



## Notes from SAFE regional meeting in Athens

### Jon opens with welcome

Welcome from Greek Association representatives

-Konstantinos – Welcome on behalf of the new patient association

-Alexandros – On behalf of Hellenic Neurological Society – both a University Professor and a stroke survivor, both his parents died of stroke

What is self-management of stroke?

-Harriet Proios – speech therapist, first person in Greece to create support association for aphasic patients, included in the new society Alliance

-Athina – neurologist on the board of director of Alliance

-Anna – neuropsychologist and has worked with many patients

-Harriet

- Hellenic Alliance first organised in April
- Why information is important to the role of stroke care professionals
- Woodrow had a stroke and couldn't communicate his desire for US to join League of Nations, Lenin had a stroke and couldn't communicate his desire for Trotsky to succeed him instead of Stalin. Stroke impact has changed the course of history!
- Group treatment benefits over individual therapy helps with relearning socialisation skills
- Patients seem to like online social support groups even more than live (more flexible)
- Documentary 'my beautiful broken brain' recently on Netflix
- Aphasia team has a wide range of international experience including working in US and Zurich before forming in Greece, Thessalonika
- 'Get together and your problems will disappear' – peer reflection, maximise motivations, analyse one's own values for serving community, improves quality of care and communication

- Awareness of aphasia – self representation within legal framework for public workers, firefighters and banks etc.
  - Key issues and challenges to growth – ‘Greek factor’; lack of history with group support; challenges in unitary healthcare BUT
  - Strengths – professional skills, great network
- Athina
- Role of stroke care professionals to organise patient support groups and achieve active participation
  - Multi-disciplinary team including psychologist, occupational therapist (everyday living activities), speech therapist and social worker (practical daily needs)
  - Cardiologist manages AF patients
- Anna
- Role of peer to peer support for stroke survivors
  - Peer support associated with decreased loneliness, enhanced social functioning, emotional and informational support both for themselves and other survivors
  - Talked through mechanisms of peer support (Aims and Mechanisms of Change)
  - Positive impact all round
  - Partnership = success
  - What does peer support mean for you?
- Q&As

Jon catalysing discussion: SSOs largely driven by needs of patients and their families. What is the role of SCPs in aiding patients and their families to self-manage so they are independent of SCPs in the long term?

Goal is curative and to integrate stroke survivors into the community

Raise awareness of lay people so they accept the patient into the community and overcome prejudices against them

Life after stroke is a new life for the patient but the SCP has lots of experience and can help the patient understand it

Foster membership of something bigger than the individual

Peer to peer – learn from experiences of other people who have had stroke

Link doctor and Stroke Support Groups – how can they connect patients as they go through the system

UK SA could make training programmes available to other groups around Europe

How many organisations place information in the stroke care units?

### **Presentation from Israel on Stroke Clubs**

#### **Pnina**

-600 members from 16 clubs for survivors and their spouses (either together or giving free time to spouses)

-4 hours a day, exercise, workshops

-Need to reach more people and attract more stroke survivors

-How to combine the experience with the real needs of the people

-What is it that people want from their stroke groups and make them want to attend them?

oTry something new plus surveying people

oIssue of different age generations in the same group is universal across Europe. Consider different groups to reflect different interests

oMaybe don't call it a 'stroke group' but something else like a 'cinema club'

### **Presentation on Reaching Out**

#### **Eli from Catalonia**

-I am a stroke survivor, not a patient!

-After writing a guide for the stroke survivor, Eli asked herself the million dollar question; now what? I was a lawyer but I couldn't do it anymore

-So we started the Foundation

-Developed a campaign using UK FAST model – in Catalan RAPID

-Used website, Facebook page

-Not ideal to reach patients when in the acute stage, as they just want to recover and leave hospital!

-Follow up after the event

-Visit specialised rehabilitation hospitals

-Speak with caregivers and patients

- Started local patient organisations in each major city in Catalonia
- Develop a telethon as a very significant source of funding
- ICTUS Foundation acts as umbrella providing national campaigns and supporting research, plus it then gives each local association concrete support in their territory
- Wide range of quality services and activities e.g. rehab, counselling, leisure activities
- Showed that stroke survivors can do the same as anyone else

## **Supporting Supporters and Volunteers**

### **Nicoletta and Francesca from Italy**

- Have done a lot for patients' rights, now also want to be doing more for carers' rights
- Stroke has a big impact on the carers – family (spouses, children, parents, wider family, friends and neighbours)
- Lots of different kinds of support – giving medicines, networking with SCPs, helping with meals, emotional support, supervision and practical household management
- In Italy there are over 3 million (!) stroke caregivers, about half are children, a third are the spouse, 169k carers are teenagers 14-15 years old
- Give more than 50 hours a week of care, 2-3 times morbidity risk, 60% not employed, 7 hrs per day in direct care and 11 hours in supervision (average data)
- Strong case for prevention!
- ALICe conducted survey of carers in 2011, with University of Florence and a private centre for social studies Gensis
- 1,000 patients in 20 regions across Italy
- Many daughters in law caring for their mothers in law
- 60% of carers live with the patient
- Lack of free time is a huge issue
- Body weight changed in 40%
- Have mood disorders and get ill more often, seeking medical aid
- Paid carers is typical Italian phenomenon, consequence of social changes in society and lack of support from local health authorities, usually from other countries not Italy, mainly in central and north of Italy owing to socio-economic factors

-In 2011, 830 euros per month average income (plus taxes) for paid carers

-Need to care for universe of carers? What can be done?

-ALICe developed online courses for paid stroke carers

-Family Carer Act has been achieved to support the role, recognition, empowerment, rights, value of carer and their interaction with government, health services and civil society

-Needed to achieve a new law, as this is the paradigm. Can't see 'survivors' as a problem, will never get anywhere. Have to shift the paradigm by changing the law.

-Actions come from the law.

Self management and prevention programmes on the internet

Bridget and Catherine from the UK SA

-Train the trainers course originally for expert patients, became patient self management

-My Stroke Guide is the key resource since 2014-15

-Self-management; why digital? Usage stats support it

-<http://mystrokeguide.com> – digital self mgt tool for stroke survivors and their carers – focus on secondary prevention

-Developed with input from stroke survivors

-Available since June 2015, in 17 different areas of the UK as an NHS Commissioned service

-Designed to be easy to use for people with visual or dexterity impairment following a stroke

-Includes 250 videos on essential guides, constantly keeping fresh with new content

-Each guide contains an overview guide, always with a survivor/carer and HCP

-Recommended web sites for further information and recommended Apps 'tried and tested' by stroke user group

-Secondary prevention video on AF

-SA says client not patient or person

-Techniques for taking tablets, Tupperware kept in socks drawer

-Looked at feedback and these resources have massively increased confidence, 'it's like an extra friend', 'helps to cheer me up'

-Future developments

-Free access digital tool to all stroke survivors in 2017

-Increased confidence in life after stroke

-Will have around 400 videos eventually!

## **SAFE Research Update and the Burden of Stroke Report**

### **Jon, SAFE President**

-Update on the report and its value as a powerful political document to improve stroke care across Europe

## **SAFE round up of activity**

### **UK**

-Go Purple for Stroke: purple becomes synonymous with Stroke (like pink for breast cancer). Also consistency for branding across materials sharing if all in the same colour, avoids redesigning etc. SAFE logo has changed from blue to purple.

### **Italy**

-Policy Awareness Activities including AF awareness with Rotary Clubs, and another initiative on a bill on AF – lots of AF focused activities (6 or more)

-They have an amazing campaign of activities! Really impressive.

### **Portugal**

-There are some other patient support groups but not many

-Conducted national meeting with 55 participants (16 stroke survivors) with multidisciplinary participants

-Three Mutual Support Groups in preparation across different regions in Portugal

-Expect the birth of a national association by the end of the year

-With clear objectives and goals, activity plan and website and presence on social networks, as soon as officially constituted, a member of SAFE!

### **France**

-France AVC Federation Nationale

-Post stroke they are often depressed, Asclepius is not with them (Roman god of medicine and healing)

-46 entities spread throughout France

## **Malta**

-Pleased to attend

-No stroke units – the patients mixed with other neurological patients

-In acute hospital, will have a small unit for stroke patients but don't have a dedicated stroke specialist, general neurologist only

-Want to develop an information booklet for stroke survivors

## **UK**

### **Arni**

-Lottie and Abbie – volunteers for Arni

-Running a fundraiser to create a centre in Lingfield for rehabilitation

-Arni is a rehab / recovery charity using physical support and exercise

-They have 67 instructors throughout the country and want to have any stroke survivor to be within a 5 mile radius of a physical instructor

### **Spain**

-Veronica, Monica, Carmen

-Working on supporting members of association

-Economic and financial problems impact their members

-Every year they run a campaign on stroke prevention, held an international meeting for SAFE members

### **Miguel**

-Relationship between SAFE and ESO

-Working more closely together to include the patient perspective in ESO activities

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