



## Notes from SAFE Regional Conference - Oslo

### 9am welcome

#### John and Greta

Building towards the annual meeting in Dec in Amsterdam, important and more details to come shortly.

Greta is a stroke survivor of 22 years, has just left the board of the Norwegian association but has joined the SAFE board as Treasurer which will be the focus of her energy now

### 9.15

#### John on SAFE activities in 2016

Got Weber Shandwick in Brussels to be their free PR agency and has introduced them to the WHO, established who is responsible for stroke, European Health Lab who is responsible for stroke, EP the mechanisms through which they can get involved in health policy. WS have contacted these people and introduced SAFE.

Two day meeting with the German Stroke Foundation, wanted them to host a new post for SAFE – responsible for raising awareness of stroke in the media and advocacy work. But after 9 months they hadn't done anything so in the end they didn't give the post to the Germans. Now established post and given to Jelena Mistrá, from Serbia. Starts work for SAFE on July 1, PR professional. Will produce materials centrally and send to all members. Coordinate international activities e.g. Awareness days.

Attended the EU Chronic Conditions conference in Brussels. And from that SAFE is now part of the EU Health Forum for the first time. Seat at the table. Need to nominate someone to represent SAFE in that role. Someone who is interested in EU health policy. The commissioner said they are interested in making stroke one of the priorities for Europe. Opportunity for SAFE to step up.

EU Burden of Stroke. 2007 Report commissioned by Arne on stroke services in EU. Follow up study, in even more detail, now in progress. Funding from Daiichi Sankyo, European Critical Care Foundation and BI, conversations with Pfizer, Allergan,

Penumbra, Bayer. Very confident that more sponsors will come forward. Major update of 2007 report. Powerful political document to support policy change. Will be able to provide country comparisons. Case studies in best practice. Definitive figures on the burden of stroke. ESO members, researchers interviewing leading physicians what are they most proud of in terms of stroke care in their own country. **We should connect them to Dr Gupta's initiative in the UK!** Share the EU Healthcare Pioneers Report too.

Want to look at the whole stroke care pathway. Prevention, acute care, rehab, care in the community, assistance with dying. Want to have 16 key indicators along the pathway all the way through and to say, on these 16 points, what is happening in each country. E.g. in point 11 say, support when come out of hospital, compare point 11 by country. Problem is the limited amount of money, 16 points is too much, can we only do 10, SAFE is saying no still want to do 16 but discussion ongoing. Some countries don't collect data e.g. ambulance response times to ambulance response time. Interested even when there isn't any data, important to record to lobby for data to be collected! Can't assess quality of service otherwise.

Strategy for stroke? Quality assurance (national or regional audit?), H'care system (structure by country), Process of care (pathway), is there patient and family involvement in services and research (SSOs)? Led by Prof. Charles Wolfe at Kings College London (one of original report authors). Do again in 3-4 years' time to see if things have improved or not. Basis for lobbying.

Meeting with ESO to address engagement issues. Valeria Caso President of ESO spoke at SAFE General Assembly. Spent a lot of time discussing. The ESO is changing and understanding much more that they have to work with Stroke Patient Organisations. At the next ESO they will set aside a whole day for how to build SSOs, how HCPs should support SSOs, what SSOs can do. Trying to raise the profile of SSOs among professionals to encourage closer working. Miguel SAFE representative on the ESO Board. BoS – ESO wants to sponsor, opening up membership lists to researchers, want to be at the launch in May in Brussels to support what needs to be done. Coming together of PAGs and professionals in a united combination to influence the decision makers to do more for stroke. Excellent. As well as industry support, united and powerful voice to effect change together.

SAFE has agreed that purple will be the colour we want the world to associate with stroke. Try to use purple in some way, introduce the colour if possible. Important to separate understanding of stroke from heart disease. WHO has now changed its definition and moved stroke out from under CVD and made it a stand-alone condition. Also use colour in society e.g. light up monuments in purple. Jelena will send out all materials in a purple colour palette.

World Stroke Day 2016. Hoping to get Jelena onto the WS Day Committee. Three themes over the next 12 years in rotation. Stroke is preventable, treatable and support for life after stroke. 2016 the focus is on treatable. Need to get materials out early for planning.

Q Arne: Purple varies, can we have the Pantone colour number. Sandra will send to everyone.

## **What is the self-management of Stroke?**

### **Liisa, Finland (Finnish Brain Assn)**

- Provided aphasia case study (see hand-out)
- One Life, joint effort, Brain, Heart and Diabetes Assns working together to promote vascular health. Priceless Processor.
- Now will talk about peer support in One Life and role of social media to enable connections
- One Life Peer Activities: support money can't buy. Support can be the turning point that helps people turn from victim to survivor. Message – not alone and life goes on, gives hope
- Scientific evidence to support
- One to one or in groups
- Training peer support persons and facilitators
- Supporting peers
- Implementing peer support care pathways
- Social media and peer support: 'there's no replacement for face to face" but social media provides an important channel and "there is demand for peer support". FB not interactive enough.
- Shows video that worked well 'works in mysterious ways' as it acted as peer support. One way to communicate the message that 'you are not alone'
- 5k kilometre fund raising cycle ride by 20something stroke survivor – 3 countries in 4 months with his husky dog.

## **Use of www for peer support**

### **Ronald, Sweden**

- Have a home page for members
- Used by media and researchers too
- Always trying to improve services
- Use YouTube to send information e.g. congress speaker presentations
- Wanted to target young people – stroke in the middle of the life – smil – which is also smile in English

- Developed a FB group, originally open but used badly so changed to closed access
- Important source of information with people sharing their stories on stroke, asking for help and information, a lot of comments in a helpful way, many people aren't members but it's an important way of reaching them. 2,224 members in the FB group

## **John UK SA**

Conducted a needs survey for peer to peer groups. People wanted:

Medical information, how to do things e.g use of arm, who can help, equipment, relationships, help with making decisions, what are my rights (finance, employment, pension etc)

Presented a list of what's important to stroke survivors in terms of quality of life – long list relating to society, family, personal considerations

SA has a publications area, WSO has a 'patient education repository', listed by language and no copyright so easy for anyone to use

COPE Technique – create once, publish everywhere – write so can be used across different channels

Makes for more efficient use of capacity

Quality tested to a recognised standard e.g. first professional draft with references, then redrafted in reading age 7-9 years with simple words, user tested, professional checkover and references updated, 'The Information Standard – Certified Member'

Channels to deliver information: hard copy, digital including apps, social media, websites etc, radio and tv, posters and billboards, in person and telephone helplines using volunteers

Have digital user groups to test and rate apps e.g. aphasia

Need for specific information for people at different moments along their pathway. E.g. when having their stroke it is the relatives who most need the information. Redesigned web site so it is mobile friendly and the first information is relevant to a relative in a stroke unit at a moment of acute care. Also need to ensure it is tailored to the individual psychology and cognitive capacity. Can track users through their journeys to recognise and adapt website to offer what they're likely to be most interested in first.

Presented a stroke care pathway to identify the places where information can be provided. Often stroke care professionals aren't as empathetic as they need to be! They couldn't answer the majority of the questions that were identified in the needs assessment. So as people move out of acute care, the role of SSOs becomes increasingly important. In terms of information, it's often the carers "people in proximity" who get left out and this is an area that should not be neglected and very important. Canadians provide a book for carers to help them adjust and brief on access to rights etc. Also there are accredited training programmes for carers (family members).

## **Presentation on stroke clubs**

### **Lineke, NL**

Lots of regional groups, over 100, all run by volunteers, focus on exercise e.g. cycling, swimming and exercise, language training groups, art painting and music activities, excursions and day trips

Three merged associations

Aphasia is a major issue

Bringing people together – they find a way to communicate somehow even if they find it difficult to speak

Theme – Good, better, best for the art group

National, annual activities. E.g. one day meetings for families with aphasia, brain tumour contact groups, social and educational

Important to be aware that you can look normal on the outside but a lot going on inside in terms of how coping with the impact of stroke

National family day for everyone that has had a brain injury – including children

Young stroke survivor weekend, children's weekend and self-management days (the latter being Lineke's project, organised since 1996)

Confidential content, 'Chatham House' rules.

Peer groups are so important, not miserable people sitting in a circle but positive, support, mutual understanding. Not for everyone but works for many. Everyone understands each other, even without words. Nothing to explain. Important to understand the cognitive issues.

Q&A: Great to focus on children and carers.

### **Arne, Norway**

Stroke clubs in Norway, the most important part of the organisation. Supporting peer work (vital as major source of funding), social activities, rehabilitation, physical activity and cultural/historical activities

Schooling of adult people, supporting them getting grants for course, physical activities, often the first trip for years etc. important social connection. Life hasn't stopped

Establishing a stroke club – lots of things to take into account

Try to find new organisers around Norway

Have to make it easy e.g. identify a location to hold the meeting

Provide admin assistance in registration of the club, accessing funding and providing some seed funding / initial capital

Reduce fear of paperwork and support with that

Structure clubs with 3 board members, Chairman, Treasurer and Secretary

## **Reaching Out**

### **Kjell, GM of Swedish Stroke Assn**

Working at national, regional and local levels (clubs at local and regional levels)

79 Assns, 9.3k members including many stroke units and staff

Visiting 72 stroke units. Providing educational materials to hospitals.

In this phase it is hard to connect with the stroke survivor as they are still in the 'shock' phase

Visit rehab and healthcare units – meet stroke survivors, more successful as at this stage they need the help

Word of mouth is important

National Stroke Day activities – events, concerts, meetings with Ss

Advertise in the media to recruit members

The stroke fund – way to support research, some of the ads are to support recruitment for studies

Fund makes the group very famous through its research work

Q: Finland – do you get funding from legacies? Now and then. 2-3 a year.

Website is a key way of reaching out – can donate and apply for research funds. Not just national but nearly all local clubs have their own website too.

Stroke Competence Education – educate staff since 1994, educated more than 10,000 colleagues in the healthcare world – people in stroke and rehab units and in the municipalities through the care chain

## **Arne, Norway**

### **Reaching Out**

Provided three publications

Distribute leaflets on European Stroke Day, brochures, website

Ten things you should know about stroke

Brochure for stroke survivors and their dependents, updated every few years – includes information on prevention of stroke

New website

## **Supporting Supporters and Volunteers**

### **Inese, Latvia**

Focused on various CVD diseases including stroke

Untreated AF causes more than 40% of strokes

Treatment with old medicines or none at all

Fighting for access to new medicines for AF and to raise awareness of AF

What do with patients? Organise different events e.g. INR school for old medicine warfarin...

Also talk about alternatives to treat about newer treatments OACs

Educational events around national stroke days – EU and World stroke days too  
Quite active on social media, use FB and Twitter – FB for patients, Twitter for influencers

Publish different articles and share experiences of patients

Untreated AF is just like Russian Roulette!!

Magazine published twice a year in Latvian and Russian

Do editorial tv work too – Inese and neurologist on tv interviews

Leaflets, flyers etc

Test FAST – ATRI

## **Self management and prevention programmes on the internet**

### **Ville, Finland**

- Presented on their stroke awareness campaign
- Objectives – raise awareness of hypertension is the most common risk factor for stroke, regular bp tests, lifestyle modifications, measure over 10k people's bp via 100 measurement points – exceeded all targets by 20%
- Media and experiential implementation
- Link brain health to CVD e.g. bp
- Fabulous infographic for the link – bicycle pump to inflate the brain!
- Won WSO Best campaign in a high income country 2015 award
- 2016 – Can do even better e.g.
- Social media add-ons and website as a hub
- Upping the broadcast media channel activities (radio and tv)
- Build calculator for measurement points onto website

## **BoS Report – Research Update**

### **Jon**

SAFE EU Proposals

Per previous meeting reports

BoS Indicators – point 3 is key for us

What about secondary prevention? In the box currently called primary, title will be changed.

How best to decide how to handle?

There will be two days to discuss.

Would be good to have paper early and in advance.

Everyone will know what the indicator areas are in advance for discussion so organisations can come to Amsterdam with an organisational point of view.

Jon: Should we have the researchers presenting their findings – 16 indicators, 16 presentations.

What will be the discussion? What recommendations would SAFE like to make to the EC on the basis of the findings that have come through. Basically what's the call for action.

How decide the specific calls for action. Have around 80-90 delegates from stroke associations, break into working groups of 20 each, have researchers present on four topics to each group, have those groups discuss, present conclusions back to the whole group and then vote on that without going into detail for each individual presentation.

Get a venue big enough with meeting rooms.

How do we decide who discusses what – by level of interest etc. No more than one person from each organisation per group. SAFE board should allocate who goes into what group.

Support for event organisation? TBC

Working Conference, delegates and researchers, come up series of broad level recommendations

What's the next stages?

Should we send the draft round or say that's the job of the SAFE board to look at the detail of the draft?

Arne – should be the job of the SAFE board otherwise it will drag out.

Jon - Create a reference group to test the recommendations

Also need to keep it confidential so results don't leak before launch

Ville – should be one round of sharing with organisation, to access other expertise in the organisation, ensure it is as robust as possible. Send a draft version to all orgs to get input and then to SAFE board. Shot down in flames. Issue is time.

Recommendations will come out of the working groups at the Working Conference

Timeline to be given to organisations including deadline for comments

Three key outputs:

- Results doc with recommendations
- Recommendations
- Publication plan – peer review papers
- Presentation at ESO

Launch in May but when at ESO? Media launch first week in May in Brussels, ESO will be HCP launch.

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