



Stroke prevention and life after stroke during the pandemic: Advocacy activities at EU level

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My presentation

- Stroke Alliance for Europe – who we are and what we do
- Why do we advocate for stroke
- Life after stroke
- Prevention and life after stroke activities at the EU, European and national level

Who we are

Stroke Alliance for Europe (SAFE)

- Membership organisation
- We represent stroke support organisations (SSOs) from more than 30 European countries.
- We are the voice of stroke survivors in Europe.

Our vision

- To work towards greatly decreasing the number of strokes in Europe and that all who are touched by stroke get the help and support they need.

What we do

to the advancement of stroke prevention and the improvement of the quality of life of stroke survivors:

- Help grow and develop SSOs
- Campaigning at a European level, and by supporting members to do so locally.
- Encouraging research

Why advocate

The human rights case
for a stroke action plan

Global Stroke Bill of
Rights, World Stroke
Organization, 2014

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

Why advocate

"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

Why advocate

"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

Why advocate



The projections in this report indicate that between 2015 and 2035 overall there will be a

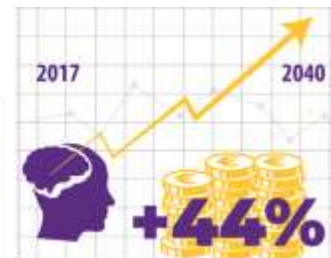
34%

increase in total number of stroke events in the EU from 613,148 in 2015 to 819,771 in 2035

Number of people living with stroke as a chronic condition from 3,718,785 in 2015 to 4,631,050 in 2035 an increase of almost

25%

or 1 million across the EU



Why advocate

Investing in stroke care

Three interventions which are in the latest stroke guidelines:

- the treatment of atrial fibrillation to **prevent** stroke
- mechanical thrombectomy (the clot retrieval from the blood vessel in the brain) **treatment** in the **acute phase** of stroke
- **rehabilitation** after stroke

Interventions work – overall

- improve outcomes
- tend to generate cost savings
- generally good value for money for all countries involved in the research



Why advocate

- 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
- **Stroke is an increasing cause for concern BUT it is a viable investment proposition**

➔ **Fuels the need for a action to confront stroke & its impact on our European citizens**

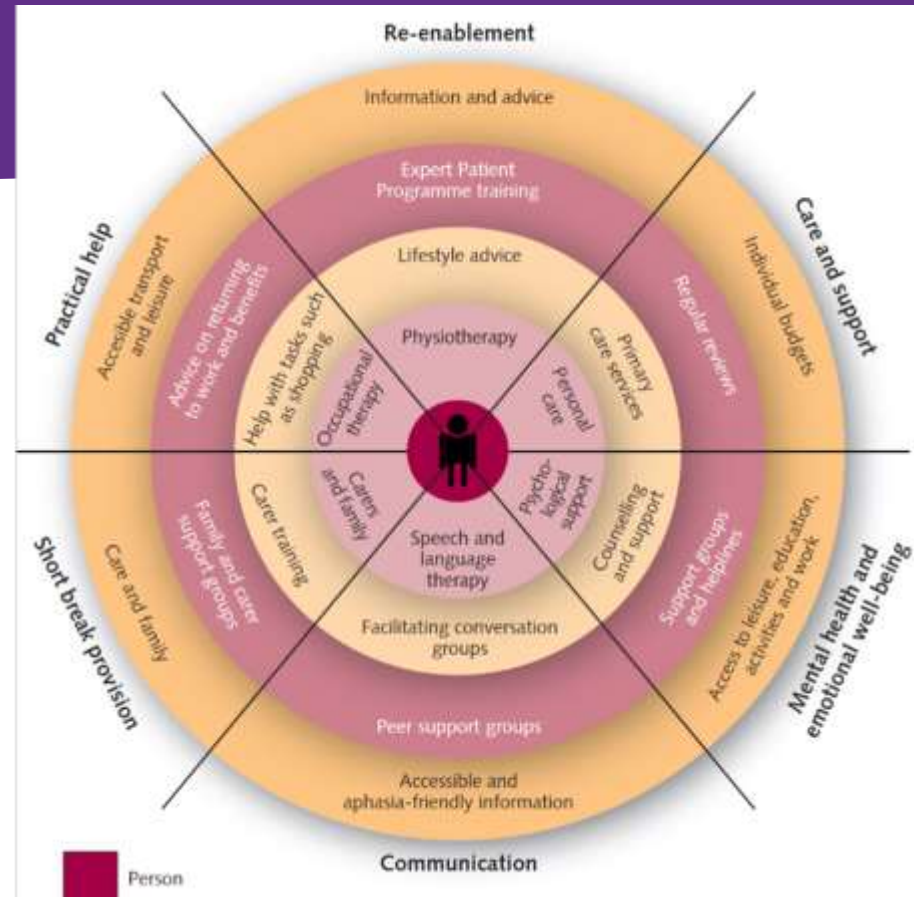


Life after stroke

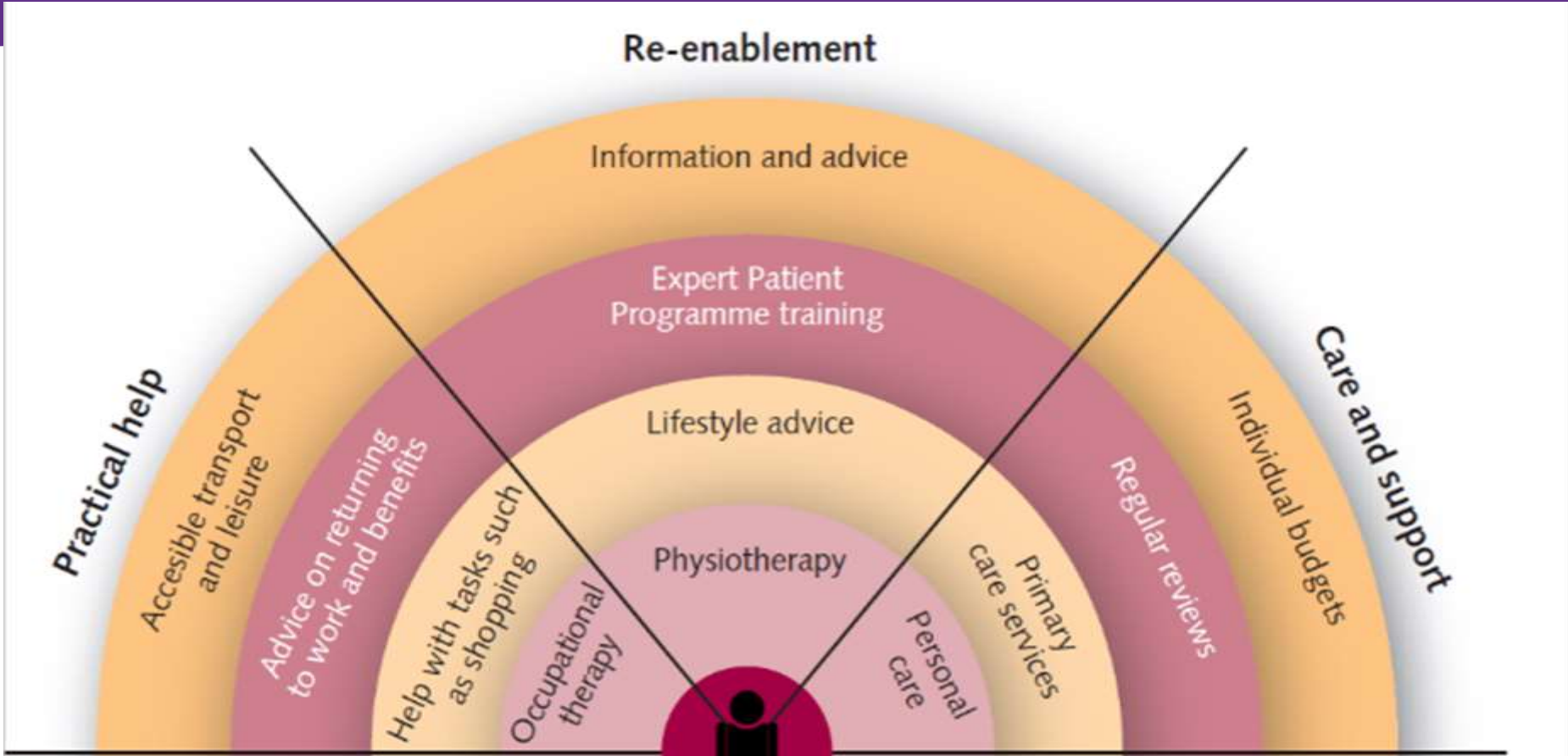
- Stroke can be caused by a blockage cutting-off the blood supply to, or through, part of the brain; by a bleed from a burst blood vessel
- Treatment - a clot-dissolving agent or removal of the blood clot
- Some stroke survivors may experience a disability following stroke. The level of seriousness and permanence of this disability will depend on which part of the brain has been injured and how severely it has been affected.
- Common stroke disabilities
 - Problems relating to paralysis or movement
 - Problems with speech or understanding language
 - Thinking and memory difficulties
 - Sensory disturbances eg visual problems
 - Emotional problems
- Stroke is more than a stroke

Life after stroke

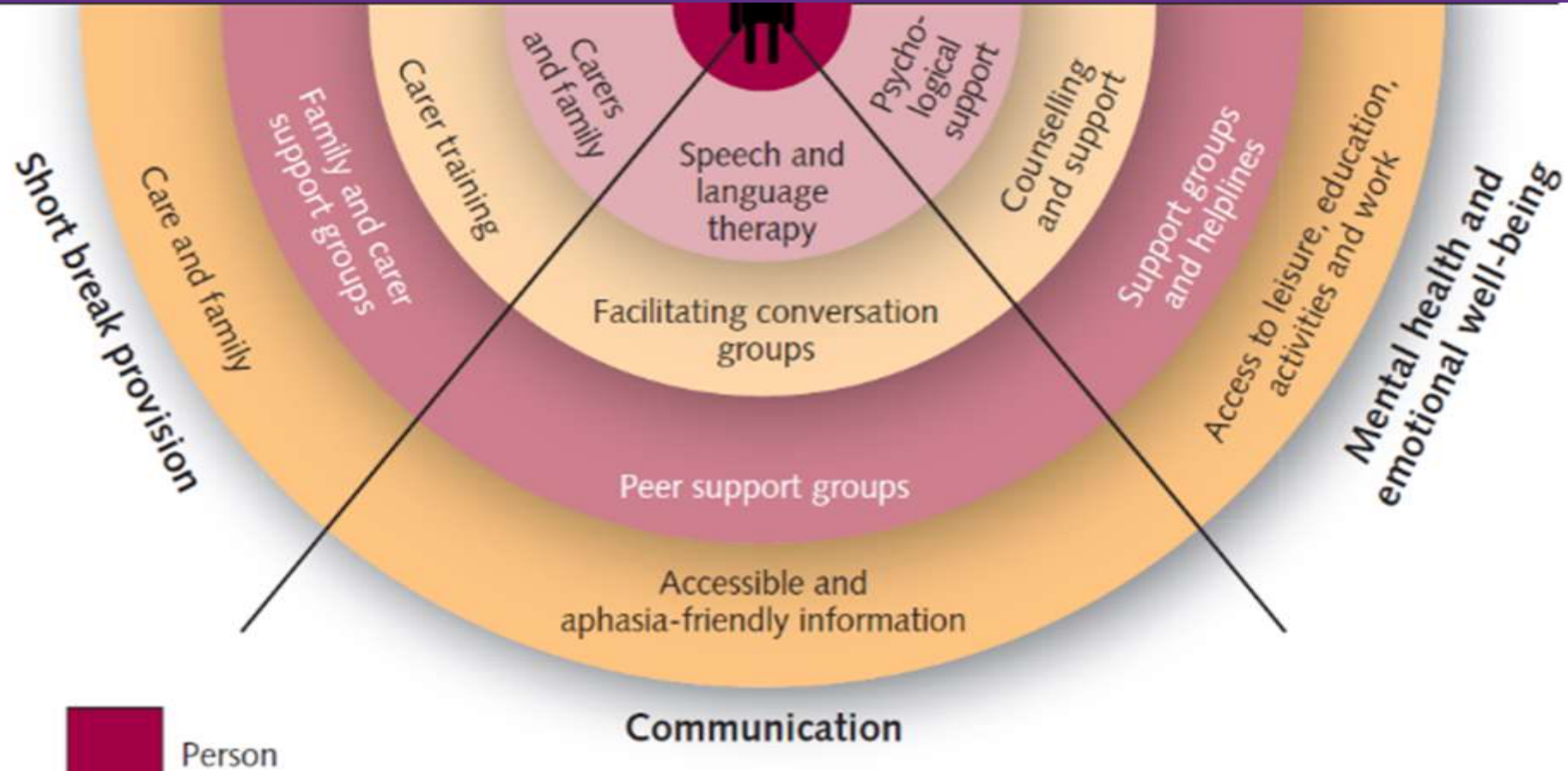
- Re-enablement
- Care and support
- Mental health & emotional well being
- Communication
- Short break provision
- Practical help



Life after stroke



Life after stroke



EU and national action



EU and national action

What are we trying to achieve

- Getting each European Government to commit to implementing a **national stroke plan**, to **funding stroke services** and to **audit those stroke services**

How will this help?

- highlight stroke services that are not meeting minimum standards
- identify what needs to be done to bring about improvements in services
- plan for the recruitment and training of the stroke specialist workforce needed
- enable SSOs to work with local health systems to promote public awareness campaigns and to provide much needed life after stroke support
- highlight issues between countries

Most important of all - lead to better outcomes – fewer people will die from their stroke, and more people will make a quicker and better recovery from the impact of their stroke

EU and national action

1. Developing and supporting national coordinators in each county in 2020/2021

- Information meetings and advocacy training sessions
 - How to write a stroke strategy
 - How to involve people affected by stroke
 - How to work with key stakeholders – politicians, media
- Developed the Stroke Action Plan for Europe website
 - <https://actionplan.eso-stroke.org/>
 - Resource centre
- Result
 - 48 countries have coordinators in potential 52 countries
 - 89 people named coordinators



EU and national action

2. Country commitment

- Declaration of support: <https://actionplan.eso-stroke.org/the-declaration-for-action-on-stroke>
- Launch on European Stroke Awareness Day
- Declaration has been translated in **17** languages



EU and national action



each
European Alliance for Cardiovascular Health

ehp ESC EKHA ecda
MedTech Europe AIM SAFE efpia
EUCOPE Global Heart Hub COCIR FH Europe ESO

Aims

European Commission elaborate an **ambitious plan to address the burden of CVD** and really make a difference by improving the lives of millions of people.

The plan should promote **ambitious actions across the whole disease pathway** primary and secondary prevention :

- early detection, screening, and diagnosis
- access to care and optimal treatment
- rehabilitation
- quality of life after a CVD event

In summary:

Lots going on
Watch this space
Keep up to date on
Twitter @StrokeEurope
Facebook @safestroke

Thank you for listening
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