



PATIENT INFORMATION

CFS/ME Management Workbook



Use this workbook alongside the Understanding CFS/ME booklet. It is to help you understand some of the routines that you have at present and to think about if these are helpful or not helpful, and to plan and monitor any changes that you make. Please bring it to your rehabilitation appointments so you can record and remember information that we talk about.

There are activities for you to carry out in this workbook and they are marked by a tick  to make these stand out for you.

Provided by Children's Chronic Fatigue Service, Torbay Hospital.

Contents

- Managing Daily Activities
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- Goal Setting








How to use this booklet?

It is common for people with CFS/ME to experience cognitive fatigue and you may find it difficult to read and concentrate for long periods. Remember this when reading the booklet and stop before you feel this fatigue worsening.

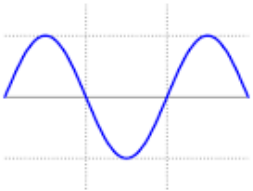
Managing Daily Activities

To be able to help you manage your energy levels better you need to understand what you do in a day and how much energy each of those tasks involves. Complete the activity diaries that are attached at the back of this workbook to help you understand this better. In the table below we list some examples of different types of activity and this will help you fill in your diaries. It would also be helpful for you to write down any different activities that you do that we have not included and how much energy you think you use doing them.

✓ High Energy Activities	✓ Low Energy Activities	✓ Rest/Relaxation Techniques
<p data-bbox="107 501 680 603"><i>Physical Activities e.g. walking, running, PE, sport, showering, brushing hair, car journeys</i></p>  <p data-bbox="107 715 680 858"><i>Cognitive Activities e.g. TV you are engaged in, school work, using a computer, chatting with friends, reading books you're engaged with</i></p>  <p data-bbox="107 986 680 1054"><i>Emotional Activities e.g. worries, arguments, thinking a lot about things</i></p> 	<p data-bbox="743 501 1384 683"><i>E.g. Watching TV that you are not really interested in, watching a DVD or TV programme you've seen lots of times before, reading magazines, getting ready for craft activities, colouring in</i></p> 	<p data-bbox="1402 501 1964 571"><i>E.g. meditation, yoga, deep breathing, mindfulness, relaxation techniques</i></p> 

If you find specific tasks difficult think if there is any way that you could *make them easier* e.g. sit down to do them, or break up the time that you do it for or do you need to do them at all? Are you doing enough *fun activities* - we tend to focus on schoolwork but having social time with friends is just as important and should be included in your diaries somewhere.

During your rehabilitation sessions we will look at your diaries and see if we can see any patterns and also how you felt whilst filling them in – was it confusing or was it helpful?



Patterns that we will look for are '*boom or bust*' cycles or doing everything in one part of the day or having prolonged rest periods during the day or having lots of one colour and not many others! We will also use your diaries to set a general baseline for how much red/high energy activity you should aim to do a day.

What is a baseline?

A baseline is an amount of activity that you should be able to do every day without making your symptoms worse. We usually work this out by counting up all the time spent on high energy activity across two weeks and then taking the average of this but you can also do it for individual tasks e.g. how long you go for a walk or read a book for. The aim is to increase your baseline at regular intervals and we recommend 20% every 2 weeks. We will talk about this and plan these at your appointment. Sometimes you may feel that 2 weeks is too soon and that is fine – we will go at a pace that is manageable for you.

An Example:

If you had a total of 74 hours of high energy activity over two weeks the average of this would be just over 5 hours a day. Guidelines suggest that initial baselines should be half of that average number, so in this example would be 2.5 hours a day. Therefore, you should aim for 2.5 hours of red activity a day. This may sound like not a lot compared to what you have been doing previously but it may be that on some days you have managed more and on other days have done less – this is about doing the same amount every day and that's why it may seem lower.

How to make activities easier?

Using some of the suggestions below you can begin to think how you can start to make changes to how you do some things. How can you do this:



- Timing – how long you do it for – remember what we have just said about baselines.



- Speediness – take your time. Trying to do things quickly often ends up in us making mistakes and having to re-do it and use more energy and is less helpful than taking longer.



- Rest – pause and take a time-out during a tiring activity.

We often have a lot of high energy activities in our day and it is difficult to think of activities that use less energy. It might be helpful for you to make a list of low energy activities below and then you can choose from that list each day rather than spend time thinking about what you could be doing, as that will be using up energy!! Low energy activities include; reading magazines or colouring in.

✓ **Some low energy activities that I could do are:**

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-
-

Sleep



Most people with CFS/ME have difficulties sleeping. It may be helpful to keep a record of this so that we can try to see if there is any pattern to your sleep. Complete the sleep diary attached to the back of this workbook and bring it to your rehabilitation appointments so that we can discuss them.

If sleep is still difficult then look back at the section in your booklet on things to do to try and help it. Have you tried some of those suggestions? Remember that it can take weeks or months to re-set your sleep habits so stick with it.

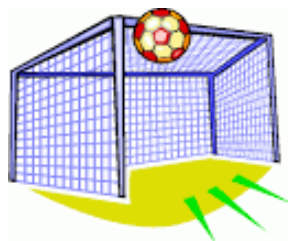
Rest/Relaxation

Rest and relaxation is something we are often not very good at fitting in to our lives. There are some free applications you can try, to help build in this type of rest, such as Headspace, Stop Breath and Think and Smiling Mind. Some of the activities involve zoning in to things like your breathing, the environment, or zoning out and imagining yourself somewhere else (like a tropical island). Relaxation can also reduce feelings of worry, which can help you to get better more quickly. Try to practise techniques at a time you do not feel worried. You may get the best results by practising at a regular time, for a few minutes, twice a day.

Thoughts/Feelings

Young people with CFS can sometimes feel down, stressed or think differently to other people. Sometimes this can be in the form, of what we call negative thinking or negative thoughts. This can come from having a condition for a long period of time, but can also be about the way (or style) we think. This might mean that we focus on the things that did not go so well, the things that we cannot do, always think how it could have been better (never feeling like things are good enough) or you expect bad things to happen, or consequences if you do something you want to do. Creating an awareness of these styles of thinking can help us to manage them. Next time one of these thought arise, stop and think is there a different way of looking at this? What would by friend/parent/ teacher say? Sometimes negative thoughts can lead to us avoiding certain activities and this is what may need to be gradually done differently in order to help you to make changes.

Goal Setting



Having goals is really important in recovering from CFS/ME as it gives you something to aim for. This may be something that you used to do but can't do at the moment or be something completely new. Everyone has their own goals and you will talk about these within your rehabilitation appointments. Use the space below to think about what one or some of your goals might be. For example, one goal might be to walk to the park to play basketball with friends. This would be your long term goal and your therapists can help you break this down into several achievable steps (short term goals). These might be that first you need to be able to walk to the park so how far is that and gradually build up your walking distance, you might need to improve your basketball stamina so you can play a game and this could be done practising with a hoop at home, starting at 5 minutes and building up over time, until you can put it all together and achieve your goals.

✓ Try to fill in the first two columns and we can think about the third in one of your appointments:

What I would like to be able to do?	What is stopping me from doing this?	How can I help myself to do this?

At each session we will try and set you some short term goals that will help you go on to achieve your main goals that you have written above. These will be activities that will be achievable in between your appointments and you can use the goal sheets at the back of this workbook to help you keep track of them and remind you of what you need to be doing.

✓ Activity Diary

Week commencing:.....

	AM											PM											Total high energy activity for day		
	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9		10	11
Monday																									
Tuesday																									
Wednesday																									
Thursday																									
Friday																									
Saturday																									
Sunday																									

Week commencing:.....:

	AM											PM											Total high energy activity for day		
	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9		10	11
Monday																									
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Sunday																									



Sleep (Blue)



Rest (Green)



Low energy activity (Yellow)



High energy activity (Red)

Week commencing.....

	Morning - AM											Morning PM											Total high energy activity for day		
	12	1	2	3	4	5	6	7	8	9	10	11	12	1	2	3	4	5	6	7	8	9		10	11
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Sleep (Blue)



Rest (Green)



Low energy activity (Yellow)



High energy activity (Red)

✓ Short Term Goals (to be completed at rehabilitation sessions)

Date:	Before my next session I will:	How will I do this	Did I achieve this? - we will answer this at your next session

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