



Young Stroke Project

Recovery 4.

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"?

- having cookie cutter depersonalised approach in rehab with no investment from health professionals
- having professional / medical staff shocked and unaware of young stroke
- feeling isolated without any straightforward answers
- being handed stroke journey which was non reflective to the age demographic
- there was an impersonal and unprofessional approach
- having a negative prognosis
- being Aboriginal!! It wasn't a common occurrence
- being located regionally
- being admonished and felt patronised
- was made to feel as though she was stupid and young by health professionals
- was misdiagnosed
- was admitted into cardiology – discharged
- having a lack of coordination between specialists
- having a lack of information on how to communicate with others
- not being able to discuss with children what has happened – childhood trauma
- how to mitigate the risk factors
- was trying to find initial diagnosis
- having no information / education
- having people close to them confused / uneducated in how to work with / look after partner - capacity in close unit
- having full recovery but unable to have other people understand
- trying to talk about the stroke
- having organisations that don't listen or create career paths for their staff eg Baptistcare
- was prescribed medication that is generally given to older stroke survivors

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

- Having modern rehab equipment
- Having very supportive family and friends!!
- Able to talk to people about the physical deficits both physically and mentally
- Having very supportive family members
- *Having "Compack" opportunity – support for 6 weeks – through a social worker*
- People with lived experience of good therapists- eg neurophysio, - therapists are worth their weight in gold
- Having strong interpersonal relationships who could help other people understand without needing to explain
- Feeling understood
- Having a great neurologist – explained was not his fault – supportive to continue life to the fullest
- Hopeful lens
- Feeling more committed and more focused
- Being assisted by Disability Coordinator to return to work

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

- More equity in the system
- Having someone with lived experience to talk to –
- Having personal contact to make you feel like you're not alone
- Having someone in the same age bracket with lived experience to talk to
- Having contact by professional / stroke liaison some time after you leave hospital and reiterating what was discussed
- Help understand the pathway of the journey ahead