

RELAPSES, EXACERBATIONS AND FLARE-UPS

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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 improvement – which is why it is often described as a fluctuating medical condition.

Even so, many people will reach a point when their condition stabilises to some degree - sometimes described as a 'glass ceiling' - from which they find it 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 setbacks and improvements, there will be times when relapses or exacerbations occur for no obvious reason even when you are doing all you can to manage ME/CFS correctly.

However, there are a number of factors that 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 a good management strategy.

The most common factors:

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



Relapses, exacerbations and flare-ups was written by Dr Charles Shepherd (pictured above), Trustee and Hon. Medical Adviser to The ME Association.

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DISCLAIMER

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS.

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Other factors:

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

PREVENTION

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 factors which do seem to play a role, here is a summary of what can be done to cut down the risk:

ACTIVITY AND ENERGY 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.

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 a leaflet covering activity/energy management and pacing. The new NICE guideline on ME/CFS also provides sound advice on activity and energy management:



Energy Management & Pacing:

<https://meassociation.org.uk/h8qj>

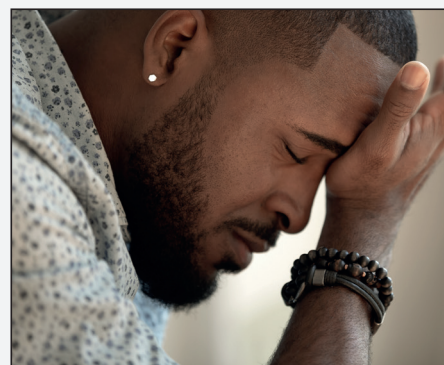
NICE Guideline for ME/CFS: An ME Association Summary:

<https://meassociation.org.uk/9d0l>

NEW INFECTION

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

Trying to avoid catching infections is obviously very sensible – but not always practical. You can, however, take sensible precautions and avoid close contact with people who have a cold, a dose of flu, or a chest infection. At times of the



“It is hard. I have had ME/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 lie 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.”

COMMUNITY COMMENT
(MEA FACEBOOK)



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year when there is a lot of respiratory infection around, avoid crowded public places and public transport if you can, and possibly wear a face mask.

Taking care with food hygiene, or when eating out if 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 improvement 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 techniques involving relaxation strategies, as they apply to ME/CFS:

Stress and How to Handle It:

<https://meassociation.org.uk/2h22>

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:



Website Mental Health Category:

<https://meassociation.org.uk/mhme>

Website Symptoms Category:

<https://tinyurl.com/mwz9zebs>

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. This is a gland that helps to regulate body temperature - rather like a thermostat.



“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.”

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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 (or even a hot bath) can also have an adverse effect – something that needs to be carefully considered if you are planning to travel abroad to a hot climate.



■ The MEA has an information leaflet, Cold Hands & Feet (Incl. Raynaud's Phenomenon):

<https://meassociation.org.uk/jseb>

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 relapses and additional complications.

ANAESTHETICS AND SURGERY

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

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

Going into Hospital:

<https://meassociation.org.uk/m83s>

Anaesthetics: Your Questions Answered:

<https://meassociation.org.uk/ayqa>

MEDICATION

All drugs – prescription and over-the-counter – can cause side-effects. As well as fatigue, side-effects can include many of the common symptoms of ME/CFS.

If an exacerbation of symptoms links in with starting a new form of treatment, always check with your doctor or pharmacist to see if the medication might be responsible. If it is likely to be the case, then you can discuss trying a different treatment or building up to the recommended dose more slowly.



“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.”

COMMUNITY COMMENT
(MEA FACEBOOK)



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MENSTRUATION AND THE MENOPAUSE

Some people with ME/CFS experience an exacerbation of symptoms around period time – especially if they have pre-menstrual syndrome. Many of the symptoms of the menopause also overlap with ME/CFS – especially problems with cognitive function, temperature control and emotional lability. So it's not surprising to find that some women who are entering, or going through the menopause, find this coincides with an overall deterioration in their ME/CFS symptoms.

If this is the case, and there are no medical or lifestyle contraindications (e.g 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 contraindicated.

■ The MEA has an information leaflet covering the Pre-menstrual syndrome and ME/CFS and the Menopause and HRT:

Menopause – Female Hormones & HRT:

<https://meassociation.org.uk/fhrt>

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 reports following a vaccination from people who predate the onset of their ME/CFS, or a relapse of existing illness.

Vaccines provide very effective protection against a range of potentially fatal infections. However, they need to 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, the first thing to do is 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.



“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 Headspace that have nice short meditations you can do. I always do half of what I think I could do.”

COMMUNITY COMMENT
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You will also need more support from carers, family and friends – so make sure 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) physical and mental activity may then be appropriate.

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

AFTER A RELAPSE

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 an antibiotic this should be used. Claims that people with ME/CFS should not take antibiotics are inaccurate.

If you are clearly not improving, or you are having an unexpected and more severe relapse, you should always see your GP – just to exclude the possibility that there is another medical explanation. This may involve arranging some routine blood tests and some further investigations.

SETBACK PLAN

There may be things that you can learn from having a relapse that are going to help with future management of a relapse and possibly reduce the amount of future setbacks, or their severity. So it's worth developing a 'setback plan' that involves you and those around you to bring into use when a setback is starting or may be starting.



“Brain puzzles have been a big distraction for me. They have given me a confidence boost because sometimes I can do them pretty well.”

COMMUNITY COMMENT
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WHAT DOES THE NICE GUIDELINE ON ME/CFS SAY ABOUT RELAPSES AND FLARE-UPS?

1.14 Managing flare-ups in symptoms and relapse

1.14.1 Explain that flare-ups and relapses can happen in ME/CFS even if the person's symptoms are well managed.

1.14.2 Tell people with ME/CFS that:

- they are likely to be having a flare-up if they experience a worsening of their symptoms beyond their normal day-to-day variation, which lasts a few days

- a relapse is when there is a sustained and marked exacerbation of ME/CFS symptoms lasting longer than a flare-up and needing substantial and sustained adjustment of energy management

1.14.3 Include guidance on managing flare-ups and relapses in the person's care and support plan.

1.14.4 Evaluate and investigate any new symptoms or a change in symptoms and do not assume they are caused by the person's ME/CFS.

1.14.5 Discuss and agree self-management strategies with the person with ME/CFS to help them respond promptly if they have a flare-up or relapse, and record these in their care and support plan. This should include:

For a flare-up:

- identifying possible triggers, such as acute illness or overexertion (in some cases, there may be no clear trigger)
- temporarily reducing their activity levels
- monitoring symptoms, recognising that,

although flare-ups are transient, some will develop into a relapse

- not returning to usual activity levels until the flare-up has resolved.

For a relapse:

- reducing, or even stopping, some activities
- increasing the frequency or duration of rest periods
- reassessing energy limits to stabilise symptoms.

1.14.6 If a flare-up or relapse cannot be managed using the person's self-management strategies outlined in their care and support plan or they are worried about new symptoms or a change in symptoms, advise the person to contact their named contact in primary care or their ME/CFS specialist team.

1.14.7 When a person with ME/CFS has a relapse, review their care and support plan with them (if needed), and discuss and agree a course of action, taking into account:

- possible causes of the relapse, if known
- the nature of the symptoms
- the severity and duration of the relapse (bearing in mind this can be years).

After a flare-up or relapse:

1.14.8 Once a flare-up or relapse has resolved or stabilised, discuss with the person:

- whether their care and support plan needs to be reviewed and adjusted to reflect their current symptoms and energy limit if this is different from before the flare-up or relapse (for people participating in physical activity or exercise programmes).
- their experience of the flare-up or relapse to determine whether strategies can be put in place to manage potential triggers in the future.

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BECOME A MEMBER



For a small annual subscription you can receive quarterly issues of **ME Essential** magazine, keep updated with the latest information on ME/CFS and with stories from other members of the charity.

You don't have to be personally affected by ME/CFS to join the ME Association. Membership is available to carers, family members, and anyone with a professional interest in the condition.

Visit our website to find out more:

<https://meassociation.org.uk/8cjm>

The MEA website shop:

The ME Association has the largest selection of ME/CFS advice leaflets in the UK on: **Medical Management; Mental Health; Diet & Nutrition; General Information; Fundraising Leaflets; Benefits & Social Care; 'To Whom It May Concern' letters; and leaflets written by ME Connect:** <https://meassociation.org.uk/shop>



THE ME ASSOCIATION

me



Freephone

0800 538 5200

Monday to Friday 10am - 6pm
(Late night until 9pm on Thursdays)

Saturday & Sunday
10am - 12 noon & 7pm - 9pm

ME CONNECT

The Support and Information Service
for people affected by ME/CFS/PVFS
and Long Covid

Contact ME Connect
3 WAYS TO GET IN TOUCH:
by phone, email or
social media private message



HERE TO LISTEN

We are here to listen,
validate and empathise
with any issues you might
be facing.



VITAL SUPPORT

We are here to help
you reach an informed
decision.



SAFE ENVIRONMENT

We provide a safe,
confidential and
understanding
environment where
you can be heard
and understood.

We're here for you!



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