

Living with fatigue

For many people with a heart condition, fatigue is an everyday reality. Get tips on how to cope from both an expert and people living with it

When Bedwyr Gullidge first developed atrial fibrillation it was so draining it felt like he was “walking against water in a pool”



If you find yourself lacking energy when you have a heart condition, you are not alone.

Fatigue is very common in people with conditions like heart failure and cardiomyopathy. Certain heart medications can also make you feel tired.

When it comes to defining fatigue, one challenge is that it means different things to different people. “For some people, fatigue is a constant presence, while for others, it comes and goes,” says Professor Julia Newton, a consultant geriatrician with over 20 years’ experience researching and treating people living with fatigue. “It can also be linked to symptoms like brain fog and muscle aches.

“Essentially fatigue is the overwhelming feeling of lacking energy. People often describe it as a battery running out. They might start the day with a full battery, but it runs down too quickly.”

Professor Newton adds: “Another common sign of fatigue is when people wake up feeling just as exhausted as they did yesterday, even after sleeping reasonably well.”

Facing emotional challenges

Professor Newton explains that people with fatigue face several challenges. “Because fatigue levels cannot be tested and you cannot actually see how tired someone feels, other people may doubt the experience of people living with fatigue. As a result, people often battle on in silence rather than admitting they do not feel 100 per cent.”

“Because you cannot see how tired someone feels, others may doubt people living with fatigue

Many people are also forced to give up or scale back on activities they find fulfilling such as work, hobbies and spending time with loved ones. “Many of us feel defined by our roles at work or in the family. Not being able to fulfil those roles can lead to feelings of low self-worth,” Professor Newton says.

It is not unusual for people with fatigue to experience challenging emotions. Professor Newton explains: “People use words like ‘guilt’, ‘frustration’ and ‘anger’. They feel like fatigue is somehow their fault, that they are a burden, that they are not doing enough.

“But dwelling on difficult emotions can become a problem. Anger, for example, uses up precious energy – energy you could put towards something you want to do.”

Learning to pace yourself

Living with fatigue may not be easy, but it is certainly possible to adapt on both a practical and psychological level.

“We all have a ‘pie of energy’ that we use to do things every day,” says Professor Newton. “With fatigue, your pie is smaller. It might be possible to enlarge that pie over time, but in the meantime it is important to manage it so you can get through each day.”

To achieve this, it all comes down to a strategy called pacing, says Professor Newton. “If you use up today’s energy and start borrowing from tomorrow, you are going to crash. Pacing helps you avoid cycles of ‘boom and bust’. It means breaking tasks down into small, manageable steps that you can tackle one at a time.

“For example, could you spread out the spring cleaning over a series of days or weeks? You might need to accept there are certain things you cannot do in the same way as before. But it’s better to achieve something small every day than take on too much and be out of action for the rest of the week.” ▶

Rediscovering rest

Professor Newton also highlights the importance of resting at regular intervals, but points out not all rest is equal.

“In modern society, we’ve forgotten what rest is. You might think sitting down to check your emails counts, but it does not. However, things like mindfulness and yoga can help you get some energy back.”

You can also look for ways to save energy during tasks. “Ask yourself, ‘is there a less tiring way to do this?’” says Professor Newton. “I once saw a teacher who believed she always had to stand in front of her class. Initially she found the idea of sitting uncomfortable before realising it would make life easier.”

“You do not have to make sweeping changes; simple ones can make a difference. If you work a four-day week, for example, would it be better to take Wednesday off rather than Friday? A mid-week pause could give you more relief than a long weekend.”



3 simple tips for managing fatigue

- Learn to read your body. For example, you could fill out an activity diary like the one at bhf.org.uk/fatiguediary to get familiar with your limits and help you plan each day with pacing in mind.
- Stick to a routine. Include not only ‘must-do’ activities but also enjoyable ones, such as socialising or learning a hobby. But remember to pace fun activities too.
- Stay positive. Living with fatigue can feel demotivating, but try to focus on what you can do rather than what you cannot do.

Bedwyr’s story

“I’ve learned to listen to my body”

Bedwyr Gullidge, 37, from Pontypridd in Mid Glamorgan, was born with holes between the four chambers of his heart, a condition called atrioventricular septal defect. He now has permanent atrial fibrillation and early symptoms of heart failure. He reflects on the challenges of living with fatigue.

“I had three open-heart surgeries as a child, and it was always tough getting back on my feet after the op.

But being diagnosed with atrial fibrillation in my 20s was a whole new challenge. I started to notice I could not do as much and felt washed out towards the end of each day. I compare it to the feeling of walking against water in a pool, because for me, just walking can be draining. At that time, I was working full-time in a cinema, spending all day on my feet. I was needing to drive there more often because the 30-minute walk would exhaust me before even starting work.

In the years that followed, I learned to listen to my body. In my job as a lecturer in cardiac physiology at Swansea University, I have the option to work from home some days, depending on my lectures. I also plan each day carefully. If I have three lectures, I’ll take breaks between and head home early to recover.

It helps to be open with your manager. I might ask, ‘I’m getting worn out doing X, Y and Z. Can I just concentrate on X and Y for now?’

The same applies to family and friends. I’ll say, ‘Can we take a break rather than continuing shopping?’ I try to spend time with people who appreciate my limits and my needs.

I still like to challenge myself but I’m mindful of when to stop. On a recent electric mountain biking trip, I became aware that my legs were exhausted and I felt like my heart rate was really high. So I stopped. If I’d I pushed on, I would have come off the bike.

When I realise there are things I can no longer do, it can be demoralising. But in those instances, I focus on what I can do, and ask myself: ‘How can I build up to that? Can I do something related?’ It also helps to know that I’m not alone in this; other people have gotten around the same challenges.”

Bedwyr plans each work day carefully, making sure he has breaks between lectures



Sarah’s story



Journaling every morning helps Sarah stay positive

“I’ve found ways to live the best life I possibly can”

Sarah Fisher, 52, from Warwick in Warwickshire, has had three strokes and two heart attacks in the last decade, after which she was diagnosed with heart failure. She describes how she copes with fatigue.

“When I’m fatigued, my body becomes a lead weight and I get brain fog. It’s as if I’m constantly getting over the flu. I do not think I’ll ever get used to waking up tired every single day. There are times when I feel defeated before even getting out of bed in the morning.

What really helps is pacing myself, which was drummed into me during cardiac rehab. I’ll get up, take my medications, rest, have breakfast, rest, do the washing up, and rest again. I factor every activity into my routine, which can feel relentless.

I’ve also had to learn how to rest. That can be hard, because when I’m feeling good it’s so tempting to overdo it. But overdoing it can knock

me out for days, even weeks. My body tells me when I’m approaching my limit. I begin to ache all over, the brain fog kicks in and normal sound levels can be too much to bear. It feels as if the world’s volume setting is turned up too high. My husband and I recently chose to make our bedroom free from screens. I like to drift off reading a book or listening to an audiobook. Meditating every morning and evening also helps me stay calm.

Another thing that helps is writing a journal every morning. Looking back

“**I do not have a choice about my condition, but I can choose how to respond**



Have you tried any of these tips?

Did any of the tips in this article help you manage your fatigue? Any more to share? Send us your thoughts at hmeditor@bhf.org.uk or write to the address on page four.

at what I achieved yesterday, and planning my day ahead, keeps me positive and focused on realistic goals, such as a daily walk outside for fresh air. But again, pacing is key. At first, I could only walk around the garden patio, but after building up I can get around my local estate.

Keeping my brain active is also good for my energy. I’ll do something creative each day like drawing, knitting or photographing the night sky.

I’ve become kinder to myself and begun to accept my limits. Psychotherapy has been helpful with that. I’ve come to realise something: I do not have a choice about my condition, but I can choose how to respond.

It’s not about pretending I’m over it. It’s about finding ways to cope better and live the best life I possibly can.” ●