



Living Well After Stroke event

Saturday 11 May 2019 in Perth

Appendix

Full report from workshops

1. Journey back to work. Workshop aim:

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

This workshop was led by Kate Wyatt, Partner at Lindsays Solicitors. Paula Leask and Scott Hutchinson then contributed the story of their return to work following stroke

Employers have an obligation to make 'reasonable' adjustments to accommodate someone with a disability.

Impairment can be physical or mental. The person might not consider themselves as being 'disabled' but this doesn't matter; if they need support to work then they should expect to be treated fairly.

The law can prevent employers discriminating unfairly over things like the need for a person to take extended sick leave.

The idea of what is 'reasonable' is a bit of a grey area but Citizens Advice or a solicitor can advise.

Employees can help their cases by thinking through what their needs are and foreseeing and overcoming the reservations the employer might have. They should also try to consider the impact adjustments might have on other members of staff. For example: if a person suffers from fatigue and this is particularly bad in the mornings they could suggest that they come in later and work later. Will this work for the rest of the team? If a person finds stairs are a problem, is it reasonable to relocate their desk downstairs.

Remind the employer of the cost implications associated with recruiting and training a replacement employee.

If a person needs to go for lots of medical appointments, the employer might agree to extended sick time for a period so the employee isn't penalized for taking the time off.

They could look for another role within the organisation that's more suitable.

They can point the employer to agencies for support such as:

Access to Work

Equality and Human Rights Commission (EHRC)

Advisory, Conciliation and Arbitration Service (ACAS)

They can suggest a trial period of weeks or months to see the impact of the changes and adjust accordingly.

Remind employers that there might be staffing shortages due to Brexit. How would they fill the role?

If the employer has made reasonable adjustments and the placement doesn't work then it is fair for the employer to terminate the contract.

Some health issues are obvious i.e. in a wheelchair, whereas some are difficult to spot such as fatigue. Occupational Health and Safety can assess people for jobs and advise employers of what adjustments might be required. They will also be able to advise the employer if the adjustments will be temporary as the person might improve or whether they are permanent.

People should give their employers permission to get in touch with their GPs so they can help to explain the person's illness/disability.

Big firms might have more resources to make adjustments whereas SME's might find it more difficult but this isn't always the case.

If a person's hours need to reduce then their wages will also be reduced. If a person wants a phased return then they might need to weigh up the financial implications, as their benefits etc. might stop as soon as they return to work.

If there is a disagreement between the employee and the employer about what is a reasonable adjustment, then a tribunal would decide. It would take into consideration things like length of service, size of the company and its resources, etc.

Wellness box: as part of this workshop Paula Leask described her return to work following stroke, her journey included volunteering for CHSS which then led on to a paid role with CHSS. Paula described her wellness box and its importance to her:

I have a wellness box. It's for me when I have a bad day. It's my little box to have a moment dedicated to cheer me up.

Inside it has a fidget toy for when I feel anxious.

A picture of my kids and husband to make me smile.

A positive note to me from me!

A pic of Eminem ~ when I listen to him I go all gangster and I feel like I can take on the world.

A pic of my other favourite album – music is really good for lifting low mood

A pic of the Netflix symbol as I never really take time to sit and chill watching tv. I'm always doing two things at once.

Some lavender oil ~ because this scent relaxes me.

Bubble bath ~ having time for a bath is a rare luxury with kids.

Workshop 1 report written by Darlene Drummond

2. Dealing with stress, anxiety and feeling down. Workshop aim:

- to share practical solutions for dealing with low mood / stress / anxiety

Report from this workshop:

The format of this workshop was:

1. Introduction and welcome from workshop leader
2. Free sharing of “what do we do now to manage when we feel sad, anxious or frustrated?”
 - a. People offered their ideas
 - b. Noted on flipchart
 - c. Discussion as to what seemed to be things that really helped (and what didn't help to some extent)
3. Comparison with what the “evidence” from research says helps. Which is:
 - a. Staying physically active
 - b. Learning to relax/meditate
 - c. Talking/sharing feeling in formal therapy
 - d. Having a sense of purpose – maybe a new direction/learning a new skill/trying a new job/volunteering experience
 - e. Seeing the emotional part of us as important as the physical
4. Brief mindfulness exercise at end

Outputs:

- People felt the things that helped are:
 - Talking to someone who had been through a stroke
 - Simply expressing how you feel and not holding back
 - Crying
 - Having things that took your mind off it all – hobbies, activities, physical activity
 - Yoga – especially yoga breathing

- Family – but many people talked about how family sometimes didn't help as they over protected you or were uncomfy if you got upset/angry
- Watching a TV/film that absorbed your interest
- Reading or listening to audio books
- Exercise
- The outdoors – just watching nature/seeing the sky
- Relaxation
- Feeling part of things – not an invalid
- Music – having playlists for different moods
- Massage – with oils/aromatherapy
- Other people who were further along their recovery

Workshop 2 report written by Dave Bertin

3. Managing money issues and worries. Workshop aim:

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

Report from this workshop:

The Citizens Advice Bureau (CAB) workshop provided very detailed information and concentrated in the most part of debt and assistance with getting out of debt. The slides were too wordy and too detailed and may be very complicated for someone who has had a stroke-a lot of legal terminology. I do think that the workshop was very informative but if doing again then perhaps you could request that the focus is more on the financial impact of losing/reducing salary and definitely less written information.

(Learning for organiser re briefing of workshop contributors: the original briefing meeting with CAB was done very early in the event planning, January. It was clear that some of the original request re wording on slides, content of session, etc. had been lost with the passage of time. In future the organiser should revisit this briefing much closer to the event. Apologies to workshop participants and CAB)

The time for discussion was limited but it was very significant that there were two opposing experiences. One attendee had received help and support from CAB and

had received assistance completing relevant paperwork. She talked about the real worry and fear of the financial impact of loss of earnings and became very emotional recalling her memory. She did, however, talk about how helpful CAB had been and had helped reduce anxiety by providing information.

Another attendee had the opposite experience and is still struggling to know where to go for financial support and help completing Personal Independence Payment (PIP). However, the speaker was able to guide her. She talked about being left to “just get on with things” and not knowing where to go for help or advice with financial matters. This same attendee talked about loss of income and being self-employed.

The speaker advised all that CAB are able to provide a range of financial advice beyond debt but his key focus was on debt.

The afternoon session became a one-to-one with an attendee. The attendee at that one will have benefitted from the one-to-one personalised service.

There was a lot of emotional and shared support which was a privilege to witness.

Workshop 3 report written by Heather McArthur

4. Effect on children and family life. Workshop aim:

- to share experiences and identify practical solutions and support needed

Workshop Output

General

- **Attendees – 12 in total at the two workshops**

Participants – 9

Different Strokes - 2

CHSS – 1

- **Participants Lived Experience**

Young children when the stroke happened

Teenage children when the stroke happened

Children born after the stroke

Young adult when parent had the stroke

No family however other young relative – niece

Young grandchildren when the stroke happened

Mature adult who had a stroke with elderly parents one with dementia

One child participant

Feedback

It's all new to everyone and uncharted territory as to what to expect, what to do and what support is there.

What works/worked well for you?

- Emergency services were aware of the impact on the children and were sensitive towards the situation. For example when going to hospital they did not sound the siren or put on the blue lights until away from the house so the children were not more upset than they already were.
- Peer Support to discuss how to deal with stroke issues.
- Having a family get together twice per year to discuss how things are going.
- Peer Support Group visiting hospital to talk to carers and family in hospital to let you know what is out there for you – financial help, groups, coffee & catch up meetings, NHS support available.
- Attending a Young Carers Group, meeting people in a similar situation to me. I have made really good friends there.

What didn't work well for you?

- The ward I was in was mainly much older people and it felt more frightening to my children and families.
- Lack of practical help about family scenarios so most support aimed at stroke recovery however more focussed on older people. Examples would be – picking up and holding babies & children, changing nappies with only one arm working,
- Nothing specific provided for children to help them understand what is happening and what emotional support they will need.

- So much to deal with as an adult when it first happens that it is hard to be aware of the impact on the children and no one really highlights the need for this focus.
- Most info and guidance provided focusses on what needs to happen to support the recovery of the person who has had the stroke and very little to none considering how the carer feels, what they need to be alert to and how to care effectively. This also does not take into account the additional responsibilities the carer needs to take on in the family/home situation- caring for children, taking the bins out, school runs.
- No help with finding equipment that might help you.
- Everything seemed to be on a trial and error basis rather than being provided with more help/details.
- The medical professionals I met with initially told me 'well you won't be able to work again'. I am now working full time.
- The impact of being discharged from hospital back home and not feeling confident about how to deal with the situation.
- Poor to zero support about stroke and the role of the carer and what is the best approach to take in various situations.

Note

This is a point I wanted to make that I observed during the workshops and feel worth mentioning especially if we are engaging with and sharing output with Health & Social Care professionals. It was perhaps more obvious as we were engaging with people of working age who were younger and many with young families. It struck me that, as soon as the person had the stroke there was a major change for the wife/husband/partner/children in how their role in the family was defined.

Apart from dealing with the change in circumstances, they suddenly lose their title and overnight become 'a carer'. Whilst I appreciate that is now their role my observation was that people introducing themselves struggled a bit to take that title and preferred to still be referred to as wife/husband/partner/child.

I think this also shows a sensitivity towards the person who has had the stroke as the title adds to how they feel, dealing with the impact of the stroke and then realising the person who was their wife/husband/partner/child is now their carer.

What would have helped you more?

- Guidance on where to get help – on-line would be good and also help/support from a wide range of organisations not just one.
- Book for children to read telling them in simple language about how stroke happens and encouraging them to understand how things will work going forward
- Something to help children understand about mood swings in adults who have had a stroke

- More focus on telling family & friends how they can help – don't let them think they are helping if it is not what you feel helps you most.
- Help & support – there must be a way for organisations to work together to provide help. Example would be how to change a nappy with one working arm, there must be information for amputees about this and it would be exactly the same for someone who has had it a stroke. This really highlights the need for focus on people who need to carry on with family life where as potentially most support and guidance is aimed at older people?
- Peer Support for kids.
- Carer support peer groups – helping with the different layers of care and the stages of recovery.
- Different ways to seek help, e.g. if you have to travel to provide help or stay if group is not near you.
- Travel can be an issue so support for travel would make a difference.

Workshop 4 report written by Linda Gill

5. Adapting to new circumstances: keeping socially connected and active. Workshop 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

Main contributor to the workshop was Paul Burns, Peer Supporter in the Positive Stroke Solutions course in North Lanarkshire which is run by Anne Armstrong (CHSS Specialist Stroke Practitioner).

Paul's family have made videos of his recovery and two of these were shown at the workshop with Paul narrating what was happening. He particularly stressed the importance to him of:

- Setting goals – particularly the steps he needed to get back to doing Tae Kwon Do. He encouraged others at the workshop to get back to doing a favourite activity and identifying goals that would lead them towards that outcome however long term
- The importance of the support and encouragement of his family which is clearly demonstrated in the videos
- Peer support – the Positive Stroke Solutions course was a key turning point for Paul, meeting others who were going through the same thing at the same

time, sharing hints, tips and solutions, supporting and encouraging each other. He now volunteers with the group and is also back at work

- Determination – Paul talked about how if the physio told him to repeat an exercise 4 or 5 times a day, he would be doing that exercise 40 times a day. He talked about how exercises like using a pack of playing cards and turning them over one at a time was surprisingly tiring but helped him to dramatically improve the mobility in his affected arm

There was then a general discussion in the workshop about what had worked for others in terms of staying socially connected and active. For some it was also physical activity, especially walking, and peer support but others mentioned taking up new art and craft activities too. One of the main barriers identified for joining in peer support was difficulties with transport including distance to travel. The Different Strokes closed Facebook forum was cited by some as their means of peer support in these circumstances. The need for more groups aimed at younger stroke survivors was brought up. If you are 30 and needing a group but your local stroke group is mainly 65+ then it does not feel relevant or appealing. “What if you don’t want to play dominoes but want to talk about getting back to work, money worries and the effect on family life with other people who are going through the same challenges”

The workshop finished with an opportunity to compete in a game of Boccia. New Age Kurling was also on offer at the event.

If you would like to see Paul’s videos then they are available on YouTube:

https://www.youtube.com/watch?v=X_3weHwcDAA

<https://www.youtube.com/watch?v=j137tWHnXvw>

Workshop 5 report written by Deborah Slater