The Stroke Alliance for Europe **Manifesto**

For a world where there are fewer strokes and all those touched by stroke get the help they need.

S·A·F·E
Stroke Alliance For Europe

Summary

We work towards all patients in Europe with stroke having rights of access to a continuum of care. From prevention and risk identification, through emergency response to organised stroke units in acute phase, to appropriate rehabilitation and secondary prevention measures by 2015.

A stroke is a brain attack.
There are two main types of stroke:

- Ischaemic stroke – the most common type of stroke caused by a blood clot in the brain.
- Haemorrhagic stroke – caused by a bleed in the brain.

A Transient Ischaemic Attack (TIA), also known as a 'mini stroke', occurs when the brain's blood supply is briefly interrupted. The symptoms of a TIA are very similar to a full stroke but last under 24 hours.

Symptoms of a stroke

The immediate symptoms of stroke include sudden numbness; weakness or paralysis; sudden difficulty in speaking or understanding speech; dizziness; confusion; unsteadiness; severe headache; sudden blurring or loss of vision and loss of consciousness.

In the longer term stroke survivors may have one of the following symptoms in any combination; weakness or paralysis on one side of the body, speech and language difficulties, difficulties in perception and cognition, fatigue, emotional changes and mood swings.

Incidence of stroke in Europe

Stroke is the third leading cause of death in Europe, behind heart disease and cancer, and the most common cause of adult physical disability, with an estimated 650,000 stroke deaths each year.

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Introduction

Stroke is the third biggest killer in Europe and the biggest cause of serious disability.

Most people have heard of a heart attack, but stroke is a less well-known term. It is, however, just as important and serious as heart disease.

- Only a third of stroke sufferers are likely to recover within one month.
- One third are likely to be left disabled and needing rehabilitation.
- One third will die within one year.

Stroke kills 650,000 people a year in Europe and imposes a significant burden on society and on healthcare budgets, accounting for 3-4% of the total health care costs in Western European countries.

Eastern and Central European countries have higher stroke rates, and with the forecast in growth in Europe's older populations, incidence across Europe is set to rise, with a corresponding impact on Europe's healthcare budgets.

With more investment in organisational change the costs to healthcare budgets across Europe could be significantly reduced:

- **The establishment of specialised stroke units needs to be increased in much the same way as coronary care units.**

  It has been shown that acute interventions, as well as specialised, dedicated care for acute stroke victims can not only be lifesaving, but also result in long-lasting and substantial decreases in long-term disability. In addition, the disease burden for carers can be minimised when comparing stroke unit care to the kind of care offered on general medical wards.

For every ten people who die of stroke, four could have been saved if their blood pressure had been controlled.

- **The good news is that of all neurological diseases, stroke is the most preventable one.**

  In fact, research shows that two thirds of physicians consider most first strokes to be avoidable. People can reduce their risk of having a stroke through having regular blood pressure checks, receiving appropriate treatment for high blood pressure, and implementing certain lifestyle changes.

Stroke is the most common cause of adult physical disability in Europe.

Introduction

SAFE's **vision** is **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.**

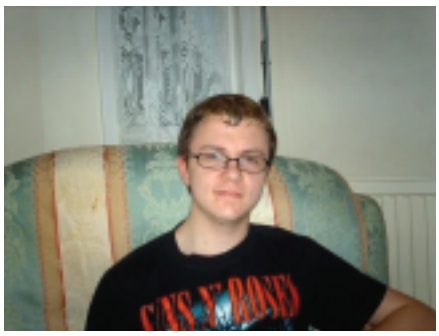
SAFE therefore engages in activities such as campaigning, education and encouraging research, which contribute to the advancement of stroke prevention and the improvement of the quality of life of stroke survivors, their families and carers.

The overall aim of SAFE is to reduce the numbers of, and ameliorate the effects of, strokes across Europe.

This manifesto sets out the key messages that the Stroke Alliance for Europe believes the European Parliament should endorse.

SAFE calls on all citizens of Europe to make sure that our work is supported.

Adam Fontain (17)



Adam was a normal active child when he suffered his first stroke aged 7. A year later he suffered a second more severe stroke that left him unable to walk or use his left arm. After 3 months of physiotherapy and occupational therapy Adam was allowed home in a wheelchair.

Through sheer determination and the support of his friends, family and school he started walking again. Adam now leads as normal a life as he can, although he still has some trouble walking and cannot lift his left arm. In 2002 he joined a disabled sports club and took up air rifle shooting and table tennis.

Adam has won the junior title in shooting, against able bodied shooters. He trains with the British Paralympic Shooting Team, who hopes he will be in the 2012 Paralympics. Over the last year Adam has been studying at college that has taken up a lot of his time. He is still doing his sports, table tennis and Air Rifle Shooting. In 2006 he came second at the England Disabled Nationals and in September 2007 Adam was asked to join the Great Britain Shooting team, this is what all the training and hard work was for. In December 2007 Adam went to Luxemburg for his first International Shooting competition, he did not disappoint - he shot 592 out of 600, and 590 out of 600. Adam has also just competed in the British National Shooting Championship and came away with two Gold Medals and One silver. In 2008 Adam will travel to Germany with the Great Britain Shooting Team for his second International shoot.

Prevention

Each region should have written pathways for a continuum of care, each hospital treating stroke patients should have evidence-based clinical protocols and each country should have evidence-based national guidelines

Prevention

Stroke is the most preventable of all diseases associated with the brain. However, many people underestimate its seriousness. 600 million people worldwide have high blood pressure, which increases the risk of stroke by four times as it leads to strain on the tubes (blood vessels) through which the blood circulates through the body. These blood vessels may then burst at a weak spot.

Controlling blood pressure therefore – via improved diet and lifestyle and proven therapy for example – is one of the most effective ways to prevent stroke.

It is vital that the citizens of Europe are given greater choice and access to information and initiatives to enable them to make informed decisions on healthy lifestyles that could reduce their risk of stroke.

Prevention

Our call

- **We call** on the European Parliament and all the Governments of Europe to ensure that in all communities people are made aware of stroke, and the risk factors associated with stroke, through ongoing stroke awareness campaigns, and easy access to information;
- **We call** for regular blood pressure testing of all citizens on a regular basis, and the provision of appropriate assistance to reduce high blood pressure and maintain it at a healthy level;
- **We call** for mandatory, consistent and clear labelling of food products, especially in regard to salt and fat content, to empower people to make decisions about what they and their family eat;
- **We call** for mandatory, consistent and clear labelling of alcoholic drinks, in regard to the number of units they contain, and the dangers of binge drinking.
- **We call** for restrictions on "junk food" advertising, especially when aimed at children;
- **We call** for a complete ban of smoking in all public places;
- **We call** on all European institutions to encourage and enable physical exercise for citizens

We call on all Governments to increase ring-fenced funding for stroke research.

Stroke is a medical emergency

All too often the symptoms of stroke and TIAs are not recognised and diagnosis and treatment are delayed. This reduces recovery outcomes, which in many cases is a matter of life and death.

It is now accepted that a more urgent response to both stroke and TIA will save lives and reduce long term disability.

The evidence for treating TIA has developed significantly in the past few years: the time in which there is a significant risk of having a major stroke is now acknowledged as much shorter, which means the response needs to be urgent.

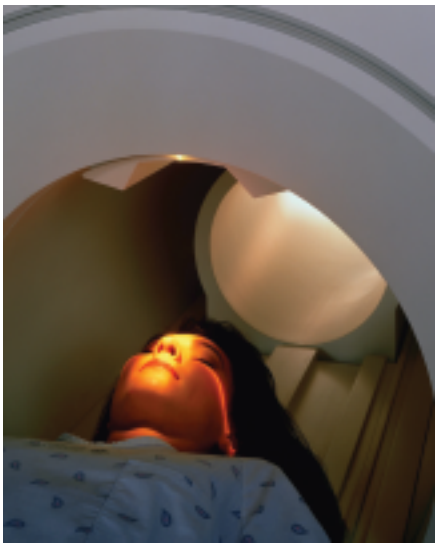
However, an emergency response cannot be delivered unless all those who have contact with the public are able to recognise the symptoms of stroke or TIA and understand the importance of dealing with stroke as rapidly as possible.

Knowledge and awareness of stroke is poor both amongst the general public and health and social care professionals

Procedures also need to be in place to ensure that patients with suspected stroke are immediately transferred by ambulance to a specialized stroke unit offering immediate clinical assessment, scans and clot busting drugs throughout the 24 hour period

Our call

- **We call** on Governments to fund public awareness campaigns to ensure that everyone knows the warning signs of stroke and know that they should use emergency services to be delivered to an effective diagnosis and treatment centre;
- **We call** on the European Parliament to encourage constituting Governments to ensure that three hours is the maximum wait for a brain scan and that treatment commences within three hours to reduce mortality and improve outcomes;
- **We call** on the European Parliament and all country Governments to set a target for suspected TIA to be investigated in a specialist service within seven days, and patients with more than one TIA in a week to be investigated in hospital immediately.



Organisation

High blood pressure, smoking, excessive levels of alcohol, some illegal drugs, high cholesterol levels and physical inactivity all increase the risk of stroke.

Our call

- **We call** on all European Governments to address the social, emotional and practical needs of carers in supporting stroke survivors, by ensuring sufficient organisation of these areas of provision.

Manuela Messmer-Wullen

I had a brilliant job and enjoyed my work. I was on a foreign business trip and one morning I tried to jump out of bed and fell on the floor. I tried to stand up but fell again. I had to rock on my stomach to get to the bathroom and when I saw my face which was totally damaged on the left side, I realised something had happened with my brain. I was very angry, panicked and tried to get back to the telephone. When I got there I couldn't read the numbers to dial. In panic I tried everything to get somebody on the line and was lucky someone answered. I managed to call for help but then lost consciousness. I was in intensive care for over six weeks and in rehabilitation for over six months without going home.

My family visited me at the weekends and in their spare time. I wouldn't have achieved what I have if they had not been with me. It was really hard work to become the person I am today but I am not the same person as before. This is a very big problem but I am so glad that I can move, think, react and handle the telephone. After 18 months I went back to work and realised that I couldn't function. When the phone rang I couldn't remember what the person was calling me for, his or her name, what I should do or what my job was. It was very difficult. Things have really changed because money is nothing if you can't move, if you can't enjoy life, if you can't visit friends or participate in sport. My family, partner and kids think I am fine now, fit and can do nearly everything for myself. Of course they can't understand that my brain has changed.

In hospital

The establishment of specialised stroke units needs to be increased. It has been shown that acute interventions, as well as specialised dedicated care for acute stroke victims, can not only be lifesaving, but also result in long-lasting and substantial decreases in long-term disability.

There is overwhelming evidence that stroke units reduce death and increase the number of independent and non-institutionalised individuals.

Once in hospital rapid access to diagnostic tools such as brain scanning is essential as is treatment with clot busting drugs where these are appropriate.

It is important that stroke patients are admitted to a stroke unit on day one and spend the majority of their time at hospital in a stroke unit with high-quality stroke specialist care.

Stroke units should provide high-dependency care including physiological, neurological monitoring and rapid treatment of stroke and associated complications, early rehabilitation and palliative care.

Unfortunately the quality and resourcing of stroke units varies and these inconsistencies are causing people to suffer from worst outcomes after their stroke.

Our call

- **We call** on all European Governments to pursue the implementation of specialist stroke acute units and specialised stroke units where support and rehabilitation can be delivered to an optimum standard to comply with effective evidence based standards.
- **We will** campaign for stroke units across Europe.
- Continuing information /education of patient's families/carers.
- If a radiologist is not always available in-house, the application of telemedicine technology should be made available to ensure real-time online consultation to enhance dedicated stroke care.
- Whilst stroke is covered by elderly services in many European medical provisions, it is vital that the particular service needs of the tens of thousands of people under 55 who have a stroke each year are met. It is essential that mechanisms are in place in each country to ensure that stroke is recognised and treated as a condition that strikes irrespective of age.

In hospital

- **We call** on all European Governments to ensure that targets are set for the direct admission of people with stroke to an effective specialised stroke service or unit, and that they then receive ongoing treatment in specialised stroke services/units.

Willi Daniels Story

While blowing up a balloon on New Year's Eve 1997 my first stroke occurred. I thought: "Ok, something must have happened in my brain".

As I lost total ability to speak, I could not inform anyone about my condition. Neither my family nor myself imagined that I was having a stroke.

The emergency service was informed, but could not assign the symptoms properly (short unconsciousness, loss of speech, disability to stand erect) as well. The doctor told us that everything would be all right very soon.

When there was no sign of recovery after half an hour, the emergency service was called again. This time, it was recommended to go straight to the hospital. No ambulance was sent, so I was carried to an accident and emergency department of a nearby hospital by car. My admission was refused in the beginning, because I was not transported in a horizontal position. It was not until heavy arguments between hospital staff and my family that I was finally admitted. At last I laid in the emergency department and waited for the doctor to come. During the brief examination that followed I had the impression that the doctor had a preconceived idea of my status (for it was the night of New Year's Eve). He offered me a bed to have a good's night rest and I got an infusion to recover much faster. I needed almost three days (without being able to speak) to explain the staff that something was wrong with my brain and that they should apply a CT scan.

The next day (the day my discharge was originally planned) I was informed that I had a left-hemisphere stroke and I had to stay in the hospital. I objected, shaking my head.

I am sure, if I had paid attention to stroke before as a healthy man it would have saved me and my family a lot of trouble and worries. With the knowledge about risk factors and symptoms of stroke, it is much easier for bystanders and stroke victims to inform the emergency medical service in a more detailed and qualified way, in order to get a quick and efficient therapy.

From hospital to community

A seamless transition of care is vital for stroke survivors to move effectively between health and social care providers and the services offered by voluntary organisations.

Where health and social care services work together to facilitate a smooth return home it can help people recover quickly, reduce the pressure on the individual and their family and prevent unnecessary readmissions to hospital. Individuals need to feel reassured that when they leave hospital they know what arrangements for ongoing care, support and rehabilitation have been made and how to access information and advice, as well as who will take forward the next stage of their rehabilitation and support.

Stroke survivors need access to a comprehensive rehabilitation service that is staffed by a multidisciplinary team including physiotherapists, occupational therapists, speech and language therapists, and psychologists

Stroke is a condition that can improve over many years, so people need both rehabilitation, to help them improve and recover, and support, to help them manage the disabling factors caused by a stroke that may continue in the long term.

The impact of stroke varies hugely, and so support in the long-term needs to be tailored to meet the individual's needs.

Our call

From hospital to community

- **We call** on all European Governments to ensure regular assessment and reassessment of care and services provided in the community – not forgetting those who move into residential care. Ongoing long term support is vital.
- **We call** on all European Governments to improve the availability of short and long-term rehabilitation to enable all stroke survivors to have access to life changing support.
- **We call** on all European Governments to increase access to speech and language therapists, occupational therapists, psychologists, family, and dysphasia support services, all of which will help to restore the quality of life of stroke survivors.
- **We call** on all European Governments to ensure that the stroke survivor, their carer and family are given the opportunity to be involved in the decision making process about their future care and rehabilitation.

From hospital to community

- **We call** on all European Governments to ensure the transition from hospital to home or residential care is improved, through provision of a full range of information, supported discharge activity, training and support to carers, and appropriate assistance for adaptation.

Resources

- **We call** for all European Governments to ensure that the appropriate resources are being allocated to the training; development and employment of stroke care specialists, such that the recommendations above can be implemented.
- **We call** on all European Governments to support the growth and development of self-help and advocacy stroke related organisations within each country.
- **We call** on the European Parliament to support the growth and development of the Stroke Alliance for Europe as a part of the struggle to raise awareness and prevent strokes, and combat their effects.
- **We call** on all European governments to ensure adequate financial support to those families and individuals devastated by stroke, and to provide assistance back to meaningful occupation if appropriate.

Research and Development Priorities

SAFE will advocate prioritisation and development, assisting where possible in these areas:

Research

- the cost-effectiveness of different types of stroke services;
- investigating the long-term outcomes achieved with different models of stroke services;
- encouraging adherence to secondary prevention;
- identifying political and organisation-based barriers preventing implementation of evidence-based stroke care;
- we will assist, where possible, in encouraging and developing better ways to deliver continuing stroke education to the general public, professionals and decision makers;

Development

- developing guidelines for stroke care delivery, including pre-hospital and post hospital stroke care;
- developing telemedicine systems for management of stroke.
- developing the concept of primary and comprehensive stroke service centres that optimise the use of multidisciplinary teams to improve the outcome of acute stroke patients;
- we will encourage patients to take part in well-planned and executed controlled randomised trials of stroke prevention, acute care and rehabilitation;
- patient self-help and peer support programmes in all their forms.

Conclusion

In the next hour an estimated 225 people in Europe will have a stroke. 75 of those people will recover, 75 will have permanent disabilities and 75 will die.

We urge you to ensure that the needs of stroke survivors, their families and their carers are acknowledged and provided for to reduce the devastating impact of stroke. Improvement to prevention, care and rehabilitation will reduce both the personal, social and financial costs of stroke and will help rebuild the lives of thousands of people across Europe.

We are counting on your support.

For more information, or to make a donation, please go to the SAFE website www.safestroke.com
or email the Secretariat at mail@safestroke.com

Every 20 seconds someone in Europe has a stroke. A stroke does not discriminate. It can happen to anyone at any time in their life. Strokes are sudden and their consequences can be devastating.

The Stroke Alliance for Europe
is the leading European patient organisation solely concerned with helping everyone affected by stroke in Europe.

Our vision is to have a world where there are fewer strokes, and all those touched by stroke get the help they need.

The Stroke Alliance for Europe (SAFE)
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