

Prague 10-11 March 2025





Thank you

Thank you to everyone who joined us in Prague for our third in-person European Life After Stroke Forum and for contributing to its success.

Our goal was to create a space where stroke survivors, caregivers, healthcare professionals, researchers, and advocates could come together to address the real-world challenges of life after stroke. We are thrilled that our event in Prague achieved this – fostering knowledge exchange, showcasing new research, and sharing best practices in this often-overlooked area.

What makes our Forum truly unique is its collaborative approach. The programme was co-designed with people affected by stroke, who played key roles as speakers, chairs, and attendees, alongside leading researchers and healthcare professionals. By working together, we can push life after stroke care and support to the forefront of European healthcare discussions, shaping a future where everyone can thrive beyond stroke.

Thank you for being part of this vital journey – we look forward to seeing you in Stockholm next year!



Professor Anita Arsovska Co-chair, European Life After Stroke Forum Scientific Committee



Dr Nicola HancockCo-chair, European Life After Stroke Forum Scientific Committee



Professor Hariklia ProiosPresident, Stroke Alliance for Europe





European Life After Stroke Forum: Prague, 10-11 March 2025

Event overview

- · One-and-a-half-day event.
- 3 plenaries
- 12 parallel sessions
- 12 topic areas plus highest scoring scientific and service development abstracts

Notable activities

- Our event is centered around people with lived experience: the programme was co-developed by stroke survivors, medical professionals and stroke support organisation representatives. Our speakers and chairs included stroke survivors and carers.
- The event was opened by a video of support from the Czech Health Minister Professor Vlastimil Vále
- We launched a new abstract category for people with lived experience. We received 73 abstracts, 13 were accepted as abstracts, two were accepted as oral presentations and three as posters.
- 63 scientific abstracts and 25 service development abstracts were accepted for the poster exhibition
- Sponsors: (Bayer, Boehringer Ingelheim, Daiichi, Ipsen, Merz, NovoNordisk and Sankyo)
- Endorsers included: AKL, AOTI, BIASP, Česká asociace ergoterapeutů, COTEC, EAN, EBC, EFNA, EPF, ESO, World Physiotherapy Europe Region, Unify, WFNR, World Stroke Organization had a stand at the exhibition
- We involved the local stroke support organisation, Cerebrum, who supported us with volunteers, a singer (Genny Ciatti) and an art exhibition at our welcome reception, and a blood pressure monitoring area.
- Stands from local patient organisations: Czech Patient Organisations (Cerebrum and SCMP)
- Exhibition stand by SAFE's EU Research Partner (RES-Q)
- SAFE exhibition area
- Cerebrum also held a press conference at the event inviting Czech national press



Registrations and attendance

- This was our third in person event after several years of webinars during the pandemic.
- Barcelona, 2023, 175 attendees.
- Dublin, 2024, 316 attendees
- In Prague, 302 people registered and 287 attended. Delegates included stroke survivors, carers, stroke support representatives, researchers, students, physicians and allied health professionals.
- 44 European countries were represented (32 in both 2024 and 2023) with seven countries from outside of Europe represented
- 100% of attendees said their experience was excellent or good (98% in 2024)
- 79% said they were very likely or likely to attend again (81% in 2024)
- 94% said they would recommend to a friend or colleague (97% in Dublin)
- 98% said the quality of speakers was excellent or good (98% in Dublin)



Arriving to ELASF2025









Poster presentation



Main plenary room



Programme overview



Event video: https://youtu.be/RhB38QVCEmA

Monday 10 March

Open Welcome from the Scientific Committee chairs

Life after stroke in Czech Republic

Plenary 1 Long-term secondary stroke prevention

Parallel 1 Quality of life after stroke in women: when gender matters
Parallel 2 How to involve people with stroke as research partners
Parallel 3 Parallel: Enhancing health literacy and skills to reduce risk of

secondary stroke

Plenary 2 Life after stroke and the Stroke Action Plan for Europe

Workshop: Reimagining wellbeing for life after stroke: a call to action

Parallel 4 A technology enabled life after stroke

Parallel 5 Caregiving

Tuesday 11 March

Plenary 3 By survivors, for all: Inclusive approaches to life after stroke

Parallel 6 Returning to work: Empowerment to make the invisible visible

Parallel 7 Communication challenges in long-term stroke Parallel 8 Top scoring scientific and service abstracts

Close Closing remarks from our co-chairs





Welcome and opening

The co-chairs of the ELASF scientific committee, Professor Anita Arsovska and Associate Professor Nicola Hancock, welcomed delegates who had joined us from all over Europe and beyond.



The co-chairs of the ELASF scientific committee, Professor Anita Arsovska and Associate Professor Nicola Hancock welcomes delegates to the Forum.

An overview of stroke in the Czech Republic was given by Dr Dagmar Součková, which included a special address by the Czech Health Minister Professor Vlastimil Válek https://youtu.be/blDHZc4yQvc.



Dr Dagmar Součková provided a short overview of life after stroke in Czech Republic.





We heard from Karolina Rysova (a stroke survivor) and her friend Katerina Bockova. Karolina told us about her stroke she suffered two years ago. After brain surgery, she was partially paralysed on her left side and experienced difficulties with her vision. Her university studies were interrupted, and she struggled to come to terms with her condition. One of the biggest challenges she faced was how others treated people with disabilities. However, peer support was instrumental in helping her move forward. Katerina talked about Karolina's stroke from her own perspective as a close friend.



Young stroke survivors Karoline Rysova from the Czech Republic, told the delegates about her recovery and how peer support was key to her moving forward.





Plenary 1: Long-term secondary stroke prevention

Chairs: Associate Professor Aleš Tomek, Czech Republic and Nenad Nikolić, Stroke Association, Serbia

This secondary prevention session covered the perspectives from the clinical, allied health professional and individual point of view.

Professor Simona Sacco, University of L'Aquila, Italy opened the session with a presentation about 'Long-term secondary prevention after stroke':

- She stressed the importance of personalised discharge planning and medical management for secondary stroke prevention
- She also talked about the risk factors that cannot be controlled and those that can be controlled

Associate Professor Olive Lennon, School of Public Health, University College Dublin, Ireland spoke about 'Approaches to lifestyle modifications and rehabilitation strategies for long-term secondary stroke prevention'

- She highlighted the challenges with adhering to medication to prevent a second stroke
- Telling stroke survivors what lifestyle changes to address alone doesn't work, also support them in how to do it
- Discussed how interventions needs to meet the individual person's capacity and needs

Stacie Broek, a public advocate and person with lived experience from Switzerland, spoke about 'Holistic prevention post-stroke'.

- She discussed her initial fear of how her children would cope after her stroke and the tools she used to try and address her fears
- Stacie also spoke about the importance of focusing life on what you love and following your passions



Professor Simona Sacco opens the first plenary session with a presentation on Longterm secondary stroke prevention.





Parallel 1: Quality of life after stroke in women: when gender matters

Diana Wong Ramos, Stroke survivor, Portugal and Katherine Staley, Stroke Association, UK

This session explored the key differences between men and women in life after a stroke. It highlighted epidemiological differences, with women facing unique risk factors. The discussion revealed that women tend to experience a poorer quality of life after a stroke compared to men, due to factors such as older age, more severe strokes and higher rates of depression.

Speakers:

- Associate Professor Hrvoje Budincevic, University Hospital Sveti Duh, Croatia – 'Cognitive impairment after stroke in women'
- Professor Ivan Milojevic, General Hospital Cuprija, Serbia 'Pain and depression after stroke in women'



Associate Professor Hrvoje Budincevic and Professor Ivan Milojevic, speakers of the session Quality of life in women after stroke.





Parallel 2: How to involve people with stroke as research partners

Chaired by Dr Marina Charalambous, Cyprus University of Technology, Cyprus

The session explored engaging people with stroke as research partners, providing attendees with practical strategies and an understanding of the benefits of inclusive research practices.

Speakers:

- Alexia Kountouri, stroke survivor, Cyprus: 'A personal experience as a research partner'
- Dr Hatice Ozkan, UCL Queen Square Institute of Neurology, UK: <u>Enhancing patient involvement in stroke research</u>
- Associate Professor Jytte Isaksen, University of Southern Denmark, Denmark: 'How to involve patients with communication difficulties in stroke research'



Alexia Kountouri, a Stroke survivor from Cyprus, shared her personal experiences with working as a research partner.





Parallel 3: Enhancing health literacy and skills to reduce risk of secondary stroke

Chaired by Grethe Lunde, stroke survivor, Norway and Associate Professor Carina Persson, University of Gothenburg, Sweden

This session complemented the first Plenary session. It focused on the role of knowledge and skills in relation to secondary stroke prevention materials, resources and interventions, as well as how to incorporate modifiable healthy changes into daily life to reduce the risk of recurrent stroke.

Speakers:

- Professor Susanne Guidetti, Karolinska Institutet, Sweden: 'Prevention strategies through multiple methods and engaging everyday activities'
- Dr Suzie Xu Wang, Leeds Beckett University, UK: 'Mood management for stroke secondary prevention'
- Associate Professor Olive Lennon, University College Dublin, Ireland: <u>'Lifestyle behaviour change theories/techniques relevant to stroke secondary prevention'</u>



Professor Susanne Guidetti and Associate Professor Olive Lennon spoke about health literacy and skills.





Plenary 2: Life after stroke and the Stroke Action Plan for Europe

Chaired by Associate Professor Melinda Roaldsen, University Hospital of North Norway, MD with lived experience, Norway and Professor Avril Drummond, University of Nottingham, UK

In this session, we discussed the new Stroke Action Plan for Europe (SAPE), with a particular focus on life after stroke. We heard how experiencing a stroke has changed the perspective of a neurologist who recently had a stroke and how she hopes her experience will drive positive change in the life after stroke domain. We explored the latest data from the SAP-E stroke services tracker and showcased examples of good practice across Europe aimed at improving the lives of people after their stroke.

Associate Professor of Neurology, Melinda Roaldsen, shared her experience 'My perspective on life after stroke':

- Her stroke and examples of good life after stroke care in Norway.
- The importance of government strategies in improving stroke care and recovery.
- How experiencing a stroke has changed her research interests as a neurologist.
- How her personal experience can drive change in the life after stroke domain.

Professor Avril Drummond talked about the new life after stroke chapter in the SAPE a 'The new Stroke Action Plan for Europe, life after stroke focus':

- Life after stroke is about supporting survivors to live their best lives, not just adjusting to their condition.
- Currently gaps in data and research with variability in services across Europe
- Updated SAPE sets out new research priorities and targets for countries to work towards
- The Stroke Services Tracker data sets out to measure achievement against targets

Katherine Staley and Jacqui Cuthbert from the UK Stroke Association gave an overview of how their stroke support organisation collaborates with different stakeholders in their presentation '<u>Life after stroke care provision in England –</u> a collaborative approach':

- An overview of how NHS England plans and structures life after stroke care.
- The role of the local stroke support organisation in shaping guidance to meet the needs of stroke survivors.





- How the UK Stroke Association's service aligns with national plans and contributes to life after stroke care.
- How the NHS, government and stroke support organisations worked together to create an integrated and needs-based life after stroke care system.

Professor Janika Kõrv outlined of a new programme in Estonia in her presentation '<u>Life after stroke care provision in Estonia – a new national stroke</u> navigator programme':

- Collaborative approach Working with the local stroke support organisation to improve access to post-stroke rehabilitation.
- Stroke pathway innovation project An insurance funding initiative enhancing rehabilitation and quality of life for stroke survivors.
- Research findings Highlighting the importance and value of the stroke coordinator role in supporting recovery.
- Nationwide implementation Integration of findings into the national stroke pathway, standardising care, formalising key roles, and improving patient outcomes.
- Practical guidance Hints and tips for others looking to adopt a similar collaborative approach.



Professor Janika Kõrv outlined the innovative approach they took to improve Life After Stroke in Estonia.





Workshop: Reimagining wellbeing for life after stroke: a call to action

Chaired by Saran Chamberlain stroke advocate, researcher and survivor, Australia and Professor Lisa Kidd, Glasgow Caledonian University, UK

This workshop brought together people affected by stroke, clinicians and researchers from across to share ideas and experiences on wellbeing after stroke.

Workshop attendees discussed two core questions:

- 1. What does wellbeing and life after stroke look like?
- 2. What are the priorities and opportunities for embedding wellbeing after stroke and involving people with lived experience in shaping and delivering future stroke care and research?

The workshop was facilitated by: Associate Professor Felicity Bright, Auckland University of Technology, New Zealand, Saran Chamberlain, Stroke advocate, researcher and survivor, Professor Avril Drummond, University of Nottingham, UK, Professor Marie Elf, Dalarna University, Sweden, Professor Susan Hillier, University of South Australia, Australia, Professor Lisa Kidd, Glasgow Caledonian University, UK and Associate Professor Elizabeth Lynch, Flinders University, Australia.

The workshop findings were presented in the final closing remarks and will be written up into a paper for publication which SAFE will share through our communications channels.



ELASF delegates discuss the future of wellbeing in life after stroke in workshop session.





Parallel 4: A technology enabled life after stroke

Chaired by Yago Bundgaard, Stroke Survivor, Denmark and Associate Professor Nicola Hancock, University of East Anglia, UK

The session discussed how technology-based tools and interventions can provide enhance rehabilitation and life after stroke but the adoption of technology in clinical stroke rehabilitation has been slow Speakers discussed how the community can work together to improve uptake and ensure these advancements benefit stroke survivors.

Speakers

- Associate Professor Nicola Hancock, University of East Anglia, UK: 'A technology enabled life after stroke'
- Dr Andy Kerr, Strathclyde University, UK: 'Co-creating a technological approach to rehabilitation and life after stroke'
- Veronika Nemcova, Health Management Institute, Czech Republic: 'Patient Virtual Assistant and insights into the RES-Q+ project'



Discussing the use of technology in life after stroke with panel of speakers.





Parallel 4: Caregiving

Chaired by Christina Franzisket, German Stroke Foundation, Germany and Dr Hrvoje Jurlina, Specialised Doctor of Family Medicine, Croatia

This session provided a holistic understanding of caregiving, balancing personal experiences with professional perspectives. Delegates heard from a caregiver, a stroke support organisation and an occupational therapist, who shared insights on long-term approaches to supporting caregivers.

Speakers

- António Célio Ramos, Carer, Portugal: 'My experience of being a caregiver'
- Esther Duarte, Fundacio Ictus, Catalonia: '<u>The role of a stroke patient support organisation in supporting caregivers</u>'
- Doubravka Koubková, ERGO Aktiv, Czech Republic: 'Concept of long-term support for caregivers'



Esther Duarte from Fundacio Ictus, Catalonia spoke about how a stroke support organisation can support carers.





Plenary 3: By survivors, for all: Inclusive approaches to life after stroke

Chaired by Stacie Broek, Public Advocate, Person with Lived Experience, Switzerland and Ass. Professor Nicola Hancock, University of East Anglia, UK

For the first time at the ELASF, we had a plenary session that was stroke survivor led. The session offered tools and ideas for self-advocacy and strengthening individual capabilities. It demonstrated the power of partnerships between stroke survivors, stroke support organisations and medical health professionals to improve stroke care, support and quality of life.

We heard about the experience of stroke advocacy from our four lived experience members of the ELASF scientific programme committee (Stacie Broek, Switzerland, Grethe Lunde, Norway, Diana Wong Ramos, Portugal, and Associate Professor Melinda Roaldsen, Norway). We also had presentations from Elin Andersson (Sweden) and Colin Jenkinson (UK) the top two scoring abstracts from our lived experience abstract programme.

They summarised their experiences in the joint presentation and discussion about 'Advocacy in action: personal perspectives and broader impact':

- Grethe spoke about the power of storytelling in advocating for change
- Diana spoke about co-founding the first Stroke Support Organisation in Portugal
- Melinda spoke about going form a healthcare professional to patient and stroke survivor and the importance of person-centred care approaches
- The team used Slido polls to ask the audience about support for stroke survivors, speaking up for changes in stroke care, peer support and the role stroke survivors should play in improving recovery and care.
- (see linked presentation)



Our scientific committee members with lived experience discusses their advocacy work







The word cloud generated from the question "What is your biggest hope for life after stroke recovery" Slido poll.

Elin Andersson spoke next about 'The power of changing mindset'.

- She shared a video about her journey to recovery https://youtu.be/IRFV-jp-5Ut8
- She spoke about the loneliness as a young stroke survivor inspired her to share her journey on Instagram and how she now has over 40,000 followers from all over the world



Elin Andersson, Stroke survivor from Sweden spoke about the Power of changing your mindset.



Colin Jenkinson spoke about his 'Lived experience of acalculia after stroke'.

- He worked as a maths tutor before his stroke
- Post-stroke he experienced aphasia (a post-stroke condition that affects a person's ability to communicate) and acalculia (a post-stroke condition that affects a person's ability to perform simple calculations)
- He shared his struggles with recovery and creating his own strategies to re-learn number skills
- He has now co-authored research and works with the UK Stroke Association to develop toolkits to support others



Colin Jenkinson, Stroke survivor from UK spoke about his challenges with acalculia as a maths teacher after his stroke.



Our lived experience speakers.







Parallel 6: Returning to work: Empowerment to make the invisible visible

Chaired by Grethe Lunde, Stroke Survivor, Norway and Helen Gaynor, Irish Heart Foundation, Ireland

This session focused on the invisible disabilities of stroke survivors and the challenges they face when returning to work and daily activities. It provided practical examples of how to manage these disabilities in the workplace.

Speakers:

- Grethe Lunde, Stroke Survivor, Norway: 'Navigating invisible disabilities in the workplace a stroke survivors' perspective'
- Ciara Breen, Galway University Hospitals, Ireland: <u>'Navigating the road back to work after stroke: what does the evidence say'</u>
- Dr Emma Patchwood, University of Manchester, UK: <u>'Acceptance and Commitment Therapy (ACT)</u>: Pr"ACT"ical Takeaways for Stroke Survivors
 Returning to Work'



Dr Emma Patchwood, University of Manchester, UK spoke about Acceptance and Commitment Therapy for stroke survivors returning to work after their stroke.





Parallel 7: Communication challenges in long-term stroke

Professor Jean-Marie Annoni, University of Fribourg, Switzerland and Board of Aphasia International and Dr Marina Charalambous, Cyprus University of Technology, Cyprus.

This session highlighted the communication and psychological challenges faced by individuals after a stroke. It brought together the International Aphasia Association, Afasia Hispano American Ligue and European aphasia groups to create a platform for sharing experiences and insights.

Speakers:

- Professor Jean-Marie Annoni, University of Fribourg, Switzerland and Board of Aphasia International: 'Introduction: Survivors' choice: a Roadmap to select topics in communication impairment after stroke'
- Jernej Sluga, Person with lived experience of stroke and aphasia, Slovenia and Jelena Bartolović Vučković, University Hospital Sveti Duh, Croatia: <u>'Awareness of aphasia and the communication challenges of long-term</u> stroke'
- Hanka Mayhew, Person with lived experience of stroke and aphasia, UK and Dr Marina Charalambous, Cyprus University of Technology, Cyprus: <u>'Psychological changes in people with communication difficulties after stroke'</u>
- Professor Katerina Hilari, City University London, UK: <u>'ESO aphasia rehabilitation guidelines'</u>



Professor Jean-Marie Annoni, University of Fribourg, Switzerland and Board of Aphasia International spoke about communication challenges after stroke





Parallel 8: Top scoring scientific and service abstracts

Chaired by Jennifer Crow, Imperial College London, UK and Chris Macey, Irish Heart Foundation, Ireland

The highest scoring scientific and service development abstracts were presented in this session.

Service development

- Suzanne Smith-Bayley, March of Dimes, Canada: <u>'Service development:</u>
 Experience implementing best practices in a stroke support organization: navigation, peer support and virtual programs'
- Helena Heffernan, Irish Heart Foundation, Ireland: <u>'Service development: A vocational return to work programme for stroke survivors in Ireland'</u>

Research

- Dr Hatice Ozkan, UCL Queen Square Institute of Neurology, UK: <u>'Scientific:</u>
 <u>Prevalence and Predictors of Patient-Reported Sexual Dysfunction After Stroke: A multi-centre observational study'</u>
- Absent due to illness: Ms Syeda Hashmi, University of Toronto, Canada: <u>'Scientific: Exploring Unmet Psychosocial Care and Recovery Needs in Young Survivors of Stroke'</u>



The three high-scoring abstract speakers receive their certificates following their presentations.

From left: Session co-chair Jennifer Crow, Dr Hatice Ozkan, Suzanne Smith-Bayley and session co-chair Chris Macey.





People's choice: Best poster



Diana Wong Ramos et al won People's Choice Poster award for their poster 'Mapping the journey and experience of people living with post-stroke spasticity'.





Evening reception 10 March

The evening reception provided an opportunity for delegates to network, review the posters on display, and enjoy photos and artwork created by Czech stroke survivors.

SAFE President Harriet Proios welcomed everyone and introduced our special guests, singer Genny Ciatti, a stroke survivor from Czech Republic, and Professor Simona Sacco, the President of the European Stroke Organisation.



SAFE President Harriet Proios welcomed delegates to the evening reception



Stroke Survivor Genny Ciatti from the Czech Republic performed at the evening reception.







Special guest Simona Sacco, ESO President spoke of the importance of focus on life after stroke.





The SAFE and Seren Teams

The European Life After Stroke Forum is organised by SAFE with support from Seren Events (PCO).



The SAFE team from left: Arlene Wilkie (Director General), Sandra Jackson (Secretariat) and Anna Scott (Communications and Engagement Manager).



The Seren Events team from left: Garry Kinnear, Bonnie Jamieson, Taliana Rontard and Chantel Courtney.

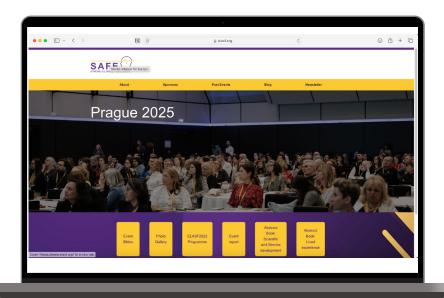




Resources

All assets from ELASF2025 are available to view or download here, including:

- · Event slides
- Photo gallery
- Programme
- Abstract Book: Scientific and Service Development
- Abstract Book: Lived Experience





Thank you to our sponsors





















Thank you to our endorsers









































Social media quotes

European Life After Stroke Forum

"It was a true pleasure to be a part of #ELASF2025 as a presenter, to meet new friends and collaborators, and to enjoy the stimulation and learning in beautiful Prague. Going home with lots of new ideas to implement!"

"The event was well organised. Being an early career researcher, it was a great learning experience for me. Learning from stroke survivors themselves has increased my passion and interest in health economic research in the area of stroke. I also love the way the content was organised in that it accommodated both individuals with technical expertise and those without"

"Still buzzing from #ELASF2025. A highlight for me was the plenary on advocacy by people with stroke with @DianaWongRamosi @grethelunde @MelindaRoaldsen Elin Andersson Colin Jenkinson @ staciebroek"

"A fantastic couple of days in Prague with Stroke Alliance for Europe (SAFE) at the #ELASF2025 where one of the biggest takeaways from the last two days was the need to make funders, policymakers and insurers more informed, and committed to enhancing life after stroke."

"The overall tone of the conference prioritising the voices of lived experience comes through so strong. The lived experience plenary was a wonderful highlight"





See you in 2026!



