

European
**Life After
Stroke**
Forum

ELASF 2025

Abstract Book

Lived Experience

Hosted by

SAFE 
STROKE ALLIANCE FOR EUROPE

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Lived experience of acalculia after stroke

Mr Colin Jenkinson

Describe your experience with stroke and how it relates to the chosen theme. Focus on specific events or insights that highlight your journey and how it impacted you

I was a maths tutor before I had a stroke in 2016. I now have aphasia and acalculia.

Acalculia is an acquired disability affecting 30-65% of stroke/brain-injury survivors. It involves difficulty processing numerical information (e.g. phone-numbers, measurements), problems with calculations and understanding quantities. Acalculia negatively impacts independence (particularly financial) and wellbeing.

Despite the availability of assessments, acalculia is not routinely screened for. Therapists helped me with my aphasia - with my speech, writing and reading - but support for acalculia was very limited. This made me angry and frustrated because I needed help. As a maths tutor, I had to develop my own strategies to re-learn numeracy skills. One speech therapist asked me to help others with acalculia. Eventually I returned to maths teaching.

Give a short summary of the presentation including key points, personal insights and how it relates to life after stroke. Focus on education, practical advice, strategies and recommendations based on lived experience

I began contributing to research and working with the UK Stroke Association on different projects. I became a co-author on: 'A qualitative study into the experience of living with acalculia after stroke and other forms of acquired brain-injury', which was published in Neuropsychological Rehabilitation.

The study concludes that there is an urgent need to increase awareness of acalculia amongst stroke survivors and professionals, and to develop suitable interventions. The study reveals useful strategies and suggestions regarding effective timing, targets and approaches for intervention.

Share strategies that informed and changed treatment, policy and/or support services

The team have used these to develop a toolkit to help clinicians assess numeracy level with their patients, and we are working on developing interventions for rehabilitation of numerical skills after a stroke.

No stroke survivor should be left without help for acalculia.

The power of changing mindset

Mrs Elin Andersson

Describe your experience with stroke and how it relates to the chosen theme. Focus on specific events or insights that highlight your journey and how it impacted you

In January 2023, my life changed dramatically due to a stroke. This unexpected event left me questioning everything but ultimately taught me the transformative power of mindset. Recovery wasn't immediate. Initially paralyzed on my left side, I faced challenges that seemed insurmountable, yet with each step, I learned that "nothing is impossible; the impossible just takes a bit longer."

Give a short summary of the presentation including key points, personal insights and how it relates to life after stroke. Focus on education, practical advice, strategies and recommendations based on lived experience

My presentation will share insights from my journey, illustrating how a shift in perspective can redefine our approach to life after a stroke. I'll discuss the importance of setting realistic goals and building a vision for recovery, much like setting targets. Achieving mobility milestones, maintaining daily rehab routines, and adapting to new limitations were vital strategies that helped me regain strength and purpose.

I hope this presentation will provide attendees with useful strategies for supporting stroke survivors, from building new routines to setting attainable goals. I also advocate for policies encouraging personal storytelling, enabling patients to connect, find motivation, and thrive. This journey reinforced that change is possible, no matter the challenge, with resilience and a growth-focused mindset.

Share strategies that informed and changed treatment, policy and/or support services

I will address the need for structured support in post-stroke recovery. My experiences with digital communities, including my Instagram account "elinstrokefighter" and co-hosting "StrokePodden," highlighted the value of shared stories and practical advice. These networks have inspired both my followers and me to keep moving forward.

Life After Stroke - 16 years Lived Experience

Mr Raymond Newland

Describe your experience with stroke and how it relates to the chosen theme. Focus on specific events or insights that highlight your journey and how it impacted you

This presentation traces the journey of life after stroke of an active Australian man, Ray Newland, from age 68 in 2008 through to age 84 in 2024.

It shows how a critical stroke patient was able to progress through initial personal fear to gain acceptance and understanding of stroke and how, through many trying times and dedicated rehabilitation with skilled therapists, this patient was able to achieve a level of recovery that culminated in a near normal life for the ensuing sixteen years.

Give a short summary of the presentation including key points, personal insights and how it relates to life after stroke. Focus on education, practical advice, strategies and recommendations based on lived experience

It highlights observations of how “fear of stroke” adversely affected the mental mindset of fellow stroke patients severely limiting their motivation and potential recovery. It emphasizes the importance of person centered care in enhancing levels of recovery. It discusses, from a stroke survivors personal experience, overcoming the embarrassment and physical disabilities of sexuality and intimacy issues and how, in the opinion of the author, life after stroke can be improved through “story telling” for stroke patients, clinicians and nursing staff of major hospitals providing stroke treatment and rehabilitation.

Share strategies that informed and changed treatment, policy and/or support services

The presentation also illuminates how offering these “lived experiences” in service to the improvement of stroke care and recovery in the health care community resulted in the author becoming a “consumer advisor” serving 9 years on key committees of a major health service in the state of Victoria and ultimately being appointed for a twelve-month term to the Board of the health service.

In conclusion it will show the scope, possibilities and benefits of involving consumers with “lived stroke experience” on key planning and policy committees with relevant executives, clinicians and allied health staff of public hospitals and health services.

Raymond Newland

Stroke Survivor

My journey: from stroke survivor to movement specialist

Ms Gamze Öztürk

Describe your experience with stroke and how it relates to the chosen theme. Focus on specific events or insights that highlight your journey and how it impacted you

In 2016, I suffered a hemorrhagic stroke at 27, leaving my right side paralyzed. I spent months in intensive rehabilitation—learning to walk again, with each step a struggle. My doctors couldn't promise recovery, yet through sheer persistence and mindful exercise, I began to regain my abilities. This experience changed my life. I left journalism and became a Pilates instructor and osteopath to help stroke survivors like myself.

Give a short summary of the presentation including key points, personal insights and how it relates to life after stroke. Focus on education, practical advice, strategies and recommendations based on lived experience

In my presentation, I'll share how this journey led me to focus on "life after stroke." I will discuss the power of repetitive, mindful movement in stroke recovery and how exercise, especially Pilates, accelerated my healing. Attendees will gain practical advice on the physical and mental aspects of recovery. I'll highlight strategies that helped me, from daily exercises to finding motivation through small victories.

Share strategies that informed and changed treatment, policy and/or support services

I'll also address the need for change in stroke care, from improving support in rehab centers to creating community programs for long-term wellness. As the Coordinator for MENASO's Stroke Survivors Community, I've worked to shape policies for better care and access. My experience shows that meaningful support can transform lives, and I hope to inspire changes in how we approach recovery.

Mums, dads and siblings: the tremendous impact of childhood stroke on families

Ms Renée Wallen and Ms Nancy McStravick

Describe your experience with stroke and how it relates to the chosen theme. Focus on specific events or insights that highlight your journey and how it impacted you

Over 400 children a year are diagnosed with a stroke in the UK. This can have a devastating impact not only on the children, but also on their families.

My 13 year old son suffered a stroke in 2009. Although, thankfully, he went on to make a full recovery, our family was placed under immense pressure and I was diagnosed with PTSD. We became financially unstable as I stopped work to become a carer and his father lost his job due to taking time off for hospital visits. Sadly, our story is not unique.

Give a short summary of the presentation including key points, personal insights and how it relates to life after stroke. Focus on education, practical advice, strategies and recommendations based on lived experience

Since 2010 I've supported over 1300 parents in a safe, online support group. Participants have said that this group provides them with a lifeline, as there is little support available for families.

Parents' contributions highlight the need for dedicated NHS or funded mental health support for parents and siblings. This presentation will outline the key lessons from our support group on the effects of Childhood Stroke on families.

Share strategies that informed and changed treatment, policy and/or support services

I volunteer with the Stroke Association, raising awareness of childhood stroke and advising on childhood stroke services, speaking in strategy meetings, at Parliament, on the radio and TV. I've co-hosted Parent Support Days across the UK. Our small volunteer team has helped staff recruitment, produced clinical guidelines and new resources for paramedics, schools and medical students.

My work with my Parents' Support Group has shown that more resources are needed for families. By supporting families, they can provide better care for children, improving paediatric stroke outcomes.

Empathy, Recovery and Empowerment: The Potential for Digital Peer Support Networks

Mr Simon Harris

Describe your experience with stroke and how it relates to the chosen theme. Focus on specific events or insights that highlight your journey and how it impacted you

My ischemic stroke 4yrs ago invalidated my family's basis for navigating our lives.

It is still scary.

I've found Life After Stroke **much** improved within a community of peer #StrokeThrivets. Folk 'just get-it', they share setbacks & progress. 24x7 emotional empathy & practical support received (and given!)

I couldn't have managed as well without them

Give a short summary of the presentation including key points, personal insights and how it relates to life after stroke. Focus on education, practical advice, strategies and recommendations based on lived experience

How sharing my fears, needs, challenges, discoveries, insights & progress has been crucial to recovery's struggles with anxiety, medication, decompensations, rehab motivation etc

Communities I've used on Facebook, Instagram, Reddit, stroke organisations; Everywhere.

Why all are currently sub-optimal in configuration, moderation attitudes and skills.

How they could be:

- Used by therapist to extend rehab services,
- Reducing pressures on services,
- Delivering superior & quicker outcomes for #StrokeThrivets and greater job satisfaction for professionals.
- A research data source

Stroke community's demographic has changed.

Services & funding must evolve too in ATTITUDES, EXPECTATIONS & **IMAGINATION** (Charities & institutions must become enablers - not BARRIERS)

Share strategies that informed and changed treatment, policy and/or support services

I'm Co-Chairing a Steering Committee to build hybrid Physical / Digital hubs in my local NHS trusts. A university school of Allied Health Professions is collaborating to align under- & post-grad curriculums to embrace and leverage the **sociology** of digital community rehab.

Experience shows successes improve with all stakeholder's collaboration developing/ adjusting: Curricula, Service delivery practices, Governance, Policies, AI use of Data, Software.

'We've' formed a Stroke Improvement Group for all stakeholders to advocate (Charter at <https://bit.ly/SIGcharter> #StrokeThrivets wishing to pay forward support received (are invited to) sign social media posts "member SIG")

How peer support helped me reclaim purpose following near fatal Covid-19 infection causing a stroke

Mr Laurence Gilligan

Describe your experience with stroke and how it relates to the chosen theme. Focus on specific events or insights that highlight your journey and how it impacted you

On January 4, 2021, I was thrilled to learn of my promotion to a senior management role. That same evening, I contracted Covid-19, and would never work again. I spent two months in the ICU, much of it in a induced coma. Doctors warned my family to expect the worst. While I survived, my ordeal wasn't over. After a tracheostomy restored my voice, it was discovered I'd had a stroke. This experience challenged me to confront life's unpredictability, reshaping my goals, identity, and understanding of resilience.

Give a short summary of the presentation including key points, personal insights and how it relates to life after stroke. Focus on education, practical advice, strategies and recommendations based on lived experience

My presentation will focus on the reality of adjusting to life after a stroke. After four months in hospital, my single focus was to return to my newly acquired position. But I was told I could never go back to work, a devastating blow that forced me to come to terms with feelings of loss and diminished self-worth. Over time, I realised that rebuilding a sense of purpose required patience, community, and adaptation.

Share strategies that informed and changed treatment, policy and/or support services

This journey has taught me the importance of support systems, both formal and informal. Today, I volunteer with the Irish Heart Foundation, connecting with other stroke survivors in ways that provide purpose and mutual understanding. Through online forums, exercise classes, and social gatherings, I've found a renewed sense of self by engaging with others who understand the complexities of life after a stroke. This experience underscores the need for accessible, peer-driven support services that empower stroke survivors to reclaim their lives.

Let's talk- Mental Health, Sexual identity, Incontinence

Ms Saran Chamberlain

Describe your experience with stroke and how it relates to the chosen theme. Focus on specific events or insights that highlight your journey and how it impacted you

In 2013, I experienced a stroke that profoundly impacted my physical and emotional health. The aftermath was challenging, particularly dealing with mental health and changes in my identity. These aspects were rarely addressed in my early recovery, leaving me feeling isolated. Over time, I learned the importance of discussing these hidden struggles and found that sharing my experiences helped me regain control and find support.

Give a short summary of the presentation including key points, personal insights and how it relates to life after stroke. Focus on education, practical advice, strategies and recommendations based on lived experience

The presentation focuses on three key topics often neglected in stroke recovery: **mental health, sexual identity, and incontinence**. Survivors frequently feel isolated due to the silence around these issues. The presentation will offer practical strategies, such as fostering compassionate spaces for survivors to discuss their struggles. Personal insights will highlight the importance of holistic recovery, addressing not only physical but also emotional and intimate aspects. This educational approach ensures survivors feel empowered to reclaim their identities and navigate life post-stroke.

Share strategies that informed and changed treatment, policy and/or support services

Through my advocacy, I have promoted the integration of lived experiences in stroke recovery programs. I've contributed to co-designing projects that address mental health and intimacy in recovery, leading to more inclusive and supportive policies. By sharing my journey, I've influenced discussions in healthcare settings to consider the holistic needs of stroke survivors, ensuring mental health and emotional well-being are part of treatment and support services.

EMPOWERING Stroke Survivors: The Impact of Aphasia and Accessible Voices Involvement Group.

Ms Janet Rockliffe

Describe your experience with stroke and how it relates to the chosen theme. Focus on specific events or insights that highlight your journey and how it impacted you

My name is Janet Rockliffe. I had a brain haemorrhage in 1994, which left me with right-sided hemianopia, aphasia, dyspraxia, and severe fatigue. My verbal skills have improved, but my written skills are still affected. Reading and writing apps are a great help. Over 20 years, my stamina and skills have slowly improved.

Give a short summary of the presentation including key points, personal insights and how it relates to life after stroke. Focus on education, practical advice, strategies and recommendations based on lived experience

My involvement with professionals is essential, bridging the gap between stroke survivors and those who wish to help them.

I started working part-time for the Stroke Association 20 years ago. I am the Accessibility Assistant. I love my job, especially running the Aphasia and Accessible Voices Group (AAV), a specialist group for stroke survivors with different accessible needs from across the UK.

The group helps shape the Stroke Association's internal work to be as accessible as possible.

My talk focuses on the group's work and how people with aphasia and accessible needs contribute to invaluable involvement.

Over the last three years, the group has shaped numerous projects, including the new Communication Support Packs and an accessible election manifesto.

Share strategies that informed and changed treatment, policy and/or support services

The group has also externally helped create accessible resources for a bank and advised National Rail.

It is wonderful to see members develop confidence and understand their roles.

They appreciate their work is impactful and not just a token effort.

Staff working with the group always share how they have used the group's feedback.

The AAV work makes a significant difference in the lives of stroke survivors.

Our journey as a young black family learning to live with stroke.

Mr Emmanuel Okino and Mrs Sarah Okino

Describe your experience with stroke and how it relates to the chosen theme. Focus on specific events or insights that highlight your journey and how it impacted you

In this presentation, we reflect on our learning about self-advocacy, peer empowerment and the need to talk about stroke within the black communities. Emmanuel experienced a stroke shortly after the birth of our third child. He was 40 years old and the main breadwinner. We now know black people are more likely to experience stroke at a younger age. But this was a shock at the time; no one had talked to us about the risk. We have been open about our experience and discovered that stroke is not openly discussed within our community. We're still learning ways to overcome stigma and get support.

Give a short summary of the presentation including key points, personal insights and how it relates to life after stroke. Focus on education, practical advice, strategies and recommendations based on lived experience

We had to confront challenges navigating the healthcare system. Initially professionals tried to make decisions without consulting us together as a couple or used 'othering' language about black people which created much anxiety. We learned to stand up against this and insist on what was right for us.

Share strategies that informed and changed treatment, policy and/or support services

Joining a research project about black people's experiences of stroke this year provided us with a safe space to share our story and hear from others. This highlighted the difference peer support can make. We're now on a co-design team creating a film sharing stories about adapting following stroke, with tips to increase skills and confidence amongst black people to seek the support needed from wider family, our communities and healthcare professionals. We want to motivate others to thrive and are disseminating the film as a tool for empowerment and encouragement for black communities to talk about stroke.

A strategy and presentation of the benefits of greater stroke survivor participation in research projects

Mr Paul Quinn

Describe your experience with stroke and how it relates to the chosen theme. Focus on specific events or insights that highlight your journey and how it impacted you

Stroke Experience

I had two strokes in late summer 2023. The impact was cognitive, affecting speech, comprehension and memory. This resulted in early retirement and had severe consequences for my podcasting, publishing and writing activities.

Future involvement and desire to improve research outcomes

Due to the brilliant care of medical professionals and therapists, I have had a significant recovery. I now, passionately, want to use my stroke experience as a means of helping fellow survivors and improving participation in stroke research, thereby increasing its effectiveness.

Give a short summary of the presentation including key points, personal insights and how it relates to life after stroke. Focus on education, practical advice, strategies and recommendations based on lived experience

Benefits of greater participation of stroke survivors in research

- Great advocacy for individual research programmes
- High quality, meaningful impact on research outcomes
- Huge benefit to stroke survivors and families, providing an opportunity to “give back”, participate in better outcomes and importantly increase self-value and worth
- Creation of stroke survivor communities

Share strategies that informed and changed treatment, policy and/or support services

Strategy:

To provide stroke survivors, their families and carers a pathway to participate in research programmes starting from the point of leaving hospital and entering post hospital care

Objective:

To inform patients, families and carers of research opportunities whilst in recovery and the benefits of research to participants and the wider population. Seek maximum participation, thereby increasing the effectiveness of research programmes. Promote the benefits of wider participation to research programmes and funders but also importantly to the stroke survivors and families. I passionately believe greater awareness, participation and engagement can only improve the self-worth of stroke survivors and must present the opportunity for better post-stroke outcomes.

Second chance of loving life from age 37, my journey with Aphasia - improving life everyday

Ms Lisa Kenny

Describe your experience with stroke and how it relates to the chosen theme. Focus on specific events or insights that highlight your journey and how it impacted you

My son Alfie was 4 days old when I had my stroke 5 years ago.

Aphasia was most difficult not being able to communicate and for my daughter Emily learning to know me again because of my speech.

Lost power on my right-hand side of my body, it is still gone.

Give a short summary of the presentation including key points, personal insights and how it relates to life after stroke. Focus on education, practical advice, strategies and recommendations based on lived experience

'Strong Story Lab', creating my 'Lisa's Aphasia Story' presentation on my journey, delivering it to friends, family and other survivors online.

Aphasia Research Opportunity 16 weeks x 3 hours focusing on different ways to communicate.

Physiotherapy 2 hours a week to help me with pro-massage gun and massage on the right side of my body.

10-minute walk to start as fatigued, now can do 1 whole hour. This have given me back my mental health and life!

Share strategies that informed and changed treatment, policy and/or support services

National Rehab Hospital (NRH) Outpatients, I was with Dr Morgan, leg splint, shoulder injections, speech and language and practical skills.

Acquired Brain Injury (ABI) Caroline Flannagan. Goals were giving me independence and freedom including making a cup of tea! Accessing public transport, speech tasks for inclusion in the community. Life skills including reading, math, telling time and comprehension.

My strategy was increasing my interactions, researching online the availability to connect with more people who understood my journey and could help. I wanted to encourage, educate, and improve myself. Lots of praise for 'Virtual Connections' Aphasia recovery community. Our motto is 'I pick you up when I'm down'. We always laugh together.

Aphasia Home Café, Ireland. This gave me peer support and friendships.

Navigating Life After a Thalamic Stroke – Empowerment and Self-Advocacy for Hidden Challenges

Mr Paul Lumsden

Describe your experience with stroke and how it relates to the chosen theme. Focus on specific events or insights that highlight your journey and how it impacted you

After my thalamic stroke, I experienced unexpected sensory changes and emotional instability that made everyday life a challenge. Simple tasks like focusing on conversations or even dealing with sudden emotional shifts became exhausting, but these struggles were often invisible to others. One day, a doctor dismissed my observation of fatigue as normal, but I knew these feelings were much deeper and needed attention.

During a follow-up appointment, I was told to 'just be patient,' so I decided to take control of my care. I researched the effects of thalamic strokes and found resources that confirmed my experience. This knowledge empowered me to return to the doctor with more informed questions, advocating for therapies that eventually helped me to manage my cognitive challenges. Self-advocacy became a turning point in my recovery.

This inspired me to support others who were struggling with their own hidden symptoms. Becoming a peer mentor allowed me to use my journey as a source of strength, helping me – and others – feel empowered.

Give a short summary of the presentation including key points, personal insights and how it relates to life after stroke. Focus on education, practical advice, strategies and recommendations based on lived experience

I share my journey of navigating life after a thalamic stroke, focusing on overcoming hidden side effects like sensory and cognitive challenges. My goal is to provide both survivors and caregivers with practical strategies, educational insights, and empowerment tools drawn from my lived experience.

Share strategies that informed and changed treatment, policy and/or support services

Realising that invisible side-effects were often overlooked; I started sharing my story to raise awareness of these challenges. Speaking out has highlighted the importance of policies that include support for sensory and cognitive impairments, ensuring all survivors get the accommodations they need for sustainable recovery.