



Young Stroke Project

Recovery 5.

Peer-Led research by genyus with Stroke Foundation - September 30, 2020
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Summary of discussion

What are the things that have hindered you most in your "Recovery journey"?

- being in hospital rehab, OT said you'll never get any better
- being told had aphasia after 12 months
- having depression and fatigue and not being educated or prepared for it in stroke and feeling alienated and isolated because of it
- not being able to meet other people with same lived experience - peers
- losing her partner because unable to cope – interpersonal connections compromised
- having her family unable to care / find ways to improve
- being your own worst enemy – having high expectations and wanting to be pre stroke 'just wanted to get back to the old me'
- being told a fixed time frame of recovery
- feeling they'll be a burden
- whilst seeing therapists as a champion – kernel of truth - instead they were the obstacle 'lucky if you'll be able to talk again' – condescending arrogance and expertise knowledge based on what?
- having the Clinical staff not understanding or supporting YSS
- having society not seeing or understanding or comprehension YSS the invisible deficits
- having milestones set eg. 2 years to fully recover by Clinical staff – limitation
- feeling like a lot of the processes and structure focussed on older people
- not meeting other lived experts and feeling like you're alone
- having family and friends not educated in being able to support – not enough capacity in the family unit

What are the things that have helped you most in your "Recovery journey"?

- Being put on medication
- finding a stroke support group with Aphasia
- feeling like having a role and purpose
- being able to do exercise again
- having family support – husband and in laws every step of the way
- having a great direction for recovery
- understanding of another stroke survivor (brother)
- having an active reflective gratitude practice
- having a great GP who organised a Medical plan
- having a similar lived expert group – aphasia
- having a very supportive family
- using instagram to actively document your progress and what's important in your journey
- being able to watch and read about other lived experiences
- having more focus on just return to work rather than hobbies and socialising
- having great IT platforms / equipment to assist as another arm for recovery
- having ongoing, newer type therapies to continue
- having accessible innovative therapy to increase agency over themselves - empowerment

What should the ideal YSS “Recovery journey” look like?

- having access to content that outlines and demonstrates multiple recovery journey's
- having mentor with lived experience make you feel connected
- having access to a community of peers
- having innovations that focus on you as a person – identity, relationships
- having more of a direction once you're out of the hospital rather than a list of contacts which aren't necessarily up to date
- Paired with a transition leader once you're out of hospital and rehab with a wholistic approach
- having content with documented action steps
- having access and direction path to peer community
- Peer guidance to increase capacity to share own story