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Some Recommendations to address The Burden of stroke in Europe

"Time is brain" is a concept that perfectly encapsulates the need for swift action when stroke strikes. The sooner stroke symptoms are realised, the sooner the person gets the care they need, the greater the chances for survival and life with fewer disabilities.

What happens in Europe is that a person who has a stroke for example in Catalonia, Spain, and a person who has a stroke in Bulgaria will not receive the same care, which influences their chances of survival.

Stroke Alliance for Europe (SAFE) is a non-profit-making organisation that is a coalition currently of 30 Stroke Support Organisations from across Europe. These Stroke Support Organisations (SSO's) mutual goal is to drive stroke prevention and care up the European and national political agendas, preventing stroke through education, and supporting stroke care and patient centered research. SAFE aims to raise awareness of the major impact stroke has on individuals, and on the health and economy of Europe.

The Burden of Stroke in Europe Report, commissioned by SAFE, conducted by King's College in London and published in May 2017, has projected that between 2015 and 2035, overall there will be a 34% increase in the total number of stroke events in the EU (from 613,148 in 2015 to 819,771 in 2035). This means that stroke prevention should be a high priority for governments and health care systems. The research findings indicate that stroke is widely undertreated, with the risk factors not being controlled and treated the way they should be.

The Report painted a gloomy picture of the present situation when it comes to stroke and how much we know about the quality and extent of stroke care, which was variable across countries, but also indicated that public awareness campaigns were not regularly occurring. In many European countries people, in general, do not know what causes stroke and how to prevent it. For most of them, stroke is still an act of God, for which mistakenly they believe there is no treatment. Risk factors such as High Blood pressure and high cholesterol, Atrial Fibrillation, diet and lack of exercise can all be combatted. When it comes to the acute phase, we know that stroke units save lives and improve outcomes, but we don't have a Europe-wide applied pursuit of the essential elements of stroke unit care. Despite over thirty years of evidence showing the difference stroke units make and despite their inclusion in European and national guidelines, it is estimated that only about 30% of stroke patients receive stroke unit care across Europe. This figure masks startling inequalities between countries, and in particular the East-West divide in stroke unit provision.

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After obtaining the results from this research, conducted in 35 European countries, SAFE recommends continuous, sustained, effective awareness campaigns, which should be included in national stroke strategies and financially supported by Governments, so more people will know how to recognize stroke symptoms. Also, there should be a more systematic approach towards setting up the stroke care pathway, with planned training for healthcare professionals. The performance of the system should be regularly evaluated, using evidence-based methods and on-going assessment of its implementation and effectiveness. Finally, there is a need to ensure the improvement of emergency pathways in order to reduce the time from the first onset of stroke symptoms until the appropriate treatment is administered.

Another important factor when dealing with stroke in Europe is the standard of care across Europe. There are many disparities among all European countries which took part in the Burden of Stroke research, but all of them lead to the conclusion that there should be a European action plan which sets the standards for stroke prevention, treatment and rehabilitation for all European countries. It is incredible to think that at present a visitor from one European country to another may go from world class care to almost minimal care.

The research findings from this report have led SAFE to generate a number of action points for EU policy makers, national health system representatives and stroke support organisations. These recommendations are outlined in full in the report which can be freely downloaded from the internet.

The recommendations aim to alleviate the current situation and stop the future catastrophic impacts of stroke in Europe;

1. A systematic evidence-based approach to public education across Europe about stroke risk factors, and on how stroke is preventable is needed.
2. Stroke prevention awareness should be raised to a higher level, especially when it comes to high blood pressure and atrial fibrillation. Improvement in diagnosis and treatment of AF in particular for at risk populations needs attention.
3. Timely assessment of suspected TIA patients in specialist clinics should be widely available.

When Stroke strikes there is a need to get people to call the emergency services immediately, and for those services to clearly understand the route into emergency care for the individual. In many countries this response to stroke is not to the levels one would expect.

4. There is a need to improve public education on the symptoms and response to stroke.
5. There is a need to improve emergency pathways to reduce Door to Needle times.

There are still too few people across Europe being treated in dedicated stroke units with stroke specialist multidisciplinary staff in appropriate numbers. Thrombolysis rates have increased significantly over the last decade. However, large variations exist between and within countries. Even countries with comparatively high thrombolysis rates have room for improvement. Apart from improving public stroke knowledge, several organizational factors have been found to improve rates and merit further assessment of their effectiveness and feasibility according to the individual country's context.

Accurate international comparisons of stroke care quality, e.g. thrombolysis rates, are difficult, because of a lack of standardised, internationally agreed and widely collected quality measures. Within the EU, there are numerous stroke registers on a local, regional, national, and sometimes international level collecting varied data with different methods. International stroke registers with standardised datasets exist, e.g. SITS-MOST and RES-Q (see example), but data reporting is voluntary and therefore coverage varies significantly. With the advent of potentially highly effective treatments such as thrombectomy , there is a positive driver to once again consider national stroke strategies and pathways to implement life and cost saving interventions in acute stroke Structural changes to acute stroke care within the respective national and local context could help improve rates and patient outcomes.

If used more extensively data registers could contribute to reliable international benchmarking, providing valuable insights into inequalities of care and the performance of different healthcare systems and helping to focus on areas where improvement is most needed.

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6. SAFE recommends that every stroke victim should be treated in a stroke unit and improvement plans should prioritize the consistent implementation of key elements of organised stroke unit care, as laid out in ESO and national guidelines.
7. Thrombolysis is still under performed across all of Europe, and Thrombectomy is currently unavailable to the majority of patients, health care systems must respond positively to drive dramatic improvement.
8. SAFE recommends that there needs to be a Europe-wide system of standardised assessment criteria of stroke unit care that would encourage international benchmarking and could drive quality improvement.

AFTER THE STORM HAS PASSED, AND THE STROKE VICTIM BECOMES A STROKE SURVIVOR, THE PROVISION OF SUPPORT FOR THE FORWARD JOURNEY IS TOO OFTEN NOT CLEAR

Stroke survivors across Europe are waiting too long to have their immediate rehabilitation needs assessed and therapies started. In general, the rehabilitation they get is not intense enough, is too short, and often fails to address on-going issues, such as depression. Very few people get follow up reviews. In the long term, support is too often non-existent.

Many stroke patients have problems with mobility, fatigue, speech, memory and/or emotions among others and need support from one or more therapy areas (such as physiotherapy, speech therapy, occupational therapy and/or psychology). These problems affect their ability to complete daily activities at home and to participate in the community. The problems related to stroke can be long-lasting. After 15 years, two-thirds (63%) of survivors are living with disability, nearly two in five (39%) have depression and over a quarter (30%) have cognitive impairment. Furthermore, stroke patients are much more likely than people who have not had a stroke to be living with another illness.

Health and social care services need to understand and address gaps in rehabilitation and support, as inadequate rehabilitation can leave patients with disabilities that could have been avoided. There is a particular lack of occupational, speech and psychological therapy across Europe.
Stroke patients often find that health and social care services do not meet all their needs. For example, in one UK study, up to 59% of patients reported unmet clinical needs. There is a need for reviews of progress for stroke survivors, on an annual basis, to enable support and recovery needs to be identified and addressed. Post-stroke disability contributes significantly to long-term healthcare resource use; therefore effective rehabilitation will potentially save costs.

9. SAFE recommends that a multi-disciplinary assessment takes place in the stroke unit so the rehabilitation can start as soon as someone is medically stable.
10. Access to rehabilitation therapy must be improved, and its provision should be related to meeting the needs of patients not constrained by organizational factors.
11. Countries should set targets for secondary prevention, screening for depression, and for psychological and social support.

Too many stroke survivors leave hospital without on-going rehabilitation being in place. This is of particular concern for Early Supported Discharge (ESD) schemes. The evidence is clear that the effectiveness of ESD schemes relies upon access to rehabilitation at the same intensity as would have been provided on the stroke unit.
When it comes to ongoing, long-term support and the follow up, they are inadequate in many parts of Europe, and there is too much ignorance of the contribution that well organized and supported Stroke Support Organisations can make through assisting with information, peer to peer, and self-management activity. In many European countries there are still inadequate mechanisms for consulting with those who know the weaknesses of the stroke care system, - the survivors and their families. To mature stroke care in Europe the growth of stroke support Organisations, able to aid life after stroke, provide advocacy, information, and support for stroke research is necessary.

Jon Barrick, SAFE President

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