Lessening the impact of fatigue in inflammatory rheumatic diseases: a randomised clinical trial

The cognitive behavioural approach:
Manual for therapists

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This manual was developed for use by trained therapists in the LIFT trial. It describes a cognitive behavioural approach to managing fatigue in inflammatory rheumatoid disease (IRD) that can be delivered after brief training by health care professionals who have experience of working with people with IRD. The therapy has been tailored for delivery by internet-based audio/video calls or telephone.

This is not a self-help manual and is not intended for use by untrained therapists.

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Section A: Background

Introduction

Welcome to the therapists' manual. The aim of this manual is to describe the process of delivering a cognitive behavioural approach to people with inflammatory rheumatoid diseases (IRD), who are experiencing fatigue.

Section A contains background information

Section B describes each session in turn

Section C explains a range of different interventions for use in any session

Appendix 1 contains the patient handouts (They have been sent to them by post in advance).

Throughout the manual, instructions on what to do are indicated by an arrow; while sample text of how a conversation might unfold (<u>not to be read verbatim</u>) is enclosed in a box.

➢ Instruction on what to do next

> ***Sample text***
> Of how a how a conversation might unfold……

Fatigue in Inflammatory Rheumatoid Disease (IRD)

"Inflammatory rheumatoid 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, causing inflammation, swelling, pain, stiffness and deformation of joints. Some of the most common IRDs are rheumatoid arthritis (RA), ankylosing spondylitis (AxSpA) system lupus erythematous (SLE), all of which are included in the present study. The inflammation, pain and stiffness caused by IRDs is well known, but another common symptom, which may be overlooked is fatigue. In fact, 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.

Cognitive behavioural understanding of fatigue

The cognitive behavioural understanding of fatigue draws a distinction between the factors which cause fatigue in the first place fatigue (or precipitate a recent exacerbation) and those which lead fatigue to become a lasting and serious problem (maintaining factors). In the case of IRD-related fatigue, there may be a host of biological factors which precipitate fatigue. It should be noted though, that the relationship between measurable biological indicators such as inflammation and subjective fatigue is often weak – that is, the severity of disease indicators is not always a good indicator of the severity of fatigue. In the cognitive behavioural approach, fatigue is understood to be affected by *multiply interacting* cognitive (beliefs and perceptions), behavioural (e.g. doing too much or too little), emotional (e.g. demoralisation, fear) and biological factors (e.g. the disease process, disrupted sleep, loss of fitness).

Cognitive, behavioural and emotional perpetuating factors

The following are factors which may perpetuate IRD-related fatigue:

Over-vigorous activity alternating with resting for long periods.

Some people refer to this as the boom or bust pattern. This refers to doing too much at times followed by resting for long periods. This resting is often an enforced rest, or ‘crash’ with fatigue. Frequent crashes may re-inforce a person’s belief of ‘I must get everything done today as I will be exhausted tomorrow’, thereby creating a self-fulfilling prophecy. This pattern inadvertently makes the problem worse in the longer term as it is hard to establish any routine.

Inadequate or inappropriate rest.

While resting for long periods is associated with worsening of fatigue, it is important to get good quality rest and to achieve a balance between rest and activity.

A disturbed sleep pattern.

Sleep may disturbed for various reasons, including pain. An irregular bed-time or getting-up time, resting too much during the day or sleeping for long periods during the day may contribute to disturbed and un-refreshing sleep at night. Not sleeping well at night is likely to increase feelings of fatigue.

Fear about activity making the situation worse

Experiencing pain or fatigue after doing activity may naturally be read as a sign of doing harm. These thoughts then lead to safety behaviours, such as avoiding activities, and resting for too long. Resting for over-long periods can actually make fatigue worse by reducing activity tolerance and reducing fitness.

Avoidance of activities

While some people with IRD fatigue may attempt to do too much, others may start to avoid activities for fear of making the fatigue worse. However, stopping doing things on a regular basis can lead to loss of confidence in being able to do them. For example, they may have stopped socialising with particular friends, managing their home, doing exercise, etc. Resuming these activities may provoke fear and lead to further avoidance.

Life stress and low mood

People may experience major on-going life stresses and problems related to the effects of their illness. These may include financial difficulties, worries about keeping a job, difficulty in maintaining studies or feelings of social isolation due to a reduced ability to socialize. These difficulties can understandably trigger feelings of frustration, helplessness and loss of control over life. These feelings, which are a natural human response to stress, can lead to low mood for some people and depression in others. Low mood can lead to a variety of problems including tiredness, which can further reduce the desire to be active.

Perfectionism

People who are perfectionists are likely to have more difficulty in taking breaks or rests in the day as they feel that they are “wasting” time and “should” be doing something useful. This may lead them to adopt a “boom and bust” approach to activity, which makes it difficult to establish a routine.

Your role as a therapist

Your role is to deliver CBA by telephone to patients with inflammatory rheumatoid diseases (IRD) and who are experiencing fatigue. Each patient will receive an assessment session and 6 additional sessions at different intervals with a follow up session at week 22. The assessment session will be between 45 and 60 minutes and all other sessions will be 30-45 minutes. Patients will also be sent information/ handouts and diaries to read and work with. We will be asking you to record all treatment sessions (including any cancellations), session length, number of sessions and content, and to participate in supervision. More information is available in the Appendix 2. It may be useful to describe to patients what your role is – the following sample text may be helpful in informing how you discuss this (sample conversations are not to be used verbatim):

Sample text:

Your therapist is like a personal fitness trainer. If you go to the gym or play sports, personal fitness trainers don't do the actual physical work of getting you fit. That's up to you. However, the trainer will help devise a fitness plan, monitor your progress and keep encouraging you when the going gets tough. As your therapist, I will act in the same way by listening to you, providing techniques which can help and offering support and encouragement.

General competencies, knowledge and skills required to deliver the intervention

Engaging the patient

In order to engage the patient in making cognitive and behavioural changes, it is important that the therapist conveys to the person with IRD and fatigue their belief in the reality of symptoms, distress and effects on their lives. The therapist should be able to demonstrate a sound knowledge of IRD conditions. It is important right from the start that an integrative model which incorporates biological and psychological factors, e.g. inflammatory flares and behavioural and the patient's emotional responses to them, is used. It is important to listen to the patient and to understand their beliefs about their fatigue, in order to develop a self-management plan appropriate for each individual.

Open questioning (Ask, don’t Tell)

Open questions will encourage engagement by enabling the patient to tell their story, explain their own context and values. Use of open questions is key in helping people work out the links between their patterns of behaviour and fatigue, and also the thoughts and feelings that may drive those behaviours. Changing behaviours is hard, and people are generally more convinced by their own arguments than ours, thus an open questioning style (rather than didactic information-giving) is crucial. An open question for example, would be ‘What do you think might help with those crashes of fatigue when you get home from work?’ as opposed to the more didactic ‘You need to fit a lunch break to prevent the evening fatigue crashes’. The skill of the therapist is in guiding the discussion to enable the patient to reach their own understanding of the problem and possible solutions.

Warmth and empathy

It is important that you convey warmth and empathy at your first meeting. The assessment provides a wonderful opportunity for patients to tell their story, and may be the first time that they have had an opportunity to go into their problems. Allowing patients time to describe their symptoms and then acknowledging the difficulties they have encountered are both important.

Sensitivity

We know that fatigue, being a common feature of normal experience and everyday life may not have been taken seriously in the past, and the extent and implications of patients’ fatigue may not have been understood. Some patients may be sensitive to the use of “normalising” words which undermines the importance of their fatigue symptoms. For example asking them how often they feel *tired* can provoke irritation in someone who differentiates strongly between *IRD fatigue* and *‘normal’ tiredness*. It is worth listening to the language that patients use and trying to use language that is not going to be alienating. It is best to use the language and words that the patient uses to describe their symptoms.

Collaboration

Collaboration is an essential skill when working with people who are experiencing fatigue. Prior to this study, some patients may not have been included in the management of their fatigue. They may not have been asked their opinion and may feel helpless and out of control. Collaborating throughout treatment will help the person feel more involved and help them to regain a sense of control.

You will be demonstrating a collaborative style at your first meeting when you individualise the IRD fatigue model to the patient, discussing factors the patient feels contribute to their fatigue and drawing up a shared understanding. Agreeing an agenda for each session, asking the patient for their input in making suggestions for their activity programme and evaluating previous sessions will help them feel valued and included in the treatment process.

Positive reinforcement

It is important that you provide positive reinforcement for patients' achievements. Some patients may be better at pointing out what they have not achieved than what they have. It is important that you emphasise and are positive about what they have achieved. Every session should positively reinforce all of their achievements, however small they may seem.

Providing therapy by telephone/internet-based calls – general points

Delivering CBT 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 – i.e. name, role, part of LIFT study, where you are located and some details about yourself (i.e. 'I have been working as a rheumatology health professional for a number of years and work with both children and adults'
- Determine if the patient 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.
- Set a codename with the patient which they can use if they need to end the call (although all calls are scheduled patients have told us that it has been difficult to end the call if something unexpected happens e.g. neighbour calls round).
- 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.
- Working with lots of different patient groups we have found (except for the assessment session) most sessions last about 30 minutes.

Section B: The sessions

Delivering the intervention

This is a step by step guide to help you in delivering the intervention. Brief details of what should be included in each session are described in the ‘session review box’. Below each review box there is a more detailed explanation of what should be covered during the sessions.

There are a number of issues that might arise in any session, for example unhelpful thoughts, and you will find information on techniques to address these in Section C (Interventions for Therapists). Related handouts for patients are in the Appendix 1 and should have been sent in advance to patients.

We do recognise you as skilled clinicians and the detail is only to help you deliver the intervention as close to the protocol as possible.

The intervention will consist of an initial assessment of between 45-60 minutes, followed by six additional sessions of 30-45 minutes duration by telephone/internet-based calls. There will be a further session at week 22.

Week	**Session No**	**Content**	**Suggested length**
Week 0	Session 1	Assessment, engagement	1 hour
Week 1	Session 2	Establishing baselines, planning therapy	45 minutes
Week 2	Session 3	Active treatment session	30-45 minutes
Week 4	Session 4	Active treatment	30-45 minutes
Week 6	Session 5	Active treatment	30-45 minutes
Week 10	Session 6	Active treatment	30-45 minutes
Week 14	Session 7	Continuing to manage fatigue	30-45 minutes
Week 22	Follow-up session	Review progress	45 minutes

Session 1 – Patient-centred assessment

Session 1 overview

Orientation to the session

Complete patient centred assessment

Write problem statement

Introduce the rationale (CB approach)

Write down ABC and personal links

Encourage patient to complete the activity/rest/sleep diary

Feedback on session – final questions – make next appointment

Orientation to the session

- Introduce yourself and your role– is there anything else the patient wishes to know about you?
- Confirm the patient's full name; identify the purpose of the interview and approximate duration of the interview.
- The extent of confidentiality should be explained.
- Also explain about the use of the telephone/internet-based calls to deliver therapy – i.e. use of a code in case they are unable to continue with the call, pauses when writing things down, to treat the calls like a session i.e. in a quiet place without disturbances, to have their diary and pen and paper.

Orientation to the intervention

Roles of the patient, therapist, the handouts or worksheets, and friends or family

Role of the patient:

- Emphasise that the patient is the most important part of the intervention team, i.e. they are the experts in how they are feeling now and what they want help in managing to change.

Role of the therapist:

- You need to explain your role which is supporting and advising people to use interventions that will help them manage their fatigue better.
- Emphasise collaborative working – i.e. the patient has the expertise of their individual experience of fatigue, your expertise lies in working with people through the use of CBA to enable people to make changes which will lead them to manage their fatigue better.

- Explain telephone working – and how that will work – i.e. scheduled calls, to treat the calls like a session- the use of a code name in case they are unable to complete the call.

Patient handouts:

- There are a number of handouts in the Appendix 1, which patients may find helpful and which should have been sent in advance.

Friends and family:

- Emphasise that for most people, friends and family are usually the people that we are closest to, and that it is usually useful to involve them in helping people to help themselves. At this point it should be asked whether the patient has somebody that they think would be involved in the team. Inform the patient that if they are willing then you would be pleased to talk to a friend or family member.

Initiate patient-centred assessment

- Elicit what the patient prefers to be called and introduce the assessment with an opening statement:

> ***Sample text:***
> What would be helpful now is for me to understand more about you, how you are feeling, and particularly the impact that your fatigue is having on your life now.

We know that many patients use metaphors to describe their own experience and believe it important to incorporate this into the assessment. Try to elicit the language and metaphors that they use.

As with any patient-centred assessment, the idea is to understand their experience of the way they are feeling but also to elicit other necessary information. The tension between patients wanting to tell their story and you eliciting information can be difficult. However you do this, the following areas need to be weaved into the interview**:**

- The W's (What, Where, When, with Whom)
- Eliciting the ABC - try to use the language of what they feel (A), what they do (B), and what they think (C). Elicit Autonomic symptoms (A) i.e. physical/bodily symptoms they experience with their IRD fatigue. This might be pain or other symptoms such as headaches, feeling anxious/stressed/sad difficulty sleeping, sleeping too much, exhaustion, stiffness, poor concentration, tearfulness, or poor appetite.

- Elicit Behaviour (B), ie things they do or don't do/or difficult because of the fatigue. Ask about any boom or bust behaviours (over-vigorous activity alternating with resting for long periods).
- Elicit thinking or Cognitions (C) i.e. thoughts around feeling worthless, sad or angry, or thoughts that things won't improve or can't change which make us feel less confident. Also explore the patient's beliefs about their fatigue such as what they feel is causing their fatigue and what they feel is making it persist. It is useful to gain an impression of their strength of beliefs. You should listen to what they say without passing any judgement. Note any fearful thoughts such as fear of activity making their symptoms worse leading them to stop doing things.
- Impact – Ask about how their fatigue is affecting their life (work, social, friends and family, personal leisure, home). What other symptoms are present? e.g. Pain, Sleep complaints, Appetite etc.
- Modifying factors (what makes the fatigue better or worse?)
- Onset and maintenance (When IRD was diagnosed – when fatigue started – course of fatigue i.e. fluctuates i.e. predictable/unpredictable, progressively worse/no change/ progressively better)
- Mental state – mood, anxiety and risk (to self, others, from others) thoughts, plans, intent, access to means, past history and protective factors
- Past treatment
- Medication prescribed – elicit what, how often, take as prescribed , identify any illicit or over the counter drugs
- Current living and family situation, employment, education,
- Lifestyle, alcohol, smoking, diet exercise
- Risk (to self, to others, from others, neglect, vulnerability)
- A key question to ask patients is *"Is there anything that we have not covered in our discussion that is relevant to your difficulties"* i.e. *"is there anything else that you would like to add"?* Thank them for information that they have given so far.

Complete a summary statement

- Explain the rationale for the summary statement, see sample text below:

Sample text:
It is often helpful for us both to have a shared understanding of your difficulties and we try to do this by pulling out the key issues for you so we just write the most important things to you down in a couple of sentences. An example of this is:

"I feel sad and angry much of the time because I am in a lot of pain and no one understands. I don't sleep well and am tired and exhausted all the time, I get irritable with my family and don't do any of the things that I used to do. I have put on a lot of weight and this makes me feel even more useless than I feel already. I don't go out anymore and can't work."

Shall we try and write yours now?"

The Cognitive Behavioural Approach for IRD fatigue

- Explaining the CBA model and providing a rationale is crucial in demonstrating an understanding of the patient's problems. It is important to say that fatigue affects people in different ways but that you want to come to a shared understanding of how they experience their fatigue. The following is an example of how you can do this.

Sample text:
Firstly, let us look at how we can make sense of the way we feel. These can be broken down into 3 areas *[use the information that was gathered in the assessment to individualise]:*

- Things we feel physically
- Things we do or stop doing (our behaviour)
- Things we think

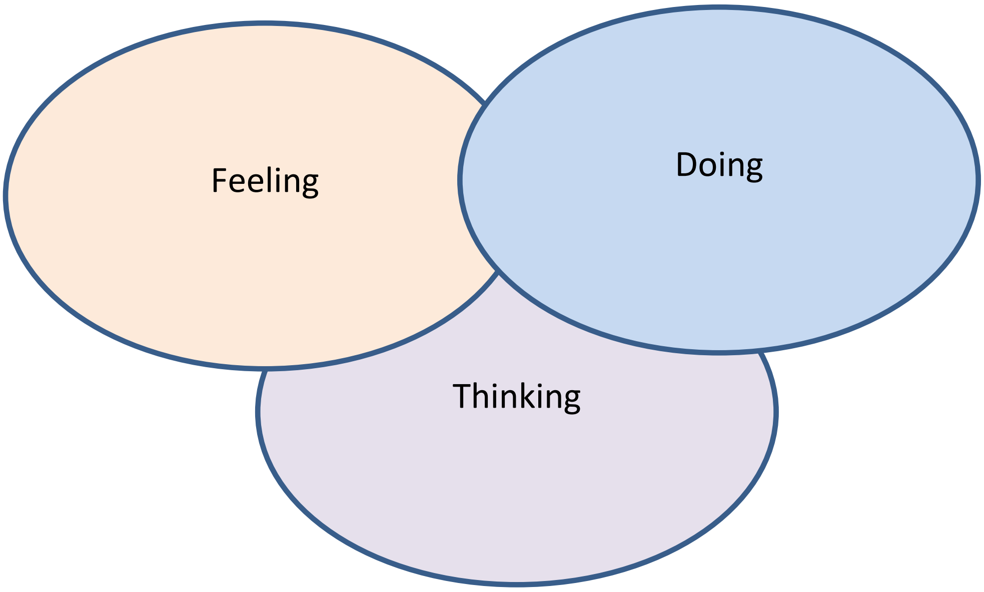
- Use the circles overleaf to complete with the patient – this is provided as Handout 1a in the Appendix 1, with a slightly different version as Handout 1b

Sample text:

Things we feel physically include the physical symptoms you experience; this might be pain or other symptoms such as headaches, feeling anxious/stressed/sad difficulty sleeping, sleeping too much, exhaustion, poor concentration, tearfulness, or poor appetite.

Things we do or stop doing include avoiding things that we used to do or doing them less, or not enjoying them as much.

Things we think include some of the unhelpful thoughts that you might be having such as worthless, sad or angry thoughts or thoughts that things won't improve or can't change which make us feel less confident.



The 'Vicious Circle' of feeling, doing and thinking

The things we feel, do and think are all related to each other. For example, our physical feelings can lead to changes in the way we do things and the way we think. If we stop doing things we can feel worse physically and have unhelpful thoughts. These thoughts can mean that we stop doing things and this can make our physical feelings/fatigue worse. This 'vicious circle' of unhelpful thoughts, changes in behaviour and physical symptoms can cause these symptoms and feelings to continue.

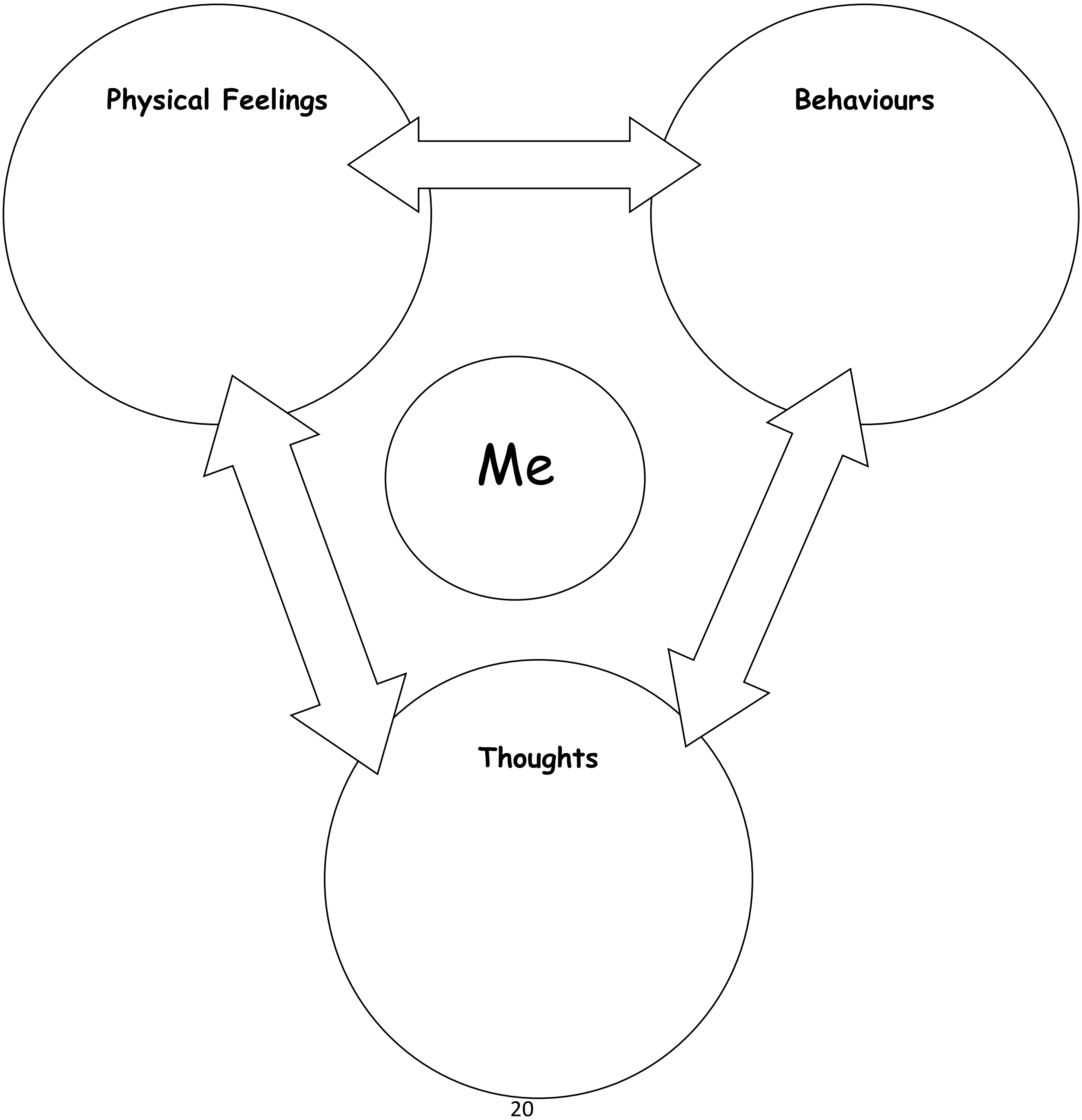
<u>Write down ABC and personal links</u>

Now let's think about you and look at these three areas might be linked to see if any unhelpful patterns or vicious circles have developed.

My physical symptoms, behaviours and thoughts are linked in the following ways:
…… …… …… …… ………

If you prefer a diagram you can use the following (Appendix 1 Handout 1b):

My vicious cycle



The following is an example of how you can do this. You may say something along the following lines:

Sample text:
Thank you for giving me such a clear account of your fatigue which has helped us to understand it better and the opportunity to think about it how it could be managed. From the ABC diagram and the links you have made, it seems that several factors are involved in your fatigue. You've mentioned that (use patient's own examples and try to link in thoughts feelings and behaviours), e.g., you sometimes push yourself too hard and then you feel worse and have to rest for a while which makes you feel really frustrated that you can't keep going. How does that sound so far? So it's possible that managing all of these things slightly differently would help you to be able to make a difference to how you feel. Would you be willing to try that?

So, in a nutshell, the cognitive behavioural approach aims to help people with fatigue related to inflammatory rheumatic diseases, such as [diagnosis that patient has], to change certain patterns of thinking and behaviours that may be partially responsible for maintaining their fatigue**.**

To start with, we will work towards you having a consistent amount of planned activity and rest throughout the day based on the average amount that you are now having. So for example, rather than (use the patient's example), e.g. keeping going for a block of 2 hours in the afternoon and then feeling exhausted, you might do the same amount of work but take a break for 20 minutes half way through.

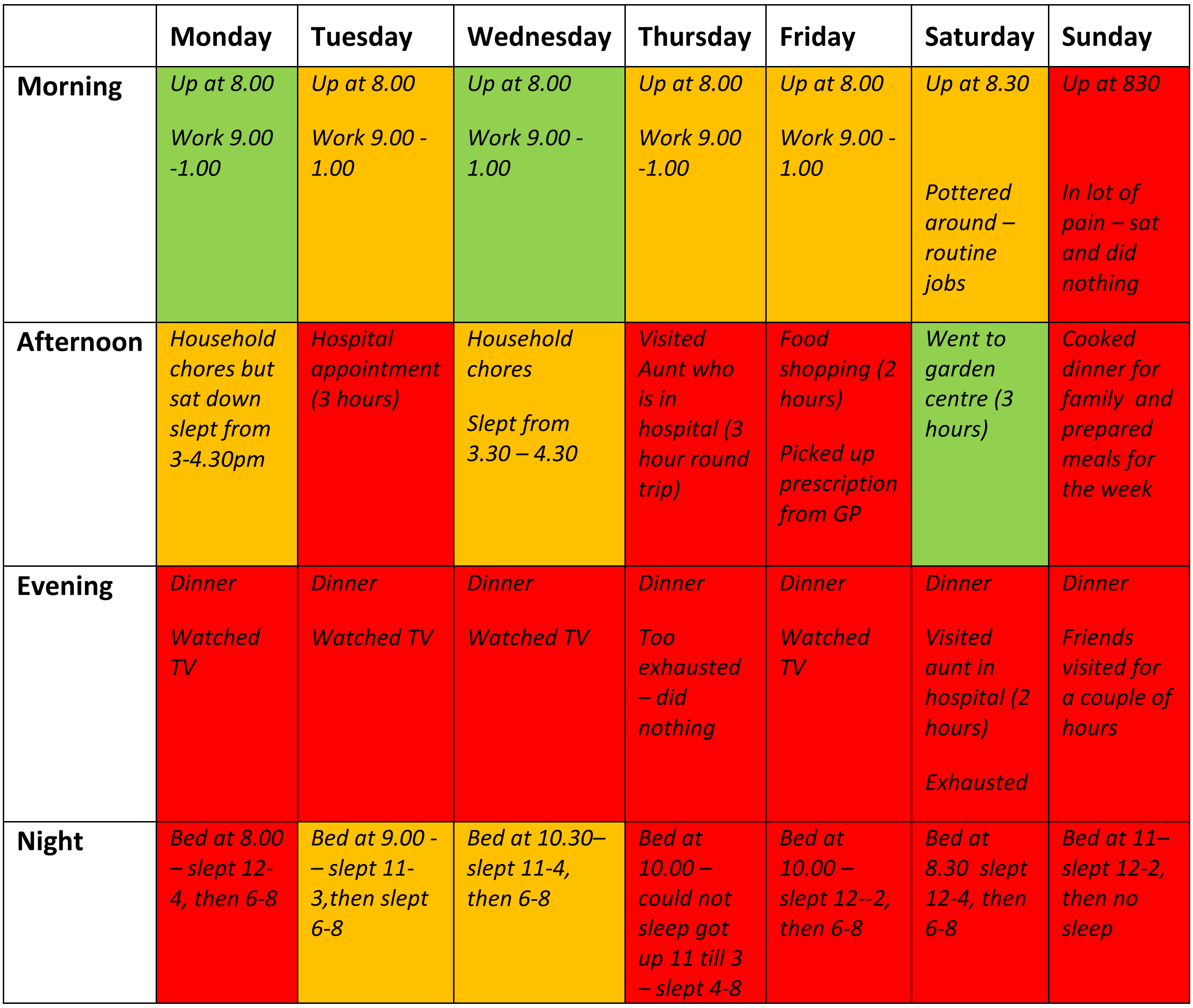
Changing the way you do things may understandably make you feel a little worried about the effect on your fatigue. Over the weeks we will look at these thoughts together, with the aim of helping you to identify more helpful alternative ways of thinking, which will hopefully help to reduce some of your worries/fears/anxieties etc. Do you have any questions about what I have just said so far?

Encourage patient to complete the activity/rest/sleep diary

- Introduce the patient to the activity diary (Appendix 1 Handout 2)

> ***Sample text:***
> What is important is for us both to understand the fatigue you are experiencing and to help us with this I would really like you to fill a diary in. What we are trying to capture is your activity, how fatigued you felt and how you slept. Let me explain [ask the patient to look at the activity diary, Handout 2] – we would like you to fill in the activities you do every day, including your sleep. This does not have to be too detailed but captures what you do. We would then like you to rate your levels of fatigue using 3 colours by shading the boxes in with red (very fatigued), orange (moderately fatigued) or green (not fatigued).

An example is detailed below for you to discuss with the patient so that they are clear on what we are asking. Colour coding – red (very fatigued) orange (moderately fatigued) and green (not fatigued). [Appendix 1 Handout 2].



	Monday	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**	**Sunday**
Morning	🟩 *Up at 8.00* *Work 9.00 -1.00*	🟧 *Up at 8.00* *Work 9.00 - 1.00*	🟩 *Up at 8.00* *Work 9.00 - 1.00*	🟧 *Up at 8.00* *Work 9.00 -1.00*	🟧 *Up at 8.00* *Work 9.00 - 1.00*	🟧 *Up at 8.30* *Pottered around – routine jobs*	🟥 *Up at 830* *In lot of pain – sat and did nothing*
Afternoon	🟧 *Household chores but sat down slept from 3-4.30pm*	🟥 *Hospital appointment (3 hours)*	🟧 *Household chores* *Slept from 3.30 – 4.30*	🟥 *Visited Aunt who is in hospital (3 hour round trip)*	🟥 *Food shopping (2 hours)* *Picked up prescription from GP*	🟩 *Went to garden centre (3 hours)*	🟥 *Cooked dinner for family and prepared meals for the week*
Evening	🟥 *Dinner* *Watched TV*	🟥 *Dinner* *Watched TV*	🟥 *Dinner* *Watched TV*	🟥 *Dinner* *Too exhausted – did nothing*	🟥 *Dinner* *Watched TV*	🟥 *Dinner* *Visited aunt in hospital (2 hours)* *Exhausted*	🟥 *Dinner* *Friends visited for a couple of hours*
Night	🟥 *Bed at 8.00 – slept 12-4, then 6-8*	🟧 *Bed at 9.00 - – slept 11-3,then slept 6-8*	🟧 *Bed at 10.30– slept 11-4, then 6-8*	🟥 *Bed at 10.00 – could not sleep got up 11 till 3 – slept 4-8*	🟥 *Bed at 10.00 – slept 12--2, then 6-8*	🟥 *Bed at 8.30 slept 12-4, then 6-8*	🟥 *Bed at 11– slept 12-2, then no sleep*

Feedback on session – final questions – make next appointment

- Remind the patient that there are 5 - 10 minutes of the session left, summarise the session and ask them to provide some feedback about the session (things that worked well and anything that did not work well).
- Elicit any final questions/concerns from the patient.
- Reiterate the importance of completing the activity/rest/sleep diary.
- Negotiate the date and time of the next appointment – explain that the following sessions will be about 45 minutes long.

Session 2

Session 2 overview

Review previous session

Review Rest/activity diary

Establish goals

Discuss interventions

Discuss and plan activity/rest/sleep diary and collaboratively plan intervention

Ending: Feedback on session – final questions – next appointment

Review Previous session

- Welcome the patient, orientate them to the purpose and duration of session (30-40 minutes).
- Elicit feedback and ask if they have any questions about the previous session.
- Review and ask about any previously held risk factors or risk factors that have arisen.

Review rest/activity diary

- Use open questions to elicit information on between-session work

Sample text:
In our first session we discussed [brief recap] and what I had suggested would be helpful was if you completed Handout 1 on your links between thoughts, feelings and behaviours related to your fatigue. We also agreed that you would complete a rest/activity diary – can you tell me if you were able to complete it? If so describe it both in activity and colour coding- can you see any patterns emerging? What did you learn (if anything about your fatigue). We will come back to the diary in a few moments but what would be helpful is if we discuss some of things you want to work on during our sessions – we call these goals.

Establish goals

Handout 3 is the 'Wheel of Life' which may help patients reflect on important areas of life they wish to work on.

Sample text:

Many people find it a really good idea to set themselves some goals to start managing their fatigue. You could base these goals around any areas/issues that you want to change. For example, this may include socialising more, feeling more confident, improving sleep, managing feelings, returning to work, reducing alcohol or stopping smoking, taking medication, increasing exercise and healthy living. Goals can be anything that you want to work with. Remember, you can work with your therapist who will help you with this.

Goals will help you to:

- keep focussed
- be clear about what you want to achieve
- give you feedback on your progress

Examples of goals might be:

To return to work full time
To be able to sleep through the night
To go for a 20 minute walk every day
To spend more time with friends

- Ask the patient the two rating scales on Handout 4 overleaf – how important it is to them to do this goal, and how confident they are that they will do it.

Sample text:

So that you know how you are doing, we have written down a simple scale underneath each goal. Circle one of the numbers for each one. This will tell you how difficult you find each goal. You can re-rate your goals every 2-3 weeks to show you how you are doing. [See overleaf, which is also Appendix 1 Handout 4].

- Then discuss this with them. If a confidence (self-efficacy) score is lower than 6/10 they are unlikely to initiate a behaviour change. In this case, praise them for the score they have given and ask them which bit they are so confident about, and then what makes them hesitate about scoring it a 6? Then help them address that problem using the problem-solving technique described in Section C, Intervention 3 (Problem-solving).

Patient's long-term goal 1

Now break the goal down into small, achievable targets:

Example A: Long term goal is to be able to walk to the shops three times a week.
This week I will **walk** *(what),* **to the end of the road** *(how much),* **before lunch** *(when),* **on three days** *(on how many days)*

Example B: Long term goal is to be able to swim two lengths twice a week.
This week I will **find out about the swimming pool** *(what),* **the times and prices** *(how much),* **on Saturday** *(when)*

My goal: This week I will….

--- **What I will do**

--- **How much I will do**

--- **When I will do it**

--- **On how many days?**

Now check how important this goal is to you:
0 = goal not very important to me; 10 = goal very important to me

0	1	2	3	4	5	6	7	8	9	10

Now check how confident you are that you can do this goal:
0 = not at all confident I can do this goal; 10 = very confident I can do this goal

0	1	2	3	4	5	6	7	8	9	10

Next week, during our telephone discussion we will discuss how you are getting on:

I can do this now (circle a number):

0	**1**	**2**	**3**	**4**	**5**	**6**
Not at all		**Occasionally**		**Often**		**Anytime**

Discuss interventions

- Reiterate the vicious circle with the patient – getting ‘buy in’ and engagement is crucial to success so this is so important. Use the ABC, other relevant assessment material and their fatigue diary to show maintenance and discuss how cycle can be broken and where and how interventions might help.
- We have suggested a number of interventions in Section C: Cognitive restructuring or thinking about things differently; Behavioural experiments; Problem solving; and lifestyle interventions (sleep, diet, irritability, poor concentration). However, we would advise that patients start with establishing a baseline of activity and rest and (if necessary) a regular getting up/going to bed time before moving onto other interventions. Handouts 5, 6 and 7 may be helpful (pacing for boom and bust, achieving a balance, sleep).

Discuss and plan rest/activity diary and collaboratively plan intervention

- The baseline rest/activity diary (which you will have reviewed earlier in the session) needs to be discussed to set up an agreed initial programme. Use information from the patient’s activity diary to review the total amount of rest and activity they have in a typical week and any patterns of fatigue that are arising (i.e. particular times, following particular activities etc). The aim of the second session is to help the patient understand their behaviours and the relationship to fatigue, then start to balance the amount of activity and rest that they have each day.
- For example, periods of activity might be agreed for regular times and for a proposed duration. Periods of rest should be based on individual need and should also be taken at regular times and for a set time(s) perhaps in the morning and afternoon, but these must also fit in with their life demands so flexibility and pragmatism is essential. Furthermore, patients must be able to respond to inflammatory flares appropriately, rather than feel constrained to an activity programme set in advance.
- When the patient’s sleeping hours are erratic, if they are oversleeping or not getting enough sleep, then in order to provide more structure, you could agree a getting up time and/or a going to bed time. For example, you may agree to take an average of the time the patient has got up or gone to bed in the previous week. Patients may be fearful about doing things in such a structured way and therefore care should be taken to ensure that you are spreading what they are already doing over a week, rather than increasing activity at this stage.

- Encourage the patient to include a range of activities in their diaries such as work (if employed), chores, social and private leisure activities.
- Patients should populate a blank rest/activity diary with their planned activity and rest (as you will be doing this over the phone or internet-based call then write the programme out so that you have a copy).
- Agree that their activity programme is an experiment and ask them to predict what they think might happen. Agree to discuss their experience of the programme at the next appointment.
- *Important:* Make sure you warn patients who have been very inactive that a temporary increase in fatigue at this stage is nothing more than their body getting used to a new way of doing things, and that this should pass. Patients who have been over active with little rest breaks will need encouragement to slow down and take breaks, as they will find this difficult.

Examples of an initial activity programme

For someone who is not resting at all:

- To get up and dressed by 8 am daily
- To have 3 x 30 minute rests in a chair (e.g. at 10am, 2pm and 6pm), daily
- To go for 3 x 15 minute daily walks
- To read for 20 minutes daily
- To do chores for 1/2 hour x 2 daily
- To talk to friends for 15 minutes daily on the phone
- To go to bed by 11.00 pm

For someone who is currently resting for about 3 hours a day:

- To get up and dressed by 8 am daily
- To have 3 x 1 hour rests in a chair (e.g. at 10am, 2pm and 6pm), daily
- To go for 3 x 10 minute daily walks
- To read for 20 minutes daily
- To do chores for 1/2 hour x 2 daily
- To talk to friends for 15 minutes daily on the phone
- To go to bed by 11.00 pm

Ending: Feedback on session – final questions – next appointment

- Thank the patient for their time
- Recap the session and next steps. Summarise session and reiterate between session work.
- Ask for feedback from the session and ask if they have any final questions
- Arrange next appointment.

Sessions 3 - 6

Sessions 3 - 6 overview

Review previous session

Review activity/rest/sleep diary

Review progress on the intervention and collaboratively plan next stage of intervention or new intervention

Ending: Feedback on session – final questions – next appointment

Review previous week(s)

- Welcome the patient, orientate them to the purpose and duration of session (30-45 minutes).
- Elicit any previously held risk factors or risk factors that have arisen.
- Elicit information about completion of diaries, lifestyle changes etc.

Review activity/rest/sleep diary

- Review the activity/rest/sleep diary – use open questions to explore progress

Sample text:
How did the planned activities and rest work for you? How fatigued did you feel?

- You may want to compare with the baseline diary.
- Ask what is working and what is not working with the diary?
- Identify any barriers, 'stuck points' with the intervention and progress. Use the patient's own experience to work with them

Sample text:
You must have experienced barriers in your life before, what has worked for you to overcome them?

- ➢ To help you review and collaboratively plan the next diary the following questions may help:

Planned activity

- What percentage of agreed activities (walk, meet friends, chores etc.) did the patient manage to do?
- What percentage of the activities were done for the agreed time?
- Where the patient didn't manage to stick to the agreed activities, were they doing them more or less often, and/or for longer or shorter periods?

Planned rest

- What percentage of planned rests were taken?
- What percentage of planned rests were for the agreed time?
- Where the patient didn't manage to stick to the agreed rests, were they resting more or less often, and/or for longer or shorter periods?

Sleep

- What percentage of times did they get up at the agreed time?
- And go to bed at the agreed time?
- How often did they refrain from sleeping during the day?
- How often did the wake at night and for how long?
- How many hours did they sleep in total?

Review progress on the intervention and collaboratively plan next steps of the intervention or new intervention

- ➢ Discuss whether they want to continue with the same diary or make incremental changes.
- ➢ If participants are confident with their activity pattern, introduce the idea of identifying and addressing unhelpful thoughts – preferably using patients' own examples.
- ➢ During this phase the therapist will help the patient to:

- Become aware of unhelpful thinking patterns, e.g. beliefs that they should battle through fatigue or that the fatigue will never improve
- Test negative beliefs by implementing gradual behaviour change
- Address blocks to recovery such as ongoing stressful situations, excessive work requirements or lack of effective support
- Work on any other problems that may be amenable to the cognitive behavioural approach, such as anxiety problems

- ➢ During this phase new therapeutic techniques may be introduced depending on the individual's problems. Patients will be encouraged to take an active role in suggesting tasks for their between-session work.

- With patient, discuss whether they also want to work on another area e.g. stress (problem solving), unhelpful thoughts (cognitive restructuring and behavioural experiments), lifestyle changes.
- **Details of these interventions if appropriate are in Section C, Interventions for Therapists, with handouts for patients in the Appendix 1.**

Ending: Feedback on session – final questions – next appointment

- Recap the session
- Recap next steps of the intervention, ask them to read or listen to the intervention selected and reiterate what they have agreed to do before the next session.
- Ask for feedback from the session and ask if they have any final questions.
- Arrange next appointment.

Session 7 (Continuing to manage my fatigue)

Session 7 overview

Review previous weeks

Review progress on intervention (measure progress towards goals)

Introduce the concept of continuing to manage their fatigue

Managing setbacks

Ending: Feedback on session – final questions –closure of the session – next steps

Review

- Welcome patient, orientate to purpose and duration of session (30-40 minutes).
- Review patient’s fatigue and functioning using open questions
- Elicit any previously held risk factors or risk factors that have arisen.
- Elicit information about completion of diaries, lifestyle changes etc.

Review progress on intervention (measure progress towards goals)

- Identify any barriers, ‘stuck points’ with the intervention and progress.
- Use the patient’s own experience to work with them

Sample text:
You must have experienced barriers in your life before, what has worked for you to overcome them?

Introduce the concept of continuing to manage fatigue

- During the last few sessions (usually between 6 & 7) it is important that you introduce the concept of continuing to manage their IRD fatigue in the future. Bad days and relapses can and do occur so it is important to look at relapse and relapse prevention.
- With the patient you should review their overall progress, what has been helpful – what has not – what barriers and facilitators do they see that will help them to manage (or not) their fatigue in the future and problem-solve.

- As with the intervention this should be a collaborative process and directed by the patient.
- For some people their management of fatigue will have improved a lot, for others moderately and for some there may not have been any improvement. What is important is that you tailor these sessions to the individual:
- For those that have made a good recovery it is important to discuss the things that they can do to continue to manage their fatigue.
- For patients with moderate improvement it is important that the discussion is centred on what has helped and any other aspects of their lives that require changing or moderating. Of course there are many life circumstances that cannot be changed and it is important that these are acknowledged. Many of us manage adverse life circumstances by ensuring that we maximise other good areas in our lives. The concept of respite is important in that we all do things that help us deal with unchanging difficulties, this can be anything but often includes social contact, having a confidant, going out, or they can be things done alone such as reading, taking a bath etc.
- For patients who have not improved it is important that this is acknowledged and that next steps are considered, i.e. specifically asking the patient what they think might help - if referral to another agency is considered this needs to be discussed in full [though clearly the decision making for this will rest with the GP].

Management of set-backs

- Patients who have experienced a set-back during the course i.e. a flare up of fatigue or increased pain from a disease flare may have learned some useful strategies to help them to overcome any future set-backs.
- However, if a patient has made steady progress throughout the course, with no set-backs or exacerbations in fatigue, then it is important to discuss practical ways of dealing with them, should they occur.
- For all patients, it is useful to discuss potential triggers to set-backs, e.g. viral infections, life events, stopping using techniques that you have discussed during session etc.
- Patients should be asked whether they feel confident that they could identify warning signs for set-backs, and asked what specific steps they would take to prevent or manage a set-back. It is important to emphasise that a set-back does not mean that they are going back to square 1 and it

can in fact help them to understand their IRD-related fatigue better and enhance the way they deal with it in the future. See related Handout 9.

Ending: Feedback on session - final questions - closure of the session - next steps

- Recap the session, particularly highlighting staying well and relapse prevention.
- Reiterate the next steps that you have agreed.
- Arrange appointment for the follow up session.

Session 8 (follow-up session)

Session 8 (follow-up) overview

Review progress on goals since session 7

Discuss any problems (and solutions) that have occurred since session 7

Problem-solve any outstanding problems

Review their understanding of the model

Discuss further goals

Feedback

Review progress on goals since session 7

- Discuss the patient's progress since session 7. Discuss and re-rate goals that were set at session 2.
- Discuss whether they are maintaining a planned consistent programme of activity and rest. If the diaries show prolonged periods of activity or rest, or an erratic sleep pattern etc, discuss the patients' reasons

Discuss any problems (and solutions) that have occurred since session 7

- Discuss any problems that they have encountered since session 7. These may be related to their fatigue or other problems.
- Discuss strategies that they have used in order to overcome their problems.

Problem-solve any outstanding problems

- For any outstanding problems that the patient feels they have been unable to overcome, generate some alternatives with the patient and try to agree a plan to enable the patient to be able to resolve the problem.

Review their understanding of the model

- As this will be the last time you will be seeing the patient, it is important to check their understanding of the model and to resolve anymisconceptions.

Discuss further goals

- If patients have reached some of their goals then it is useful to discuss others that they would like to work towards over the coming months.

Feedback

- Elicit feedback from the patient about the intervention and their experience of the intervention delivered by telephone/internet-based calls.
- Thank the patient for being part of the study.

Section C: Interventions for therapists

1 Cognitive restructuring (or thinking about things differently)

2 Behavioural experiments

3 Problem-solving

4 Managing specific symptoms and lifestyle changes

1: Cognitive restructuring (or thinking about things differently)

Cognitive restructuring is a way of changing our unhelpful thoughts by looking at them and challenging them. When we are stressed/fatigued or in pain or other symptoms we may have many unhelpful thoughts such as “I am worthless”, “Everything I do is wrong”, “Why does nothing ever go right for me?” Sometimes these thoughts might take the form of worries or fears about bad things that might happen in the future, or unpleasant things that have happened in the past. These unhelpful thoughts often stop us doing things that we want to do. The more unhelpful thoughts we have, the less confident we are and the lower our self-esteem becomes. It is yet another vicious circle.

Cognitive work involves checking understanding the link between thoughts, feelings (emotional and physical) and behaviours, which should be discussed using the patient’s own examples. It is important to initially focus on thoughts related to between session difficulties and then move onto thoughts on symptoms, rest, sleep, self-esteem, performance and expectations. Patients will be taught how to identify unhelpful patterns of thinking (thinking errors), find evidence for and against their unhelpful thoughts, generate a number of alternative thoughts and write an action plan.

The effectiveness of the alternative thoughts will be reviewed by measuring the patient’s belief in their unhelpful thoughts before and after generating alternatives. How they felt emotionally at the time of their unhelpful thought will be compared to how they felt after generating alternatives. Their action plan will be discussed in terms of how effective it was in helping them to break negative patterns of thinking. A patient-friendly copy of the unhelpful thoughts and thinking errors listed below is in the Appendix as Handout 10.

Unhelpful thoughts:

- seem automatic. We don’t think them on purpose, they just appear in our heads.
- seem believable and real at the time they appear.
- are the kind of thoughts that would upset anybody.

Thinking errors

Certain types of thinking errors are common in people. When you start writing down your thoughts, watch out for any thoughts that fall into these categories.

- **All or nothing thinking (black and white thinking) -** Thinking in black and white terms, for example, anything less than a perfect performance you may view as a complete failure.
- **Overgeneralising -** Viewing the outcome of a single task, or a single event, as having implications for all future tasks or events in your life
- **Catastrophizing** - Thinking that just because something didn't go as you wanted this time it will never go as you want, or that everything will go wrong for you in the future.
- **Should, must or ought** - Other patterns of thinking common in people include demanding thoughts, which take the form of 'should', 'must' and 'ought' statements. For example 'I should always appear happy and friendly to others', 'I must be loving to my children at all times', 'I ought to be able to handle this by now'.
- **Mind-reading –** Assuming we know what others think, feel or intend even though we cannot actually know.
- **Emotional reasoning –** Assuming that if you feel something this means that it is true - for example, if you feel nervous this must mean that you are not prepared, if you feel anxious that must be because you are in danger.
- **Personalization (it's all down to me) -** Assuming that you are a cause of a negative event although there may in fact be many causes.
- **Jumping to conclusions -** When we believe things to be true even though we lack evidence. This can include 'mind-reading', when we make assumptions about what others think without checking this out with them, or when we predict the outcome of something that we might do and treat this as a fact rather than a prediction.
- **Mental filter/disqualifying the positive (Tunnel vision) -** Seeing only the negative and ignoring the positive or, when something good does happen, downplaying its importance.
- **Magnification or minimization -** Similar to disqualifying the positive, we may exaggerate the importance of negative things and downplay the positive.

These 'rules' are extremely inflexible and if we break them we often feel extremely guilty or upset.

How do I do cognitive restructuring? (sample discussion with patient)

If you want to do some work with your thoughts you can use a thought diary to collect and write down your thoughts.

Stage 1

Each time you feel fatigued, fatigued, stressed, depressed, in pain, worried or irritable:

- Write down in the first column of your Thought Diary a brief description of the situation where the thought occurred. You should write down where you were and what you were doing.
- In the second column write down the actual feeling you had. This may be sad, anxious or angry. Also record how bad that feeling was on a scale of 0 –100%. 0% is *'not bad at all'*, 100% is *'the worst it could be'*.
- In the third column write down exactly what your thought was and how much you believe that thought to be true. Here 0% is "*I do not believe this at all*", 100% is *I totally believe this thought*". An example can be found on the thought diary below.
- For the time being, ignore the last two columns of the diary.

Thought Diary

Situation	**Feeling** *Rate how bad it was (0-100%)*	**Thought** *Rate how much you believe this thought (0 –100%)*	**Revised thought** *Rate how much you believe this thought (0 –100%)*	**Feeling** *How bad was it? (0-100 %?)*
E.g. Sitting doing nothing	Sad (70%)	'Things will never get better' (90%)		

We suggest that you should collect your thoughts for one to two weeks in this way. It is also helpful to talk to your therapist about what you have written in the diary.

Stage 2

Stage two is all about collecting evidence to see if you're thought is true or not. There are many ways to collect evidence. In this booklet we have described one of the most common ways to do this. It is also one of the most straightforward to use yourself. We suggest that you look at one thought at a time.

Write the thought down on top of the 'evidence table'. Add in your percentage rating of how much you believe it. In the evidence table, one column is labelled ***evidence for*** and one is labelled ***evidence against***.

Next, imagine that you are the judge in a court where the evidence for and against the truth of your thought is being examined. Write down the evidence for and against the thought being true. Remember that you are the judge and you need to present the full picture so that a fair decision can be made.

My Thought	**My % belief**
Evidence for	**Evidence against**

Sometimes people find this quite difficult. To help you to give your thought a 'fair trial', use some of the following questions:

- *If my best friend or partner were giving evidence, what would they say for and against this thought?*
- *If you rate the belief in your thought as 75%, then there is 25% of the thought you do not believe to be true. Ask yourself what makes up that 25%.*

Stage 3

Now you need to reconsider the thought in light of the evidence you have collected. You should be able to come up with a revised thought. Use the fourth column of the thought diary to write down this new thought. You should also rate how much you believe the revised thought.

In the final column rate your feelings again using the same 0-100% scale. Notice how by changing your thoughts, your mood may change. This is the way cognitive restructuring can work to change the way you feel.

Challenging unhelpful thoughts

The following questions, which patients can ask themselves, aim to help them to look for more helpful and realistic alternatives to their unhelpful thoughts by:-

- detecting possible thinking errors or distortions
- looking at the situation from another point of view
- finding evidence that does not support their initial thoughts

- What thinking errors am I making?
- Have I had experiences that indicate that this thought is not true all of the time?
- Am I assuming that this view is the only one, or might another person look at it in a different way?
- If my best friend or someone I loved had been in a similar situation, would I say the things that I have said to myself to him or her? What might I say to them?
- If my best friend or someone that is close to me knew that I was thinking these things, what would they say to me?
- What is the actual evidence that this thought is true?
- Is there any evidence that this thought may not be entirely accurate?
- Are there any small things that contradict my thoughts that I might be discounting as not important?
- Am I blaming myself for something that wasn't entirely my fault?
- Am I being too self-critical and expecting too much of myself?
- What are the advantages and disadvantages of thinking this way?

Helpful hints when changing unhelpful thinking

- Unhelpful thinking takes time to change. Often you will need to challenge your thoughts several times before change takes place.

- Ask a friend you trust to help you look for evidence for and against your unhelpful thoughts.

- Practice cognitive restructuring with other thoughts. Use your evidence table to judge them.

- As you become more expert in this, try to catch the thoughts and judge them as they actually occur

- Carry your diary with you so that you can catch and challenge your thoughts straight away.

2: Behavioural experiments

Behavioural experiments can be beneficial in helping patients to test their unhelpful thoughts and constructing and testing new more adaptive perspectives.

There are two broad types of behavioural experiments that can be used at various stages of therapy. One is based on hypothesis-testing, i.e. “Is it true that …” and the other is based on discovery, i.e. “What would happen if……”

Hypothesis-testing experiments can be used to test the validity of a particular unhelpful thought/belief (negative prediction). For example, “if I do not sleep in the afternoon, I will get worse”. “If I walk for more than 10 minutes I will collapse”. They can also be used to support evidence for a more adaptive cognition. For example, “If I get up at the same time each day, my sleep will gradually improve”.

Discovery experiments can be used when patients are unclear about the processes maintaining a problem, or about what might happen if they acted in a different way. These experiments can help in the development of the formulation, in designing treatment strategies and in creating and refining new perspectives. For example, a patient may be unclear about what may happen if they change what they are doing at the beginning of their treatment.

Behavioural experiments may also be used to test out the validity of the patient’s existing “unhelpful” thoughts, assumptions and core beliefs. They may then be used to strengthen new, more “helpful” thoughts, assumptions and core beliefs.

Types of behavioural experiments

There are a few different types of behavioural experiments that can be used to help patients to test their negative cognitions and construct new more adaptive perspectives. These include active experiments, gathering information from other sources and direct observation. However, the most commonly used experiments are active experiments which are described below.

In active behavioural experiments the patient will deliberately think or act in a different way in the “problem” situation. For example, patients may have previously sat down for a rest when they experienced symptoms following increased activity. You may ask them to keep going for X amount of minutes to see what happens. They should be encouraged to note what happens, and reflect on the implications for their thinking and behaviour in the longer term.

In certain situations where the patient feels that an experiment is going to be difficult, it can be useful to use role play. For example, if the patient has little help from family members at home, they may fear that asking someone to help may provoke a negative response. Role play could be used to practice requesting help in different ways, which may lead the patient to increase their confidence and feel more able to tackle this problem in real life

Recording of behavioural experiments

For specific behavioural experiments it would be useful to ask patients to complete a behavioural experiment record. This will enable you to review the outcome of the experiment and help you both to decide how to move forward

3: Problem-solving

(sample conversation with patient)

We all have problems that at times can seem overwhelming and impossible to solve and which make us feel unhappy or anxious. Such difficulties often go round and round in our head and appear to have no clear solution. Problem-solving is a structured way to help you manage current problems. It helps you:

- to feel more in control of your difficulties; and
- think of realistic and practical solutions.

How do I start to do this?

There are several stages to problem solving. If you choose to try it, your therapist will help you to make a start.

The stages are:

1. Identify and write down what the problem is (you need to define the problem as clearly as possible). If you have a number of problems start with the one that is most important.
2. Write down as many possible solutions to the problem as you can (even if you think that they are not likely to work).
3. Go through each solution and decide on the good and bad points of each one.
4. Choose the solution, which is the most realistic and practical.
5. Write down each step that you need to do to resolve or change the difficulty. Decide when you will do each step.
6. Work through each step keeping a personal diary of your progress.
7. Review how helpful the solution was, whether it solved the problem.
8. Decide what to do next.

You may find that in trying out your chosen solution you uncover problems underlying the original problem. This does not mean that your attempt has been a failure as you have succeeded in gaining further understanding of the problem, understanding that you would not have if you had done nothing.

It may be necessary then to go through the problem-solving process again to find solutions to the underlying problem.

Problem-solving can be useful for lots of different types of problems. Once you get used to using the steps you will find it becomes easier to apply in day to day situations.

4 Managing specific symptoms and lifestyle changes

(Sample conversation with patient)

There are a lot of different things you can do to improve your symptoms and feelings and how these might be locked into a vicious circle. The idea is to get the vicious circle working in reverse. If our physical symptoms improve, our behaviours and thoughts can also change for the better. Changing thoughts can lead to different behaviours and improved physical symptoms. Your vicious circle can be turned into a ‘recovery circle’.

We have listed some techniques that can help with the common physical symptoms experienced by many people. If they sound like the kind of things that you would like to try, you should discuss them with your therapist.

Improving your sleep

Sleep problems can take many forms. Some people have difficulty getting off to sleep, some people wake early in the morning and are unable to get back to sleep and for others they wake frequently whilst others sleep but wake up without feeling rested. Some people sleep too much, sleeping throughout the day. Other people sleep a lot because they feel so tired and have lost energy.

If your sleep is disturbed here are some useful do’s and don’ts about sleep which you could find helpful:

- Try not to sleep in the day. The problem with not sleeping at night is that we then feel down, tired and washed out. This tempts us to nap in the day. Unfortunately napping in the day just creates another vicious circle. The more we take daily naps, the harder it becomes to sleep at night.
- Ensure that you prepare yourself for sleep **before** going to bed. Try to relax for an hour or so before going to bed. Some people find it useful to have a warm bath or a milky drink.
- Eating a large meal in the evening may prevent sleep, so try to eat earlier.
- Don’t drink tea or coffee before going to bed. Such drinks contain caffeine which is a stimulant and will keep you awake.
- Don’t watch TV in bed as this can be stimulating at the wrong time.
- If you cannot get to sleep, try to relax your body and mind. Focus on resting rather than sleeping. For some people doing some mental relaxation exercises can help.
- Try to go to bed and get up at the same time each day. Keeping to the same routine every day is more likely to restore your sleeping pattern.

- Try to do some exercise every day. This could just be a brief walk or doing some gardening. ‘Little and often’ and ‘start small’ are good pieces of advice. A 10 minute walk every day is a great start.
- Keep a notebook and pen by your bed so if you are troubled by thoughts that won’t go away you can jot them down and deal with them in the morning.

Improving your diet

When people feel stressed/low in mood or have other physical symptoms they often lose their appetite. For other people, they find that they eat more. We sometimes stop bothering to cook, shop or prepare a meal. Even if we are tempted to eat, we may choose convenience or ‘junk’ foods. This kind of food makes us feel temporarily better but quickly leaves us craving for more.

If your symptoms/feelings are causing you a problem with eating here are some useful do’s and don’ts which you may find helpful:

- Try to eat small meals regularly. It is often easier to face small amounts of food often rather than a huge meal all at once.
- If you don’t want to make a lot of effort to prepare food, try to buy healthy food that doesn’t need much preparation. Fruit, yoghurts, salad and fish are examples of foods which are easy to prepare.
- Try to avoid too much comfort eating – it rarely feels comforting in the end. It is easier not to buy it at all when you go shopping than to resist eating it when it is in the cupboard.

Managing irritability

Irritability is common for many people when they are in pain/have other physical symptoms or feel low or stressed. We end up being intolerant of people and may snap at them. We do this with our loved ones, our work colleagues and even people we don’t know. Sometimes this can go beyond irritability and we can end up being quite angry with everyone. We can get angry with our employers for not understanding our situation, angry with our families for constantly bothering us, and angry with our doctors for nagging about health issues.

If irritability or anger is one of your symptoms overleaf are some useful do’s and don’ts which you could find helpful:

- Try reminding yourself that the way you are feeling is because of your physical symptoms or stress. This is not the ‘real’ you. It is a symptom.
- Many people find they need help to relax. Some simple relaxation exercises might help here. Your therapist will be able to teach you some easy relaxation techniques that you can use at home on a regular basis. Listening to your favourite music is another good way to relax.
- Most of us need to take time out for ourselves but many of us struggle to do this. Taking time out just for you is important for our physical and mental health. Mostly it will include something that you find pleasurable, something just for you. This could involve a simple activity such as having a relaxing bath, listening to some favourite music or reading.

Dealing with poor concentration

Experiencing difficulties with concentration is difficult. Many people find that they cannot pick up a book or newspaper anymore. Even the thought of reading can be off putting. Our memories seem to deteriorate and we forget what we have just read or heard. This can happen in conversation with people, not just when reading or watching the TV.

Actually, our concentration may not be as bad as we fear. In fact, when we are feeling stressed or low we tend not to listen as carefully as we normally do. Because we don’t listen clearly, we don’t remember information properly. We then end up worrying about our concentration. Once we start to worry, our concentration gets even worse. It’s another vicious circle.

If concentration is a problem for you here are a couple of useful ideas which you may find helpful to try:

- One useful suggestion is to write things down. It can be helpful to keep a list of important things to do.
- Because our concentration can be affected we often simply stop doing things like reading. One solution is to read regularly but for small periods of time only. Alternatively, we could read something that is slightly easier to digest than the material we are used to.

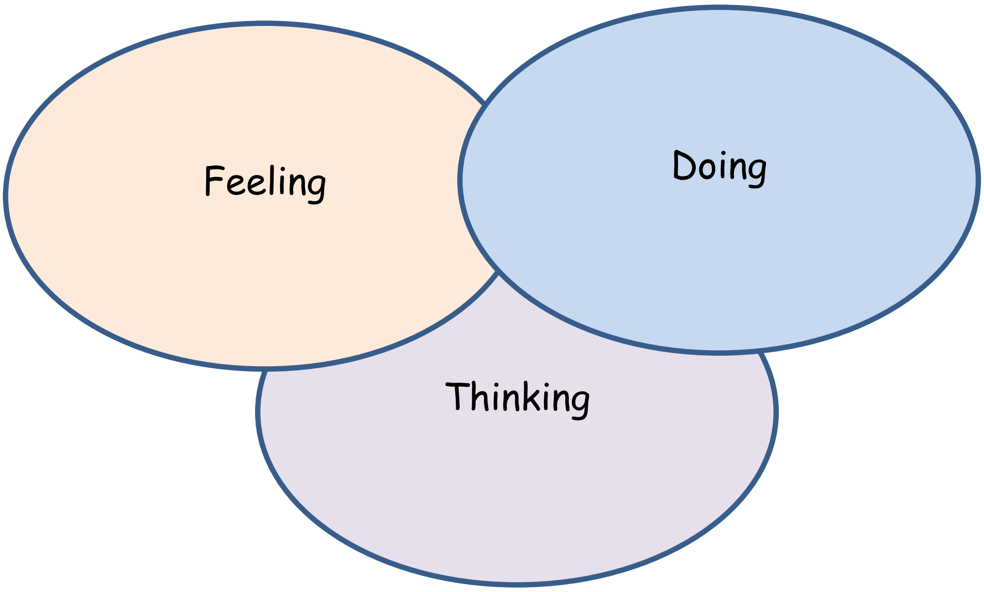
Appendix 1: Patient handouts

1a Thoughts, feelings and behaviours (write a list)
1b Thoughts, feelings and behaviours (write in the circles)
2 Daily Activity Diary
3 Wheel of Life
4 Goal-setting
5 Boom and Bust
6 Achieving a Balance
7 Sleep and Fatigue
8 Managing Stress
9 Coping with setbacks
10 Unhelpful ways of thinking

Appendix 1: Patient handouts

Handout 1a:

Thoughts, feelings and behaviours



My physical symptoms, my behaviours and my thoughts are linked in the following ways:

………

………

………

………

………

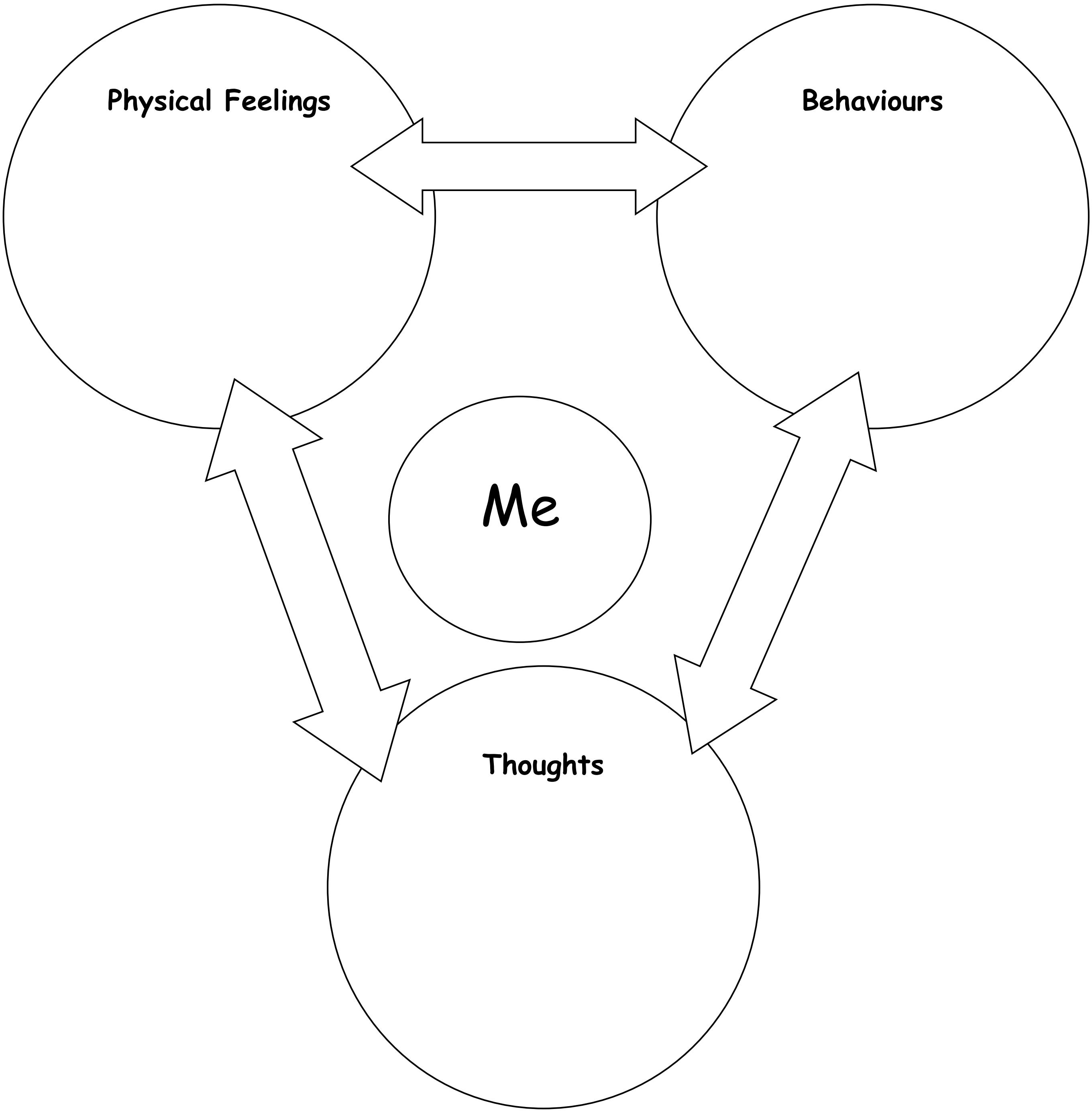
………

………

Handout 1b:

If you prefer a diagram you might like to use this slightly different layout:

My vicious cycle

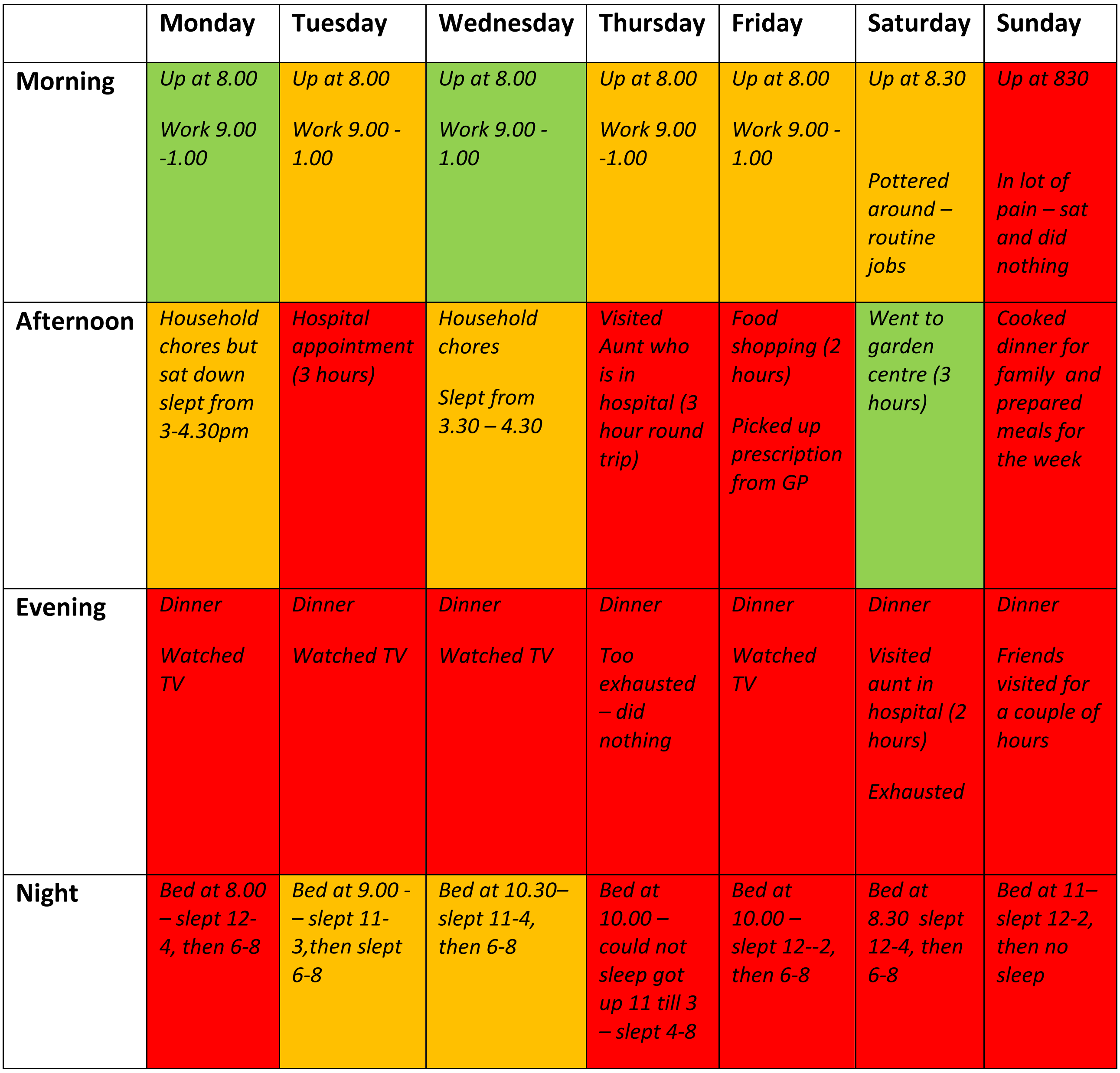


Handout 2:

Daily Activity diary (example, blank diary overleaf)

We are trying to capture your activity, how fatigued you felt and how you slept. We would like you to fill in the activities you do every day – this does not have to be too detailed but captures what you do. We would then like you to rate your levels of fatigue by using 3 colours to shade in the squares:

Red = very fatigued
Orange = moderately fatigued
Green = not fatigued



	Monday	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**	**Sunday**
Morning	🟩 *Up at 8.00* *Work 9.00 -1.00*	🟧 *Up at 8.00* *Work 9.00 - 1.00*	🟩 *Up at 8.00* *Work 9.00 - 1.00*	🟧 *Up at 8.00* *Work 9.00 -1.00*	🟧 *Up at 8.00* *Work 9.00 - 1.00*	🟧 *Up at 8.30* *Pottered around – routine jobs*	🟥 *Up at 830* *In lot of pain – sat and did nothing*
Afternoon	🟧 *Household chores but sat down slept from 3-4.30pm*	🟥 *Hospital appointment (3 hours)*	🟧 *Household chores* *Slept from 3.30 – 4.30*	🟥 *Visited Aunt who is in hospital (3 hour round trip)*	🟥 *Food shopping (2 hours)* *Picked up prescription from GP*	🟩 *Went to garden centre (3 hours)*	🟥 *Cooked dinner for family and prepared meals for the week*
Evening	🟥 *Dinner* *Watched TV*	🟥 *Dinner* *Watched TV*	🟥 *Dinner* *Watched TV*	🟥 *Dinner* *Too exhausted – did nothing*	🟥 *Dinner* *Watched TV*	🟥 *Dinner* *Visited aunt in hospital (2 hours)* *Exhausted*	🟥 *Dinner* *Friends visited for a couple of hours*
Night	🟥 *Bed at 8.00 – slept 12-4, then 6-8*	🟧 *Bed at 9.00 - – slept 11-3,then slept 6-8*	🟧 *Bed at 10.30– slept 11-4, then 6-8*	🟥 *Bed at 10.00 – could not sleep got up 11 till 3 – slept 4-8*	🟥 *Bed at 10.00 – slept 12--2, then 6-8*	🟥 *Bed at 8.30 slept 12-4, then 6-8*	🟥 *Bed at 11– slept 12-2, then no sleep*

Daily Activity diary

We are trying to capture your activity, how fatigued you felt and how you slept. We would like you to fill in the activities you do every day – this does not have to be too detailed but captures what you do. We would then like you to rate your levels of fatigue by using 3 colours to shade in the squares:

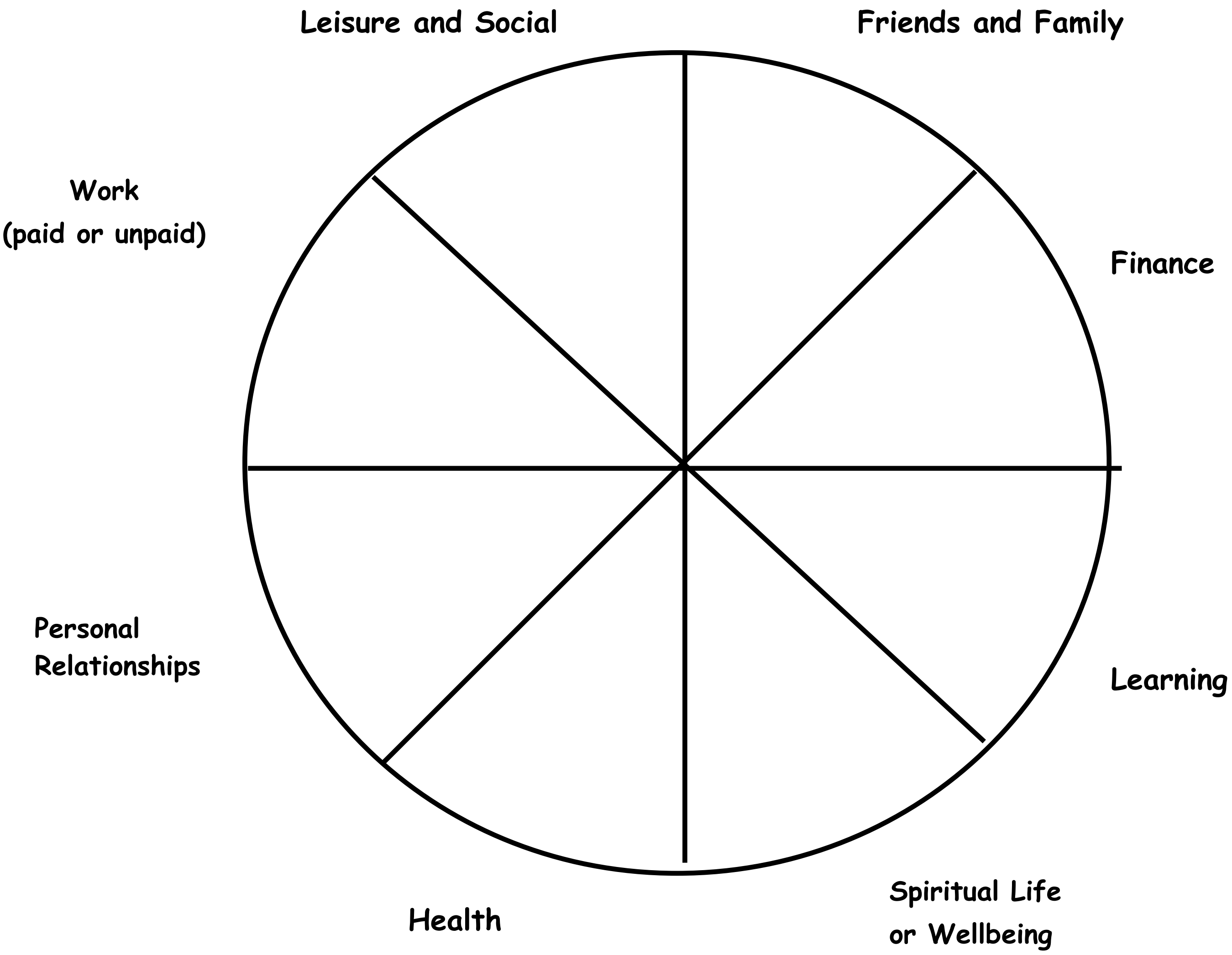
Red = very fatigued
Orange = moderately fatigued
Green = not fatigued

	Monday	**Tuesday**	**Wednesday**	**Thursday**	**Friday**	**Saturday**	**Sunday**
Morning							
Afternoon							
Evening							
Night							

(Material kindly contributed from the RA fatigue programme RAFT)

Handout 3:

The Wheel of Life



- Score each segment of the circle out of 10 for how satisfied you are with is 0 = least satisfied, 10 = most satisfied
- Look at the segments that scored the lower and ask:
  - What would 10 out of 10 feel, look and sound like to you? Is that perhaps unrealistic?
  - How would your life be different if you scored higher in that area?
  - What area of your life would you most like to work on?
  - What can you do to move that score up just **ONE** point?

Appendix 1: Patient handouts

(Material kindly adapted from the RA fatigue programme RAFT)

Handout 4:

Goal-Setting

What are goals?

They are a clear statement of your own ambitions, and can vary from person to person. Some examples of different peoples' goals are:

Being able to walk to the shops three times a week
Being able to swim two lengths twice a week
Managing to vacuum two rooms at a go
Getting to the cinema
Starting some voluntary work
Weeding the garden for fifteen minutes twice a week
Going out with friends

An example of how goal-setting can be difficult

Linda decided that despite her fatigue she really wanted to get into swimming. She had been talking to her friends about going for months but she would often forget, things kept cropping up, she had jobs to do, and she never got round to it. Eventually she found herself with an afternoon off and she decided this would be the day that she returned to the swimming pool. She loved it. She swam for over an hour and got out feeling refreshed and rejuvenated, tired but happy. It wasn't until the next day that there were any negative effects. It had been too much and her body let her know it. Overwhelming fatigue left her feeling totally drained. She had had high hopes of success after so months of meaning to go and now it seemed as though it had been a bad idea from the start.

Linda learned from this experience and she adopted a goal setting approach. For her next attempt she set a realistic target based on what had happened, to be able to swim for 15 minutes without feeling fatigued by the end of the next month. She planned when and how to slowly build up her activity before she reached her target. Then she followed this action plan, going to the pool regularly but swimming for a short spell each time and by the end of the following month she had reached her 15 minute target. She then felt confident enough to set a higher target and decide on an action plan for the next 4 weeks. If she aimed slightly too high she knew she could learn and adjust with something more manageable next time.

How to set goals:

1. Choose a goal that will give you enjoyment, or achievement

2. Be realistic about what you can achieve. An activity diary is a helpful way to record your current ability and help you to set a baseline

3. For a large or long-term goal, break it down into attainable chunks. For example, the goal about walking to the shops could be broken down into targets like this:
    - week 1: walk halfway to the shops, five days a week
    - week 2: walk another fifty yards towards the shops, five days a week

   And so on!

4. State your goals clearly, how far, how many, when, who with, for how long etc.

5. Write your goal down, display it somewhere obvious at home, tell your friends or family, get some support and encouragement, and reward yourself when you succeed!

6. Ask yourself 2 questions:

   Is this goal important to me?
   Am I confident that I can do this goal?

Remember: goals should be "SMART":

• **S**pecific	Is your goal too vague? If so, try to be clearer about it
• **M**easurable	How will you know if you have achieved your goal?
• **A**chievable	How likely are you to be successful?
• **R**ewarding	Will you enjoy the results?
• **T**ime limited	When do you want to have achieved your goal?

Clearly state your long-term goal:

Long-term goal 1

Now break your goal down into small, achievable targets:

Example A: Long term goal is to be able to walk to the shops three times a week.
This week I will **walk** *(what)*, **to the end of the road** *(how much)*, **before lunch** *(when)*, **on three days** *(on how many days)*

Example B: Long term goal is to be able to swim two lengths twice a week.
This week I will **find out about the swimming pool** *(what)*, **the times and prices** *(how much)*, **on Saturday** *(when)*

My goal: This week I will….

-- **What I will do**

-- **How much I will do**

-- **When I will do it**

-- **On how many days?**

Now check how important this goal is to you:

0 = goal not very important to me; 10 = goal very important to me

0	1	2	3	4	5	6	7	8	9	10

Now check how confident you are that you can do this goal:

0 = not at all confident I can do this goal; 10 = very confident I can do this goal

0	1	2	3	4	5	6	7	8	9	10

Next week, during our telephone discussion we will discuss how you are getting on:

I can do this now (circle a number):

0	**1**	**2**	**3**	**4**	**5**	**6**
Not at all		**Occasionally**		**Often**		**Anytime**

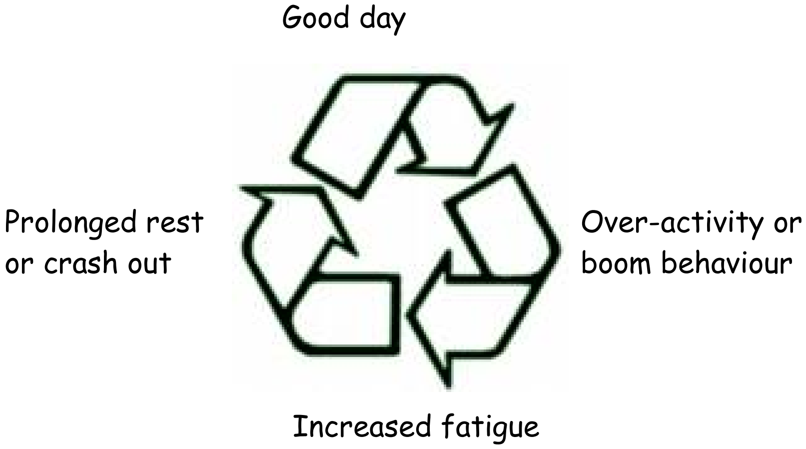
Appendix 1: Patient handouts

(Material kindly contributed from the RA fatigue programme RAFT)

Handout 5:

Pacing to Manage Boom and Bust

Often people with inflammatory rheumatic diseases describe as having varying amounts of energy from one day to another or even within the same day. This lack of energy may lead people to attempt to do too much on a better day and then spend several days recovering from it. This is referred to as the boom and bust approach:



The problem of staying in this 'boom and bust' cycle is that every time you overdo it you become more likely to avoid doing these activities in the future because you worry that you will crash out again.

People stay in boom and bust because…

- There is work that "has to be done"
- It feels better to finish the job
- Of feeling guilty about overloading others
- Of trying to ignore or beat the loss of energy

What are the negative consequences of boom and bust?

- Setbacks or crashes for long periods (hours or days)
- Temptation to avoid activities in order to prevent a crash
- Harder to make longer term progress with activities that you want to do
- Fatigue decides how much you do, not you!
- Feelings of frustration and failure

Q. How can this 'boom and bust' approach to activity be changed?

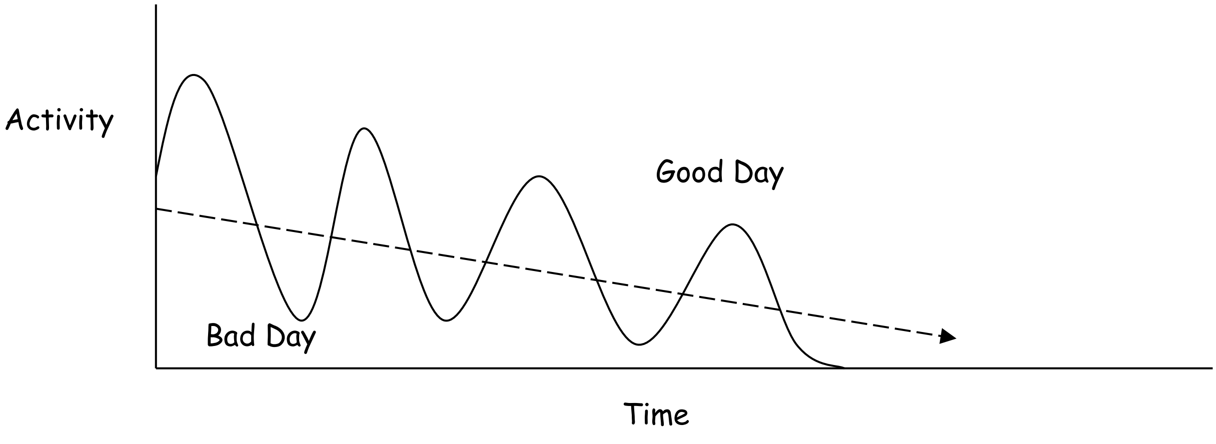
- Acknowledge that this is how you tend to approach activity
- Start to analyse how much of an activity you can do on a good day and a bad day, the aim is to sustain the same amount each day (in practice this will normally mean that you set a baseline of activity, which is initially lower than you would normally attempt on a good day)
- Balance short periods of activity with regular short rests
- Keep an activity diary, paying attention to which activities are high on energy requirement
- Set realistic goals to help bring about change

What is pacing and how can it help?

Pacing is all about balancing daily activity and rest to bring about improvements in the way you feel. The word activity is used in a broad sense, to include mental and emotional activity as well as the more obvious physical sort. Pacing is the way all of us should balance our daily activity. It is especially useful if you have an inflammatory rheumatic disease as your energy stores are much lower and therefore balance becomes even more important.

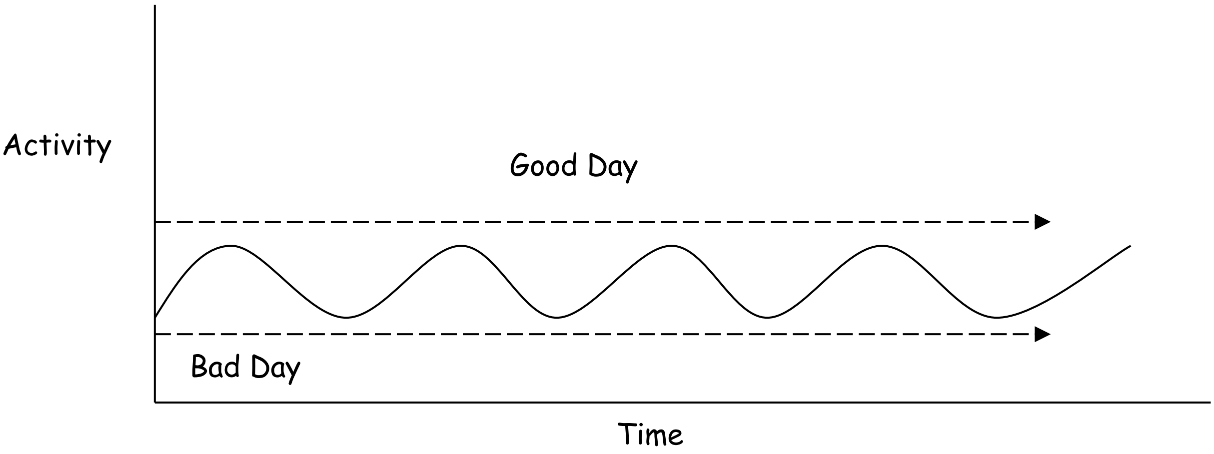
Boom and bust

Most people tend to do a lot when they feel good and not very much when they feel unwell. This can lead to big swings in activity and if you have RA you may find that you overdo it one day and then have to spend several days recovering. Over time this tends to get worse.



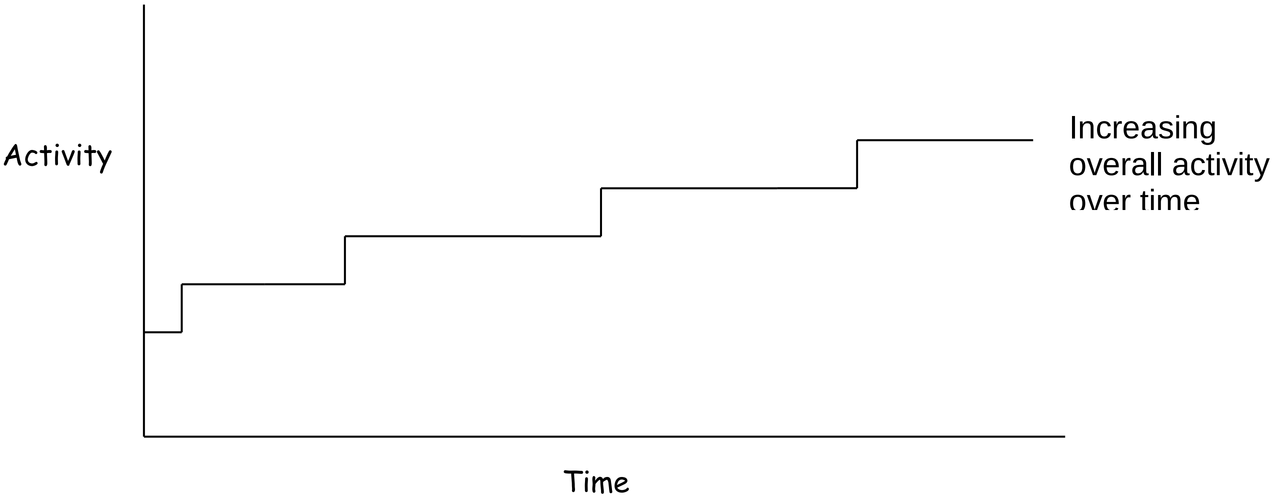
Taking a balanced, steady approach to activity counteracts the common tendency to swing from one extreme to another. It avoids the inevitable ill effects that follow so you can start the process towards recovery.

Before you start pacing you need to keep a record of your activity levels using the activity diary we have provided. You then need to decide rough maximum and minimum levels of activity that you will be able to do on good days and bad days. You would then try and keep your activity between those limits:



Pacing gives you awareness of your own limitations, which enables you to positively plan the way that you use your energy, maximising what you can do with it.

Over a period of time, when you are pacing, you should be able to increase your overall activity levels without ill effects. Some people call this increase in activity 'graded activity' but for many people this will happen naturally as you get better at pacing.



Using rest as part of pacing

To understand pacing, it can be helpful to think of your available energy as being like a mobile phone battery:

- If you completely drain the battery, you will have to wait a while for it to recharge before you can use it again
- If you use some of the battery and make regular top-ups then your phone will always be ready for use when you need it

Managing your energy through planned periods of activity and rest will mean that you are more likely to be able to do the activities that you want to do, when you want to.

What pacing is NOT about....

It is important to understand early on what pacing is not about. It does not give you a free hand to push through activities, with rest and recuperation afterwards.

Pacing takes an altogether smoother approach:

- If you are prone to trying to cram in as much activity as you can in the morning then have a sleep during the afternoon or the next day to recover, pacing helps you to break this habit.
- Similarly, pacing discourages you from resting too much through the day and then attempting a burst of activity later in the afternoon or evening.

(Material kindly contributed from the RA fatigue programme RAFT)

Handout 6:

Achieving a Balance

Achieving a balance in your life, when you have limited energy……

Pacing	your activities
Planning	how you will get things done
Prioritizing	what is important, including rests and treats
Positive	mental attitude, you can control your thoughts and attitudes
Patience	in trying to climb that mountain!
Persevere	when there are difficulties or setbacks
Participate	and have a go, even when you don’t really feel like it

Appendix 1: Patient handouts

(Material kindly contributed from the RA fatigue programme RAFT)

Handout 7:

Sleep and Fatigue

Some people with inflammatory rheumatic diseases experience sleeping difficulties. This needs to be taken seriously as a problem in its own right because sleep loss will usually add to the various other difficulties which already occur as a result of this illness. Exhaustion and poor concentration are examples of this. Some people will have the opposite problem, and will feel the need to sleep for more hours than usual. This can reduce the quality of sleep, and certainly leaves fewer hours awake to function.

Can anything be done about sleep loss?
IRD may cause problems with getting to sleep and repeated waking during the night. But this is rarely the only reason why sleep is disturbed. The good news is that usually these other influences can be easily changed to improve sleep.

What is a normal good night's sleep?
This varies from one person to the next, and changes as people get older. New born babies sleep for 18 out of 24 hours, young children up to 12 hours, young adults on average sleep for about 7 to 8 hours, whilst older people take even less, about 6½ hrs, on average. So, how does your sleep compare with what you would expect to be getting? If you are concerned about this the next question is:-

What is the nature of the problem?
If your sleep is disrupted do you feel tired and drowsy as a result? On the other hand, do you feel you have adjusted to it fairly well?

Is there a problem getting off to sleep? Is it that you keep waking up throughout the night? Is it that you wake early and cannot get back to sleep again? Is it that despite having slept you don't feel you have slept well?

Do you feel the need to sleep longer in the morning, go to bed early, or sleep in the daytime? Over-sleeping can increase levels of fatigue, worsen concentration, and reduce motivation and enjoyment of life.

It is important to work out what kind of disruption is taking place. This helps in deciding what changes might help.

What conditions are you trying to sleep in?
Give some thought to how comfortable their bed is. You need to be comfortable but the mattress should not be too saggy. Next, is the room helping? Temperature is important. It's hard to sleep when it's too warm, as well as when it's too cold. Are there any noises disturbing you that you could do something about? Some people are better able to sleep when there is a little noise going on in the background, and can't sleep when it's too quiet. What is the ventilation like? Some prefer a window open but others find it too cold or a distraction. Try to get the conditions right to suit your needs.

Exercise and sleep
There are strong links between exercise and good sleep. Inflammatory rheumatic diseases can lead people to take less exercise during the day. This will make sleeping more difficult. On the other hand if during the programme you have been increasing the amount of exercise you take in the day you may be already reaping one of the benefits, better sleep.

Research evidence suggests that afternoon exercise helps more than morning exercise. Exercise taken late in the evening tends to liven people up when they would be better winding down. Some people manage gentle exercise in the evening without disrupting sleep.

Emotions and sleep
Some people will say that they do their worrying at night when everyone else is asleep. Although you might say that there's nothing you can do to sort your anxieties out when you're in bed, it's sometimes hard not to worry anyway. If you cannot switch off from your worries then perhaps you are not ready to go to bed yet. If you want time to think things through on your own, it can be better to do this sitting in a chair before going to bed. Even better, find a time earlier in the day to think about your concerns, perhaps writing them down, as many people have found this process useful. Try to associate going to bed with going to sleep.

Some people will wake early and find they are unable to go back to sleep. If this is happening, and if you think that you will not drift off to sleep again afterwards then it's probably better to get up. If you're still weary then take rest in a chair instead.

The golden rule for good sleep: establish a regular pattern
It's possible to ignore most of the rules about sleeping and still manage alright. There are many people who have a cup of tea and cigarette before going to bed, or who take the dog for a walk. They probably manage this because it is part of a regular habit of getting ready to go to bed.

However, being inconsistent with the time that you sleep is asking for trouble - you need a pattern. Taking care of this is by far the most important thing you can do. Going to bed late one night, and then early the next is extremely disruptive to sleep. Your body needs a pattern. It needs to know when to EXPECT to get some sleep. You must respect this. We cannot simply change the time of sleep and assume our bodies will adjust. This is basically what has gone wrong when someone flies to another part of the world and experiences "jet-lag".

Another example is what is known as "Sunday Night Insomnia". This would be someone who has gone to bed late on Saturday night and got up late on Sunday morning who then finds that they can't get off to sleep at the usual time on Sunday evening. The mistake was to alter the pattern the night before. It will usually take a couple of days to adjust afterwards.

If your sleep is being disrupted try to work out the times you get your best sleep and build on them. If you want to improve your sleep at night and you currently sleep in the day, make a plan to gradually reduce your daytime naps to catch up, because otherwise this will become part of your 24-hour pattern. Daytime sleep can reduce the quality of night-time sleep, because it changes the pattern of deep (restorative) sleep which we get in the night.

If you are finding that you are sleeping for more than 8 hours, it might be worth trying to reduce your sleep, so that your sleep quality can increase. You will need to do this gradually, to allow your body to adjust. Most people find it is easier to set an alarm clock for a fixed time in the morning, and then to gradually set the alarm clock earlier. There is nothing wrong with a 5 or 10 minute change per week, if you are making progress in the long-term.

The reason for making the change in the morning is that our "body clock" is set when we first see daylight in the morning. Once the "body clock" is set, we will tend to feel naturally ready for sleep approximately 16 hours later. Opening the curtains a little can help with this process, but the sooner in the day that you can tolerate outdoor daylight the better. During the initial phases of any sleep reduction programme people often feel more tired, but this usually improves within two to three weeks. The rewards for this in the long-term are better sleep quality, and more hours in the day in which to pace activity and rest.

To sum up

- Good sleep is about quality not quantity
- Gradually cut out daytime sleep. Substitute with more rest periods
- Stick to a regular bedtime, and more importantly, stick to a regular time to get up.
- A good balance between activity and rest during the day will help.
- During the evening, particularly just before bedtime, it helps to have a regular set of activities that involve you winding down. Take less exercise at this time of day, avoid stimulants such as coffee, and avoid other things that wind you up.
- If you wake in the night and can't get back to sleep straight away (20 minutes) get up! Try to relax and take rest instead. Only go back to bed when you have a good chance of falling asleep again.

Appendix 1: Patient handouts

(Material kindly contributed from the RA fatigue programme RAFT)

Handout 8:

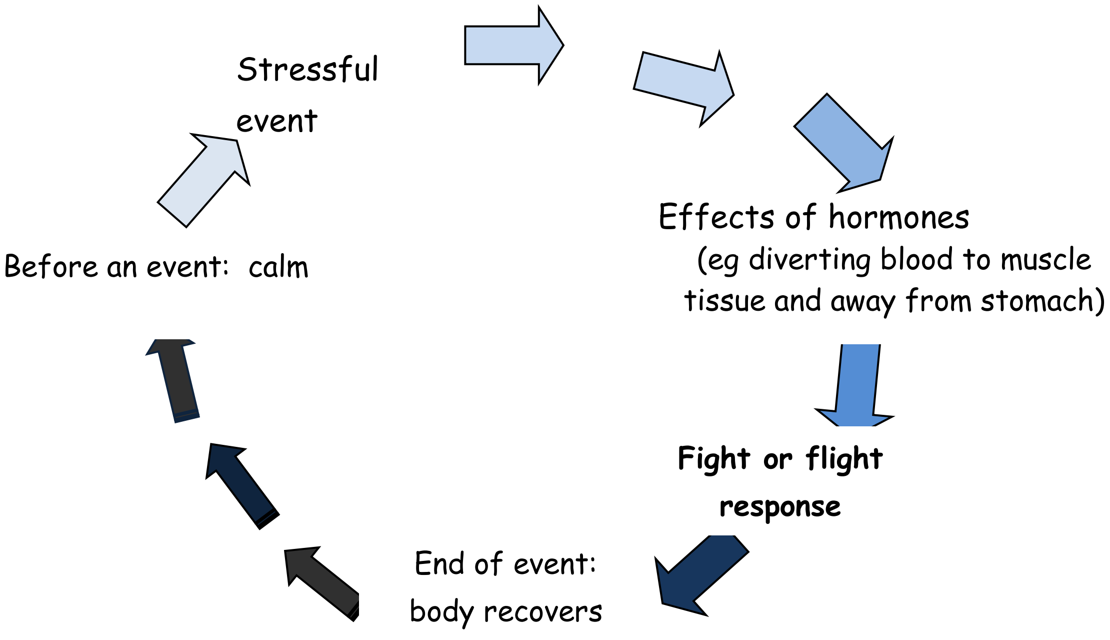
Managing Stress

Constant demands, negative events, being put under pressure, and the way it makes a person think, feel, and behave, are often labelled as stress. In some circumstances the instinctive ways a person reacts are a useful response that helps deal with a challenge or avoid danger. However, prolonged stress, over days, weeks and months is exhausting and has negative effects on health and well-being. Examples of this are:

- Disturbed sleep
- Lack of energy
- Loss of sex drive
- Inability to concentrate
- Low mood

Think of a time when you had to deal with a situation that was a particularly stressful challenge. Were you aware of any physical changes that took place? We react biologically to a stressful event by releasing two stress hormones, adrenaline and cortisol. This process is known the 'fight or flight response', where the body prepares itself to fight or flee from dangerous situations. This is an instinctive response. It can help you escape a threatening situation.

Flight or Fight Cycle: a normal cycle that resolves itself



It works as a trigger for several different levels of reaction affecting thoughts feelings and behaviour as well as the immediate biological reaction. Here are some examples:

BODY	**THOUGHTS**	**FEELINGS**	**BEHAVIOUR**
• Increased heart rate • Problems with digestion • Headaches • Prolonged muscle tension, aches and pains	• "I'll never be able to cope" • "I haven't got time for this" • "This isn't fair"	• Frustrated • Tired • Fearful • Irritable/angry • Low	• Argumentative • Avoiding people • Unable to start or finish jobs • Inflexibility • Difficulties making decisions

Different people react differently to stress: We may all have the same basic biological response but this is triggered at different levels in different people. Someone who can keep their head in a crisis situation may be unable to stay alert when listening to a long and complicated explanation of something that is nevertheless important. There is an idea that for everyone there is a zone of good functioning in relation to stress. Problems begin when there is either too little or too much stress. This is a particular concern wherever the demands of a situation are persistently exceeding what that individual feels they can comfortably manage.

- ❈ Being over-stressed means that we are less likely to enjoy ourselves, to be efficient in what we do and to think clearly

- ❈ Being over-stressed means we are wasting energy and we can become more fatigued

Most people have some effective ways of coping with stress but could also add to these and learn how to manage stress more successfully in the longer term. The first step in this is recognising their own stress symptoms.

Successfully responding to excessive stress will help to reduce fatigue as well as boosting your immune system

Are you able to recognise your own ways of reacting? Try to make a list…

- ✵ ____
- ✵ ____
- ✵ ____
- ✵ ____

For each of these ways of reacting to stress, ask yourself these questions:

Q. How does this strategy help?
Q. Does it work in the long-term?
Q. If not, what else could I do?

Space to add your own ideas:

....

....

....

....

....

....

....

....

Examples of stress management strategies

Behaviours

1. Be clear about what you can and can't do
2. Break large jobs into achievable tasks
3. Set goals/ an action plan
4. Accept offers of help

Tackle Negative Thoughts

1. Challenge these…. are they reasonable or magnified?
2. Be positive….. what do you know to be true from your experience? Try and take a balanced view
3. Distract from negative thoughts….. for example start an activity, watch TV or use relaxation techniques

Relaxation

1. Self-soothe by doing nice things for yourself e.g. music, soft fabrics, good food, and aromatherapy.
2. Deep breathing
3. Stretches, exercise
4. Use rest periods thoughtfully and effectively, to recuperate but not to crash out

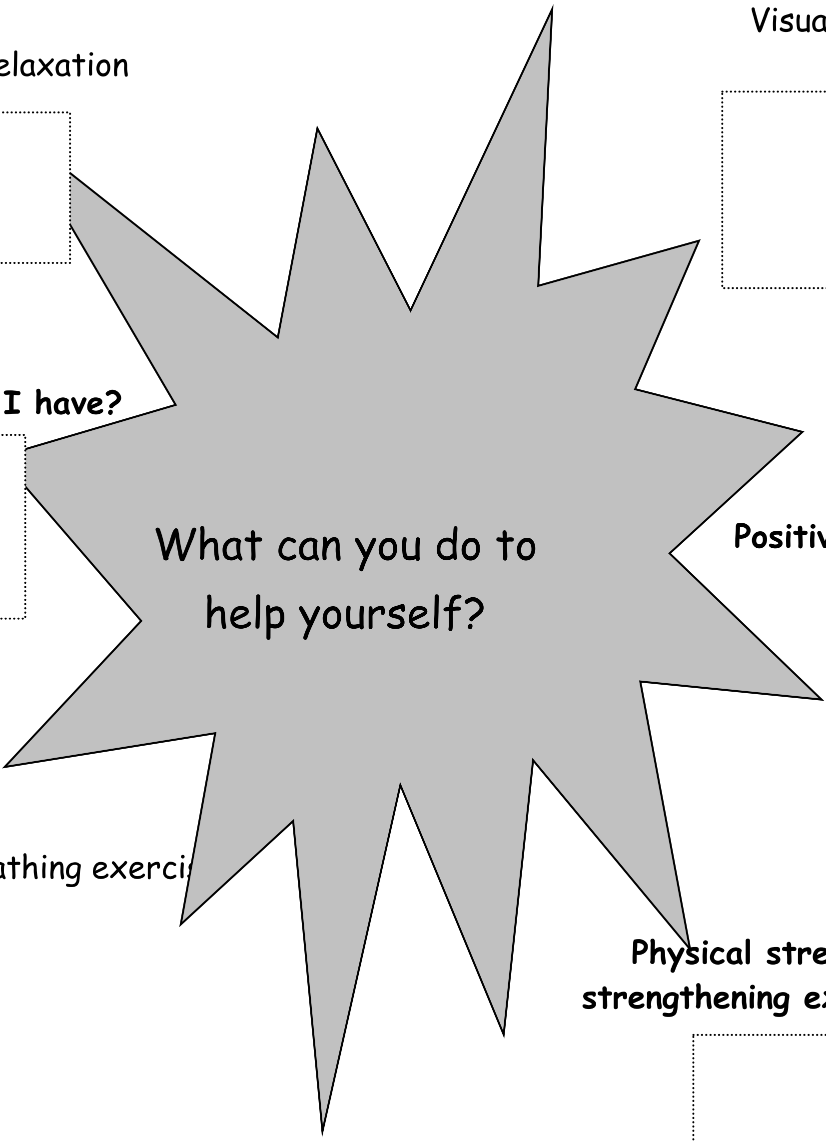
Q. ***So… what strategies could you use to help when feeling stressed?***

Add your own strategies in the boxes

Relaxation
Thoughts
Mantra
Meditation
Physically-focused relaxation

Distraction
Puzzles
TV and Radio
Visualisation

What resources do I have?



What can you do to help yourself?

Positive self-talk

Breathing
Controlled deep breathing exerci

Physical stretches & strengthening exercises

Avoidance versus facing things

⇩

Break down activities
into achievable tasks

Self-soothe

Touch
Vision
Taste
Smell

Appendix 1: Patient handouts

(Material kindly contributed from the RA fatigue programme RAFT)

Handout 9:

Coping with Setbacks

Most people with inflammatory rheumatic diseases will experience setbacks; times when symptoms worsen for a period of time. It can be difficult to maintain your levels of activity during these times. Different things will provoke setbacks, and they may last for varying lengths of time. Each person will have different ways of dealing with a setback. The purpose of this handout is to encourage you to become aware of those things that provoke a setback for you, and to develop a plan for coping with a setback when it happens.

What provokes a setback?

Setbacks don't always have clear-cut causes, but there are a number of things which can contribute to one:

Overdoing it – This may be the result of taking on too much, or simply as a result of doing one activity for too long. Setbacks can be started if you fail to **pace** yourself properly, or if you fail to **plan**, prepare and **prioritise**.

Stress – A period of stress in your life may provoke a setback. Be aware of those things that upset you and spot the signs that you are becoming unduly stressed. Stress management may be especially helpful at these times.

Periods of illness – Following a flare-up of your condition you may be more prone to a setback. Remember to restart activities and exercise gradually by pacing yourself.

Low mood/seasonal factors – Many people find that there is an interaction between their frame of mind and their energy levels.

Not all these factors apply to everyone. It is worth recognising as many signs and characteristics from your own experience of setbacks to help you next time. Use the space below to list those warning signs which you have noticed before, and add any new ones as you become aware of them.

My warning signs:

Even with the best of planning, it may be impossible to avoid a setback. However, if you do have one, could you use it as a way to learn? Did you ignore the signs? What could you have done differently?

Setback Management

An important part of learning to manage your inflammatory rheumatic disease is learning to manage setbacks as best you can. This means that you will be able to get over your setback more quickly, and feel more confident in the way you handle setbacks. During the programme we have discussed a number of ideas for managing them, and here are some reminders:-

Relaxation:	Remember the importance of proper, recuperating relaxation? Try to use your favourite relaxation technique.
Planned rest:	What have you found out about the most effective use of rest? Is it planned, time limited and enjoyable?
Exercise:	It’s tempting to stop completely when you are fatigued – don’t. Remember what you have learnt, and adjust your baseline accordingly.
Prioritise:	Put your energy into the most important areas of your life first.
Compromise:	Are you asking too much of yourself at present? Don‘t be afraid to step back and reconsider your expectations during a setback. Remember to recognise what you are achieving!
Socialise:	If you’re very tired, it’s easy to feel like isolating yourself. Remember that being in touch with someone can be helpful, so what about giving someone a ring, or inviting a friend round?
Pamper:	If the going is tough, pace yourself and give yourself a break. If a massage or relaxing shower or bath helps, why not? Decide now how you will indulge yourself as a kind of compensation next time a setback occurs.
Thinking:	Remember the way we think influences how we feel. In the midst of a setback it is easy to slip into bad habits and dwell on the negatives. Try to be aware of this, and try out different ways of thinking.

Not all these strategies will apply to you, and you may have developed some additional ideas for successfully managing or reducing the length of a setback. Use the space below and write down those ideas that you have for managing your own setback, and add any new ones that may help.

Handout 10

Unhelpful ways of thinking (Thinking errors, or distortion)

Unhelpful way of thinking	Description	Example	An example of my own thoughts
All-or-nothing or black-and-white thinking	Looking at a situation as two extremes only. There are no in-betweens, or shades of grey. Anything less than perfection is a failure	*"If I don't succeed in doing all the housework then I'm a total failure"*	
Overgeneralising	Making a negative assumption that because something has gone wrong once or twice, it will always do so	*"When I tried to exercise once before, my pain increased, so my pain is bound to increase if I exercise again"*	
Thinking it will be a catastrophe	Thinking about events as if they are a lot more negative than they are	*"My pain is really bad today, I must be doing permanent damage to my body"*	
'Should', 'must' and 'ought' statements	Fixed expectations on how you think you or others should behave	*"I should be able to vacuum the house in one go."* *"The doctor is so busy I ought not to bother her with my worries"* *"I must always appear happy, I mustn't let family know I feel sad"*	

Continues onto 2nd page

Unhelpful way of thinking	**Description**	**Example**	**An example of my own thoughts**
Mind-reading	Believing that you know what others are thinking, even though you cannot know	*"My friends must think I'm a really boring person and they don't really want to be here with me"*	
Emotional reasoning	Taking a feeling as being evidence of fact	*"I feel anxious, I know something dangerous is going to happen"*	
It's all down to me	Blaming yourself for anything unpleasant or taking too much responsibility for things that are not under your control	*"It's my fault that……."* *"It's my responsibility to sort out…."*	
Jumping to negative conclusions	Drawing a negative conclusion when there is no evidence to support it	*"They won't like me, so why even try to join in?"*	
Tunnel vision or mental filters (discounting any positive aspects)	Focusing solely on the negative aspects of a situation. The whole picture is coloured by what may be a single negative detail, ignoring any positive aspects	*"I am just as tired as 2 months ago, I haven't improved at all" (discounting the fact that you are now going out with friends more)*	