

## **Managing setbacks**

As you become fitter, more energetic and your muscles and joints become stronger you will find that activity results in less fatigue than previously. Obviously you will need to continue to pace your activities and take care of yourself whilst being more active.

Despite the improvements you notice, you will inevitably have “setbacks”. Your fatigue may worsen and this may be accompanied by an increase in other physical symptoms such as pain. CFS/ME is a relapsing condition, you will have setbacks or relapses or bad days, these are part of having CFS. Having a relapse does NOT mean that you are not recovering. It can be frustrating and disappointing but having strategies for managing these setbacks will help them occur less frequently and last for less time. Expecting temporary setbacks and feeling confident in your ability to manage them will also help you deal with the frustration and disappointment and prevent feelings of hopelessness.

It is important to developing a setback plan BEFORE the setback occurs so that these skills, strategies and resources are already in place.

## **Your Setback Plan**

The setback plan comes into action when you don't feel so good. This might mean that you feel particularly physically tired, mentally drained or emotionally vulnerable. You might have a resurgence of your symptoms or you might pick up a cold or flu that exacerbates your CFS symptoms. You might have had a particularly bad, difficult or stressful time lately and be worried that this will have a negative impact on you and your symptoms.

When you notice your symptoms have increased, this can be a cue for reviewing your management strategies and a reminder to be compassionate and take care of yourself. Your setback plan will need to be adjusted to the circumstances you find yourself in, however there are some general guidelines which apply in any situation.

### **1. Do not panic**

- panic will make you anxious and tense which makes you more tired
- panic will prevent you from thinking things through properly
- panic provides fertile ground for negative automatic thoughts which lead to depression

### **2. Put strategies into action**

- relaxation and diaphragmatic breathing
- continue activity management and pacing your activities but increase rest
- gently reduce levels of activity and exercise
- talk to supporters/family/friends
- challenge any unhelpful/distressing thoughts ie. “this means I'll never get better”

**3. Resume your usual activity and normal living as soon as possible**

- a couple of days later gradually begin to build up your activities
- slowly begin to decrease your rest periods
- keep using the relaxation or mindfulness practice, even as you begin to feel a little better
- contact any people/appointment that you cancelled and rebook your arrangements

**4. Read your setback plan!**

- Make sure you do not have to search the house for your written plan. You might like to keep these points handy, perhaps on a card in your pocket or stuck up somewhere around the house.
- Make sure that you write it clearly and simply

e.g. *Keep calm and remember to practice slow breathing through the day*  
*Reduce activity back to previous level*  
*Increase frequency of relaxation periods to 4 times per day*  
*Challenge negative automatic thoughts (especially about going back to square one)*  
*Play favourite cd 'The Monkees'*  
*Ring Auntie Joan*

- Make sure you do not have to search the house for your written plan. You might like to keep these points handy, perhaps on a card in your pocket or stuck up somewhere around the house.
- Have a setback emergency kit with all the things you need and like to do during the times when you have more symptoms. E.g. affirmation cards, relaxation tape, favourite postcard, list of achievements, breathing handout, helpful reminder cards, aromatherapy oils, cuddly toy etc.

**Setbacks are unpleasant ..and they can also be useful.**

Of course you want to minimise the frequency, length and severity of your setbacks. However, you can also use your setback as an opportunity to review your progress and give yourself credit for getting through a difficult time.

- spend some time reviewing how you coped this time
- try and loosely identify any mental or physical stressors or over-under activity which may have been involved in having increased symptoms
- think about what have you learnt and what you may like to do differently next time
- congratulate yourself for having made it through a difficult time

**MY SETBACK PLAN:**

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