

European  
**Life After  
Stroke**  
Forum

# Abstract book **Lived experience**

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**#lifeafterstroke**

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# Lived Experience

## Oral Abstracts

### Finding My Voice Again: Turning Silence Into Strength

Mr RICHARD DJAN-KROFA

*United Kingdom*

**Theme: Advocacy and empowerment strategies**

**Your stroke experience (What happened? How did it change your life?)**

#### **A Journey from Silence to Advocacy**

On May 12, 2008, I survived an ischemic stroke that left me temporarily paralyzed and unable to speak. Through months of intensive speech therapy, I rebuilt my voice one word at a time. That experience revealed the emotional and physical challenges stroke survivors face, and the power of resilience and support. Reclaiming my voice became a mission to raise awareness, promote early detection, and advocate for accessible stroke care. Through public speaking, campaigns, and community engagement, I empower survivors and educate others. My voice, once lost, now serves to uplift, inform, and inspire lasting change.

**How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

Surviving a stroke in 2008 profoundly changed my life. Losing speech and mobility was devastating, but through determination and therapy, I reclaimed my voice — one word at a time. That journey ignited a mission to ensure others never face recovery alone. As a Lived Experience Ambassador and advocate, I've influenced stroke care, awareness, and policy through roles with global organizations, parliamentary groups, and community campaigns. I train professionals, engage underserved communities, and amplify survivor voices through media and public speaking. My lived experience drives my commitment to equitable healthcare, early intervention, and empowering stroke survivors to be seen, heard, and supported.

**How it can help others (advice, lessons learned, recommendations)**

Advice

- **Rehabilitation is a journey, not a race**
- **Use your story to connect**
- **Engage with professionals**

Lessons Learned

- **The power of communication**
- **Community matters**
- **Representation is critical**

Recommendations

- **Promote early intervention**
- **Improve access to speech therapy**
- **Include survivors in policy-making**
- **Empower through education**

## **Falling off a cliff: how getting involved helped the climb back to a full life!**

*Mrs Margaret Cheng  
United Kingdom*

### **Theme: Rehabilitation and therapy programmes**

#### **Your stroke experience (What happened? How did it change your life?)**

I had a haemorrhagic stroke 10 years ago. I was running a successful market research consultancy and my youngest was starting university. Life as I knew it came to an abrupt end. I became economically and socially inactive overnight and didn't work for 18 months. I found my way back through volunteering, becoming a charity trustee and taking a part time job with the Stroke Association. 10 years on I am an advocate for public involvement in all aspects of health and social care, a public contributor for several UK health sector organisations, and a co-applicant on stroke-related clinical research trials.

#### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

I became an advocate for patient and public involvement (PPI). I directly contributed to the formulation of stroke Guidelines as a lay member of NICE committees and was a Patient and Public Voice Partner with the NHS England National Stroke Board. I am a public contributor with the National Institute for Health and Care Research (NIHR), and the Health Research Authority (HRA). I was a PPI team member for ReTaKe (Return to Work after Stroke), Nottingham University, and a co-applicant for LEAP (interventions to reduce post-stroke emotional difficulties), Leeds University.

#### **How it can help others (advice, lessons learned, recommendations)**

I worked to find and secure the help and support I needed from many different organisations, and to rebuild my confidence. I will share the highlights of my journey from zero to ten years and demonstrate the life-affirming impact of becoming a public contributor with particular emphasis on research trials ReTaKe and LEAP. Survivors can shape the post-stroke world!

## Posters

### 76 - Co-developing Inclusive Psychological Support - Stroke Survivors Shaping the Wellbeing After Stroke-2 (WATER-2) Study

*Mrs Ann Bamford<sup>1</sup>, Mr Stephen Taylor<sup>1</sup>, Mr Billy Edwards<sup>1</sup>, Mrs Sanya Karim<sup>1</sup>, Mr Rudolph Edwards<sup>1</sup>, Mr Jav Rehman<sup>1</sup>, Mrs Wendy Simms<sup>1</sup>, Professor Audrey Bowen<sup>2</sup>, Mrs Kate Woodward-Nutt<sup>2</sup>, Mx on behalf of WATER-2 Study Management Group<sup>2</sup>, Dr Emma Patchwood<sup>2</sup>*

*<sup>1</sup>Research Advisory Panel at University of Manchester, Manchester, United Kingdom. <sup>2</sup>University of Manchester, Manchester, United Kingdom*

#### **Theme: Advocacy and empowerment strategies**

#### **Your stroke experience (What happened? How did it change your life?)**

After my stroke, I lost a sense of purpose. Being part of the WATER-2 research advisory panel (RAP) helped me – and others – continue to rebuild confidence.

I now lead Patient, Carer and Public Involvement (PCPI) on the WATER-2 study, which has co-developed and tested online group therapy to support adjustment after stroke. From the start, we built an inclusive and empowering PCPI model, centred around a diverse RAP, which I chair. It includes:

- Stroke survivors;
- Carers;
- People from groups underrepresented in stroke research (eg: different ethnic backgrounds; communication difficulties)

We meet every 2–3 months to shape the study. We also reach out to individuals and community groups, including through ‘community connectors’, to hear from those who can’t attend the RAP. We have representation in study management and steering groups.

#### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

I use my experiences of stroke and PCPI to ensure WATER-2 is relevant. Together - with the wider research team - we co-designed: how the therapy is delivered online; adapted study materials for accessibility; and advised on culturally-sensitive language around mental health.

This work requires significant time and resource — we prepare materials in accessible formats, arrange one-to-one support, and ensure contributors are properly paid and included. This supports meaningful, flexible involvement and improves the study.

#### **How it can help others (advice, lessons learned, recommendations)**

Our model shows that inclusive, respectful involvement is possible and powerful. It shapes better research giving those involved purpose and connection; helping people grow from patients into confident contributors. We would love to share more at ELASF26.

## 77 - Fast Mind, Broken Processing: struggling with a creative brain after stroke

Mr Ruben Bos  
The Netherlands

### **Theme: Advocacy and empowerment strategies**

#### **Your stroke experience (What happened? How did it change your life?)**

After a stroke at 32, my fast-thinking, creative brain became a challenge. I've always been an associative thinker, full of ideas. I thrived on these traits in my work as a creative director and as a university teacher, but after a stroke my information processing and sustained attention was severely impaired. I was forced to stop working, and my family life, social connections and hobbies became severely limited.

Occupational therapy taught me to take breaks and reduce effort, but this didn't take into account that my brain meanwhile kept seeking opportunities and making plans. With damaged information processing, this high-achieving mindset caused energy drain.

Coping with cognitive overload, I increasingly avoided activities, unsure how to spend days without overloading.

#### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

In my presentation, I'll share how I improved my life in ways that may support stroke survivors and their practitioners facing similar challenges.

Understanding my brain's characteristics and the mismatch after stroke, helped me find a healthier balance between over- and understimulation. Defining a clear purpose proved essential: by focusing my limited energy on what truly mattered, I achieved better balance, improved my mood, and reconnected socially. I started volunteering, developed an app for brain injury survivors, and started a weekly illustrated newsletter

#### **How it can help others (advice, lessons learned, recommendations)**

Characteristics of giftedness, like creativity, motivation, associative thinking, perfectionism and high sensitivity can complicate recovery from stroke. More research is needed.

Occupational therapists should anticipate that these characteristics need tailored approaches to manage over- and under-stimulation.

Defining a new purpose in life can help high-achieving stroke survivors.

## **78 - Volunteering for stroke Public and Patient Involvement (PPI) projects to aid rehabilitation after stroke**

*Mrs Claire Angell  
United Kingdom*

### **Theme: Advocacy and empowerment strategies**

#### **Your stroke experience (What happened? How did it change your life?)**

A major basal ganglia stroke in 2014 aged 45 devastated my life overnight. With complete right-sided weakness, expressive aphasia, difficulty with reading, writing and numeracy, I found myself on a noisy geriatric ward with limited staff and no therapy. Six months later I struggled to move forward with my recovery and rehabilitation. I was desperate to find a balance between therapy and using work skills that I could no longer apply.

#### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

I threw myself into volunteering for stroke PPI projects.

- Co-designing the local stroke care pathway; having a key role improving patient experiences of ambulance care, the hospital system of rehabilitation and discharge home. Using my own hospital experience I suggested improvements to care for patients, including ongoing home rehab. for as long as required.
- Stroke research as a patient partner and participant in innovative rehabilitation methods; testing medical aids, co-designing apps and virtual reality games for improving physiotherapy and occupational therapy, which helped improve my own aphasia through public speaking, reading skills, mobility and dexterity.

It's inspiring for me to work alongside stroke clinicians and stress the importance of hearing the patient voice. I'm passionate about encouraging my peers to get involved and it's so much more interesting than conservative therapy.

#### **How it can help others (advice, lessons learned, recommendations)**

Volunteering for PPI at groups or for research offers stroke survivors opportunities for activity and improvement of individual skills. General wellbeing and avoiding isolation are paramount to stroke recovery. Grab opportunities to volunteer whenever they arise and use them to develop new skills that could help future survivors.

## 79 - My journey with Vasa Concept - from darkness to light

*Mrs Johanna Persson  
Sweden*

### **Theme: Rehabilitation and therapy programmes**

#### **Your stroke experience (What happened? How did it change your life?)**

I had a stroke in 2018 at the age of 48, ending my career as a classical musician when my right side was affected. After two years of standard rehabilitation within the Swedish healthcare system, I was told that further therapy would no longer be covered. By coincidence, I discovered the Vasa Concept after 2 years post-stroke. Traditional rehabilitation focuses on making my muscles move again. Through Vasa Concept, I realized the real issue wasn't the muscles... The muscle is in fact a victim itself! It's being held hostage by the lesion in your brain... By using gravity, you communicate with your brain in its own language!

#### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

There are no Vasa Concept-trained therapists in my part of Sweden. I now train for free with Dr Rajul Vasa, the inventor of the method. from India. I co-founded a non-profit association, VasaConceptGöteborg. We are applying for three-year funding from Allmänna Arvsfonden. In collaboration with Vasa Concept instructor Mari Tynkkynen from Finland. The project will amongst other include continuous workshops with therapists and patients, and theme conferences.

I also participate in research projects in Gothenburg. Not only as a way to help stroke survivors, but also to raise scientific interest in Vasa Concept. My continued progress, even years after stroke, invites researchers to explore how and why Vasa Concept supports recovery in the chronic phase.

#### **How it can help others (advice, lessons learned, recommendations)**

Discovering Vasa Concept has really changed my life! Now I want to be able to tell my story to stroke patients and therapists throughout Europe!

## 80 - Bridging the Recovery Gap: A Survivor's Perspective on Post-Stroke Support

Dr Maria G. Raso<sup>1</sup>, Ms Florencia Rago<sup>2</sup>, Ms Lucila Rago<sup>2</sup>  
<sup>1</sup>The Stroke Foundation, Sugar Land, USA. <sup>2</sup>

### Theme: Support systems

#### **Your stroke experience (What happened? How did it change your life?)**

In 2014, I suffered a stroke that changed every part of my life. Overnight, I went from being fully independent to needing support for even the most basic activities. Recovery was difficult—not only physically, but emotionally and financially. I quickly learned that while acute stroke care was strong, the support systems that follow discharge were fragmented, inconsistent, and often inaccessible. My family became my main source of strength, helping me navigate a system that felt overwhelming and isolating.

#### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

Six years later, drawing on that experience, we founded *The Stroke Foundation*, a nonprofit dedicated to bridging the critical gap in post-stroke care. One of our first initiatives was the *Stroke Survivor Fund*, which offers financial support for rehabilitation therapies not fully covered by insurance. What began as a family effort has since grown into a community platform offering educational resources, mental health support, and peer connections for both survivors and caregivers. This journey has shown me that lived experience is not only valid—it's essential. Survivors and caregivers have insights that should shape care practices, guidelines, and recovery models. I've learned that small, practical interventions—such as clear information, direct support, and emotional validation—can transform someone's path forward.

#### **How it can help others (advice, lessons learned, recommendations)**

My recommendation is simple: include survivors in every conversation about stroke recovery. Their voices can help create systems that are more compassionate, realistic, and effective.

## Abstracts

### Patients on Panels: Using Research Engagement to Add Meaning and Validation to Your Recovery

Dr Peter Hooper

n/a, Mold, United Kingdom

**Theme: Advocacy and empowerment strategies**

#### **Your stroke experience (What happened? How did it change your life?)**

I had a major ischaemic stroke in June 2020, shortly after turning 60. I was incredibly fortunate to receive a thrombectomy within a few hours, but I have been left with issues like fatigue, anxiety, and an inability to concentrate. But my stroke opened my eyes to the stroke community, which I am now part of. And how so many stroke survivors have such important stories to tell of their own lived experience of stroke. My story matters because it shows what can be achieved with a prompt and almost seamless treatment pathway, but every stroke survivor's experience matters because each story can illuminate a different facet of stroke - be that treatment, rehabilitation, recovery or life after stroke.

#### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

I started engaging with the Stroke Association's 'Stroke Voices in Research' and then a similar initiative run by Stroke Hub Wales. Becoming a stroke survivor advising researchers about stroke has transformed my life. Researchers need to know what life is like as a stroke survivor, whichever aspect of stroke treatment or stroke services they are researching. I live in Wales and I work with both the Stroke Association (Wales) and Stroke Hub Wales as a stroke survivor advising on stroke research.

#### **How it can help others (advice, lessons learned, recommendations)**

My advice to all stroke survivors is that your experience matters. It is vital that researchers looking to design new treatments or services hear your voice and get your perspective on their project. We need a broader base of lived experience and stroke outcomes to feed into research and advocacy.

## **Lisa's Aphasia Journey**

Ms Lisa Kenny

Ireland

### **Theme: Advocacy and empowerment strategies**

#### **Your stroke experience (What happened? How did it change your life?)**

My son Alfie was 4 days old when I had a haemorrhagic stroke in 2019, my daughter Emily was 6. I was in an induced coma. I had a craniotomy and skull reconstruction. I still have no power still on the right-hand side of my body. I spent 9 months in hospital and rehab during Covid, it was extremely tough; the isolation.

Aphasia is lifelong, it's difficult not always being able voice feelings, needs or wants. My mission is to continually improve my comprehension and speech, whilst advocating and spreading awareness.

#### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

Creating 'Lisas Aphasia story' then the Irish Heart Foundation shared online during Aphasia Awareness Month to 3k, and it was in all the national newspapers. Increasing interactions, researching availability to connect with others who understood my journey and could help like 'Aphasia Home Café' & attending National Stroke Conference.

My Dad released 'Dave's 60th 60mins Album' in aid of Acquired Brain Injury Ireland raising awareness.

#### **How it can help others (advice, lessons learned, recommendations)**

Neuro-fatigue is Aphasia its physical, take a nap!

Surround yourself with inclusive people, **Aphasia is a language disorder. It doesn't affect intelligence.**

In the NOW, focus on what you can control.

Personal Goals, all mindset and what you **WILL & CAN** do, don't take it personally, challenge out of comfort zone.

I'd like a Dublin hub to create connections socially, educationally, sharing and laughing as most people have not heard of Aphasia.

Communicating through texting & emails learning to write, be patient with yourself.

**We need to listen and take part and make others listen to us!**

## ***Sue, Stroke Survivor: How I Transformed Personal Adversity into a Powerful Force for Change***

Mrs Sue Sandars

United Kingdom

### **Theme: Advocacy and empowerment strategies**

#### **Your stroke experience (What happened? How did it change your life?)**

In 2010, aged 48, I experienced a life-altering stroke, which left me hospitalised for seven months. Once a fast-paced professional, balancing work and family, I faced a sudden shift: partial paralysis, communication challenges, and the slow, painstaking work of rehabilitation.

In rehab, I received an hour a day of all therapies, determined to reclaim my independence, I researched alternative equipment and rehabilitation to try; methods of therapy; grants to help me buy equipment. I explored every way I could to enable a better recovery for me, better life for my family. I embraced therapies ranging from hydrotherapy to mirror box exercises, and even trialled a revolutionary robotic leg that helped retrain my brain and leg muscles.

#### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

Recovery wasn't just about regaining mobility; it became a chance to rebuild my identity. Determined to support other young stroke survivors, I've become a passionate advocate for them. I joined Gloucestershire Younger Stroke Survivors Network and volunteer with charities like Different Strokes and ReConnect. I visited & supported survivors in hospital and home, campaigned for better funding, pushed for more inclusive rehabilitation options, spoken to directly & challenged healthcare professionals about improving post-stroke care.

#### **How it can help others (advice, lessons learned, recommendations)**

At every opportunity I've sought to challenge the misconception that strokes only affect the elderly, raise awareness, empower; enable; advocate about the unique needs of younger survivors.

My mantra is "I kissed death, & now hugging life" – a reminder that my journey is not simply one of recovery, but of evolution, using my experiences to help reshape/change the lives of many others.

## **The importance of advocacy & peer to peer support from the perspective of lived experience**

Mr Paul Quinn

[www.stroke-survivors.org](http://www.stroke-survivors.org), London, United Kingdom

### **Theme: Advocacy and empowerment strategies**

#### **Your stroke experience (What happened? How did it change your life?)**

As a 60 year old male, living in central London I had two ischaemic strokes in July and August 2023, a week apart. My second left me unconscious and unattended for 9 hours before first responders broke down my door to recover me.

Initially I suffered significant cognitive impairment, predominantly memory loss, speech, comprehension and an inability to perform simple tasks such as operating a mobile phone.

My life changed completely. I could no longer work, run my business of 34 years & travel internationally. Given my post-stroke condition I had no option but to retire.

I was extremely fortunate. My experience was like escaping from a burning building. I was singed and frazzled. A significant part of my life burnt in that building. Yet I escaped.

Today life is entirely different.

#### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

I run [stroke-survivors.org](http://stroke-survivors.org) an independent non-profit fledgling organisation to promote peer to peer support among stroke survivors, families and carers. We operate virtual support groups and will start physical groups in September. I write & podcast on lived experience

#### **How it can help others (advice, lessons learned, recommendations)**

Peer to peer support improves outcomes, is hugely cost effective. Strategically filling the gap between future resources and growing demand as stroke numbers increase. Additionally as high dependency stroke services improve, more survivors will live longer, requiring greater post hospitalisation support.

I'm passionate about patient advocacy. It's so important that survivor voices are heard, not only improving future services but giving ownership and agency to those with lived experience. The greater the power of advocacy the better future outcomes must be.

## **Knowledge, hope, empowerment, and/or advocacy: journey of a blogging stroke survivor**

Mrs Katarzyna Siewruk

Poland

### **Theme: Advocacy and empowerment strategies**

#### **Your stroke experience (What happened? How did it change your life?)**

I had my first severe brain stroke at 24. At the time, I knew little about strokes—just a few symptoms and that they can be fatal. The stroke took many things from me, but not my ability to read.

Once I got my smartphone back, I started researching. The information was shocking. There were so few positive stories. I read that I'd be severely disabled, have a high risk of another stroke soon, and never walk, work, or live the life I had before.

But that didn't happen. Over time, I sat up, used a wheelchair, a walker, and finally walked again. I was disabled, but not as severely as predicted.

#### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

I realized the lack of recovery stories online had taken away my hope—my recovery gave it back. That's when I started a blog, first to update friends, then to reach others. Despite poor style and many language mistakes, the feedback meant everything. It showed me I was loved—and that my story mattered.

As a trained journalist, I follow key principles: never give false hope, avoid medical advice, share only what I'm sure of, and show others they're not alone.

#### **How it can help others (advice, lessons learned, recommendations)**

People need every kind of story to keep fighting. Mainstream narratives often miss that. Personal stories—like mine—can give hope, influence attitudes, and even change lives. Also, it can give hope, influence attitudes, and even change lives, in the end, and maybe contribute to changing policies.

## **From Paralysis to Perseverance: Recovering to Run through boundaries after a Stroke**

Mr Daniel Hulston

Stroke Association, Manchester, United Kingdom

### **Theme: Advocacy and empowerment strategies**

#### **Your stroke experience (What happened? How did it change your life?)**

In March 2022, I experienced a near fatal haemorrhagic stroke caused by a ruptured AVM, which left my left side significantly affected, spasticity and drop foot included. Through intensive rehab and relearning to walk, I pushed myself to go beyond what I thought was possible.

Although the stroke brought physical and cognitive challenges, I see it as one of the most transformative moments of my life. It changed my outlook, awakening a resilience I didn't know I had. I took control of my recovery, turning this adversity into an opportunity for growth and self discovery, and I've worked hard to become the best version of myself.

#### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

I delved into neuroplasticity, transformed my life with a brain-healthy diet, completed running events and triathlons to prove the power of mindset, and began a new career with the Stroke Association to inspire and support others going through similar experiences. Knowing how devastating and isolating it is I want to help as many people not feel as scared, lonely and afraid as I did in the early stages.

#### **How it can help others (advice, lessons learned, recommendations)**

Throughout this journey, I realized I am stronger and more resilient than I ever imagined. About a year into rehab, I started setting longer term goals, driven by a desire to prove that even in tough times, positivity and strength can prevail. Importantly, I wanted my 10year old daughter who saw my near-death experience to understand that challenges can be overcome and that inner strength is within all of us.

**Life With Disabilities**  
Mrs Marijeta Mojasevic

**Theme: Advocacy and empowerment strategies**

**Your stroke experience (What happened? How did it change your life?)**

I survived two strokes in 2003, second one with severe consequences. Most serious disabilities that I acquired are hemiparesis and diplopia. My reality was completely changed, but my feet stayed on the ground.

**How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

My journey as a stroke survivor activist has begun during last academic year of my university studies. I wanted to share my experience as a person living with several disabilities caused by stroke with my colleagues, future social workers. Five years later, in December 2016, as youth adviser in the local Youth Office, I delivered my very first presentation titled "Life with Disability: How to Stay the Same and is the Essence in that?" in local high school. This presentation is one of the main reasons why I was on BBC's list of 100 inspiring and influential women from around the world for 2023. Using the method of storytelling, my story makes people's lives easier, without stereotypes and prejudices. I want us to be seen as a part of society, not separated by invisible fence of prejudices. My advocacy is about equal rights and fostering greater understanding, starting with young people but reaching society at large for everyone affected by stroke.

**How it can help others (advice, lessons learned, recommendations)**

The success of my presentations was excellent, which could be seen by reactions of young people. What I really love to see is their empathy, and I could see it many times. Strong message that life can and should be lived after stroke is the background of my story.

## **From Stroke to Strength**

Miss Omotola Dehinde

United Kingdom

**Theme: Advocacy and empowerment strategies**

**Please state below if other only:**

London

### **Your stroke experience (What happened? How did it change your life?)**

I remember switching on a washing machine, something I had done countless times. But that day, I looked at the screen and couldn't understand it. The words seemed scrambled. I simply took some tablets and went to bed, hoping I would wake up feeling better; the next day my cousin called. I wasn't slurring my words, but I wasn't myself. My responses were laboured. She asked if I was ok. I said yes, but I wasn't. She told me to sit down and said she was on her way. When she arrived and saw me in person, she didn't hesitate, she called an ambulance.

### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

My stroke happened only 7 months ago, & while I'm still living through the aftershock, I have made a decision not to stay silent. It simply gave me a new assignment. I want to use my lived experience to raise awareness, educate others, and push for better care and understanding of what life after stroke truly looks like, particularly for people living with multiple health conditions.

### **How it can help others (advice, lessons learned, recommendations)**

- As someone living with Sickle Cell Disease, I had been documenting my health journey through writing. I am now writing a book that captures the emotional, physical, and psychological toll of stroke recovery, especially when compounded by chronic illness and disability. I want the book reaches not only patients, but also carers, policymakers, and medical staff who may not grasp the realities of recovery, for Black patients and other underrepresented communities. I am looking at doing a PhD.

## Reorganizing thoughts: acceptance, purpose and direction in adult life after childhood stroke

Miss Loula Weller

### Theme: Support systems

#### **Your stroke experience (What happened? How did it change your life?)**

Experiencing stroke as a newborn means I have always lived with its effects. My stroke damaged the left side of my brain resulting in permanent right-sided weakness and, more recently, loss of balance, migraine, and severe lack of trust for my body. There is no 'before' to return to, and I have to live with this no matter which direction my life takes. When I truly realised this aged 20, I became profoundly depressed.

#### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

The exceptional support I received from my music lecturers at university, including support about my stroke and its toll on my mental health, saved my life. Reflecting on this, I realised how absent equivalent awareness and support was at school. My postgraduate degree has given me opportunities to explore this in a national context. In response, I put forward a case for the potential to utilise music as a pathway for integrative, accessible neurorehabilitation: music *lessons* designed to help young stroke survivors cope with the demands of education after stroke, accompanied by training for music educators to provide this.

#### **How it can help others (advice, lessons learned, recommendations)**

Overall, my recent experiences have instilled in me a sense of purpose I struggled to find for a long time. I accept what I cannot change, but I am determined for young stroke survivors to have their needs effectively met. While understanding among educators about the effects of childhood stroke remains limited (UKABIF, 2018), it does not have to stay this way. Children deserve unconditional support in this area, and teachers deserve the tools to help.

## The Treasure that helps me to help others

Ms TAMARA FORTUNA

**Theme: Support systems**

**Your stroke experience (What happened? How did it change your life?)**

At the age of 35, I experienced my first stroke. I lost my speech and only remembered my name. Already in the hospital, I played pantomime with my mother, connecting words with my whole body, sound, and movement. Despite the option of rehabilitation in my mother tongue, I decided to first learn the language of the country I live in. With persistent practice, my language skills and speech progressed well. After a second stroke in 2012, I was back to square one. In 2016, I joined a group of people with aphasia. At first, I couldn't even introduce myself.

**How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

Just two years later, I became the head of the aphasia group. The leadership of the group is tailored to those activities that, based on personal experiences, meant the most. The dynamics in the group resemble a game that captivates, relaxes, and yields the greatest results. With exercises at home, we prepare for group meetings, strengthening non-verbal communication through pantomime. We enrich our vocabulary with word and sentence games based on a specific letter, as well as discussions on a specific topic.

We have begun creating a communication book as a joint project of the group. We maintain a positive mindset, celebrating every progress together, which gives us strength and hope for further improvement. We collaborate with students of health sciences in conducting internships and creating theses.

**How it can help others (advice, lessons learned, recommendations)**

Be playful like a child and persistent like an athlete, do different exercises every single day and believe in success. Take baby steps!

## **Stroke at young age can lead to relapse of symptoms at aging**

Mr Henk Lindeman

PFN, Utrecht, Netherlands

### **Theme: Other**

Support of growing older after a stroke

### **Your stroke experience (What happened? How did it change your life?)**

I got a stroke when I was 38 years old. After I could work 3 days a week till I became 60 years old. Then I had to stop, due to more severe fatigue.

After publishing my book about living with a stroke for 25 years, I was contacted by two women who noticed aging brought back stroke symptoms they thought had resolved. I then studied three more patients, and all five experienced increased symptoms as they aged. Reviewing about 100 scientific articles, I theorised that recovery from stroke depends on brain compensation mechanisms, which are also needed for normal aging. Since stroke survivors have already relied on these mechanisms, they tend to experience age-related decline earlier and more severely. A professor of neurology expressed interest in our research, resulting in the joint publication of two articles in the Dutch Journal of Occupational Medicine.

Furthermore, she submitted a research proposal grounded in my pilot study, which received approval and validated our initial observations. The key finding indicated that nearly 40% of individuals who experienced a stroke at a young age suffered a recurrence later in life.

### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

My pilot research, published in the Dutch Journal of Occupational and Insurance Medicine, will help improve diagnosis and preparation for aging among stroke survivors. In this oral poster presentation, I will explain the Post Stroke Effect and share key research findings.

### **How it can help others (advice, lessons learned, recommendations)**

This presentation informs stroke survivors about the mechanisms of early consequences of aging, which they don't know till so far.

## **The Power of Volunteering After Stroke**

Mrs Christine Holubec-Jackson

Covenant Health, Edmonton, Canada

**Theme: Other**

Volunteering and Patient Centred Care

**Your stroke experience (What happened? How did it change your life?)**

I am a 3x hemorrhagic stroke survivor. My life changed significantly. I lost my career but then began volunteering on a provincial council called Patient, Resident and Family Advisory Council (PRFAC). I have done many things to help other stroke survivors but my work with the PRFAC is the most impactful.

**How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

The council is a mixture of healthcare staff and volunteers. The volunteers all have lived experience in healthcare. While serving, I had another stroke and brain surgery. I spent months in hospital. Having volunteered with PRFAC gave me a unique perspective, becoming a patient again.

Eventually I rejoined the council. My presentation is focused on the importance of healthcare organizations to listen to people with lived experience. I feel I have come full circle, from receiving all the care to giving back. I want to share how I've transformed my stroke journey into making a difference, elevating patients to be at the centre of their care and valued members of their healthcare team. I feel privileged to use my stroke to help others while advocating for care of the whole person, not just the medical emergency, including transition out of hospital, which is of paramount importance.

**How it can help others (advice, lessons learned, recommendations)**

The goals of this council are to listen to volunteers, incorporating their voices into healthcare decisions. I want to share how the council includes volunteers' insights to guide policies, best practices, collaboration, and strategies for improving healthcare quality. Also, how volunteering after stroke gave me purpose while fulfilling my passion for helping others.

**Everything Changed From "I have to" to "I GET to"**

Mrs Michelle Humphrey<sup>1</sup>, Ms Molly Buccola<sup>2</sup>

<sup>1</sup>(none), USA. <sup>2</sup>Beyond Stillness - Stories After Stroke Podcast, Bend, Oregon, USA

**Theme: Other**  
the 'new' normal

**Your stroke experience (What happened? How did it change your life?)**

"Oh **HER**, she's just going to **die** tonight anyway..."

[Nursing shift change rundown of patients on the night of my bi-lateral pons stroke while pregnant, which was also my (now = only) child's second birthday in 2013...]  
That nurse's comment altered my life as much as the stroke did. I swear, I didn't die that night out of spite (and SISU)-- I never again closed my eyes that night (because I had the silly idea that you could not die with your eyes open...

Now that I'm a Strokie Dinosaur in my 12th year, the lessons learned far outweigh the deficits--to the extent that I now feel sorry for those who haven't had a stroke. I wouldn't trade in this experience for the world.

**How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

Helping to build community and information flow amongst stroke survivors through weekly "Pay It Forward Monday" and "Strokie Spotlight" posts on my @stroke\_mom Instagram account. Second to that I donated monthly (handmade goods) to the @AVM Superhero's Caregiver gift baskets

**How it can help others (advice, lessons learned, recommendations)**

To hopefully demonstrate that you have EQUAL % chance of life actually getting BETTER in your 'New Normal' as you do having it get worse. If only someone had pointed out this simple fact to me early on, my dark early days would have been profoundly different.

**The power of communication throughout stroke recovery.**

Mr Paul Lunn

Roundhsy stroke support club, Leeds, United Kingdom

**Theme: Other**

How language has both helped and at times hindered recovery.

**Your stroke experience (What happened? How did it change your life?)**

May 2022 I remember going to the bathroom. Then waking up in hospital to be told I'd had a "massive" stroke. Helpful as it fast tracked me to thrombectomy, however "massive" stuck with me. On my recovery journey, language was to play a major part.

**How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

From using words to cue my muscle actions in order to relearn to climb stairs. "Lift, Down, Up." To feeling I was a "Victim," thankfully later to be a "Survivor" and after a year a "Volunteer". All three are powerful labels. As a volunteer at Roundhay Stroke Support club I learned the power of the "Yet" at the end of limiting sentence uttered by a fellow survivors. I learned how to look for which hand to shake with club members knowing that such contact between humans was powerful, especially for aphasia survivors. I learned so much on my recovery. The power of words to label, to affirm encourage, the power of non verbal cues. Internal talking and sometimes talking out loud to my affected left hand and to my quick to take over right hand, helped me to give my affected hand/arm some affirmation encouragement. As a science teacher I read many words on neuroplasticity in order to really believe my brain could develop new pathways to counteract the limiting medical view "the only major changes will occur in the first 18 months:

**How it can help others (advice, lessons learned, recommendations)**

My recovery journey has been unique to me. I've tried to learn and pass ideas/thoughts on, Stockholm 26 is another opportunity.

**One Stroke – Three New Beginnings**

Mr Nebojša Aleksić

M'udar, Banja Luka, Bosnia and Herzegovina

**Theme: Other**

Rehabilitation, reorganization and community

**Your stroke experience (What happened? How did it change your life?)**

After surviving a non-fatal stroke, I found myself at the beginning of three profound reorganizations: in my brain, my daily life, and in creating a new community for life after stroke. Through neuroplasticity, emotional resilience, and strategic adaptation, I began rebuilding both my inner world and outer reality. I start share my journey of recovery and the founding of a support association for stroke survivors — a story of turning struggle into purpose.

**How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

During rehabilitation, I tried to find information and guidance for stroke survivors — about recovery, everyday life, and what comes after the hospital. But there was almost nothing. In a conversation with social worker Jelena, I said: “We need to talk about stroke, share experiences, and offer guidance to others.”

At the same time, I started reading about neuroplasticity, especially Dr. Edvard Taub experience in book *The brain that change itself*, N. Doidge, and began applying everything I learned — from books, therapists, and doctors. Stroke became a moment to rethink my life, reduce some activities, and focus on what truly matters. We also build SOS throw we send a message of hope, information, and motivation to others stroke survivors.

**How it can help others (advice, lessons learned, recommendations)**

There are tree life lessons that arrive in powerful ways. When the body says “No.” it’s time to listen. If your brain’s core mental functions remain intact after a stroke, then you have the chance to rethink and create a new arrangement, to use neuroplasticity, to live better quality of life and to share something meaningful in your community.

**The Ripple Effect - one family member's experience of the widespread impact of life after stroke**

Miss Alexandra Reece<sup>1</sup>, Mrs Frances Reece<sup>2</sup>

<sup>1</sup>Headway Surrey, Guildford, United Kingdom. <sup>2</sup>Mother, Guildford, United Kingdom

## **Theme: Other**

### **Please state below if other only:**

My theme relates to all four of the themes above

### **Your stroke experience (What happened? How did it change your life?)**

Eighteen months after my father died of stomach cancer, my mother was making breakfast with a girlfriend visiting from overseas when a clot travelled to her brain, causing a severe stroke. An ambulance was called.

Two hours later, I joined them at the hospital to find my mother had been identified as a suitable candidate for a clot-busting drug, which she was given. Our family's world, as we knew it, had changed instantly, fundamentally, and, in many ways, for the better.

### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

Few relatives of stroke survivors will have had such strong support from their employer, family and friends. I could visit my mother daily, firstly in the acute ward and then in the rehabilitation unit. Eight years later, she continues to thrive, her positivity daily lifting everyone around her.

Inspired by my mother's tenacity and the professionals who supported her rehabilitation, after over 25 years in the arts sector, I retrained and have now qualified as a speech and language therapist. Combining a clinical and research career, I am keen to explore how best to support other stroke survivors and their families.

### **How it can help others (advice, lessons learned, recommendations)**

Alongside studying, I began voluntarily contributing my lived experience to research projects with Marie Curie and accessibility projects with the UK Stroke Association. I came today to highly recommend these experiences as a way of informing and influencing future healthcare research and priorities, and of finding a network of peers to support you. My mother's stroke changed *her* life; it has also given *mine* new purpose and direction.

## Using Photography As Therapy: Creating 'Perfectly Imperfect'

Mr Andy Watts

United Kingdom

### **Theme: Rehabilitation and therapy programmes**

#### **Your stroke experience (What happened? How did it change your life?)**

In 2018, I had a stroke that turned my life upside down. I was left struggling with my confidence, mental health, and sense of identity. I was left partially sighted and therefore unable to drive and unable to return to my career, I was also left with epilepsy which affected my mental health greatly.

During recovery, I picked up a camera and photography became my therapy – a way to get out of the house and move my body and my mind.

It gave me focus, achievement, and a way to express myself. It helped me reconnect with the world.

#### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

Inspired by how photography helped me, I wanted to share and use this experience to inspire and help others.

I created a programme called **Perfectly Imperfect**. It gave other stroke survivors and their families a safe, creative space to explore photography as part of their recovery. The programme ended with an exhibition, celebrating participants' work and stories. It helped them build confidence, feel seen, and connect with others who understood. This was more than art - it was emotional therapy, self-expression and empowerment.

#### **How it can help others (advice, lessons learned, recommendations)**

Stroke recovery isn't just physical, it's emotional and mental. Creative tools like photography can be powerful, helping people process what's happened and rebuild their identity. Stroke services should consider creative programmes as part of rehabilitation and peer support. Giving survivors space to explore, create, and share their stories can improve confidence, wellbeing, and hope. Lived experience-led programmes like **Perfectly Imperfect** show the impact of community, creativity and shared recovery

## Relearning to walk using the principles of infant movement development

Mr Steve Cairns

United Kingdom

**Theme: Rehabilitation and therapy programmes**

**Your stroke experience (What happened? How did it change your life?)**

Aged 47 I suffered a haemorrhagic stroke. I lost the ability to walk, had distorted vision, left sided weakness and problems with choking and breathing twice leaving me unconscious. I had 10.5 hours of surgery to remove a Cavernoma from my brainstem after which I lost the movement skills to even crawl. My prognosis was a 2-3 year recovery with a possible need for a walking adjunct. Conventional rehab strategy focuses on immediately regaining walking skills. I focused on range of movement and gaining competence in the movement skills that walking depends on (the movement milestones of a developing infant). Rather than use mobility adjuncts I 'lived my rehab', I learned to crawl and used crawling to satisfy my mobility needs. I bettered my 2-3 year prognosis inside of 10 weeks. After my 3 month post-surgery review my Neurosurgeon agreed to co-author an abstract on my methods for the 2020 World Congress of Neuro Rehabilitation (WCNR).

**How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

Via multiple charities I helped brain injury survivors regain movement. Conventional rehab strategies state little or no significant progress can be made once 3-6 months post-injury. In a research project for a WCNR 2022 I demonstrated consistent significant improvement across 9 subjects ranging from 6 months to many years post-injury, all had previously completed conventional therapy with disappointing results.

**How it can help others (advice, lessons learned, recommendations)**

All rehab was carried out via the internet, without additional equipment and continued to be effective beyond 6 months post-injury. This has significant implications for recovery, cost and can greatly impact rehabilitation in poorer nations.

## **Rehabilitation traffic light. STOP-SHIFT-START**

Mr Nebojša Aleksić

M'udar, Banja Luka, Bosnia and Herzegovina

### **Theme: Mental health support**

#### **Your stroke experience (What happened? How did it change your life?)**

After surviving a non-fatal stroke, I found myself at the beginning of three profound reorganizations: in my brain, my daily life, and in creating a new community for life after stroke. Through neuroplasticity, emotional resilience, and strategic adaptation, I began rebuilding both my inner world and outer reality. I start share my journey of recovery and the founding of a support association for stroke survivors — a story of turning struggle into purpose.

#### **How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

A traffic light can symbolize the stages of stroke survivor rehabilitation. In the beginning, there is a red light — everything stops. It's a moment of shock, uncertainty, and physical limitation. Then comes the yellow light — a time to prepare for change, to shift into a new arrangement of behavior, mindset, and daily life. Finally, the green light appears — representing new beginnings: the awakening of neuroplasticity, new thoughts, emotions, and behaviors. This “rehabilitation traffic light” reflects the stages of recovery and transformation after stroke.

#### **How it can help others (advice, lessons learned, recommendations)**

So, my message is: we have to be prepared for all the “seconds” of the traffic light — as a metaphor for life after stroke. First comes the red light — a period of stillness, crisis, and pause. Then the yellow light — a time for rehabilitation, reorganization, reflection, and a mental reset. And finally, the green light — the moment to move forward again, with a new life arrangement and a renewed way of living.

## **Surfing the Waves: A Life Devoted to Emotional Recovery from Stroke**

Dr Lori Gray

Western Michigan University, Kalamazoo, USA

**Theme: Mental health support**

**Your stroke experience (What happened? How did it change your life?)**

In 2017, I survived a massive ischemic stroke. Initially, I was paralyzed, all but my left upper quadrant. I couldn't speak or process thoughts. I could not remember my full name.

Over time, I made gains that my rehabilitation team told me would be impossible. Let me say that again — I was told that further gains would not be possible. I made those gains anyway. Approaching the eighth year of an entirely new life and inner identity, I continue to engage in rehabilitation. Even when the “me” I knew was thrown into a storm of crisis and confusion, there was still part of me- a “presence” – that remained accessible and steady. I call this my “mindfulness muscle”.

**How you used your experience to create change (to improve your life or the lives of others, through better care, support information, guidelines, policy, and/or research)**

Before the stroke, I was a mindfulness practitioner and teacher in Mindfulness-Based Stress Reduction (MBSR). The strength and extent of my recovery would not have been possible without mindfulness meditation skills.

I often say, “You can't stop the waves, but you can learn how to surf.” And now I teach other stroke survivors how to surf as well - privileged work. I founded the “Mindful Stroke Project”.

**How it can help others (advice, lessons learned, recommendations)**

Anyone can learn to practice mindfulness to support recovery from a stroke.

Mindfulness skills have supported me as a stroke survivor:

1. Healthy grief of the losses I experienced due to stroke.
2. Support brain health; research suggests that those who meditate regularly may be able to encourage neuroplasticity.
3. Patience with myself when the stress and frustration of stroke rehabilitation tempt me to give up.