



EVENT REPORT

European
**Life After
Stroke**
Forum

Dublin
11-12
March
2024

#lifeafterstroke

Thank you!

Thank you to everyone who attended our second in person European Life After Stroke Forum in Dublin and for making the event so successful.

We set out to create a Forum where stroke survivors, caregivers, healthcare professionals, researchers and advocates could come together to tackle the practical challenges of life after stroke. We are delighted to say that our event in Dublin succeeded in providing this platform for exchanging insights, exploring new research and sharing best practices in this often-overlooked domain.

We are proud of the uniqueness of our event - the programme was co-created with people affected by stroke and they were involved as speakers, chairs and attendees of the event, alongside eminent researchers and healthcare professionals. By working in this way, we will, collectively, drive life after stroke care and support to the forefront of European healthcare agendas, paving the way for a future where everyone can thrive beyond the challenges of stroke.

Thank you for being part of this important journey, we look forward to seeing you in Prague next year!



Professor Avril Drummond
Chair, European Life After Stroke Forum
Scientific Committee



Professor Hariklia Proios
President, Stroke Alliance for Europe



European Life After Stroke Forum

11-12 March 2024

Event overview

- 3 plenaries
- 12 parallel sessions
- 11 topic areas plus highest scoring abstracts
- 328 registrations and 316 attended the one-and-a-half-day event.
- Our delegates included stroke survivors, carers, stroke support representatives, researchers, students, physicians and allied health professionals.

Exhibitions / Activities

- 62 poster sessions
- Sponsors (Bayer, Ipsen, Medtronic, and Merz)
- Endorsers (ESO and WSO)
- Blood pressure monitoring
- Irish Patient Organisations (Irish Heart Foundation, Croi Heart and Stroke Ireland, Headway Ireland, Acquired Brain Injury Ireland)
- EU Research Partner (Validate)
- [Escape Room \(Prestige AF\)](#)

Notable activities

- This was our second in person event after several years of webinars during Covid. We held our first in person event in Barcelona in 2023 with 175 attendees.
- The event was opened by a video of support from the [Taoiseach](#)
- We more than doubled the number of abstracts that were submitted and we showed 62 at the event.
- We extended the event from one day in Barcelona to one and a half days.
- We increased the number of attendees from 175 to 316 (328 registrations).
- Our event is fully centred around people with lived experience: programme was co-developed by stroke survivors and allied health professionals, our attendees included stroke survivors as well as allied health professionals and researchers, and our speakers and chairs included stroke survivors.
- We involved one of our research partner Prestige-AF to deliver an Escape Room that was based around recruiting patients into stroke research.
- We involved the Irish Heart Foundation who supported us with volunteers, a choir and art exhibition at our welcome reception, a blood pressure monitoring area and they curated the final plenary focusing on life after stroke highlights from Ireland which was chaired by the National Clinical Lead in Stroke.
- Our exhibition included stands from local patient organisations: Headway Ireland, Acquired Brain Injury Ireland and Croi Heart and Stroke Ireland



The ELASF poster exhibition



Three ELASF delegates participates in the Prestige-AF Escape Room



The Irish Heart Foundation was one of the exhibitors at the ELASF

Programme overview

Monday 11 March

- Open Taoiseach video and Professor Avril Drummond
- Plenary 1 Building the evidence for support for life after stroke
- Parallel 1 A disproportionate burden? Life after stroke in women
- Parallel 2 Spasticity: To understand what spasticity is and the ways it can be managed
- Parallel 3 A vision for vision after stroke:
- Parallel 4 No decision about me without me – speaking together with one voice
- Plenary 2 Life after stroke support in action
- Parallel 5 Highest scoring abstracts
- Parallel 6 Spasticity: To understand what spasticity is and the ways it can be managed
- Parallel 7 A vision for vision after stroke
- Parallel 8 Exploring mental health post stroke

Tuesday 12 March

- Parallel 9 Secondary stroke prevention – managing blood pressure and the benefits of exercise
- Parallel 10 Exploring mental health post stroke
- Parallel 11 A disproportionate burden? Life after stroke in women
- Parallel 12 No decision about me without me – speaking together with one voice
- Plenary 3 A showcase of life after stroke in Ireland

Opening

The chair of the ELASF scientific committee, Professor Avril Drummond, welcomed over 315 delegates who had joined us from all over Europe. There was a [special welcome address](#) by the Taoiseach Leo Varadkar.



Professor Avril Drummond welcomes delegates to the Forum and introduce the welcome address by Taoiseach Leo Varadkar.



328 registrations and 316 attended the one-and-a-half-day event. Our delegates included stroke survivors, carers, stroke support representatives, researchers, students, physicians and allied health professionals.

Plenary 1: Building the evidence for supporting life after stroke

Chaired by Professor Avril Drummond

Building on the “A Life Saved is a Life Worth Living” report, this session presented current evidence and research on supporting people and their families to live well after a stroke. The session highlighted key gaps in the evidence base and identified priorities for more funding, more lobbying and more evidence

Grethe Lunde, stroke survivor, Norway opened the session with a presentation on ‘What’s important for life after stroke, and what difference evidence makes to people’s lives’.

- Grethe had a severe and life changing cerebral sinus venous thrombous (CVTS) on her 22nd birthday and woke from an induced coma totally paralysed.
- In rehabilitation she had to start over on many levels and had to relearn how to speak, read and write, and most importantly how to sit, stand and walk again.



Grethe Lunde opens the first plenary session with a presentation on the difference evidence makes on stroke survivors’ lives.

Professor Amanda Farrin, statistician and trialist from University of Leeds, England discussed what works for supporting life after stroke, in particular 'Mapping the evidence base for life after stroke: a research perspective'

- She discussed the effectiveness of interventions for life after stroke
- Addressed the challenges in the evidence base for life after stroke
- Discussed areas for future life after stroke research

Associate Professor Margit Alt Murphy, physiotherapist from University of Gothenburg Sweden discussed 'How can we use research evidence to improve life after stroke: a clinical perspective?'

- She discussed the development of a clinical routine – giving an example from a 7-year long R&R work at the Sahlgrenska University Hospital, Sweden to ensure an even more evidence-based, efficient, equal, knowledge-based and individually tailored rehabilitation for patients with stroke
- Improved follow-up treatment tailored to the patient's function and resources, and stroke survivor literacy and involvement in rehabilitation was highlighted.



Plenary 1 speakers are responding to audience questions.

Plenary 2: Life after stroke – support in action

Chaired by Dr Else Sandset

This session focused on the different perspectives of what a good life after stroke' looks like through discussion and presentations around different experiences and good practice from different countries.

The session opened with three European stroke survivors telling us about their experiences after leaving hospital. They told us about the support they received, what they found most helpful and what they felt was missing: Julie from the United Kingdom, Daniel from Catalonia and Nadica from North Macedonia. See the full video [here](#).

The session was then followed with the perspective from European stroke support organisations who provided an overview of the different projects and the areas of unmet needs they address. The presentations were based on the question: 'What types of support have made the most difference to people's lives and what have been the most successful strategies?'

Dr Michael Brinkmeier from Stiftung Deutsche Schlaganfall-Hilfe in Germany talked of how their stroke navigators take care of the patients and support them individually in their life after a stroke:

- Set targets for secondary prevention
- Motivates to change lifestyle or monitor care
- Improve the overall care of patients along the patient pathway



Dr Michael Brinkmeier from Stiftung Deutsche Schlaganfall-Hilfe SSO in Germany presented his organisation's work with stroke survivors

Mercé Ayesta from Fundacio Ictus Catalonia presented how their ABRIC programme supports stroke survivors:

- Providing initial support after discharge from the hospital by assessing individual needs of stroke survivors and their families
- Delivers educational and informational resources and developing personalized support plans in collaboration with stroke survivors
- Provides immediate assistance and tailored professional guidance in their live after stroke journey.



Mercé Ayesta from the Fundacio Ictus Catalonia Stroke Support Organisation, gives an overview of her organisation's activities to support unmet needs in Catalonia.

Katherine Staley from Stroke Association UK talked about the range of peer support they offer.

- Online – an online community, which can be accessed through their website and other online channels, offers different activities and peer support sessions which people can join live through video calling
- Telephone peer support – where trained volunteers offer peer support over an 8 week period centred around common interests or their own stroke experiences
- Community peer support – provided through their Stroke Group Network connecting and supporting nearly 400 local groups across the UK.



Katherine Staley from UK's Stroke Association, outlined the work they do to support stroke survivors.

Plenary 3: A showcase of life after stroke in Ireland

Chaired by Professor Ronan Collins

In this session, the group shared how they developed a support service in Ireland to meet the unmet need of those affected by stroke, the challenges and opportunities faced, and they shared top tips on how to set this service up in other countries.

Helen Gaynor, Irish Heart Foundation (IHF), Ireland discussed 'The Stroke Connect Service - Filling the gap for support post discharge in Ireland'

- She gave an overview of IHF services - background to the service and who is meeting the unmet need
- What the IHF offers to meet the need for information and support on discharge from hospital
- Impact to date
- Challenges and opportunities

Fiona Bardon, stroke survivor, discussed 'My journey through the Stroke Connect Service and beyond'

- Fiona had a stroke in August 2019 at the age of 33, just days before she was due to move from Ireland to start a new teaching job in Dubai. Being a stroke survivor has changed her life completely and, as with all experiences in life, there are good and bad elements to it.
- She discussed advocating for better services for stroke survivors post-discharge from hospital.



Fiona Bardon talks about her journey with the Irish Heart Foundation's Stroke Connect Service after her stroke

Wendy Moynan, Tallaght University Hospital and Dr Aine Connolly, St James Hospital, Dublin discussed 'Meeting the unmet need for information on stroke for children and young people (CYP) - The CHATS booklet'

- Why is it important to talk to and support children after stroke
- Guide co-created with stroke survivors
- Includes Ideas about how to explain a stroke and how to support children

The plenary session finished with a conversation between four stroke survivors from Ireland in the room with the speakers and the audience

- This session was facilitated by Fiona Bardon and the discussion was with Kieran O'Carroll, Cliodhna Ni Bhrion, Gerard Gill and David Walpol
- They discussed 'What does a good life after stroke mean for you and what support did you need to make it happen?'



Four Irish stroke survivors, Kieran O'Carroll, Cliodhna Ni Bhrion, Gerard Gill and David Walpol tells the Forum delegates what good life after stroke means to them.

Parallels 1 and 11: A disproportionate burden? Life after stroke in women

Chaired by Dr Liam Healy and Mercé Ayesta

This session discussed the specific and unique issues that women face after stroke. It covered the historical lack of representation of women in stroke research before moving on to specific issues for women in relation to secondary prevention of stroke and managing life after stroke. The session highlighted the need for a greater understanding of the impact of biological sex and gender on clinical practice and research on life after stroke. The session closed with a discussion on 'How can longer-term stroke care and secondary prevention strategies be tailored to the needs of, and specific risk factors in, women living with stroke?'

Speakers:

- Dr Else Sandset, neurologist from Oslo University Hospital, Norway - Contextualising sex and gender to improve stroke research, policy and practice
- Professor Anita Arsovska, Neurologist from Universities of Cyril and Methodius', North Macedonia - Specific secondary stroke risk factors in women after stroke
- Diana Wong Ramos, stroke survivor, Portugal



Diana Wong Ramos, a stroke survivor from Portugal delivers her presentation on how stroke affected her.

Parallel 2 and 6: What is spasticity and how can it be managed

Chaired by Professor Avril Drummond and Grethe Lunde /
Dr Nicola Hancock and Sophie Vandembremt

In this session, our first speaker covered what spasticity is, why it happens and the problems it causes. This was followed by a discussion of a range of strategies and management of spasticity.

Speakers

- Dr Iwona Sarzyńska-Długosz, neurologist from Institute of Psychiatry and Neurology Warsaw Poland - What is spasticity?
- Dr Stephen Ashford, physiotherapist from Kings College London England - Management of spasticity with botulinum toxin/physiotherapy management



Dr Stephen Ashford talks through strategies on how to manage spasticity

Parallels 3 and 7: A vision for vision after stroke

Chaired by Dr Carina Persson, Christina Franzisket and Katherine Staley

This session considered the impact of visual impairment and/or sight loss after stroke. The session included talks from a stroke survivor about his experiences of sight loss after a stroke and how he has coped with this. We also heard from researchers and support organisations working to develop ways to better assess and provide care for people who experience visual impairment or sight loss after a stroke.

Speakers

- Professor Helle Falkenberg, optometrist from University of South-Eastern Norway – 'Vision assessment in stroke care services: the KROSS project'
- Dr Lauren Hepworth, orthoptist from University of Liverpool, England and Jeremy Johnston, stroke survivor from Hillsborough, Northern Ireland – 'What helps in coping with and self-management of slight loss after stroke'



Professor Helle Falkenberg explains how they do vision assessments in their stroke care services.

Parallel 4 and 12: No decision about me without me – speaking together with one voice

In this session, we addressed the challenges faced by those affected by stroke when treatment and support decisions are being made. We did this through a short role play introduction session with Hariklia Proios (AHP) and Marianne Tangen (stroke survivor), with Hariklia asking the wrong questions, followed by Marina Charalambous (AHP) and Marianne (stroke survivor), with Marina asking the right questions.

We then heard from stroke survivors Stacie Broek and Marianne Tangen, and those involved in advocacy - Chris Macey, Hariklia Proios and Marina Charalambous. They outlined strategies and skills for successful communication to ensure that those affected by stroke are central to their treatment and support decision making process.

Finally, we heard from Professor Katerina Hilari, speech and language therapist from the City University of London, England on 'SUpporting wellbeing through PEeR Befriending: Outcomes of the SUPERB trial for people with aphasia'. Her presentation highlighted issues with psychological wellbeing after stroke and aphasia and she presented the main findings of the SUPERB study, testing peer-befriending with people with aphasia.



Discussing audience questions following the advocacy / role play session. From left: Professor Katerina Hilari, Chris Macey, Stacie Broek, Marianne Tangen, Dr Marina Charalambous and Professor Hariklia Proios.

Parallel 5: Highest scoring abstracts from research and service provision

Chaired by Dr Carina Persson and Yago Bundgaard

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

Service

- Socialising from home - Peer support and communication practice at the Aphasia Café. Dr Helen Kelly, Speech and Language Therapist, University of Cork, Ireland
- Enhancing the competency of coordinators in a stroke support organization; creating a self-assessment framework. Suzanne Smith-Bayley, Occupational Therapist from the March of Dimes, Canada

Research

- Addressing sexuality post-stroke: Can a targeted implementation change practice? Associate Professor Margaret McGrath, occupational therapist from University of Sydney / University College Cork, Ireland
- Life one year after stroke – results from the Swedish Riksstroke quality-of-care review. Professor Mia von Euler, neurologist from Orebro University, Sweden



The four high-scoring abstract speakers receive their certificates following their presentations. From left: Session chairs Dr Carina Persson and Yago Bundgaard, Professor Mia von Euler, Suzanne Smith-Bayley, Professor Margaret McGrath and Dr Helen Kelly.

Parallels 8 and 10: Mental health post-stroke – what can I do?

Chaired by Professor Nuno Ferreira and Dr Lisa Kidd

Following from the 2023 Life saved life worth living report, this session focused on issues around mental health. The session explored how these difficulties can affect stroke survivors and carers and will review what research tells us about post-stroke mental health difficulties. Practical tips on how to recognise and deal with mental health difficulties were provided. The session ended with a discussion about what can be done better in post-stroke mental health.

Speakers

- Professor Niall Broomfield, psychologist from University of East Anglia, England ‘What do mental health difficulties look like in post-stroke?’
- Professor Maggie Lawrence, stroke research nurse from Glasgow Caledonian University Scotland ‘What should you do when you are struggling?’
- Stacie Broek, stroke survivor, Switzerland ‘My mental health and me’



Professor Niall Broomfield starts the Mental health post-stroke parallel session with an overview of the mental health difficulties a stroke can lead to.

Parallel 9: Secondary stroke prevention – managing blood pressure and the benefits of exercise

Chaired by Dr Liam Healy and Hrvoje Jurlina

This session focused on two important aspects in the prevention of further strokes – managing blood pressure and exercise. We discussed the importance of controlling high blood pressure, how best it should be measured and managed both with and without medicines. We also discussed the importance of exercise in healthy ageing and what exercise, in what quantity, makes a difference. Practical tips for stroke survivors, carers and professionals were discussed.

Speakers:

- Dr Eamon Dolan, stroke physician, Connolly Hospital, Ireland 'Stroke secondary prevention – managing blood pressure'
- Dr Noel McCaffrey, Cappagh CEO, ExWell Medical and Sharon and Olivia Merrigan (stroke survivors), all from Ireland 'Stroke secondary prevention – the benefits of exercise'



Dr Eamon Dolan presents on blood pressure management in secondary stroke prevention

Evening reception 11 March

The evening reception provided an opportunity for attendees to network, view the posters on display, and enjoy artwork created by Irish stroke survivors.

SAFE President Hariklia Proios greeted everyone and introduced our special guests Marianne Tangen, a stroke survivor from Norway, and Peter Kelly, the President of the European Stroke Organisation. Additionally, there was a heartfelt performance by a choir made up of stroke survivors from across Ireland, 'Rhythm for Recovery', marking their first ever live performance.



SAFE President Hariklia Proios welcomed delegates to the evening reception



The choir of stroke survivors from all over Ireland 'Rhythm for Recovery' performed for delegates for the first time



*Choir of stroke survivors
'Rhythm for Recovery'*

Marianne Tangen, a stroke survivor from Norway told delegates her story and why the ELASF is so important to her and other stroke survivors



Special guest Peter Kelly, ESO President spoke of the importance of focus on life after stroke.

The SAFE and Seren Teams

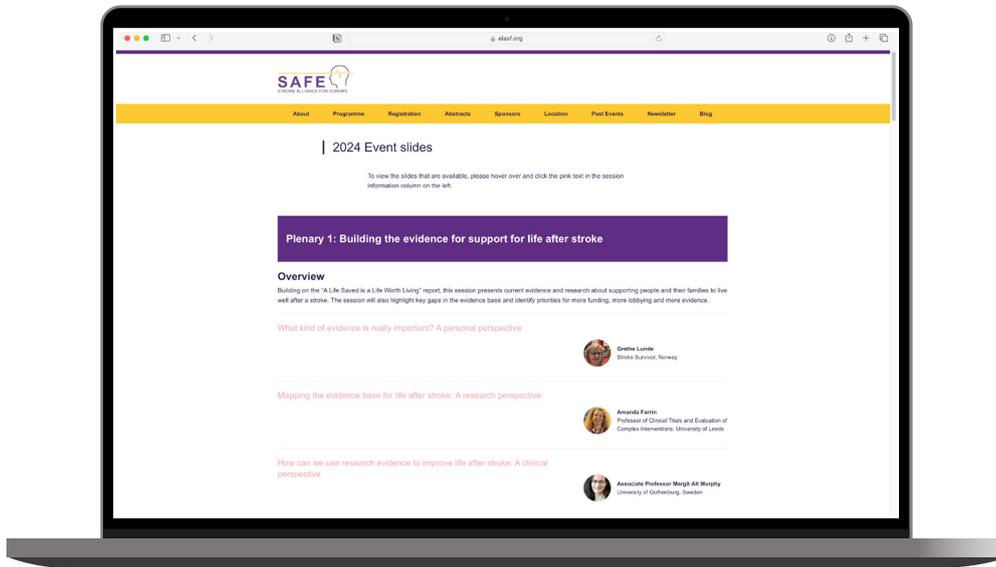


The European Life After Stroke Forum 2024 was brought to you by the team at Stroke Alliance for Europe (SAFE) and the Professional Conference Organiser (PCO) Seren Events.

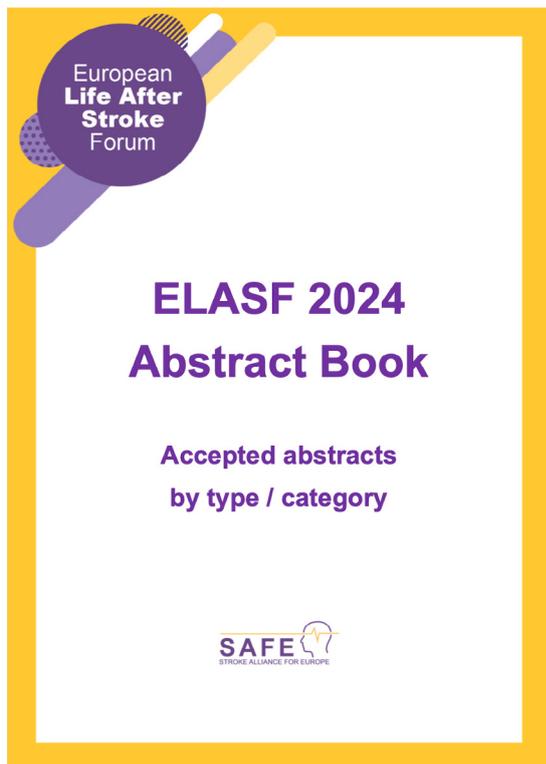
From left: Bonnie Jamieson (Seren Events), Garry Kinnear (Seren Events), Sandra Jackson (SAFE), Arlene Wilkie (SAFE), Anna Scott (SAFE), Sarah McGovern (Seren Events) and Rosie Gibson (Seren Events).

Resources

All presentations from the forum are available to download [here](#).



The abstract book is available to download [here](#).



Thank you to our sponsors



Thank you to our endorsers



Thank you to our endorsers - continued



Social media quotes

“What an incredible 2 days at the European #lifeafterstroke conference....so many take homes and areas for improvement but for me, the unmet mental health needs of our stroke survivors was the most striking. We can, and must do better at recognising and treating. #ELASF2024”

“What a way to close this conference #lifeafterstroke which has moved me to tears and re-energised my passion & commitment to prevent stroke and support people surviving stroke”

“Wow what a powerful few days in Dublin at my first @StrokeEurope European Life After Stroke Forum! I loved that the voice of stroke survivors was central over the 2 days. Thank you for sharing your experiences and expertise”

“Running out of positive words and sounding like a cliché BUT another fantastic session on advocacy in action in #LifeAfterStroke thinking about what is important to each person how this impacts goals and the SUPERB benefits of peer befriending for those with aphasia”

“You can never say I have heard enough #lifeafterstroke stories, each provides a new nugget of information or perspective.”

See you in 2025!

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PRAAGUE



#lifeafterstroke