Stroke association
Scotland Stroke Assembly
Conference 2016

15 March Jon Barrick
Twitter- @jonbarrick1
Stroke a growing Global Problem

- Stroke is number one cause of long term severe disability
- Stroke is second biggest killer in world
Figure 92 World map showing burden of cerebrovascular disease (DALYs) (age standardized, per 100,000) (5).
Stroke Care in UK was inadequate in 2000

Year 2000

• Few Stroke Units
• Less than half people getting proper stroke care
• Low funding of stroke research
• Public not aware of stroke
The percentage of patients by country who had a CT brain scan before randomisation in the IST

Weir NU et al. Stroke 2001; 32: 1370-77
Research funding for stroke in the UK

Charitable research funds 1998/99 (£ millions)

Lancet 2001;357:1612-16
Voluntary Sector 2000

• Stroke Organisations did not exist at UK, European level and at world level had 2 competing bodies
• Cancer organisations were merging to form Cancer research UK
• RNIB was merging with other organisations and as bigger body they were able to drive along the disability discrimination act
• BHF UK wide drove £millions
• Stroke pitifully fragmented and weak.
Strategy 2004

• Get Government and NHS to take stroke seriously
• Get public to understand what a stroke is and what to do if a stroke happens
• Unify Stroke sector in UK to get better care
• Create and argue for stroke organisations to work together at Europe and World level
• Get more stroke research happening
The Stroke Alliance for Europe (SAFE)
The beginning.....

In 2000 no European coalition of stroke organisations. The Stroke Alliance for Europe (SAFE) was formed in 2004 formed by 8 Stroke Patient Organisations,

• to put forward the case for effective stroke care,
• awareness,
• prevention
• research activity within the European Union.
First stop, the 530 Stroke clubs

• A network of affiliated Stroke Clubs that individually feel supported and valued by The Stroke Association, and that are working with the organisation to achieve a range of common goals.

• Started annual stroke club conference
Speechmatters merge with Stroke Association 2006

Northern Ireland

Challenging Stroke Across the UK
1st UK Stroke Forum Conference

07-08 December 2006

Harrogate International Centre

Sponsored by

- sanofi aventis
- Bristol-Myers Squibb
- Boehringer Ingelheim
- Pfizer
- AstraZeneca
- Genzyme
survivor told us that she could hardly speak at all initially after her stroke, but that attending an aphasia group had helped her enormously (Case Study 9 overleaf). The Stroke Association provide this kind of support to around 4,000 people a year, which is around a fifth of the number of patients that are discharged with a continuing need for therapy addressing communication problems.

2.18 Voluntary organisations can promote alternative but effective support through events and groups, rather than on an individual basis, and so can deliver services at a significantly lower cost than the nearest comparable type of service provided by the NHS. An external
Suspect a stroke? Act FAST. Call 999.

Facial weakness
Can the person smile? Has their mouth or eye drooped?

Arm weakness
Can the person raise both arms?

Speech problems
Can the person speak clearly and understand what you say?

Test all three symptoms

Stroke is a medical emergency. By calling 999 early treatment can be given which can prevent further brain damage.

Stroke helpline: 0845 3033 100  www.stroke.org.uk
In Scotland
Stroke
Association open
office 2007 in
Edinburgh,
Campaigning progress in England and Wales, as Stroke moves close to Priority one. Welsh Health Circular 2007(058), “confirms that tackling stroke is now one of the Welsh Assembly Governments top priorities”
UK Stroke Assembly

gathering together stroke survivors

Scotland Stroke Assembly

Hosted by

Stroke Association
A new era for stroke services is dawning (2007)

The environment with regard to stroke has changed dramatically since the concept of stroke units was promoted in the NSF for older people in 2000.

With the publication of the Stroke Strategy in December 2007 our task is to drive forward the implementation of practical systems along the whole care pathway to ensure we deliver effective care and support to stroke patients and their families.
Together we are stronger

SAFE
Stroke Alliance for Europe

Stroke Alliance for Europe
Together we can improve things faster
European Stroke Awareness Day
2nd Tuesday in May

• Make May Purple
• Person to be recruited offers chance for central co-ordination
• Each European Country raises stroke awareness in May
Coverage highlights

‘After my stroke, I might have killed myself. Paula saved me’

Ann Gibson’s life changed when a woman she had just met became her carer; Gabriella Swirling writes

On her 29th birthday, Ann Gibson suffered a stroke that left her severely disabled. A month earlier in 1992, Ann had met Paula Courier, 52, at a church meeting. Ann was training to be a nurse and it was only when she didn’t show up for work that people became suspicious. Paula said, ‘Poking knowingly at the door down and finally found her lying there.’

Ann, now 53, had suffered a stroke and had been lying unconscious in her flat for three days. She was paralysed down her right side, unable to communicate, and spent a year in hospital undergoing physiotherapy and speech therapy. Paula regularly visited her, read her little extracts and kept her company. ‘I just felt something within me was really touching my heart and I kept going to see her,’ Paula said.

Ann had grown to mistrust others after a traumatic upbringing in New York where she was fostered by one family who told her they were only keeping her for the money. Her youth was marred by episodes of self-harm, overuse and suicidal thoughts. Paula, of Cramlington, Northumberland, said: ‘One fact she would just turn her back on me because she was so used to rejection. But I think going to church eventually she began to talk to me – with her股指升降 because she could speak at first – and she began to relax.’

Even superfit gym bunnies have strokes

Jackie Ashley

My husband suffered, as have many others since. With a few checks we can reverse this awful trend

I was shocked in the morning and my husband, the broadcast meteorologist Andrew Marr, has just finished yet another gruelling photo opportunity session. It’s more than two years since he had a major stroke, at the age of 55, but the long, slow path to recovery seems endless. With four sessions a week, every week, he makes small advances, though he still walks with a stick and a left limp, and cannot use his left arm.

He is fortunate, because in the early stages, he can still walk, whereas some acute strokes can occur, and with a regular exercise programme, there may be no reason not to check blood pressure. And in Andrew’s case, he regularly runs eight miles round Richmond park, and was not overweight, so it never entered his head to check his blood pressure.

For him, it was over-exercising that caused the stroke. An intense session on a rowing machine caused a fatal artery to tear. Autism is a surprisingly common cause of stroke, we have seen stroke survivors with autism.

Stroke of Inspiration

Woman’s Weekly

Every year, the Life After Stroke Awards throw up zing stories of people affected by stroke. Here celebrate the awards’ inspirational effect on stroke survivors

Robots to help treat stroke patients

1 July 2014 Last updated at 06:17 BST

More than 150,000 people in England have a stroke every year, making it the largest cause of adult disability in the UK.
World Stroke Organisation

- Established October 2006 through merger (of the International Stroke Society and the World Stroke Federation)
- Today, WSO has more than 2000 individual members and over 60 society members from 85 different countries.
Run World Stroke Day, October 29 each year
Run World Stroke Congress every 2 years, now incorporating sections on growing stroke support organisations
www.world-stroke.org
United Nations
Global Health conference on non-communicable disease, World Health Organisation April 2011

Worked to get World Health Organisation to shift emphasis from communicable diseases to non communicable diseases such as Stroke.
United Nations in October 2012, Stroke is built into new global agreement on Health
The non communicable Diseases framework

- Stroke is a priority
- Has targets against most of the risk factors for strokes
- Accepts the need for specialist stroke care units
Lack of Stroke policy or strategy relates directly to poorer health and worse outcomes
Figure 92  World map showing burden of cerebrovascular disease (DALYs) (age standardized, per 100 000) (5).
Stroke: made progress

30 Day Mortality Over Time

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<th>% of patients who died within 30 days</th>
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Length of Stay Over Time

- Patients who died in hospital
- Patients discharged alive

Year of Audit

Year of Audit
Stroke strategies introduced in NHS from 2007 onwards
Advances

- In England, Wales, Northern Ireland, Stroke association services now available to 50% of stroke survivors and their families through referral from NHS
- 24/7 access to thrombolysis organisationally now in latest SSNAP audit
- Access to stroke units is now standard care
- Nursing levels up from 8 per 10 beds(2012) to 9 by 2014
Welcome to Speakability

Speakability and the Stroke Association Join Forces

Speakability, the national charity supporting people with Aphasia, is set to merge with the Stroke Association from April 2015. The merger is part of ambitious plans to ensure more stroke survivors across the UK living with the communication disability receive vital support.

Melanie Derbyshire, Speakability Chief Executive, said: “For those who have Aphasia, every aspect of their day-to-day life and relationships are likely to be negatively affected.

When Action for Dysphasic Adults (now Speakability) was formed by Diana Law 35 years ago, there was little or no provision for people living with Aphasia. Now much has changed, in no small part due to our campaigning work and our national network of local Self-Help Groups.

Whilst stroke is not the only cause of Aphasia, it is by far the biggest single cause. Our merger with the Stroke Association will enable us to direct finite resource to reaching and offering support to many more of the estimated 400,000 people in the UK living with Aphasia as well as their families and carers.”
Together we can conquer stroke
Strokes, what does the future hold?

- It is often said there are two types of forecasts… lucky or wrong!!!!

- “Prediction is very difficult, especially if it’s about the future.”
UK Stroke Mortality rate halved, what’s the problem?

• over the next 40 years the population over age 45 is expected to increase by more than 50%.

• Among those over 45, the proportion of the “oldest old” will approximately double, and the ethnic minority representation among those over age 45 is expected to substantially increase.
Projection of the distribution of incident stroke events for the years 2010 and 2050, shown by race/ethnicity and age (for ages 45 and over). This projected distribution of incident stroke is the product of the shifts in the population (see Fig. 1) and estimates of stroke incidence (see Table 1).
Aging Population, now add Obesity?

• **increasing obesity** and comorbidities could reverse these declines in stroke incidence

• Increasing prevalence of obesity (i.e., the “obesity epidemic”) will lead to **increased prevalence of hypertension and diabetes**, with increase in vascular disease and **stroke** in particular

• By the year 2050 the number of stroke events will expand by 2.25 times to a total of 337,000 stroke events per annum in the UK.

• In addition, over one-third (34%) of the stroke events will occur above age 85, and nearly two-thirds (66%) will occur above age 75.
Stroke Prevention: do we do what we know works?

Lifestyle Advice

Treat Blood Pressure to target

Detection and management of Atrial Fibrillation

Detection and management of diabetes

Detection and management of hyperlipidaemia

Avoidance of air pollution

Sleep Apnoea
Silent Strokes

- Routine brain scans in a group of middle-aged people showed that 10 percent of them had suffered a stroke without knowing it, raising their risk for further strokes and memory loss, U.S. researchers said.
- 5x as many silent strokes as Physical effects strokes
- People with atrial fibrillation, the most common type of irregular heart beat in people over 65, had more than twice the rate of these silent strokes, they said.
- Silent strokes associated with memory loss, cognitive decline, the hidden effects of stroke
- Up to 80% of Dementia attributable to stroke

Read more: [http://www.dailymail.co.uk/health/article-1029992/One-10-people-silent-stroke-study-says.html#ixzz3o5aVgtbn](http://www.dailymail.co.uk/health/article-1029992/One-10-people-silent-stroke-study-says.html#ixzz3o5aVgtbn)
Stroke, Dementia, Alzheimers

- Compared to Alzheimer's disease, which happens when the brain's nerve cells break down, stroke related vascular dementia happens when part of the brain doesn't get enough blood carrying the oxygen and nutrients it needs.
- Stroke takes out parts of the brain whereas alzheimers damages the cells.
- 80% of dementia relates to stroke damage.
- Researchers talk about the “knot of confusion” which requires a much greater understanding of the overlap between Alzheimer’s disease, vascular dementia and stroke. We cannot study them separately any longer.
- Greater collaboration between these disciplines is needed before we can untie the knot completely.

http://blog.wellcome.ac.uk/2012/05/23/focus-on-stroke-the-tangled-knot-of-dementia-and-stroke/
Thrombectomy or Mechanical extraction of clots

• WSO President Prof. Stephen Davis noted “organised care in stroke units and the selected use of intravenous tPA (Alteplase) are the standard of care for ischemic stroke presently.

• However, the new information presented by these trials represents a paradigm shift in the treatment of ischemic stroke, on top of best available therapy.
Have we enough Medics and therapists?

- 26% vacancy rate for stroke Physicians, Not enough Nurses, not enough Psychologists.

- Lack of planning to train stroke Physicians and specialist staff to care for the doubling of stroke patients will offer remarkable challenges.

- **Parliamentary report** Stroke Mortality rates fell, owing in part to improved acute care and better control of risk factors. It is projected that there will be extra stroke-related deaths per year by 2020 because of expected increases in population size, lifespan and the prevalence of lifestyle choices that increase the risk of a stroke.

researchbriefings.files.parliament.uk/documents/...PN.../POST-PN-459 Feb 2014 Stroke
Childhood stroke

- Few specialised units
- Different aetiology to adult stroke
- Recurrence rate high
- Transitional issues into adulthood
- Urgent need for research
- May need national or international consortia of researchers to achieve numbers for studies
- SA supporting update of national guidelines for childhood stroke
SAFE members cover most of Europe now
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Ambition to be part of EU Health Forum

To do this have to pass the tests of:

• Being a non-governmental grouping of patients' organisations
• Competently Covering a broad range of issues, prevention, research, treatment,
• Having member organisations in all or most EU countries, (have scale and sustainability)
SAFE Campaign to 2017

• State of stroke care in each country of Europe (Burden of Stroke)
• Useful to know for each country
• Essential to know for influencing European community activity.
• Building Partnerships with funders
• Commission some Universities to produce report
• Presentation to media and EU, at local and euro level
Stroke Association

My Stroke Guide

My next appointment
No upcoming appointments

Welcome
Sophie

0
Messages

My favourites

News

All media

Essential guides

My social

My goals

My area
To achieve we need Supporters, more the better

• Where are we going to get them?
• How do we inspire them?
• How do we use our limited resources to best reach, engage with, and convert people to our cause?
Stroke association
The changing world of Stroke care and activity

• Better care needs to be established across europe, new treatments are being developed, We predict this will lead to reduction in deaths
• Aging and obesity trends indicate number of strokes occurring each year will rise in future, so need for more trained stroke care staff. Probably will not be enough staff
• self management will be very important, within a system that reduces demand on paid medical staff.
• Therapies and augmentative activity overseen by professionals but delivered or participated in outside hospital and often in the home. More peer to Peer support
• The psychological and cognitive impact of stroke will become more understood, opening up need for emotional and corresponding support activity.
• Connections between dementia and stroke will become more understood, stronger possibilities of joint work with dementia and alzheimer organisations.
• Information increasingly delivered digitally
Research team write new Strategy and win highly commended award from Association of Medical Research Charities
Ambition to get Stroke Care Professionals to support growth of Patient organisations

- Stroke Care Professionals must be persuaded to support the growth of Stroke Support Organisations.

- Must be persuaded to lend their names, time, money and networks, and to be on board.

- To make information on stroke support organisations available in stroke Units.
Gala Ball in Belfast is another success, followed by us winning Best medium charity award in N Ireland 2008