prevention of other diseases such as cardiovascular disease can be emphasised.

Participants should be taught how to continue PEP 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. The participant should be encouraged to try different types of exercise, and to have confidence in planning new activities. 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?

### **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 monitoring their heart rate. 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.

If their Borg scores are particularly high, then the participant can be encouraged to continue to monitor their heart rate for a little longer, to provide an objective measure for exercise intensity.



Participant ID

Date: d d m m m y y y y

## Session 7

### Session content

Discuss length and content of session

Review *Physical activity and exercise diary* of previous 4 weeks

Review exercise: congratulate achievements and overcome difficulties

Review goals and add new/alter goals if necessary

Negotiate Physical activity and exercise goals for the next 8 weeks

Give participant Exercise diaries for the next 4 weeks

Focus upon independence and variety of exercise

Discuss how to be flexible with exercise (e.g. weather, season)

<input type="checkbox"/>
<input type="checkbox"/>
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<input type="checkbox"/>
<input type="checkbox"/>
<input type="checkbox"/>

### Discuss homework and write plan in notes:

Complete Physical activity and exercise diaries for weeks 15-22

Consider Future Goals and Break into manageable steps

<input type="checkbox"/>
<input type="checkbox"/>

### Encourage participant to read the following:

*Into the Future*

<input type="checkbox"/>
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### Paper work to complete after session:

Complete session checklist (this page)

Complete RAP notes, including plans for next session

Complete attendance record and book sessions if appropriate

Complete reflective review of session

Any adverse events since last session? (*Please tick only one*)

*If yes, please confirm with participant if this has been recorded previously and complete the report form, if required*

Yes

<input type="checkbox"/>
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No

<input type="checkbox"/>
<input type="checkbox"/>
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Session duration (minutes) \_\_\_\_\_

Signature \_\_\_\_\_

Date

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**RAP notes Session 7**

**R: Review of returned documents and participant homework discussed**

**A: Analysis and clinical reasoning**

**P: Plan:**

Signature

Date

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## **Session 7 – Participant material**

### **INTO THE FUTURE!**

#### **Where do I go from here?**

Throughout your PEP you have learnt how to manage and increase your exercise in order to improve your fitness and general wellbeing. You will have had experience at setting realistic goals and how to break them down into manageable achievable steps. You may have experienced setbacks and barriers to achieving the goals you had chosen, and will have worked through solutions to these with your therapist.

All of these skills will help you to approach new challenges in a realistic and graduated way and allow you to know how far you can push yourself and how your body will respond. Your physiotherapist may have acted as an initial facilitator but now you are now ready to face new challenges with many tools in your possession!

#### **Where to start**

By now you should to have improved your fitness and physical strength, and are likely to find that you will be able to do many daily tasks more easily. Activities that were initially part of your programme may now be much easier to do and it is very important to maintain your current physical capacity level, whilst working towards new things.

The goals that you originally set may be completed or close to being completed by now. In order to maintain this progress and aim towards new achievements certain aspects need to be considered.

#### **Current goals and new activities**

Are the goals you set originally still relevant?

Can the goals that you originally chose be expanded or increased to challenge you further?

Are there any new activities you want to consider?

#### **Lifestyle changes and diversification**

Having built up your tolerance to exercise will have had a subsequent effect on your ability to do normal everyday tasks. Your new goals do not necessarily have to be about physical gains. It may be more important to you to now use your ability level to become more involved with friends and family.

#### **Maintaining motivation and direction**

If you still have outstanding goals that you are working towards, it may be useful to use the paperwork to monitor your progress. This record of your achievement will act as a motivator to future challenges. Even though the programme has ended there is no reason why you can't use the monitoring techniques you have become familiar with to continue to progress your exercise goals.

## Session 7 – Participant material

### NOTES ON USING THE FUTURE GOALS SHEET

- **Goal number**

This is the number of the goal and indicates which goal has highest priority

- **Goal**

A brief description of the goal including the activity, duration ( e.g. the time the activity should be carried out for), frequency (e.g. how often it is to be achieved) and intensity (e.g. how effortful the task is, for example walking on flat or an incline)

- **How to record progress**

What markers will you use to show how close you are to achieving that goal (e.g. the duration or frequency of the task, physical markers in the landscape or physical effort markers)

- **Time scale**

This is an idea of how long you may give yourself to achieve a certain goal – it can be days, weeks or months

- **How realistic is the goal**

This is a score from 0-10 as to how realistic you feel it is to be able to achieve the goal. Generally a score of 7 or above indicates a realistic likelihood of completing the task

### FUTURE GOALS RECORD SHEET - Example

Goal number	Goal	How to record progress	Time scale	How realistic is the goal (0-10 scale)
1	<i>Walking all the way to work in the morning 3 times a week</i>	<i>Count number of bus stops passing on the way (5 in total)</i>	<i>12 weeks</i>	7

**Session 7 – Participant material**

**FUTURE GOALS RECORD SHEET - Template**

<b>Goal number</b>	<b>Goal</b>	<b>How to record progress</b>	<b>Time scale</b>	<b>How realistic is the goal (0-10 scale)</b>

**Session 7 – Participant material**

**FUTURE GOALS: BREAKING DOWN GOALS INTO MANAGEABLE STEPS - Example**

Goal number: 1 *Walking all the way to work in the morning 3 times a week*

<b>Step number</b>	<b>Description of step</b>	<b>Time scale</b>	<b>How realistic (0-10)</b>
Step 1	<i>Get off the bus 1 stop earlier 3 times a week</i>	<i>2 weeks</i>	6
Step 2	<i>Get off the bus 2 stops earlier 3 times a week</i>	<i>2 weeks</i>	5
Step 3	<i>Get off the bus 3 stops earlier 2 times a week, 2 stops earlier once a week</i>	<i>2 weeks</i>	7
Step 4	<i>Get off the bus 4 stops earlier 2 times a week, 3 stops earlier once a week</i>	<i>2 weeks</i>	7
Step 5	<i>Walk to work once a week and get off the bus 4 stops earlier 2 times a week</i>	<i>2 weeks</i>	6
Step 6	<i>Walk to work twice a week and get off the bus 4 stops earlier once a week</i>	<i>2 weeks</i>	8
Step 7			
Step 8			
Step 9			
End goal	<i>Walk to work 3 times a week</i>		



## Session 7 – Participant material

### FUTURE GOALS: BREAKING DOWN GOALS INTO MANAGEABLE STEPS - Template

Goal number: \_\_\_\_\_

<b>Step number</b>	<b>Description of step</b>	<b>Time scale</b>	<b>How realistic (0-10)</b>
Step 1			
Step 2			
Step 3			
Step 4			
Step 5			
Step 6			
Step 7			
Step 8			
Step 9			
End goal			



### ***Booster session (Session 8)***

#### **Purpose of booster session (Session 8):**

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/relapse management
4. To clarify any areas of concern and to answer last questions

This session should be used to review PEP and health status in the previous 8 weeks, paying particular attention to the frequency, duration and content of exercise sessions.

A review of any relapses 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.



Participant ID

Date:

## Session 8

### Session content

Discuss length and content of session

Review *Physical activity and exercise diary* of previous 8 weeks

Make discharge plans according to new goals

Give participant any helpful paperwork, exercise records etc.

Discuss how to maintain exercise after discharge

Answer any questions or concerns


### Paper work to complete after session:

Complete session checklist (this page)

Complete RAP notes

Complete attendance record and book sessions if appropriate

Complete reflective review of session

Any adverse events since last session? (*Please tick only one*)

*If yes, please confirm with participant if this has been recorded previously and complete the report form, if required*

Yes

No


Session duration (minutes) \_\_\_\_\_

Signature

Date

\_\_\_\_\_

d	d	m	m	m	y	y	y	y
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Participant ID 

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Date: 

d	d	m	m	m	y	y	y	y
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**RAP notes Session 8**

<b>R: Review of returned documents and participant homework discussed</b>
<b>A: Analysis and clinical reasoning</b>
<b>P: Plan:</b>

Signature

Date

d	d	m	m	m	y	y	y	y
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