



## ***Life after stroke – what is the problem?***

Article from the Stroke Alliance for Europe

Stroke is the biggest cause of adult disability in Europe and impacts on all aspects of life. There are more than nine million people living with stroke in Europe and with numbers of stroke survivors predicted to increase,<sup>1</sup> life after stroke is even more important and must be a priority for health and social care.

Currently, research, policy formulation and resource allocation with regard to stroke is primarily focussed on the areas of prevention and intervention at the point of stroke up to discharge from formal expert medical care.

This is an understandable priority. Yet survivors of stroke on discharge from a largely medicalised pathway, enter a world where support is usually unclearly defined, often fragmented or non-existent, and where cultural expectations can dramatically impact quality of life and any success of ongoing recovery.

A stroke shatters lives and leaves many issues for a stroke survivor to solve, not only stroke related disabilities and co-morbidities, but it also affects mental health and wellbeing. Having to adjust to a new post-stroke life can affect relationships, work, self-confidence, finance, transport, aphasia, cognitive disruption and intimacy issues. Survivors of stroke and their loved ones may face decades of existence in which they are largely reliant on self-management.

These issues are compounded by little research in these areas and the voice of stroke survivors goes unheard. It is assumed that those in the medical area of the pathway have relevant knowledge that extends beyond the hospital experience.



In various parts of the world there is an increasing realisation that the care pathway for stroke needs to take a more integrated approach. If we really want to help people with stroke get their life back, they must have full and coordinated support from all sides - family, state, medics, other stroke experts and stroke support organisations.

We need to promote research into all aspects of life after stroke, and to build mechanisms of support around the needs and wants of stroke survivors and their families. This sentiment was articulated in the 2007 English National Stroke strategy and in the Stroke Action Plan for Europe 2018- 2030.<sup>2</sup> (see box 1)

## The Stroke Action Plan for Europe 2018-2030

The Stroke Action Plan for Europe focuses on seven domains: primary prevention, organisation of stroke care, acute stroke care, secondary prevention, rehabilitation, evaluation of outcomes and life after stroke.

Notably, it represents an aspirational framework to drive healthcare policy, patient-focused care, local stroke management and research priorities.

The Stroke Action Plan for Europe includes four overarching targets for 2030:

1. To reduce the absolute number of strokes in Europe by 10%.
2. To treat 90% or more of all patients with stroke in Europe in a dedicated stroke unit as the first level of care.
3. To have national plans for stroke encompassing the entire chain of care from primary prevention through to life after stroke.
4. To fully implement national strategies for multisector public health interventions to promote and facilitate a healthy lifestyle, and reduce environmental, socioeconomic and educational factors that increase the risk of stroke.

## STROKE ACTION PLAN EUROPE 2018 – 2030

The recognition of the needs of stroke survivors and their families after their hospital and rehabilitation care has not previously been given the focus it deserves. It is in the period after return to the home that the struggle for a new life occurs, which is often characterised by stroke survivors as being cast adrift to find their own way, through maybe decades of cognitive, communication, relationship, financial, mental and physical health issues, complications and changes.

There is a lack of research studies into life after stroke covering the entire lifespan and this is something that needs to change. There are growing numbers who believe that pain, depression, relationship breakdown, secondary prevention effectiveness, financial, vocational and stigma issues, as well as the ongoing matters of daily living, mobility, communication, cognition

and the absence of ongoing review and support are worth being researched and addressed.

Few opportunities exist regarding conferences, workshops, and shared networking events for advocates and researchers in this neglected but vital area of care.

## Taking the lead

The Stroke Alliance for Europe is a coalition of patient organisations across Europe and is the voice of stroke survivors, advocating for better support and care. Our goal is to reduce the number of strokes in Europe and ensure that every person with stroke has access to high quality joined up services and information from first symptoms and throughout life.

Life after stroke is a key priority for the Stroke Alliance for Europe (SAFE) (see box 2). Every step in the stroke care pathway should matter equally. In 2019, SAFE worked with stroke support organisations from around 30 European countries to find how stroke survivors and their families are coping. These interviews evidenced the most burning life after stroke issues and demonstrated that leaving the hospital and starting with the basic rehabilitation is simply not enough.

To address this issue, SAFE launched the European Life After Stroke Forum in October 2019 to recognise the need to consider this neglected area of the care pathway in a holistic way. The aim was to create an opportunity at least once a year for those who wish to operate in this life after stroke area, whether researchers, scientists, medical professionals, health policymakers, advocacy, or support groups, stroke survivors and their carers to come together and share and network.

In addition, the forum will put a human face on the consequences of stroke, and on the consequences of not addressing prevention and treatment in the first place.

## Impact of Coronavirus

The pandemic has negatively affected stroke care, causing

disruptions to the care pathway and worsening the stroke burden. Less people access and seek timely stroke care, those at risk of stroke have a poorer outcome if they contract COVID-19 and evidence has shown that COVID-19 patients are at higher risk of having a stroke. The importance stroke and its impact has never been more important and should not be overlooked even during a global pandemic.

### Virtual European life after stroke forum series of events for 2021

The first Life After Stroke in Europe event planned for 2020 aimed to shine a spotlight on this important part of the stroke care pathway. The pandemic meant the conference had to be postponed. In its place, we (the European Life After Stroke Forum Scientific Committee and SAFE) are running a series of virtual events during 2021 to stimulate debate and build interest for our 1st European Life After Stroke Forum conference planned for 11 March 2022.



### Life after stroke: priorities, challenges, and ways forward - 12 March 2021

In this opening session, speakers from Europe shared experiences on service provision and support for stroke survivors and their families, longer term. We heard updates from Sweden, the UK, Ireland and Italy on experiences before and during the pandemic, and how healthcare and support services have adapted to meet the challenges of post-pandemic stroke care.

### Intimacy and sex after stroke: how to start the conversation - 20 May 2021

In our second event of the series, we covered the important topic of intimacy and sex after stroke. For many stroke survivors this is an uncomfortable subject with many struggling to come to terms with their 'new' body or identity and coping with the implications of this. Additionally, many healthcare professionals do not feel confident or able to talk about sex or to know how to best advise and support patients or their families.

Both these webinars are now available to view on demand at [www.elasf.org](http://www.elasf.org)

There will be two more virtual events in autumn (29 September) and winter 2021 (date tbc). You can find out more and reserve a free place at [www.elasf.org](http://www.elasf.org)

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*Professor Drummond also chaired the life after stroke domain within the Stroke Action Plan for Europe 2018 – 2030.*

## REFERENCES

1. At What Cost, the Economic Impact of Stroke in Europe [https://www.safestroke.eu/wp-content/uploads/2020/10/03.-At\\_What\\_Cost\\_EIOS\\_Full\\_Report.pdf](https://www.safestroke.eu/wp-content/uploads/2020/10/03.-At_What_Cost_EIOS_Full_Report.pdf)
2. Norving B, Barrick J, Davalos A, Dichgans M, Cordonnier C, Guekht A, Kutluk K, Mikulik R, Wardlaw J, Richard E, Nabavi D, Molina C, Bath PM, Stibrant Sunnerhagen K, Rudd A, Drummond A, Planas A, Caso V. <https://pubmed.ncbi.nlm.nih.gov/31236480/>. Eur Stroke J. 2018 Dec;3(4):309-336.