Different Strokes
Reclaiming lives after stroke

The Invisible Side of Stroke

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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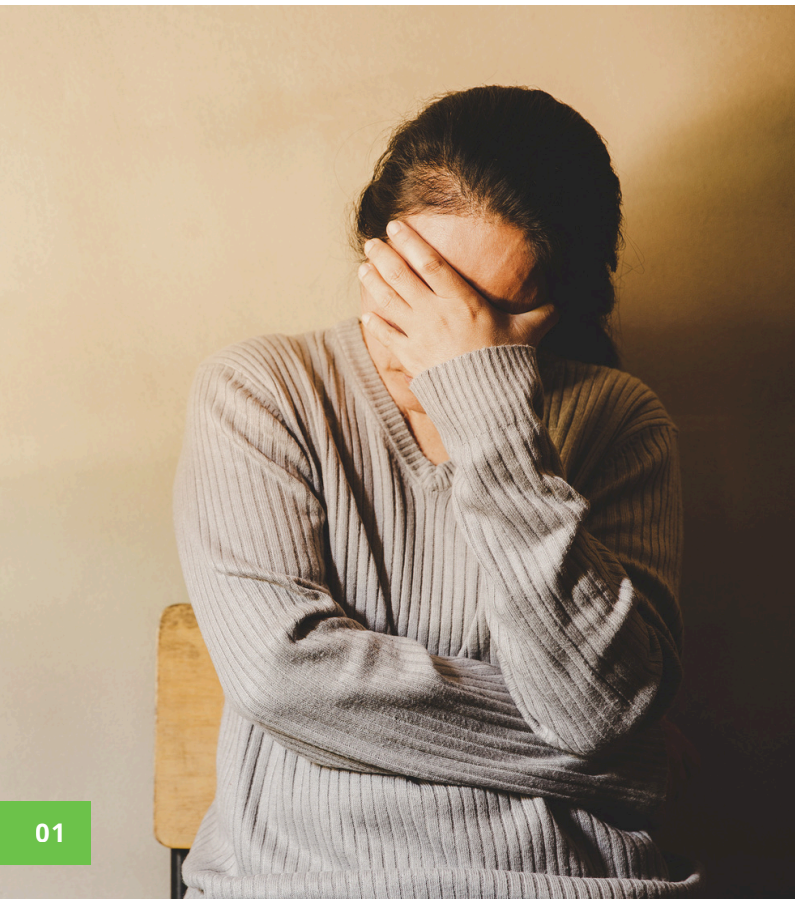


A Letter From **Jak**

Hello.
I'm Jak, a 52-year-old stroke survivor, teacher, piano player, geek, and an all-round scruffy, noisy little so-and-so.

If you're a fellow stroke survivor, my best wishes to you. If you're reading this because a family member, friend or loved one is a stroke survivor, thank you. You've taken the time to understand our experiences and how best to support your survivor, or yourself. My best wishes to you too.

So: Most of me woke up on a March morning in 2021, but some of me hit the snooze button.

I'm lucky. That might sound strange, but I really am lucky. Not unchanged, not well, not unscathed, not who I was, but lucky. I'm still here, and I'm able to write to you.

But here comes the handbrake screeching tone shift:
Trauma. Shock. Panic.

Lost in the scramble for support, rehab and recovery is the shock. One moment we're one person, and then we're not. We may not even look the same. We move differently, speak differently, interact differently. Or we may appear unchanged and still hear the loathsome phrase, "You don't look like you've had a stroke."

Either way, it's a profound shock. It's trauma. While we're trying to absorb information, deal with treatment and medication, and keep on top of everyday life - bills, forms, "life admin" - we're also screaming internally: **Why me? Why did this happen? Who am I now?**

This part gets lost. Even well-intentioned medical professionals can miss it. I'm lucky to know people in counselling and therapy, but even then, it didn't occur to me that I needed help until the nightmares, panic and flashbacks began.

It took several attempts to find the right treatment. Persistence is key. Even finding what's available can be exhausting, and our batteries are a valuable, limited resource. But please, persist. After the tenth phone call, the twentieth email, the thirtieth letter, keep going.

I eventually found a brilliant EMDR therapist who was 'himself' a brain injury survivor. It helped. The nightmares lessened. The panic still happens, but I've found new, better ways to manage it.
Please, persist.

Bloody-mindedness is a virtue! If the first technique feels like it doesn't help, try something else. Keep trying.

It's not failure. After all... different strokes for different folks.

Jak

What ‘The Invisible Side of Stroke’ Means

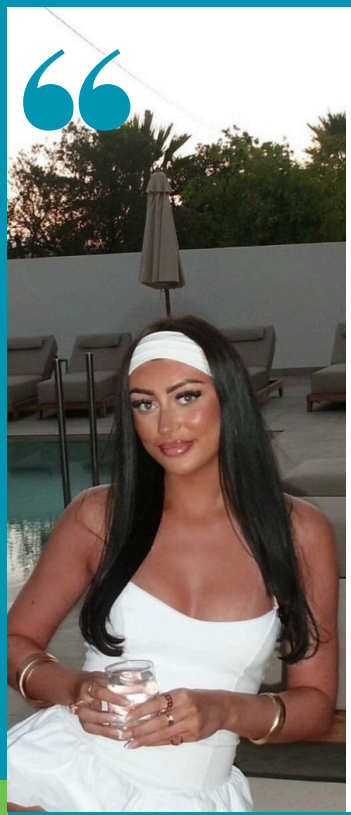
Hidden Symptoms vs. Visible Impact

A stroke impacts a person's **physical, cognitive** and **emotional** abilities. While some effects are obvious, many are hidden, meaning survivors do not always receive the help they need.

The "hidden side" refers to symptoms and experiences that are not immediately visible to others but represent a very real challenge for the stroke survivor.

Why This Matters So Much

Hidden symptoms can be as life changing as visible ones. Without a visible impact it can be very difficult for stroke survivors who may ‘look fine’ to explain their experiences to medical professionals, family and friends. This lack of understanding or dismissal of invisible symptoms can make recovery harder.



“Mobility has been one of the hardest parts. When I walk I’m very slow and unsteady on my feet; mostly down to fatigue. I rely on a wheelchair, and while I’m grateful it gives me freedom to move – it also reminds me every day of what I’ve lost.

At times I even feel like a fraud sitting in it. People see me in the chair and, because I’m young and sometimes able to take a few steps, I worry they assume I don’t need it – or worse, that I’m exaggerating. Just because I “look fine”. Which is bizarre because before I never cared what anyone thought of me, especially not strangers. What they don’t see is how quickly fatigue causes me to crash, how walking even a short distance can completely wipe me out, leaving me in pain and forcing me to spend hours, sometimes days, recovering in bed.”

SASKIA, HAEMORRHAGIC STROKE AT 22

Cognitive and Memory Changes

Cognitive effects are as common as physical ones. They can affect the way your brain understands, organises, and remembers information.

90% **of stroke survivors report at least one cognitive impact**

Memory Problems

Affect 83% of stroke survivors

This can present as **short-term memory loss**, making it difficult to remember recent conversations or learn new things.

You might find it harder recall names or words or remember practical things such as where you parked the car or the route to a familiar place.

Concentration Difficulties

About **8 out of 10 stroke survivors report problems with concentration.** This includes being unable to follow a TV programme or read a book.

The brain may struggle to filter out background noise, making sticking to a task very challenging. Many stroke survivors can also lose the ability to **multi-task**.

Coping Strategies for Cognitive Issues:





Many stroke survivors find the following helpful:

- **Write things down** or keep a diary to track important information.
- Maintain a **consistent daily routine**.
- **Reduce background noise** when possible.
- Take **frequent rest breaks** to avoid mental fatigue.
- Give yourself **plenty of time** to practise new skills and **be patient with your progress.**

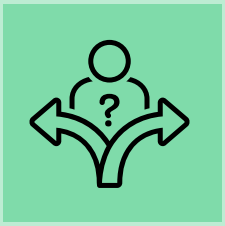
Planning, Decision Making and Personality

Information Processing

You may find that you are **slower at processing information**, and that you can't take in as much information as you could before your stroke.

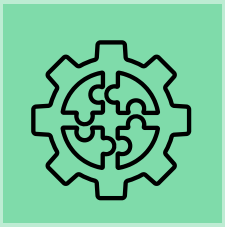
Planning and Sequencing:

The skills needed for everyday tasks like **getting dressed, making a meal or following a routine** can become impossible or slower to do.



Decision Making:

You may find that you rush into things without thinking, **struggle to make choices**, or **get confused** about what needs to happen. This can lead to feeling frustrated and overwhelmed.



Lack of Flexibility in Thinking:

Your brain may find it much **harder to grasp complex ideas**, see two sides of a story, reason through a problem, or come up with suggestions.

Personality Change and Apathy

Changes in how the brain works can sometimes affect how a person behaves or how others see their personality.

- You may **lose your filter** and say what you are thinking without meaning to upset anyone. This can sometimes surprise or upset people. You can explain to friends, family, or new people that this is a result of your stroke and not how you really feel. This can help them understand and make things easier for you.
- You may notice you feel less interested or motivated to do things you normally enjoy. This is called **apathy**, and it is different from low mood or depression, even though it can look similar. It can show up as doing less, not starting tasks, or needing more prompts. Understanding what this is can help the people in your life encourage and support you or help you to seek the right support.

Emotional and Psychological

Low Mood, Depression, and Anxiety

Feeling low or anxious after a stroke is very common. You may notice **irritability, sadness, mood swings, loss of motivation, or a reduced ability to enjoy things**. Some people feel restless, and a small number experience suicidal thoughts. Many also become anxious around the anniversary of their stroke or worry about having another one, sometimes feeling afraid to sleep or leave the house.

These feelings can be overwhelming, but support is available. Speaking to your GP, stroke nurse or therapist can help you understand what's happening and find the right help. Turning to family, friends or the Different Strokes community can also provide reassurance. Even small steps towards asking for support can ease pressure.

Emotional Lability and Disinhibition

- **Emotional lability** is difficulty controlling emotions, specifically sudden, uncontrollable crying or laughing. The intensity of your reaction may be much greater than normally expected and it can feel embarrassing, leading to some stroke survivors avoiding social situations.

- **Disinhibition** can include being less able to control outbursts such as anger, or exhibiting more extroverted behaviour.

Noticing triggers, pausing before reacting and using calming strategies such as deep breathing or distraction can help. Stroke specialists, therapists and peer groups can also offer guidance.

Dealing with Grief and Acceptance

A stroke is a traumatic, life-altering event that involves loss. These losses are very different for everyone. Some may be permanent and some temporary, whether in your mind, your body, or your career. You may need to grieve the life you thought you would have or the one you hoped for. This can bring feelings like sadness, frustration, anger, fear, or guilt. Like all grief, it takes time and will ebb and flow. You cannot change what has happened, but acceptance and adjusting to your new reality are important. **Be gentle with yourself and make space for these feelings whilst you learn to adjust.**

Fatigue and Sensory Changes

Post-Stroke Fatigue

Post-stroke fatigue is experienced by **86% of stroke survivors.** It is different from normal tiredness; it is an all-encompassing exhaustion and it often does not get better with rest. Fatigue affects people both physically and cognitively, making everyday tasks feel hard to complete.

Coping:

Learn to listen to your body, structure your day with built-in rest periods, and avoid overdoing it, even on a "good day," to prevent exhaustion the following day.

Read more in our dedicated booklet:
Living with fatigue

Sensory Overload and Hypersensitivity

After a stroke, **your brain may find it harder to manage background noise or busy environments.** This can make it difficult to stay focused or comfortable in everyday situations. You might become more sensitive to bright lights, sudden noises, strong smells or chaotic spaces.

Some people notice changes in how their body feels too. Muscle tightness or spasticity can create uncomfortable sensations, and touch may feel different, either too light, too intense, or sometimes even irritating or burning.

Spatial Neglect

Spatial neglect (sometimes called inattention) happens when **your brain struggles to recognise one side of your body or the space around you**, most commonly the left side.

This is not a problem with your eyesight. Instead, your brain simply does not register that side, which can lead you to bump into objects, leave food on part of your plate, or miss things placed on the affected side.

Many people are unaware this is happening which can make it even more challenging.

Invisible Physical Impacts

Not all physical effects of stroke are visible. Many people live with symptoms that cannot be seen from the outside but still have a major impact on daily life. These challenges can vary day-to-day, which can make them even harder to explain.

Pain and Changes in Sensation

Some people have ongoing discomfort after stroke, including **muscle, joint or nerve-related pain**. Pain may come from tight muscles, swollen joints, or nerve damage.

Some people experience **neuropathic pain**, which happens when nerves misfire pain signals without an obvious cause.

If this is due to damage in the brain, brain stem or spinal cord after a stroke it's known as **central pain syndrome**. This is a type of pain that can feel constant with sensations like burning, aching, or freezing.

Others notice changes in sensation such as **numbness, altered touch or skin that feels overly sensitive**. These feelings can make everyday tasks more tiring and affect balance, mobility and confidence.

Muscle Weakness and Proprioception Difficulties

Weakness does not always mean paralysis. **Many people have strength but lack the fine control, balance or coordination** they once had. Proprioception, the internal sense that helps you understand your body's position, movement, and the force you're using, can also be affected. When this sense is disrupted, **movements may feel unpredictable or clumsy,** even if you appear to walk or stand normally. These subtle difficulties often require more focus and energy, which **can add to fatigue.**

Dizziness and Balance Problems

Dizziness, vertigo or a feeling of being off balance can persist long after a stroke.

This can make shopping, travelling or standing in busy places more challenging. These **sensations may come and go**, which can make others assume they are minor, even though they **can affect confidence and independence.**

Sleep Disturbances

Sleep changes are common but often overlooked. Some people **struggle to fall asleep, wake often or have sleep that does not feel refreshing.** Others need more sleep than before or feel tired even after resting.

Sleep difficulties can intensify other symptoms such as **fatigue, irritability** and problems with c**oncentration or memory.**

Temperature Regulation Changes

After a stroke, your **body may find it harder to regulate temperature.**

You may **feel unusually cold or hot, sweat more or less** than before or find that temperature changes affect you more strongly. These fluctuations can be **uncomfortable and can add to fatigue or sensory overload.**

Remember, if your quality of life is really impacted by any of the above, its important you seek help. No matter how far into recovery you are, you're entitled to support to manage the ongoing effects of your stroke.

Communication Challenges

Communication Difficulties

- **Aphasia:** Difficulty with speaking, understanding, reading, or writing.
- **Dysarthria:** Speech that becomes slurred or unclear because the muscles you use for speaking are weak or hard to control.
- **Dysgraphia:** Difficulty with writing. Specifically, it makes it much harder to turn your thoughts into writing.
- **Cognitive communication difficulties:** Issues with memory, attention, or processing information that can make conversations harder to follow, even if your language skills are intact.

Social Effects

Struggling to communicate or remember the thread of a conversation can be frustrating and embarrassing. You may find yourself wanting to withdraw from social situations to avoid feeling self-conscious.

"I have the mildest residual aphasia, dysarthria and dysgraphia. They are barely noticeable unless I'm very tired. However, it knocked my confidence greatly at first. Both spoken and written language have been affected. When I was in hospital writing a short text took me 45 minutes of painstaking concentration, only to find out from the receiver it made little sense.

People don't understand just how exhausting it can be to string sentences together some days, it's much harder to interject in conversation or to make a 'timely quip'. It's hard for people to understand why it is you can appear to do everything you used to one day, and then need twelve hours sleep the next, or not be able to concentrate on anything at all the next day. It's certainly made me significantly more aware of hidden disabilities."

CHARLOTTE, ISCHAEMIC STROKE AT 50

Aphasia

Aphasia is a communication difficulty caused by damage to the language centres of the brain. It can affect **speaking, understanding, reading, writing** and **using numbers.** It does not affect your intelligence. Many people describe it as **knowing exactly what they want to say but being unable to get the words out.** Others often say it feels like "being locked in my own head."

1 in 3 stroke survivors in the UK live with aphasia.

Ways to Help Communication

You may find the following approaches useful:

- **Use other ways to communicate:** pictures, photos, gestures, pointing, drawing, maps, or writing key words.
- **Use tools that support communication:** smartphones or tablets for texting, video calls, photos, maps, text-to-speech, and therapy apps.
- **Carry an aphasia explanation card:** helpful for public situations and reducing pressure.
- **Keep communicating daily:** even small conversations help build confidence and maintain progress.
- **Take breaks:** communication can be tiring; short rests help prevent overwhelm.
- **Find others living with aphasia:** groups, peer support, and online communities can reduce isolation and help rebuild confidence.

Tips for Family and Friends

Supportive communication makes a huge difference:

- **Choose a quiet environment** with no background noise.
- **Make eye contact** and use simple, clear sentences.
- Stick to **one topic at a time.**
- **Allow plenty of time** for the person to respond, avoid finishing sentences for them.
- **Use visual clues** where possible.
- **Write down** key words, numbers, dates or names.
- **Check understanding** gently, including yes/no responses.
- **Be patient and honest** - say if you haven't understood.
- **Encourage the person** and highlight progress.

Relationships and Intimacy

Impact on Family

Stroke affects the whole family. Loved ones may have faced the **fear of losing you** and had the additional **stress of hospital visits**, **childcare**, **finances** and **supporting your recovery.**

Emotional changes such as irritability or withdrawal can add pressure. When you feel short-tempered, tired, or unmotivated in rehabilitation, family members may feel unsure how to help or as if they're 'walking on eggshells'.

Impact on Friendships

Friendships may also shift in ways that feel painful or confusing. You might have had many visitors early on, only to find that contact fades once you are home.

Some people feel unsure how to talk to you or struggle with seeing you unwell. This can feel isolating, but connection is still possible. **Reaching out** to people you miss, joining a **support group**, or getting involved locally can help rebuild a supportive social circle.

Relationships and Intimacy After Stroke

Emotional changes, physical effects, fatigue, or altered body function can affect closeness and sexual relationships. These changes can be challenging for both you and your partner.

Adjusting to a new dynamic:

Your relationship may shift in ways that take time to navigate:

- Guilt or sadness over changing roles from equal partners to patient and carer.
- A shift in domestic and financial responsibilities.
- Frustration, resentment, or exhaustion on both sides.
- Feeling controlled or overly dependent can affect self-esteem.

Practical Tips

- **Openly communicate needs**, feelings and boundaries.
- **Set aside time for connection,** shared activities and small moments of closeness.
- **Accept that intimacy may look different** right now; explore ways to be affectionate beyond sexual activity.
- **Support from healthcare professionals, therapists, or peer groups** can be invaluable.

Social and Practical Challenges

Dealing with Loneliness and Loss of Social Life

After a stroke, many people feel misunderstood. When physical recovery is visible, others may assume you're "back to normal." Yet inside, fatigue, anxiety, or sensory overload can make even simple conversations draining.

You may feel:

Misunderstood: "I look fine, but I'm not."

Overwhelmed: Crowded places, noise, or too much talking can make your senses feel flooded.

Isolated: It's easier to stay home than explain what's going on.

These reactions are completely valid. Many survivors describe needing to "go dark" sometimes - stepping back from texts or visits to recover mentally. But regular contact, at your own pace, really does help mood and confidence.

"Having a stroke has made me much more aware, and I won't lie – I've been scared at times, especially worrying if it might happen again. But it's also made me far more grateful for life. One of the hardest parts for me has been the loneliness. After the stroke, I had thoughts and feelings that I'd never experienced before. During my recovery, I know of two people to we lost to suicide - one family, one friend - and that had really hit me mentally. I suffered with anxiety, depression, OCD, and PTSD, along with some truly hellish intrusive thoughts that I found myself listening to.

The hardest part was that people - even my own family - didn't really understand what I was going through mentally. I put on a lot of weight because I couldn't bring myself to leave the house. It was a scary and dark time... but I'm still here. And I'm so, so grateful that I've made it through and learned so much from the experience."

CHRIS, ISCHAEMIC STROKE AT 39

When and Where to Get Help

Seeking Proffessional Support

If **anxiety, low mood, or sadness** don't improve with time, it's important to speak with your GP. They can assess how you're feeling, discuss medication if needed, and refer you for talking therapy or a clinical psychologist.

You are entitled to emotional support after stroke - it's not a luxury. Counselling gives space to talk through feelings, regain confidence and find a clearer path forward.

Where to start:

- **GP referral:** Often free (but may involve a wait).
- **Local charities:** Groups like Mind or Headway offer low-cost or free sessions.
- **Private counselling:** Some people prefer this for flexibility; however this option is not accessible to everyone as it comes at a cost.

Medication: Removing the Stigma

Antidepressants can make a real difference to mood and motivation after stroke. They don't change who you are - they help restore balance when your brain chemistry has been through trauma.

Medication should always come with clear explanation, a plan for follow-up, and honest discussion about side effects. It's not a sign of weakness to take what helps you heal.

EMDR and CBT: Therapies for Trauma and Anxiety

After a sudden or frightening event like a stroke, it's common to feel jumpy, replay memories, or experience nightmares. This may be post-traumatic stress.

Two therapies often used are:

- **CBT (Cognitive Behavioural Therapy)**: Helps you notice unhelpful thoughts and replace them with realistic, balanced ones.
- **EMDR (Eye Movement Desensitisation and Reprocessing)**: A structured approach that helps your brain safely process traumatic memories.

Both are evidence-based and can be life-changing. Ask your GP, stroke team, or psychologist whether these therapies might suit your situation.

How We Can Help:

The invisible side of stroke is a broad and complex topic, and it's likely that some of the challenges you experience haven't been included in this booklet.

At Different Strokes, there is a community of younger stroke survivors who understand what you're going through and can offer support. Through our website, you can access a wide range of services to help you navigate life after stroke.

Online Webinars

Online Support Groups

Virtual Meetings

Online Exercise Videos

Survivor Helpline

Local Groups

Information Packs

Physio Bursary Fund

Getting Further Support:

The **NHS** provides ongoing medical support and rehabilitation. They can also signpost you towards different kinds of support.

www.nhs.uk/conditions/stroke

The **Stroke Association** is a UK charity that provides comprehensive support to people affected by stroke of any age

www.stroke.org.uk

The **Brain & Spine Foundation** provides expert support to people affected by neurological problems.

www.brainandspine.org.uk

Headway is the UK-wide charity that works to improve life after brain injury.

www.headway.org.uk

We're here for you. Get in touch.

Different Strokes
Reclaiming lives after stroke

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Let's stay social.

Different Strokes Charity
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