

Minutes: Cross Party Group on Heart Disease & Stroke

Tuesday 4th June 2019

Topic discussion: Aphasia

Attendees

Alexander Stewart MSP (Co-Convener)
Colin Smyth MSP (Co-Convener)
Katherine Byrne (Secretariat)
Mark Smith, NHS Lothian (speaker)
Paul Hodson, Stroke survivor (speaker)

Fergus Doubal (NHS Lothian)
Philip Heritage (CHSS)
Sarah Vivers (CHSS)
Kristina Link (CHSS)
Brian Jackson (Stroke survivor)
Carole Jackson
Allan Cowie (CHSS)
Jacqueline Slater (CHSS)
Christine McAlpine (NHS Greater Glasgow & Clyde)
Karen Garrott (Stroke Association)
Wendy Davies (SLT, NHS Greater Glasgow & Clyde)
Alison Bain (SLT Renfrewshire)
Joe O'Neill
Margaret O'Neill (Stroke survivor)
Roslyn Todd (SLT NHS Lothian)
Hazel Moore (SLT NHS Lothian)
Kay Anderson (SLT NHS Lothian)
Saskia Dade (SLT)
Lorna Nicholson (SLT)
Anne Feist (SLT)

1. Welcome and apologies

Co-convenor Alexander Stewart (AS) welcomed everyone to the second Heart Disease and Stroke Cross Party Group (CPG) of 2019. AS thanked all the speakers, noted that Fiona Campbell, one of the planned speakers had been unable to attend and thanked Mark Smith for speaking at short notice.

2. Minutes of the last meeting

The group last met in March, the topic was air quality and three Cross Party Groups came together to discuss this issue. The minutes for this meeting will be made available on Scottish Parliament website on the Heart Disease and Stroke CPG page.

3. Topic discussion: Aphasia

Co-convenor Colin Smyth (CS) also welcomed everyone and introduced the 3 speakers: Katherine Byrne, Paul Hodson and Mark Smith

Katherine Byrne, Chest Heart & Stroke Scotland: Overview of aphasia

- Around one-third of stroke survivors are affected by aphasia, when the communication centres of the brain are damaged by the stroke. As a lifelong hidden disability, aphasia can be extremely isolating.
- Importance of receiving support to self-manage and cope with aphasia.
- Issues with availability of regular speech and language therapy.
- Current recommendations in Scotland are that speech and language therapy should be provided two hours a week for 6 months, contrasted with England's recommendations for 45 minutes each day.
- Chest Heart & Stroke Scotland have communication support resources including a new Talk With Me app, communication rehabilitation support, and a pilot aphasia café in Edinburgh. Training about aphasia is available for health and social care professionals including online resources STARs (Stroke Training & Awareness Resources) and that education was needed to make communities aphasia friendly.
- CHSS are campaigning for a Right to Rehab - everyone with a communication difficulty should get access to communication support.

Paul Hodson: A stroke survivor's experience of living with aphasia

- Paul had a stroke in 2007 after a triple bypass, and subsequently received speech and language therapy.
- He was unable to continue working, and now volunteers with Chest Heart & Stroke Scotland and at a speakability group run by the Stroke Association, as well as volunteering with British Heart Foundation.
- Paul described the daily impact of living with aphasia, such as his difficulty understanding spoken numbers, for example travel announcements about platform changes or delays. There are simple steps which can help, for example if he is attending a conference, to receive all the presentations in advance.
- Paul gave examples of the improvements he had made and his experiences with aphasia over the past 12 years, including the adaptations he uses such as mobile apps.

Mark Smith: NHS Lothian AHP consultant in Stroke

- Mark outlined his work on supporting improvements in stroke rehabilitation, and that access to rehabilitation is a human right.
- Priority 7 of the Scottish Stroke Improvement Plan (SSIP) covers transition to the community and priority 8 covers supported self-management. Currently all 14 health boards self-rate their performance when benchmarking themselves against these priorities. The SSIP highlights that access specialist clinical neuro-psychological services for stroke survivors is lacking. The Information Services Division of the NHS (ISD) and other partners were looking at ways to get better data that was not self-reported such as capturing data about stroke

survivors who receive 45 minutes of rehabilitation a day in hospital. Stroke care pathways for all 14 health boards will be published online in due course.

- There is a need for more community rehab tailored to survivors' needs. The SSIP should be more closely correlated with the Sentinel Stroke National Audit Programme carried out in the rest of the UK. New hyperacute medical interventions will result in greater numbers of stroke survivors which will increase demand for rehabilitation.

Roundtable Discussion and Questions

- **Question:** Can carers get more training in supporting people with aphasia?
Responses: Local carers support such as VOCAL in Edinburgh and Midlothian could provide support but this was not specific for carers of people living with aphasia. Speech and language therapists would love to work with carers but have limited resources. The community speech and language services are quite stretched. Online resources such as CHSS' Stroke4Carers are available.
- **Question:** Do you see the opportunity to deliver high dosage therapy of speech & language therapy in the community and is there evidence that early intervention makes a difference?
Responses: Yes, the benefits of early intervention have been demonstrated. There is also evidence that interventions later on make a difference. An example was given of an intensive communication support programme (ICAP) which has been delivered between CHSS and the NHS in which people with aphasia received 30 hours of speech and language therapy a week in the community. Queen Margaret University (QMU) also runs a similar intensive programme. Provision for therapy can vary depending on where a person lives and a basic standard is needed across all of the health boards in Scotland.
- **Question:** Is it common that if a stroke survivor can walk then they are discharged from hospital, despite there still being non-physical challenges such as communication difficulties?
Responses: People with communication difficulties are not being kept in hospital, where regular speech & language therapy is most available. Once returning home they often experience long waiting times to see a therapist. It was suggested that aphasia should have equal status with physical mobility needs when determining if discharge is appropriate.
- **Question:** How accurate is self-reporting in the stroke audit and how do health boards use it?
Answers given: There are lots of measures of acute stroke care in the stroke audit but for downstream care (post-acute) the measures are quite subjective. Representatives of the Stroke Audit visits should be asking why the health board has categorised themselves a certain way.
- **Question:** Is there a shortage of speech and language therapists?
Responses: No, there is a shortage of posts available for qualified therapists. The bulk of speech and language therapy in the acute setting is with swallowing issues and there is a small pool of speech and language therapist for this.

- **Question:** Is 45 minutes of therapy a day suitable for all stroke survivors?
Responses: The evidence suggests up to 45 minutes of therapy for those who need but this does not mean 45 minutes in one instalment is suitable for all cases. There are many patients for whom 45 minutes would be too much, and so treatment needs to be built around patients.
- **Question:** What can be improved for aphasia survivors?
Responses: Flexibility of service, breaking down the barriers between acute and community communication support and the services being more person centred. A platform for people with aphasia where their voices can be shared and people with aphasia can get together and learn from each other. Raise awareness of aphasia in the community.
- **Question:** Is there an aspirational standard for speech and language therapy in stroke survivors?
Responses: Yes, the International Best Practice Guide for Speech and Language Practice.
- Personal experience was shared by a stroke survivor with aphasia that he wants to practice talking more and finds it frustrating when people speak for him rather than waiting for him to speak.
- It was highlighted that June was Aphasia Awareness Month and that the group and the public should encourage the promotion of this.
- Members noted how beneficial it had been to bring together therapists for the discussion.

Next steps

- Action Point: The Co-Covenanters agreed to jointly write to all MSPs to highlight the importance of raising awareness of aphasia in their constituencies. They will report back to the Cross Party Group about the outcomes of that.

Date of Next meeting

The next meeting will be in September/October and the topic for discussion will be heart failure.