

Living With Fatigue





With Thanks



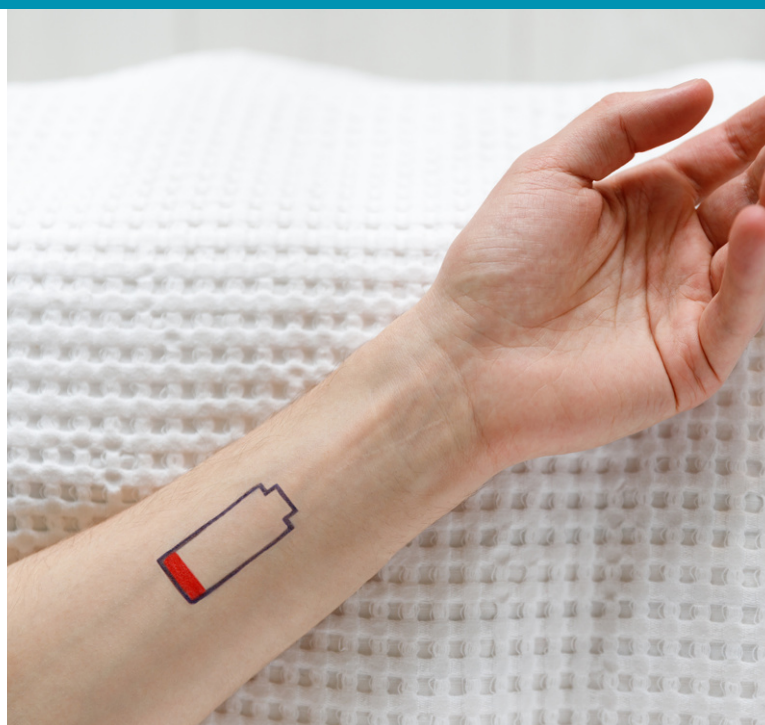
All of our booklets are made together with our community of stroke survivors and their families.

Thank you to everyone who contributed their experiences, feedback and advice.

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A Letter From Karl

Dear fellow stroke survivor,

In this booklet we're talking about Fatigue. Not the "I'm a bit sleepy" kind of fatigue, but the "feels like walking through a muddy field in an iron suit while juggling kettlebells" kind. Mine usually comes with a few expletives. It's 9 am as I type this, and I'm already exhausted.

This is one of the hidden effects of stroke. Fatigue might be physical (struggling to walk to the bathroom) or neurological (unable to focus on a book). It can have a huge impact, and it's the symptom I've struggled with most.

My severe post-stroke fatigue led to medical retirement at 44. As you'll read elsewhere in this booklet, there are many possible causes - and to be honest, I don't think many doctors fully understand them. It's frustrating and annoying, but you can't let it stop you living your life. Over the past eight years, mine has improved a bit - mostly because I've learned what I can and can't do.

Planning, planning, planning - that's my best advice. If you're going out socially, have a medical appointment, or even just a phone call, make sure to rest afterwards. Don't be afraid to tell people you need a power nap. I find short naps a great way to reenergize, especially if I have plans later in the day. Fatigue can hit the next day or even two days later, so listen to your body - and to friends or family when they say you look tired or overstimulated. Take that as your cue to rest.

It's not easy. I still get it wrong sometimes. Don't beat yourself up over it. Try using the "spoon theory" to explain your energy levels, or colour-coded wristbands to show when you need quiet time. Use your Access Card or Sunflower Lanyard for queues and invest in good noise-cancelling headphones - my favourite item.

Remember, you are not alone. You CAN win your battle with post-stroke fatigue - one step at a time.

Now I'm off for a nap. Zzz...

Karl

What is Post-Stroke Fatigue?

What Is It?

Post-stroke fatigue is a **profound and overwhelming tiredness** that is fundamentally different from typical tiredness.

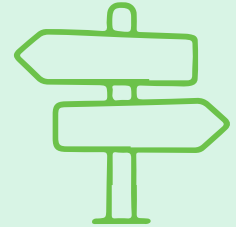
Unlike ordinary tiredness, it often **doesn't improve with rest** or sleep, and it can **appear suddenly** and **without warning**.



Why Does It Happen?

A stroke is a **brain injury**. After a stroke, the **brain has to work harder** to reroute messages and make up for damaged areas.

This is sometimes called '**neuro fatigue**' or '**brain fatigue**'.



Everyday Impact

As **the brain is working so hard**, almost **any activity** - talking, reading, watching TV, or even thinking - **can become tiring** much faster than before.

Think of it like a car having to take a longer, slower detour - it uses more fuel to go the same distance.



In the same way, **your brain uses more energy to carry out everyday tasks**.

Sensory Overload

The brain also has to filter out background information - such as noise, movement, or bright lights.

After a stroke, this filtering process may not work as efficiently.

As a result, **busy** or **noisy** environments can quickly become **overwhelming** and **drain energy** levels further.



Remember: Post-stroke fatigue is **common** and **real**. Understanding it can help you **pace yourself**, **plan your day**, and **explain to others** why you might need extra rest.

Why is Post-stroke Fatigue so Unpredictable?

Post-stroke fatigue is **highly unpredictable** and **inconsistent**, not only **from person to person** but also from **day to day** for the **same individual**. **One day**, a stroke survivor might **feel relatively well** and manage several tasks, while **the next**, they could be **completely exhausted** with no apparent reason.

This variability is due to several factors:

- **Brain Rerouting and Healing:** The brain is constantly building **new pathways** and **working to heal**, which is an energy-intensive process. This underlying "brain work" can fluctuate.
- **Limited "Battery" Capacity:** The brain's "battery" often starts the day at a **lower capacity** (e.g., two-thirds full) compared to a non-injured brain and **drains much quicker**.
- **Individual Triggers:** What triggers or worsens fatigue is highly personal.

Common triggers include:



Sensory Input: Noise, bright lights, busy environments (like supermarkets or social gatherings), or even too much music or TV.



Cognitive Load: Concentration, thinking, reading, writing, or trying to process multiple conversations.



Emotional Stress: All types of emotions, happy or sad, as well as stress.



Illness or Unforeseen Events: Being unwell or unexpected changes to plans can rapidly deplete energy reserves.



Inability to Filter: The impaired ability to filter out irrelevant sensory information means the brain is constantly processing everything, leading to rapid overload and "shutting down."

Why Distraction Feels So Draining

What The Research Shows

New studies have found **post-stroke fatigue** is closely linked to **how the brain handles distraction** and **focus**.



Inside The Brain

Researchers found that:

- **People** with **higher fatigue levels** respond **more strongly** to **background distractions**, even when they weren't aware of them.
- Their **reaction times slowed more** when **tasks** became **mentally demanding**.
- **Over time**, their **brains** became **less able to suppress distractions**, meaning **focus got harder** the longer they kept going.



Everyday Examples

These findings help explain why everyday situations can feel exhausting:



Busy places: supermarkets, cafés, or social events flood the brain with **noise, lights** and **movement**.



Conversations in groups: the brain struggles to tune in to one voice.



Screens or multitasking: flashing images, scrolling, or **switching between tasks** add to mental load.

What Can Help?

- **Choose quiet; calm spaces for concentration**
- **Limit multitasking** – focus on one thing at a time
- **Take breaks early rather than waiting until fatigue hits**
- **Reduce background stimulation** (turn off TV or music when reading or talking)
- **Manage sound** - use noise cancelling headphones, either silent or playing non stimulating music.

Recognising & Responding to Warning Signs



When fatigue worsens, your brain is signalling overload.

Stop and rest at the first signs - **pushing through** often leads to a “crash” that can take **days to recover from**.

Cognitive Signs

- **Brain fog or confusion**
- **Slurred speech**
- **Sensory overload** (especially in noisy or bright places)

Physical Signs

- **Weakness or unsteadiness**
- **Blurred vision**
- **Facial changes** (paleness, drooping)

What to Do

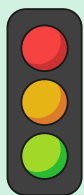
If these signs appear:



- **Stop what you're doing** and, if you can, rest in a quiet, dark place.
- **Focus on slow, steady breathing** or use gentle grounding exercises (for example, notice five things you can see and four you can touch).
- **Tell people close to you what to watch for** - they can help if you're too tired to notice the signs yourself.

Practical Tools - from Survivors

- **Pacing:** Plan activities with rest in mind.
- **Traffic Light Wristbands:** Non-verbal way to show your energy level.



Red = very fatigued.

Yellow = getting fatigued

Green = not fatigued

- **Tiered To-Do Lists:** “Need to do,” “would like to do,” and “if I've got the energy.”
- **Mood Journal & Meditation:** Manage emotions and track progress.
- **Talk to others:** Fatigue can feel isolating - you're not alone.

Managing Post-Stroke Fatigue

Diet and Hydration

SMALL, FREQUENT MEALS

For those with **swallowing difficulties** or **fluctuating appetite**, **smaller, regular meals** can **ensure consistent energy** intake without overwhelming the system. Viewing **food as "fuel"** helps maintain energy.



CAFFEINE & ALCOHOL

Responses to caffeine vary; some find it unhelpful or even detrimental, while others find moderate use acceptable, but it's **not a universal solution**.

Alcohol should generally be **limited** due to its **impact** on the brain and **increased risk of falls**, which can be more serious for stroke survivors.



HYDRATION

Staying well-hydrated by regularly **drinking water** is consistently recommended and can **significantly improve** general feelings of **wellbeing** and help with "sluggishness," which might be confused with fatigue.



BALANCED DIET

Eating healthy, balanced meals provides **sustained energy** and supports overall wellbeing. **Avoiding excessive junk food** can **prevent sluggishness**.



Medication



LIMITED MEDICATION OPTIONS

Currently, there is **no universally effective medical treatment** for post-stroke fatigue. Antidepressants, for example, have generally shown no significant effect on fatigue, even if they treat other effects such as depression.



SUPPLEMENTS

Some stroke survivors may be **prescribed supplements** for **specific deficiencies** that may impact fatigue. However, there is **no conclusive evidence** that non-prescribed supplements significantly alleviate post-stroke fatigue.



CONSULT A GP/NEUROPSYCHOLOGIST

It's important to **discuss any medication or supplement** use with your **GP, neurologist, or pharmacist**. They can advise on possible interactions and how different treatments may affect you.



MODAFINIL

This **medication** that **treats sleepiness** has shown some **moderate beneficial effects** on stroke survivors in certain studies. Its effectiveness is still being explored, and it is **not currently a standard treatment** for post-stroke fatigue.

In some cases, **neurologists may consider prescribing it off-label**, but access can vary.

Explaining Fatigue to Others

Fatigue after stroke is invisible and **often mistaken for normal tiredness**. **Clear explanations** can **help others understand** what you're going through.

USE ANALOGIES OR METAPHORS

Describe your brain as a **damaged battery that doesn't fully charge**, or a **motorway that's been rerouted** - it takes more effort to do simple things. Or use the **spoon theory**, a metaphor where each task uses up a limited number of "spoons" of energy, helping others understand that your energy supply is smaller and needs to be managed carefully.



CLARIFY IT'S NOT NORMAL TIREDNESS

Rest doesn't always fix it and fatigue can appear even without much activity.



SHARE PERSONAL EXAMPLES

Explain how fatigue affects you, for example 'When I am tired, I might slur my speech or seem confused'.



HIGHLIGHT THE INVISIBILITY

People might see you as "recovered," unaware of the **hidden effort** your brain is making.



FOR EMPLOYERS

Provide documentation from neuropsychologists or occupational health. Explain that **reasonable adjustments** (like **reduced hours**, **flexible work**, **working from home** or **using noise cancelling headphones**) prevent setbacks. Even this booklet might help your employer to understand more.



FOR FAMILY & FRIENDS

Teach them your warning signs and use **visual cues** - for instance, a traffic light system - so they can support you before you reach exhaustion.



Does Fatigue Go Away?

For some, fatigue improves gradually or even disappears, but **for many, it remains a long-term part of life** after stroke. Around a **third to half of survivors** still experience it **ten years later**.

Over time, improvement often comes from **learning to manage it better** rather than the fatigue itself vanishing. Many describe it as “a marathon, not a sprint” - something you **adapt** to and **live with**, recognising that it **can fluctuate** in waves.

Here Belinda shares her experience with fatigue:



“I didn’t understand the impact of fatigue after my stroke. It took a long time to grasp what causes it and how to manage it. It felt bizarre that even a simple conversation could leave me unable to function.

The fatigue is strange and frightening. I get a tight, squeezing pressure in my head that affects my balance and makes my head too heavy to hold up. Things look unfamiliar, almost alien. My jaw feels heavy, my words won’t come, my limbs are uncoordinated, and my hands and face are burning. It’s like shutting down completely.

I’ve learned to rest and let it pass, but it can last for days and used to really scare me.

After 18 months, I found the Different Strokes Facebook Group - my lifeline. Realising others experienced the same thing was a relief.

They understood the struggles with concentration, multitasking, and processing information. Later that year, a local group started up, and meeting other survivors has been fantastic. We support each other and laugh together, which helps so much.

Now, I no longer feel embarrassed when I lose words or can’t focus. I’ve learned to be patient, to rest without guilt, and to take one day at a time. I’m doing it my way, - **and I’m kicking stroke’s ass!”**

What Survivors Wish They'd Known

Many stroke survivors say they wish they'd understood fatigue sooner - and that someone had told them:



ITS NORMAL

You haven't done anything wrong. Feeling exhausted isn't weakness or laziness.



IT'S LONG-TERM

Fatigue often lasts for years, so **managing expectations early helps reduce frustration.**



IT'S NEUROLOGICAL

Your **brain is healing and working harder** to reroute pathways



SELF-MANAGEMENT HELPS

Planning, pacing and rest are essential recovery tools, not optional extras.



PEER SUPPORT MATTERS

Talking to others who **"get it"** can be **life-changing.**



ACCEPTANCE TAKES TIME

You'll have good days and bad days, learning to **work with fatigue rather than fight it** makes life easier.



We're here for you. Get in touch.



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Let's stay social.

 **Different Strokes Charity**

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Different Strokes is a registered charity in England and Wales (1092168) and Scotland (SC044190).



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