



## Notes from SAFE Regional conference 2 - Skopje

### *Intro from Macedonian host organisation*

Maja and Anita

Young organisation, growing knowledge about stroke

Since joining SAFE they have grown their membership

Honour to be hosts of conference

Jon and Sandra are an inspiration to us all, thank you so much for organising

Hope meeting will help mutual cooperation regionally, share ideas and solutions, welcome!

### **Jon's introduction**

Macedonia 6 delegates, neurology and Red Cross

Slovenian Assn 2 delegates, 1 professional, President is a stroke survivor

Serbian Assn, 3 delegates, neurologist, medical student, care nurse

Poland (Adam), HCP

Jelena, Advocacy manager

Dutch Brain Assn (broader than stroke alone), x2 speech therapist & fundraiser

Montenegro 2 delegates, neurologists

Bosnia 1 neurologist

Croatia 1 neurologist

### **SAFE update**

**Jon**

EU Burden of Stroke Commissioned led by Kings College London, collaborating with lots of University depts. across EU to look at the burden of stroke. An update of 2007 SAFE report. Looking at the stroke care pathway in every EU member country so can create a comparison. How many people are having stroke, how many specialist units, care staff etc. Case studies of best practice and each SSO will be able to create an advocacy plan for better stroke services using the results. Will produce a number of reports and academic publications, all SSOs will receive the report to use the detail for their own national activities. Also going to launch at the European Parliament, date tbd but most likely on European Stroke Awareness Day (second Tues in May 2017). Want to have national launches at the same time and work with organisations to plan and coordinate their activities. Want SSOs to complete information on Country Data.

European Health Policy Forum – SAFE at last member. Discuss allocation of EU funding for health research across key diseases. First time been able to secure a seat at the table. Also involving the ESO to sit in those meetings together to argue for the same policy positions to get more funding allocated to research and care across Europe.

SAFE Working Conference in December in Amsterdam will be discussing all of the BoS findings. (BI is invited to be there for a research debrief, with other sponsors). Opportunity for delegate to discuss the key findings and what goes into the eventual report that will be launched.

Jon encouraged organisations to start thinking about their comms planning for this. SAFE board discussion, needs to get Stroke higher up the agenda. Going to get purple to be the colour for stroke, across EU for consistency. Will use same colour in all materials. Want all SSOs to use purple in their colour palette and branding. Use UK campaign as inspiration. Launching the BoS should be associated with the colour purple, just as breast cancer is pink and CVD is red etc.

World Stroke Day Oct 16: Committee of WSO is working on what the theme should be. This year is about Face The Facts, Stroke is Treatable. Many people don't understand that it can be treated. This can be adapted by countries.

Encouraged them all to contact Jelena to help with advice on planning. She will also be producing some core materials for everyone to translate and use. Jelena will be doing a lot to coordinate the May BoS results launch.

## **Self mgt after Stroke**

### **Maja, Macedonia**

Overall number of stroke related deaths are increasing

Impact of stroke on social and physical functioning

What is self mgt? Individuals making the most of their lives, coping with difficulties and minimising impact of condition's limitations to do as much as possible to feel happy and fulfilled

How does it benefit patients? Build confidence and knowledge in disease mgt (monitoring etc), role mgt (active role in care plan) and emotional mgt (impact on person, family and carers)

Lots of evidence to show benefits of patient self-management in objective terms

Stroke has a massive physical and psycho-social impact on survivors and their carers

Goal priorities after stroke: chronic post stroke setting. 79% problems in self-care e.g. taking a bath; 32% productivity e.g. concentration.

Self mgt is importance for secondary prevention, impact modifiable risk factors e.g. activity, diet, smoking, drinking, adherence etc

HCPs play an important role in educating, guiding, helping and facilitating patient self-mgt (importance of dialogue, MDT)

Stroke teams should be MDT but also interdisciplinary team work, e.g. goal setting and decision making by group via at least weekly meetings

Large team: 11 different disciplines listed!

Barriers faced: organisational issues, time pressure, lack of joined up care, lack of capacity and education

The importance of personal action plans

In Macedonia there is a lot to do to achieve best practice in patient self-management!

Nice cartoon on self-management, in English!

Jon question: all information from HCP point of view. Maja - Will come on to patient point of view

### **Anita: Role of peer to peer support**

Stroke has such great impact, affects relationships with family hugely. Doesn't just affect the patient but family and society.

Friends and family may feel uncomfortable, 's/he isn't the same person as before', may disappear from the survivor's life. Survivors feel uncomfortable too and don't fit in as they did before.

Lots of daily activities become so difficult, talking, walking, writing, eating, using public transportation, leading to feelings of being isolated and confused

Family relationships often become strained. Care givers have feelings too. Impacts their physical and emotional wellbeing too. Feel guilty for negative feelings about their family member and don't know how to cope. These feelings have negative impact on rehab and recovery! The longer the survivor is isolated from society, the longer it takes for them to be reintegrated again. This is why stroke support organisations are so important in helping people and carers adjust to the changes in their lives.

Peer support groups offer huge value and importance in stroke recovery

In Macedonia, nursing homes are nearly all private but not equipped to handle stroke survivors – lack of care facilities is a huge issue

Run through the roles of key people on the MDT

Occupational health therapists don't exist in Macedonia, so ask the physiotherapists to cover this role

Important for HCPs to step away from the computer and engage, be present, for the patients!

Emphasised the importance of accessible and easy to read materials

How to stop people reverting to their (bad) old habits after three months?

## **Stroke Clubs**

### **Ivan and Jelka, Serbia and Slovenia**

#### **Ivan:**

Working with seniors clubs, want to do 'train the trainers'

Lots of challenges from lack of funding to losing the interest from managers in public institutions (as the patient group wanted to steer clear of politics and not be involved in corruption and bribery)

Not giving up!

SAFE Board is looking to set up a fund, particularly to help groups get off the ground without bumping into some of the issues being faced

Discussion: Corruption in the political system the main barrier in Eastern Europe and is a common problem!

#### **Jelka:**

Involved since 2003 in SAFE

Been running stroke clubs in Slovenia since 1998, have nearly 2,500 members of whom 1,600 are active

Funded from Lotto (80%)

MDT advisory board, President is a stroke survivor

Provide a wide range of support activities from education to rehab, transport, social activities, sport, creative workshops, etc.

Cater to young stroke survivors and people with aphasia too

Have a walking club for rambling and climbing

Hold a national gathering for stroke club members

Exhibition of stroke survivors' art every year

Run awareness campaigns on national awareness days (Sept 9 in Slovenia)

Impact of stroke on carers – habits and role changes, fear of another stroke, active search for information

Discussion: Jon in UK only 1/3 people want to be involved in stroke club but lots of different points of engagement, coming and going. Don't be disappointed if not everyone joins straight away. Jelka: presidents are very proactive in their follow up to get people along. Need someone locally who is dedicated to getting people out of their houses.

## **Reaching Out**

### **Maja, Macedonia**

One of main issues is reaching out

Stroke is the third cause of mortality and first cause of invalidity

Most in Skopje

'Leader' in Balkans in smoking (37% of population), people eat too much and obesity in children is worrying.

Assn formed in 2014

Want to focus on prevention, treatment and rehabilitation

Biggest challenge is reaching out – change how people think about stroke

Second biggest challenge is fundraising, stroke is underfunded compared with other disease areas

Third challenge is organisational e.g. facilities, transport, access, venues usually use free public spaces where possible

Reaching out focus: Lack of awareness of stroke, in Macedonia a high proportion of people don't have internet access (45% over age of 60 years)!

Use alternative channels e.g. printed materials, lectures, face to face meetings

Do activities in public in town squares, sports locations etc., risk factors, individual consultations etc. to bring people in, often linked to awareness days. Cover risk and prevention as well as treatment and ongoing care / rehab

Discussion: how many people involved? No people who work just for the assn. All volunteers, all is unpaid. How many volunteers? Not too many but help from the Red Cross, volunteers often medical students, retired doctors, 30-40 changing volunteers perhaps 10 per city. Just 3-4 consistently the same people coordinating everything. The Red Cross is amazing with their help, support and good quality volunteers!

## **Supporting Supporters and Volunteers**

### **Mimoza, President of Red Cross, Ohrid (Macedonia)**

Follow 7 international principles in their work.

1,000 volunteers in Ohrid (450 young ones)

Strong governance

Caring for elderly workshops on health prevention topics and humanitarian aid in rural areas

Target large chronic and infectious diseases e.g. diabetes, CVD, tuberculosis

Stroke prevention campaign

Also do first aid training for disabled people to show them how they can help themselves

Blood donation programmes

Water safety centre with >80 lifeguards engaged on lakes in the summer season

Also have a mountain rescue service

Wide range of activities to attract a large group of diverse volunteers

Self-management and prevention programmes on the internet

Sabrina from Montenegro

Need to define stroke, its risk factors and its impact

Profile patient population

Divided into primary and secondary prevention programmes

Newer OACs rare in many of the E European countries as they're not reimbursed and people can't afford to pay for them

FAQs online / recognising signs of stroke

Discussion: Who will be the funder of this project? Volunteers will help with technical support and build. Also looking for help from Neurological Society NOT The Ministry that's for sure. A lot of the health ministry staff come from surgery and don't understand prevention and treatment side of healthcare.

Jon: What is happening to improve internet access? Internet supported by satellite/cable tv and telecoms companies but still a challenge.

## **Research Update**

### **Jon**

SAFE has been offering to the EU community, help for people who would like to access funding of \$120bn available for medical research

Content per Athens meeting

Communications between SAFE and members haven't been optimal i.e. denying they received the information for translation when emails were sent out

Ask for slides?

## **SAFE round up of activities**

### **Bosnia**

Stroke is increasing, smoking and hypertension are the 1 and 2 risk factors respectively. 37% of people are under the age of 55!!!

Would like to host next year conference in Sarajevo!

### **Holland**

Dutch has already gone purple! Had a big bicycle tour for people with brain damage and cyclists from the NLs

Doing a conference from patient perspective for HCPs on care of stroke, for 500-600 delegates

SAFE General Assembly will be in central Amsterdam – 6-9 Dec focusing on BoE plus constitution changes, etc. Will have CEO of EFNA, BoS researchers. ESO. Would be appropriate for BI to attend.

### **Poland**

Doing a big campaign to focus Govt on young stroke survivors to try and improve their care and practical support.

They are preparing a skiing camp for young stroke survivors

They have a running team, visit ten cities in Poland, there is a marathon and their team participates wearing their t-shirts, fund-raising activity, includes corporate sponsorship from BI.

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