Report on

LIVING WELL AFTER STROKE

Gathering

Saturday 11 May 2019 in Perth
Event aims:

- To explore the most effective ways for young people to be supported following stroke
- To gather the voice of people who have had a stroke at a young age to inform us and enable us to develop meaningful services
- 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

The event included:

- Inspiration from speakers’ stories and information giving
- Focus groups to identify issues that are important to young stroke survivors
- Workshops to generate ideas that may become solutions
- Service user stories: what worked well, lessons learnt and identifying gaps in services available
- Supporting people to be physically active (seated exercise, Boccia, New Age Curling)
- People signing up to be involved with the charities – campaigning, developing services, awareness raising of health messages, etc
- The opportunity for peer support – sharing lived experience
This event was run in partnership between Chest Heart & Stroke Scotland and Different Strokes.

Seventy seven people attended in total (this figure included staff, volunteers, speakers, workshop contributors and stall holders).

Sixty people registered for the event, 45 of those attended. 45 of those registered opted in to further contact.

People travelled from all across Scotland to attend the event, including participants from Aberdeen, Kilmarnock, Arrochar, Dunfermline, Hamilton, Edinburgh and over the border from Carlisle.

For some people the distance to travel was a barrier to attending. In the future smaller regional gatherings would be better than a national event held centrally.
How did people find out about the event?

- Other (inc DS) 28%
- Word of mouth 25%
- Facebook 15%
- Chest Heart & Stroke Scotland email 10%
- Other Chest Heart & Stroke Scotland event 5%
- Event flier 5%
- Other email 3%
- Event poster 3%
Speakers:

Hearing from people about their own stroke experience was a highlight of the day for many. Debbie Matthew opened the event with an inspirational and emotional speech about life since her stroke. Debbie touched on many of the themes that then followed in the workshops such as the effect on children and family life, the journey back to work and staying socially connected.

Neil Francis closed the event with a motivational speech about his journey and how becoming a golf caddie played a huge part in his recovery from stroke. Neil emphasised the importance of learning how to deal with fatigue that follows stroke. Neil has written a number of books and more information can be found on his website www.neil-francis.com

“The highlight for me was the final speaker describing how to let go of the old you after a stroke and move on with the new you.”
Revitaliser:

There was a short seated exercise session after the first speaker. This was led by Hannah MacRae and Chris Rolland (Chris is a Physical Activity Student at Queen Margaret University, who volunteered for the event). This session demonstrated the benefits of physical activity for everybody but also highlighted the difficulty of knowing how much activity each person should do depending on their circumstances.

An important session was What Matters To You? This informed Chest Heart & Stroke Scotland and Different Strokes about what support is currently needed.

What Matters To You?

1. In terms of support you get from organisations such as Chest Heart & Stroke Scotland and Different Strokes, what parts of that support work well?
2. What are the things you wish we did? Give some detail as to what they might be and the difference they would make to you?
3. How best is any support to you delivered?
4. Out of the above, pick the most important two points you wish to make?

“I wish I had made more contacts, the time just vanished.”
Key points from this session:

1. Every group mentioned how beneficial peer support is
2. The current support that people are receiving is largely through online support and attending groups
3. This support is giving people the opportunity to build their confidence and self-esteem
4. It’s important to hear peoples’ successes and how you can recover from a stroke
5. More face-to-face support would be hugely beneficial
6. An online peer support group specifically for younger people would help
7. More networking with healthcare professionals to make them aware of Chest Heart & Stroke Scotland and Different Strokes is needed
8. Leading on from this, more marketing and promotion of our work and organisations in general is needed – some stroke survivors were not aware of us for a long time
9. Another key priority is more support for carers. This includes events that the whole family can take part in, not just the stroke survivor
10. More information in hospital would be good, and for information to be provided at point of discharge, as well as through more sources than just a leaflet. Quote of the day was “you can’t ask a pamphlet a question”
11. More help with benefits is needed
12. People need greater access to transport

Remember that Different Strokes run a closed Facebook page for young stroke survivors. Following feedback from this event perhaps a separate Facebook group would be useful for family members.
Workshops:

The five workshop topics were chosen following the results of a survey completed earlier in the year. The full report on each workshop can be found in Appendix 1. The following is a summary:

“Having time to attend ALL of the workshops would have been better.”

1. Journey back to work. Aim:

- To understand what the law says for employees and employers
- To share how people have managed their return to work

Suggested actions:

- Highlight the services offered by organisations like CAB, Access to Work, ACAS etc and signpost people there
- Increase awareness of the many different roles available within volunteering
- Chest Heart & Stroke Scotland to actively promote the use of a wellness box

Key findings:

- Discussion around ‘reasonable’ adjustments expected by employers
- Employees should suggest what would help them in terms of pacing, phased return, etc
- Make use of agencies that provide support such as Access to Work, Equality & Human Rights Commission (EHRC), Advisory, Conciliation & Arbitrations Service (ACAS)
- Seek advice from a solicitor or Citizens Advice Bureau (CAB)
- Consider volunteering as part of your journey back to work
  Paula introduced her wellness box as part of what helped her journey back to work
  (full details of Paula’s wellness box can be found in the appendix)

“Paula Leask in Workshop 1 Journey Back to Work was brilliant and inspiring.”

“A highlight was being able to swap tips, etc. with other stroke survivors.”
2. Dealing with stress, anxiety and feeling down. Aim:

- To share practical solutions for dealing with low mood, stress and anxiety

**Key findings**

- Talking to someone who has also been through a stroke
- Equally important for other members of the family too
- Feeling part of things, not an invalid
- Expressing how you feel and not holding back
- Having things that take your mind off it all – hobbies, activities, physical activity, yoga, especially yoga breathing
- Family but many people talked about how family sometimes didn’t always help as they could be over-protective or were uncomfortable if you got upset or angry
- Distraction, something to absorb your interest e.g. film, TV, reading, audio book, podcast
- Being outdoors – just watching nature or seeing the sky
- Learning relaxation techniques – belly breathing, mindfulness, massage with aromatherapy oils, listening to music and having playlists for different moods

**Suggested actions:**

- Higher profile for peer support groups across Scotland and resources like www.stroke4carers.org
- Better signposting to community groups offering physical and other activities
- Links to useful resources for relaxation e.g. relaxation Apps, Spotify, etc.
- Attend a Living Well course run by Chest Heart & Stroke Scotland
3. Managing money issues and worries. Aim:

- To leave the event with useful contact details and practical strategies to tackle any money worries including debt management and benefit entitlement

**Key findings**

- There is a huge fear of the financial impact and loss of earnings after a stroke
- Some felt they were left “to just get on with things”
- Seek assistance to complete the relevant paperwork. Citizens Advice Bureau (CAB) can help
- CAB is able to provide a range of financial advice beyond debt. This includes the Financial Health Check – a free helpline run through its network

**Suggested actions:**

- Encourage people to call the Financial Health Check free helpline on 0800 085 7145 to find out if they are receiving all the money they are entitled to, this is run by Citizens Advice Network
4. Effect on children and family life. Aim:

- To share experiences and identify practical solutions and support needed

Key findings:

- Need peer support specifically aimed at younger people who have had a stroke. Reps of that group should visit the hospital regularly to publicise themselves.
- Support should be a more definite offer, not finding out about support on a trial and error basis.
- A lot of stroke recovery is aimed at older people; it needs to be more personalised, eg. how to change a nappy one-handed.
- Negative messages from healthcare professionals are not helpful. We want to hear more constructive and encouraging messages.
- More emotional and practical support for other family members as the stroke has happened to the whole family. Peer support is important for everybody in the family, being able to share the challenges with other people who truly understand.
- Book or other resources for children telling them in simple language about how stroke happens and encouraging them to talk about how things will work going forward. Plus something to help them understand mood swings in adults who have had a stroke.
- Guidance on where to get help – online would be good and also help and support from a wide range of organisations not just one.
- Life changes in every way for the partner even suddenly being called a “carer” instead of wife/husband/partner/child. Why does that label need to be given?
- Different ways to seek help, e.g. if you live in a remote place. Travel can be a big issue so support for travel would make a difference.

Suggested actions:

- Need for peer support groups specifically for younger people who have had a stroke “I don’t want to go to a group where everybody else is 70+. I have very different issues to discuss like supporting my young family financially”
- Help with travel to attend groups
• Peer support needed for the rest of the family too
• More education for Health and Social Care Partnerships around positive language and the importance of good communication
• Signpost people to resources like the Supporting Children booklet produced by Headway. It offers suggestions of how to talk to and support the child

“Very informative, inspirational and emotional! Thank you.”
5. Adapting to new circumstances: keeping socially connected and active. Aim:

- To discuss dreams, expectations and overcoming barriers
- To set some goals before leaving the workshop
- To join in some physical activity during the conference - try something new

Key findings:

- Setting goals, particularly the steps needed to get back towards doing a favourite activity
- The importance of the support and encouragement of family but not being wrapped in cotton wool
- Peer support, meeting others who are going through the same thing at the same time, sharing hints, tips and solutions, supporting and encouraging each other
- Try something new – people talked about taking up an art or craft activity for the first time or a new physical activity like yoga, tai chi or boccia
- Being able to easily find out what groups / activities are available in the local community

Suggested actions:

- As above: peer support
- Signposting to community resources that provide access to new activities including physical activity. National websites like ALISS www.aliss.org and local websites
- Attend a Living Well course run by Chest Heart & Stroke Scotland

"The format of the day got people talking to each other. It was also inspiring to hear how other people had managed to rebuild their lives"
General feedback received about the event:

There are quotes from feedback throughout this report but full feedback can be read in Appendix 2.

“Great attendance and people had travelled quite some distance to attend, so it shows how much it was needed as an event. There were so many rich stories highlighting the value people placed on the event – one young person who attended said it was the first event she had been to on her own since having her stroke.”

“The workshop on returning to work was a highlight and also, from networking, realising I’m not alone in terms of coping with people’s attitudes to invisible disabilities.”
<table>
<thead>
<tr>
<th>Ideas/Solutions</th>
<th>What will this look like?</th>
<th>Measure of success</th>
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| Closer working relationship between CHSS & Different Strokes (DS) | • Increase options for service users  
• Increase in support for service users | • Number of people using services across CHSS & DS  
• Level of satisfaction with services |
| Keep hearing the voice of people using services and their families | • Increase the number of opportunities for people’s voices to be heard | • Number of regional gatherings (CHSS)  
• Number of people attending regional gatherings |
| Importance of peer support and networking:  
• Groups specifically for Younger Stroke Survivors  
• Groups that the whole family can participate in | • Increase awareness of peer support network  
• Increase options for face to face support for all of the family (CHSS)  
• Provide or facilitate transport to facilitate people getting together more easily – volunteer drivers (CHSS)  
• Increase online forums inc one specific for young stroke (DS)  
• Improve mutual signposting between CHSS & DS | • Number of peer support groups (CHSS)  
• Number of peer support groups for the whole family (CHSS)  
• Number of volunteer drivers (CHSS)  
• Number of online forums (DS)  
• Number of people in the online forums (DS)  
• Level of working with other charities that offer family support |
| Tools to help self-manage mood e.g. Paula’s wellness box | • Provide boxes to encourage this as a tool for promoting wellbeing  
• Encourage peer groups to make boxes as an activity (CHSS) | • Number of boxes distributed  
• Number of boxes created  
• Amount of increased interest in CHSS |

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<th>Ideas/Solutions</th>
<th>What will this look like?</th>
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<tbody>
<tr>
<td><strong>Volunteering opportunities should be better known</strong></td>
<td>• Improve awareness of volunteering opportunities</td>
<td>• Number of volunteers</td>
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<td></td>
<td>• Develop support mechanism to encourage volunteering</td>
<td>• Level of interest in volunteering</td>
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<td>• Increase self-confidence of volunteers</td>
<td>• Ability to match people to volunteer roles that will help them to develop</td>
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<td>• Number of people moving to paid work</td>
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<td><strong>Labels – why do husbands, wives, parents, children need to be relabelled “carers”?</strong></td>
<td>• Examine our own resources for positive / negative language (CHSS &amp; DS)</td>
<td>• Level of satisfaction with resources / publications being inclusive</td>
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<td>• Explore actions for improving education for HSCPs around good communication and positive language</td>
<td>• Level of satisfaction with interaction with HSCPs</td>
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<td><strong>Better signposting to organisations that can help like CHSS, Different Strokes, CAB, etc.</strong></td>
<td>• Increase profile of CHSS &amp; DS</td>
<td>• Number of people using DS and CHSS websites</td>
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<td>• Increase presence in stroke units, etc</td>
<td>• Number of people using DS and CHSS resources</td>
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<td>• Increase staff awareness of other organisations that can help (community mapping)</td>
<td>• Number of people referred to other community resources</td>
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<td>• Increase liaison with other appropriate local services</td>
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