



## Young Stroke Project

"Support Crew" journey - Roundtable 2

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Peer-Led research facilitated by Ian Rixon of genyus network, February 25, 2021

*What Hindered your journey?*

- Sons young age was barrier of engagement - nothing specific for him and his age
- The NDIS wasn't that helpful
- I couldn't find age appropriate peer groups for support
- Had so many questions as to 'why' my wife has had this?
- She was frustrated, and I knew that - but I was the conduit to the Health Pro's and her quality of life and that was frustrating
- I felt restricted in my capacity to be a good supporter
- My own ignorance
- My Parents (Supporters didn't travel to hospital) - they didn't get help from anyone because of my age
- Sons friends don't understand the journey/his needs - feel so isolated
- Support groups are dull and sad
- Children's hospital won't help because of barriers of associations
- Because my son so young, exercises weren't applicable so all had to be experimental
- Parents just didn't understand (lack of knowledge/insight)

*What Helped your journey?*

- Meeting other husbands of Young Survivors was helpful
- My wife (survivor) sourced/gave me the appropriate research/materials
- Children traveled to hospital
- Support networks for Young Survivors - super helpful (we traded successes)
- BBQ's that organized by Young Survivors for Supporters themselves (also a social experience)
- Zach, and our entire family doing it on our own - with assistance from OT and Physio
- School has been supportive with educational support
- Friends/Family have been making food to help
- There's nothing specific enough for YOUNG SURVIVOR / SUPPORTER
- Stroke Foundation Young Stroke Project - grateful for link to genyus
- Because my son was so young, we had to be experimental and that was good.
- I want my son to connect online - but he wants to avoid it (loves computers but not ready mentally/emotionally - needs in-person connection)
- Social workers (WA carers) helped by checking in: A Cleaning service takes pressure off

*What might the ideal "Support Crew" journey involve?*

- A Young Stroke Group in Perth (Locally)!
- Being able to meet other People who have gone through it - to offer their reflections on their experience
- To get lived expert advice/experience - to then form an opinion based on experience not just clinical guesstimates
- A REAL-LIFE connection with a Peer - that'd be great support for all of us
- Online information resources - specific to my situation!
- Online connection with Peers!