

Update on the Stroke Action Plan for Europe's Life After Stroke Pillar

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Conflicts

- ▶ None to declare

Reference

Christensen et al, on behalf of the SAP-E collaborators, Stroke Action Plan for Europe 2018-2030 (SAP-E): **mid-term review and update**, *European Stroke Journal*, Volume 11, Issue 1, January 2026.

<https://doi.org/10.1093/esj/aakaf026>

Topics

Primary prevention

Organisation of stroke services

Management of stroke services

Secondary prevention

Rehabilitation

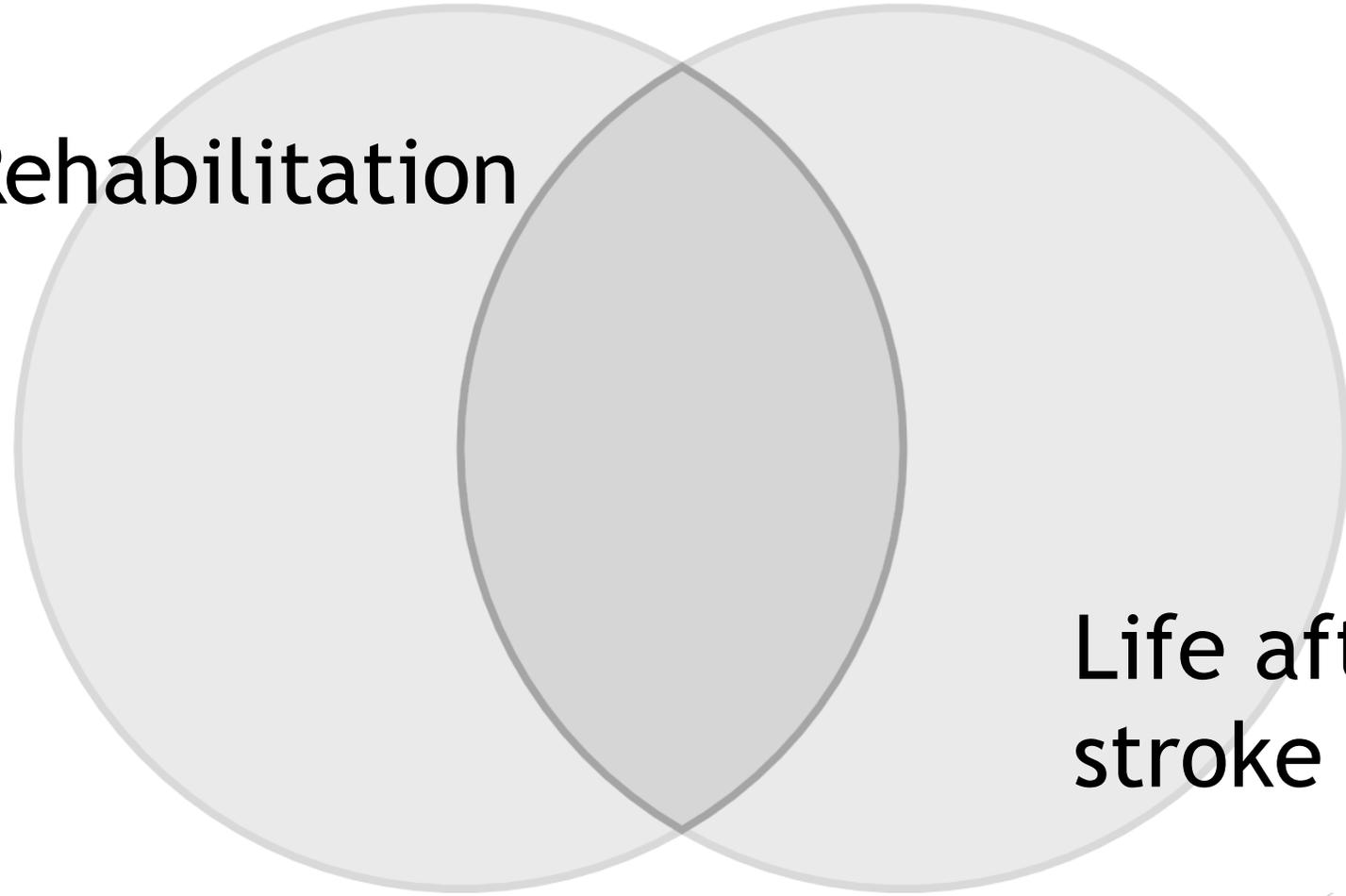
Life after stroke



Evaluation of outcomes and quality improvement

Translational research

Rehabilitation



**Life after
stroke**

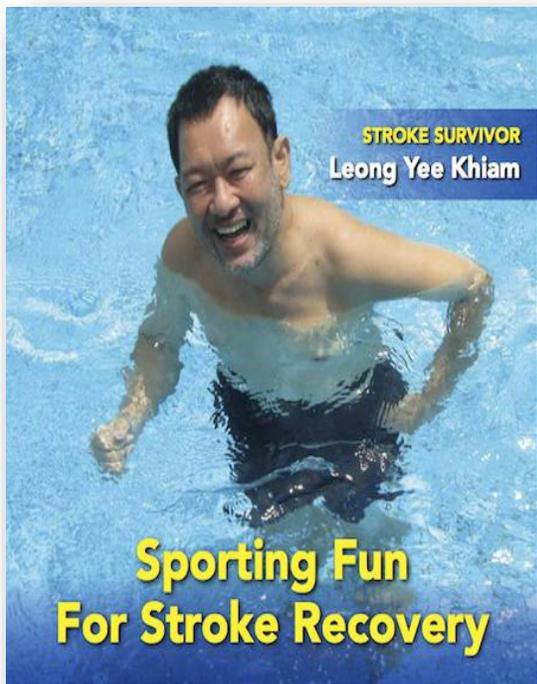
Background

-Life after stroke

Focus is on helping individuals navigate, adjust to and manage long-term effects of stroke (Children through to very old people).

Wide range of issues ranging across communication, relationships, emotional well-being, engagement in activities, and return to work. It is the largest domain.

It is NOT about simply helping people to live the life they are left with after their stroke but helping support people to live their best lives. Thrive not survive.



Life after stroke is different, but it doesn't have to be necessarily worse.

My life's changed obviously, I mean, life has changed totally but I think I'm adjusting.



Life after stroke

Still a lag here behind other domains in terms of available data and research.

‘Life after stroke’ is an emerging term, thus making identification of new evidence problematic.

Authors are only beginning to use this term when classifying papers. We need to use **#Life after stroke!**

Facts

Facts demonstrate the prevalence of **unmet needs**, physical, cognitive and psychological consequences, effects on daily functioning, employment and sexuality, and the burden experienced by caregivers.



Facts

- ▶ More than 6 in 10 survivors rely on support to help them with daily activities such as getting dressed, making meals or going to the shops (UK Stroke Association, 2019).
- ▶ Post-stroke fatigue affects around 50% of survivors (English et al, 2024).
- ▶ Prevalence of depression around 30% up to 15 years after stroke (Ayerbe et al, 2013).
- ▶ 1 in 4 survivors are of working age; one 1 in 3 will have to give up their job (UK Stroke Association, 2019).
- ▶ Caregivers at high-risk of developing a mental health condition (Skajaa et al, 2024).

State of the art

Transition and Care

Health

Longer Term recovery

Participation

Relationships

Involvement

Carers



Observations

- Provision of long-term Life after stroke support **varies widely** between, and within, European countries.
- Formal services, charities, and voluntary groups have great **potential** to evaluate their contributions and share best practices.
- ▶ Most stroke survivors experience **unmet needs**: each stroke survivor experiences an average of 2-5 unmet needs, including difficulties with mobility, work, leisure, lack of information, transport, access to therapy, personal care, fatigue, pain, cognitive and neuropsychological issues, and emotional needs
- ▶ Mitigating these needs is **hampered** by lack of resources, and weak evidence and inconsistencies in reporting.

Importantly

Overall, the lack of data collected on outcome is compelling.

This has significant implications both

- for individuals who can easily get lost or forgotten in existing systems and
- for planning support for stroke survivors strategically in an informed way.

Targets for 2030: top 5 priorities

- ▶ Providing comprehensive stroke **follow-up** that addresses all aspects relevant for life after stroke (KPI 12a).
- ▶ Using a recognised **post-stroke checklist and functional assessment** to capture all stroke-related health problems. People should be referred to as appropriate (KPI 12b).
- ▶ Providing equitable support, established through national stroke care plans and in conjunction with SSOs, to stroke survivors, regardless of their place of residence and socioeconomic status. **Minimum standards** should be agreed for what every stroke survivor should receive regardless of where they live (KPI 1 and KPI 2).
- ▶ Ensuring appointment of government-level individuals or teams responsible for inclusion of **life after stroke in national stroke plans**, with supporting national databases in place for quality improvement.
- ▶ Exploring implementation of **supported self-management** information and assistance systems needs as a priority area.

Research and development: top 5 priorities

- ▶ What are the experiences and needs of stroke survivors at different times during their lifespan, considering **different cohorts of stroke survivors** and challenges of those with multiple morbidities—and their carers—to inform the design of optimal care pathways?
- ▶ What would a model of **best care and long-term support** look like? This should include the opportunity for reviews and specific roles to provide holistic, coordinated support.
- ▶ How can **data on life after stroke** best be collected within stroke registries to improve understanding of the long-term outcomes of stroke and service planning, and what data should this comprise?
- ▶ What **products and services** (digital and physical) would support self-management, community integration, education and healthcare?
- ▶ How can high-quality information and training to help **non-specialist staff**, especially social care staff, be targeted? It is envisaged that this will involve research around staffing levels, core competencies and the involvement of non-governmental and non-profit-making bodies such as charities and voluntary groups.

Conclusion

Life-after-stroke services and support are essential to enable those affected by stroke to navigate, adjust to and manage the long-term effects of stroke.

Only with structured follow-up—addressing practical, social, emotional and clinical needs after hospital discharge—can survivors (and their carers) live the best life possible.

However, the funding of such services and research to maximise their impact is routinely under-prioritised.



WHAT'S
NEXT?

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Proposed life after stroke definition?

Life after stroke begins as soon as someone has a stroke, is long-lasting and is often life changing. Stroke involves not only the individual but their family and carers, and covers all aspects of life. Life after stroke support must be dynamic and comprehensive and enable stroke survivors to live their best life and be supported to redefine their life goals, dreams and roles.



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#LifeAfterStroke

