



MANAGING FATIGUE AFTER A CARDIAC ARREST

Advice for people experiencing fatigue following a cardiac arrest



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ABOUT...

Fatigue is clinically important, commonly misunderstood and the number one post-cardiac arrest sequelae that survivors report. This document aims to provide an overview of the current evidence base regarding factors contributing to persistent fatigue and the need for understanding an individual's experience, the involvement of family and others, peer support and self-management.

Sudden Cardiac Arrest UK is a peer support organisation for those who have survived a cardiac arrest or have been impacted by the survivor's event. Donna Malley is an Occupational Therapy Clinical Specialist and current Chair of the Royal College of Occupational Therapists Specialist Section Neurological Practice. She has over 25 years' experience working in the NHS and at the Oliver Zangwill Centre for Neuropsychological Rehabilitation where she developed her interest in fatigue. She has authored and co-authored a number of important publications regarding brain injury rehabilitation and fatigue.



WHAT IS FATIGUE?

Persistent fatigue is a common experience following many types of illness; however there is no universally agreed definition of exactly what this is by scientists.

It is a personal experience, a bit like pain, which makes it hard to measure objectively and compare one person's experience with another. It is felt, and only seen by others when energy reserves are almost depleted, which makes it hard for others to understand.

Clinicians agree that persistent fatigue is a feeling of exhaustion which seems disproportionate to our activity levels; compared to prior to the Sudden Cardiac Arrest (SCA), fatigue is more intense, lasts for longer and is not necessarily alleviated by rest. It may also exacerbate other symptoms you may have following the cardiac arrest. If we are unable to perform meaningful activities effectively, we may become frustrated, or low in mood, and withdraw from activities altogether as our confidence is eroded. It is not laziness and because it is one of the 'hidden' challenges following a cardiac

arrest, it can go unrecognised as a symptom for some time. It's often not until they are back home and trying to participate in their usual occupations, that people are aware that they have fewer mental and physical resources, are experiencing more difficulties than they expect.

Fatigue is a feeling of exhaustion which seems disproportionate to your activity level

Fatigue can impact during or after any practical task, from walking and talking, to personal care, domestic activities such as meal preparation, to managing correspondence, social interactions, recreational activities and work. It is typically worse after engaging in new/novel activities, and sometimes we may not feel fatigue until some hours later, which makes it difficult to know what has contributed towards it.



WHY DOES FATIGUE OCCUR?

There are many different reasons why people may experience persistent fatigue following a period of ill health. A cardiac arrest may result in an interruption of oxygen supply to the brain. Brain cells (neurones) require a consistent oxygen supply to function properly, and can die if they are deprived of oxygen for several minutes. This process is called cerebral anoxia or hypoxia.

Hypoxic brain damage can affect cells in different areas of the brain, making it harder for these areas to communicate effectively with one another, and with other parts of the body. The brain also requires energy to heal and repair itself (plasticity) so may have difficulty sustaining energy over time. Disruption between certain regions e.g. within the brain stem and frontal lobes, makes it harder for the brain to initiate and sustain mental and/or physical effort required. So, one way to make sense of fatigue is that more effort is needed to think, to communicate, to move about and to manage our emotions

when there are disruptions to communication within the brain.

Fatigue can also be the result of another medical condition, treatments, medications, viral illnesses, anaemia, disturbance of sleep, or a disruption to the regulation of hormones in the brain and body. Blood tests can help identify if hormone depletion is the cause, so it's always helpful to get yourself checked out by your Doctor.

Adjusting to the range of changes to our lives as a result of an SCA can impact the regulation of our emotions. Many people experience understandable stress and worry e.g. is this going to happen again, when can I get back to work? This can contribute towards low mood which fatigue commonly occurs alongside.

Fatigue often makes planning ahead, resuming previous roles and daily activities more difficult. Because many different factors contribute to the fatigue experienced, one solution doesn't work for everyone.

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WHEN DOES FATIGUE OCCUR?

Fatigue can impact what we think, how we feel and what we do.

When the brain is processing a lot of information at once, or having

to focus on something for a period of time, it will need energy to do so. Therefore fatigue may be experienced or exacerbated:



Following mental (thinking), physical, or emotional activities, e.g. dealing with correspondence, completing forms, conversations, childcare.



When in a multi-sensory or group environment, e.g. attending a sporting event, supermarket, restaurant, pub, travelling



When we find it hard to 'switch our head off' from attempts to problem solve or think things through, which also can impact our sleep, creating a vicious cycle



After disrupted sleep which can contribute to daytime tiredness



Due to insufficient or irregular nutrition/hydration.



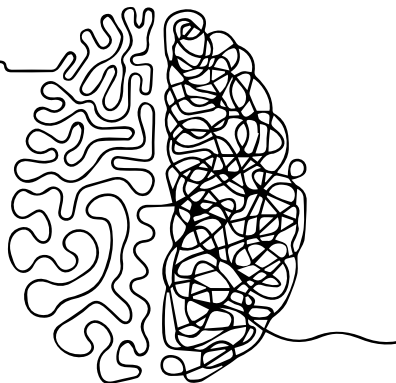
When we become unwell

Whilst clinicians may use the term 'fatigue', most people use their own language to describe their experience. People may say they feel exhausted, lacking in energy, weak, have difficulty motivating themselves, or feel excessively tired. These descriptions are typically used when the person feels they have completely exhausted their energy reserves and may include phrases such as:

It's like "the brain just shuts down"

"thinking through treacle"

"brain fog"



"Pleurgh!"

"like a wave which comes over me out of nowhere"

Before this happens, there may be 'early warning signs' that energy levels are dropping, but which the individual doesn't notice at the time. The analogy of a smartphone battery can be useful; early warning signs may occur at different levels, and are personal to everyone, so it's important to discover what yours are. Sometimes others may notice signs before you do, so ask family and friends what they notice.

Here are some of the more common warning signs:

- **Thinking skills disrupted** – easily distracted, need someone to repeat information, forget plans, lose track of time
- **Communication** – harder to find the words you need, harder to follow conversations, miss subtle humour, speech becomes slurred
- **Emotional** – want to be on your own, feel more irritable, motivation wanes
- **Physical** – eyes or limbs feel heavy, headaches, feel nauseous, harder to focus eyes, extremely tired.

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WHAT CAN I DO TO MANAGE FATIGUE?

Managing fatigue is about making the best use of our available physical and mental resources; at the end of the day we should feel tired, but not completely exhausted, and have little energy the following day! Understanding why fatigue happens and making adaptations based upon our personal circumstances will enable us to make choices about where we use our available mental, physical and emotional resources.

This enables us to consider the three P's:

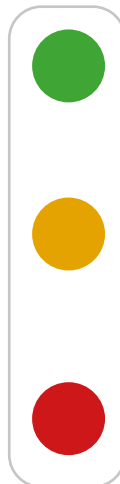
Planning

Pacing

Prioritising

1 Listen to your body

We need to listen to our body and work out when it is feeling tired but not exhausted, which is not easy! Some people find the analogy of a traffic light helpful here:



Green = good to go

Energy levels are high (typically, but not always, earlier in the day)

Amber = take action

Notice the early warning signs and do something soon to recharge yourself.

Red = stop!

You are exhausted and need to take a proper break. You may need to rethink your plans for later in the day.

2 Structure & routines

Which combinations of activity work best for you? Work out which activities drain you quickly and which gradually use your energy over time. How often do you need to take a break? Taking breaks throughout the day is really important if you struggle to notice early warning signs, a 'little and often' approach.

3 Avoid a 'boom then bust' approach

This is easier said than done and will depend on individual circumstances. Planning ahead once your triggers are understood, and prioritising will help to keep energy levels on a more even keel, but occasionally you may choose to use your energy up because the activity is really important to you.

4 Maintaining a healthy lifestyle

A healthy lifestyle is an important aspect of fatigue management. Eating healthily and regularly, using slow release carbohydrates and staying hydrated. Physical exercise can help boost mental energy levels, whether this is taking a walk

outside or going to an exercise class. Getting adequate sleep, is the main way our brain and body can 'recharge'. Having a regular sleep-wake time, not napping after 4pm or eating late at night, avoiding stimulants such as caffeine later in the day can all help promote good quality sleep. Shift working, small children, uncomfortable mattresses, hot & light bedrooms and snoring are not conducive to a good night's sleep!

5 Working out ways of 'recharging your battery' during the day.

These are short activities we can do which may not recharge us fully but can give our energy levels a boost to enable us to fulfil our plans. This might be something like taking a short walk outdoors, doing a meditation exercise, or listening to a favourite piece of music. It can take time to work out what can give us an 'energy boost' but it's vitally important as napping during the day is not feasible for many of us.

6 Use strategies to support thinking skills; think of these as 'mental scaffolding' or a 'safety net'

We all make attention or memory slips from time to time, but these typically become more frequent as we drain our mental energy. Removing distractions (e.g. turn off background noise), writing things down (e.g. plans for day, lists, recipes), setting alarms as reminders can all help us stay on track and achieve things more successfully.

7 Managing the environment

Reducing the need for the brain and body to respond to unnecessary stimuli will help use mental and physical energy more efficiently. If we are distracted or not feeling physically comfortable, then more of our mental energy will be diverted to these sensations and not what we really want to focus on. We will then likely make more mistakes and become frustrated with ourselves. Reducing background noise, having good lighting, being in a reasonable temperature, not hungry or thirsty, wearing comfortable clothing and having supportive seating can make

a huge difference. So pay attention to what environment works best for you, depending on the activity you are doing, and make changes when/where you can to suit you.

8 Be kind to yourself

Your brain and body are healing and working hard so it is understandable you may feel fatigued more frequently. Manage levels of personal stress and worry by talking to others, using relaxation or meditation exercises, doing things you take pleasure in, and speaking to your GP if it becomes impossible to switch your head off from unhelpful or self-critical thoughts.

9 Let others know how you are feeling

It is important to have a shared understanding with family, friends & work colleagues about how you are feeling and what works for you, so they can help you to put the right management strategies in place. It's really hard to predict how you may feel, so plans may need to be rearranged at short notice; other people will usually understand if they know what you are experiencing.



Survivor survey

We undertook a survey to understand how fatigue had affected survivors of a cardiac arrest. We had a fantastic result with well over 200 responses within a couple of days, obviously, this is an issue of utmost importance to survivors!

The first thing we asked was whether survivors had been warned about the possibility of fatigue post-cardiac arrest. Only 1 in 5 had, which is in stark contrast to the fact that nearly all had experienced it in some way since their event.

As you will have seen, fatigue can manifest in a number of ways and the majority of respondents reported that it affected them in a physical way, 4 out of 5 said that it required extra effort to think and concentrate on daily tasks, nearly three quarters stated it affected them in a psychological way in that they lacked the motivation to do things and that it got worse in stressful situations. It's clear that fatigue can affect people in a variety of ways and with nearly two thirds rating it as a big impact on their daily lives, it's not to be dismissed lightly.

However, there is some good news though, as around a third report that their fatigue has improved with time. The most improvement is often seen in the first year but anecdotally it can be very variable and obviously factors such as age and previous levels of activity have to be taken into consideration.

The underlying mechanisms of fatigue after a cardiac arrest are not well understood but we asked what the survivors thought their fatigue was down to. There was a multitude of answers with the three most popular ones being medications, hypoxic brain injury and damage to heart. It's highly likely that all three of these are significant factors, but until in-depth research is done we'll probably never know for sure to what degree they affect us and how we can improve them.

Of course, you're reading this as you want to know how to manage your fatigue and so we asked the survivors what they thought helped them. Perhaps unsurprisingly, the most popular answer was getting more rest, next was using coping strategies, closely followed by

engaging in exercise and activities. Finding what works for you can take time, so be patient and don't fall into a boom/bust cycle by trying too much too soon.

Our final question was whether they had any tips or advice for other survivors and many common themes cropped up with some very good advice:

1. Listen to your body and brain and make rest a daily priority
2. Take your time, rushing makes it worse. Wait for your body to really feel that it wants to try things that used to be the norm.
3. Try to learn to understand what your body is now telling you as your body's requirements have changed i.e. how much sleep you need, what food and drink to have and when. How often you need to take a break etc
4. Check with your doctor whether it is your medication causing the fatigue.
5. Rest when you need it and don't feel guilty!
6. Be patient, persistent and most importantly, kind to yourself.

7. Try not to feel guilty about the way you're feeling, accept your body is different now.
8. Open up to family, friends and medical staff. Try to connect as soon as possible with other survivors
9. Do what suits you and your situation. No two survivors are the same and what works for one may not work for another.
10. You're not lazy!!! Learn your limits, and if you're going to exceed them, be ready for the crash, plan for it and accept it may happen. Don't let fatigue, or the threat of those crashes, stop you enjoying life, but do listen to your body when it needs downtime.

Overall, the message from our survey was quite clear, fatigue is a big deal for survivors and it's an area that needs to be looked into more. For now, though it's about giving good solid information that helps sufferers understand their situation and adjust and adapt accordingly and we hope that this leaflet helps in some small way.



Further advice and information

Professional help

If you are experiencing persistent fatigue and would like more individualised advice, please speak to your GP and/or Medical Consultant. You may want to request a referral to an occupational therapist.

Peer support

People who have experienced an SCA, or other types of illness which results in persistent fatigue, maybe a useful source of support and information. Sudden Cardiac Arrest UK has an active online community which can be a great source of support and inspiration.

For more information, videos, podcasts and additional resources see:



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Please remember to always speak to your doctor before trying any new dietary or medication advice.