Different Strokes
Reclaiming lives after stroke

Getting The Care You Need

Understanding Your Rights and Advocating For Yourself

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 **Satinder**

Dear fellow stroke survivor,

When I had my catastrophic left CVA aged twenty, I was in a coma, expected to die and definitely not expected to have a meaningful vibrant life, let alone return to medical school.
40 years on and several serious illnesses later, I remain disabled, yet have led a full adventurous life. Now aged 60, I have successfully juggled a medical career, raising a family, divorce, finding love and very much looking forward to dragging my aching arthritic ageing body into my 70s and 80s with new career directions.

It is not easy and we have our additional challenges of hidden as well as exposed disability. Everything we do and say requires effort and often pain. We experience unconscious and conscious bias, unkind words or gestures, being othered and having assumptions made about our abilities.

Gentle plea from a GP with lived experience. Don't permit others to make you feel less able to grow your life beyond your diagnosis. I'm living proof that our history, our diagnosis and our brain scan is not our destiny.

It takes daily effort. You have to be committed to living well. It is also vitally important to find meaning and purpose in your life. What floats your boat? If your body won't comply, be inventive, create an alternative reason to get out of bed. My life has often been unbearable but living well and aligning my purpose in life with my values, has provided a life raft of positivity which has tossed me along my own river of life, relatively safely.

Ensure your choices become congruent with who you really are and don't be grateful for mere scraps. You will become embodied with a clear vision and provided with much needed resilience to follow through no matter what.

Be kind to your heart and embrace your vulnerable part. You become more congruous with your thoughts and less emotional.

At the end of the day, stroke or no stroke, make every breath count. We have approximately 4000 weeks (76.7yrs) in which to live. Choose to live them well.

With love,

Satinder

Why Advocacy Matters

Advocacy means speaking up for yourself and making sure your needs, views and challenges are heard. It is about standing up for your rights and making sure your voice is part of every decision about your care and recovery.

Sometimes this is not easy, especially if your stroke has affected your communication, memory, or confidence. In these moments, **a loved one or professional advocate can help** to make sure your wishes and needs are understood.

Many stroke survivors are surprised by how important advocacy becomes after a stroke. **You and your support system often need to make sure the right care and rehabilitation are in place.** It can be hard work and it can feel unfair that you have to push for what should be automatic in an already difficult time.

The truth is that **people can often fall through the gaps in care.** Services can be confusing and sometimes it takes persistence to get the help you deserve.

It might feel uncomfortable to question professionals or to ask for more help**.** Please remember that **it is not about being difficult. It is about making sure your recovery and wellbeing come first.** You are the expert on your own life and your voice matters.

That is why we have created this booklet. It brings together practical advice, lived experience, and clear information to help you **feel confident in asking questions, knowing your rights and seeking the support you are entitled to.**

Whether you are speaking up for yourself or for someone you love, we hope this guide empowers you to do so and gives you some reassurance that you are not alone. **Advocacy is not just about speaking up - it is about being heard, respected and supported on your journey to recovery.**

Knowing Your Rights

Your Rights to Health and Care Support

Your Rights In hospital (acute care):

- You have **the right to timely, high-quality treatment** under the **NHS Constitution.**
- **Hospitals should follow** National Institute for Health and Care Excellence **(NICE) guidelines.**
- You have a **legal right** to receive information in a way you can understand. Under the **Accessible Information Standard**, NHS services must provide information in formats that meet your needs. This could be **easy read, large print, audio**, or **extra time and communication support**. This is especially important if you have aphasia, sensory changes, fatigue or other communication difficulties.
- **If you're unhappy with care,** you can **raise a concern with PALS** (Patient Advice and Liaison Service) or **make a formal complaint** through the **NHS complaints procedure.**

Your Rights After Leaving Hospital (community and rehabilitation):

- You have a right to an **ongoing assessment of needs** under the **Care Act 2014** (for social care) or NHS Continuing Healthcare (for health needs).
- **Your local authority must assess** whether you need help with **personal care, housing, transport,** or **daily living.**
- You should be offered a **review at 6 months and 12 months post-stroke** to check progress and ongoing needs.
- Carers also have a right to a **Carer's Assessment** to identify their support needs.
- You have the **right to access your NHS medical records** by making a **Subject Access Request (SAR)** under the **Data Protection Act 2018.** To get your records, contact each service provider (like your GP or hospital) that holds your information.

Your Right to Additional Support:

- If you find it hard to manage your NHS care, you can give a trusted person permission to help. Your **GP surgery can set up proxy access** so they can manage things like **appointments, prescriptions** and **health records** on your behalf through the NHS App or website.

- At any point in recovery you can ask your **GP** about your **"stroke care pathway"** and what ongoing rehabilitation you're entitled to.

At the time of publishing this booklet there are two sets of NICE guidelines relating to stroke, which you can access online:

Stroke and transient ischaemic attack in over 16s: diagnosis and initial management: www.nice.org.uk/guidance/ng128

Stroke rehabilitation in adults www.nice.org.uk/guidance/ng236

"I was taken to hospital in an ambulance but after 12 hours of sitting in the waiting room and a clear CT scan, I was diagnosed with a complex migraine and advised to come back 10 days later for a precautionary MRI scan.

The MRI showed that I had suffered a stroke in two areas of my brain. In an instant it felt like my whole world had fallen apart. I was 28; how could this be happening? I left the appointment with blood thinners and no information on next steps.

Luckily, I found the Different Strokes Facebook group and the support was incredible. I realised that I wasn't the only young person to have had a stroke and there was this amazing community. The group helped me to advocate for myself, and as a result I then pushed for a referral to the cardiologist, haematologist and the local stroke team. After multiple tests I was diagnosed as having an atrial septal defect (ASD), known as a hole in my heart. In 2023, I had the hole in my heart closed."

HANNAH, ISCHAEMIC STROKE AT 28

Knowing Your Rights at Work

If You Were Working Before Your Stroke

- **You are protected under the Equality Act 2010.**
- **Stroke and its effects** (e.g. fatigue, weakness, communication changes) **are likely to be classed as a disability.**
- **Employers must make reasonable adjustments** to help you return to or stay in work - for example, flexible hours, equipment to help you, or a phased return.
- You can get specialist help through **Access to Work**, which can fund adaptations, travel, or job coaching.
- If you can't return to your old job, you may be entitled to **occupational health** support or **vocational rehabilitation.**

Useful Contacts:

Access to Work:
www.gov.uk/access-to-work

ACAS:
www.acas.org.uk

Your Right to Benefits and Income Support:

You may be eligible for:

- **Statutory Sick Pay** (SSP) or **Employment and Support Allowance** (ESA).
- **Personal Independence Payment** (PIP) if you need help with daily living or mobility.
- **Universal Credit** (UC) if you have limited income.
- **Carer's Allowance** (for someone supporting you).

Useful Contacts:

Citizens Advice:
www.citizensadvice.org.uk

entitled to:
www.entitledto.co.uk

Scope:
www.scope.org.uk
Call 0808 800 3333
or email helpline@scope.org.uk

Stroke Association:
www.stroke.org.uk
Call 0303 3033 100
or email helpline@stroke.org.uk

Keep copies of all your hospital and therapy letters - they can help support benefit applications.

General Rights and Advocacy

Under the Equality Act 2010, a person is classed as having a disability if they have a physical or mental impairment that has a substantial and long-term, negative effect on their ability to do everyday activities.

For a stroke survivor, this can matter a lot.

If you have problems with **speech, movement, memory or fatigue** that last **12 months or more,** or are likely to, then you may be legally **classed as disabled.**

This gives you important protections.

People **must not treat you unfairly** because of your disability.

They should make **reasonable adjustments** to remove barriers. Examples include longer appointments, accessible buildings, or easy-to-read information.

You have the right to be involved in decisions about your care and support.

If communication or thinking are affected, **you can ask for an advocate** to help you express your views and make sure your wishes are respected under the **Care Act 2014.**

You can also plan ahead by **appointing a Health and Welfare Power of Attorney**, so someone you trust can make decisions for you if you cannot now or in the future.

The **Equality Act 2010** protects you from discrimination in services, housing, education and public life.

If you believe you have been treated unfairly, you can seek advice from:

Citizens Advice: www.citizensadvice.org.uk

Equality and Human Rights Commission: www.equalityhumanrights.com

Disability Rights UK: www.disabilityrightsuk.org

Asking the Right Questions

Whether you are advocating for youself or someone else, here are some practical steps that might help you during this process.

Ask questions and speak up. If something isn't clear, or you feel your symptoms are not being taken seriously, politely ask for clarification. You can say things like, "Could you explain what that result means?" or "I'm concerned about X symptom." Your questions can prompt doctors to double-check or give better explanations. Remember, asking questions is your right – the NHS Constitution guarantees you the right to be involved in decisions about your care.

Bring an advocate or family member. If you feel anxious or think you might forget to mention something, bring someone you trust to appointments. They can take notes, ask questions, or speak up if needed. You don't need a special reason to have someone with you – it could be a family member, friend, or even a community support worker. They can help ensure you get all the information and support you deserve.

Use interpreter or translation services. If English isn't your first language or you feel more comfortable in another language, ask for a medical interpreter. NHS trusts must provide interpreting or translation services. You could also bring written notes in your language or ask for translated info leaflets.

Prepare and document. Before a hospital visit or GP appointment, write down your symptoms and questions. Afterward, note down what was said. Having a written record helps avoid misunderstandings. Also keep copies of any letters or reports. This makes sure that no information "slips through the cracks".

Above all, trust your instincts. You know your body best. If something feels wrong, insist on being checked. Be polite but assertive. Doctors and nurses generally want to help and many welcome questions and input from patients and families. By working together you reduce the chance of anything standing in the way of your care.

Unconscious Bias

Unconscious bias means making quick judgements about people. Most people do it without realising that they are. However, it can have a big impact.

These judgements can be about someone's:

- **Age**
- **Race**
- **Gender**
- **Disability**
- **Sexuality**
- **Background**

Bias does not mean someone is trying to hurt you. It is a habit of thinking.
But it can affect your care and how seriously your concerns are taken.

For example:

- A doctor might think a younger person is too young to have a stroke.
- They might think an older person's symptoms are just age.
- People may feel their pain, tiredness, or memory problems are ignored.

"I do sometimes feel judged and that assumptions are made because I'm Asian.

During my recovery I mentioned to the therapist how lonely and isolated I felt and how I had lost many of my friends. Though she was lovely, she made a comment about how it was okay, I would be alright because Asian people have a lot of family and how she was pretty sure they'd help me. Though she may have been trying to be nice, the comment angered me.

I felt dismissed and frustrated because I didn't appreciate the assumption and the idea that it was the responsibility of my family."

NISHA, HAEMHORRHAGIC STROKE AT 31

Research shows bias can affect healthcare.

- The NHS Race and Health Observatory (2022) found **racial bias can stop people being heard.**
- The MHRA found some tools, like pulse oximeters, are **less accurate on darker skin.**
- The Stonewall Health Report (2018) found one in seven **LGBTQ+ people avoid healthcare** because they **fear discrimination.**
- A study into the effect of gender on stroke management in Glasgow, found **Women may be less likely** to **get fast stroke treatment and rehabilitation.**

Bias can make you feel **unsafe, ignored, or anxious.** It can also stop people from **getting help quickly** after a stroke.

What you can do:

Speak up

Ask for a second opinion or a different clinician if you feel unheard.

Bring someone with you

a friend, family member, or advocate can help you be listened to.

Ask for reasonable adjustments

for example, more time, written notes, or quieter appointments.

Write down your experiences

it can help if you choose to make a complaint.

Raise concerns

contact PALS at your hospital or the Equality and Human Rights Commission for advice.

Bias is not your fault. Recognising it is about **awareness and action.**

You have the right to be **listened to, respected, and treated fairly.**

Speaking up is an important way to **advocate for yourself.**

Legal Advice

Are you considering taking legal advice after a stroke?

We asked Caroline Klage, Partner and Head of the Brain Injury Division at Bolt Burdon Kemp LLP what you should know.

If you are concerned about medical care related to a stroke, you may be wondering whether to speak to a solicitor. The thought of starting legal action can be daunting, but specialist solicitors can advise you whether to claim, and if so, reassure and support you through the process.

Q: Why make a claim?

A: Although people are often concerned about their future and want to have some practical support and financial security, some people start a claim to find out what happened and why. They may also feel angry and want to prevent something similar happening to others.

Financial compensation can pay for things you need now and, in the future, and can also give peace of mind to you, your family and friends, that you will be looked after in the future.

Making a claim can also sometimes prompt learning and training which can lead to improvements in healthcare standards and prevent future mistakes from happening. Often our clients get closure and a sense of justice having brought a claim.

Q: What can compensation provide?

A: **Compensation can fund life-changing support, including:**

- Specialist therapies, such as speech and language therapy, physiotherapy, occupational therapy and input from a psychologist or neuropsychologist
- Specialist care and assistance in the home and community from fully trained support workers/rehabilitation assistants
- Equipment such as wheelchairs, adapted vehicles and communication aids
- Housing adaptations or a more suitable home
- Financial security to ensure your needs are met for life.

Q: What about the cost?

A: Thankfully, our clients don't have to worry about paying legal fees. With our funding arrangements you don't pay anything upfront and, if the claim is successful, most of the legal costs will be paid by the defendant.

It may also be helpful for you to know that compensation payments don't come directly from NHS resources. Rather, they come from the NHS's insurer, so you would not be diverting funds from NHS services.

Q: Will the NHS treat me differently if I bring a claim?

A: This is a common worry, but the staff treating you usually know nothing about the claim. We've never had a case where a patient was treated differently because of a claim.

Q: How long does it take?

A: Every claim is different. Claims usually settle fully once long-term needs are clear, although interim payments of compensation may be available before final settlement to meet the cost of specialist care and assistance, therapies, equipment, a vehicle, accommodation and other essentials.

Q: Is it too late to claim?

A: In most cases, to protect your right to make a claim, you must issue court proceedings against the defendant(s) on or before the third anniversary of the date on which you were first aware you had suffered an injury due to substandard care and realised you could make a claim as a result.

However, there are exceptions to the general rule, including where an injured person doesn't have the mental capacity to bring a claim without help, however, steps do need to be taken to evidence this and it's always best to seek specialist advice to ensure your position is protected as soon as possible - missing the time limit could result in your claim being time-barred and you losing the right to claim compensation.

For more information on seeking legal advice, head to our website.

How we can help:

We know there is a lot of information to take in and you may have more questions than answers. **You're not alone in this**. There's a community of younger stroke survivors who can support you as you navigate life after stroke.

- **Online Webinars**
- **Online Support Groups**
- **Virtual Meetings**
- **Online Exercise Sessions**
- **Survivor Helpline**
- **Local Groups**
- **Information Packs**
- **Physio Bursary Fund**

If you have any questions about our services, email us for more support at:
info@differentstrokes.co.uk

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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