

What does our stroke community look like?

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Stroke
Association

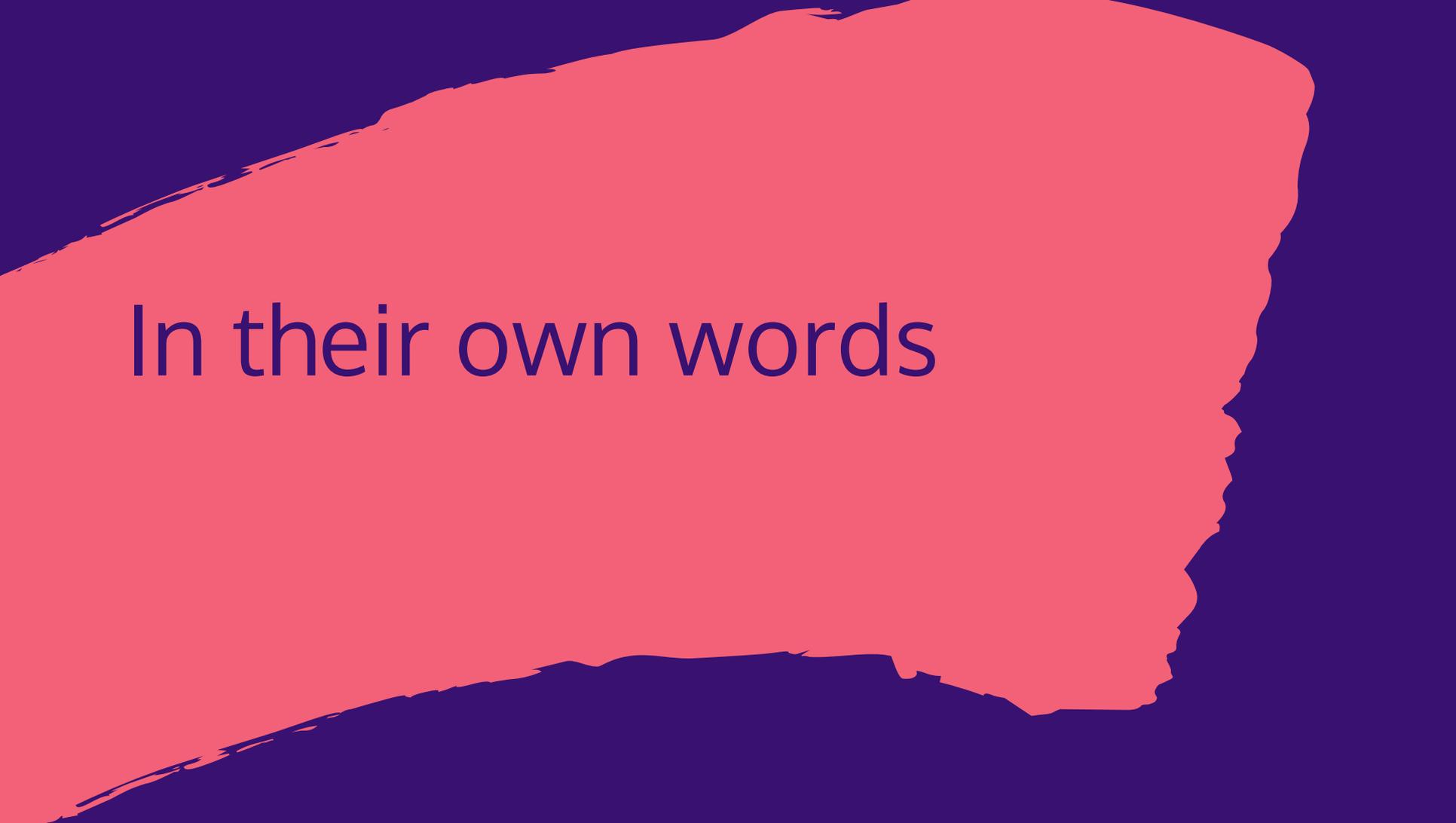
stroke.org.uk

Getting to know you

- This workshop is for us to spend some time getting to know the seven stroke survivor groups we identified in our recent Stroke Survivor and Carer survey

Getting to know you

- Just a reminder –a nationally representative group of 1,880 stroke survivors and carers took part in our online survey
- And more than 9,000 stroke survivors and carers who had support from the Stroke Association completed a postal questionnaire
- From this we have identified seven distinct groups. We would like your help in bringing these groups to life

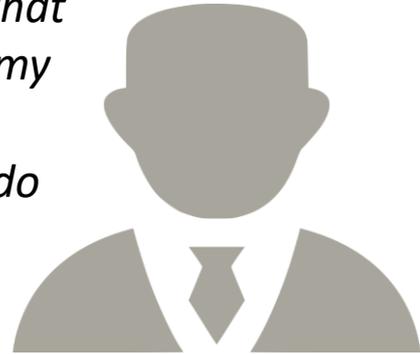


In their own words

Ali, Cardiff (75) had a TIA 18 months ago

TIA

“Let me tell you how lucky I am. I was reading in bed when I suddenly slumped down and couldn’t move or speak, my wife found me and called 999 immediately. I’ve made a full recovery, the NHS were impeccable and my wife was there in my hour of need. In that week after being discharged, I was quite tired but my wife just did everything for me, what an angel she is. I didn’t need anything or anyone else. At the back of my mind, though, I always know that this could have been the first of something more serious. You never know what happens next, and I do worry about that sometimes.”



Graham, North London (58), stroke 6 months ago

Adjustment

“I think I’ve been lucky. They tell me I have. I couldn’t believe it when I had a stroke – I’m healthy, I go to the gym 2 or 3 times a week (well, I did), I’m fit and active. The only thing I did do is smoke, but I can’t do that now.... The hardest thing was how tough it was getting back into normality: even getting out of the flat took 20 minutes at first and I was embarrassed to just walk up the street; I wanted to hide... I know a lot of people in this area and I felt stupid hobbling 20 metres up the road in front of them... I feel angry sometimes that I can’t just get back to the gym and do what used to be so easy. I think I will, I’m able to do exercise now and I’m doing better every day, but getting back to how I used to be takes time.”



Geraldine, Devon (87), ischaemic stroke 1 yr ago

Physical & Cognitive Priorities

“The stroke was the final straw that means I now live here in the care home. They look after everything for me here, but it’s not about getting better, it’s about managing all of my problems. I am very emotional, I cry a lot and feel it would be easier to die, easier on me and on my family. I really want to go back to the specialist hospital for strokes, doing the exercises really made me feel like I had a purpose. I talk to the nurses here when I’m feeling low and they are a good comfort, but sometimes the frustration of my body giving up on me is too much to cope with.”



Shawana, London (67) ischaemic stroke 3 yrs ago

Physical priorities

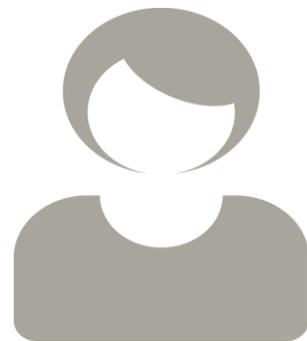
“I can’t work anymore and that has been difficult to get used to. Because I can no longer stand up for too long, working in the shop isn’t an option. I rely on my daughter and son in-law to help me day-to-day, they also make sure my husband has everything he needs like I used to. I used to be the one running the household but now it is more shared out which also took some getting used to! I don’t really think about the stroke anymore, I’d say that when it comes to my health, I worry about my diabetes the most, so I do what I can to manage it – it takes a lot of effort.”



Joyce, Wales (53), ischaemic stroke 8 months ago

Cognitive priorities

“I found trying to work very hard afterwards: I tried going back, but I was embarrassed by how long it took me to do the simplest things, like writing an email. Suddenly I couldn’t find the right words, and my spelling – which was always good – was suddenly awful. I have been passed over for promotion several times now; I’ve made my peace with that but it’s depressing. My anxiety has been up and down because I fear that the slightest tingling, numbness or headache is a massive stroke – I don’t have a clue what is normal or not and it scares me. I really want more information on this and ideally to be able to talk to someone who has been through the same thing.”



Christopher, South Gloucester (34), stroke in 2004

Emotional (Mental Health) priorities

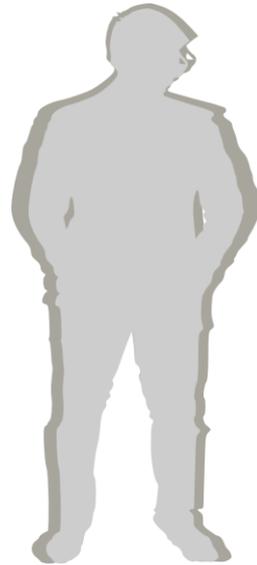
“They don’t know what caused it. I’ve had years and years of scans. They don’t know. There was no explanation for it. It made it very hard to come to terms with. There’s no end point for it. It’s just up in the air. It turned my life upside down. I’d just started the career I’d been training for for 3 years. I was in a well paid job. My future was taken away from me. I struggled to cope. I couldn’t talk to my family. I wouldn’t talk any one about my feelings. There was no where I could go to let my feelings out. I lashed out and was angry all the time. At them. At everybody. I started drinking to numb myself from how I felt.”

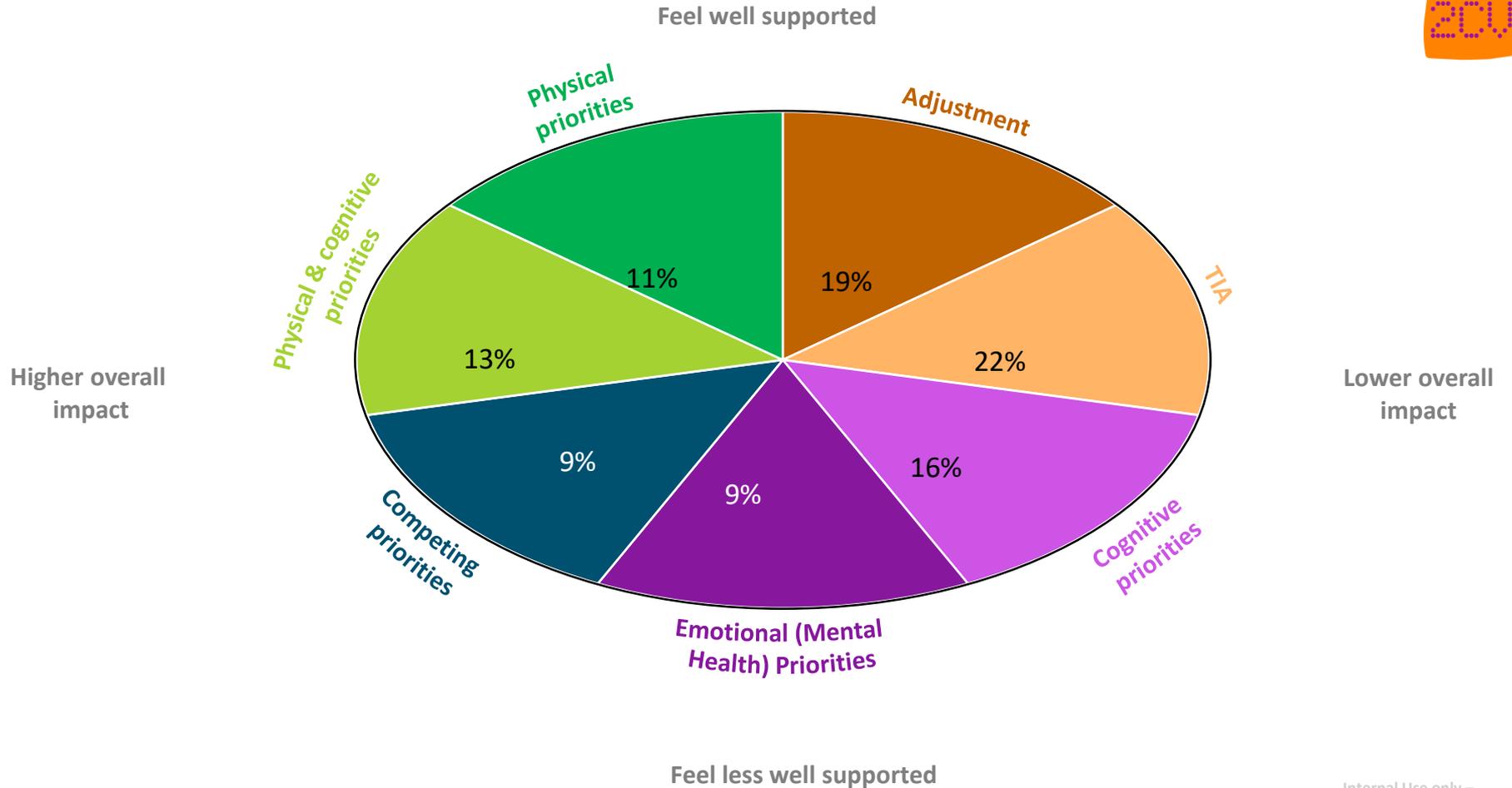


Bill, Scotland (52), had a stroke in 2014

Competing Priorities

“In the first three months I couldn’t seem to settle anywhere, it didn’t feel right anywhere – I was surrounded by much older people. I need to be around people like me so I can fit in – my friends would never come and visit. I don’t have any friends now especially as my best friend died while I was in hospital and I can’t be bothered with the rest of them. My mum cares for me every day and she always tries to get me out the house but I just don’t care. I am not me anymore. I lost my job because I went back as a butcher and had forgotten all of my recipes, my kids rarely visit me. My mum says I’m depressed but I’m not sure, I think I am doing and feeling what anyone else in my shoes would”





TIA (Ali) 22%

- Have had a TIA, or multiple TIAs, but have not had a stroke
- Physical and cognitive impact is low
- May not even see themselves as a 'stroke survivor'
- But they are not unscathed
 - May be more anxious and uncertain about the future
 - Aware of being 'at risk' of further TIA or stroke
- Feelings: optimistic, happy, anxious

Adjustment (Graham) 19%

- As a group, experienced relatively low impacts from their stroke and feel mostly recovered
- But fatigue and cognitive issues are common
- Have adjusted, and found a 'new normal'
- Getting on with their lives
- Feelings: shocked, optimistic, hopeful

Physical+Cognitive priorities (Geraldine) 13%

- This group has been severely impacted by their stroke both mentally and physically
- Tend to be older and most likely of all the groups to be in a care home or have a full time carer in their own home
- Frustrated at loss of independence
- May be in denial about their situation
- Fearful for the future
- Feelings: frustrated, anxious, frightened

Physical priorities (Shawana) 11%

- Stroke has impacted this group mostly physically
- Appearance has been affected
- Knock on effects on career and independence
- Most likely to have other health conditions such as cancer, diabetes or heart failure
- Because of this, may be focussed on other conditions rather than stroke
- Feelings: frustrated, nervous, exhausted

Cognitive priorities (Joyce) 16%

- Stroke has had a moderate impact on sleep, fatigue, concentration and memory
- Also on personal relationships, happiness and self esteem
- Feel relatively positive and closer to recovery than most
- Feelings: stressed, hopeful, happy

Emotional (mental health) priorities (Christopher) 9%

- This group has experienced severe impact on mental health
- Stroke has affected every area of life, from work to relationships to self esteem
- Younger overall, compared to other groups
- More likely to have been working at time of stroke
- May experience lack of confidence, personality change and panic attacks
- Feelings: frustrated, confused, stressed

Competing priorities (Bill) 9%

- This is the most severely impacted group
- Stroke has affected all areas of their lives, including mentally and physically
- Feel furthest away from recovery of all of the groups
- Experience lack of confidence, mood swings, depression, personality change
- Feelings: angry, embarrassed, useless

Table activity

Questions for discussion

- How easy is it for you to distinguish one persona from another?
- Which persona(s) do you identify with most and why?
- How easy is it to identify your persona?
- Do the personas ring true for other stroke survivors you know?
- If they are unsure about which persona you fall into, what extra information would you need to decide?
- What would help to bring each persona to life a bit more?



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Association

Rebuilding lives
after stroke