

Briefing for Scottish Parliament Members' Debate: Stroke Care in Scotland

June 2017

About Chest Heart & Stroke Scotland

- We help improve the quality of life for the increasing number of people in Scotland living with long-term conditions – 500,000 people are affected by chest and heart conditions and stroke – some 10% of Scotland's population. These are Scotland's biggest killers, the biggest cause of disability, and they affect more people than cancer.
- We are uniquely wholly Scottish, and receive no funding from Scottish Government. Most of our income relies on fundraising, retail, legacies, and trusts.
- We put people at the centre of what we do not their health conditions asking what matters to them and providing them with the support they need to reach their goals and get their lives back after a life changing illness. We do this by funding 100 staff to provide advice and information and direct support in the community which helps people build their confidence to manage their condition.
- We work locally with health boards and local authorities, and nationally with the NHS and Scottish Government.
- Our specialist Advice Line nurses run our free, confidential service providing information and advice to families, carers, service users, health and social care professionals.
- We rely on our 1,500 volunteers to deliver services and fundraise for us and we are the largest national organisation to date to be re-accredited with the Quality Award Investing in Volunteers.

Stroke in Scotland

Key points:

- Whilst mortality rates continue to decrease, the numbers of people living after a stroke continue to increase. More people than ever are therefore needing long-term community based support, which the NHS cannot provide.
- Stroke is the biggest cause of disability, and its impact is on both physical and mental health, leaving people at risk of anxiety, depression, social isolation and loneliness.

- The shift by the Scottish Government and the NHS towards self-management within communities is very welcome, however must be matched by investment. Charities like Chest Heart & Stroke Scotland are key to the delivery of that support, but are challenged by the availability of resources.
- National statistics show a continuing long-term **downward trend in Scotland's mortality** rates from stroke which is welcome and reflects the medical advances made over the last generation. Over the decade up to 2016, the mortality rate for stroke decreased by 39% [source ISD Scottish Stroke Statistics Jan 2016].
- The challenge now is that more people than ever some 124,000 in Scotland are living with the long-term effects of stroke, around half with a disability. With an ageing population, this will continue to increase.
- 3. The NHS is able to treat acute incidents and keep people alive after a stroke, however many people are now living with the effects for the rest of their lives. Stroke is the biggest cause of disability in the UK. These effects are often physical but sometimes disabilities are not visible, with communication difficulties, cognitive impairment, and fatigue all being significant health impairments after stroke.
- 4. A recent study by King's College London estimated that incidents of stroke will increase in the UK by 44% by 2035, largely due to our ageing population (compared with 34% across the rest of Europe) [source: Burden of Stroke in Europe report]
- 5. With stroke being the biggest cause of disability, there is ever greater need for ongoing support in the community which provides rehabilitation, long-term support, and maintains people's wellbeing, both physically and mentally. The impact of the life-changing effects of stroke cannot be underestimated and without ongoing support people are more likely to be readmitted to hospital and visit their GP more frequently.
- 6. Once people return home from hospital they can often feel 'abandoned' by the system, with very little dedicated support. Third sector organisations like Chest Heart & Stroke Scotland play an increasingly vital role in providing community support, at a time when the NHS is under greater pressures than ever before. The Government's strategic shift is quite rightly away from acute care and towards communities and people being able to live full lives at home, but there need to be support systems or pathways in place within communities to meet that aspiration.
- 7. The services Chest Heart & Stroke Scotland provides include specialist stroke nurses in some health board areas, a national Freephone Advice Line staffed by nurses; one-to-one community based support for survivors; peer support groups across Scotland's communities; communication support for people living with aphasia (communication difficulties after stroke), web-based resources including <u>SelfHelp4Stroke</u>, <u>Stroke4Carers</u>, stroke education training, and health information and advice at <u>www.chss.org.uk</u>

- 8. In six Health Board areas Highland, Grampian, Fife, Lothian, Dumfries & Galloway and Lanarkshire Chest Heart & Stroke Scotland work in partnership with the Health Board (who provide at least 50% funding) to provide specialist stroke nurses. (Several other health boards do provide stroke nurses, but the scope of their services is more limited.) Our stroke nurses support people in the transition from hospital for up to a year, visiting them in their homes to provide the support people need in order to regain their lives. We ask that more health boards support us in providing stroke services across the country, to help reduce the 'postcode lottery' of care and support.
- 9. In Scotland, Scottish Stroke Care Standards (2013) and the Scottish Stroke Improvement Plan (2014) set the standards for stroke care, with challenging targets against which the regional Health Boards are audited each year. Responsibility for delivery of the standards lies with the CEO of each Health Board. Scotland's rural geography and dispersed population in some areas also clearly impact on the availability of, and timescales for receiving, some clinical care.
- 10. With the integration of health and social care, within the third sector we are finding it increasingly more challenging to respond to local commissioning processes, at a time when funding is also diminishing and there are pressures to maintain resources for acute care instead of investing in community-based care. In responding to these circumstances, in some areas we are having to reconfigure the services we provide due to funding restrictions, whilst endeavouring to reach the maximum number of survivors
- 11. There are particular **challenges for stroke survivors in keeping active** when they return home to improve recovery, wellbeing, and aid secondary prevention etc. There are a number of barriers to this which include insufficient referrals from GPs to exercise maintenance, lack of suitably qualified exercise instructors who specialise in support for people with long-term conditions, difficulties with physical access, transport, and communication difficulties, in addition to fluctuating health and fatigue. Chest Heart & Stroke Scotland support groups across the country aim to address these where we can.

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