





# PREVENT, TREAT AND SUPPORT: A MANIFESTO FOR STROKE SURVIVORS

Every year, nearly 1.5 million people suffer a stroke in 32 European countries<sup>1</sup>. Stroke can be devastating – leading to death or life-long disability<sup>2</sup>, shattering the lives of all those affected. Those who survive will join the more than nine million European stroke survivors who live with long-term health, social, and financial impacts<sup>3</sup>.

The EU Non-Communicable Disease Initiative, Healthier Together, launched by the European Commission in 2022, provides opportunities for policy action that both EU-level and national policymakers should build on. We call upon all EU level policymakers, to prioritise stroke in health policies, to support member states to develop national stroke plans and lead research into the under-examined areas of stroke.

The burden of stroke falls upon us all, but especially on stroke survivors and their carers living with its consequences every day. Let us take action to reduce and minimise the burden of stroke on our societies.



We call for the implementation of the following policy proposals:

**1** Prior to a stroke

### 80% of strokes are preventable<sup>4</sup>, and effective prevention measures can help to ease the burden on health systems.

**Primary prevention and risk factor control:** Address highly prevalent stroke risk factors by implementing policies dealing with lifestyle and medical issues. Public health interventions should facilitate a healthy lifestyle and ensure universal access to screening and treatment.

**Implement legislation for public health interventions:** Addressing stroke risk factors (especially smoking and air pollution, but also healthy low-salt nutrition) by promoting a healthy lifestyle and reducing environmental, socioeconomic and educational determinants. Many risk factors for stroke are shared with multiple chronic diseases, including cancer, cardiac events, and dementia so multiple benefits can be expected from these measures across major diseases.

**Implement risk factor screening and treatment programmes:** Make evidencebased screening and treatment programmes for stroke risk factors available, such as detecting and controlling blood pressure, high cholesterol, and atrial fibrillation.



#### Amidst the stroke

Time is brain, fewer than 10% of stroke patients across Europe reach the hospital within 60 minutes of symptom onset<sup>6</sup>. A person loses 2 million nerve cells every minute they don't receive medical treatment during a stroke. The more nerve cells that are lost, the greater the chance of slurred speech, paralysis, and permanent disability<sup>6</sup>.

**Quality of care and stroke management:** Rapid assessment and initiation of treatment are vital for achieving better outcomes, reducing the likelihood of permanent disability. Stroke is a medical emergency, and the benefit of treatment is time dependent<sup>7</sup>. To improve the quality of stroke services, they need to be constantly monitored, reviewed and benchmarked.

**Ensure equal access to acute stroke care:** Increase the availability and rapid accessibility of certified stroke units across the EU. For all stroke patients, ensure they are treated in a stroke unit as the first level of care, guarantee access to treatments to restore brain blood flow and reduce onset-to-treatment time.

**Establish a quality improvement system for stroke services:** Involve stroke support organisations and scientific societies in the design, evaluation of stroke services and in the implementation of national stroke plans. Ensure stroke care is delivered by competent, well equipped and trained personnel, and that all stroke services undergo continuous auditing.



## Around a third of stroke survivors are disabled, have poor post-stroke cognitive ability and poor mental health<sup>5</sup>.

Non-clinical support meeting the practical, social and emotional needs of stroke survivors are also desperately needed and the sense of abandonment at the hospital gates stroke survivors in all countries face will persist until these services become part of what they can expect to receive.

**Prevent further stroke and take care of those who had one:** Secondary preventative measures, ranging from medicines to patient education, empowerment and follow up, can reduce additional stroke and complications<sup>8</sup>. A stroke can leave people with significant disabilities. Rehabilitation is a critical step to enable the return of stroke survivors to their communities<sup>9</sup>. Following discharge from specialist services, pathways must be developed for those affected by stroke, to ensure holistic and coordinated long-term support.

**Implement post-rehabilitation personal care plans that offer non-medical support:** Communication, social relationships, loneliness, incontinence, fatigue, and finance needs are unmet in current care plans, and social integration is missing. There is a strong need for coordinated personal care plans and support after rehabilitation ends to ensure mental health is addressed and stroke survivors are not left abandoned at the hospital gates.

**Provide sufficient secondary prevention services:** Within five years after a stroke, 30-50% of patients will have another stroke, heart attack, or vascular death<sup>10</sup>. Ensure secondary prevention management and lifestyle advice are made accessible for all stroke survivors.

Guarantee equitable access to rehabilitation prior and post discharge: Ensure access to early rehabilitation within the stroke unit, and provision for discharged stroke survivors to access physical fitness programmes and plans for self-management.

**Develop a European framework of reference for stroke care quality:** The framework should collect, measure and publish long-term data, including patient reported outcomes, on stroke quality, and audit national guidelines.

**Empower a dignified life after stroke:** Address stroke survivors' and their families' long-term unmet needs by formalising the involvement of stroke support organisations to identify country issues and solutions to develop best support practices.



#### **Understanding stroke**

# Stroke research funding as a percentage of the total funding for stroke, coronary heart disease, and cancer is uniformly low, ranging from 2% to 11%<sup>11</sup>.

Although the clinical burden and cost of stroke are at least as great as those for cancer, European stroke research is severely underfunded. If this current low level of research spending continues, the potentially preventable long-term sequela for patients and society will result in an increasing burden of stroke during the coming decades<sup>11</sup>.

**Provide sufficient research funding:** Ensure adequate funding is allocated to all eligible entities, including health organisations and NGOs, for stroke-related research projects, such as through the Innovative Health Initiative, the Healthier Together, EU non-communicable diseases Initiative and Horizon Europe.

**Improve stroke services with better data:** Research makes it possible to improve stroke services and enables us to identify priorities and targets. The EU should build on existing funding opportunities for stroke research and encourage the adoption of national stroke plans to improve stroke prevention, treatment and recovery.

**Encourage research into under-examined areas of stroke:** Stroke research has so far focussed mainly on medical management. Still, more attention needs to be paid to rehabilitation and life after stroke, including the study of patient-reported outcomes, as this is one of the most critical aspects for stroke survivors and their families.





Stroke Alliance for Europe (SAFE) is a non-governmental, non-profit organisation that represents patient organisations from 30 European countries, fighting together against stroke.

Our goal is to help prevent stroke-related death and disability throughout Europe, by raising awareness about the need to take action on stroke, among policy makers, the general public, researchers and the medical community.

We will succeed in reducing the number and impact of stroke in Europe by tirelessly advocating for better stroke prevention, equal access to treatment, better and more post-stroke care, rehabilitation and long-term support.

For more information about SAFE, please visit <u>www.safestroke.eu</u>



The European Stroke Organisation (ESO) is a pan-European society of stroke researchers and physicians, national and regional stroke societies, and lay organisations.

The aim of ESO is to reduce the burden of stroke by changing the way that stroke is viewed and treated.

This can only be achieved by professional and public education, and by making institutional changes. ESO serves as the voice of stroke in Europe, focusing on European level projects while working towards global solutions.

For more information about ESO, please visit www.eso-stroke.org



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