



SAFE Meeting notes - Krakow

Introductions

Adam (Polish Stroke Foundation) welcomed everyone

Most delegates are HCPs (neurology, speech therapists, surgeons)

SAFE activities during 2016 an update

Jon

Secured Weber Shandwick as their PR agency on a pro bono basis at pan-EU level

WS gets credibility with clients, helping with contact names and addresses, talking to WHO in Geneva, key people inside the EU health commission, etc.

Two day meeting with the German Stroke Foundation Schlaganfall Hilfe Deutsche Sche (Michael Brinkmayer who is Head, and Marcus) talked about what they need to do to grow. Want to encourage them to do more. Marcus will be coming back to help SAFE. Particular skills in looking at research and prevention activities – a key person to help drive these topics forward.

SAFE got a place at EU Chronic Conditions Conference, some good outputs; e.g. have now got onto the EU Health Forum, the body that makes influencing over where EU money should be spent. Now registered as an organisation that can make contributions, comment and suggest new topics for discussion at EU level. Can impact the policy agenda. Need to form partnerships with others.

EU Burden of Stroke Report for SAFE – update. Create a report that looks at 12 points along the stroke care pathway and compares the performance of healthcare systems in each country on those 12 points. Enables country comparisons of standards of care and an overall picture of where stroke care is in Europe. Can be used to lobby at national and pan-European level. Can use with the media and go to the decision makers to advocate for improved standards of care. SAFE would like to commission this report every three years to be able to benchmark changes in standards of care. Did a similar report in 2007 but not so detailed. Want to produce a number of reports from BoS, one for EU politicians and commission. Another will be country details. A third will be producing a raft of papers for academic journals all

over the world to talk about how stroke care is organised and best practices etc. It will inform actions for health policy makers, healthcare providers, SSOs and industries. Will also look at AF detection and treatment / prevention of AF related stroke, interventions etc like thrombectomy. Will be looking at communications on stroke and Emergency Response e.g. taking people to stroke units etc.

SAFE will be sending a survey to each SSO and they need to reply to help establish a foundation of content for the report. When will it be sent out? Jon doesn't know but in the next six weeks?

The ESO has agreed to make their membership list available to the researchers so they will be talking to a random sample of medics from each country to get an idea of how they feel. So there will be qualitative as well as quantitative content in the report.

Will launch the Report with ESO in May in Brussels and commercial partners. Report will carry logos of all of the organisations and will be powerful.

Jon shared the suggested indicators (to be circulated). There are 12 indicators.

BoS will be led by Prof Charles Wolfe at Kings College London.

The medical team will come to the next SAFE board meeting to report on their findings.

In December when have working conference and general assembly, will have two days with research team presenting findings, time to discuss what the recommendations should be in the Reports and what communication activity should be put into place as a result. Will be a real opportunity to shape what the recommendations will be. Everyone has a stake and can influence the outcome.

ESO update: Their President, Valerie Caso, is proving to be a very good friend to SAFE and understands the need to involve patients

Purple will be the colour of stroke. The group was supportive.

What is the self-management of stroke?

Adam (Poland)

Poland is an heart shaped country

70,000 strokes a year

One stroke every 8 minutes

15-20k are due to AF

What is the self-mgt of stroke?

- Set goals

- Make plan
- Be patient
- Stay focused
- Stay organised
- Work hard
- Reach goals

Adam is a physiotherapist

Information is really key

Thanks to BI, main partner, they provide patient information to people in stroke units (on what next to expect...)

Self mgt of stroke guidebook: Three key topic areas - Coping and support, communications challenges, prevention

Liliia (Ukraine)

45 million people

Life expectancy 66-76 years

No change in life expectancy since 1960!

Owing to the war, health expenditure on population has declined since 2002

Biggest health risks – alcohol, smoking, obesity, low happiness (owing to war)

Biggest diseases in Ukraine, CVD and Cerebrovascular is the biggest

After CVD, stroke is the biggest issue

High stroke mortality and disability in survivors

Now have national stroke programme, prevention programme (AF) and national guidelines

Organisation of assistance for stroke patients

Issues with payers around value of prevention but they will pay for AF anticoagulation

Run a school for stroke patients, conference for patients, PR,

Publish help for stroke professionals to help them manage stroke

Health Economic presentations for payers – achieved free MRIs for suspected stroke patients and thrombolytics covered by healthcare system too

A range of rehab activities, both physical and intellectual e.g. art therapy

Opened a rehab clinic for people who are most likely to be able to get back to work, very aggressive rehab programme, also work on social reintegration

Also working on medical student education, role play simulations of how to care for acute stroke patient 'on the street'

Organise regular congresses / conferences for HCPs

Also do awareness raising actions around World Stroke Day, e.g. in main park in Odessa, music and bp testing, dance and exercises in public squares

Good results. In past two years, they have decreased morbidity and mortality of stroke

Be a stroke champion – do not blame others for lack of stroke care; look in the mirror and you will see who can improve stroke care in your country

Jon Q: 1,000 visitors a day to Poland website. How do you use that to build visitors into supporters?

Adam: Uses google analytics, website manager, to see who / where enquiries are coming from. Many UK visitors (Polish ex-pats perhaps!)

Jelena Q: do you have subscribers?

Adam: It is tough. Jelena, it is easy. Adam, no it isn't owing to data protection rights.

Jelena: I will show you how!

Jon: who writes the material? The leaders of the patient associations. Adam aggregates news feeds, selects the most relevant, useful information for the patient and the family. This is why they do so well on the Google rankings... relevant content that is regularly referred to. Jelena: there are ways to optimise your websites by using content production and distribution smartly.

Jon: Would it be a good idea to have a session at the working conference on how to build and maintain a website easily? Delegates: YES! Jon: Also look at capturing database of names.

What is a stroke support organisation

Sarah WSO/SA UK

What is an NGO

Not for profit, voluntary (not coerced), charitable

Independent of govt and private companies

With an agenda for public health, social welfare

Definition

Legally constituted, created voluntarily, operate independently of govt interference, towards the welfare of people

Stroke Support (what do they offer and what do they engage in)

Offer: e.g. a decent accessible and clear website; information materials e.g. leaflets; facts about stroke; social activity e.g. peer support

Engage in: e.g. lobbying, partnership working,

Stroke support, decrease the number of strokes and all who are touched by stroke to get the support they need e.g. prevention, treatment and care

How to set up an SSO

Don't underestimate the amount of time it takes, research and paperwork and discussion of priority needs, talking to others' to gain their experience, tension between time and commitment. Never think we don't need help and advice; vital to share experiences and challenges

Key Questions

Why do you want to set up an SSO?

What activities will you undertake in your SSO?

Are there other NGOs doing similar activities in your area (beyond your disease / shared agenda)

Who are the people who will help you? (and those who might feel threatened / work against you?)

Governance

Rules and structure of your organisation, management of it

Resources e.g. finance, people, materials, premises, equipment

E.g. set up a decision making board, CEO, advisory committee, regional structure – all appropriate to size and scope of work

Include patients at the centre of the organisation

Policies, processes, legal compliance, roles and duties, responsibilities, structure

SSO Toolkit is available on the WSO website

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SAFE member organisations on Stroke Clubs

Adam

Adam sharing his experience on how he started and how found partners to help him establish and grow the organisation

Who can be a partner? Hospital, outpatient clinic, Different organisations e.g. MS!, local government but be careful as they might want to use the group in activities they don't agree with, e.g. firms, but again be careful in case they try to gain product endorsement inappropriately in return for financial support.

What can you offer to a partner? Knowledge, experience, information materials, communication channels and professionals

Found a very good partner called Medisystem – provide specialist patient outclinics. Private but also have a contract with public hospitals on post stroke rehab. Five years' partnership. This year started a stroke support group for first time. Lessons for carers on e.g. 'how to move the patients', handling skills. Stay in touch with these people.

Plans for the future – more groups in other cities, start up clubs for people with aphasia, Ski Camp or Summer Camp would allow the stroke carer to have a rest, and the stroke survivor to have a week away. (Sandra: NL does weekend camps as a less time intensive way in to the project). Adam: who pays / who is sponsor? SAFE – people pay to attend.

Jon: Stroke clubs often happen regularly e.g. once every couple of weeks, include activities, listen to a talk on a relevant topic e.g. restarting hobbies like gardening and then a meal / tea with plenty of interaction time. Adam – do you have contracts with volunteers? Jon – often it's the relatives. Poland also writes contracts, very important to be clear. Adam got place, physio from the partnership in Poland. Contract is not financial for volunteers but one for services, behaviours and what should not do as well!

Supporting Supporters and Volunteers

Adam

Provide information, direct aid,

Information e.g. helpline, website, YouTube instructional videos, FB, Smartphone app, Educational Materials.

Adam looks at SA UK website as a valuable source of ideas! J

Their helpline is always with them, goes through to their mobile phones, try to be available for patients 12 hours a day. Most people ask help, other about access to medicines

Easier to provide FB than website

What should go on the social media content: personalised help for patients! Make sure it is relevant.

Educational material – available in most book stores, the Guidebook for stroke survivors

Next book will be written with stories from stroke survivors

Brochure from Poland - How to talk to doctors – be a partner with doctors – Adam provided this in Polish, will send me the English version by email

Supporting volunteers; interesting activities e.g. Running Team that visits a different city every month, takes part in a local run, have a tent, provide information to other participants

Volunteers are not medically trained, just info on access to hospital, law etc. Same in UK, will not give medical advice over the phone, have to see someone but can give advice on how to access HCP, get more info. But many people ring as they are lonely / living with stroke questions not so much on medication

Jon: Find the work being done in Poland is inspirational and a model for others.

Self-management and prevention programmes on the Internet

Jon

Why digital self-management?

By 2020 80% of adults will own a smartphone

81% of EU families have internet access

90% of young people use mobile in most W EU countries

Rise of e-health and apps in the last 3 years

Use of gamification to support rehabilitation

Use of social media access to build virtual communities

Lots of stroke apps including bp monitoring, memory games

My stroke Guide

Has been developed to look the same no matter how accessed

Designed to be accessible e.g. for people whose fine motor skills aren't great

Structure has been kept simple

Physical

Emotional

Practical

Aphasia and communication

Currently has 160 videos but planned to have around 400!

Ability to talk to people online

Help with goals and goal setting

Can change the look e.g. high contrast depending on visual disabilities etc.

Not generally available as being piloted in certain regions with UK NHS but next year can access via password sign up on UK SA site, with donation link.

People become depressed after stroke owing to isolation, family changes etc not necessarily because of neurological damage. It's more about the human, psycho-social impact of their stroke, linking them to people as a vehicle for recovery. We need to explain that we don't know how people are going to react or recover, they need to take the information and do with it what they can. Many people don't get to see the stroke physician 8 years after their stroke, this is an attempt to fill that void.

SAFE Research Update

Jon

Horizon 2020 is a big funding pool from EU

People who want the money for research have to access SSOs to ensure the patient voice is representing

SAFE can be an accredited partner to medical academics who want to apply for funding

Currently supporting four stroke related EU projects

See notes from previous meetings

Precious – raft of treatment for complications of acute stroke e.g. secondary infections like pneumonia

Amsterdam meeting

Will be discussing BoS report.

Also encourage others to suggest topics e.g. volunteering and websites per today's discussion

Will be up to 100 delegates this year (doubled the number of delegates in two years)

Sandra will be coordinating and sending out details in July for response

ESO Congress 2017

Will be a full day of SSO discussions for the first time, SAFE will lead most of that

SAFE board

Planning to deepen the calibre of people on the board

Consider whether delegates would be interested in standing for the SAFE board

Want to raise the standard for SAFE activities

Ensure that small as well as big organisations are represented to ensure that the areas of interest for start-ups are included

Send notes from all four meetings to Jon

NB Poland has produced the AFA OAC booklet, and translated it!

These notes are courtesy of Mike Kan, Global Head of Healthcare at Cohn&Wolfe