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### A word from our Chair

Welcome to the spring 2019 edition of the Scottish Stroke Nurse Forum Newsletter. The SSNF has been busy with lots of new pieces of work and campaigning since our last newsletter. There have been a number of changes in the Committee and our website has moved to a new address. [www.ssnf.org.uk](http://www.ssnf.org.uk) As part of these changes notes of meetings will be posted and we plan to introduce a new educational resource. We would value your input as members on what this educational resource should look like and what the content could be. Please feedback to me or your local committee member with any ideas you have.

We are currently planning our 2019 SSNF Conference which will be held in the Dewars Centre in Perth on the 19<sup>th</sup> Sept 2019 so save the date. There is more information on the conference later in the Newsletter.

The last 6 months has seen stroke services under scrutiny. Campaigns for a Scottish Stroke Thrombectomy Service have seen questions raised in the Scottish Parliament, in the media and on-line. The SSNF fully endorses the development of Stroke Thrombectomy Services in Scotland that are safe, fully staffed and fully funded. The SSNF as part of this development want to see the creation / development of a stroke nursing role that will support and help to deliver this crucial service. The SSNF would want the opportunity to contribute to the development of this service and to the role of the stroke nurse role in thrombectomy. Stroke thrombectomy will be one of the topics at this year's annual conference and the SSNF would hope to see significant improvement in the thrombectomy delivery for Scottish stroke patients before then.

Rehabilitation has also hit the headlines and the Stroke Improvement Day in Nov 2018 explored current stroke rehabilitation services and what rehabilitation means to those who have had a stroke. See the report on the Stroke Improvement Day later in the Newsletter.

The new National Career Framework for Stroke Nurses meetings led by Ismailia de Sousa, with myself representing the SSNF is now well underway. The framework will be UK wide and the descriptors will be based around the Four Pillars of learning in Scotland (and the equivalent in the other 3 nations) and the Elements of Professional Practice. The funding for this work is coming from the RCN and work will be completed by the end of 2019 and it is hoped that it will be launched at the UK Stroke Conference in Telford in December.

We continue to meet the aims of our 5 year work-plan and will be looking for members work on a subgroup on recommendations for Physiological Monitoring post stroke and to help roll this out once completed. If you are interested in this development please get in touch.

We know that the 2019 will present stroke nurses with further challenges so remember the SSNF is here to support and help you meet these, to lead with good stroke nursing practice, to strive to meet all of the Scottish Stroke Care Standards and continue to work to improve care for our patients and their families. Keep up the good work SSNF members.

Linda Campbell, Chairperson SSNF.



### **CHSS & Different Strokes Living Well After Stroke Event**

**11<sup>th</sup> May 2019 Dewars Centre Perth**

## **LIVING WELL AFTER STROKE**

Chest Heart & Stroke Scotland, together with Different Strokes, are holding a free one day event for young stroke survivors to talk about the challenges and experiences of living well after stroke.



**The event will include two keynote speakers and discussion workshops on:**

- The journey back to work
- Dealing with low mood
- Managing money issues and worries
- The effect on children and family life
- Keeping socially connected and active

**Date:** Saturday 11 May 2019  
**Registration:** 9.30am - 10am  
**Event finishes:** 3pm

**Venue:** Dewars Centre,  
Glover Street, Perth, PH2 0TH

The event is open to stroke survivors of working age and anyone close to them. **Tickets are free but booking is essential (see information overleaf).**



**NO LIFE HALF LIVED**

#### **What is the aim of the event?**

- To raise awareness of young stroke in Scotland
- To connect people who have survived stroke at a young age
- To share experiences and challenges of living with the effects of stroke and to work towards positive solutions
- To explore the most effective ways for young people to be supported following stroke

#### **Will it cost me anything to attend?**

No, the event is free, you just need to pay your own travel expenses. Lunch will be provided and you can let us know any dietary requirements when you register.

The two charities running the event will be paying £50 to cover the cost of each place. Please let us know if you register but then cannot attend. Your place can then be given to someone else.

For more information on the event and **to book tickets** go to [www.chss.org.uk/lwas](http://www.chss.org.uk/lwas) or call Deborah Slater on **07388 378604** or email: [deborah.slater@chss.org.uk](mailto:deborah.slater@chss.org.uk).

Please note that the event is not intended for healthcare professionals.

## Role of Activities Coordinator in Stroke Rehabilitation (Submitted by Norma Moir)

As activities coordinator for SGSU I facilitate group therapy sessions for patients at least twice a week, which include craft card and decoration making, cake decorating, jewellery making and gardening, this promotes functional and cognitive stimulation to keep the brain and mind active. We play darts, lawn darts, pool and bowling. This encourages movement, balance and exercise to retain physical ability and reduces stiffness. We sing along with music, have parties and events. This promotes social engagement and develops friendship and stimulation amongst patients and relatives. We have pampering days doing hair, makeup, manicures and pedicures. This promotes self-esteem a sense of feeling cared for and sense of value and importance. We listen to music and do hand massages. This maintains sensory awareness and encourages communication and self-expression. The activities are run at least two or three times a week. They are mostly carried out in the dining room. Hair, makeup etc. are carried out in the patient's room.



*Pictures from Christmas 2018 crafting activities. Easter 2019 activities are now underway.*

## Journal Club

So following on from the work of the Activities Coordinator in SGSU this edition of the Journal Club article is looking at the benefits of activities in healthcare settings. There are several articles relating to activities coordinators in care homes & dementia cares settings. But the article discussed here (published earlier this year in the Nursing Times) looks at the potential benefits of artistic activities in medicine for the elderly ward areas.

Local art students and student nurses at Aintree university hospital offered ward based activities including art therapy sessions, dressing up in 60s clothing and playing music relevant to the patients and wearing vintage clothing, singing and poetry reading. Ward staff were encouraged to get involved in the sessions too.

Noted benefits to patients included: Improve communications, increased sense of empowerment & a temporary relief of symptoms including pain and/or depression.

Noted benefits to staff included: less stress & burn out, improved mood, wellbeing, enhanced work environment and better performance at work.

Patients felt the therapy improved function and their wellbeing and ward staff felt the therapy increased self-management of care & quality of life for patients.

It was also beneficial to the art students and student nurses coordinating the activities as they gained valuable work experience while enhancing patient and staff wellbeing.

For further details and access to the full article see reference link below.

### References:

McNeill, E. et al (2018). Use of artistic activities on hospital wards to enhance wellbeing. Nursing Times [Online], 114 (8), Pg. 57-59. Available at:

<https://www.nursingtimes.net/roles/nurse-educators/use-of-artistic-activities-on-hospital-wards-to-enhance-wellbeing/7025172.article>

### SSNF Members Health Board Updates

#### Argyll and Bute

Current embargo on attending meeting out-with area. Submitted by Hazel Hamilton.

#### Dumfries and Galloway

We have introduced new pathway for thrombolysis and new proforma

Looking at how we are going to meet the new CT standard which has generated a number of concerns within radiology. We have been working on improving the bundle compliance and we have gone from 50% to 64% in 2018. Submitted by Christine Carter

#### Fife

Stroke MCN has gone through its first joint annual review process with the other local MCNS and Clinical Governance. Quite a lot of work/documentation required from each MCN. Still awaiting formal feedback.

Our local FAST campaign so far has visited high schools in both Kirkcaldy and St Andrews with over 1400 pupils teachers and staff in attendance. Feedback from schools so far has been very positive (even trending on schools twitter accounts). It is currently on pause while schools have been going through the Prelims. Plan to do a 2<sup>nd</sup> round of offers spring 2019.

Our local 'Stroke Times' winter newsletter went out before Christmas. Plan to get spring edition out April time.

Lots of work continues on stroke pathway developments including: Psychology Distress management, Spasticity, Dysphagia.

Fife MCN ran a Stroke Update education afternoon (Feb 2019). The event concentrated on new developments (including pathways) within stroke services locally and nationally. Topics include: Spasticity/ Vision/Distress management/Vocational rehabilitation/ Driving/ Cognition/Personal outcomes & Good conversations/Thrombectomy. We are still to appoint a CHSS Education facilitator for Fife. Interviews planned April 2019. Submitted by Katrina McCormick

#### Highland

New system set up to meet NVC standards a few blips first of all but now starting to work well. Staffing on the Unit has been an issue. Education template / standards review shows good compliance across all of NHS Highland hospitals admitting stroke patients.- Submitted by Linda Campbell

#### Lothian

I have been invited to participate on an advisory board to discuss IPC use for peri-operative patients and how to implement a European guideline. This is in Amsterdam at the end of the month. Submitted by Trish Elder Gracie

#### West Lothian

#### Shetland

Our NHS Shetland MS Nurse has recently resigned after a long period of sick leave, so because I have covered for her off and on over many years I have been offered and accepted her 15 hour post. This means that from 1<sup>st</sup> April I will be the Specialist Nurse for Stroke/MS and MND for 35 hours per week at Band 6 which will be counted as one Specialist Nurse job. It will make life easier in some ways having one job and one Line Manager, although it will be challenging covering all three specialities each week. We still have no Clinical Lead for Stroke since Dr Unsworth's retiral, and have been unable to have Stroke MCN meetings for some time due to various staff shortages and vacancies. However I have been keeping the team informed, especially of the changes to the CT scan targets and consequently the Stroke Bundle. The Intermediate care team and Physiotherapy teams work well with stroke patients who are discharged from hospital. They are unable to cover some of the outer islands to provide this type of support and rehabilitation. Thankfully this has not been needed in recent times, and all the patients have been pleased with the level of support and rehabilitation they have received from myself and the above noted teams. Submitted by Dorothy Storey

### Western Isles

1. We are in the process of trying to re-organise and improve our TIA Clinic Pathway. Currently it is only available every Wednesdays, within the Day Hospital. Obviously this is not ideal in order to see people within the 4 day requirement. The hope is therefore to offer a Monday to Friday service. Lots of negotiations currently underway!
2. FAST campaign organised 18th - 22nd March in collaboration with CHSS, covering Lewis, Harris, Uist and Barra.
3. Further STAT training ongoing.
4. Thrombolysis Governance has been an issue, but improvements have been made, and we are now meeting once a month to review patients.
5. Referral pathway for Exercise after Stroke is up and running and proving a great success.
6. Vocational Pathway is being updated.
7. Finally, Ann and I are now Prescribers.. Submitted by Dolina MacLeod



### **Scottish Stroke Care Audit (SSCA) Update Spring 2019**

The Scottish Stroke Care Audit is continuing to provide monthly management reports to all the Health boards in NHS Scotland. We have recently began reporting on the new standard for brain imaging. The new standard is now 90% of patients will be scanned within 12 hours of arrival at first hospital. The expectation is that all patients with a suspected stroke will have CT/ MRI imaging as soon as possible after admission.

Whilst the SSCA Steering Group and the National Advisory Committee for Stroke recognise that this new standard is not as challenging as the NHS England standard of 4 hours, we feel that there is no robust evidence to support the English standard and that a 4 hour standard would be unachievable in many rural health boards, unless there is significant investment (which would be challenging to achieve with the available evidence). The enhanced standard of 12 hours would be testing for health boards but it is in line with the available evidence around antiplatelet prescribing in recently published trials.

Over the last 12 months, 79% of patients have received brain imaging in 12 hours. This annual report will measure health boards' performance against the previous standard of 95% within 24 hours, as this was the standard for 2018.

#### **National Meeting**

The SSCA national meeting will be taking place in the Suttie Centre in Aberdeen on the 29<sup>th</sup> August and I look forward to seeing as many of there as possible. We are also looking for posters to showcase some of the quality improvement work that has gone on across the country. Registration will be opening shortly.

Please get in touch at [NSS.ISDStrokeAudit@nhs.net](mailto:NSS.ISDStrokeAudit@nhs.net)



### **Implementing supported self-management:**

#### **What does it look like and what makes it work? (Research Study)**

Dr Lisa Kidd, SSNF Committee Member and Reader at University of Glasgow has recently been awarded funding from The Stroke Association for a research study to look at how supported self-management for stroke is delivered in local communities across Scotland. 'Supported self-management' is a term that is often used to describe the type of help and support that staff in community rehabilitation services offer or signpost to people when they've been discharged from hospital. The idea of 'supported self-management' is to help people to 'get on with life', to help them to feel in control and confident to look after themselves well, and to feel able to manage any longer-term effects of their stroke. Research has shown that support to help people to 'self-manage' can be beneficial for stroke survivors and their families and supporting self-management features as a key priority in the Stroke Improvement Plan. Stroke teams are currently delivering and/or working on plans to ensure that supported self-management is an embedded component of the longer-term stroke pathway, however, we know from the Scottish Stroke Care Audit (SSCA) that the type and standard of support available for self-management can vary across Scotland. In this research project, we want to look at how different factors such as geography or the organisation and structure of service provision can affect availability and access to supported self-management services in different areas. It is likely that what is suitable for, and works well, in one health board area may not be suitable or work so well in another, and vice versa. We want to find out about the barriers and facilitators that community teams experience in delivering supported self-management and what can be done to help teams ensure that stroke survivors in their local areas have access to relevant, appropriate and timely supported self-management services.

The project begins in March 2019 and will focus on four health board areas initially (NHS Greater Glasgow & Clyde, NHS Lanarkshire, NHS Highland and NHS Grampian). We have plans during the project to look at how the findings apply to other parts of the UK and we are keen to seek funding for further research to look at similar issues in other health board areas in Scotland. The project will involve interviews and focus groups with stroke survivors and their families, and a range of health and social care professionals delivering community rehabilitation services and those with a strategic remit for community-based stroke service provision. We will ask participants to 'rank' and prioritise the kinds of self-management support that is most important and relevant to them. We will also ask participants about what kinds of support works well (and what doesn't work well) in each area for helping people who have had a stroke to 'self-manage', both from the perspectives of individuals receiving or delivering supported self-management. This project will help to tell us more about people's experiences of supported self-management in different areas across Scotland. In particular, it will help identify the barriers and facilitators that are specific to local areas so that we can work with teams to develop localised guidance about what works and what doesn't work in relation to providing supported self-management for stroke survivors and their families in each area. This research, in combination with the Stroke Improvement Plan Workshops and other activities, will help to support community teams to deliver the priorities set out in the Stroke Improvement Plan in relation to longer-term self-management after stroke.

For more information about the study or if you are interested in being involved in some way, please contact Lisa Kidd ([lisa.kidd@glasgow.ac.uk](mailto:lisa.kidd@glasgow.ac.uk)).

## Antarctica Adventure

### Antarctica Adventure (submitted by Di Rennie)

I love the feeling of having a new destination where I can meet new and fascinating people and challenge myself physically, mentally, and educationally. After crossing off a good chunk off my bucket-list adventuring across the six more accessible continents I have had my heart set on Antarctica for a very long time.

It isn't exactly easy to get to and close to impossible on your own. In my head a cruise seemed to be the antithesis of everything I loved about travel. Someone else navigating and then telling me when to and what to do? There would be no going back or altering my route if I felt like it on a whim!

I booked an expedition, you can't just call this a trip because it is so much more, Antarctica!

We left from Ushuaia, the world's southernmost city and starting point of our expedition. As we slipped moorings and set sail through the Beagle Channel passing the island of Tierra del Fuego, it really does feel like the end of the world - where the great Andean mountain range finally meets the sea. Heading south across the Drake passage towards true wildness my Antarctic dream began to come true as we watched Pelagic seabirds including the majestic albatross from the panoramic open decks.

The Drake Passage wasn't the most pleasant of rides as we crossed the over the Antarctic Convergence. The biological boundary of the Southern Ocean rough seas are well documented and didn't disappoint. Despite the ships stabilizing fins my sea legs didn't hold out too well.

The South Shetland Islands are the northernmost islands in Antarctica and were my first sighting of land. This wild and beautiful island chain contained numerous landing sites with abundant wildlife and historical significance. Among them Deception Island were the flooded caldera of an inactive volcano harbours an abandoned whaling station. Between 1912 and 1913 alone, according to estimates about 5,000 whales were killed and processed in the regions. However, in just over 20 years all the whales in the South Shetland Islands were wiped out and the station eventually closed in April 1931. It is a timely reminder for current times when some continue to hunt them. At the top of the food chain whales are vital to the overall health of the marine environment. Unfortunately their large size and mythical aura does not protect them. Six out of the 13 great whale species are now classified as endangered even after decades of protection.





## *Antarctica Adventure continued*



Moving on further south the Antarctic Peninsula lies just 1,000Km from the southernmost tip of South America and has the mildest climate in Antarctica. Like a beckoning finger the peninsula extends to discover the unearthly beauty of the 7<sup>th</sup> Continent. The biggest thrill of any Antarctic cruise is setting foot on the frozen continent itself. Across the unpredictable Drake Passage, Antarctica's most accessible mainland contains everything one might expect to experience. You enter a magical blue-white world of hypnotic scale and beauty in which glaciers, peaks, and abundant marine wildlife vie for attention with gigantic icebergs and haunting historical sites. The Gerlache Strait area contains sheltered bays, accessible wildlife and stunning scenery. Names like Paradise Bay are the epitome of everything Antarctic: glaciated mountains, towering icebergs, feeding whales, seals on ice floes and bustling penguin colonies. At the most southern end of the Gerlache Strait lie the famous Lemaire Channel, also known as the "Kodak Gap" because of the photogenic way the mountainous sides of the narrow channel are reflected in calm waters strewn with icebergs.

By the middle of the first day I knew I was alright. The energy of both the crew and passengers was contagious and electric. I was on a boat with expedition staff full of passion and expert knowledge about the South Polar Region and 114 like minded fellow travellers.

There was no time to be bored. Each day paced with educational lectures on wild life, geology, history of the south Polar Regions and an extensive library of books. I'd recommend you put *Endurance*, the story of Shackleton's famed Antarctic voyage on the top of your list. Even the bridge of the ship was open almost all day and night with a crew happy to answer questions and binoculars close to hand.

My days were filled with memorable excursions, sumptuous meals, presentations by experts and enough incredible scenery and wildlife to fill my camera and at times overwhelm my emotions especially whilst camping. Yep! After digging what can only be described as my own grave in the ice I lay down my sleeping bag and as the sun slowly set I could unwind and let my senses fully absorb the awesome sights and mysterious sounds of this legendary wildness. The noise of the ice moaning, groaning and calving is spine-tingling.



Antarctica is like no other place on the planet with my highlights including:

- Huge icebergs
- Five penguin species, but I only managed to see the Adelie, Chinstrap and Gentoo
- Seals
- Several whale species including humpback and killer (orca)
- The Polar research stations representing several different countries exist in the peninsula regions and we managed to visit Port Lockroy (United Kingdom) on Wiencke Island and Imirante Brown (Argentina). The Chilean army even joined us for a spot of a\*se sliding behind Imirate Brown as the Argentineans were out of town. Great fun!

We must understand we all have a responsibly to protect and preserve its spectacular scenery, unique wildlife and wilderness values for future generations. Many scientific, government and non-governmental organisations work together to keep Antarctica pristine, and our own contribution to this work cannot be overestimated. British scientists began measuring the Antarctic ozone in 1956. The aim was to understand the important role that ozone plays through absorbing solar energy and in determining the temperature profile of the stratosphere and its wind circulation. These measurements lead to the discovery of the Antarctic ozone hole, providing an early warning of the dangerous thinning of the ozone layer worldwide, which has spurred international efforts to curb the production of CFC's. The provisions of the Montreal Protocol of 1987 on Substances that Deplete the Ozone Layer have since been revised and strengthened. There is a reasonable prospect that the Antarctic ozone hole will permanently repair itself, but not until around 2070.



**A personal story from a 52 year old lady admitted to stroke unit at RIE last year. Now living at home.  
(submitted by Trish Elder Gracie)**

**Reason to be a stroke nurse:**

Although not the most glamorous of medical jobs but few is more rewarding. You may end up being kings and queens of the bedpan but you will have the privilege to travel on a journey that will change people's lives hopes and dreams and see how by your daily actions, these people will improve and eventually regain what they have lost. By doing so you have the admiration for the special people you are to us. From having been one of the people with a stroke and to know how frightening this journey is with so many twists and turns, ups and downs like an everlasting nightmare.

The first couple of weeks are a blur, by week three reality kicks in and that is so scary, you realise you cannot move on one side of your body. You no longer have the ability or dignity to take yourself to the bathroom, you are easily confused, your sight might be okay but your brain isn't. Every single thing is hard work you become totally reliant on the angels who are your nurses and they are far more important than doctors or consultants. Sorry to be the doctors who looked after me but I know where my loyalty lies!

**A few pointers to new nurses:**

- We are sorry but we won't remember your name, so try to stand out, be respectful and jolly.
- We may well want to hear about what you did last night (Cinema, Pub etc.) Let's face it we no longer have a life for the foreseeable future.
- Always remember you will have patients who can have a laugh and those who can't and age does play a part in that.
- The nurses and doctors often look like they have just come from kindergarten; the generation gap is a big deal. Even if we are not really old stroke patients any more, the thought of a young man younger than our son /grandson wiping our bottom is totally mortifying.
- What we have to deal with is huge and very hard, continuity guys and I cannot stress this enough, it helps us build up trust and as a patient we really need that as we are really very scared.

Why the NHS continually changes nurses and doctors all the time we don't understand it is awful and don't get me started on new doctors.

**Doctors please:**

- Read the patient notes before you ask what they are in hospital for or can you get onto the bed when you've come from a stroke ward or you are a doctor working on a stroke ward, the clue is in the word STROKE. It is very annoying and doesn't give us much trust in you.
- Also please do not send us for investigations / procedures and not tell us what they are for, this is very bad.

**Week 3 – 4:** Meet the kings and queens of the hospital; they are of course the physio therapist and occupational therapists. I firmly believe they are trained by the SAS in another life they are however the key to your escape. Trust them, do what they ask to a point, if your body can't take anymore say it loud! It is amazing how quickly things will change once the therapists have started to work with you, also say goodbye to the laxatives when the physio starts...Hurrah! This means fewer trips to the toilet. I do have one wonderful thing to say about my journey, the thing that saved me and my sanity in the nightmare was the art therapy. This was our escape we get to do childish things to talk and laugh (very important) and sing all whilst mixing with the other patients being able to talk about our experiences. This reduces the fear and panic and if you can't do all the things you used to you will at least leave with a picture or a clay ornament to prove to your family that you are getting better before the dramatic stuff like walking kicks in. Making friends is important it encourages you and them to improve.

**The things I have learnt so far:**

- I will get better and stronger
- I have met some amazing and lovely people, patients and nurses
- My outlook and the way I will live my life have completely changed probably for the better.

# Scottish Stroke Nurse Forum Newsletter

## *Patient story Continued & Save The Date!*

### **Patients - how to survive a stroke ward:**

- Work out the rota and timetable (routine) – when you get woken up; bed changing; breakfast; drug rounds washing and dressing etc.
- When you understand the routine you will learn to slot in when nurses are more available for toileting, showers etc.
- Try to work with the nurses not against them they are there to help you and have a hard job.

The hardest time are the weekends no physio or OT. You will be bored and may get depressed; this is not helped when they (staff) keep moving you out of your room or ward etc. Continuity matters it is important to us.

### **Note to the family of a stroke patient:**

This is as much a mental illness as a physical one, as much as you are desperate to get your family person home, as it may look like they are getting better the mental side will take a lot longer than you think, please be patient. The great thing about learning to walk the first time was you were too young to remember how hard it actually was. Remember it's our brain that is injured everything makes us so tired, even you guys visiting. We love seeing you but we need three times more sleep to heal.

Family please bring in a constant supply of knickers, comfy clothes and goodies. Pears are great and help with constipation. We like our own shampoo sponges and socks, socks and more socks, a warm jumper or blanket and don't bring war and peace to read. Some magazines for an easy read and note book plus pen or diary. Some nice food we don't all like the hospital food. Bring a mini DVD player because you need to re mortgage to pay for the pay to view television at the bedside – shocking!

I'm getting bored and tired now!

Save The Date!!

**The SSCA national meeting will be on 29<sup>th</sup> August in the Suttie Centre in Aberdeen.**

**SSNF Conference 2019 on 19<sup>th</sup> September in the Dewars Centre, Perth:**

This year's theme will be 'Spotlight on Stroke'

**Early Bird** booking rate **£35** is valid until **31<sup>st</sup> July**. Thereafter cost to attend will be £50.

Bookings for the conference will open shortly.



**If you would like to have an article considered or if you have something you think would be of interest for the next Newsletter please contact: [linda.campbell8@nhs.net](mailto:linda.campbell8@nhs.net) or your local committee member.**