



**S·A·F·E**

Stroke Alliance For Europe

THE STROKE PATIENT  
VOICE IN EUROPE



# LIFE AFTER STROKE: Stroke Survivors' needs across Europe

Exclusive country by country insight provided  
by SAFE member organisations

2019

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Life after stroke is a key priority within SAFE's overall strategy, as we firmly believe that every step in the stroke care pathway matters equally. Our campaigning work remains committed to this and in 2019 we worked hard to find how stroke survivors and their families are coping with it throughout Europe, so that we can shed light on issues on the key issues that people are facing.

To inform our findings, we have worked with our stroke support member organisations and have talked to representatives of stroke patients and carers from around 30 European countries. We are now able to proudly bring to you a unique insight into real-life needs of stroke survivors in each of these countries.

A stroke shatters lives and leaves many issues for a stroke survivor to solve, such as relationships, work, self-confidence, finance, pain management, transport, aphasia, cognitive disruption and intimacy issues. A stroke survivor cannot deal with all these alone. If we really want to help people get their life back, they must have full and coordinated support from all sides - family, state, medics and other stroke experts, and the stroke support organisations. The work documented in these interviews enables us to gather the most burning life after stroke issues from across Europe and show that leaving the hospital and starting with the basic rehabilitation is simply not enough.

With this in mind and with the evidence we have gathered over the years, I am pleased to announce the next SAFE project: the 1st European Life After Stroke Forum, coming up end of 2020.

SAFE is deeply committed to improving life after stroke in Europe, because we could and we should all do better for all stroke survivors and their families, regardless of where they live or what is their socio-economic status.

**Arlene Wilkie**  
Director General  
Stroke Alliance for Europe

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Apr 12, 2019

## STROKE SURVIVORS' NEEDS IN NORTH MACEDONIA: Lack of multidisciplinary teams in after stroke care



This week we are talking with Dr Maja Bozinovska Smiceska, President of Association for a fight against stroke "Stroke" in North Macedonia.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

*"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."* said Dr Maja Bozinovska Smiceska, President of Association for a fight against stroke "Stroke" in North Macedonia.

One aspect regarding rehabilitation in their recovery is intensive work with multidisciplinary team. So, the first problem in our country is deficiency of such team in most of our cities or inequality in specialized stroke recovery. All stroke survivors have approach to physical therapy, part of them of them have language therapy at disposal, but just a small percentage have luck to be rehabilitated by a multidisciplinary team.

### About "Stroke" ( North Macedonia)

*Our organisation is formed 2014. Our idea was to improve stroke care in our country that was very poor and unequal in different regions. Main goals of our organisation are raising the consciousness of the public and education; join care for improving the health condition of the patients with a stroke; informing about the new scientific and practical achievements in the treatment of the patients with a stroke; providing professional help in the field of action; encouraging and strengthening the cooperation with domestic and foreign organisations and institutions which have same or similar goals. We started with activities for stroke prevention and post stroke consultations for patients and caregivers that included not just spreading information trough media but also field work of teams consisting different specialists, doctors, nurses, clinical psychologists and physiotherapists in different cities. These activities are still going on, and we have upgraded our work. Our organisation is now member of SAFE and WSO.*

Second very important problem is that there is no national strategy, a specific path, that will simplify the struggle of patient and family. Considering not just rehabilitation but also their adaptation to situation and inclusion in society, helping them to be productive as possible or providing to others specific help according to their needs like financial help or accommodation.

**SAFE: What would be the solution, i. e. what is your organisation's position regarding this issue?**

**MBS:** As the only organisation that deals with stroke patients in our country, we are continuously increasing public awareness and educating public using different media, where and how to find help and to whom to address their specific problems. Also our network is offering annually reviewed data. We organise lectures for specific groups considering certain post stroke problems.



Our organisation in 2017 formed a special team consisting of Stroke neurologists, nurses stroke survivors and caregivers that created a document in which we included recommendations for life after stroke. Members of our team already had two meeting in Ministry of health of Northern Macedonia, and this document was given to the counselor of the minister.

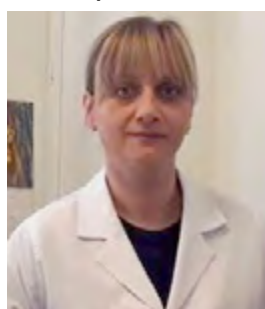
What we consider important is forming a team in Ministry of health that deals with the issues of stroke, generally they should create and implement national strategy.

Our next goal is to organise peer to peer meetings and that way to improve self- management in stroke survivors and caregivers.

Apr 19, 2019

## STROKE SURVIVORS' NEEDS IN GEORGIA: Swallowing problems after stroke not addressed properly lead to lung infection

"There is no stroke rehabilitation center in Kutaisi, Georgia, and after their hospital treatment, patients are discharged to go home. Unfortunately, patients' carers do not have enough information on how to take care of them once their loved ones are back home. Due to swallowing problems, many of stroke survivors return to the hospital very soon after their discharge, this time not because of stroke, but because of aspiration pneumonia- a



type of lung infection that is due to a relatively large amount of material from the stomach or mouth entering the lungs" says Tamar Janelidze, MD, neurologist, co- founder and board member of Georgian stroke support organisation, Medical Foundation Mkurnali.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**TJ:** In Georgia, there is an observed growth trend in cerebrovascular diseases. For last years, at the national health sector level, special attention is paid to acute strokes. In general, stroke is one of the main causes of disablement of the population of Georgia. In particular, most of patients that survived stroke are disabled, and 30- 40% of them needed permanent care. Because of a deficiency in rehabilitation services in Georgia, no correction of

neurological impairment can be made completely for stroke patients that reduces the quality of life. In response to the urgency of this disease, it is very important to study the methods for fighting this disease and for the management of its complications, as well as for its proper diagnosis.

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### About Georgian stroke support organisation

*Our organisation participates in s patient' s educational program not only for stroke patients. We also have relations with government of Kutaisi and also Kutaisi University and try together to make our patients' lives better.*

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In Georgia, at our hospital, at the premises of the neurology department, there have been established the stroke management units, the so- called stroke units, which allow not only for effective treatment of stroke patients, but also for assessing the complications and possible risks associated with stroke. 65% of patient had dysphagia, which evolves as a result of infringement of brain blood circulation, and appears as inhibition of swallowing reflex, or as its complete elimination.

**SAFE: What would be the solution, i. e. what is your organisation' s position regarding this issue?**

**TJ:** There is the risk of an aspiration of foods in the airway that consequently may lead to aspiration pneumonia. Our organisation contributes to

the introduction of dysphagia screening in the neurology department, which include the studies were actively started for the detection of dysphagia. First, swallowing reflex is checked and lingual condition is assessed in all patients, as well as there is differentiated whether dysphagia is a neurological complication or not. Then the studies are carried out through video- photofluorography roentgenoscopy. Patient swallows the contrast substances of different consistencies, and radiologist assesses radioscopically the swallowing process. Also, in some cases, of high importance is to assess the pharynx condition, for which we apply to an endoscopy.

After the mentioned examination, an attending physician and radiologist make decision on how the dietary regime of patient should be carried out. Of all 120 examined patients, dysphagia was detected in 85, and an appropriate examination regime and treatment were chosen for them, and in some of them the need of gastrostomy was identified. Analysis of latest data has shown that the problem of proper diagnosis of dysphagia allows for reducing the complications, even such as aspiration pneumonia that in turn is the most dangerous complication in terms of mortality.

Thus, proper diagnosis is a guarantee of preventing possible disablement and anticipated mortality.

*Apr 25, 2019*

## **STROKE SURVIVORS' NEEDS IN PORTUGAL: Rehabilitation must be possible and accessible to everyone**

"Currently, in Portugal, when a stroke occurs, the first phase of treatment, the acute phase, happens in similar conditions to the ones of the best practices in Europe. The first rehabilitation, still within a hospital circle, is already implemented with great differences across our country, and, on average, isn't as satisfactory. After... when the real life

only in the continuity of the strictly therapeutic recovery, but also in the social and psychological support, among others..." says António Conceição, President of the Portugal AVC, a stroke support organisation that is part of SAFE.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

AC: In Portugal, above all, it's necessary to remind people, specially people with influence (not only political but other), that survivors have a life after stroke! That they can be active and useful citizens just like everyone else.

And an essential contribution for that is making rehabilitation possible and accessible to everyone, as well as making it starts fast, timely and multidisciplinary (since it needs to involve multiple medical and therapeutic areas, that don't restrict themselves to the physical or motor situation).



after stroke begins, the survivors and care givers, generally, feel alone, helpless! It's mostly in that moment, when the biggest problems start (including the psychological, socioeconomic, life reorganisation, etc. ones), that, in most cases, there are flaws. Not



**SAFE: What would be the solution, i. e. what is your organisation' s position regarding this issue?**

AC: Our procedure, especially in our possibilities of public intervention, has been directed towards two themes: life after stroke and the defense of a better rehabilitation. Recently, we celebrated in Portugal the National Day of Stroke Survivor (31st March). All of our communication, including the one on social communication, followed this line of work: the defense of a fast, timely and multidisciplinary rehabilitation. We pointed out some very concerning flaws. The Portuguese Stroke Society (a medical and scientific organisation) also followed an identical theme in its communication. Furthermore, the president of this society, a very prestigious person, said a sentence, a few years ago, that we also repeat many times: "Rehabilitation isn' t a charity, but a right! If needed, during the entire life!" We have conscience that our action has contributed to give prominence to this subject too.

Deeply connected to this theme is the defense of life after stroke, with the maximum quality possible, and the Action Plan for Stroke, by giving the proper importance to life after stroke, has helped us in this struggle. In Portugal, for initiative of the Portuguese Stroke Society, we are working on adapting this plan to our national situation. Unfortunately, we are aware that our action is only starting...

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#### About AVC ( Portugal)

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AC: Portugal AVC is a national association, made of stroke survivors, but also of caregivers and health professionals, founded in September 2016. Working like this, we have been functioning very well. We have, as statutory goals, to contribute to the prevention of stroke and to respond to the needs felt by stroke survivors and their caregivers. And we defined three areas of action as priority:

- 1 Making information available**, about all "stages" of stroke, from the prevention to the life after stroke.
- 2 To be the voice of survivors and caregivers**, in the government entities and social communication.
- 3 Mutual help**. By giving answer to the multiple requests we receive, including by telephone, email, Facebook, ... But also, we have promoted and supported the appearance of Support Groups ( GAMs). We have already 14, in different places in the country. Among other activities, we highlight the "Portugal AVC Meetings". They are moments of interaction with the survivors, caregivers and health professionals, that have had a strong adherence and fantastic environment. We already organised seven, always in different locations, from the north to the south of the country. However, we are aware that, considering the needs, we are only beginning...

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May 3, 2019

## STROKE SURVIVORS' NEEDS IN SERBIA: The state provides up to three months of medical rehabilitation- after that, you' re on your own



"Our country is small in population, around 7 million in total, but we are among the countries with the highest stroke incidence. Approximately 25.000 strokes occur every year in Serbia. With numbers as high as this, a person would

think that we are getting closer to a solution of how to take care of those who survive stroke, but the reality is- we are still very, very far from it. As the [Stroke Action Plan for Europe 2018 – 2030](#) stated, the issues that stroke survivors are facing long term have historically been ignored, and this is what we are hoping to see changed, with the implementation of this Plan, over the next 10-12 years" says Dr Ivan Milojević, Vice President of the Serbian stroke organisation "[Moždani udar](#)" and [SAFE Board member](#).

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**IM:** One of the basic things we consider as the biggest problem in Serbia is the nonexistence of an organised service which would deal with patients after stroke. In our country there is a rehabilitation that involves active participation of medical institutions up to 3 months after stroke and later after that patients are left on their own, or to their families. Even if there is an early rehabilitation provided shortly after stroke in the stroke units, and rehabilitation provided later after that in rehabilitation centres and specialized physical rehabilitation facilities, that is not enough, and stroke survivors long term needs for rehabilitation after stroke are not satisfied. Apart from regular check- ups by a neurologist, there are no other forms of organised monitoring of stroke survivors.

**SAFE: What would be the solution, i. e. what is your organisation' s position regarding this issue?**

**IM:** One of the main ideas that led to forming our association was, among others, about finding a way to organise stroke survivors' gatherings, so they could share their experiences as peer to peer support, and to include them in social activities. We tried to form Stroke clubs, and we are still working on finding the most suitable way to organise this activity.

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### About "Moždani udar" (Serbia)

Association "Moždani udar" was founded on 30th July 2012 as an NGO. As representatives of stroke patients, we are dedicated to raising awareness of all aspects of stroke. We are involved in many activities and campaigns that cover primary prevention, stroke symptoms early recognition, stroke treatment, rehabilitation, and life after stroke. We were and are part of European and World stroke campaigns, as well as some of the most prominent European projects (Angels Initiative, Stroke Support Organisation Faculty Tool – SSOFT etc). We also share an up- to- date progress information of EU funded stroke research projects by disseminating materials on our language.

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Unfortunately, this is not easy, because our organisation is small and doesn' t have financial sustainability that would enable us to have our own space or to rent one for this type of gatherings. Our association has an active two-way communication with stroke survivors via our social network pages. They share with us their stories and we share them through our website and social media channels. We hope these stories might inspire and encourage other stroke survivors to overcome their problems. In that way, and by organizing public campaigns and actions, we are helping the voice of patient to be heard.



May 10, 2019

## STROKE SURVIVORS' NEEDS IN GERMANY: There is no structured, standardised care management for stroke- patients when they return home

"Every year the German national "Day against Stroke" takes place on May 10th. In 2019 it will have the slogan "I can feel something you can't see", which is based on the German name of the child's game "I spy with my eye...". We want to raise public awareness to the unseen consequences of stroke like concentration and memory problems, visual impairment or states of anxiety.

The foundation aims for major media coverage of the topic" says Dr Michael Brinkmeier, CEO of the German Stroke Foundation, [Stiftung Deutsche Schlaganfall- Hilfe](#).



**SAFE:** What is one issue related to the life after stroke in your country that you think needs special attention?

**MB:** The survival- rate of stroke- patients in Germany has been increasing over the past 25 years due to excellent treatment in more than 320 specialised stroke units. Usually the stroke- survivors stay at the hospital for a couple of days and a rehabilitation clinic for a couple of weeks before they return

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### About "German Stroke Foundation" (Germany)

*The "German Stroke Foundation" celebrated her 25th birthday last year. When our president Liz Mohn established the foundation in 1993, there was hardly any specific stroke treatment at all. Due to this many patients were not treated at all, and the public, but also even experts had no idea that young people and even children could suffer from stroke. These days – fortunately – belong to the past. Thanks to the effort of many committed stroke experts working together with the foundation we now have more than 320 certified stroke units in Germany and one of the best systems to treat acute stroke in the world. About 400 self-support groups are supported by us and more than 200 doctors, mainly neurologists, dedicate time as volunteers being regional representatives of the foundation. We cooperate with more than 30 so called "stroke-offices" all over Germany where stroke-survivors and their families can get information and support. The national "Day against Stroke" on May 10th has been established by the foundation in 1999. It helps raising awareness to the topic for example with media reports and many events, in which our network and other partners from industry and the public sector are included.*

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home. This is when the situation becomes very difficult in most cases. Common questions of stroke survivors are: How often and where do I get the necessary therapies? Where do I get financial support to adjust my home for my disability? How can I return to work and what happens if I can't? Will I be able to drive a car again? There are hundreds of questions that stroke- survivors and their families have to deal with. Many of them are overwhelmed by all the challenges they have to deal with – and they are left alone. So far, there is no structured, standardised case- and care

management for stroke- patients in Germany when they return home. We know that the quality of life decreases after stroke – not only for the patients but also for their loved ones.

But all the administrative issues are not the only challenges. Some people have difficulties to maintain a healthy lifestyle after stroke or pause their medical treatment without consulting a doctor. Many still have difficulties to return to their usual social lives, especially when they suffer from invisible or in the public not well known psychological consequences.

Employers have no understanding why employees after a stroke suddenly have concentration- issues or can't remember or process new information. Friends are confused or even offended when leaving a party after an hour. Neighbors find it weird when being passed on the street without saying "Hello" – simply because the lack of seeing on that side. There is still a lot of work to do to support stroke survivors in the month and years after their stroke and increase understanding.

**SAFE: What would be the solution, i. e. what is your organisation's position regarding this issue?**

**MB:** The goal of the "German Stroke Foundation" is very precise: We want every stroke- victim to get a stroke coordinator (a case and care manager) to support them for at least one year after stroke.

In 2017 we installed a project called "STROKE OWL" in the region of Ostwestfalen- Lippe ("OWL"). The project is financed with seven million euros by the German "Innovation Fonds". Specialised stroke case managers get in touch with the patients at the stroke unit. The stroke survivor can take part in

the program if he or she fulfills certain enrollment criteria. The coordinator informs patients and their families about everything they need to know, gives them advice and support. The manager organises the treatment and therapies, helps filling out applications and forms and looks after the patient in general. The foundation plans to enroll up to 2000 patients into the program. The project will be evaluated scientifically by the University of Bielefeld and all main health insurance companies of the OWL- region – covering two million people – are involved. By proving the advantages and positive effects of a case and care- management not only for the patients but also for the health care system in general the German Stroke foundation strives to support the establishment of stroke case management, which in the end is reimbursed by the insurance companies. Additionally there have been established many smaller, but similar projects all over Germany, which are connected to and supported by our foundation.

Some hospitals employ case managers, others are financed by communities or medical organisations – all with the same goal to improve the quality of life after stroke and reduce recurrent strokes.

Apart from building up a network of professional case managers the foundation has developed another complementary project: We have developed a curriculum to educate and train volunteers becoming so called "Stroke- Helpers". These volunteers help stroke- survivors in their everyday- life. They get groceries with them, go for a walk or play games. There are more than 300 "Stroke- Helpers" in Germany by now trained according to the standards set by us and numbers are rising.

May 17, 2019

## STROKE SURVIVORS' NEEDS IN THE NETHERLANDS: Only 1 out of 10 stroke survivors eligible for medical specialized rehabilitation

"It is wonderful that more and more people survive a stroke, but that only about 10 percent of those survivors end up in medical specialist rehabilitation is at least worrying. And this low number applies to the entire group with brain injury, so also, for example, to people with injuries due to an accident" says Monique Lindhout, SAFE Board Secretary and Director of the [Hersenletsel.nl](https://www.hersenletsel.nl).

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**



**ML:** The extent to which a stroke survivor can participate in society is largely dependent on the degree to which they are rehabilitated. In The Netherlands only 1 out of 10 stroke survivors is eligible for medical specialized rehabilitation.

It is good that a diagnosis is made quickly in hospital and treatment is started quickly. In addition, there is pressure from insurers to keep the treatment as short as possible. In practice, this means that triage also takes place quickly – often too quickly. The triage determines what the rehabilitation process will look like. Can a patient handle the intensive treatment in a rehabilitation institution, is geriatric rehabilitation in a nursing home appropriate? Or can someone go home immediately?

Far too often, people, young and old, are sent home under the motto "too light, no need for rehabilitation." And there is another group: the people who are sent to the nursing home under the motto "damage done too serious, non- recoverable." This too is still too common.

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### About "Hersenletsel.nl" (Netherlands)

*Hersenletsel. nl is a patient association for people with non- congenital brain injury and their loved ones and focuses on the lifelong consequences of ( non- congenital) brain injury. It stands for promoting self- reliance and social participation in a way that does justice to both the possibilities and limitations of people with brain injuries. The pillars of the association are contact with fellow sufferers, information provision and advocacy. Hersenletsel.nl is the leading patient association for people with non- congenital brain injury and their loved ones in the Netherlands. The association wants to achieve adequate care, guidance, facilities and support structures for both people with a non- congenital brain injury and their loved ones. The association offers added value for its individual members through suitable and usable products and services. The association can be found in every region in the Netherlands as an active patient association for people with brain injuries and those close to them. The association is the designated discussion partner for stakeholders at international, national, provincial, regional and local level. The association is also the initiator and participant in NAH centers and aphasia centers and has an active role in monitoring the quality of these centers from a patient perspective. The association is the designated participant in the development of care standards and quality criteria from a patient perspective for the care of those affected with brain injury.*

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**SAFE: What would be the solution, i. e. what is your organisation' s position regarding this issue?**

**ML:** We truly believe that 'a life saved needs also to be lived' and that it is us, as a society, as a patient organisation, as healthcare professionals, as friends and relatives of stroke survivors, that will have to make this possible for all stroke survivors.



We therefore focus on 4 different aspects:

### **1. Involving family in the recovery process**

Involving family gives a win- win- win situation:

- The patient wins: greater chance of recovery and of maintaining a network in the chronic phase
- The loved ones win: they help, grow with and grow towards good "dealing with" in the chronic phase. An active network prevents overloading of one of the primary caregivers.
- The professionals win: better results in less time
- Society wins: less burden of care and costs in the chronic phase.

### **2. Training stroke survivors to become 'ambassadors'**

We developed a course 'Ambassador' in which stroke survivors learn to use their own story and their own strength to support others. Over 200 stroke survivors are now successfully active in this field in a position that fits their interest, passion, competencies, available time and energy.

### **3. Developing technical tools (apps, e- health) to enable people to work on their own rehabilitation at home**

### **4. Use an extensive media campaign on this subject**

May 24, 2019

## **STROKE SURVIVORS' NEEDS IN CROATIA: The lack of logistical coordination within the system itself**

"For stroke survivors the real battle begins after they have been discharged from the hospital. The bio- psycho- social burden on any society (family unit), if they are not properly prepared or organised, can very quickly become devastating" said Hrvoje Jurlina, M. D., stroke survivor from Croatian Stroke Society.



**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**HJ:** As in every country the healthcare system has its flaws. The root to a great percentage of these imperfections within the healthcare system lies in the lack of logistical coordination within the system itself. For example: "If a bus driver does not know his own bus route how can anyone on board the bus be expected to arrive successfully to their desired destination?" (The Bus symbolizes Stroke, the bus driver represents the healthcare system, the bus route substitute as 'Life after Stroke', the bus stops depict the specific levels of care, therapy, and rehabilitation the stroke survivor must go through, and the desired destination of the stroke survivor within that bus route represents the desired level of recovery from the burden of stroke.) This is very much so the situation in many healthcare systems in regards to stroke patients. Once the stroke survivor is released from the hospital, the stroke survivor and their primary caregiver ("get on that bus") are given very little if any information regarding post hospital recovery procedures and care options. The information given is most often very superficial and lacks a realistic picture of what awaits the stroke survivor and their primary caregiver in the immediate and distant future.

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### About "Croatian Stroke Society"

*Croatian Stroke Society (Hrvatsko društvo za prevenciju moždanog udara) was founded in 1997 with the aim to prevent stroke among persons at risk and stroke survivors, and to improve diagnostics, treatment and rehabilitation, based on the latest scientific knowledge. Raising the stroke awareness in Croatia, which will lead to the reduction of stroke by creating a healthier and more conscious society, is our vision. The Croatian Stroke Society is divided into two branches which are collaborating – stroke survivors section and professional/ scientific section. Our activities are focused at educating the population, stroke survivors, caregivers and the medical staff about stroke to improve diagnosis, treatment and rehabilitation. The stroke survivors section members are primarily involved on raising the stroke awareness among the population including stroke survivors and their family and caregivers organizing public campaigns, patient groups, lectures with stroke risk assessments, activities on social media channels, etc. The professional/ scientific section members are primarily involved on raising the stroke awareness and education of health professionals as well as providing the medical scientific background to the public and stroke survivors. Croatian Stroke Society is proud member of the Stroke Alliance for Europe, European Stroke Organisation and Central and Eastern European Stroke Society.*

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### SAFE: What would be the solution, i. e. what is your organisation' s position regarding this issue?

**HJ:**The need for some form of standardized criteria regarding recovery, care options as well as an insight into patient rights for stroke survivors and their primary caregivers is thoroughly needed. 'The bus route must be laid out, all of the bus stops must be clearly marked so that the stroke survivor as well as their primary caregiver may successfully navigate and reach their desired destination, which is the recovery from the burden of stroke. To achieve these goals a firm foundation must be put in place in which an alliance of all parties involved in the stroke survivors rehabilitation and recovery can come together in order to maximize a successful post stroke outcome. Without complete collaboration and cooperation (within all branches of health care, social services, patient advocate groups, and the stroke survivors primary caregiver) no true recovery from the burden of stroke can fully be achieved. This continuous burden not only inhibits all aspects of the stroke survivors life but directly influences the lives of their family members and society as a whole.

## STROKE SURVIVORS' NEEDS IN TURKEY: Stroke consequences not addressed adequately

"In our country, our patients are facing several problems after stroke. The number of physical therapy units is adequate, however, we should pay extra attention for the subjects such as lack of training and methods, inadequate speech rehabilitation therapy, lack of environmental physical conditions for stroke cases, and often overlooked dementia and depression after stroke" said Füsün Mayda Domaç, Assoc. Prof, MD, Msc and Vice President of BEYİNDER, Turkish Stroke Support Organisation.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**



**FMD:** One of the most noteworthy issues is the establishment of a number of rehabilitation centers by government incentives in Turkey. Although the physical facilities and numbers of the centers are adequate, the lack of physical therapists and physiotherapists, who are well equipped for

neurorehabilitation and especially for stroke rehabilitation, is quite lacking. The number of physical therapy sessions that the Ministry of Health has provided free of charge in patients after stroke is insufficient. Although the physicians are willing to start treatment in patients in the early period, the number of free sessions and an inadequate number of equipped personnel negatively affect the success rates. In our country, physical factors create difficulties for the cases of stroke. It is extremely important to reintroduce stroke survivors to an active, disability- free life with an intensive rehabilitation program. Other important issues we have come across in most stroke survivors are the isolation of social and work environment, fear of not recovering, and psychiatric problems such as depression and

anxiety. Besides, vascular dementia can develop due to localization and severity of stroke. However, because we need to examine a large number of patients in a short time due to health policies in outpatient clinics, urgent and important complaints are considered at the forefront and psychiatric cognitive problems can be ignored. This situation complicates and delays clinical recovery in patients.

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### About "BEYİNDER" (Turkey)

*FMD: Stroke patients are not alone anymore in Turkey. "BEYİNDER" which is Turkish cerebrovascular diseases patients' society was established in August 2017 in Istanbul. BEYİNDER is a non- profit, national society for stroke patients, their families, caregivers and also for health professionals. Our aim is to provide help and support for all stroke patients in Turkey and provide public education by accurate information about cerebrovascular diseases. Our society has a [website](#). The web site of our society provides information about our society, understandable information about clinical signs and symptoms, primary and secondary prevention, therapy and rehabilitation of stroke for patients and care givers, information about communication and news about stroke in media. Our society also has several social media accounts including Facebook, Instagram and twitter in order to make people aware of the society and its website. Official journal of the association began publishing in 2018 and the 4th issue is on the way. Editor of the journal is Prof. Uludüz. The journal provides general information on vascular health of brain for patients. We also send journal to hospitals in order to give patients and relatives at out- patient or in- patient clinics. The online version of our journal is also available on the website.*

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**SAFE: What would be the solution, i. e. what is your organisation's position regarding this issue?**

**FMD:** The short duration of rehabilitation treatment and lack of adequate qualified personnel negatively affect the healing process even though the physical therapy centers are sufficient. In this context, in the neurorehabilitation, it will be helpful to prepare a training CD of physical therapy applications for stroke which explains practices in detail. In addition, neurology and physical therapy branches need to come together and exchange information on neurorehabilitation with joint meetings. Training sets can be prepared in cooperation with the Ministry of Health, and detailed brochures about hints and issues to be considered during physical therapy can be prepared and distributed. The Ministry of Health may be asked to supervise physical therapy centers in more detail and to support fully- equipped rehabilitation centers for stroke rehabilitation. The number of free service periods and sessions can be increased by discussing the

necessity of having a long- term and intensive treatment protocol after stroke with the Ministry of Health. Beyinder works intensively on all these solutions.

Due to the health policies in our country, there is not enough time to examine stroke patients in the outpatient clinics. In addition, it is not easy to make detailed evaluations except for the basic complaints. In this respect, assessment forms for depression, anxiety, and cognitive problems can be prepared and asked to fill it with the help of a patient and/ or their relatives before their visit and these forms can be evaluated quickly in the outpatient clinics. Assessment forms should be developed and implemented easy- to- read taking into account the health literacy of patients so that they can fill forms on their own. In order to raise awareness among neurologists, information brochures about post- stroke psychiatric and cognitive situations can be prepared and distributed.

*Jun 7, 2019*

## **STROKE SURVIVORS' NEEDS IN SLOVAKIA: Socialization of stroke survivors as the biggest issue**

"When patients after stroke meet and can get together with others – even with non- stroke- patients, their self confidence grows, they start to connect with people, and that is for us very important" says Alžbeta Husarovič, the President of the Slovakian Stroke Support Organisation Porážka.sk and a stroke survivor.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**AH:** If we have to choose only one issue, it would probably be the socialization. Because with socialization starts all the patient's effort to 'start over' and to be able to get back to his previous life as much as it is possible. We believe, that step by step this might be the key to the mental recovery, which is as important as the physical one.

**SAFE: What would be the solution, i. e. what is your organisation's position regarding this issue?**



**AH:** During the last couple months, we at our organisation Porážka.sk are focusing on different activities, which might be helpful to stroke survivors. We believe that one of those is our Charity run (called Beh neporazených) which unites the patients with healthy people, who are running to raise money and create better conditions for patients.

This is the most powerful (but also emotional) project of our organisation so far, where the socialization of stroke survivors is really visible.

Other our project is focusing on small sheltered workshop, where the patients with disability becoming a real paid work. Sheltered workshop

is going to be a place where again patients are exposed to real life and can communicate and bond with others.



Photo credits: Porazka.sk [Facebook page](#).

### About Porážka.sk (Slovakia)

Our association Porážka.sk was created in 2013 by Alžbeta Husarovič, stroke survivor. We have three important activities.

- We are trying to spread stroke awareness by organizing various public events such as Unbeaten RUN, Fashion Show etc where we always invite stroke survivors, famous faces and media people.
- We help individuals, stroke survivors and their families in three ways. Financially, by lending to survivors physiotherapeutical equipment and guide them after leaving hospital.
- We are going to give to stroke survivors a place, where they can meet, talk, compare each other, rehabilitate and what is the most important, we are going to give them a work.

Jun 14, 2019

## STROKE SURVIVORS' NEEDS IN UKRAINE: Special needs of stroke survivors neglected both by society and government

This week we spoke with leaders of two SAFE member organisations from Ukraine, Prof. Liliya Zviagina, MD, PhD, President of the stroke support organisation 'Victory over Stroke' and Dmitriy Gulyayev, MD, PhD, Director of publishing and research projects, Medical adviser of public subdivision, Ukrainian Anti- Stroke Association.



"I would say that in the information related to stroke and stroke care in Ukraine, provided by some specialists and even institutions, there is a lot of inaccuracies, mistakes, and even obvious and impertinent lie and falsifications" said Dmitriy Gulyayev at the very beginning of our conversation.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**DG:** Current state of stroke care in Ukraine is poor, so it is not easy to pick just one problem. In my opinion, one of the major issues is that special needs of stroke survivors are neglected by the society and the government. Stroke survivors are isolated from public – physically (due to inaccessible public transportation, buildings etc.), and psychologically (as they are often ashamed of their disabilities). They are not in focus and are almost 'invisible' for the society. Despite the fact that virtually anyone in Ukraine has a family member or a friend who suffered a stroke, they do not realize how many stroke survivors there

are in Ukraine, how challenging their life is, and how unfair the society and the government treat this huge sub- population – stroke survivors, their relatives and caregivers.

Unfortunately, stroke survivors themselves rarely volunteer to share their experiences and challenges, and thus we are unable figure out the list of their priorities, and often have no other choice than initiating projects at our own discretion. Moreover, stroke survivors are not prepared to join their forces to speak up about their problems and the unmet needs. As a result, official institutions, take care of those who are younger, more mobile, more active, and who are shouting about themselves louder. Particularly by this reason, among others, for example, rather influential social movement "Patients of Ukraine" was established and is managed and promoted by activists of HIV/ AIDS and hepatitis organisations, and stroke items are far out of their interest and attention.



**LZ:** Stroke is the leading cause of morbidity and mortality death in Ukraine and is the main cause of disability in adults. Number of sufferers varies from 200 - 300 per 100 000 population, depends on region. The main risk factors for stroke are well understood and include atherosclerosis and high blood pressure as well as bad habits. Stroke has a harmful impact on social and family life.

Quality of stroke service varies from region to region and depends on sometimes from personal activities and forces of doctors. To promote good service for stroke patients we have understand what is wrong and what we could to do in existing conditions.

Stroke service in Ukraine is only in the beginning of the way, people could not always access the services they need. I would like to stress on some common problems in Ukraine and what changed during last years.

1. People are not aware about stroke;
2. Not all people address in time to get help;
3. Not enough stroke units;
4. There are not insurance, and patients must pay for their treatment;
5. Stroke patients get treatment in general neurological department
6. Not so many departments use modern treatment (thrombolytic therapy and thrombectomy);
7. Not so many departments are equipped for monitoring vital parameters of stroke patients;
8. Not so many departments have trained staff to perform all needs of stroke patients, particularly who has a dill with sufferers who have communications problems caused by stroke, such as aphasia;
9. Not so many departments have multidisciplinary teams;
10. Early and later rehabilitation are poorly organised;
11. Not all stroke survivors and their carers are provided with the recommendation they need when they discharge from the hospital;
12. There are not system for observe patient during the first year;
13. Not all patients are offered individual budgets or direct payments within the first six weeks of their returning home;
14. Not all people has a good knowledge of primary and secondary stroke prophylactic



Photo credits: Facebook ( Roman Shwed, featured photo); profile photos of the interviewed persons: Personal archive



## About "Victory over Stroke" (Ukraine)



School for stroke survivors "Victory over stroke" was established within Odessa neurological society in 2008, after visiting SAFE conference. We started with a small group of stroke survivors, trying to manage their life better, arranging some musical concerts, meetings and courses. We work and people help us as a volunteer. Since 2013 I became general neurologist of Odessa health department and from this time, I try to change the system of patient's service and act more globally. We are working on many directions:

People information, (TV, meetings, newspapers)

Stroke prevention (patients and doctors)

We are involved in city program "Health" which let our patients get access to CT in acute stage for free and get three days treatment according to protocol, this year we have plan to open three stroke units (one is ready now)

Thrombolytic therapy will be paid by this program as well as thrombus retrieving.

There two telemedicine centers, where patients from the countryside have access for consultations

We teach doctors, manage local, national and international conferences.

Late rehabilitation center was open in one of Odessa clinic, where patients have access to improve their motor dysfunction, be adapted to the city and home environment

I joined school to University of third age, where people improved social life to study a lot of new subjects, computers, languages, tourist's routes, where I teach people different medical questions, presented brochures, given to our organisation by SAFE, and presented new directions of stroke treatment, etc. This kind of activity plays positive role, students of the university recognized stroke in one of the visitors and give help him immediately

Mortality after ischemic and haemorrhagic stroke decreased

## About UASA (Ukraine)



The Ukrainian Anti-Stroke Association (UASA) is the All-Ukrainian nongovernmental organisation established in 2004 with the purpose of integrating efforts of medical professionals, scientists, teaching staff of medical educational institutions, workers of social services, mass-media and people at large for improving the health care system in treating patients with stroke, primary and secondary stroke prevention, rehabilitation of patients after stroke and improving quality of medical and social help for patients who had stroke. Since its establishment, UASA is one of the most aggressively working Ukrainian NGOs in the field of medicine and health care, and the single organisation totally devoted to stroke. UASA elaborates, publishes and disseminates National Guidelines on stroke care, holds the most important Ukrainian scientific and education events for stroke physicians and allied health care professional, publishes as its official printed matter the single Ukrainian professional journal totally devoted to stroke "Sudynni Zakhvoryuvannya Golovnogo Mozku" (Cerebrovascular Diseases). For 4 years (2010- 2013) UASA was publishing the Russian- language version of the "International Journal of Stroke" – the official printed matter of the World Stroke Organisation – for all countries where Russian language is in use, including Russia. Several years ago, UASA has initiated and since then is a leader in the SUNEP – stroke unite nurses education project, which is very useful and successful not only in Ukraine, but in other countries of Eastern and Central Europe. Main directions of work with general population are educational events for stroke survivors and their caregivers, educational materials for patients and general population, particularly the brochures on different aspects of stroke, "Guidebook on neurological diseases for laymen", etc. The book "Stroke: Information for those who are concerned" has been re- published 8 times. We fulfil wide educational activity in Facebook, and currently are on the way to finalize and publish the popular web- resource on stroke for general audience. UASA always was the principal organizer of the activities related to the World Stroke Day in Ukraine. UASA is member of World Stroke Association and European Stroke Organisation and is on the final stage of joining SAFE.

**SAFE:** What would be the solution, i. e. what is your organisation's position regarding this issue?

**DG:** Obviously, there is no magic wand to solve this deep social problem. We have to be ready for long-lasting, often thankless routine activities. We have to:

- widely distribute through different channels stories about stroke survivors' life, needs, problems, solutions – not only in Ukraine, but in other countries with different level of social and economic development;

- build different platforms (both real and virtual) for communication of stroke survivors – peer-to-peer, and with surrounding world;

- involve stroke survivors into elaboration of stroke care on national, regional and local levels, encourage their active self-advocacy.

**LZ:** This can be summarized in couple of points:

1. The ministry of health declares some prevention measures; there is program -“Available medications”, which covered costs anti-hypertensive medicine, medicine to treat diabetes, ...

2. The ministry of health proved protocol of ischemic stroke treatment N602 from 03/ 08/ 2012 which is act till now, should be revised according new trends, including thrombectomy

Over the last years the number of stroke units and thrombolytic therapy increased considerably as well as clinic where clot retrieving is available.

Despite of it we must improve these directions, which are help not only survive but return to social life.

Jun 21, 2019

## **STROKE SURVIVORS' NEEDS IN NORWAY: Problems start when local municipal takes over the rehabilitation**



Photo: Bjørn Bakke, private archive

“The municipalities (in Norway) govern themselves regarding the economy and the government can't earmark money to be used in the municipalities for each purpose. The municipal decides what they want to use the money for. And too often we see that there are no more money left when it comes to give patients the treatment they need, and which Norwegian law grants them” says Bjørn Bakke, leader of the Norwegian Stroke Support Organisation, [Norsk forening for slagrammede](#), which is a member of SAFE.

**SAFE:** What is one issue related to the life after stroke in your country that you think needs special attention?

**BB:** In Norway we see that the situation for stroke survivors gets worse after the initial treatment in the stroke unit in hospitals and the first rehabilitation in the hospitals. These treatments (medical, surgery,

rehabilitation) are financed by the government and follows in most cases national guidelines which are developed and refined during the (last) years. These treatments are usually of a very high quality.

The problem arises when the patient leaves the governmental treatment and the local municipal takes over the rehabilitation. There are of course laws regulating that a patient is granted the same treatment. But unfortunately, this is not necessarily so – in most cases. Norway has approx. 400 municipalities and every single one has a different approach to this issue. To be short, it comes down to economy.

**SAFE: What would be the solution, i. e. what is your organisation's position regarding this issue?**

**BB:** There are 4 stroke organisations in Norway, and we have all concluded that we must engage politicians so that the parliament can pass new laws to strengthen the rights for the patients. This year we have local elections, and this gives us all a great opportunity to address municipal politicians all over Norway. We have a lot of work to do to address the public and the politicians with arguments. This means writing to the politicians and in newspapers and influence the wherever possible, like using Facebook etc.

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#### *About Norsk forening for slagrammede (Norway)*

*BB: Our organisation is driven by stroke injured people and our main issue is to work for stroke injured people. We are a nonprofit organisation having approx. 1250 members spread all over Norway in 19 local organisations. We plan to establish more local organisation, but we see also that we need to change our structure a bit in some places. Some of the local organisations cover a too large area and it is not possible for them to gather people from all over their area, so we may need to split some large organisations into smaller units.*

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## Neuropathic Pain After Stroke

Dr Hege Ihle- Hansen, specialist in inner medicine and geriatrics at Oslo University hospital, Ullevål, told us that in follow- up after stroke a neuropathic pain is also mapped, and this is included in the national guidelines concerning follow- up 3 months after stroke.



Grethe Lunde, a stroke survivor, member of Norsk forening for slagrammede and SAFE Board member is one of many stroke survivors who live with neuropathic pain.

"How to live with muscle pain/ neurological pain after 25 years as a stroke survivor? Well, I am really happy to be a knitter, as knitting often cuts the link to the "pain button" in our brain. It is a great way to disconnect from what is hurting.



Knitting is also great fun and a really good tool for enhancing the mobility in your hands. Knitting distracts you from chronic pain. A study conducted by Harvard Medical School's Mind and Body Institute, found that knitting lowers heart rate, by an average of 11 beats per minute, and induces an "enhanced state of calm, similar to that of yoga" concluded Grethe.



Jun 28, 2019

## STROKE SURVIVORS' NEEDS IN CZECH REPUBLIC: Due to deficiency of post- stroke services, stroke survivors leave for psychiatric hospitals or institutions for mentally handicapped people

"Due to deficiency of post-stroke services, stroke survivors leave for psychiatric hospitals or institutions for mentally handicapped people. The support or assistance provided is very low, and there is a complete exhaustion and often the disintegration of these families. At present there are very limited possibilities of specialized and comprehensive rehabilitation in the Czech Republic. Cerebrum responds to this situation and seeks to create a system of aftercare in the scope and volume as allowed by current grants and funds" says Jana Dobrkovská, the CEO of **CEREBRUM** – Sdružení osob se získaným poškozením mozku a jejich rodin, Czech organisation that is member of SAFE.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**JD:** In the Czech Republic we have an excellent system of acute care for stroke. Our stroke centers are high- end facilities that provide the best acute stroke assistance. However Czech health insurance system is limited by volume of support for people after stroke in non acute phase. When the paid physical treatment ends, the survivors no longer continue in any rehabilitation cover by insurance action, although their physical condition would allow them to do so. Also our current system of long- term care for this target group of people is a disjointed with lack of continuity and interconnection of services for the patient after acquired brain injury. Due to deficiency of services, these people leave for psychiatric hospitals or institutions for mentally handicapped people. However, these types of devices are neither identified nor able to provide adequate assistance. If the family decides to take care of themselves, the support or assistance provided is very low, and there is a complete exhaustion and often the disintegration of these families.

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### About "Cerebrum" (Czech Republic)

**JD:** We currently help clients who need help from psychologist, speech therapist, physiotherapist. The arrangement of assistance is non- acute care in the form of individual and group therapies. The main objective is to raise the awareness of the Czech public about the wide range of consequences of brain injury and the possibilities of rehabilitation. We provide advice in this area and map services that are intended for people after this injury. We also perform our own therapeutic activities and ergotherapy in the home environment. Our team is a psychologist, an occupational therapist, a speech therapist, physiotherapist. Our clients are people after a stroke (stroke), injuries (accidents, sports falls and the like) or with consequences after treatment of malignant diseases. We also try to provide help and advice to the clinic' s family, carers and relatives. Size of our organisation is 16 employees, with a 45.000 EUR turnover in 2017.

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**SAFE: What would be the solution, i. e. what is your organisation' s position regarding this issue?**

**JD:** We currently help clients who need help from psychologist, speech therapist, physiotherapist. The arrangement of assistance is non- acute care in the form of individual and group therapies. We provide advice in this area and map services that are intended for people after this injury. We also perform our own therapeutic activities and occupation therapy in the home environment. Our team is made of a psychologist, an occupational therapist, a speech therapist.

Our clients are people after a stroke (stroke), injuries (accidents, sports falls and the like) or with consequences after treatment of malignant diseases. We also try to provide help and advice to the clinic' s family, carers and relatives. This year we launched a project in selected hospitals in Prague, where, we provide support for families of patients who leave for home care.

Our coordinator provides advice and support in everything that home returns often represents; where to buy compensation aids, how to ergonomically adjust housing, where to go for help in the social sphere and more. Another priority of the project is relief and mental support for carers.

The aftercare segment has been waiting for the adoption of the Rehabilitation Act for many years to unify post- stroke aftercare procedures.

Our activity is also to draw attention to this situation and to influence the general and professional public and raise the awareness o about the wide range of consequences of brain injury and the possibilities of rehabilitation.

### **Brief description of Stroke situation in Czech Republic**

#### **Statistic**

Hospitalized and deceased for cerebral vascular disease in the Czech Republic (2003-2010)

The number of hospitalizations for cerebral vascular disease from 64, 399 cases in 2003 to 57, 484 of cases in 2010 decrease by 10.7%

In stroke hospitalizations between 2003 and 2010 there has been a decrease by 7.8% from 44,585 to 41,111 cases (after conversion to 100,000 inhabitants, the trend is also falling. Looking at the cerebral vascular disease group in detail, there has been a steep decline in the number of hospitalizations for unspecified patients stroke from 21,037 cases (in 2003) to 10,762 (in 2010), i. e. by half. In contrast, ischemic attack was diagnosed in 23,871 cases in 2010 compared to 18,055 cases in 2003, ie an increase of about 32%.

Despite the modest increase in other cerebral vascular diseases types, there is an overall gradual decline in all cases. However, the treatment period is lower for stroke (14.1 days in 2003 at 13.6 days in 2010). The average age of hospitalized patients in 2010 ranges from 66. 2 to 76.6 years. Compared to 2003, the average age of all cerebral vascular diagnoses was moderate hospitalized in accordance with the increasing demographic aging of the population mortality rates 11.1 deaths per 100 hospitalizations in 2010 compared to 14.5 deaths in 2003. A total of 11,567 people died in the Czech Republic for cerebral vascular disease in 2010, which represents 10. 8% of all deaths in a given year. Compared to 2003, this is a decrease of 31%.

## Social situation of people who suffer from stroke and other cerebral vascular diseases in Czech Republic

The awareness of the importance of health-enhancing physical activity among stroke patients in Czech country is very low. To keep effective social inclusion, the information campaign and knowledge training about such disabilities is crucial. This social inclusion is very poor in Czech Republic. To set up participation in social and public activity for cerebral disease survivors including stroke patients, is very important. This activity needs to be arranged not only for wide population, but it is more important to present the importance of such activities to the survivors themselves. Cerebrum has experience with clients who show good progress in physiotherapy, but do not have the courage to resume normal social daily activities like

they did before stroke. These people also have no calls from public events to join. On the other hand event providers do not offer services with conditions to participate these people in their limitations. And likewise here are very good activities for disabled people in the Czech Republic, which, however, do not often involve people without disabilities. We want to increase the knowledge of the public in Czech republic and create the link between usual daily living and brain damage survivors. Cerebrum's employees and association partners are professional therapists, who understand physical limitation of stroke survivors and therefore can act as a mentor for such methodology and trainers education. Czech health insurance system is also limited by volume of support for people after stroke. When the paid physical treatment ends, the survivors no longer continue in any rehabilitation cover by insurance action, although their physical condition would allow them to do so. We see an opportunity in this area too.

*Jul 4, 2019*

## STROKE SURVIVORS' NEEDS IN SPAIN: Limitations regarding care access related to age

"Our system promotes health, prevents disease and provides assistance to serious patients in an exemplary manner, trains its professionals properly and generates a high added value in biomedical research, but it still has one remaining issue: to rehabilitate, take care of both the patient and the caregiver and properly reinsert citizens back into society" says Carmen Aleix, the President of the Spanish Federation of Stroke (FEI).

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**CA:** Rehabilitation in patients with stroke occupies a very irrelevant role in most health decision-making forums throughout Spain, including Catalonia. We know what our patients think about how the service is provided "beyond the acute phase" They notice limitations regarding care access related to age and perceive that there are no



homogeneous referral criteria when accessing to certain social benefits. They also sense lack of information and greater difficulties regarding access to attention when there is cognitive damage associated with severe behavioral disorders. Patients also report important differences in the quality of the benefit

depending on the center to which the patient is referred. Rehabilitation should be the main actor and not the secondary or even the absent one, as has been up to now in any plan or strategy on stroke or any other disease that produces disability. Patients demand to live with dignity.



**SAFE: What would be the solution, i. e. what is your organisation' s position regarding this issue?**

**CA:** The Spanish Stroke Federation defends the need to carry out in- depth reforms of the system to ensure its sustainability. Encourage patient self- care, health promotion, adjustment of resources to needs and continuity in care. Our current health model needs to adapt to the new social reality marked by population aging which has become chronic, and the continuous development of technological services. For this, it considers that the person must be placed in the center of our National Health System (SNS), in order to achieve that the needs of the patient to be the ones that vertebrate all the infrastructures and sanitary and sociosanitary services, and demanding a much more active participation in the design and execution of the services that are provided, which is already happening in the most advanced countries in terms of health. Ideally, we should be able to count on a NATIONAL NETWORK OF CONTINUED CARE and to know clearly how the rehabilitation expense is managed in the Social Security and why now is there so much deficiency, so few sessions and so terrible attention in the rehabilitation of stroke patients.

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### About The Spanish Stroke Federation

**CA:** *The Spanish Federation of Stroke (FEI) is a non-profit organisation at the national level, independent of the administrations, of volunteering, which was founded in 2006. The lack of interest and the scarce sensitization of the health administrations towards stroke was a sufficient reason for the constitution of the federation. The mission of the FEI is to promote information and education on stroke, prevention and adequate and equitable treatment throughout the national territory. Its values are Participation, Commitment, Responsibility, Social Change.*

#### Commitment for 2019

1. *The FEI is participating in the prevention campaign #GeneraciónInvictus.*
2. *It is also conducting online surveys to participate patients and caregivers.*
3. *We have signed a collaboration agreement with the Spanish Society of General and Family Physicians, through which an epidemiological study on the knowledge of stroke in primary care will be carried out jointly, as well as the organisation of other workshops and joint activities.*

*A picture is worth a thousand words. To learn about our activities, please follow us on:*

[https:// ictusfederacion.es/](https://ictusfederacion.es/)  
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[unictusunahistoria.com/](http://unictusunahistoria.com/)



Jul 5, 2019

# STROKE SURVIVORS' NEEDS IN CATALONIA, SPAIN:

## The life after stroke is the poorest point of the care process

"The life after stroke is the poorest point of the care process, especially in the chronic phase" says Esther Duarte, member of the board of Fundació Ictus, and rehabilitation doctor at IMIM Institut Hospital del Mar d' Investigacions Mèdiques in Catalonia, Spain.

**SAFE: What is one issue related to the life after stroke in your country or region that you think needs special attention?**

**ED:** In Catalonia, stroke patient associations have few members, therefore they have little power in society and official institutions, as well. In consequence, more public resources are always allocated to young patients with other illnesses, such as cancer and ischemic cardiovascular pathology. Moreover, these associations are only useful for a small percentage of patients. One of the aspects that are not taken into account is labor protection. Few patients return to work because there are no policies to facilitate it. Furthermore, other aspects with bad attention are those related to sexuality or driving, for example. On the other hand, there are few research groups focused on life after stroke and how improve patient- centered outcomes. In conclusion, access to rehabilitation services is not guaranteed in all cases and the needs of patients and caregivers are not always met.

**SAFE: What would be the solution, i. e. what is your organisation' s position regarding this issue?**

**ED:** The main goal of Fundació Ictus is to improve the quality of life of stroke survivors and their caregivers. We collaborate with patient associations to meet their needs and help them in finding resources for their activities. We also help stroke survivors with specific training for caregivers and volunteers.

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### About Fundació Ictus (Catalonia, Spain)

*Fundació Ictus is an entity with a social presence with the mission of publicizing the disease, promoting research on it and supporting people who have suffered a stroke. Our main goals are popularizing the disease and spread how to prevent it, how to avoid it and how to treat it. Furthermore, we support stroke patients, offering support to people with disabilities, with alliances with other entities. In addition, we promote research on the disease in all its stages and from all perspectives.*

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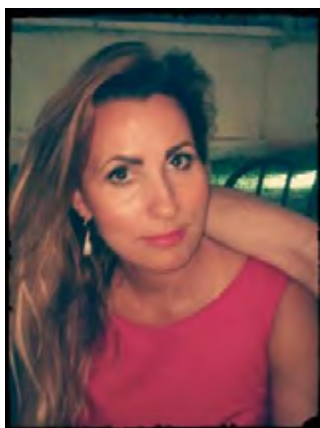


That's an important point, because there is not any specific course focused on stroke addressed to any professional, except the hospital nursery course that we have organised for 11 years. We also encourage patient- centered research, otherwise there is no way to advance in giving a better care to stroke survivors. Moreover, we offer advice in different dimensions: legal, labor, social, driving and sexual. Finally, we are trying to develop new platforms oriented to patients and caregivers that integrate all the information.

Jul 12, 2019

## STROKE SURVIVORS' NEEDS IN GREECE: The lack of relevant transitions from clinic to real life in the outside world

Continuing our conversations with SAFE member organisations from across Europe, we spoke this week with Pinelopi Vlotinou, Occupational Therapist and Anna Tsiakiri, Psychologist from the Greek stroke support organisation, Hellenic Alliance for Stroke.



**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

Engaging and making relevant transitions from clinic to real life in the outside world that are meaningful and thoughtful. Often the missing link of the "rehab puzzle" means announcing to the family prognosis for improvements which may not always be positive and may require environmental adaptations that should be individually geared and best suited for the patient. After a stroke there are "fog" issues not only for the patient but for the family. Trust issues about what works best as well as a unfamiliar new home, social as well as professional environment. It is important that regaining social roles and the return to the previous state of life, taking into account the consequences of stroke. Life goals as well as family needs should be balanced. They require that the patient should establish good relations with someone they trust and implement changes and transitions into daily decisions. Support and

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### **About Hellenic Alliance for Stroke (Greece)**

*Hellenic Alliance for Stroke consists of research and academic organisations of health care providers such as the Greek Neurological Society and the Hellenic Society of Cerebrovascular diseases, institutions, health professionals, voluntary support structures, caregivers and patients. The aim is to make a concerted effort both to inform and educate the public about prevention, early diagnosis and treatment of a stroke and to the health policy makers in order to achieve improvement of health services for the treatment, care and rehabilitation of the patient with stroke at the national level. Main goals:*

- Communication and cooperation between members, coming from the scientific field and members, coming from the field of stroke survivors, in order to update and exchange views, knowledge and experience which we believe is the best possible ways to treat, restore and help improve or maintain quality of life not only for the stroke survivor but the family at large.*

- The support and promotion of scientific research on issues related to strokes, aiming at better prevention, rehabilitation and reduction of consequences and social costs.*

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framing by a group of specific health professionals who will direct towards the optimum course of action.

**SAFE: What would be the solution, i. e. what is your organisation' s position regarding this issue?**

**Solution:** The awareness of the fact that rehabilitation is long term but must be individualized. Therefore the families make cultural competent adaptations that are considered in their options which are provided by health care staff as well as society at large after the hospitalization.



## Proposals:

Every stroke unit should define a "Stroke advisor". His/ her role summarizes at the following:

- ★ Connect the patient and his family with "health professional system"
- ★ Provide support, information and guidance
- ★ Keep a six month "follow up" with the patient
- ★ Provide "monitoring" of the patient even at home. Adaptations, ergonomic and ecological suggestions, modifications

even to the working environment of the patient can be an additional action to help the individual

- ★ Provide resources about stroke support organisations and about local available services
- ★ Provide access to patient and family to informational leaflets such as angels initiative.
- ★ All neurological clinics/ stroke units should establish a common protocol about patient management

Jul 19, 2019

## STROKE SURVIVORS' NEEDS IN HUNGARY: Social reintegration is one of the most important issues

"In Hungary even nowadays people are ashamed of this disease (stroke), they do not talk about it, they live their life withdrawn, stopping all social activities, and therefore the beneficial rehabilitation opportunities often cannot be brought to their attention. In many cases, the society and the relatives give up on the stroke survivors" says András Folyovich, MD PhD – Board member of the National Stroke Prevention and Rehabilitation League – Hungary.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**AF:** Among the serious consequences of stroke, social reintegration is one of the most important issues, which needs special attention. Stroke survivors recovering with residual symptoms experience that their roles in the society are significantly affected: they can no longer fulfill their former work, and everyday tasks. They may even be forced to resign and thus the economic situation of the families becomes insecure. Significant number of stroke patients need constant care, and the families face big financial burden.

### About The National Stroke Prevention and Rehabilitation League' (Hungary)

*AF: Our non- profit civil organisation was founded in 1993 and named ' The National Stroke Prevention and Rehabilitation League' in 2011. Our mission is the prevention and the rehabilitation of stroke patients through services, personal assistance, information, advocacy and cooperation with health professionals.*

**Our core activities include:**

- ★ Organising free health screening events (Stroke screening day at Szent János Hospital)
- ★ Editing and issuing healthcare brochures and their distribution (e. g.: Physiotherapy exercise booklets to those who live in the countryside)
- ★ Providing access to transfer and mobility equipment
- ★ Personal assistance and advocacy to stroke- patients and their relatives
- ★ Participation in national and local health related events
- ★ Recruiting new members

Moreover, family members often must quit their jobs too due to patient care. This emotional and financial burden is very difficult to live with for the affected families.

**SAFE: What would be the solution, i. e. what is your organisation's position regarding this issue?**



**AF:** In our opinion, civil organisations can help a lot in the successful reintegration into the community.

The majority of stroke survivors are discharged into the community. However, after the hospital discharge stroke- survivors and their caregivers are not fully aware of the available

further rehabilitation options (physiotherapy, speech and language therapy, stroke support organisations etc.). The situation is worse for those, who are living in the countryside, as there are limited rehabilitation opportunities.

Stroke support organisations can help to give the useful information about the existing support groups, rehabilitation facilities and various equipment. Providing orthotics and transfer- and mobility equipment may assist for patients to be able to leave their homes and to start to fulfill the roles, they used to do before.

Support groups can also be helpful to give a platform, where stroke- survivors can meet and share their experiences and support each other.

In summary, our vision is a world, in which the number of stroke cases decreases significantly and all stroke patients receive a personalized, short and long- term support and care, with successful social reintegration.

The League's services and programmes are available for everyone. In order to make our work more effective we also co- operate with other national and foreign organisations and governmental decision-makers (e. g.: Aphasia Club, International, Pető Institute, SZIV SN Association for heart diseases etc.)

The National Stroke Prevention and Rehabilitation League is currently unable to fulfil their tasks appropriately, due to the lack of funding. The League cannot count on direct financial support either from the government, or from pharmaceutical- and other medical companies.

The reason for this is that traditionally the Hungarian Stroke Association (the medical- professional company) organises the stroke- days and the public awareness events, which means that the financial support arrives there.

The solution may be the revaluation of the National Stroke Prevention and Rehabilitation League and the Hungarian Stroke Association. For which, there is a good chance with the current leadership. In close co- operation, it is necessary to redistribute the tasks. The League should deal with the public issues, while the medical- professional company should be responsible for the professional background. It would be beneficial to contact with the neurological departments of Hungary, and to organise the civil organisations around these departments.

Jul 26, 2019

## STROKE SURVIVORS' NEEDS IN CZECH REPUBLIC: More clubs for stroke victims

"The life of stroke victims is made difficult in several aspects. It is not only the physical handicap, but also a state of desolation. Family members can act against these troubles with good vigor and vitality, nevertheless a support of the surrounding society would be much helpful." says Prof. Pavel Kalvach from Czech stroke support organisation Sdružení pro rehabilitaci osob po CMP (Czech Association for stroke victims).



**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**PK:** This is a point, which we should stress in our Czech community: more clubs for stroke victims, for stroke carers, more encouragement in terms of mutual communications, music, creative activities. The people affected by stroke can produce these activities partly on their own, but they need necessarily organisational as well as logistic support. Given such meetings would be established, we could believe, that they could

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### *About the Czech Association for stroke victims*

*The activity that the Czech Association for stroke victims takes the most merit for is the arrangement of summer camps, aiming at rehabilitation. These courses occur in recreational regions of Czech republic. Care of physiotherapists, of medical doctors, psychologists and logotherapists is provided for groups of approximately 40 persons. These courses are financially supported by our Ministry of health, who would cover ½ of the expenses. The other ½ is covered by each person himself. Besides of the medical and psychological individual and group training also cultural activities are organised, like visits to the sightseeing around, or collective singing, or even dancing. People take great pleasure in such course, but the number of those, who achieve to participate is still too low: About 200 per year. If we compare this with the prevalence of stroke victims in Czech Republic, this number make less then 5% of people, who could profit.*

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then run already spontaneously. Certainly much enthusiasm is needed to put these intentions into reality.

**SAFE: What would be the solution, i. e. what is your organisation' s position regarding this issue?**

**PK:** The Czech Association for rehabilitation of stroke victims provides counselling, provides courses, activates clubs throughout the country, but its reach is by far insufficient. Many healthy, retired people, who could actively contribute to the care of those less happy in their physical health state, ignore the needs of stroke individuals and thereby also their eventual personal pleasure of making good deeds. Our organisation should be more proactive in sharing knowledge and encouraging people in those activities. Self- supporting groups could be conceived and we should reach out to put them in life.



Aug 2, 2019

## STROKE SURVIVORS' NEEDS IN ICELAND: A lack of follow- up from the healthcare system



*"According to circumstances in ICELAND we are unable to make significant survey on prevention, treatment and rehabilitation of the stroke or exploring the burden of the stroke because we have only 360. 000 citizens. Therefor it is difficult for the authorities to answer our queries about the incidence of stroke across the country. But however we are trying to follow Stroke Action Plan for Europe 2018- 2030 by taking the guidance of professionals and health authorities."* says the Chairman of [HEILAHEILL](#), Icelandic stroke support organisation, Thorir Steingrímsson.

On the International Stroke Day 2018 our members HEILAHEILL, patients, neurologists, etc. to promote the disease and disseminate information to the public in KRINGLUNNI, Reykjavík' s largest shopping center, which attracted much attention. Chairman of HEILAHEILL Thorir Steingrímsson and the specialist in neurology (thrombectomy) Bjorn Logi Thorarínsson in National University Hospital of Iceland | LSH · Department of Neurology. were at the stand to answer all visitors' questions.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**TS:** Being in SAFE gives us the opportunity to compare ourselves with other health systems in other European countries regarding the stroke. Many things are similar to us and the other Nordic countries, but there are a number of factors that

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### About HEILAHEILL (Iceland)

*TS: HEILAHEILL is a independent companionship for stroke survivors with individual membership for the whole country. The company have opportunity to meet the decision- makers by the authorities face- to- face, and they have supported us in our policy and it is also close relationship between people In HEILAHEILL and professionals over the country.*

*Therefore there is compelling evidence in ICELAND 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 and most of all, a good and powerful communication with patient organisations.*

*The benefits of tPA in patients with acute ischemic stroke are time- dependent, and guidelines recommend a door- to- needle time of 60 minutes or less. Professionals in Iceland say the average has dropped from 80 minutes to 25 minutes in the last three years!*

*HEILAHEILL has released an app in smartphones with information on the first signs of stroke. And when it is inserted in the beginning you place your social security number, it makes it your personal safety button to the emergency line and they positioning the device with precision. The smartphone tells who is calling for help, age, gender, wherever you are in the country!*

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are similar to the burden of the stroke with other nations, for example there is a lack of follow- up from the healthcare system, when individuals are enrolled in the community.

The main problem in our country is that the health authorities and ÖBÍ (The Organisation of Disabled in Iceland) which we accept money from, do not recognize aphasia after stroke as a special disability category in the healthcare system, but it is mixed with aphasia due to age or other trauma. The majority of those who have aphasia after stroke in our country do not experience themselves as ratifying the citizens of society. It is a great shame. Therefore, HEILAHEILL has worked with professional, speech therapists and other patient associations to raise the awareness of the health authorities and the public of this disability. We realize that this is starting to work, as the current government is beginning to recognize the problem i. a. support us financially specifically in equating education with this disability category

**SAFE: What would be the solution, i. e. what is your organisation's position regarding this issue?**

**TS:** We still have opportunity to do many things, which larger nations find difficult to do, for example make a plan for decision party about stroke treatments over the hole country. In comparison, we can be likened to a little drill next to a big oil ship.

Healthcare professionals have done tremendous progress in thrombectomy, over the past two years in Landspítali in Reykjavík, which is the largest and leading factor in healthcare in the country and estimate it to be national 2020! HEILAHEILL has decided to introduce this improvement among the public and in the country and use this opportunity to raise public awareness of the first signs of stroke and and urges the public to push the government to put more money into reducing the burden of a stroke!

*Aug 16, 2019*

## **STROKE SURVIVORS' NEEDS IN CYPRUS: Patients and their families seem to be underinformed**

Eva Pettemeridou from the Cyprus Stroke Association spoke this week with SAFE team about Stroke Survivors' needs and #LifeAfterStroke in her country. She pointed out the lack of information and services after stroke as one of the most important issues.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**EP:** One of the issues pertaining to life after stroke in our country is the lack of information and services following the initial stroke treatment and prognosis. Initially, patients and their families seem to be underinformed, if at all, on the effects of stroke for each individual case, and as an effect the importance of receiving in or out – patient rehabilitation. As a result, the individual returns home without receiving individually tailored treatment that will help in improving post- stroke deficits.



Therefore, these individuals and their families return home with little awareness of what is to be expected from the patient cognitively, physically, and psycho- socially, and potential changes necessary for the individual to function independently.

**SAFE: What would be the solution, i. e. what is your organisation' s position regarding this issue?**

**EP:** The Ministry of Health can hire staff that can provide information on the importance of receiving rehabilitation based on the needs of each individual, and potential services provided in Cyprus. However, for this to be feasible the Cyprus Stroke Association (CSA) should focus its efforts in influencing all relevant authorities and stakeholders.

This may be addressed via directly contacting politicians, writing newspaper articles, and using of social media to bring greater awareness. In addition, by establishing collaborations with different national and international organisations (incl. universities) and companies (e.g. rehabilitation centers, pharmaceutical companies), CSA may be able to further influence relevant authorities in providing maximum support to stroke survivors.

### About The Cyprus Stroke Association (CSA)

The Cyprus Stroke Association (CSA) was founded on February 10, 2009 (Registration number 3419) and is a Non- Governmental Organisation acting within the Cypriot and European legislation. The vision of the CSA is to work towards the prevention of cardiovascular incidents in Cyprus and to offer maximum help and support to individuals who have suffered a stroke, their families and kin environment. The mission of the CSA is to prevent strokes, and reduce symptoms through information and education. The aim of the CSA is to identify high- risk individuals and inform them appropriately, access people with stroke and help them receive appropriate treatment and care and improve the quality of life of people with stroke and their families. We also aim to formulate existing legislations for people with stroke, provide information about their rights and the sponsorship offered by the state apparatus.





Aug 23, 2019

# STROKE SURVIVORS' NEEDS IN LATVIA: Rehabilitation without waiting lists and medicines' availability

## About ParSirdi (Latvia)

*ParSirdi. lv is non-governmental organisation founded in 2011, bringing together various heart and cardiovascular disease patients and their relatives. Our mission: to reduce the impact of heart and cardiovascular diseases by promotion of healthy living, educating society regarding the risks of diseases, ensuring the access to health care information and advocacy of patients.*

### Our aims are:

- ★ *Protecting the rights of cardiovascular patients to access quality medical care (medicines, devices and services);*
- ★ *Identify and reduce factors that prevent patients with cardiovascular disease from receiving quality healthcare;*
- ★ *Improve the quality of life of people with cardiovascular diseases through active involvement in the development of national cardiovascular policy, in cooperation with state and municipal institutions;*
- ★ *Facilitate the exchange of information between patients, medical professionals and the public with the aim of helping patients with cardiovascular disease to successfully organize their daily lives, integrate into public life, and achieve professional success;*
- ★ *Carry out educational work to raise awareness among cardiovascular patients and the general public about cardiovascular disease, its prevalence, risk factors and treatment;*
- ★ *Promote a healthy lifestyle;*
- ★ *Develop projects to improve the quality of life of patients with cardiovascular disease.*

*Since 2013 patient organisation ParSirdi. lv is an associated member of the international organisation SAFE (Stroke Alliance for Europe).*

According to data of Stroke Units, there are many patients who return to the hospital and one of the reasons is discontinuation of medication. This is due to both – the financial capacity of the patients and also the lack of understanding of the need for medication and poor cooperation with their physicians and specialists.

This week, Inese Maurina from Latvian organisation [Parsirdi.lv](http://Parsirdi.lv), offered SAFE team an insight into the needs of the Stroke Survivors and # LifeAfterStroke issues in her country.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**IM:** I would like to stress two things:

1. Rehabilitation – there are long waiting lists to get the rehabilitation services after stroke. Patients and their relatives are also confused because of lack of sufficient information on where to go, what to do next, where to look for help, where to get rehabilitation services, etc. Due to these reasons lot of patients receive rehabilitation too late or not as much as needed.
2. Availability of medicines and patient adherence. Increasingly effective medications are available for the prevention and treatment of stroke risk factors, but often patients cannot afford to pay for them, so they stop taking them or even do not start to use medicines. This leads to very serious consequences – illness, disability or death. Similarly, many patients do not qualify for medication reimbursement due to very strict requirements.

**SAFE: What would be the solution, i. e. what is your organisation' s position regarding this issue?**

**IM:** Not only stroke has serious health consequences, but it also has a very heavy social and financial burden on patients, their families and society as a whole.

According to estimates of the Latvian Health Economics Association, patients and their relatives bear almost one third of the total cost of stroke treatment in Latvia, which is over 70 million euros per year. According to health economists, such a "co-payment" for stroke patients is too high given the high rates of disease mortality and disability. The burden of the disease on the social security budget could be substantially reduced by ensuring timely stroke prevention, treatment and quality rehabilitation.

It would be important to increase the healthcare budget spent on the post- stroke rehabilitation services in order to make this service available to all patients and without long waiting lists. There is also a need for specialists and innovative technologies to improve the rehabilitation services in Latvia. It would be also important to develop clear patient pathways information materials to be disseminated to both stroke units and GPs.



The health budget for stroke prevention needs to be increased, as it will reduce the number of sudden strokes and thus require lower treatment, rehabilitation and disability costs. There is a need to increase also budget for innovative and effective medical medicines and to improve the collaboration of patients and doctors in order to increase the patient adherence.

*Aug 30, 2019*

## **STROKE SURVIVORS' NEEDS IN FINLAND: Stroke rehabilitation insufficient as it is now**

When it comes to stroke treatment and aftercare, Nordic countries are often believed to be among the most advanced in Europe. Even so, there is a room for improvement as we learned from our conversation with Finnish Brain Association's Executive Director Tiina Viljanen.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**



**TV:** The rehabilitation, for sure. In our country's hospital districts, at best more than 40 per cent of stroke survivors are admitted to multi-professional rehabilitation. This is in line with national recommendations. In some hospital districts, however, multi-professional

rehabilitation is only provided to a select few patients. This means that our country's overall situation in stroke rehabilitation is poor: only 10– 20 per cent of stroke survivors are referred to multi- professional rehabilitation. That is less than half of those who need rehabilitation. Every year, approximately 26, 000 Finns suffer a stroke. A third of them die.

We also see that follow- up care for stroke patients in Finland depends too much on the patient's domicile and age.

Age and domicile play a role in both whether the patient receives rehabilitation and how long the rehabilitation lasts. Those over 65 are the most disadvantaged.

We work to end this kind of age discrimination and remind that studies show rehabilitation of elderly stroke patients in particular is worthwhile. We

point out that timely, efficient stroke rehabilitation saves costs for society, as it reduces the need for long- term institutional care and decreases social welfare costs, among other things. Sadly, insufficient support measures for those affected by aphasia too. Therefore, the Finnish Brain Association keeps demanding that that people with a speech impairment also be provided with immediate, appropriate therapy and the possibility to express themselves.

**SAFE: What would be the solution, i. e. what is your organisation' s position regarding this issue?**

**TV:** Solution to insufficient stroke rehabilitation has to come from and by decision makers, in other words politicians, who regulate our healthcare system. Hospital districts and municipalities too have key role, while responsibility to arrange rehabilitation lies on to them. Therefore, we strive to educate, inform and influence decision makers and public service providers at all levels of the system, starting from very up from the Parliament. In the Parliament we have our own "spearhead", the Brain - group, in which we have members from every acting political party. The most powerful argument we can use while influencing decision makers is money. Stroke is third the most costly NCD in our country. This expenditure could lowered

alone by targeting rehabilitation correctly. Having said this, I have to stress that we also do work intently to raise public awareness on prevention of stroke, stroke symptoms, living with stroke and legal rights of stroke survivors.

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#### About Finnish Brain Association

*Finnish Brain Association is a non- governmental organisation and we have just celebrated our 40. anniversary. Our funding comes from Veikkaus, the single gaming company owned by the Finnish State. We have over 40 local member associations and we operate nationwide. Association' s headquarters, The Suvituuli- center, is situated in southwest Finland in the city of Turku. Our main goal is to ensure that all stroke survivors receive high- quality and professional support and to minimize the number of stroke patients. We organize adaptation training courses, rehabilitation and recreational activities and educate our members and professionals in the field. We are active on the social media and publish the Aivoterveys (Brainhealth) magazine plus various other publications dealing with cerebral circulatory disorders. And last but not least, I would like to mention our prized Priceless processor - project through which we support the prevention of cerebral circulatory disorders.*

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## STROKE SURVIVORS' NEEDS IN SLOVENIA: Patients' families have even less support than patients themselves

"Patients' families have even less support than patients themselves and are often left alone to manage their life and organise the life of their family member with stroke." said Milan Čuček, President of the Slovenian Stroke Support Organisation and the Vice President Tatjana Erjavec added "It is challenging for carers to assist them with integration into relevant social networks. Stroke support organisation is currently trying to bridge this gap."

This week we are investigating what is the main after- stroke problem from the patients' perspective in Slovenia.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

Stroke Care starts in hospitals and majority will have multidisciplinary teams to take care of stroke survivors. Patients with severe disabilities and rehabilitation potential will continue their rehabilitation either at the Rehabilitation Institute or in dedicated Spa's around Slovenia. This process takes up to 6 weeks. Nowadays, stroke survivors have the possibility for ongoing visits to neurologists. Systematic rehabilitation support is, however, lacking.

Majority of stroke survivors return to their homes with limited access to further rehabilitation programmes. There is a possibility for subsidies home help for maximum 20 hours per week and if medical condition requires, also visits from nurses. Primary level provides physiotherapy across Slovenia, but only on the outpatient basis and in limited amount. Occupational therapy is only available in three primary level institutions around country and it is delivered in patients' homes. Psychology and speech therapy is virtually not available in the community. Private services are possible and this creates imbalance considering

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### About Slovenian Stroke Support Organisation

*Slovenian Stroke Support Organisation is going to celebrate 30 years of its existence. It operates through 22 stroke clubs around Slovenia and it has 3000 members; mainly stroke survivors and relatives, but also few professionals (volunteers) and other supporters. Leaders of local stroke clubs are stroke survivors. Registered is as a Humanitarian organisation working in public interest. Main financing comes on annual basis from National lottery (FIHO). Additional income comes from local municipalities where clubs are operating, public calls for NGOs, memberships, donations and sponsorship, collaboration in research projects. Main activities are enabling long- term rehabilitation support via SPA's, organised physiotherapy in stroke clubs, sport activities, organised exercises (Nordic walking), organised walks. In addition, social networking, educational sessions for stroke survivors and families, organised creative workshop. In last years we provide workshops about self- care and aphasia group. Each year is organised National gathering and this year it will be in Postojna cave for over 370 members. Twice per year, journal KAPNIK is published and the website is constantly updated. With respect to promotion we organize several events, including traditional walk around Ljubljana, for the European stroke day. Several events are also organised around World Stroke Day. The WSO has given award to our SSO for the best campaign in high income countries for year 2018.*

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access to health services in favor of those who are financially stronger. Majority of stroke survivors are retired and with lower pensions and have therefore limited access to private therapies. In addition, it is observed that central Slovenia and bigger cities have better long- term support comparing to rural parts around country and North West part of Slovenia.

**SAFE: What would be the solution, i. e. what is your organisation' s position regarding this issue?**

Slovenia is a small country with population of 2 million and a good network of primary care. So far, primary care provides social service, limited access to physiotherapy and limited occupational therapy services. Ministry of Health has appointed special group, dealing with organisation of long term support for stroke survivors and creating a document for local long- term multidisciplinary stroke care. In addition, the legislation, dealing with long- term home care also includes multidisciplinary care. The challenge remains implementation of both, related to provide enough financial resources.

Slovenia has well developed Spa rehabilitation. Stroke survivors have an access to Spa rehabilitation in acute stage. Regular access to Spa rehab in

sub- acute and chronic stage is not guaranteed by insurance. Stroke Support Organisation highly value this rehabilitation programs for stroke survivors and their relatives and therefore enables it for 100 members per year, being aware that this is not enough.

Ongoing support for carers is essential and it could be organised via educational sessions, self- help groups, organised respite care.

Patient organisations, providing social and health support in public interest, should have an ongoing financial support. Accessing finances via public calls requires professionally that can hardly work voluntarily all the time.



# STROKE SURVIVORS' NEEDS IN SWEDEN: A follow up system after stroke



The number of people suffering strokes in Sweden is declining with 600 fewer cases in 2017 compared to the year before. On top of that, many people think that Scandinavian countries have everything perfectly set up when it comes to stroke and the entire stroke care pathway, from prevention to life after stroke. This week,

SAFE spoke with Kjell Holm, General Manager of the Swedish stroke association STROKE- Riksförbundet, who told us about some room for improvement.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**KH: A system for follow- up after stroke. Many stroke- survivors are not provided with rehabilitation after stroke and don't know where to apply for it. The Stroke- survivor and carers also need a**

healthcare contact after stroke to talk about their needs and new situation.

**SAFE: What would be the solution, i. e. what is your organisation's position regarding this issue?**

**KH: The Swedish Stroke association focuses on and highlights on a system for follow up after stroke for all patients. One tool is the "Post Stroke Check List" and an individual plan for the follow up and rehabilitation.**

## About the Swedish Stroke Association

**KH: The Swedish Stroke association started in 1983 and has now 9000 members and 83 associations/ clubs all over Sweden. We also have a Stroke fond that contributes to stroke science with 3 000 000- 4 500 000 Kronor each year. We are included in providing stroke education for the staff in the stroke healthcare. We distribute a lot of stroke information as books, films, papers, leaflets, website, pod, YouTube, twitter. We also write articles and have meetings with the politicians and decision- makers.**

**STROKE-Riksförbundet**

**STROKE**  
- propp eller blödning i hjärnan  
Vid plötsliga symptom RING 112

**Testa stroke med AKUT-test**

**Ansikte**  
Ansiktsförändring?  
En och två ändringar?  
Är personen rött i ansiktet?  
Hänger munnen? **RING 112**

**Kroppsdelen**  
Förändring i en arm?  
En eller två ändringar?  
Är armen och foten  
svaga i 10 sekunder?  
Har personen svårt att  
stå? **RING 112**

**Uttal**  
Svårigheter att tala, läsa eller förstå tal?  
Säg mening: "Det är vackert väder idag".  
Har personen svårt att hitta ord, säga rätt ord eller tala  
sluttigt? **RING 112**

**Tid**  
Symtomen kommer plötsligt och måste behandlas snabbt!  
För mer information besök [www.strokeforbundet.se](http://www.strokeforbundet.se)

**Vad är stroke?**

Stroke är ett samlingsnamn för hjärninfarkt (blodpropp i hjärnan) och hjärnblödning. Det är cirka 85 procent som får hjärninfarkt och omkring 15 procent som får hjärnblödning. Stroke är en av våra största folksjukdomar. I Sverige får cirka 25 000 personer stroke varje år, en person var 20:e minut. Medellåden för insjuknande i stroke är 75 år, men hela 20 procent är under 65 år. Stroke är den sjukdom som kräver flest vård dagar inom den somatiska (kroppsliga) sjukvården och beräknas kosta samhället 18 miljarder kronor per år (i enlighet med Riksstroket). Internationellt sett är stroke den största orsaken till invaliditet och den tredje största orsaken till död. Ungefär 80 miljoner människor i världen lever med konsekvenserna efter stroke, för att inte tala om de cirka 250 miljoner nära familjemedlemmar som på olika sätt påverkas av stroke. Stroke är således ett globalt hälsoproblem.

I menyerna till vänster kan du läsa om hur stroke uppkommer, riskfaktorer, rehabilitering och mer därtill. Det finns även en meny med svar på vanliga frågor som vi ofta får in till förbundet.



Sep 27, 2019

## STROKE SURVIVORS' NEEDS IN LUXEMBOURG: No intensive aftercare centre for stroke victims

"Luxembourg needs an intensive aftercare centre where patients can go for three to six weeks in the mornings as well as in the evenings to receive an ongoing aftercare treatment for physiotherapy, speech therapy, occupational therapy in addition to psychological therapy. We also want families and friends to get the psychological support. Last but not least the patients need to be supported and assisted in being reintegrated back into the workplace" said Chantal Keller, the President of Blëtz Asbl, stroke support organisation from Luxembourg, a member of SAFE.

**SAFE: What is the one issue related to the life after stroke in your country that you think needs special attention?**



**CK:** The single most important issue in Luxembourg is that there is no intensive aftercare centre for stroke victims.

The current structure for stroke victims aftercare which is in place is that there are four rehabilitation centres which are located in the city of Luxembourg,

Dudelange, Wiltz and Steinfort. They offer aftercare treatment for a period ranging from six months up to a maximum of twelve months.

At the moment the only aftercare structure which is available after the rehabilitation centre is in the form of an out- patient treatment at the physiotherapist as well as the speech therapist. These out- patient treatments mean that the stroke patient is dependent on a member of the family to take them there as taxis are not reimbursed by the Caisse Nationale de Santé (CNS) – the Luxembourgish Health Service. In addition to this the cost of other necessary aftercare treatments such as occupational therapy or going to the psychologist are not covered.

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### About Blëtz Asbl (Luxembourg)

*Blëtz Asbl was founded in 2013 by me, Chantal Keller, who was affected by a stroke, in addition to Marc Schommer, a stroke survivor and Claudia Heiderscheidt- Landa, whose husband suffered from a stroke.*

*Blëtz Asbl's mission is to help and to offer support to stroke and aphasia patients, their families and friends. We wish to raise awareness and to offer information to patients with brain injuries as well as giving them support for their individual needs.*

### More about Blëtz Asbl

*A book called "You have to be a fighter! Life after a stroke" has been published by Chantal Keller, President of Blëtz Asbl. And contains firsthand accounts of human beings who share their stories and show how much human potential there is for resistance and creativity in the face of adversity.*

*A stroke is a major traumatic event in the lives of those effected, their families and friends. Blëtz Asbl runs a helpline and offers support. Personal meetings can be arranged.*

*Blëtz Asbl also promotes medical and scientific research in this particular area.*

*And finally, every month Blëtz Asbl hosts an open day which covers different themes related to stroke and aphasia patients.*

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**SAFE: What would be the solution, i. e. what is your organisation's position regarding this issue?**

**CK:** Blëtz Asbl. is actively working on setting up meetings and progressing with our goal which is to be able to offer an intensive aftercare stroke victims centre in Luxembourg. To date, we have the support and are under the high patronage of Her Royal Highness the Hereditary Grand Duchess.



We have also had meetings with the mayor of the commune of Bettembourg, Mr. Claude Zeimetz as well as with the mayor of the commune Mondorf-les-Bains, Mr. Steve Reckel in order to introduce and advance the urgent need for Luxembourg to have an intensive aftercare centre. In addition to this we are in the process of getting a meeting in place with the Finance Minister of Luxembourg, Mr. Pierre Gramegna. On the 30th of September we have a meeting with the Health Minister of Luxembourg, Dr. Jean- Claude Schmit.

Furthermore, we are currently in the process of getting stroke units certified in four hospitals, namely in the Centre Hospitalier Emile Mayrisch, Esch-sur-Alzette, Centre Hospitalier de Luxembourg, Hôpital Kirchberg which are both in Luxembourg city as well as the Centre Hospitalier du Nord, Ettelbruck.

Blätz Asbl. is actively promoting medical and scientific research. On the 27th of October, the World Action Day for Stroke Victims, we are pleased to be able to announce a conference with Dr. rer. Medic. Marcus Wagner, MPH, a senior expert from Stiftung Deutsche Schlaganfall-Hilfe. He was formerly the President from 2008 – 2013 of the Europäische Schlaganfallpatienten- Organisation Stroke Alliance for Europe (SAFE) and is the Vice President of this organisation since 2016. At this conference we will be showing a film from the Stroke Alliance which will be adapted for Luxembourg as well as having the world première performance of a song written by Claudine Muno, accompanied by Remo Cavallini about aphasia which has been commissioned and composed for Blätz Asbl.

Oct 4, 2019

## STROKE SURVIVORS' NEEDS IN ISRAEL: Rehabilitation in the patient's home needs better support

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### About the Neeman Association (Israel)

*There are more than 120,000 stroke survivors in Israel and it is estimated that some 18,000 individuals join their ranks each year.*

*In 1996, families of stroke survivors banded together to create the Israeli NGO, the Neeman Association. Their mission was – and is – to reduce the morbidity of stroke in Israel, improve the medical and rehabilitative processes provided to the survivors of the stroke, to promote the health and well-being of stroke survivors and to support families.*

*Among the most significant breakthroughs of the Neeman Association in recent years has been its strategic plan to improve stroke prevention and care at the national level. The Neeman Association collaborates with Israel's Ministry of Health, international specialists, decision makers and strategic leaders in medical care and rehabilitation.*

*In 2017, the Neeman Association was awarded first prize by the World Stroke Association for its advertising campaign to raise public awareness of stroke symptoms and the life-saving value of immediate emergency care.*

*Another key focus of the Neeman Association is to improve the quality of life for stroke survivors. Today, Neeman conducts fourteen social clubs in community centers throughout Israel, directed by professionals and operated largely by volunteers. For hundreds of stroke survivors and their families, the social clubs are a home and a haven.*

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"The patients and their families have difficulties in assessing the quality of care they are receiving. In addition, there often are communication difficulties, whether due to language or cultural differences and the family at home have no-one with whom they can consult on such issues.

They have no criteria for assessing the quality of the treatment and in fact can be completely alone, particularly in the periphery, where choices are very limited" says Pnina Rosenzweig, President of the stroke support organisation in Israel, the [Neeman Association](#).



**SAFE:** What is one issue related to the life after stroke in your country that you think needs special attention?

**PR:** Given the projected increase in the number of stroke cases and the increase in the proportion of patients in need of rehabilitation, there is no doubt that inpatient rehabilitation solutions currently provided by the health care system will have difficulty responding to the huge shortage of rehabilitation beds in the hospitals, especially in the periphery. They will not be able to meet the expected burden of stroke and to provide optimal treatment to stroke survivors.



One of the solutions offered today in Israel and around the world is to provide rehabilitation in the patient's home. This solution has many advantages. Among the benefits of providing rehabilitation in the patient's natural environment are reducing the risk of being hit by dangerous infections and the huge costs on the public system. On the other hand, the need to provide rehabilitative care to stroke survivor patients with complex needs calls into question the ability to respond to these needs. In the rehabilitation phase, these patients usually require many intensive medical and rehabilitative services and special teamwork.

**SAFE: What would be the solution, i. e. what is your organisation's position regarding this issue?**

**PR:** The proposed solution is to establish a system of regulatory and objective controls to test the quality of the rehabilitative process and treatments

provided in the patient's home to people with stroke.

The definition of such a monitoring system would include quality indicators of the stroke survivor's rehabilitation and audit over time. The quality indicators will examine both the quality of medical rehabilitation and the patient and family experiences, particularly their perspective on the rehabilitation process.

The final audit data will be published for decision makers in the health care system, the families of patients after stroke and general public. This publication will motivate the health system to reward only systems that will provide quality rehabilitation and the families of patients to choose only these systems, which provide optimal rehabilitation to for their family's member.

*Oct 11, 2019*

## **STROKE SURVIVORS' NEEDS IN POLAND: Access to specialist long- term rehabilitation is the biggest problem**

"In Poland, we have access to all modern methods of treating stroke patients. We have a large network of stroke wards, where patients usually arrive quite quickly after the onset of a stroke. We are able to treat stroke in a modern way, but we have a problem all the time with proper care for the patient who usually leaves the stroke unit after 8 or 10 days" says Adam Siger, the President of the Polish stroke support organisation Fundacja Udaru Mózgu and a former Board member of SAFE.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**AS:** Access to specialist long-term rehabilitation is the biggest problem for people after a stroke, as well as their families and caregivers. we don't have enough neurological rehabilitation departments. We don't have enough caring and healing centers where we could accommodate the most difficult patients.



We do not have a comprehensive support system for patients and their caregivers after leaving the hospital. Patients with aphasia as well as patients in the coma and in the persistent vegetative state (PVS) are not usually admitted to neuro rehabilitation units. Similar problem applies to patients with swallowing disorders and nutrition by intranasal probes. Patients in such post-stroke problems will be left without proper support. A very big problem is access to complete rehabilitation after a stroke for the inhabitants of villages and small towns.

**SAFE: What would be the solution, i. e. what is your organisation's position regarding this issue?**

**AS:** Since the beginning of our activity, our foundation has been undertaking a number of activities to increase the availability of modern rehabilitation and support for carers. We already have some small successes in this area but there is still a lot to do. We need to create a stroke national program for prophylaxis, treatment and rehabilitation. We believe that it is possible to consolidate the activities of many medical environments to create such a program. Every year, around 80,000 in Poland suffer from stroke. Stroke is a serious health problem but also social and economic. We hope that in the near future we will be able to interest politicians and decision-makers to create a working group in parliament

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#### About Fundacja Udaru Mózgu (Poland)

*Fundacja Udaru Mózgu is a non-governmental organisation whose main goal is to help stroke patients, their families and carers. Our mission is all activities in the prevention, diagnosis and treatment of stroke. The Foundation's activities also include prevention. Our publications on stroke, its effects and prevention are a valuable source of knowledge for the general public. We create social campaigns aimed at realizing the threat that this disease carries, using modern mass media. We provide direct material and immaterial help to patients after stroke, their family and people with other neurological diseases. We run the only helpline in Poland for stroke patients and their carers. We publish the Stroke Magazine "1 in 6" in Poland which we distribute for free at neurological departments and neurological rehabilitation throughout the country for free. The magazine is available for free on the Internet too [www.magazynudarowy.pl](http://www.magazynudarowy.pl). Thanks to the constant contact with patients from all over Poland, we know how important support and assistance is for people after a stroke.*

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that will deal with all problems related to stroke. We would like to interest politicians and decision-makers at the central and local levels to improve the situation of people after stroke

Oct 18, 2019

## STROKE SURVIVORS' NEEDS IN IRELAND: In therapy terms, patients effectively walk off a cliff after they pass through the hospital gates

"The rate of death and permanent severe disability from stroke in Ireland has been reduced by more than 20% in the last decade. But hundreds of people are still dying every year when their lives could be saved. And thousands more are not receiving basic services that would enable them to make the most of life after stroke" says Chris Macey, Head of Advocacy for the Irish Heart Foundation and a SAFE Treasurer.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**CM:** Irish stroke services compare well internationally in the vital early period after stroke occurs. But as soon as a person's life is saved they typically start to regress through poor access to basic therapies in hospital. In therapy terms, patients then effectively walk off a cliff after they pass through the hospital gates – for most physiotherapy,

speech and language or psychological services are grossly inadequate or non-existent unless they can afford to pay themselves.

As a result, more people than ever before are surviving stroke only for many to have their recoveries squandered by the failure to deliver the therapy services either in hospital or the community that will help rebuild their lives.

These services require upfront investment, but we do not need to spend more money on stroke. We just have to spend what we have in a different way. For example, our research showed that out of a direct cost of stroke to the Irish State of €557 million a year, up to €414 million was spent on nursing home care and less than €7 million on the community rehabilitation that can keep people in their own homes.

In other words the system starves vital acute and rehabilitation services of funding only then to spend huge amounts of money after the time patients can be helped most.

**SAFE: What would be the solution, i. e. what is your organisation's position regarding this issue?**



**CM:** We need to recalibrate expenditure on stroke services in Ireland, through upfront investment in acute services and a much greater priority for community rehabilitation services.

The average onset of stroke here is at age 73 and because we will have 50% more 73- year-olds here within the next decade it is vital that we futureproof acute services, first by improving the standard of our stroke units – just one out of 28 fully meets ESO guidelines at present. We need around 200 extra therapists to meet current needs. We also need to invest in thrombectomy services that Irish doctors helped pioneer and to expand Early Supported Discharge (ESD) services that get patients home quicker and improve outcomes.

The development of ESD will also start to address the chronic deficits in terms of therapists working in the community where there are few champions

at present for better services. In addition, we have helped to spearhead the development of community rehabilitation teams – working across neurological conditions – to continue therapies after ESD treatment has been completed. Their development in pilot locations and then nationally has to be speeded up however to address the huge unmet need among stroke survivors in the community.

More resources must also be provided to support stroke survivors living at home – the vast majority of stroke support in our country is provided by the Irish Heart Foundation without State assistance outside Dublin and the north west of the country.

### About The Irish Heart Foundation

*The Irish Heart Foundation is Ireland's national charity fighting heart disease and stroke. Our main activities include:*

- ★ Provides information on heart health to the public and media
- ★ Supports patients in managing heart disease and stroke
- ★ Provides heart health programmes in schools and workplaces
- ★ Co-ordinates the training of medics and the public in emergency lifesaving skills (CPR)
- ★ Supports research, education and development in the medical profession
- ★ Advocates for better patient treatment and services and for public health measures that protect and enhance cardiovascular health

*We have been particularly effective in developing progressive public health policy in Ireland. We secured improvements to stroke services that have reduced mortality by 20% and permanent severe disability by more than a quarter in the last ten years.*

*We were a leader of the coalition that ensured Ireland became the first country in the world to ban smoking in the workplace that has saved a life a day in Ireland for 15 years since and that has reduced the youth smoking rate from 41% to 12%.*

*We also secured Ireland's sugar sweetened drinks tax, along with restrictions on junk food marketing to children on TV and radio. In addition, we ensured that defibrillators are present on all flights into and out of Ireland and we helped secure major changes to the law to reduce the harm done by alcohol.*



Oct 25, 2019

## STROKE SURVIVORS' NEEDS IN THE UK: Need to put the spotlight on long-term stroke care and Rehabilitation

"Stroke survivors in the UK are going without vital care and support. There are 1.2 million stroke survivors across the UK, but sadly 45% of people feel abandoned after leaving hospital" says Juliet Bouverie, Chief Executive of the Stroke Association UK.



**SAFE:** What is one issue related to the life after stroke in your country that you think needs special attention?

**JB:** We need to put the spotlight on long-term stroke care and rehabilitation. As anyone dedicated to helping stroke survivors rebuild their lives will recognise, the condition is extremely complex. People affected by stroke need rehabilitation that covers emotional support, help with finances, support services for carers, as well as physiotherapy, and speech and language therapy. Sadly, a recent Stroke Association survey of stroke survivors across the UK found that, in the aftermath of their stroke, only 18% of stroke survivors were confident that they would get enough support to make a good recovery.

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### About the Stroke Association (UK)

*We're here to support people to rebuild their lives after stroke. We believe everyone deserves to live the best life they can after stroke. We want to drive better outcomes in stroke prevention, treatment and lifelong support for everyone affected by stroke*

*We provide specialist support, fund critical research and campaign to make sure people affected by stroke get the very best care and support to rebuild their lives. The Stroke Association also offers vital support and information through our Stroke Helpline. My Stroke Guide is our online community of over 11,000 people affected by stroke, which many people said helps with their recovery.*

*Rebuilding lives after stroke is a team effort. It takes the determination of stroke survivors and carers, the generosity of supporters and the dedication of the healthcare and research communities to get there. We work hard to connect everyone in the stroke community so that people can live the best life possible after stroke. We have a number of stroke clubs and groups which provide essential long-term peer support to stroke survivors, carers, family and friends.*

*The Stroke Association's campaign, Rebuilding Lives, aims to change perceptions about stroke, and reach more people who need support with their recovery. We hope the campaign, which includes TV advertising, will help us get our message out to people who need help and support, and raise awareness that it's possible to rebuild lives after a stroke. To find out more, visit <https://www.stroke.org.uk/rebuilding-lives>*

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And 80% of stroke survivors told us they initially feared they would be sent to a care home.

Stroke causes a wide range of physical, communication, emotional and cognitive difficulties, and more than half of survivors report fatigue,



memory and concentration difficulties, anxiety or low mood. Time and again we've seen thousands of people adapt to a new life after stroke. But it's only possible with the right specialist support – and a ton of courage and determination. But the sad truth is that thousands of stroke survivors do not receive the support they need with their recovery when they leave hospital. There are huge regional variations in stroke support and care, which leaves stroke survivors at the mercy of a postcode lottery. On average, stroke survivors receive less than half the amount of rehabilitation recommended by national guidelines and many report feeling 'abandoned' after leaving hospital.

We know there are hospitals, stroke units and dedicated professionals leading the way for stroke care and support right across the UK. But too many stroke survivors are being let down because they aren't given ongoing support to rebuild their lives.

We want everyone affected by stroke to have the rehabilitation and long-term support they need, no matter where they live. No stroke survivor should be denied the chance to rebuild their life.

**SAFE: What would be the solution, i.e. what is your organisation's position regarding this issue?**

**JB:** We know that the number of strokes is set to increase, and that too many stroke survivors aren't getting access to the services they need to make their best possible recovery after they

leave hospital. At the moment, we know there's too much variation in the quality and coverage of care: too many of therapies recommended by clinical guidelines aren't available across the country.

Stroke is also a hugely expensive condition, costing around £26bn a year across the UK. If we don't act to roll out some of the actions we know can stop stroke before it strikes, save lives and prevent serious disability, the costs will spiral. We can't afford not to act.

We want everyone affected by stroke to have access to the support they need and should expect, in line with national guidelines. That's why we're working across England, Scotland, Wales and Northern Ireland to support and drive changes which will improve the lives of people affected by stroke. In England, for example, we're working closely with NHS England to deliver the Long Term Plan for the NHS, which includes the National Stroke Programme.

This Programme supports health and care services to make improvements from prevention and treatment right through to rehabilitation and long-term support after leaving hospital, including psychological support for stroke survivors. Our focus now is to ensure promised improvements are delivered.

# STROKE SURVIVORS' NEEDS IN THE UK:

## The marginalisation of stroke survivors is an ongoing problem

"Stroke is still thought of as something that only happens to elderly people. Yet more than 25% of strokes happen to people who are of working age and younger, and in the specific 35-54 age range, strokes are increasing by approximately 2% per year.



Despite this, when stroke is portrayed in the media it is almost always in the context of an older person suffering a stroke, and this further entrenches the view that it is something that is not experienced by younger people. At Different Strokes we have helped to tackle this misconception, and a recent Stroke Association

television advert also featured a number of young stroke survivors. " said Austin Willett, Chief Executive Officer at Different Strokes, a stroke support organisation from the UK.

**SAFE: What is one issue related to the life after stroke in your country that you think needs special attention?**

**AW:** Clearly though there is still a very long way to go, demonstrated by the results of a survey which we commissioned this year. In this survey, 84% of people thought that only 1 in 50 strokes happened to people under the age of 65, while it is actually more than 1 in 4.

The marginalisation of stroke survivors is an ongoing problem. Stroke is especially isolating for working age people; often with young families to support and relying on employment but suddenly unable to work. Ensuring that there is much greater recognition of younger stroke is, for us and the people we support, the most important issue.

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### About Different Strokes (UK)

*Different Strokes is a registered charity which supports younger stroke survivors and their families, primarily of working age (18-65). This group has historically been overlooked, receiving limited rehabilitation and struggling to find the emotional support combined with the practical help required to help reclaim their lives. Different Strokes was founded in 1996 to address this, and over the last 23 years has made huge steps in raising awareness of young stroke.*

*Amongst the services we provide are a network of peer support and exercise groups, an online support group, a telephone information line, printed materials, and age appropriate resources for children whose Mum or Dad has had a stroke.*

*We also seek to raise awareness of issues that specifically affect younger stroke survivors and will work collaboratively with third parties where it is in our mutual interests to do so.*

*The ethos of Different Strokes is one of 'survivors supporting survivors', with peer support running through all that we do. Half of our staff and trustees are stroke survivors, as are the vast majority of volunteers who run local groups and support us in other ways.*

*We receive no funds from central or local government, so have to raise all our funds from individual donations, fundraising events, legacies, grants from trusts and foundations, corporate support, and self-generated income such as through our online shop.*

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**SAFE: What would be the solution, i.e. what is your organisation's position regarding this issue?**

**AW:** There are no easy answers to this, and because stroke affects everyone differently there is not a solution that will work for all stroke survivors. But broadly speaking, we would like to see:

Much greater understanding of the prevalence of stroke in younger people. Where there is ignorance about this issue, this can lead to misdiagnosis. Too often is a stroke among this age group classified as a 'brain bleed' or something other than stroke. This can lead to people waiting for extended periods of time before receiving appropriate stroke rehabilitation, or not receiving any at all.

Rehabilitation which focuses more on the specific needs of younger stroke survivors. Younger stroke survivors must learn to accept newfound physical, emotional and cognitive limitations, as well as changes to virtually every aspect of life – wellbeing, perceived quality of life, communication, mobility, employment, independence, social life and relationships. Rehabilitation needs to reflect this, and not merely be focused on the basic functions of self-care which permit a stroke survivor to return home.

Recognition that ongoing recovery of stroke is a long-term, and sometimes lifetime, process. Too often we have heard stroke survivors being told that they have plateaued to explain why their post-stroke rehabilitation has been discontinued, and a further myth about stroke is that after 6 months post-stroke ongoing recovery will cease. But post-stroke recovery trajectories vary and shift over time, and at Different Strokes we see stroke survivors of working age return to work and rediscover skills and interests which buck their disabilities long after their stroke.

**Please read next:** IRENE COST Action Meeting: Alleviating disparities in stroke care and improving outcomes after stroke



## 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](http://www.safestroke.eu)

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