

What are the major unmet needs from the perspective of patients and carers in the different regions of Europe

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My talk



- The role of the Stroke Alliance for Europe
- Why we need the Stroke Action Plan for Europe
- What the Stroke Action Plan sets out to do
- What you can do to help



The role of Stroke Alliance for Europe (SAFE)



Initiate and support activity in the areas of:

1. Public awareness of stroke
2. Stroke policy and advocacy activity
3. Enabling & promoting stroke survivor & family voice & support
4. Supporting prevention of stroke and life after stroke
5. Encouraging research into stroke
6. Supporting stroke support organisations



What people need



Global Stroke Bill of Rights

As a person who has had a stroke I have a right to:



Receive the best stroke care

- A rapid diagnosis so I can be treated quickly.
- Receive treatment by a specialised team at all stages of my journey (in hospital and during rehabilitation).
- Receive care that is well coordinated.
- Access treatment regardless of financial situation, gender, culture or place that I live.
- Receive treatment that is right for me as an individual considering my age, gender, culture, goals and my changing needs over time.



Be informed and prepared

- Be informed about the signs of stroke so I can recognise if I am having one.
- Be fully informed about what has happened to me and about living with stroke for as long as I require it.



Be supported in my recovery

- Be provided with hope for the best possible recovery I can make now and into the future.
- Receive psychological and emotional support in a form that best meets my needs.
- Be included in all aspects of society regardless of any disability I may have.
- Receive support (financial or otherwise) to ensure I am cared for in the longer term.
- Be supported to return to work and/or to other activities I may choose to participate in after my stroke.
- Get access to formal and informal advocacy to assist me with access to the services I need.
- Be connected to other stroke survivors and caregivers so I may gain and provide support in my recovery from stroke.



www.world-stroke.org

The human rights case for a stroke action plan

Global Stroke Bill of Rights, World Stroke Organisation, 2014

What people need – the reality: initial stroke care is not addressed adequately

“There is no state certification/ accreditation of stroke units. As such we have no medical specialty «stroke medicine». Thus stroke patients are treated not by specially educated stroke physicians, but mainly by general neurologists”. Ukraine

“We found major inequalities in treatment of acute stroke patients between and within 44 European countries, and in many countries rates are far below highest country rates, leaving many patients untreated”. European Stroke Journal

“National guidelines and generic protocol for stroke care exist but there is no appropriate resources for its implementation”. Ukraine



Patients’ families have even less support than patients themselves. Slovenia

What people need – the reality: stroke consequences not addressed adequately



"There is no structured, standardised care management for stroke- patients when they return home". Germany

"Due to deficiency of post- stroke services, stroke survivors leave for psychiatric hospitals or institutions for mentally handicapped people". Czech Republic



"Every stroke is different, and so is the recovery that follows. Patients suffer not just physical problems like weakness and impaired gait, but also difficulties with language, memory, cognition and emotional problems. Patients everyday life changes and become full of obstacles and frustration." North Macedonia.

"In therapy terms, patients effectively walk off a cliff after they pass through the hospital gates". Ireland

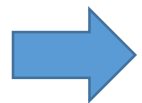
"Thousands of stroke survivors do not receive the support they need with their recovery when they leave hospital". UK

"The life after stroke is the poorest point of the care process". Spain

Patient needs are not being met - what are we going to do about it?



- Stroke is a leading cause of early death and disability
- Increasing numbers of strokes and cost of stroke care
- Disparities between & within countries along the **entire** stroke care pathway, with post-stroke support being neglected by all countries
- Many countries do not have a specific strategy for dealing with stroke, supported with adequate funding



Fuels the need for a Stroke Action Plan to confront stroke & its impact on our European citizens

Question to you



Is anyone in your country working to implement the Stroke Action Plan for Europe?

Yes

No

Don't know

What you can do to help



“As cardiovascular disease, diabetes, cancers, and other non-communicable diseases became leading causes of early death and disability, they also emerged as population health needs with the highest potential health gains—that is, where health systems could increasingly deliver the most improved outcomes via effective coverage of interventions and services”. Global Burden of Disease 2019

Today – we are going to outline an overview of implementing the Stroke Action Plan across Europe in the hope that you will commit to:

1. Improving the quality and outcomes for stroke care in your country
2. Working with us to implement the Stroke Action Plan in Europe in your country
3. Working in partnership – stroke support organisations and national scientific organisations



