



The World Stroke Organisation

STROKE SUPPORT ORGANISATION TOOLKIT



World Stroke Organization



Stroke association

Published by

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1. INTRODUCTION & FOREWORD

1.1 Introduction

Stroke Support Organisations (SSOs) have a key role in supporting stroke survivors in the community, and in giving strength to the voice of patients. They also have a role in improving services for people with stroke.

Without the work of SSOs, many of the improvements in stroke prevention and care just would not have happened. But there is still so much more we can do.

1.2 Why a Stroke Support Organisation is Essential

SSOs represent patients in a world that is heavily focused on the opinions of health professionals. SSOs can:

- help people who make decisions about stroke care understand what is important to the people affected by stroke – this is important when symptoms can be invisible or can restrict people's ability to get their point across;
- provide support for people affected by stroke that nobody else can or will provide;
- provide social support groups, which have been shown to have a positive impact on rehabilitation;
- advocate and act on behalf of people affected by stroke;
- help campaign for change and influence government policies;
- help stroke professionals communicate better with people affected by stroke.

1.3 Foreword from Professor Norrving

In 2006, at the World Stroke Congress in Cape Town, the International Stroke Society and the World Stroke Federation (WSF), the two lead organisations representing stroke globally, merged to form the new body World Stroke Organisation (WSO). Thus, the WSO comprises individual members and professionals as well as Stroke Support Organisations (SSOs). The WSO works to provide access to stroke care and promote research and teaching that will improve the care of stroke survivors throughout the world by:



- Promoting prevention and care of persons with stroke and vascular dementia;
- Fostering the best standards of practice;
- Educating, in collaboration with other international, public, and private organisations;
- Facilitating clinical research.

Part of this mission is the growth of Stroke Support Organisations, which is not as advanced worldwide as it needs to be. The Stroke Support Organisations Sub-Committee of the WSO leads on this work.

The WSO is committed to offering support and guidance to potential and existing SSOs to ensure they are able to fulfil their purpose in helping people rebuild their lives after stroke. The voice of the SSOs is an important part of the WSO.

I believe looking at the experience of others contained within this toolkit will help new SSOs learn from others about what works and what does not, as well as learning about what they themselves will be. WSO strongly supports the development of SSOs in all regions – I wish you all good luck in this important work.

Professor Bo Norrving

President,
World Stroke Organisation

2 OBJECTIVES OF TOOLKIT

The aim was to develop a 'toolkit' resource for both existing and potential new SSOs, offering guidance and support on developing and growing an SSO, in particular in areas of the world where there are no SSOs at present.

This toolkit will benefit those working with stroke survivors across the world, and help to inform the WSO about the worldwide picture of support for stroke survivors.



3 KEY FACTS

From research that exists on strokes worldwide¹, we know that:

- Around 15 million people worldwide suffer from stroke every year
- About a quarter of strokes happen in people aged under 65 years
- Stroke leaves around a third of victims permanently disabled
- Recurrent stroke is common in stroke survivors and around a quarter of people who recover from their first stroke will have another one within 5 years.
- 13 of the organisations relied on professionals, 'word of mouth' and stroke survivors and carers to help them recruit volunteers. Only 3 organisations were able to access volunteer recruitment agencies.
- **39%** of the SSOs believed that one of the main barriers to starting up their SSO was a lack of suitable staff or volunteers.

To develop this toolkit, we collected information from 19 existing SSOs around the world (see section 4) which shows us that:

- **89%** of the SSOs identified **financial** problems, such as finding funding, as one of the main barriers to growing their organisation. **50%** of SSOs felt that finances were the biggest barrier to starting an SSO.
- Only **one** organisation did not say finance was a barrier.
- **39%** of the SSOs we asked felt that one of the biggest barriers to growth is the lack of government support they receive.
- **22%** consider that stroke awareness in their country is low and that this is a significant barrier to expanding their organisation.
- Only **4 of the 19** organisations had any large assets or financial reserves.
- Of the 19 organisations we asked, 4 had no paid staff and 2 had only one member of paid staff.
- **22%** believe that there are few NGOs in their country and for those that do exist, there is no support framework available.
- **33%** of organisations have a relationship with **National** government, **27%** have a relationship with **Local** government, **16%** have a relationship with both **National and Local** government and **11%** do **not** have a relationship with government at all.
- 13 of the 19 organisations are involved in Campaigning for change. **Blood Pressure Awareness** was one of the most common campaigns with **almost a quarter** (25%) of the campaigns focusing on this. 38% of campaigning focused on **Stroke Awareness Week**.
- 22% of organisations are led entirely by volunteers. **11%** of organisations do not work with **any** volunteers at all. 38% of organisations work with 100 or more volunteers.

¹Information taken from Stroke Alliance for Europe website www.safestroke.org

4 RESEARCH FOR THE TOOLKIT

4.1 How we collected our information

Before this toolkit could be developed, information was needed about the SSOs which already exist, as well as different 'models' of organisation. The starting point was to map the activity of some existing organisations. We then developed a questionnaire based on the mapping which was sent to SSOs around the world which were known to the WSO. The questionnaire was about activities and history and asked questions like:

- What is the biggest barrier to establishing an SSO in your country?
- How did you overcome this barrier?
- What support services does your organisation offer to people who have had a stroke?
- How much influence do stroke survivors and their families have over the running of your organisation?

By asking these questions a 'snapshot' of the activities, experiences and problems of SSOs across the world in 2012 was developed which could help show others wanting to set up an SSO what is possible and what problems they may find.

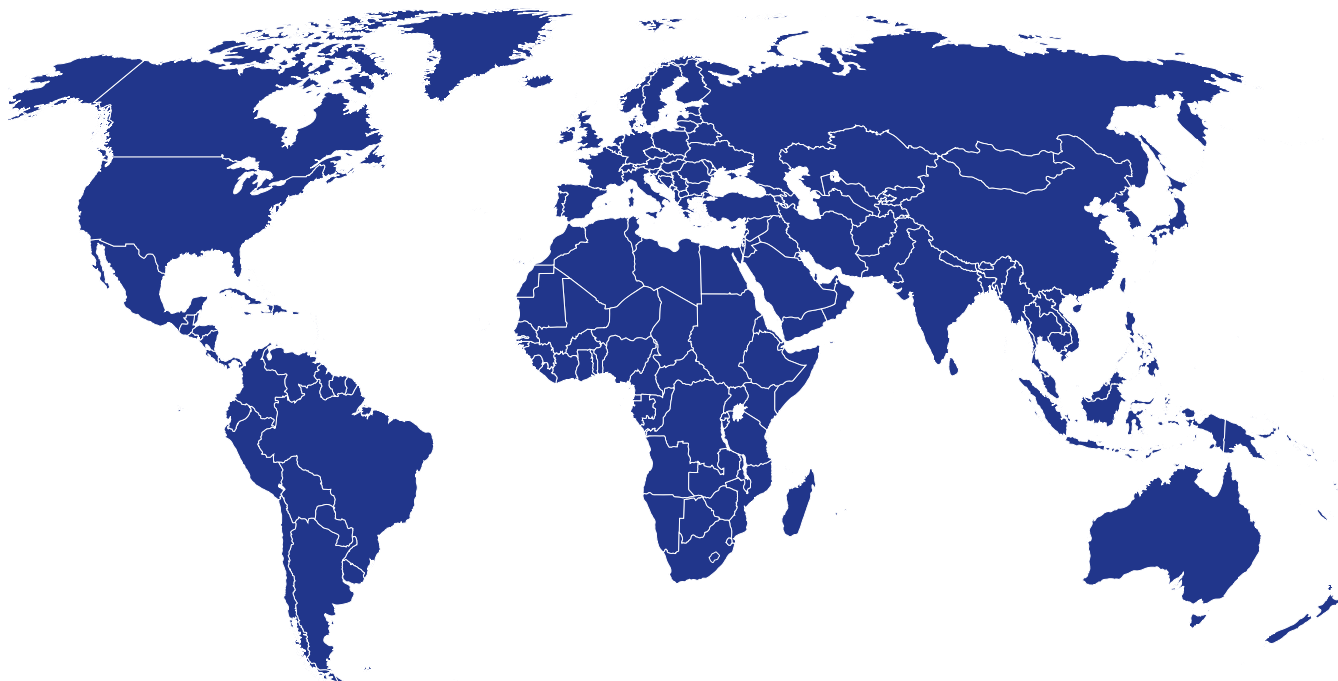
Questionnaires were sent to 35 different SSOs around the world (a list of these organisations is in Acknowledgements). When questionnaires were received, the information was used to:

- Develop guidance on different options for setting up an organisation;
- Show barriers an SSO might face in setting up and growing, giving examples of how others dealt with these problems;
- Develop case studies about different SSOs and their experiences.

4.2 How were the organisations selected?

Out of the 35 organisations who were asked to complete the questionnaire, 19 are World Stroke Organisation members **(please see Acknowledgements for details)**. The other 16 were organisations that were known either to a WSO member or member of the SSO team.

The draft toolkit was evaluated by some volunteer SSOs to see if it was helpful.



4.3 Response level

From the 35 organisations that the questionnaire was sent out to, we achieved our targeted response rate of 54%.

The majority of e-mails sent from the team were in English which may have been a barrier to some SSOs. The team ensured that responses from a range of countries and continents were reflected in the toolkit.



5 HOW TO USE THE TOOLKIT?

We have divided the toolkit into 2 main parts:

- 1. To help you start an SSO – this is section 6**
- 2. To help you grow an SSO – this is section 7**

Whether you want to start an SSO or grow an existing one, users of the toolkit will hopefully find most of the contents helpful. It is designed for readers to select the most appropriate sections for them.

We are also very grateful for a number of case studies that have been submitted by existing SSOs. These real-life examples of how SSOs have overcome particular problems should be both inspirational and instructive.

6 HOW TO START

Although some of our SSOs are large organisations with many staff and volunteers, they share one thing in common – they started from a small group of people who were inspired by a common cause.

We hope that section 6 of this toolkit will provide you with all the information you need to successfully start your SSO.

6.1 What makes a good SSO?

Our research suggests that successful SSOs have the following characteristics:

- One person or a few people with enthusiasm and determination;
- An ability to engage with large numbers of people;
- Understanding that the desire to change the world of stroke will be achieved by focusing initially on doing a small number of things well;
- And as we can see from the research and key facts in section 3 - money, money, money.



6.2 Finding people to help

Dealing with stroke can be a lonely experience but it does not have to be, as there are many other individuals and organisations that can help, including:

- **Professional or Service User Volunteers**
- Retired professionals, groups of stroke survivors or carers who are passionate about stroke are likely to be willing to give their time or experience.

CASE STUDY: Involving service users in the organisation – Indonesia and UK

Indonesia found that inviting service users to events and seminars, or World Stroke Day activities, greatly increased awareness.

The UK Stroke Assembly is a forum for issues to be raised and attendees are mostly stroke survivors and carers. People affected by stroke help set the programme and make the event as accessible as possible.

- **Local hospitals/healthcare providers** – can tell you what services for stroke survivors exist, and also have contact with survivors.
- **Local or national government bureau responsible for health provision** – they may be looking for organisations to deliver stroke services or be able to offer advice or funding.
- **Professionals and therapists** – will have contact with stroke survivors who may want to use your services in future.

CASE STUDY: Target stroke professionals – Slovenia

Slovenia focused their efforts on engaging retired stroke professionals who had more time but still the passion to make change. A few professionals were proactive in the organisation at the very beginning. Slowly other specialists were attracted, mainly those who had an interest, knowledge and time. Some already had experience of voluntary work.

- **Other organisations** that may have a shared interest with you and be willing to set up in collaboration.
- **An individual or small group of champions** – who can influence policymakers or approach philanthropists to help get some initial support and funding.
- Is there an **organisation in your country which offers support and guidance to NGOs (Non Governmental Organisations)?** Approach them to see what they can offer in terms of resources, information and grants.
- **Are there any other organisations** who may be interested in becoming a partnership, to deliver some work together?

- **Organisations dealing with heart or other health conditions** may have done some work on stroke in the past. They may be open to sharing resources or to campaign about a number of conditions at once, including stroke. Consider setting up a coalition to lobby on specific issues around chronic disease, either for prevention of disease or support for sufferers.
- **Are there any potential opponents to your organisation who you need to talk to and influence?**

Existing organisations, smaller in scale, may feel threatened. Is there an opportunity to work with them rather than setting up a totally new organisation? You may need to try and raise awareness with policy makers who think an SSO is not needed. Healthcare professionals and providers such as hospitals may not be interested in your organisation and think it is a threat to their role.

- **Do you need to talk to existing patient or support groups?**

There may be small voluntary groups who you could work with, such as stroke clubs which already have volunteers and stroke survivors. You need to engage with stroke survivors and carers from the start.

CASE STUDY: Targeting Stroke Professionals – Israel

Israel negotiated with the Speech and Language Therapy Department at a local university. A training program focusing on the family implications of aphasia was offered to second year students prior to their entry into clinical training. They were required to accompany a family and create an activity at the stroke club. Results for the SSO were very rewarding – Israel was paid for student instruction, free and enriching activities were created at the stroke club and students have started choosing stroke specialisation where previously it was not favoured by them.



6.3 The First Meeting

Having identified and confirmed that a very real need exists to form an SSO, and hopefully found a number of other people who think the same, a good way to start is to call a meeting.

All meetings work much better if:

- They have a set of clear objectives that all attending are aware of;
- An appropriate amount (not too much, not too little) of information is issued before the meeting, so everyone has the same level of understanding;
- They take place at a location that helps people to be 'business-like'. Sometimes, there will be no alternative to meeting in someone's home.
- Refreshments always help!
- Someone is able to 'Chair' or 'Facilitate' the meeting, who can:
 - Communicate clearly;
 - Encourage people to participate;
 - Keep the discussions about relevant issues and within available time;
 - Summarise discussions and ask for agreements or decisions;
 - Be enthusiastic and encouraging.

Particularly in a first meeting, it may help to divide up the tasks of the Chair or Facilitator, so the work is shared and one person does not dominate the meeting.

- Someone is taking notes of the meeting, or at least writing down agreed action points and any other points of importance. Also, do not forget to get everyone's contact details - a printed form will help.

At your first meetings, you should seek to agree:

1. A list of tasks, persons responsible and dates when the tasks should be completed by;
2. Who the key people in the SSO will be, for example, the Chair, Treasurer and Secretary;
3. How many people want to continue meeting;
4. Any ideas people have to make the meetings better attended and more effective;
5. The date and time of the next meeting.



6.4 After the First Meeting

A well-attended and well-managed first meeting will help you get all the commitment you need to start an SSO. However, it may be helpful to:

- Contact the people who volunteered to carry out the actions as soon as possible after the meeting, to make sure that they are still happy to do the work and have a clear idea of how they are going to go about it. You may also find that some people do not have the time to do the tasks they volunteered for, and the sooner that you find this out, the sooner you can find someone else.
- If you had any 'difficult' people to deal with in the meeting, you might like to contact them too. They may have been difficult for many different reasons, for example because of their strength of feeling, their own personal experience or because they did not agree with some important decisions. Often, these people have a lot of passion to give to the cause, and trying to involve them now will result in big benefits later.



6.5 Contents of your first Plan

You should record what your plans are. This does not need to be a long document and it will help to engage with more people, give some structure to what you want to do, identify the key issues and provide you with something to measure progress against.

In your first Plan, you may like to consider the following:

- **What do you as an SSO want to do? You will need to consider your reasons for setting up an SSO. Is it:**
 - Because there is an increasing number of strokes and more people with disability after stroke?
 - Because of a lack of awareness about stroke and lack of organisation in dealing with effects of stroke?
 - To give lifelong support to stroke survivors and their families?
 - To develop a continuous rehabilitation pathway?
 - To support stroke survivors and their families to get speech therapy for people with aphasia?
 - To give support other than existing speech, occupational and physio therapies?
 - To prevent strokes, and reduce their effect through campaigning, education and research?
 - To fund research?
 - To support certain groups of survivors, such as young stroke survivors?
 - To prevent strokes, for example by promoting healthy lifestyles?
 - To increase acknowledgement of stroke and get people talking about it?
- To promote self-help and mutual help amongst stroke patients?
- To educate the public and promote awareness?
- **What services do you want to provide? The following list provides some ideas and will help you to decide the advantages and disadvantages of each:**
 - 1. Will you run stroke support groups?**

You need to consider how you will structure your stroke support groups. Stroke support groups can focus on helping people with communication, or just offering an opportunity for stroke survivors and care givers to meet with others, share experiences and make new friends. You need to consider how to make your groups safe and legal, for example by getting the right insurance.
 - 2. Will you offer other services to stroke survivors?**

You could offer magazines and information leaflets, telephone support, bereavement counselling, hospital visits or visits when people leave hospital, adapting homes, financial aid, exercise classes, online support through forums or online seminars.

3. Will you develop information about stroke?

How will you decide what information is needed - can existing SSOs help you? How will you issue information? Think about the different formats your information could take and the benefits and problems with each format:

- **Magazine** – full of up to date information, but expensive to produce
- **Information booklets, flyers, leaflets** – can reach many people, but how will you distribute them? They will need updating frequently with the newest information. Will you have the money to do this?
- **Website** – can be a lot of money to develop but once it is in place it can be updated easily. Will you have sections with stroke information on your website?
- **Telephone** – a telephone information service is of great benefit to stroke survivors and families, though it can take a lot of money and resources as it will need trained and informed staff/ volunteers and information needs to be updated very frequently.
- **Newsletters** – can reach a wide audience and are easy to produce, but do not always have a lot of space for detailed information.
- **Television and Radio** – advertising or campaigning on TV or radio reaches a wide audience but can be very expensive – how would you fund this?
- **Events/conferences or public lectures** – these can be very small and inexpensive or large and costly – where will you find speakers and delegates for larger events? Will enough people attend to cover costs and how will you market the event? Smaller events can be delivered in partnership or at low cost. What links with educational organisations do you need to make?
- **Social network websites** – these are free and easy to use, but they can usually only communicate a small amount of information at a time and they need to be updated very often to be effective – this can take a lot of time.

Providing information

- Before the internet, information about stroke was difficult to find – now you can be faced with too much information, and often the main problem for service users is in knowing the reliability and quality of the information. Here we show you how to ensure the quality and quantity of information are correct, useful and relevant.

Consultation

- Consult your potential users regarding their information needs, preferred formats and style. Personalising information and providing support to help understand and process it is always better than thinking the same information is right for everyone.
- Where possible, get local experts to help, like nurse specialists. They may be willing to act as a special adviser.
- Consult with any other relevant local organisations that might already have a service or have an interest in information on stroke.
- Do not forget that many stroke survivors have memory, cognition or communication difficulties, so breaking information down into small pieces may be helpful.

What to include

- Tell the full story – create information that is honest and balanced.
- Deal with uncertainty – where clinical opinion varies or where evidence is not certain, say this and be clear about the sources of evidence used.
- Provide references and links to the evidence you have used, and make sure you are using the most up to date sources possible.
- When you are talking about treatment options describe how the treatment works, its benefits and risks and what would happen without treatment.
- Write text that is “honestly optimistic”, clear and concise.
- Include sources of further information and support.
- Put a date on the information, and indicate when you plan to review it again.

Other things to consider

- Ensure that the information service supports the health professional and patient relationship.
- Produce the information in a range of accessible formats. Stroke Association UK has a publication called Accessible Information Guidelines – www.stroke.org.uk/resourcesheet/accessible-information-guidelines.
- Include a disclaimer to clarify the boundaries of your role and encourage users to seek medical advice.

4. Will you fund research?

This probably applies more to a growing rather than a new SSO but explore where you can find research funding in your country. If you cannot find funds, you can encourage staff, volunteers and service users to participate actively in research and you can promote research which is going on in your country. You can also encourage research institutes to include research questions on stroke.

5. Will you deliver training?

Consider who will want or need training in stroke – it may be your staff/volunteers, or other organisations such as NGOs and healthcare providers, or individuals like the general public, stroke survivors and carers, stroke professionals or students. The people delivering the training may need to be registered professionals, so think about where you may find these in your country.

6. Will you try to influence policy?

If you will, you need to get access to debates about stroke and spend some time developing a relationship with local or national government.

- **Think about the resources you think you will need to achieve what you want to do. Resources would include finance, people and their time, materials (such as those to help with marketing), premises, computer equipment.**
- **How you will prioritise what you want to do, particularly as you probably will not be able to afford to do all that you want. A simple way to consider your priorities is to take each of the things you want to do and score them (1 = low, 10 = very high) based on:**
 - The amount of impact it should have on the people you want to help;
 - How much resource it is likely to need;
 - How quickly you can do it;
 - How low the risks are in doing it.
 - How long can the results be expected to last?



6.6 End of the 'Start'

At the end of the 'Start' phase, you should have a written plan for the formation of your SSO. This should be a very exciting time as you will have translated all that passion and enthusiasm into a Plan that sets out what you are going to do to improve the lives of stroke survivors and their families and minimise the number of strokes.

CASE STUDY: **Show that strokes affect all ages – UK**

The **UK** recognised the need to talk about childhood strokes and has produced information leaflets which give information about the causes of stroke in children, treatment, impact on the family and help direct people to organisations which can offer support.



7 GROWING SSOs

Section 6 showed how to start an SSO. This section deals with how to grow and develop one. Some of the material in Section 7 may also be relevant to starting an SSO.

7.1 Where are we now?

Planning the growth and development of any organisation requires a full and honest assessment of where the organisation is now. Without this, you are likely to plan the wrong 'journey'. For example, you might under-estimate how much of a barrier a lack of government support will be.

There are a number of tools that provide a framework for assessing where you are now. These include:

Tool	Description
Stakeholder analysis	Identifies the people, groups and organisations that you need to establish effective relationships with.
SWOT analysis	An analysis of Strengths, Weaknesses, Opportunities and Threats.
PESTLE analysis	An analysis of the external environment in respect of Political, Economic, Social, Technological, Legal and Environmental factors which may have an effect on you.
Service or Product analysis (adapted from the McKinsey/GE matrix)	Reviewing services or products to make decisions on where to invest more or less time or money.
Risk analysis	Helps to list, sort, score and prioritise identified risks.

Full details are provided in Appendix II.

Whilst all of these tools may be of interest to a growing organisation, it is important that an SSO chooses the right tools for its situation and, if necessary, adapts these general tools to make them more relevant.

As part of looking at the external environment, an SSO will need to consider the healthcare situation in its own country, including if the healthcare system is a:

- **Free system provided by government** – you may need to offer emotional support, funding or guidance on home modifications and benefits rather than healthcare.
- **A mainly free system with some contribution by individuals/employers** – you may need to advise on how to cover individual/employer costs for those with difficulty, as well as what healthcare costs for stroke are covered by the system and assess any gaps which survivors need to be made aware of, or that you may need to provide or lobby towards, for example speech or occupational therapy.
- **Costs are largely covered by personal or employment contributed insurance and those without insurance pay for their own health care** – you may need to advise on where to find affordable therapy – do you need to consider providing therapy? Do you need a grant scheme to do this?
- **Costs are fully covered by personal or employment contributed insurance and those without insurance pay for their own health care** – again, will you need to provide therapy or be able to direct people to affordable services?
- **Costs are fully covered by personal or employment contributed insurance and those without insurance pay for their own health care, except for those with little or no income (covered by the government)** – you will need to develop different types of support for both those who have insurance and those for which there is government provision.



You will also need to research if there are any relevant other NGOs for disease areas in your country. If disease NGOs are not widely supported in your country, where else might you be able to get funding? If the public do not generally give to health NGOs in your country, is this because the health service is already provided by the government, a healthcare system or the private sector? Are there any existing NGOs working in an area related to stroke? If no, this may make it easier for you to obtain funds. If yes, can you develop a partnership with them to work together on some areas and save on resources/funding?

If the NGO model is relevant in your country, you will also need to establish the funding options, including:

- **Corporate support** through partnership, sponsorship, personal relationship or agreement – research which companies have an interest in stroke or who make products for stroke survivors. Do any companies in your country make donations or form partnerships with NGOs in general?
- **Funding by application** from grants, trusts, universities and EU funding – make links with these funders, research potential funding opportunities and collaborations, attend networking events.
- **National funding body/government funding**, funding from a trust/grant giving body (non-government) – begin to develop a relationship with local and national government departments,

- **Personal contacts** - Developing relationships with rich individuals, influencers and government officials.
- **Private donations/gifts** including community events, legacies/bequests, private giving through tax system.
- **Payment for services** – consider charging for membership, or delivering a service for which you can be paid by local/national government or a health system.



7.2 Where do we want to be?

Many organisations use the terms 'Vision' and 'Mission' to describe this.

The features of a good Vision include:

- Describes the future you want
- Is idealistic
- Reflects 'horizon-expanding' ideas
- Inspires others
- Is easily understood
- Tells people you want to deliver to a standard of excellence.

The features of a good Mission include:

- Clear and easily understood
- Short and focused
- Realistic and achievable
- Says what results you expect
- Tells people your objectives over the next few years.

7.3 How to get there?

Getting from where you are to where you want to be involves two key elements – prioritising and implementing. How to prioritise is covered in section 7.4 and how to implement in section 7.5.

7.4 How to prioritise?

Section 6.5.6 of the 'Starting an SSO' section provides a simple method of prioritisation. Another way to explore the options for particular services is to consider the advantages and disadvantages of doing each of the following:

- **Experiment** – try a new way of delivering a service
- **Maintain** – keep the service the same as it is now
- **Improve quality** – make a service better
- **Increase volume** – give a service to more people
- **Combine** – deliver one or more services together
- **Reduce costs** – can services be delivered to the same quality whilst reducing costs to run them?
- **Retrench** - reduce or close services
- **Expand** – deliver to more people or in more places.



7.5 How to put plans into action

A quote from Henry Ford is important – ***“Nothing is particularly hard, if you divide it into small jobs”***. Successful implementation needs a combination of good project management, change management and performance management. There are four key principles central to all these management techniques:

Principle 1 - Measure progress

Further detail is contained in sections 6.5 and 7 but ensure that your SSO has a plan of objectives, targets and outcomes that you can measure progress against.

Principle 2 - Be realistic

Ensure that your plan of objectives, targets and outcomes is based upon the time required from identified people to complete their tasks. Particularly, in a volunteer based organisation, it is easy to be optimistic about how much time someone has got and how long it could take to complete certain tasks.

Principle 3 - Report on progress

Make sure that you can report every six months on how your SSO is performing against objectives, targets and outcomes. You need measurements, such as Key Performance Indicators, you can measure against.

Principle 4 - Be prepared to change

Focus on doing the important things well and do not be afraid to change things.



7.6 Dealing with the main issues

In the course of collecting the research from SSOs, we established that the biggest barrier to starting or growing an SSO is financial support. Section 7.6.1 deals with this and sections 7.6.2 to 7.6.5 deal with other factors that are important for SSOs.

7.6.1 Funding

Where are you going to get the money to set up the organisation?

- **People** – with an interest in your work – start with people you know, or who your volunteers, partners and contacts know.
- Create a “friends of...” to give fundraising contacts a formal connection with the organisation.
- **Trusts and Foundations** – organisations set up to provide funding for charities or NGOs – do they exist in your country?
- **Community organisations, clubs and societies** – for example sporting clubs or community clubs like the Rotary Club.
- **Companies** – it is important for companies to be seen to support the communities they work in. Companies with an interest in your work may give initial funds.
- **National and local government** may offer funding.
- **Founding members** – professionals or volunteers – may make a donation.
- **Fundraising events or campaigns**, advertising for donations through posters, adverts, letters, TV and radio or on a website.
- **Bank loans** are an option, but you need to make sure you know where your income will come from to pay this loan back.
- As well as thinking about who will give you donations or funding, think about services you can charge for, or **membership fees**. Will running events for stroke professionals bring you income? Do you have assets or reserves to help you in difficult times?
- Also, know where you can look for funding – research funding such as EU programmes (<http://ec.europa.eu/research/fp7/>), or guidance on fundraising in a variety of countries and contexts (such as www.philantropia.org).

You should be asking yourself the following questions about funding and fundraising:

1. What are our plans for generating funds over the next year, three years and five years?
2. What financial resources do we need to meet these plans?
What areas of fundraising are we relying on to get us these resources?
3. What is the overall structure of our funding and where does fundraising fit?
4. What types of income do we receive?
5. Are we dependent on one type of income or do we fundraise from a range of sources?
6. Who are the donors that we depend on most and for how long do we expect to retain them?
7. Who in our organisation is responsible for maintaining good relationships with donors?
8. How much of the income we receive is restricted and how much is unrestricted funding (this means the funder places restrictions or limits on what the money can be spent on)?
9. Do we have a contingency plan when we develop our strategy?
10. What are our income and cost projections over different fundraising activities for the next one, three and five years? What are they based on?
11. At the beginning you will need to think about who is interested in your work and would contribute financially. Set up a database of contacts and their contribution - include names, addresses, telephone numbers and email addresses as well as information about these people.

One way to improve your financial position is to secure a number of 'committed givers'.

How to promote Committed Giving?

Many NGOs can increase their income from regular "committed" giving from individuals. People find it easy, convenient and affordable as they give a small amount regularly that they hardly notice. For SSOs it provides a predictable annual income and increases the numbers of donors that you keep.

If your SSO wants to try committed giving, the key things to remember are:

1. Asking a donor to agree to pay you by direct debit is a big commitment, so suggest small amounts, such as £3 or £5 per month.
2. Provide a specific reason for your supporters to give to you on a regular basis - provide different amounts they can choose and show what each amount will pay for.
3. Decide how you are going to communicate with your committed givers. How will you say thank you? How you will store their details – does your country have any data protection rules to be followed? Provide them with regular updates to build the relationship but do not give them excessive information.
4. Invest in a good website so your online giving can grow. Explain how regular giving is more powerful than a one-off donation. Decide on a payment provider – JustGiving, Charity Checkout, Paypal and Virgin Money are examples. Make sure that they have regular giving options, that you can build pages with your SSO brand on and carefully research fee costs, including any fees in advance.

Case studies on insufficient finance

Corporate Sponsorship - Israel

For **Israel**, a turning point was the “adoption” of the organisation by a pharmaceutical company as part of a European-wide service and the marketing of their new drug against hypertension. Before this happened, the organisation faced many difficulties – relying very much on volunteers with no paid staff. Sponsorship was through financing Israel to deliver campaigns around prevention and signs. They were able to search for funding which would allow them to continue to grow after the sponsorship ended. The company funded a CEO who slowly built the organisation’s resources and developed campaigning, lobbying and fundraising expertise with considerable guidance and contacts from the sponsor. Some of the contacts including media experts and lobbyists continued to offer their services on a ‘pro-bono’ basis. The CEO developed other relationships with pharmaceutical companies whilst still maintaining the ethics of the organisation. Using the sponsorship as an opportunity to develop skills and expertise and deliver new activity, as well as funding campaigns, worked well for the organisation.

Corporate Sponsorship – Italy

Italy have a relationship with a pharmaceutical company which produces a machine to detect AF. This machine is used in prevention activities at awareness days and helps inform people about stroke symptoms and stroke awareness. The sponsor donates to the organisation for every machine sold as a result of involvement in awareness raising and prevention days.

Local Corporate Support – Hungary

Like many SSOs, **Hungary** experiences difficulty in getting local individual and company support, is affected by the external political environment and has limited capacity to develop contacts, corporate relationships and fundraising applications. Due to limited options around corporate sponsorship and limited charitable giving in Hungary, health industry support has been the focus. Here the issue of stroke is understood and relationships based on mutual understanding of the issues can be developed. Some focus has been on smaller local rather than multinational companies and this has been fruitful.

Sale of goods or services – Japan, Malaysia, Sweden and Finland

To supplement donations from the public, members who join the rehabilitation programme in **Malaysia** are asked to make a financial contribution. **Sweden** also found this covered a proportion of their running costs.

Japan found that sales of goods, for example calendars, brought them money from supporters and the public.

Finland and **Sweden** found that they needed to develop services which generated real income, for example advising pharmaceutical companies or providing services for stroke survivors which public bodies need to deliver but do not have the expertise to.

Government or authority funding – Canada

The Canadian Stroke Network was established through the Government of Canada's Networks of Centres of Excellence Program, which seeks to support initiatives such as the work of CSN in areas where it is clear there is a need.

Government grants have proved invaluable to continuing the work of SSOs in **Finland**, **Slovenia** and **Sweden**.



Membership schemes

Giving your supporters an option to join a membership scheme is also a very good way to secure a regular annual source of income and an excellent way to build a relationship with them. If you think that becoming a membership organisation will work well for your SSO, you will need to write a Constitution. In Appendix III, there is an example of a simple Model Constitution.

Building a successful membership organisation is all about recruitment and retention.

Recruitment

1. Keep track of your members on a database.
2. Ask your existing members to ask a friend to join.
3. Swap lists with other relevant organisations, but be aware of any data protection laws in your country which might prevent you doing this.
4. Advertise or place inserts in relevant publications.
5. Create a page on your website about membership and its benefits.
6. Try and get local publicity.

Retention

1. Start a retention programme from when they join – send a welcome email or letter and a membership pack.
2. Contact them by telephone or email 2 months after they have joined and carry out a new member survey approximately 6 months after they have joined.
3. Offer a special discount for the first paid event that they attend.
4. Introduce a direct debit scheme, as those paying by direct debit are much less likely to cancel their membership.

Stroke Solidarity Symbol

The Stroke Solidarity Symbol was developed to increase recognition of stroke across the world. Important messages about prevention, treatment and long-term quality care are represented by the international stroke solidarity awareness symbol, the stroke solidarity string. Such a symbol can raise awareness on a global scale. It is a global symbol for a global issue and it allows people to be part of a global movement. Using national and social media the symbol will be launched. Celebrity ambassadors will help raise awareness of the string. Effective corporate partnerships and a selection of retailers will help get the symbol out to the public, increasing awareness and fundraising. The public will be able to buy the strings online and at events. The Stroke Solidarity String will benefit survivors and the cause regionally, nationally, and internationally because:

- It is a globally recognisable stroke symbol
- It will raise awareness of stroke and funds for stroke survivors
- It will help create a stroke movement
- It tells people we need to take action on stroke

The symbol can also be a source of income for an SSO. Stroke Association UK aims to sell the bracelets after being given a licence from the WSO.

Specialised fundraising – UK

After a targeted campaign about how important legacies are to the Association, the **UK** increased their legacy income very significantly, and legacy income now accounts for 36% of overall income.

In the UK a third of donations from individuals come through legacy bequests. Stroke Association has invested in a programme of legacy promotion which provides advice to people on the general benefits of making a will, ensuring people provide for their family and information on tax benefits of leaving a gift to a charity in a will. This advice is promoted on the website and at exhibitions aimed at older people (for example The Retirement Show). Stroke Association offers a “Free Will” scheme for people over the age of 55 in which it funds the costs of having a will drawn up for people by recommended solicitors. This recommends that people using the scheme consider making a gift to the Association in their will and most people do this. Stroke Association UK may not receive the money for a long time. The number of known legacy bequests is recorded and increased from 200 six years ago to over 2,000.

People who have lost a family member or friend as a result of a stroke often want to help the Association by making donations in honour of the person who has died. Stroke Association UK offers people the opportunity to set up a Remembrance Fund for the person who has passed away. A web-page is created with stories about the person who has passed away which records money raised. Friends and family can set a target and can continue to raise money or donate on special anniversaries. Seeing the total raised and donated can be very motivating.

7.6.2 Volunteers

7.6.2.1 Finding volunteers

Recruiting the best volunteers to inspire others and increase your income is very important. You need a clear plan about where and how volunteers can be involved in the work that you do. There needs to be one policy and a structured process on volunteer recruitment for all to follow. Use tools such as the website to achieve this, and have a handbook and application form for all staff to use. Being informative means you can get volunteers started more quickly.

Understand the volunteer's reasons for volunteering for you – an efficient process will mean you keep the volunteer's interest. Initial contact, application processing, finding a role, relevant checks and introductions should be as fast as possible so you do not lose your volunteer's interest. Try to have a volunteer manager to support the process and minimise barriers to growing the number of volunteers you have.



CASE STUDY:

Using volunteers to select others – Slovenia

Slovenia found that an SSO was a new concept in their country, and that there was some stigma attached to using the services of an SSO. By starting to work with those who were motivated and using services it acted as a stimulus to invite more participants, particularly those who found it difficult to ask for support.

Volunteering support – Israel

Israel's stroke survivor volunteers were asked to:

1. Create and continue to support many social clubs. This saved money and provided great satisfaction to the volunteers.
2. Edit and write magazine content.
3. Assist in answering calls to the telephone service after some training. Initially, it was hoped that the majority of referrals would be responded to by volunteers, who underwent training.
4. Appear at public lectures, in addition to professional stroke experts, on awareness and latest developments in stroke research and technologies.
5. Assist with policy development.

Remember that if you are going to rely on volunteers to deliver some of your services, your SSO must be able to support them, offer expenses and ongoing support and counselling.

7.6.2.2 Volunteers selection

Your SSO should advertise volunteering opportunities in as many places as possible to increase the diversity and number of new volunteers and promote a variety of roles, skills and professional backgrounds to attract those affected by stroke and all age groups. This will ensure you have a wide choice of volunteers to select from. It is important to remember that you are not recruiting for a paid role – you are looking for the time, skills and passion of someone who can give these things.

For some roles you may look for a volunteer who has specific skills or has carried out the role before – the person’s willingness to learn is also important. You may decide that the person does not have all the skills, but wants to learn. Use volunteer agencies, online recruitment, partnerships with healthcare professionals, colleges & universities and other community organisations. All volunteers can benefit your SSO so be flexible in finding a place for volunteers. Do not be afraid to ask for more – volunteers may be happy to donate, fundraise, campaign, support events as well as volunteering in their main role.

7.6.2.3 Managing volunteers

Supporting volunteers is very important. Have a clear volunteering policy which shows the support available for both the volunteer and their manager. Volunteers should be offered access to; training, reviews, information on safety, new opportunities, expenses and a complaints procedure. Be clear how you reward volunteers to ensure their future support. During difficult times what you ask of your volunteers can increase, but you should be prepared to recognise your volunteer’s contribution on a regular basis. Social media is a great way of saying thank you. Creating a forum for your volunteers to speak with each other either online, at training events or at volunteer award ceremonies will increase their loyalty. Show volunteer stories in your newsletters, and allow volunteers to influence activity and strategy through regular meetings. All this will help them feel an important part of your organisation.



7.6.3 Organisational structure & governance

Your SSO could be overseen and managed through a variety of different combinations of volunteers and/or employed staff. Below are some examples of possible organisational structures:

- **Collegial decisions/voting system** – you could have a constitution detailing how you will be governed, with decisions being made through a voting system by all staff, volunteers or a mixture of both.
- **A decision making Board** could be elected from existing staff or volunteers.
- **A CEO or President** who is supported by a group of directors or managers and reports to a Board of shareholders or unpaid Trustees.
- **Board of paid directors** reporting to shareholders.
- **A series of national or regional Committees**, with representatives voted into decision-making positions.
- **National committee and local sub-committees**, all of which are volunteers.

Whatever structure you choose, you will need to consider how the decisions made by those running the organisation will be scrutinised. Will you have a board or trustees, volunteers or shareholders who look at how the organisation is being run? An example of a model constitution can be found at Appendix III.

You will need to set up your organisation formally and register it. There might be a number of different ways of setting up an organisation in your country:

- NGO's are formed as a society or association and registered with a national government department or bureau.
- Registration with local government department or bureau.
- Registration with a national board or governing body e.g. the Charity Commission in England and Wales.
- Registration with a national government department which each year requires data to renew the registration.
- Set up as private company.

What kind of organisation will you be?

Some other things to think about are:

- Do you need to establish yourself as a company or charity?
- Are there any restrictions on establishing an organisation or group in your country?
- Have you investigated all ways in which you may be eligible for tax breaks or discounts? Will you need to complete annual paperwork to qualify for this – what records will you need to provide?

7.6.4 Campaigning & influencing

If you are going to try to influence policy as part of your activity, you will need to consider how to make the biggest impact as well as decide what the most important issues to focus on are.

How will you decide your campaigns?

These may be decided by your Board of Governance or Directors, through consultation with important people such as a survey of staff, the public, volunteers or stroke survivors and carers. You may wish to choose your campaigns based on research results, or choose things that are part of your other activities and events. Government direction or policy may influence your campaign focus, as may the influence of any sponsors or corporate partners you might have.

Campaigning

- Ask yourself “do I need to campaign on this issue right now?”. Sometimes change will happen just by asking the right person at the right time.
- What is the change you want to see? Develop an inspiring and clear call to action that says why your solution will work.
- Campaigns should reflect the real lives of stroke survivors and the barriers they face.

Important decisions about your campaigns include:

- **Will the focus** be on large scale national campaigns or on smaller local campaigns?
- **Will you focus on primary or secondary prevention?**
- **What is the desired outcome of your campaign** – changes to legislation, changes to services?

If you are unable to develop campaigns, what alternatives are there to large scale campaigns – maybe you can get a presence at events, use World or European Stroke Day to promote your activities, or hold your own national awareness week.

When starting a campaign think about:

- Find out who makes the decisions and who influences the decision makers. Make a plan on how you will get to speak to both groups of people.
- Decision makers and influencers are often very busy. When you meet them, you will need to have a 30 second story to explain the problem and what you want to happen. Be clear and simple.
- Involving the media in your campaign can be useful.
- Remember to regularly review how the campaign is working.

Campaigning & Influencing

Stroke Prevention - Japan

Japan decided to run a stroke prevention campaign, which included symposia for citizens to attend, stroke awareness week posters, features on TV programs. A 'Brain attack' campaign also used TV and radio and featured posters at railway stations in Tokyo. A more focused secondary prevention campaign was run for stroke survivors and family members, which used symposia to communicate with the audience.

Focused period of activity – New Zealand & UK

Put all your efforts into one or two events that really publicise your cause – like **New Zealand**, who have established a National Blood Pressure Awareness Week and Annual Stroke Awareness Week.

The **UK** recently launched Action on Stroke Month – an annual event each May which is a month of increasing awareness with stroke survivors about the support the organisation can offer as well as asking the public for fundraising and campaigning support. Volunteers, supporters and staff across the UK are asked to promote the event by running awareness days and taking part in fundraising events. Current campaigns are also promoted during the event.

Stroke Days – Israel & Sweden

Israel, like many SSOs, found it difficult to communicate their work, encourage survivors to use their services and reach all the services and survivors who could benefit from their work. A World Stroke Day campaign was identified as a way of reaching these people, and the campaign which Israel developed was awarded second prize in the WSD competition.

During World Stroke Day all of **Sweden's** 67 associations focused on informing the public about stroke. They talked to people about how to recognise the signs of stroke, the FAST-method and how important it is to call an ambulance as soon as possible. They focused on giving information about TIA and risk factors and how to live healthy lives. Some regions held seminars for the public. They also had articles in newspapers and an internet-chat.



Develop your 'brand' - UK

You need to make your branding distinctive. Use memorable slogans and keep things simple and understandable. Remember, stroke can be hard to understand for many people.

The **UK** found that their logo and brand were not effective in telling people what they do – often people thought they were part of the health service due to the same colour being used and this was a barrier to fundraising. Stroke Association invested money in a new brand and style which is more distinctive and exciting and looks more like a charity (see below).

We're
for life
after
stroke



Partnership working – Australia, Japan & Italy

Work with other NGOs as an alliance to raise public awareness of the need to give to NGOs, including disease or health organisations. Try to make coalitions with patient organisations with similar needs, particularly non-communicable diseases.

Australia, have used partnership a lot in their work. The Australian Stroke Coalition, established by the Foundation and Stroke Society of Australasia in 2008, brings together representatives from groups and organisations working in stroke, such as networks of professionals and professional associations. This Coalition works together on priorities to improve stroke care, reduce duplication of work and strengthen the voice for stroke care. Australia is also part of Australian Chronic Disease Prevention, an alliance of five health NGOs working together in preventing chronic disease, by focusing on risk factors contributing to all diseases – poor nutrition, physical inactivity and obesity. It is also a central member of the National Vascular Disease Prevention Alliance, working with the Heart Foundation, Diabetes Australia and Kidney Health Australia to reduce vascular risk in individuals who may be affected, by developing guidelines and campaigning for changes to policy. **Israel** is part of a coalition for lobbying by NGOs representing chronic diseases, as the result of the initiative of the Patients' Rights organisation. They play an active role on the board of the new Israel Brain Council as a representative of patient support groups.

Japan created an awareness campaign in cooperation with local government and medical associations. **Italy** are looking to use celebrities to promote their work in the future, especially with younger people.

7.6.5 Evaluation & sustainability

Knowing that what you are doing is effective and sustainable are the 2 most important questions for any established SSO.

7.6.5.1 Evaluation

Unless your SSO has measurement and evaluation systems, it will be more difficult for your SSO to:

- Stay within time and cost limits and focus on what is most important;
- Produce evidence of performance against Plan to motivate and focus effort;
- Decide on corrective actions when things do not go as planned;
- Remain flexible to changes affecting your SSO.

In a simple form, your SSO needs to know how it is doing against the objectives, targets and outcomes it is seeking to achieve over at least the next 12 months.

7.6.5.2 Sustainability

What will make an SSO sustainable is probably little different to any other organisation, and will include:

- Having a clear Mission;
- Good relationships with private and public sectors;
- Committed members, volunteers and donors;
- Being flexible and able to change;
- Clear, realistic plans and strategy;
- Financial resources which cover all your costs;
- Committed and skilled staff and high quality work;
- Strong leadership;
- A legal, political and social environment which assists the organisation.

At least once a year, your SSO should be measuring itself against the points above.



8 OTHER CASE STUDIES

In this section, we have included those case studies that talk about more than one topic or look at a country as a whole.

8.1 Develop staff with the right skills

Brazil recognised the need for paid staff with knowledge about fundraising and finding resources, and found these professionals hard to find and expensive. There are laws and rules in Brazil around NGOs and taxation (NGOs pay less tax) and the SSO needed staff with this knowledge. Staff who can speak other languages, especially English, were needed to make contacts and links abroad. Developing specialised understanding of legislation and stroke would benefit all SSOs.

8.2 Legal issues

There may be barriers to accessing stroke survivors, such as legal or data protection barriers which prevent service users being referred to you by hospitals or therapists. Work out what these barriers are and how any legislation will affect you so that you can make a plan of how to get around these barriers.

8.3 Service user representation

Germany ensured there was representation from stroke survivors on the Board of Trustees.

Sweden - At the organisation's Congress members elect the board and its Chairman. Stroke survivor input is considered at this meeting.

Stroke Foundation of **New Zealand** is currently a member-based organisation - membership for all, including service users, includes voting rights.

For **Finland**, members are mainly stroke survivors and their families and are represented in the governing bodies of the organisation.



8.4 Consulting stroke survivors

In the **UK**, stroke survivors were consulted on the corporate strategy. User Involvement work includes the Reader Panel, which provides a way for people with an interest in stroke to comment on publications.

Australia feels that consumers have increasing influence on both the direction of the organisation and on service delivery. The national Board of Directors has two positions reserved for directors representing the interests of consumers. In this capacity they have influence over the strategic direction of the organisation. In addition a consumer council, a sub-committee to the Board has recently been established. In this role consumers have input into the advocacy work of the organisation. In addition all services focused on, or impacting on, care of consumers are made with consumers input via advisory groups.

In **Israel**, except for the chairman who is a leading stroke specialist, all board members are stroke survivors or their families.

For **Japan**, a representative of the National Association of Stroke Survivor Self-help groups is elected as a board member.



8.5 Country case studies

UK – Established in 1992 in a country with a free healthcare system funded by the government. The Association for the Prevention of Tuberculosis which had been in existence for many years was then converted into the Chest, Heart, Stroke Association before the Stroke Association was established in 1992. Campaigning has focused on benefits and services:

- **Ask First** - raising awareness of Atrial Fibrillation (AF)
- **My Stroke Victory** – positive stories of life after stroke
- **Know Your Blood Pressure**
- **Daily Life survey** - the most detailed and comprehensive survey ever done into what life is like as a stroke survivor

Stroke Association funds £2.5million of stroke research per year. It has a high level of contact with the government and a presence at debates central to stroke. Services offered include publications, telephone support, support groups, bereavement support, hospital visits and home adaptation.



Finland – Formed in 1977 in a country with a mainly free healthcare system. Funding for NGOs supporting disease, patients and the disabled in Finland comes from the Slot Machine Association (RAY) the main purpose of which is to raise funds through gaming operations to promote Finnish health and welfare. There are regulations concerning setting up organisations in Finland - the National Board of Patents and registration of Finland must approve the setting up of any organisation. Finland has a strategic partnership with the Finnish Diabetes and Heart organisations to promote arterial health and work together to prevent arterial diseases. Traditionally, they campaign on 10 May every year to prevent stroke. In 2011 the central issue was 'know your blood pressure'. Campaigns are decided by user input and the Board of Governance. The organisation does not fund stroke research but has some contact with government and presence at debates. Finland delivers training to other organisations, stroke survivors, carers and professionals, produces publications and information and provides support groups, hospital visits and recreation.



Slovenia – Founded in 1997 in a country with a mainly free healthcare system. All NGOs need to be officially registered in Slovenia, through the Ministry of Health or the Ministry of Labour Work and Social Affairs. There is a committee to advise NGOs in both departments. NGO funding comes from the National Foundation for Humanitarian Organisations and the Ministry of Health and Insurance Company. Donations from companies or sponsorships form a small part of the organisation's income, as does public giving, which is not well developed in Slovenia. Most of their income comes from government grants. The organisation was started by retired stroke physicians alongside some very motivated stroke survivors. They do not run campaigns but instead use a presence at events to present messages about stroke. The organisation funds stroke research and has a medium level of contact with government and presence at debates. Training is delivered mainly to staff, volunteers, stroke survivors and carers. Services include publications and information, face to face support and recreation. The organisation began as a small group of 20 people – with only a few stroke survivors who had overcome the 'stigma' attached to utilising support organisations present. It has grown and helped to raise stroke awareness among the public as well as helping to improve the quality of life after stroke for survivors and their families. This was accomplished by:

- successful establishing of activities including stroke clubs and local workshops;
- 'word of mouth' spreading of information;
- media (local radio);
- publications;
- collaboration with other organisations;
- engaging with local societies (municipalities, church communities).

Indonesia – Set up in 2008, healthcare costs are fully covered by personal or employment-contributed insurance, and those without insurance pay for their own health care, except for the very poor who have government support. There are not generally any medical or age-related NGOs in the country. Although people give to NGOs, this is something Indonesia does not benefit from. Most NGOs are self financed and some are funded by a company which is related to their activity. By law all NGOs should be registered with the local authority. Indonesia have suffered financial barriers, a lack of staff and volunteers to deliver their work. The organisation continues running operations within its capacity and capability. 2011 campaigns included seminars in Neurology for Dummies, physical therapy for new strokes and psychology for strokes. The Board of Governance decides on campaigns, and these have input from health professionals. The organisation does not fund stroke research and has a high level of contact with government and presence at debates. The organisation offers training to other organisations, the public and stroke survivors. Services offered include publications and information, face to face support, support groups, bereavement support and recreation.

Hong Kong has had an SSO since 2003. Healthcare is provided by the Public Sector and/or the Private Sector. Citizens can participate in a Public Healthcare System. Citizens can use the private sector either on their own, or through insurance systems. The Labour and Welfare Bureau takes part in the set-up of patient/medical NGOs and patients' organisations. This organisation was set up by volunteers and by stroke survivors and their families and friends as well as professionals through the joint efforts of a few brain injury and stroke self-help groups working together on public education, self-help or mutual-help activities, and information dissemination through leaflets, booklets, and an informative website. The organisation seeks to empower stroke and brain injury survivors to make a contribution to the community through public education events, such as sharing their stories with young people, peer to peer counselling and facilitating exhibitions. Executive Committees decide their campaigns. NGOs in HK are funded partly by the Government and partly by private funds from various sources, such as from commercial organisations and charitable organisations. The organisation does not fund stroke research and has little chance of having public debates with the government. The organisation focuses on providing self-help groups inside the territory. There are more than five stroke patient groups in Hong Kong. A difference in priorities was experienced in the different self-help groups at the beginning, but this has been overcome. The individual groups learned over the years how to accommodate the differences between them, then work on common goals. The organisation has just started to advocate on the need for a 24 Hours Emergency Service with the Healthcare System.

9 WHERE TO GO FOR HELP

9.1 Join the World Stroke Organisation

Professional individuals as well as professional and stroke support organisations interested in stroke are eligible to become members.

WSO current members:

- More than 1000 individual members from 75 different countries
- More than 40 Regional/National scientific and stroke support organisations.

WSO individual and Society members enjoy benefits including:

- Free subscription and online access to the **International Journal of Stroke (IJS)**
- A substantial discount to the registration fees for the World Stroke Congresses
- **Free access** to webcasted/podcasted congress sessions
- Access to the **World Stroke Academy (WSA)** – a global resource centre for information about stroke, and an opportunity for continuing education of healthcare professionals
- Inclusion in and access to the online **WSO Membership Directory**
- Right to host World Stroke Congresses and to participate in the call for bids
- Right to vote for, be nominated or elected to the **Board of Directors** 2012-2016
- Membership Certificate (upon request).

How to join

Visit: <http://www.world-stroke.org/> where an online membership application form can be accessed e-mail the WSO Membership Services (membership@world-stroke.org).

9.2 Join Stroke Alliance For Europe (SAFE)

All European national organisations which support those at risk of and affected by stroke are eligible for ordinary membership of SAFE. Associate membership is available for those who do not fulfil the criteria for ordinary membership, and honorary membership is for those who have provided outstanding support to SAFE's objectives. An application form can be downloaded at www.safestroke.org

Members of SAFE can access the discussion forum, reports from the SAFE board, newsletters and reports from Member organisations.



9.3 Key contacts and useful resources

For general questions relating to SSO Toolkit please contact Research and Information Directorate, Stroke Association:
research@stroke.org.uk

For questions relating to WSO membership please contact:

WSO Membership Services:
1-3, Rue de Chantepoulet
P.O. Box 1726
Ch-1211, Geneva 1 Switzerland
Tel: +41 22 908 9166 **Fax:** +41 22 732 2607
E-mail: membership@world-stroke.org
www.world-stroke.org

Contact the UK Stroke Association at:

Stroke Association
Stroke Association House
240 City Road
London
EC1V 2PR
E-mail: info@stroke.org.uk
www.stroke.org.uk

If you have any questions for the Stroke Alliance for Europe please contact:

SAFE Secretariat (FAO Sandra Jackson)
c/o Stroke Association
Stroke Association House
240 City Road
London
EC1V 2PR
United Kingdom
E-mail: mail@safestroke.com



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 - ESZME Association for Stroke Prevention, Hungary
 - Finnish Brain Association
 - German Stroke Foundation
 - The Heart and Stroke Foundation South Africa
 - Lembaga Swadaya Masyarakat Himpunan Peduli Stroke (The Stroke Care Association Non Government Organisation), Indonesia
 - The National Stroke Association, USA
 - The National Stroke Foundation, Australia
 - NASAM, Malaysia
 - Neeman Stroke Survivors Organisation, Israel
 - Slovenian Stroke organisation
 - Stroke Association, Japan
 - Stroke Association UK
 - Stroke Association of Victoria, Australia
 - The Stroke Foundation of New Zealand
 - The Swedish Stroke Association

Thanks to GE Healthcare, who sponsored the production of this resource with an unrestricted educational grant.

GE Healthcare is proud to support this initiative which will ensure that new and existing stroke organisations have a clearer path forward to success and enable larger numbers of stroke sufferers and families to access help across the globe.

Stroke Association UK's Involvement

Stroke Association (UK) has experience in funding research, developing findings of research into campaigns, advising the Government on policy and delivering services of the best quality to stroke survivors and their families. It is also the largest NGO in SAFE and acts as secretariat for the Alliance. Within the Research and Information directorate, there are a number of specialists in project management, research, organisational development and partnership working who have the expertise to deliver the SSO Toolkit Project.

After the SSO sub-committee of the WSO developed a proposal for the Toolkit, the Stroke Association (UK) were asked to complete this project. The project is funded by the World Stroke Organisation, with regular progress reports being sent to the WSO Board, SSO Sub-Committee and SAFE.

Project Manager:

Verity Baker, Stroke Association UK

11 DISCLAIMERS

This toolkit represents a picture of SSOs worldwide in 2012. Whilst every effort is made to ensure that information within this toolkit is complete, correct and up to date, this cannot be guaranteed. Once this toolkit is printed the information within may be subject to change or become incorrect. The information within this toolkit is correct to the knowledge of Stroke Association UK and the World Stroke Organisation at the time of going to print (September 2012).

The information within this toolkit is based in information provided by those responding to the questionnaire issued by Stroke Association UK. Stroke Association UK is not responsible for the accuracy of this information and cannot be liable for any error, omission or damages incurred as a result of the use of information contained within this toolkit. Stroke Association UK and the World Stroke Organisation cannot be liable for the content of any website or hyperlink contained within this.

Glossary

AF – Atrial Fibrillation, a type of irregular heartbeat which can lead to stroke.

EU – European Union

NGO – Non Governmental Organisation

SAFE – Stroke Alliance for Europe

SSO – Stroke Support Organisation

WSF – World Stroke Federation

WSD – World Stroke Day

WSO – World Stroke Organisation

APPENDIX I –

Stroke Association UK factsheets

Existing SSOs across the world produce a range of factsheets, many of which can be seen on their websites. Here is a list of the factsheets Stroke Association UK produces.

- We're here for you
- Smoking and the risk of stroke
- What is a stroke?
- Accommodation after stroke
- How to prevent a stroke
- Stroke in African-Caribbean people
- When a stroke happens
- Balance problems after stroke
- Life after stroke
- Bereavement and stroke
- The road to recovery
- Epilepsy after stroke
- Transient ischaemic attack
- Haemorrhagic stroke
- Driving after stroke
- Atrial fibrillation (AF) and stroke
- Communication problems after stroke
- Holiday information
- Stroke: A carer's guide
- Migraine and stroke
- Swallowing problems after stroke
- Dementia after stroke
- High blood pressure and Stroke
- Pain after stroke
- Cognitive problems after stroke
- Sex after stroke
- Healthy eating and stroke
- Stroke in South Asian people
- Stroke in younger adults
- Physical effects of stroke
- Depression after stroke
- Childhood stroke
- Blood thinning medication after stroke
- Ischaemic stroke
- Continence problems after stroke
- Emotional changes after stroke
- Alcohol and stroke
- Visual problems after stroke
- Speech and language therapy after stroke
- Women and stroke
- Diabetes and stroke
- Fatigue after stroke
- Physiotherapy after stroke
- Taste changes after stroke
- Occupational therapy after stroke
- Carotid artery disease
- Benefits and financial assistance
- Stroke explanation for children
- Resources for students and professionals
- Exercise and stroke
- Aids and equipment for independent living (including community alarms)
- Making a complaint
- Complementary therapy
- Leisure activities after stroke
- Electronic communication aids and software
- Private treatment

APPENDIX II –

Planning tools

This is the identification of your SSO's key stakeholders, an assessment of their interests and the ways in which those interests impact on your organisation. A stakeholder is a person, group or organisation that has or should have an interest in your SSO.

For each stakeholder you list:

- Their name
- Their degree of importance to your SSO (High, Medium or Low)
- Their degree of interest in your SSO (High, Medium or Low)
- Their degree of influence over your SSO (High, Medium or Low)
- Their expectations and needs
- Their attitude to your SSO's performance.

You use the above analysis to decide on their relative importance to your SSO and the strategies your SSO needs to adopt with them.

Swot analysis

A very common planning tool used to assess the Strengths, Weaknesses, Opportunities and Threats for your SSO. The Strengths and Weaknesses identify what your SSO does well and what it needs to improve on. The Opportunities and Threats identify changes or trends in the external environment that your SSO needs to take account of.

Pest analysis

PEST is a tool to help you explore the likely future external environment for your SSO under a number of headings:

- Political
- Economic
- Social
- Technological

There is an extended version called PESTLE, which also includes Legal and Environmental factors.

Once you have listed the forces or trends under each of the headings, you can prioritise them according to the amount of impact and likelihood.

Service/Product Matrix

This tool has been adapted for use in the voluntary sector from the McKinsey/GE Matrix which is a very well known business tool. It will help your SSO assess its services and products, in order to help decide where to invest, review or stop.

You need to assess if each of your service/products are high, medium or low in respect of two factors:

Market attractiveness in the sector – this would include things such as:

- Market size
- Market growth
- Market profitability
- Pricing trends
- Competitive intensity

Strength in the sector – this would include things such as:

- Strength of competencies
- Strength of brand
- Client/customer loyalty
- Record of innovation
- Access to finance

Risk analysis

This is a tool to help you list, sort and rank identified risks. For each risk, you assess the likely impact of it and the likelihood of it occurring on a scale (often 1 to 5, where 1 = low and 5 =high). For the risks with the highest combined score of impact and likelihood, you devise a series of actions and plans that will help to remove or reduce that particular risk.

APPENDIX III –

Example of a Constitution

1) Name

The name of the SSO shall be

.....

2) Aim

The aims of the SSO shall be to

.....

3) Powers

In order to achieve its aims the SSO may:

- a. Raise money
- b. Open bank accounts
- c. Acquire and run buildings
- d. Take out insurance
- e. Employ staff
- f. Organise courses and events
- g. Work with similar groups and exchange information and advice with them
- h. Do anything that is lawful which will help it to fulfil its aim.

4) Membership

- a. Membership of the SSO shall be open to any individual over eighteen (or alternative age) without regards to disability, political or religious affiliation, race, sex or sexual orientation who is:
 - interested in helping the SSO to achieve its aims
 - willing to abide by the rules of the SSO and
 - willing to pay any subscription agreed by the Management Committee.
- b. The membership of any member may be terminated for good reason by the Management Committee provided that the member concerned shall have the right to be heard by the Management Committee, accompanied by a friend, before a final decision is made.

5) Management

- a. The SSO shall be administered by a Management Committee of not less than three and not more than individuals elected at the SSO's Annual General Meeting (A.G.M.).
- b. The Officers of the Management Committee shall be: the Chairperson, the Treasurer and the Secretary.
- c. The Management Committee may co-opt onto the Committee, up to three individuals, in an advisory and non-voting capacity that it feels will help to fulfil the aim of the SSO.
- d. The Management Committee shall meet at least two times a year.
- e. At least three Management Committee members must be present for a Management Committee meeting to take place.
- f. Voting at Management Committee meetings shall be by a show of hands. If there is a tied vote then the Chairperson shall have a second vote.
- g. The Management Committee shall have the power to remove any member of the Committee for good and proper reason.
- h. The Management Committee may appoint any other member of the SSO as a Committee member to fill a vacancy, provided that the maximum prescribed is not exceeded.

6) The Duties of the Officers

- a. The duties of the Chairperson shall be to:
 - Chair meetings of the Committee and the SSO
 - represent the SSO at functions/ meetings that the SSO has been invited to
 - and act as the spokesperson of the SSO when necessary.
- b. The duties of the Secretary shall be to:
 - keep a membership list

- prepare in consultation with the Chairperson the agenda for meetings of the Committee and the SSO
 - take and keep minutes of all meetings; and
 - collect and circulate any relevant information within the SSO.
- c. The duties of the Treasurer shall be to:
- supervise the financial affairs of the SSO and;
 - keep proper accounts that show all monies received and paid out by the SSO.

7) Finance

- a. All monies received by or on behalf of the SSO shall be applied to further the aims of the SSO and for no other purpose.
- b. Any bank accounts opened for the SSO shall be in the name of the SSO.
- c. Any cheques issued shall be signed by the Treasurer and one other nominated member of the Management Committee.
- d. According to the laws of the country, the SSO shall ensure that its accounts are audited or independently examined every year.
- e. The SSO may pay reasonable out of pocket expenses including travel, childcare and meal costs to members or Management Committee members.

8) Annual General Meeting

- a. The SSO shall hold an Annual General Meeting (A.G.M.) in the month of
- b. All members shall be given at least fourteen days notice of the A.G.M. and shall be entitled to attend and vote.
- c. The business of the A.G.M. shall include:
- receiving a report from the Chairperson on the SSO's activities over the year
 - receiving a report from the Treasurer on the finances of the SSO
 - electing a new Management Committee and;
 - considering any other matter as may be decided.

- d. At least members must be present for the Annual General Meeting and any other General Meeting to take place.

9) General Meetings

- a. There shall be 2 General Meetings (excluding the A.G.M) each year.
- b. All members shall be entitled to attend and vote.

10) Special General Meeting

A Special General Meeting may be called by the Management Committee or members to discuss an urgent matter. The Secretary shall give all members fourteen days notice of any Special General Meeting together with notice of the business to be discussed.

11) Alterations to the Constitution

Any changes to this Constitution must be agreed by at least two-thirds of those members present and voting at any General Meeting.

12) Dissolution

The SSO may be wound up at any time if agreed by two-thirds of those members present and voting at any General Meeting. In the event of winding up any assets remaining after all debts have been paid shall be given to another SSO or organisation with similar aims.

13) Adoption of the Constitution

Until the first A.G.M. takes place the persons whose names, addresses and signatures appear at the bottom of this document shall act as the Management Committee referred to in this constitution. This Constitution was adopted on by

Name

Address.....

.....

Signed

Published by

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**World Stroke
Organization**



Stroke
association

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