



Young Stroke Project

Recovery 3.

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”?

- Not given information about the stroke
- No follow up, no therapy
- No physical deficits = no rehab
- Medical staff lack of knowledge of no visible deficits in therapy
- Demarcation between allied health
- Lack of knowledge of young stroke by medical professionals
- Lack of social, emotional and psychological individual support
- Looking at human as holistic approach
- Did not have any resources for therapy, did not know where to go
- Stroke Foundation My Stroke Journey directed to older patients
- Comparing pre stroke to now – mentally and physically - stifling
- Lack of teamwork of professionals after rehab to link therapy
- No diagnosis therefore therapy lacking
- No follow up support from health workers
- Have not worked because of voice problems still after 4 years
- Feeling voiceless in stroke advocacy
- Incidental injury but not seen to (injured left arm in fall)

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

- Have a much richer life since the stroke, less stress – positive reflection
- In regional, far better experience, real community connection
- Outpatient – measurements and being accountable
- Straight into speech therapy
- Lived Community – going to the gym
- Volunteer work
- Finding purpose
- Support network - family
- Mental health services
- Therapy connection
- Stroke survivor support group – meeting lived experts
- My own strength – being grateful, resilience
- Family – partner
- GP
- Stroke Foundation – information, community, volunteer work
- Intense Rehabilitation in hospital
- Research – Florey – felt valued and received information
- Return to work – continue to vocation
- NDIS – application planning was easier because of background of job so understand bureaucracy

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

- More comprehensive assessment to find deficits to be addressed immediately
- A team for full assessment – cognitive / physical
- Stroke Advocate
- Advocate with full knowledge - Resources for whole stroke journey for family – Capacity being built for family eg. Knowledge of Medicare - Family transport for connection – all out of pocket – more engagement
- Being diagnosed and informed for more capacity to understand – clinically
- Conduit for gaining employment with current capacity = meaningful activity
- Connected services once out of hospital
- Connection with Lived expert community
- Resources for what is out there for young stroke
- More active advocacy role in own recovery rather than being passive consumer
- Survivor led
- Reframing of language – no assumptions so does not exclude people
- Be able to have stroke translated – accompanying information to health professionals – personal risks so best way to explain to reach full potential