

STROKE ACTION PLAN FOR EUROPE 2018-2030

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2018-2030

Stroke Alliance for Europe

Rue Washington 40

1050, Brussels, Belgium

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Email: mail@safestroke.com

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FOREWORD

This year, around 610,000 people in the European Union will have a stroke, and, although the figures are patchy, at least 170,000 people in non-EU European countries will have one. That is more than one stroke a minute. Their stroke could be devastating - leading to death or life-long disability, shattering their lives and those of their loved ones. Those who survive their stroke will join the millions of stroke survivors across Europe who live with the health, social and financial impacts.

780,000 / YEAR
>1 / MINUTE

In 2017, the Stroke Alliance for Europe (SAFE) with the European Stroke Organisation (ESO), launched a comprehensive overview of stroke and stroke care in Europe. The Burden of Stroke in Europe Report revealed shocking disparities between and within countries along the entire stroke care pathway, with post-stroke support being neglected by all countries.


Estimated total cost of stroke in the EU* of
€45 billion
in 2015 is set to rise
*healthcare and non-healthcare costs

cost of stroke in the EU - an estimated 45 billion Euros in 2015 is set to rise.

The report showed that between 2015 and 2035 the number of strokes is expected to rise by 34% due to an ageing population and across Europe the number of people living with stroke is set to increase by one million, reaching 4,631,050 survivors. The total healthcare and non-healthcare related

That is why, in May 2017, after many years of co-operation, SAFE and ESO formally agreed to work in concert to combat stroke.

This Stroke Action Plan for Europe is a joint project resulting from the collaboration. It follows and builds on the two previous "Helsingborg Declarations" which provided a vital platform for improving stroke care across Europe. ESO and SAFE are honoured to have Professor Bo Norrving as the coordinator of the Stroke Action Plan for Europe, who was also involved with the previous Helsingborg Declarations.

70 experts, working in groups assessing all aspects of the stroke care pathway, created the Stroke Action Plan for Europe. Their task was to review the evidence for best practice, and, taking into account the current state of stroke provision, to outline the key targets all countries and health systems should be aiming to achieve by 2030.

Especially important for stroke survivors and their carers, the Stroke Action Plan tackles the challenges people face in living life after stroke for the first time.

The Plan is both an aspirational framework and a call to action. SAFE calls on all decision-makers to use it to drive health policy change, lead research priorities, improve local stroke management and patient-focussed care and to address the unmet needs unveiled by the Burden of Stroke in Europe Report.

The burden of stroke falls upon us all, but especially on the millions of stroke survivors and their loved ones, living with its consequences every day. Let us all pursue the targets set out in the Stroke Action Plan for Europe to reduce and minimise the impacts of that burden.

Jon Barrick, SAFE President,
Bart van der Worp, ESO President
Valeria Caso, ESO Past President (2016-2018)



INTRODUCTION

Stroke remains one of the leading causes of death and disability in Europe, and projections show that with a “business as usual” approach, the burden of stroke will not decrease in the next decade or beyond. An important contributing factor is that by 2030 the number of people aged 60 and over in Europe is expected to increase by 23%.

Fortunately, there is compelling evidence that stroke is highly preventable, treatable and manageable, and there is a potential to drastically decrease the burden of stroke, including substantially reducing its long-term consequences. This requires the joint actions of Ministries of Health and Social Care, other governmental bodies, scientific and stroke support organisations, healthcare professionals, clinical and preclinical researchers and industry.

Two previous Pan-European Consensus meetings reviewed scientific evidence and the state of current services, and set targets for the development of stroke care for the decade to follow. These resulted in the Helsingborg Declarations of 1995 and 2006.

The Stroke Action Plan for Europe follows the format of the previous Helsingborg Declarations (led by a steering committee of experts). Importantly this version has also involved stroke patient organisations and representatives every step of the way. The process enabled review of what is possible scientifically; the state of current stroke services; research and development priorities and targets, and added new sections on Primary Prevention and Life After Stroke as well as Research and Development Priorities for translational stroke research. The detailed science can be found in the article published in the European Stroke Journal.

The Stroke Action Plan for Europe 2018 to 2030 aligns to, and extends, the WHO Global Action Plan on NCDs 2013-2020, the WHO-Europe NCD Action Plan, and the UN Sustainable Development Goals 2015 to 2030, providing a clear road map that has the potential to drastically change, in a European perspective, one of today's and tomorrow's major public health issues - stroke.

OVERARCHING TARGETS FOR 2030

The Stroke Action Plan for Europe provides targets for each of the Plan's domains – primary prevention, organisation of stroke care, acute stroke care, secondary prevention, rehabilitation, evaluation of outcomes and life after stroke.

There are four overarching goals for 2030.

We have just twelve years to:

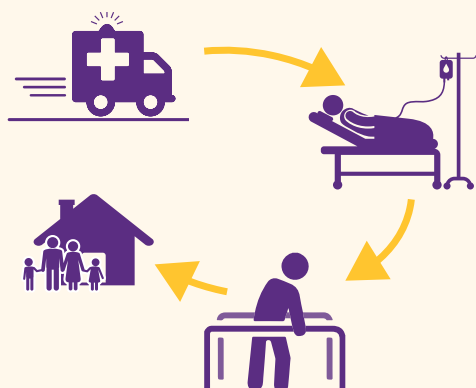


Reduce the absolute number of strokes in Europe by 10%.

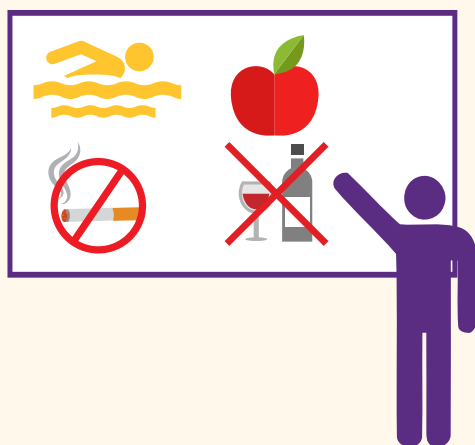
90% or more



Treat 90% or more of all patients with stroke in Europe in a dedicated stroke unit as the first level of care.



Have national plans for stroke encompassing the entire chain of care from primary prevention through to life after stroke.



To fully implement national strategies for multisector public health interventions to promote and facilitate a healthy lifestyle, and reduce environmental (including air pollution), socioeconomic and educational factors that increase the risk of stroke.

PRIMARY PREVENTION

“ When I had a stroke, I never heard about stroke. When I recovered in the hospital, the doctors said, “You had a stroke.” “A what? A stroke?” I didn’t know. Although I was a lawyer, etc.”

Elisabeth Ortinez, Fundacio Ictus, Catalonia, Spain

The 2006 Helsingborg Declaration goal was for all countries to aim to reduce the major risk factors for stroke in their populations, most importantly hypertension and smoking.

Stroke is a largely preventable condition. It shares risk factors with other cardiovascular diseases (CVDs) and also with many other non-infectious, or non-communicable, diseases (NCDs). Addressing stroke risk factors requires individual and society level interventions - addressing life-style and medical issues. So giving up smoking is an individual intervention, while tackling air pollution is a society level intervention, for example. Society level policy and action can impact on an individual’s ability to tackle modifiable risk factors.

While self-management of risk factors should be encouraged, it is very hard for individuals to maintain a lower risk of stroke in the longer term without other forms of society level support. There is good evidence that public health interventions targeting highly prevalent risk factors, including discouraging smoking and encouraging a healthy lifestyle, should be implemented. These could include legislative changes, media campaigns, labelling of food, and educational and preventive measures in schools, workplaces and the community.

Initiatives such as building cycle lanes, guiding people to use stairs, serving healthy food in public places, smoking bans, decreasing the amount of salt and sugar in processed food and soft drinks, health

education and public health campaigns to increase awareness of modifiable stroke risk factors are sensible public health interventions and should be pursued.

It is vital to target the whole population with primary prevention initiatives, not just those already at high risk. That is why concerted efforts to raise awareness of high blood pressure (hypertension) and then to provide screening and treatment are important. Extra efforts are needed to reach and work with people of lower socioeconomic status among whom stroke risk factors are more prevalent.

Medical interventions and ensuring medicine adherence are vital, but need to work with societal and individual interventions.

“ There is this paradox that even when we know which modifiable risk factors are accountable for 90% of strokes, it’s hard to decrease the terrifying number of new strokes each year... We need a strong system of preventive measures where individuals, medics and lawmakers work together very hard and very long to achieve any progress.”

Jelena Misita, SAFE Awareness and Advocacy Manager

Policy-makers should implement and strengthen national strategies for primary prevention and risk factor control. Multi-sectorial public health interventions must promote and facilitate a healthy lifestyle and ensure universal access to primary screening and treatment programmes.

Major differences among European countries concerning risk factor prevalence and control should be tackled through the development of European level guidelines for risk factor screening and treatment.

PRIMARY PREVENTION - TARGETS FOR 2030

Across Europe we need to see a step change so that everyone can get a personalised assessment of their risk of having a stroke and any treatment they may need. The target is, therefore, to:

- 1** *Achieve universal access to primary preventive treatment through improved and better-personalised risk prediction.*

New laws and national strategies are needed to address the most common risk factors. This should include public health campaigns as well as tackling the impact that poor education, deprivation and the environment have on raising the risk of stroke. The target is, therefore, to:

- 2** *Implement legislation and national strategies for multi-sectorial public health interventions that address the prevalent risk factors for stroke (e.g. smoking, sugar, salt, alcohol, polluted air) by promoting, educating and campaigning for a healthy life-style, and reducing environmental, socioeconomic and educational determinants.*

Screening for stroke risk factors and treating them should be a priority. Therefore, the target is to:

- 3** *Make available evidence-based screening and treatment programmes for stroke risk factors in all European countries.*



High blood pressure is too often undetected and untreated. The target for every country in Europe is:

- 4** *To have high blood pressure detected and controlled in 80% of persons with hypertension.*



© Združenje bolnikov s cerebrovaskularno boleznijo Slovenije

ORGANISATION OF STROKE SERVICES

” There’s a programme called Early Supported Discharge (ESD), so, that’s really moving people out of hospital beds and getting them home earlier. They get their therapy for the first 6-8 weeks at home, and it’s been proved in many countries around Europe that that improves outcomes and actually reduces overall costs for the health service as well. So, we demanded that our Minister for Finance, a stroke survivor (should do the ESD programme and)... he went on the Early Supported Discharge programme, and six weeks later he was cycling round the Phoenix Park in Dublin - six weeks after not being able to open his front door. And that brought home – to people that make those decisions – in a way that nobody else could... that brought home what that programme really means to a real person’s life.”

Chris Macey,
Irish Heart Foundation

The 2006 Helsingborg Declaration goal was that all patients in Europe with stroke will have access to a continuum of care from organised stroke units in the acute phase to appropriate rehabilitation and secondary prevention measures.

Across Europe there is wide variation in how stroke services are organised. Yet the way stroke services are organised is fundamental to the quality of care. More reliable and precise information about the structure and organisation of stroke care is needed. This should include registries for monitoring key performance indicators and programmes to certify stroke units. The role of stroke medical societies and support organisations can make a vital difference, creating pressure for better organised stroke services and enabling the practical development and audit of the quality standards needed.

In terms of emergency and acute stroke care, good organisation includes:

- continuous awareness programmes to promote public recognition of stroke symptoms;
- stroke training for dispatchers, paramedics and emergency medical staff;
- planning of stroke centre locations and ambulance routes to minimise journey times;
- the use of validated tools for stroke symptom recognition such as FAST;
- centralised admissions;
- the existence of specialised stroke teams and certified/audited stroke units;
- 24 hour access to brain scanning;
- telemedicine for remote areas;
- continuing quality improvement processes;
- planning so that early supported discharge facilitates the same level of post-acute care in the community as would be provided in hospital.

Currently, reliable and precise information about the structure and organisation of stroke care, and the implementation of stroke management pathways, is still lacking in many countries. Fewer than 10% of stroke patients across Europe reach the hospital within 60 minutes of symptom onset; and in many countries, the symptom-to-hospital delay has not decreased in recent years.

Only a minority of countries have established a certification system with well-defined quality criteria, or a regularly monitored system for benchmarking delivery of care.

ORGANISATION OF STROKE SERVICES - TARGETS FOR 2030

Stroke support organisations and stroke medical societies are vital in the development and implementation of national stroke planning, providing expertise, specialist knowledge and patient perspectives. Therefore, the target is for:

1 *Establishing a medical society and stroke support organisation in each country, which collaborates closely with the responsible body in developing, implementing and auditing the national stroke plan.*

There is a wealth of evidence about what good stroke care pathways look like. These pathways should help guide stroke services from prevention and acute care, through to rehabilitation and life after stroke. And the public need to be engaged so that they understand what to expect of their services. All countries in Europe need to make sure they are:

2 *Guiding national stroke care by evidence-based pathways that cover the entire chain of care. These pathways are understood by the public, and may be adapted to meet regional circumstances to ensure equal access to stroke care irrespective of patient characteristics, region, and time of hospitalisation.*

Good stroke care relies on highly skilled, specialised stroke personnel. Across Europe we need to make sure that well trained staff are recruited so that effective multi-disciplinary stroke team work can be carried out. Countries should ensure they are:

3 *Managing and delivering stroke care by competent personnel and teams, and creating plans for effective recruitment and training as part of a national stroke plan.*

Stroke unit care is central to reducing deaths and disability from stroke. But that is only the case if those stroke units are of high quality. To define and assess what a good stroke unit looks like, all European countries should make sure that:

4 *All stroke units and other stroke services undergo regular certifications or equivalent auditing processes for quality improvement.*



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MANAGEMENT OF ACUTE STROKE

“ *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.”*

Global Stroke Bill of Rights, World Stroke Organisation, 2014

The goals for management of acute stroke in the 2006 Helsingborg Declaration were that: more than 85% of stroke patients survive the first month after stroke; more than 70% of survivors are independent in their activities of daily living by three months after the onset of stroke; all patients with acute stroke who are potentially eligible for acute specific treatment are transferred to hospitals where there is the technical capacity and expertise to administer such treatment.

“ *Every person with acute stroke deserves the right to have equal access to optimized and efficient stroke care, diagnosis and treatment, regardless of the place of living, age, gender, culture, social and economic status.”*

Professor Anita Arsovska,
SAFE Board Member

Stroke units, staffed with a stroke specialist multi-disciplinary team, are the single most effective intervention in delivering improved outcomes. And some interventions that have been shown to improve outcomes, such as thrombolysis, can only be delivered where there is well organised stroke care and high quality acute stroke units. This is also true of newer procedures such as thrombectomy (clot retrieval).

But access to stroke units is variable across Europe and the (median) average time for people to get treatment is still far too long - onset-to-treatment (OTT) time for thrombolysis of 140 minutes in Western Europe, and 150 minutes in Eastern Europe. A median door-to-needle (DNT) time (the time it takes for stroke patients to get thrombolysis once they have arrived at the hospital) of 70 minutes has been reported in international European registries even though there are examples of just 20 minutes door to needle times in experienced and high-volume centres.



ACUTE STROKE - TARGETS FOR 2030

We know that stroke units make all the difference and yet in too many places people do not have access to them. Therefore all countries should aim to be:

- 1** ***Treating 90% or more of all patients with stroke in Europe in a stroke unit as the first level of care.***

Restoring blood flow in the brain can be of tremendous benefit for many patients, reducing long-term disability and speeding up recovery. But thrombolysis and thrombectomy are still not available universally across Europe. The target is, therefore, for all countries to be:

- 2** ***Guaranteeing access to re-canalisation therapies to 95% of eligible patients across Europe.***

The quicker someone gets these re-canalisation treatments the better the outcome. So reducing the time it takes for someone to get treatment once they are at the hospital is vital. The aim is for the:

- 3** ***Decreasing median onset-to-needle times to below 120 minutes for intravenous thrombolysis and onset-to-reperfusion times to less than 200 minutes for endovascular treatment.***

These first two targets are essential so that the proportion of people treated with clot busting drugs (IVT) or mechanical clot extraction (EVT) can increase. Countries should be aiming at:

- 4** ***Achieving Intravenous Thrombolysis (IVT) rates above 15%, and Endovascular Therapy (EVT) rates above 5%, in all European countries.***

The bottom line is reducing stroke deaths and disability. This includes for non-clot based strokes, , like bleeding internally in the brain (intracerebral haemorrhage), and on the surface of the brain (subarachnoid haemorrhage). Across Europe the aim should be:

- 5** ***Decreasing first-month case-fatality rates to less than 25% for intracerebral haemorrhages and subarachnoid haemorrhages, and increasing the rate of good functional outcomes to more than 50%.***



SECONDARY PREVENTION



In the Helsingborg Declaration of 2006, the goals for 2015 were to reduce stroke mortality by at least 20%, and for all patients with TIA or stroke to receive appropriate secondary preventive measures.



Secondary prevention measures have the potential to reduce the number of stroke survivors having further strokes by 80%. This means recognising and treating TIA (mini strokes) and making sure that proper risk assessments and treatment plans are started for people with TIA or who have had a stroke in hospital and continued throughout life in the community.

Each stroke is different and its causes need to be worked out in order to plan better secondary prevention methods. – another reason for the need for brain imaging to be universally available.

The identification of risk factors has two major cornerstones:

-  Identification and helping patients to tackle 'life-style' risk factors in a personalised approach.
-  The 'medical' risk factors, for which management guidelines exist.

Risk factors such as poor diet, alcohol and tobacco use, drug addiction, obesity, high blood pressure and cholesterol, atrial fibrillation, diabetes mellitus, and sleep apnoea are modifiable and must be addressed in every patient as they influence each other.

Non-modifiable factors, such as age, sex, race or ethnicity, and family history, also have an impact on the modifiable risk factors. National stroke registers should record these factors and the secondary prevention interventions used.

Patients with stroke or TIA often have co-existing cardiac, renal or peripheral arterial disease, and this needs investigation and treatment. Depression and anxiety can be detrimental to lifestyle and adherence, and are risk factors for stroke and dementia.

There is wide variation in the provision of secondary prevention across Europe, but the data is patchy and often out of date. We do know that more than 60% of patients presenting with a stroke have high blood pressure. Although 80-90% of these are treated, fewer than 40% will have their blood pressure adequately controlled. Reasons for inadequate blood pressure control include a lack of monitoring, under-treatment and low adherence rates. Similarly, although statin prescription rates on discharge from hospital are high, long-term adherence rates are low. And too many patients with atrial fibrillation still do not receive oral anticoagulation.



MORE THAN 60% OF PATIENTS PRESENTING WITH A STROKE HAVE HIGH BLOOD PRESSURE

SECONDARY PREVENTION - TARGETS FOR 2030

There is no excuse for someone who has already had a stroke or TIA to not be getting secondary prevention treatment, advice and support. It is, therefore, vital that countries are:

- 1** *Including secondary prevention in national stroke plans with follow-up in primary/community care.*

The vast majority of stroke survivors need specialist advice and support and need to be confident that they are able to get timely and appropriate secondary prevention management. The target should be:

- 2** *Including secondary prevention in national stroke plans with follow-up in primary/community care.*

- 3** *Ensuring that at least 90% of the stroke population is seen by a stroke specialist and have access to secondary prevention management (investigation and treatment).*

In order to accurately assess a stroke survivor's risk of having a further stroke a range of diagnostic tools and tests must be available. The target is to:

- 4** *Ensure access to key investigational modalities: CT (or MR) scanning, carotid ultrasound, ECG, 24-hour ECG, echocardiography (transthoracic and transoesophageal), blood tests (lipids, glucose, HbA_{1c} and others).*

To reduce their risk of having a further stroke, all survivors should be able to get the appropriate intervention. The Stroke Action Plan for Europe's target is for all countries in Europe to be:

- 5** *Ensuring access to key preventative strategies: lifestyle advice, antihypertensives, lipid lowering agents, antiplatelets, anticoagulants, oral hypoglycaemic agents and insulin, carotid endarterectomy, and PFO closure.*



REHABILITATION

“ The evidence from all over Europe is of inadequate rehabilitation services, often too little is given too late, or teams not able to offer all the appropriate therapies, and poor review systems, so that ongoing rehabilitation is not offered effectively either. With appropriate planning it does not have to be this way”.

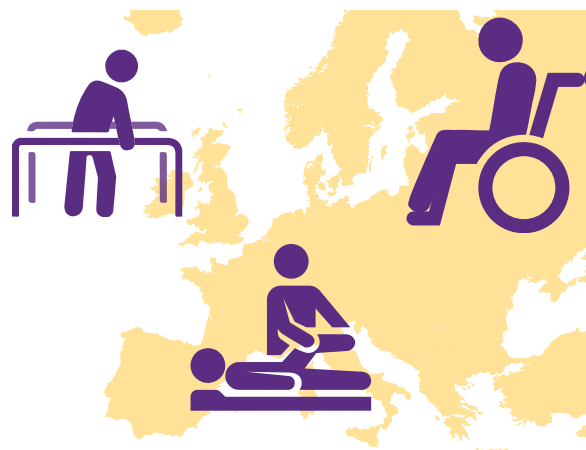
Monique Lindhout, Hersenletsel.
nl (Netherlands)

In the Helsingborg Declaration of 2006, the goal for 2015 was that all stroke patients in Europe would have access to a continuum of care from acute management to appropriate rehabilitation, delivered in dedicated stroke units.

Acute stroke care, skilled nursing care and specialist rehabilitation are all core aspects of a comprehensive stroke unit, and treatment in such facilities has been shown to reduce mortality and disability.

Rehabilitation includes occupational, physical, and speech and language therapy, with input from psychologists and social workers as necessary. It should involve a multidisciplinary approach from stroke physicians in a comprehensive stroke team, and an ordered plan for discharge from hospital with documented responsibility for continuing rehabilitation needs in the community.

However, as SAFE's Burden of Stroke report revealed in 2017, access to rehabilitation varies across greatly across Europe.



Good rehabilitation practice should include:

Information for patients and their carers about stroke, rehabilitation and planned discharge and follow-up which in itself improves knowledge, patient satisfaction and reduces depression.

Early supported discharge, mainly for people with mild to moderate stroke symptoms, where services are provided at home by a mobile rehabilitation team as part of the stroke treatment pathway.

On-going and potentially increasingly intensive interventions - for patients with aphasia, for example, this can mean high-intensity training over a prolonged period.

Training in Activities of Daily Living (ADL) which can be beneficial for up to a year after stroke.

Training to improve the fitness and physical condition of the stroke survivor preferably with access to green spaces.

Although the evidence of benefit from rehabilitation interventions after one year is sparse, it is important to recognise that improvement can continue for a long time after stroke, and that the patient's needs will vary over time. Therefore, it is never too late for rehabilitation.

There is large variability in access to rehabilitation between and within countries in Europe. These differences probably reflect international differences in the organisation of stroke services, strategic approaches to stroke, and available resources. Comprehensive stroke units are still lacking in many countries, and the slow rehabilitation documented in stroke unit trials is almost absent. Patients with moderate to severe stroke benefit even more from stroke unit care.

If this is not possible, the stroke rehabilitation unit provides an evidence-based alternative for continuing in-patient treatment.

There is a need to increase the number and capacity of comprehensive stroke units, in order to ensure that all patients have equitable access. There is also a shortage of rehabilitation and nursing staff with expertise in stroke and an understanding of rehabilitation. Rehabilitation in a comprehensive stroke unit should be available at all times.

There is a shortage of Early Supported Discharge services in all European countries, and in some areas this is not offered as part of the stroke pathway. Similarly, physical fitness training programmes are not common in Europe but are now being developed in Italy and the UK.

REHABILITATION - TARGETS FOR 2030

Getting therapy as soon as possible after a stroke at the right intensity makes an enormous difference to recovery. So all countries should aim to be:

1 *Guaranteeing that at least 90% of the population have access to early rehabilitation within the stroke unit.*

For a round a fifth of people who have a stroke, getting rehabilitation support at home at the same intensity as in hospital means they can be discharged earlier. Therefore, the aim should be:

2 *Providing early supported discharge to at least 20% of stroke survivors in all countries.*

As well as stroke specialist therapies, lifestyle support is important. The target is to be:

3 *Offering physical fitness programmes to all stroke survivors living in the community.*

Stroke survivors often talk of feeling abandoned when they leave hospital. Community-based care must be planned and documented. Once patients are discharged they (and community health and social care providers) need to know what support they require. Therefore, this target should be normal practice:

4 *Providing a documented plan for community rehabilitation and self-management support for all stroke patients with residual difficulties on discharge from hospital.*

Stroke recovery can be a very long process – many stroke survivors describe improvements in their mobility or communication after months or even years. Too often, however, they have no chance to check on that process, re-access rehabilitation and review secondary prevention. This is why it is vital countries aim to be:

5 *Ensuring that all stroke patients and carers have a review of the rehabilitation and other needs at 3-6 months after stroke and annually thereafter.*



EVALUATION OF OUTCOMES AND QUALITY IMPROVEMENT

” *The Norwegian Institute of Public Health published in 2018 numbers on a decrease in death after strokes in Norway, where the percentage is about a 30% decrease of death after strokes in hospital. For public health reasons this means that health registries such as those for stroke are important. To be able to compare numbers throughout Europe must be a really great advantage for those working with stroke on a daily basis. For those affected by stroke, it shows that if you are treated in a hospital with a stroke unit - your chances are higher to survive. But as I have said a lot of times, a saved life must also be lived.”*

**Grethe Lunde, stroke survivor
and SAFE Board member**

2006: The goal of evaluation of stroke outcome and quality assessment is that all countries aim to establish a system for the routine collection of data needed to evaluate the quality of stroke management, including patient safety issues.

Systematically improving the quality of stroke care can only be achieved where stroke guidelines and data is routinely collected, so that services can be audited. Data needs to be collected on the *structure* of stroke services (facilities, staffing etc.); the *processes* of care (door to needle times, intensity of rehabilitation provided, time to get to a stroke unit, etc.) and *outcomes* (mortality, physical, cognitive and psychological disability, frequency of complications such as pneumonia etc.).

Clear standards and assessment of the quality of stroke services are essential if quality improvement is to be achieved. This information helps individual clinicians to monitor and modify their practice and enables hospital and community-based stroke services to understand and improve on their performance. Health funders need reassurance that their money is being well-spent, and healthcare planners at national and international level need to use standards and audit data to drive improvement.

The organisation of stroke services varies considerably around Europe, which impacts on how the stroke care pathway is determined. That is why it is important for stroke guidelines to be adapted to local conditions, based upon local data.



EVALUATION AND QUALITY IMPROVEMENT - TARGETS FOR 2030

If, across Europe, we had a common set of quality standards, measured in similar ways, based upon comparable guidelines, the ability for national health services and stroke health specialists to compare and improve their practice would be greatly improved. We need, therefore, to see:

Defining a Common European Framework of Reference for Stroke Care Quality that includes:

development or update of European guidelines for management of acute stroke care, longer term rehabilitation and prevention;

definition of a common dataset covering core measures of stroke care quality to enable accurate international comparisons of care both in hospital and in the community (including structure, process, outcome measures, and patient experience).



There are plenty of examples across Europe of the positive difference made by having a person responsible for improvement in the delivery of care for specific diseases. So, all countries in Europe should be assigning a named individual who is responsible for stroke quality improvement in each country or region.

Setting standards and measuring stroke services against those standards is vital.

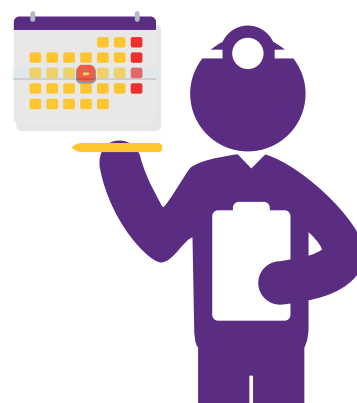
And making sure that this information can be used by stroke health professionals and the public can drive better care. The aim should be to establish national and regional level systems for assessing and accrediting stroke clinical services, providing peer support for quality improvement, and making audit data routinely available to the general public.

“ Including the expertise from patients and carers is perennially important, and helps to make the European Stroke Action Plan credible. In many countries stroke support organisations are now included in guidelines work, and speaking from my own country I am happy to report that this is now routine and mandated at the National Board of Health and Welfare and the quality registers level.”

Prof. Bo Norrving, professor of neurology at Lund University, Sweden

Systematically understanding the experience of stroke survivors can also be a driver for better, patient-centred care. There are now a range of patient reported outcome measures that should be used. Therefore, the aim is for:

Collecting patient-reported outcomes and longer-term outcomes (e.g. six months and one year), covering both hospital and community care.



LIFE AFTER STROKE

” Leaving the hospital and starting with the basic rehabilitation is not going to bring your life back or help you fully integrate unless it’s being complemented with a full and coordinated support- from your family, from the state, the medics and other stroke experts and the stroke support organisation in your country. There are still too many issues for a stroke survivor to solve, such as relationships, work or unemployment, self-confidence, finance, pain management, transport, aphasia, cognitive disruption etc. and the stroke survivors cannot deal with all of these on their own.”

Diana Wong Ramos,
stroke survivor, Portugal AVC

Stroke research, quality measures, guidelines and action plans have largely focussed on the medical management of stroke. But it is now recognised that urgent attention needs to be paid to life after stroke. Although there have been very few research studies into life after stroke covering the entire lifespan, it is clear, that for stroke survivors and their families this is one of the most important aspects of stroke support and provision. After all, people live for many years with the consequences – including communication, psychological and other health problems; financial and relationship difficulties; as well as the barriers they face as disabled people.

Around a third of stroke survivors are disabled, have poor post-stroke cognitive ability and poor mental health. Surveys show that communication, social relationships, loneliness, incontinence, fatigue and finance needs especially are unmet, and social integration is missing. There is a strong need for personal care plans after rehabilitation ends, and for coordinated support.

The development and use of Patient Reported Outcome Measures (PROMs) is urgently needed to address the paucity of data and to provide evidence for better provision.

Currently there is little evidence of holistic and coordinated support. There is no pathway for survivors and, most importantly, there is no model of what best care looks like following discharge from specialist services. The large and growing number of stroke survivors with long-term needs must be addressed; we need to develop minimum standards of care and measure these.



LIFE AFTER STROKE - TARGETS FOR 2030

The issues facing stroke survivors in the long term have historically been generally ignored. All countries in Europe need to take life after stroke more seriously though Governmental focus on the issue so that stroke plans include long-term support and minimum standards can be set. European countries should be:

- 1** *Appointing government level individuals or teams responsible for championing life after stroke and ensuring that national stroke plans address survivors' and their families' long-term unmet needs. Minimum standards should be set for what every stroke survivor should receive regardless of where they live.*

The voices of stroke survivors, as individuals and, vitally, through their support organisations is required to improve life after stroke care provision. So the aim across Europe should be:

- 2** *Formalising the involvement of stroke survivors and carers, and their associations, in identifying issues and solutions to enable the development of best patient and support practices.*

Stroke plans should not end when medical interventions stop. They should outline how long-term support needs will be met. The target is:

- 3** *Establishing, through national stroke care plans, the support that will be provided to stroke survivors, regardless of their place of residence and socioeconomic status.*

Stroke support organisations provide a wealth of support for individual stroke survivors and their families. Encouraging their growth could make a huge difference to the stroke population. The aim should be:

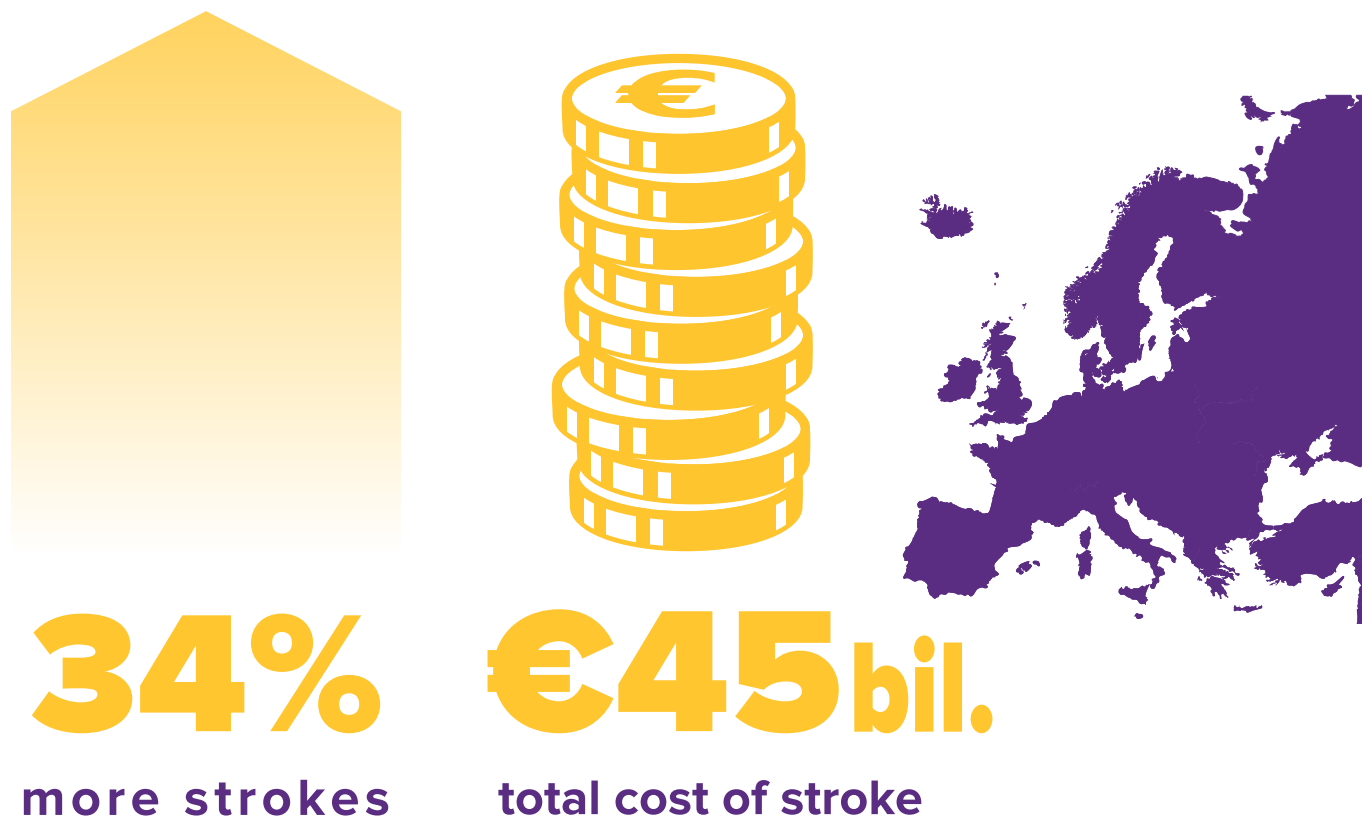
- 4** *Supporting self-management and peer support for stroke survivors and their families, by backing stroke support organisations.*

And where stroke support organisations or others struggle to provide face to face services, self-management can be enhanced through new technology. We want to see countries:

- 5** *Supporting the implementation of digitally based stroke self-help information and assistance systems.*



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CONCLUSION

By 2035 there will have been an increase of 45% in the number of stroke deaths, and an increase of about a quarter in the number of stroke survivors living with the long-lasting effects of stroke. It is estimated that between 2015 and 2035, there will be an overall 34% increase in the total number of strokes in the European Union from 613,148 in 2015 to 819,771 in 2035.

The good news is that stroke is an often preventable, treatable and beatable condition.

Since it was formed in 2004, SAFE is campaigning, educating and encouraging research about stroke. Our aim is to make progress on stroke prevention and improve the quality of life of stroke survivors, their families and carers. By doing this, both at a European level and by supporting national members to do so, we have shown that there is a need for more collaboration between all the relevant stakeholders to successfully fight against stroke.

SAFE is committed to developing and fostering partnerships with other organisations across Europe and to cooperate with the health policy decision-makers, at EU and national level. Ultimately it is politicians and other key decision-makers who can ensure the crisis of stroke is dealt with.

With the impending catastrophe of a predicted 34% rise in the number of strokes in Europe, SAFE and ESO feel that taking a foot off the pedal is not an option. Now, more than ever, we all need to work together towards making the improvements that are needed across the whole stroke care pathway and tackling the wide disparities and inequalities within countries found by the Burden of Stroke in Europe Report in 2017.

About SAFE

The Stroke Alliance for Europe (SAFE) a non-profit-making organisation formed in 2004. It is the voice of stroke patients in Europe, representing a range of patient groups from more than 30 European countries.

SAFE's goal is to decrease the number of strokes in Europe by advocating for better prevention, access to adequate treatment, post-stroke care and rehabilitation.

For more information about SAFE, please visit **www.safestroke.eu**.

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