



Post-Viral Fatigue
A Guide to Management

May 2020

Introduction

What is BACME?

The British Association for CFS/ME (BACME) is a multidisciplinary organisation for UK professionals who are involved in delivering clinically effective services for patients with Chronic Fatigue Syndrome/Myalgic Encephalomyelitis (referred to as either CFS/ME or ME/CFS).

Who has written this guideline?

The information provided in this guideline draws on the clinical knowledge of staff from a wide variety of therapy and medical backgrounds, who have many years of shared experience working in the field of chronic fatigue. People who have developed post-viral fatigue and ME/CFS; and carers of people with ME/CFS have also been involved in writing this document.

Why does it matter how you manage fatigue when you have been ill?

This guideline aims to give advice to help people after an illness, such as a viral infection, to try to manage and reduce the fatigue that they may be experiencing.

There has been very little research done looking at how to manage fatigue in the early stages following an infection. We don't yet confidently know the scientific answer to whether managing fatigue in different ways leads to different outcomes in terms of recovery. Many people who have experienced fatigue for a longer period of time, along with those who have developed ME/CFS, report that they wished they had received good advice earlier on in their illness regarding how to manage fatigue.

Fatigue can interfere with every aspect of day to day life so learning how to cope with it, and feeling confident with helpful strategies, may help to reduce the impact of the fatigue.

Background Information

What is fatigue?

Fatigue is a common symptom of many different infections. It is a normal part of the body's response to fighting an infection. Usually the fatigue goes away quickly once the body has dealt with the infection.

Post-viral fatigue is when the fatigue that started with a viral infection continues for a longer period of time after the infection has gone. Other types of infection can also lead to ongoing fatigue symptoms.

Fatigue can be difficult to describe and is often referred to as 'an invisible symptom'. People who experience severe fatigue will often describe a feeling of complete physical and mental exhaustion which is different to the everyday tiredness that everyone will experience at times. Recovery after activity changes, so rest and sleep may feel unrefreshing.

Fatigue can impact on every part of life including school or work, home life, social activities, sport and relationships.

Who gets post-viral fatigue?

Post-viral fatigue affects people of all ages, including children, young people, and adults of all ages.

The severity and length of time that someone experiences fatigue doesn't always reflect the severity of the initial infection or their previous fitness levels.

Some people can be very unwell at the start of the illness but recover relatively quickly, whilst other people may only have a mild viral illness but go on to have debilitating fatigue for a long time afterwards.

How to manage fatigue

During the infection

REST: This is **most important** as it allows your body to focus on dealing with the infection. In this context, rest means resting the body and the mind, so doing very little – no TV, phones or using the internet. Use relaxation, breathing and meditation apps to help support quality rest. If something doesn't work for you, try something else until you find something that does. Using quality rest periods regularly through your day will support your recovery – little and often is more helpful. Reduce any sensory input that makes you feel tense or is demanding – such as noise and bright lights. You can also use sensory input to help you rest and relax – like your favourite relaxing music, blanket, fragrance, or a hot water bottle.

ACTIVITY: Keep activity levels low – both physical and cognitive (thinking) activities as they both use energy. If you are struggling with boredom, your mind is busy, or you are anxious, try and think of low-energy activities that are enjoyable. Do these for short periods of time with regular rest breaks.

NOURISH: Keep eating and drinking, with as normal a routine as possible and maintain a balanced diet. Little and often may help if your appetite is low, rather than big meals. Increase your fluid intake, especially if you are not managing to eat as much.

MOVE: If possible, get up and move around slowly and gently a few times each day to keep your body moving and to aid circulation (the movement of blood around your body). If you are too unwell for this, then you can try and move around in bed a little – stretching out, moving all of your joints, and tensing and relaxing your muscles.

ALLOW TIME: Infections can affect people to different degrees, so give yourself the time you need to recover. The impact afterwards doesn't always reflect the severity of the infection. Often there will be pressure to get back to your usual activities as soon as possible. **Do not rush or push.**

HAVE FUN: Do some low energy fun activities every day. Whatever you like that is not effortful. Balance activity with regular rests.

STOP STUDIES/WORK: Unless you feel fully well, you should stop studies or work to allow your body to focus on fighting the infection and recovering. Don't forget unpaid work such as caring responsibilities is still work. In these situations, you may need outside support to take on your caring roles.

More detailed information regarding these strategies is covered on the 'Further Information' pages

Next Steps

TRY ACTIVITY: If you feel your fatigue is improving, try a small amount of light activity (probably less than you think) and then **REST** a little. Try the same activity again, perhaps the next day. Find the level which is manageable for you. Reflect and decide if your body can do more or needs even less activity. Do your best to resist pushing through your fatigue. Keep your expectations low and listen to how your body copes with this transition. Be realistic and **KIND** to yourself.

'THINKING' ACTIVITIES: When starting to improve, it can be easy to forget that 'thinking' activities such as checking emails, reading, making decisions, and worrying about yourself or others all use energy. Try limiting these activities by doing them for a set time, then take a **REST**. Gradually increase these activities in a similar way to physical activities. Some people find that these activities take longer to recover.

SLOWLY INCREASE ACTIVITY: Often people try and increase their activity levels too quickly and so have a setback. If in doubt, go more slowly but steadily. When working with people living with long-term fatigue, activity might only be increased every couple of weeks. You might not need to go this slowly, but it gives you a sense of pace. Trying to 'push through' the fatigue is normally unhelpful.

REST: Your body needs rest to continue healing. Continue to have short rests through the day, every day, even when you are improving. Stop and do nothing, calm your mind, perhaps by using breathing or guided relaxation strategies. Let your muscles relax completely.

DAILY ROUTINE: Maintain a realistic daily routine for sleeping, eating and daily activities to help the body to stabilise itself. Gradually change back to your normal routine, but don't **RUSH**. A healthy person can take 2 weeks to adjust to a sleep pattern change, so it may take you longer.

EXERCISE CAREFULLY: Exercise needs to be approached in the same way as all activity. Gentle exercise, such as stretches, or a short walk can be helpful. Even if you usually do a lot of exercise, it is important that you only do a small amount of what you normally would do and at a much lower intensity. Resume exercise **SLOWLY**, wait to see how your body reacts, then increase very gradually.

STUDIES/WORK: You may have to take longer off school/college or work than initially anticipated and arrange a gradual return. For children and young people, make sure the school is aware that they are experiencing fatigue and will need changes to their learning programme such as a later start and a quiet supervised rest area if in school, or supported work if at home. If you are working, speak to your manager and get occupational health advice to see what adaptations can be made. You may also need a Fit note from your GP. Longer term support options may need to be identified for unpaid work/caring roles.

HAVE FUN: Don't forget you need fun in your life. As people start getting back to daily life, they focus on all the things that seem necessary, but you need to balance this with enjoyment. Choose to spend some energy on fun activities too and increase them gradually like other activities.

Recognising it is difficult

EXPECTATIONS: It can be difficult to accept and adapt to feeling fatigued when you expected to make a quick recovery and return to your normal life. Many people feel guilty and try to ignore the fatigue to carry on with their usual activities. Other people around you can also have expectations that are not realistic now and this adds to feeling pressure to do more than is helpful for you at the current time.

ACCEPTANCE: Whilst it isn't always easy, trying to accept that the fatigue is real and needs managing is the most helpful way to approach it. If you accept that life will need to change for now, then it is more likely that other people around you will see that as well and support you with it. Many other health problems require a longer period of recovery (sometimes called convalescence) and post-viral fatigue will take time to improve, sometimes taking many months.

SUPPORT: Ask people around you for their support. This could be from family members, friends, work colleagues as well as health professionals such as your GP. Talk about the fatigue and explain how it makes you feel and what you can currently realistically do. Give clear ways that they can support you, such as short regular chats or texts to keep in touch, recognising you need regular rest periods, practical help such as shopping and cooking.

SCHOOL/COLLEGE: Make sure the school or college is aware that the child or young person has fatigue and that changes are needed. There are many aspects of school that can aggravate fatigue symptoms. Some examples are: the effort of getting to and from school, the noise and demands of being around lots of people, the expectation to work and behave as normal, worries about falling behind, failing exams or missing important lessons or projects. Many people with fatigue will be better able to learn if they are in control of doing it when their fatigue is less severe and by doing activity for short periods with regular rest periods. This is often easier to do at home, so it can be helpful to ask teachers/lecturers to set work that can be done at a slower pace at home. As the fatigue improves, the amount of time the young person spends in school or college can be increased gradually, ideally providing opportunities for rest periods during the day.

WORK: You may need to think differently about your approach to work. It is common for people to need long periods of time off work when fatigue symptoms are severe. As your health improves, it is worth considering how you could apply the pacing strategies in your work role such as asking for regular short rest periods, avoiding high demand tasks, doing shorter days, avoiding night shifts or variable shift patterns, or changing the days you work. You can ask for an occupational health assessment to help with the process of having adaptations made for you at work. Many people return to work on a 'phased return' and it is important that the increases in work activities are made very slowly and gradually to avoid causing an increase in fatigue.

RESPONSIBILITIES: If you have responsibilities to care for other people such as children or family members, this is work as well and will become harder to manage when you have fatigue. It is likely you will need to make adjustments. Consider asking for help from family, friends, carer support organisations or social services.

Further information

REST: Achieving good quality rest can be one of the biggest challenges of managing fatigue. If possible, create a relaxing place to take a rest. Telling others around you that you are resting can reduce interruptions. Setting an amount of time that you are going to rest for is a good way to give yourself permission to rest and remove some of the feelings of guilt.

Many people have busy minds which constantly have new thoughts, ideas and worries and this is an additional demand on the body's low energy reserves. Learning how to rest your mind can be challenging but can be extremely helpful when dealing with fatigue.

Finding a relaxation exercise that works for you and then doing it regularly, lots of times a day, every day, can be beneficial. Simple breathing exercises are a good starting point. Mindfulness type techniques which teach you to bring your focus and attention into the current moment will help with busy minds.

PACING ACTIVITIES: It is common for people with fatigue to want to increase their activity levels, but this can lead to an increase in fatigue. Some people will get into a 'boom and bust' pattern where they push themselves to do more on a better day and then feel worse for several days afterwards.

Pacing is a way of doing activities differently to try and reduce the chance of increasing your fatigue, by breaking the activities up into manageable amounts. All types of activity can impact on fatigue so pacing applies to all activity, such as cognitive or 'thinking' activity, social activity, emotional and physical activity.

When breaking up the activity into manageable 'chunks' you might then rest or may be able to change to a different type of activity. For example, don't try to do all your chores in one go, just because you're feeling a bit better. Do a task for a short time and then take a break and rest, have a drink, or listen to music or watch TV before then doing another task.

How you need to pace an activity may be different from someone else. Allow yourself enough time to complete the activity so you don't need to rush. It is better to rest before an activity has caused an increase in fatigue. Remember the phrase: **'rest before exhaustion'**. Have sufficient rest before moving on to the next activity.

Thinking about how to change the way you do an activity can reduce the amount of energy you use to do it. For example sitting for activities that you would normally stand for, asking for help from others, making activities as simple as possible, using equipment to make it easier and choosing which activities are a priority at the moment.

THOUGHTS AND FEELINGS: It is common for fatigue to affect how you are thinking and feeling, including increased anxiety, frustration, irritability, guilt, and low mood. It is helpful to acknowledge that it is a challenging time for you and those around you. Your mind and body work together so looking after your emotional wellbeing is also important for healing and recovery.

Talking about how you are feeling, keeping a diary, focusing on the present moment, doing a deep breathing exercise, or doing something enjoyable are all ways to cope with difficult feelings. Different things will work for different people, so find the strategies that work best for you.

If mood problems are persisting and impacting on everyday life, then speak to your GP to get further support and help.

SLEEP: It is common for sleep patterns to change when someone experiences post-viral fatigue. Some people will find it harder to get to sleep or wake often in the night, whereas other people may find they are sleeping far more than usual. No matter what changes have occurred, it is important to try to keep a good routine around sleep. Have a clear going-to-bed time and a regular wake-up time and try to stick to this every day, even if the quality of your sleep hasn't been good.

You should also be aware of the environment for sleep. By keeping your bed for sleep helps to cue your body into sleep mode when you go to bed. Ensuring it is dark enough, quiet, and cool will also support sleep quality.

Morning: Getting daylight exposure in the morning is helpful for sleep routines, so try to go outside soon after you get up or be near a window while you have breakfast.

Evening: Reducing blue light exposure on an evening can help with night-time sleep quality. Screen use is an important source of blue light, so try to reduce or stop all screen use before bedtime. Wearing amber coloured glasses is another way to reduce evening blue light exposure. Having a regular wind-down routine before bed can also be helpful.

Night-time: Mobile phones are our connection with the world, friends and family, entertainment, and social interactions, so they can keep our brains alert even when they are switched off. Aim to leave your phone and other electronic devices out of the bedroom at night.

Naps: Many people experiencing fatigue will take daytime naps, and this can be a helpful way of managing fatigue. However, sleeping for long periods of time during the day can prevent good quality night-time sleep, so it is better to create a clear routine around daytime naps. Aim to nap for 20-30minutes and take it at the same time each day. Late morning or immediately after lunch are the times when many people experience an energy dip. Thinking of it as a siesta can help remove the guilt.

FOOD: Eat simple, fresh, and balanced meals that you enjoy. You may find eating smaller amounts more often may be helpful.

Fatigue can make it difficult to prepare meals, so try using foods which are quick and easy to prepare but still have good nutritional value for example frozen vegetables or tinned foods. If people want to help, it is worth asking them to cook extra so that portions can be frozen for you.

Beware of reaching for sugar, caffeine, or alcohol as a way of managing fatigue. Although there may be an initial boost in energy, they will result in a 'crash' and in the long run, tend to make fatigue symptoms worse.

Keeping well hydrated with regular fluid intake throughout the day is important. If you feel that your diet isn't as good as it could be, then taking a general multivitamin may be worth considering. However, there are no supplements that have been consistently proven to help or cure fatigue, so do not spend lots of time, money or energy trying to find one.

Moving forward

You may be starting to feel better gradually, but it can take several months and sometimes a year or more for people to feel fully recovered from post-viral fatigue.

If it is gradually improving, keep going.

Don't forget to keep quality **REST**, **ROUTINE**, and **FUN** in your life to support your recovery. Remember that stress and worry use energy so give yourself time and be kind to yourself.

How do I know if I have ME/CFS?

Most people who experience prolonged fatigue after an infection will make a full recovery. However, some people will go on to experience significant fatigue for a long time and may also develop lots of additional symptoms alongside the fatigue.

In a small number of people, post-viral fatigue can develop into a longer-term or chronic illness known as Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS). This is a condition which results in a wide array of symptoms, including severe fatigue, which can cause significant changes in someone's life, often meaning they are unable to work or attend school, cannot engage in social activities and may struggle with activities of daily living. Recovery from ME/CFS is variable and some people continue to have symptoms for many years.

The risk factors for developing ME/CFS are still not clearly understood and may include some genetic factors. ME/CFS doesn't always start following an illness, however it is a common pattern to see people develop ME/CFS following an infection that occurs at a time of high demand in their life.

One of the key symptoms that occurs in people with ME/CFS is Post-Exertional Malaise or PEM. This is when there is an increase in fatigue, along with flu-like symptoms in response to activity. The activity that provokes this escalation can be simple everyday tasks including thinking activities as well as physical activity. The increase in fatigue is commonly delayed by 24 hours or more, so a typical pattern is for someone to try to do a bit more on a good day and then wake the next day feeling much worse, often with a sore throat or sore glands and generalised achiness.

As well as post-exertional malaise, people with ME/CFS develop a lot of additional symptoms with different patterns occurring in different people. Some people develop poor standing tolerance which means doing tasks while standing still (e.g. showering or washing up), can cause a rapid increase in fatigue or pain and result in them feeling the need to sit or lie down. There may also be palpitations, problems with regulating body temperature and sweating.

'Brain fog' is a common feature of ME/CFS and is where people feel mentally fatigued and struggle to concentrate. They often report forgetfulness and difficulty finding the right words when speaking or struggling to keep track during a conversation.

It is common for people with ME/CFS to experience some change in their digestion, such as reduced appetite, nausea, acid reflux or bowel changes and irritable bowel type symptoms. Some people with ME/CFS develop new sensitivities to bright lights, noise, chemicals, medications, and alcohol. Some people with ME/CFS also experience pain symptoms in joints or muscles along with headaches.

When someone has this pattern of symptoms, it is important that tests are done to check for underlying conditions that could be causing them. For some people that will just be bloods tests done by their GP. For other people, it may involve referrals to hospital for specialist opinions or investigations. This means the process of making a diagnosis of ME/CFS can take some time.

It can be helpful to follow the management strategies given in this guide while waiting for tests to be done.

What if I am not improving?

SEEK ADVICE: If you are experiencing ongoing fatigue symptoms following an infection, you should ask your GP for advice so that they can check that there aren't any other causes for the symptoms.

SPECIALIST INPUT: If you continue to experience high levels of fatigue, then specialist ME/CFS services or chronic fatigue services may be available to provide further guidance. Ask your GP regarding local referral options. The BACME website has a map showing NHS ME/CFS services.

Acknowledgements

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