



Managing setbacks and relapses in CFS/ME

(Chronic Fatigue Syndrome / Myalgic Encephalomyelitis)

This information booklet provides general information guidelines about relapses and setbacks that occur with CFS/ME.

Manchester CFS/ME helpline

0845 123 2390

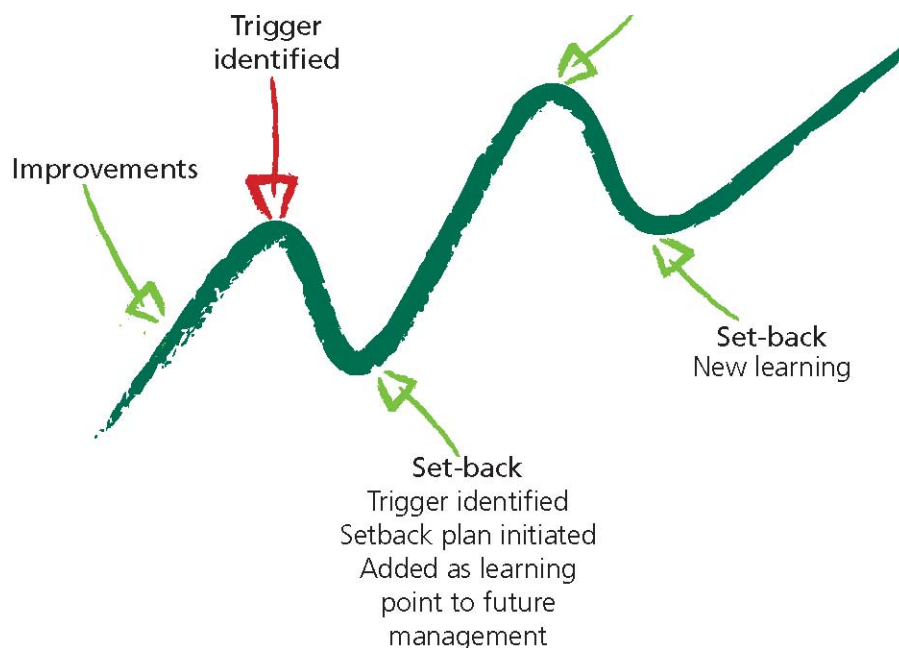
Part of the recovery process for CFS/ME will include setbacks, relapses or bad days when you feel an increase in your fatigue and other symptoms (these may be physical, mental). Setbacks and relapses are common with CFS/ME, but this does NOT mean that you are not recovering.

Although setbacks and relapses can be frustrating and upsetting; having a plan ready will help you cope while you are having an increase in symptoms.

There may be things that you can learn from each setback which will help you manage your CFS/ME in the future. This may also help reduce the number and severity of further setbacks

It is important to develop a plan for the bad days BEFORE the setback occurs so that you know how to cope with this situation, who you can contact for support, and what you can do to improve your situation again.

Progress with CFS/ME generally looks like this:



A Setback Plan

A setback plan should come into place during times that you don't feel so well. This could be during times when you feel particularly physically tired, mentally drained or emotionally vulnerable. Setbacks can occur for many reasons; sometimes it is a result of an infection (such as a cold or flu), over-activity (mental, physical or emotional). Sometimes you may have had a particularly bad, difficult or stressful time which has aggravated your CFS/ME symptoms. Sometimes it is difficult to identify any cause for the increase in symptoms.

When you notice an increase in your symptoms, use this as a sign for looking at what activities you are doing throughout the day and how you are managing your CFS/ME. This is the time to put your setback plan into place.

Have a setback emergency kit with all the things you will need during this period. This should include your written setback plan as well as things that were helpful last time (such as contact numbers, favourite music, relaxation CDs, helpful reminder cards etc) Your setback plan will need to be adjusted to each particular event, but these are general guidelines that can be applied in any situation.

1. Accept that Setbacks are a normal part of CFS/ME

- Using your setback plan will help your cope during this period and may reduce the length and severity of this difficult time
- Setbacks can occur for many reasons – if you are able to identify the trigger for this one, it can be used as a learning tool to prevent similar setbacks
- Setbacks do not mean that you will not continue to improve or recover

2. Put plans into action

- Increase your use of rest periods and relaxation. This may mean increasing the number and/or length of rest periods. It may mean increasing the use of relaxation techniques
- Start using activity diaries again so that you can plan your activity and rest periods
- Continue with activity management, but you may need to reduce duration or level of intensity of your activity or exercise. (e.g. from 20 to 10 minutes)

- Remember to do at least one activity a day that is for you and is enjoyable (e.g. watching a favourite film, listening to music, having a relaxing bath)
- Avoid long periods of inactivity or rest if possible
- Contact people around you who can support you e.g families /friends
- Ask others for assistance
- Contact extra support if needed. This could be the professionals already involved in your care, or telephone support (e.g. CFS/ME Helpline, Action for ME, Samaritans, NHS Direct,)
- Be optimistic and positive. If you have experienced previous setbacks/ relapses in the past, what has helped in the past?

3. Resume your previous activity and normal living as soon as possible

- As you symptoms improve, have the confidence to gradually begin to build up your activities (using all your principles of pacing and activity management). One step at a time.
- Slowly begin to decrease the length or frequency of your rest periods
- Keep using the relaxation, even when you begin to feel a little better
- Contact any people or appointments that you cancelled and rebook when you are able.

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
- Setbacks are unpleasant but they can also be useful. You can use your setback as a chance to check your progress and give yourself praise for getting through a difficult time.
- Spend some time reviewing how you coped this time
- Think about what have you learnt and what would you like to do differently next time
- Congratulate yourself for having made it through a difficult time

Spend some time making your own setback plan:

Consider including:

- Things that have worked in the past:
- Diary sheets
- A list of low level activities
- Written information about activity management / pacing you may have found useful before
- Things that I can do that are enjoyable
- Relaxation CDs / favourite music / films etc
- A list of contact numbers for support
- Put everything together somewhere easily accessible

Named healthcare professional involved in your care is:

Telephone Number:

Contact numbers for support:

Manchester CFS/ME Helpline: 0845 123 2390

Adult support

Action for ME – Action for ME

- Members - 0845 123 2380 / 0117 9279551
- Telephone support - 0845 123 2314
- Welfare rights – 01749 330136

Children and Young People with ME

AYME – Association of young people with ME 08451 23 23 89

Local ME support Groups

- Bury and Bolton ME/CFS group – Pam Turner on 01204 793846
- Stockport ME group: 0161 432 0390 (10.00 am - 4.00pm, Monday to Friday)

Reflective sheet

Complete this sheet each time you have a set-back. Over time you can look at these to notice anything that is similar with each setback. This may help you prevent (or reduce the severity) of some setbacks in the future. It may be useful to keep these reflective sheets with your setback plan

Set-back

What early signs built up to this set-back? i.e. increased physical symptoms (such as fatigue, headaches, pain, poor sleep), increased mental symptoms (such as poor concentration, poor short-term memory), or emotional symptoms? (such as mood swings, anxiety or depression)

What was the trigger to this set-back?

List the helpful things you did to cope with the set back?

Were there things that you did to manage this set-back that you would do less of next time around?

What have you learned from this set-back? (Think about the trigger for this setback and the way you manage it)

How can you use this new information to help manage your CFS/ME in the future?

Reflective sheet

Complete this sheet each time you have a set-back. Over time you can look at these to notice anything that is similar with each setback. This may help you prevent (or reduce the severity) of some setbacks in the future. It may be useful to keep these reflective sheets with your setback plan

Set-back

What early signs built up to this set-back? i.e. increased physical symptoms (such as fatigue, headaches, pain, poor sleep), increased mental symptoms (such as poor concentration, poor short-term memory), or emotional symptoms? (such as mood swings, anxiety or depression)

What was the trigger to this set-back?

List the helpful things you did to cope with the set back?

Were there things that you did to manage this set-back that you would do less of next time around?

What have you learned from this set-back? (Think about the trigger for this setback and the way you manage it)

How can you use this new information to help manage your CFS/ME in the future?

Who can I contact for more information?

The Manchester Clinical Network
Co-ordinating Centre (CNCC)
for CFS/ME

Telephone: 0161 219 9420

Manchester CFS/ME helpline

0845 123 2390