

Cross-Party Group on Stroke

Friday 7th October 2022, 12:30 – 14:00

Minutes

Present

MSPs

Gillian MacKay MSP [GM]
Alexander Stewart MSP
Paul McLennan MSP

Invited guests

Paula McGuire [PM] (speaker)

Katrina Brenan [KB] (speaker)

Non-MSP Group Members

Katie MacGregor [secretariat]
John Watson [JW]
Mark Smith
Margaret Mitchell MBE
Dr Christine MacAlpine
Eric Sinclair [ES]
Dr Amy Mulroue [AM]
Joanne Graham
Dr Chris Taylor
Professor Frederike Van Wyck [FVW]
Dr Fergus Doubal
Dr Terry Quinn
Sophie Bridger [SB]
Clare McDonald
Alan Flynn
Dr Leslie Scoobie
Catriona Renfrew
Dr Tony Byrne
Katherine Gillespie
Andy Wilson
Professor Lisa Kidd
Professor Rustam Al-Shahi Salman
Dr Mark Barber
Dr Jesse Dawson
Colin MacFarlane

Ian Lee
Mary-Joan MacLeod [MJM]
Dr Sarah Keir [SK]
Linda Campbell
Paul Gillen
Professor Gillian Mead [GM]
Professor Matthew Walters MBE
Dr Jackie Hamilton [JH]
Professor Andrew Elder

Apologies

Douglas Horn
Dr Matt Lambert
Dr Stephen Makin
Paul O’Kane MSP
Pam Duncan-Glancy MSP

Agenda item

Agenda item 1 – Welcome and Apologies

Chair: Gillian MacKay MSP

GM welcomed members to the meeting of the Cross Party Group on Stroke and listed apologies.

Agenda item 2 – Update from last meeting

GM updated the group on the 3 actions from the last meeting:

1. Re:write to the boards and meet with those who have been named. Link in with the MCN to do this.
2. Raise this topic with the Cabinet Secretary for Health and Social Care in August
3. Develop wider campaign into psychological care for Stroke survivors

JW provided some further insight into meeting with the Cabinet Secretary, specifically around his encouraging comments around how he believes stroke hasn’t received the attention it deserves.

Agenda item 3 – Psychological and Emotional Care for Stroke Survivors in Scotland

GM introduced the first speaker, Paula McGuire (PM). PM spoke about her experiences of a stroke which she had in November 2022 caused by a bleed on her brain. PM shared the psychological challenges that she faced and continued to face following her stroke.

Although PM has suffered with mental health challenges since childhood, all of her coping mechanisms were taken away from her following her stroke.

PM spoke about how she was surprised at how siloed psychological care is within stroke care and how it isn't yet built in as standard. PM explained how she felt mental health is weighted in a different way to the physical effects of her stroke.

PM attributes her recovery to three main points:

1. Luck
2. Strong support network
3. Her own ability to speak openly about her own mental health and see help when required

PM was very grateful for all of the light touch care she received from the stroke care staff but notes how not all healthcare staff will intrinsically know how to do that. PM stressed that it's important that it should be built into their training so everyone is given the skills and confidence to be able to ask their patients how they are feeling.

PM ends by asking that we don't separate people into psychological and physical recovery from stroke.

Agenda item 3 – Research into psychological and emotional care for stroke survivors

GM introduced second speaker, Professor Maggie Lawrence [ML], Glasgow Caledonian University

Professor Lawrence has a background in neurological rehabilitation nursing and in information science. ML's research focus is on stroke and in particular the role of lifestyle risk factor modification and stress management in the prevention of recurrent stroke. In current work, ML is focusing on mindfulness based stress reduction and yoga as means of self-managing psychosocial stress following stroke.

ML thanked PM for sharing her experiences and says that it is distressing to hear that PM is saying the same story that she has been hearing for decades. ML reiterates that we must now try to change that now.

ML highlights how important it is to bring together the mind and body. They work together and therefore should be treated together.

Yoga and mindfulness are something is often free, can be taught easily and contribute to a meaningful life.

ML talks through the preliminary findings from the HEADS-UP project. Data so far tells us that changes to people's life has been remarkable since starting mindfulness. Some people have signed up to University courses, gone back to work, trained to be mindfulness coaches. Can have profound effect. Can have positive effect on their family / friends' relationships. Whole range of relationships can be improved due to addressing psychological difficulties.

ML outlined that the study was run online and this allowed it to involve both urban and rural participants.

ML spoke about the challenges some of the researchers faced and what protocols were put in place to support those involved in the study.

ML closed her presentation but sharing the benefits of goal setting within rehabilitation and echoed what PM said about how there is so much unmet need but it [psychological care] is everyone's business.

Agenda item 4 – Katrina Brennan, Scottish Stroke Improvement Lead, Scottish Government

KB thanks the two speakers who presented before her.

KB echoed the other two presented about how this is an issue about ethos and that there must be an effort to create the right educational resources and messages to those who are delivering stroke care.

KB noted that the progressive stroke pathway initiated a review of the whole pathway and has really turned everything on its head. Used to look at rehab as an add-on to the annual review visits but now doing these visits with the Speciality Advisor, Martin Dennis and AHP leads. This has resulted in a far greater focus on rehabilitation rather than traditional audit figures. KB confirms that there will be follow up meetings to assess where improvements are needed.

KB updated how there is now a real focus around goal setting, self-management, on-going support and education across the whole pathway. The input and voice of lived experience is essential in this work and this work is being done in collaboration with the national stroke voices.

KB reaffirms how important language is. There is a huge opportunity to review how we use language and the impact it can have on a stroke survivor and their families. KB also raises how we can't underestimate how important support for carers is. The stroke improvement team are trying to draw this out in the national work.

KB closes further highlighting how psychological care is something we can all get involved with. Need to gain greater understanding of what care is currently being offered, how many psychologists are in post at the moment, what it is they offer and where the gaps are.

In terms of next steps, KB said that education is a huge next step to implementation of the model.

Agenda item 5 – Q & A / Discussion opportunity

GC – What support did you find helped your psychological health? What aspects were most useful?

- PM - Light touch stuff. I went on a waitlist for stroke psychology but took myself of it because people might need it more than me. Mental health nurse in GP practice supported me. Regularity of the meetings with the nurse really helped me. Knowing they were invested encouraged me to get better. Wasn't just stroke / neurology appointments. People around me and people knowing that I am a

whole person. Not just symptoms and not just a stroke. Consultants that took the time and asked about how I was doing mentally and physically. Hard to teach these informal things but it is so vital to recovery.

GC - People need to have a core skillset to have these informal conversations with people.

- PM - a lot of people want to ask someone how they are doing but too often they do not have the confidence or skills to be able to ask them. Not a lack of want, just a lack of confidence. Just take 5 minutes. Complete life-saver. Shouldn't be undervalued like it currently is

MJM - Looking at the Scottish Data from 2010 - 2015, one in 5 of people who came in with a stroke were on anti-depressants before they had their stroke. The rates of anti-depressant prescribing are quite high in Scotland anywhere.

Dichotomy of stroke symptoms and stroke severity. With minor stroke / TIA a lot of them have issues with depression, cognitive impairment and trouble with work. Range of issues are wide. Education that someone who looks perfectly well, doesn't mean that they are.

SB - thanked PM and how valuable her contribution is. Still a huge stigma around this and thanked her for raising it. So many common themes. Consensus developing about what we actually want stroke care to look like. We need it to be wrapped into stroke care. Ongoing – rehab, tiered approach, role of stroke nurses, peer support groups etc. Sometimes there will be a need for more specialised care and that resource must be there too. What is the opportunity for the stroke community to feed in and be a part of the revised stroke improvement plan?

- KB: The national stroke voices group have made a huge contribution to that document. In terms of it happening, that's why we do the annual reviews of the health boards – to ensure that it is happening. We now have that senior leadership identified within every health board so there will be a chain of accountability. We also talk a lot about governance at the annual review process and what the governance structure looks like within the health boards. We have engaged with CHSS about education. We have a very clear education template which outlines the necessary education that staff working in stroke care need to have. I think it goes beyond that, this is something that we need to talk about every day. We have to make sure we are pulling people into line that aren't potentially using the right language and challenge people for using language that may jar with people who have had a stroke. It is all of our responsibilities to do that. Especially patient and carers, to challenge conversations that they feel don't really help them.
- In a good place currently, we just need the opportunity and time to embed outputs of the work that has taken a lot of people the last couple of years to develop and hold the people in boards accountable.

GM: In Lothian, SK and I have developed life after stroke clinics where we get referrals from CHSS nurses from other consultants and occasionally from any GPs. The sort of things we see a lot of are a lot of post stroke pain, a lot of anxiety, a lot of fear of recurrent stroke, the low mood is very common and have conversations about suicide. Sleep is also a problem. The clinic has proved very useful for patients and they find it very useful. Q is; do you see that as part of the essential part of progressive stroke services moving forward, given there are limited resources, should we be pushing for these sorts of services or more acute intervention?

- KB – Haven't specifically talked about these clinics in the document. However, if that is how you manage this and this fits with your population then it's a really good examples that we should be sharing with other people and you should continue doing it. There are many ways of doing this, and clinics are one way of doing it. Some boards have more access to community support and links back to stroke consultants in an informal way and if that works for them then maybe that is right things for that board. It is very much up to individual boards to ensure that they are supporting people for as long as they need supported. IT's important that we don't leave this to GPs who don't necessary understand the needs of stroke patients and that we do have links back to stroke consultants and stroke specialists for that advice and support. There are a number of good examples of how best to do that and yours is a really good example of what works in Lothian.

FVW - Thanked all the speakers and for sharing personal stories. We really have a responsibility to do something with this, that this can't go to waste and that we do something now. It's a fantastic time to do something with this with the PSP. Stroke is an existential crisis. That isn't central in the training in some places. People still think about physical and mental health. We speak about holistic care but is that reflected in our practice and care with people. What are we concretely going to do about this? Is there a module that we can co-create together so that anyone that goes into the stroke workforce receives, this is essential stuff that everyone needs to learn about the informal encounters, language to use, we have stories coming in from real people. Psychological care should just be care – should not be a separate things in itself. Must be delivered with holistic care and be delivered especially within education – will take back as an action to GCU and think about what they do in their courses that involves this holistic approach of embedding psychological care within their education.

SK – Lothian experience – thing I think is really valuable is the way that CHSS stroke know about where to signpost and direct patient and carers to the right services. Services need to be accessible all the way down the line. Pleased to hear comments re: Katrina that HB can create the services that fit their population; appreciate the flexible approach. Also Lothian lead for realistic medicine, the second realistic medicine report was an empowerment to patient to ask questions of professionals rather than just receive what professionals deem them to have. Our education should incorporate this; encourage patients to challenge their professionals. Education our patients in being a co-travel on the journey rather than a recipient. How much of this is already included in education and training?

KB: Is it included to an extent in all the training in that its about an ethos. Confident that, from conversations with stroke staff, that they do get it and understand the importance to engage on this matter. But acknowledge there is a fair bit to go. Vital that we do empower people (both staff and patients) to ask the question. Might not know the answer, but I will know someone who will. Throughout the stroke community there is a real appetite to work in this way. Lots of people have done the training around psychological intervention within boards about who can deliver level 1 and level 2 intervention. There is lots of work going on in lots of different ways to achieve this. I am confident that we are getting there.

PM – every stroke staff was brilliant with me but I don't just see stroke staff. I see lots of people across the H & SC workforce. It has to be wider than stroke as we do see such a range of health care workers from across many teams.

KB: Its about how everyone is treated in the healthcare system. It's about education from the very outset.

AM: Ethos and needing to change the culture goes beyond training. As new starts come in and rotational staff come in, "I deliver 1 hour of training on awareness of psychological care" and its really limited in impact. Psychologists must be embedded within the team to allow this to be part of standard care. Shouldn't be an add on to care, it should be part of every interaction and part of this holistic model. Training and teaching is the start of this but it's not going to lead to what we hope we will achieve here.

AM noted that leadership in services is essential to help supervise and provide consultation when required.

GC echoed points that Frederike made around the need for psychological care to be a component of induction for all staff who work in stroke.

AW ES make the point that power dynamics are very important and it is not always easy to challenge professionals.

Agenda item 6 – Actions

- Launch 'Keeping Stroke Recoveries in Mind' report
- GM to lead debate in parliament on report and ask Government to respond
- Re-write to the health boards that have yet to respond