



MANAGEMENT FILE

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the ME association



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RELAPSES, EXACERBATIONS AND FLARE-UPS

INTRODUCTION

For many people, ME/CFS is a variable and very individual illness with periods of relative relapse and recovery – which is why it is often described as a fluctuating medical condition.

Even so, many people reach a point at which their condition stabilises to some degree – sometimes described as 'a glass ceiling' – from which they may then find it very difficult to make any further significant and/or sustained progress.

Within this model of outcome, exacerbations or flare-ups can be minor and relatively short-lived. Occasionally they are more severe and prolonged – when the term relapse is more appropriate.

Although unusual, ME/CFS can sometimes recur after a prolonged period of full recovery/ good health.

WHAT CAUSES RELAPSES AND EXACERBATIONS?

As the natural course of ME/CFS is often fluctuating, with periods of relative relapse and improvement, there will be times when relapses or exacerbations occur for no obvious reason.

However, there are a number of factors which do seem to make relapses and exacerbations more likely. So knowing about them, how to avoid them, and what to do when

they occur, is an important part of an overall management programme.

The most common factors that cause a relapse or exacerbation of symptoms are:

- Inappropriate activity management – doing too much mentally or physically and persistently exceeding your limitations
- New infections
- Poor symptom control – especially for pain or sleep disturbance
- Stress
- Temperature extremes – both hot and cold
- Trauma

Factors which sometimes cause a relapse or exacerbation of symptoms include:

- Anaesthetics and surgery
- Medication – prescription and over-the-counter drugs
- Menopause and other hormonal disturbances
- Vaccinations

HOW TO PREVENT RELAPSES AND EXACERBATIONS

Unfortunately, there is no simple and effective way of preventing relapses and exacerbations that may form part of the natural course of ME/CFS. In relation to those factors which do seem to play a role, here

is a summary of what can be done to cut down the risk:

Activity Management

Striking the right balance between activity and rest – according to the stage, severity and variability of your illness – is the most important part of any management programme. When people get this wrong, progress will not occur.

At the same time, doing too much physically or mentally, is likely to bring on a temporary exacerbation of symptoms. And, if someone persists in regularly exceeding their physical or mental limitations, this can result in a more severe and prolonged period of relapse.

The ME Association has leaflets covering activity/energy management and pacing.

Infection

This is probably the commonest and most predictable factor in causing an exacerbation, or a relapse.

Trying to avoid catching infections obviously very sensible – but not always practical. You can, however, take sensible precautions and avoid close contact with people who have got a cold, a dose of flu, or a chest infection. And, at times of the year when there is a lot of respiratory infection around, avoid crowded public places and public transport if you can.

Taking care with food hygiene,

or when eating out abroad, will help to minimise the risk of gastro-intestinal infections causing a relapse. Taking good care of teeth and gums is also important because dental infections can be very difficult to treat.

Stress

Any form of stress is going to exacerbate ME/CFS and a prolonged period of stress can cause a serious relapse.

If stress becomes an on-going problem, the chances of any recovery taking place are likely to be much reduced. So stress, where it occurs, is one aspect of management that should never be ignored.

The MEA has a leaflet that covers all aspects of stress, including management, as it applies to ME/CFS.

Symptom control

Poor symptom control – especially for symptoms such as depression, pain or sleep disturbance – is going to have an inevitable effect on your overall condition. If there's a sudden exacerbation of pain or sleep disturbance, this is likely to cause an equally abrupt deterioration in overall symptoms.

The MEA has leaflets covering the management of depression, pain and sleep disturbance.

Temperature extremes

People with ME/CFS are often very susceptible to changes in external temperature. This is something that is probably related to a problem with a tiny part of the brain known as the hypothalamus, a gland that helps to regulate body temperature – rather like a thermostat.

This type of sensitivity applies to both heat and cold so cold weather is likely to produce cold hands and feet and possibly an overall deterioration. Hot weather can also have an adverse effect – something that

needs to be carefully considered if you are planning to travel abroad.

Trauma

Any type of trauma, especially serious falls, assaults and traffic accidents, is likely to produce an exacerbation of symptoms. More serious traumatic events can produce a far more severe and persistent relapse.

Anaesthetics and surgery

Operations can also be traumatic events – so some people with ME/CFS report a significant deterioration in symptoms following a major operation.

The MEA has leaflets that explain what you can do to minimise the risks and one to give to hospital staff that explains about ME/CFS. We also have a leaflet covering anaesthetics that can be given to an anaesthetist.

Medication

Almost all drugs – prescription and over-the-counter – have side-effects. As well as fatigue, side-effects can include many of the common symptoms of ME/CFS. So, if an exacerbation links in with starting a new form of treatment, always check with your doctor or pharmacist to see if the medication might be responsible.

Menopause

Many of the symptoms of the menopause overlap with ME/CFS – especially problems with temperature control and emotional lability. It's not surprising to find that some women who are entering, or going through the menopause, find that this coincides with an overall deterioration in their ME/CFS symptoms.

If this is the case, and there are no medical or lifestyle contra-indications (eg marked loss of mobility), it is worth discussing the use of hormone replacement therapy (HRT). The use of HRT in ME/

CFS obviously has to be done with care but it is not contra-indicated.

Vaccinations

Vaccines mimic the effect of an infection on the body's immune system. So it's not surprising to find that there are numerous anecdotal reports from people who predate the onset of their ME/CFS, or a relapse of existing illness, to a vaccination. However, vaccines provide very effective protection against a range of potentially fatal infections.

So while nobody responsible is saying that people with ME/CFS should not have a vaccination, they should be used with care and if possible avoided during the very early post-infective phase or when someone is having a lot of flu-like symptoms.

HOW TO COPE WITH A RELAPSE

At the first sign of a relapse, or a significant exacerbation of symptoms, it's important to review your activity management programme – both physical and mental. This would normally mean reducing your activity and taking more rest.

In some circumstances – for example, an acute infection – you may find that your requirements for sleep and bed rest increase. If this is the case, listen to what your body is telling you to do.

You will also need support from carers, family and friends – so it is best if they understand what happens during a relapse before one occurs rather than waiting until you are suddenly needing their help.

If the relapse or exacerbation appears to have stabilised, or things are starting to improve, a period of convalescence followed by a very gradual return to normal (for you) may then be appropriate.

Where a relapse has been more

prolonged or severe, the way back to your more normal levels of activity may be slow and erratic. This can obviously be both frustrating and depressing.

WHEN TO SEE THE DOCTOR

If there's an obvious reason, such as an acute infection, that might require the use of antibiotics, do contact your GP.

If someone with ME/CFS has an infection that requires antibiotics then they should be used. Claims that people with ME/CFS should not take antibiotics are inaccurate.

If you are clearly not improving, you should always see your GP – just to exclude the possibility that there is another medical explanation. This may involve doing some routine blood tests and

possibly arranging some further investigations.

- ◆ Please let us know if you have any tips to pass on regarding how to avoid relapses, or how to cope with them.

Medical information contained in this leaflet is not intended to be a substitute for medical advice or treatment from your own doctor. The ME Association recommends that you always consult your own doctor or healthcare professional about any specific problems. We also recommend that any of the medical information provided by The MEA in this leaflet is, where appropriate, shown to and discussed with your doctor.



At the end of August 2017, we asked a question on our Facebook about relapses, exacerbations, and setbacks and received many comments from people listing the things they did when their health deteriorated and they were forced to take things easy. Here's what they told us:

- I think the only thing you can do is **rest and let it play out**.
- I find **Audiobooks** are a great way to rest and relax on a low energy day. When you find a genre, author or narrator you like, you'll rattle through them relatively quickly. If levels are a little higher, **jigsaws** are another fab way to get through the day without using up too much precious energy.
- **Magic Jigsaws' app on the iPad** is less physically demanding than an actual jigsaw, and you can choose the number of pieces based on how you're feeling.
- I do a **puzzle, colouring book,**

read a magazine, watch what I refer to as **'no brain' TV** like *Friends*. I also **meditate** – there are some apps like *Head-space* that have nice short meditations you can do. I always do half of what I think I could do.

- I pull in my horns and **just exist and rest**. Next time, I try not to overdo it.
- I sometimes try to see it as a **'treat' day**. Lazing in bed with the dog, maybe music, a magazine I can flick through because reading is too much. Accept that dinner will be take-out, eaten in bed. If I can manage to go in the garden in my nightwear, I deadhead a few flowers, or similar, so I feel I have achieved something. I knit a few rows for a charity baby item.
- **Podcasts**. Infinite subjects to keep you stimulated for a few minutes or for as long as you can handle it.
- I like **reading**. It takes my mind on another journey and helps me from feeling bored. I've just come out of two 'bad' days and my book is completed. Try downloading a book, if physically you can't hold one.
- I learnt to **crochet**. It keeps my mind occupied and I can also do it propped up in bed –so I feel productive without really doing anything!
- I stay in bed and play **games on my iPad** when I feel up to it. I have some mindless games, some creative, and

some more mentally challenging.

- It is hard. I have had CFS for 17 years and on some days I find it harder than others. Like the other day, I walked my dogs, but I'm still paying for it three days later. I can't lay down for long as I have arthritis in my hips and lower spine. So, on low energy days **I just play simple games on my laptop** like solitaire. I struggle with boredom but try not to let it get me down.
- **Brain puzzles** have been a big distraction for me. They have given me a confidence boost because sometimes I can do them pretty well.
- I listen to **audio dramas** and colour one of those **colouring books** for 10 minutes then rest and then colour for another 10 minutes. I find art journaling quite low energy.
- When I'm at my most severe, I can't tolerate doing very much. At these times, I do a **lot of resting and let my mind wander** to places I'd rather be, floating in warm sea, lying on a beach, sitting by a stream. If I can tolerate the radio, I go to Radio 4 or 3. Otherwise it's a matter of developing patience and knowing with time and rest it can ease. It's not easy though and it took a lot of time to get it right. But that's one thing I do have!
- **My Boston terriers** engage with

Continued on next page

me. They comfort and entertain, and allow for that mutual therapeutic touch.

- I make sure I have half an hour **meditation and sleep** when I need it.
- I make cards when I'm able. Concentration can be an issue, but doing it for short amount time seems to work for me.
- If I'm having moderate symptoms, I **craft** or **watch a film**. If I'm bad, only bed rest will help.
- I have no option but to **sleep** and sleep till I don't feel quite so ill.
- **Classic FM** is good for relaxing to – especially *Smooth Classics*.
- I rest on the sofa most of the day and **watch TV** – but nothing too demanding.
- I just sit **coping** with the fury and frustration as best as I can until I can get outdoors again!
- **Meditation**... if Buddhist monks do it voluntarily for hours at a time then it must be good.
- When I'm able to bear it, I have

the **TV** on but mostly I just sleep and lay there in hope it will be over soon. I know I'm getting better when I'm able to hold a book either to read or colour, and then, as soon as I can, I go down-stairs to see the family.

- **Watch birds in garden** while listening to easy listening **audiobook**.
- Nice relaxing **bubble bath** and listening to my **pan pipes CD**.
- **I meditate**. Sometimes I **crochet** but when I'm really bad I do **colour-by-numbers books** (don't have to use energy to decide on which colours to use), dot to dot books and games on my phone. I find the TV and the laptop are big energy drainers.
- I love listening to **CDs of nature sounds** (birdsong, thunder storms, etc). They're relaxing and transport me into a different world for an hour.
- I am in bed most of the time. **My DAB radio** is my friend. There's always something interesting to listen to on one of the BBC channels.
- I make **bracelets, do sewing and make small clay bowls** that I paint.

Sometimes, I listen to interesting podcasts but, when really severe, I just practise **deep breathing exercises and meditate**.

- Even when I can't get outside, I can do a bit of art, painting or art journaling, but I do it in short bursts and rest in between. If I am resting and get bored, I plan a painting or art journal page in my head then transfer that to the canvas or page when I feel well enough.
 - My attention span is super-short so I bounce between **cell phone games, paperback and YouTube movies and videos**, then back again. It's boring and frustrating as heck. I can only manage meditation (love *Insight Timer*) when I'm feeling a bit less flared.
 - I listen to the **radio through my iPad** which rests on the bed next to me. I can catch up on any program and love **the dramatisation of books**. If I nod off, I can easily catch up with the bits I miss. It helps the hours pass.
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