



## Young Stroke Project

"Support Crew" journey - Roundtable 1

Peers: Leisa Mckenzie, Lucas Sloan, Kim Beesley, Amanda O'Meara, Tracy Ward

Peer-Led research facilitated by Ian Rixon of genyus network, February 24, 2021

*What Hindered your journey?*

- Rehab was directed to older people / focus on discharge
- Not enough support from Health Pro's - I had to seek it myself / didn't know how to help my daughter with aphasia / capacity was only 12 months later
- My daughter's depression / grief / reforming of life was disempowering and isolating experience
- Rehab was aimed at elderly and too general (not stroke specific) it was disempowering and uncomfortable
- The meals at rehab were disgusting
- There was a lack of trust with the nursing staff / facility (students and OS workers)
- Left in bed in nappy / catheter led to UTI (neglect)
- Following Diagnosis: not enough info given - no follow up for 3x months
- Pediatric stroke was uncommon - too young to be an adult too old to be a child
- We needed guidance in the early days!
- Conflict between survivor / supporter = very challenging
- Long road to physically get to the hospital
- Managing life with aphasia = very challenging
- No information for a long time until receiving Stroke Foundation "Our Journey"
- Bombarded with Health Professionals for duration (Speechies etc)
- Lengthy duration at rehab due to rural location but that equals extreme isolation
- Had to find and pay for therapy ourselves in rural
- No O.T. has helped showing my daughter and allowed her to build her own capacity
- Not enough info on Paed stroke (at the time)
- Zoom meetings aren't helpful for some people with aphasia
- My brain was so overwhelmed dealing with my other dependants etc
- Sibling journey differs from Partner's journey - don't know how to motivate
- Nursing in hospital = need to think about gender/identity not disempower in feeling inappropriate

*What Helped your journey?*

- NDIS Package has been good - but still has limitations. It doesn't address issues of independence.
- NDIS helped at the start (but limited understanding from physio's about brain)
- Kate Ryan's (Stroke Survivor) book "One Handed tips" = awesome!
- Stroke Groups have been helpful
- Amazing (very specific) therapists (found ourselves) have been excellent!
- Knowledge = POWER!
- 'Stroke Foundation' linked to 'Little Stroke Warriors'
- Hearing other people's journeys and meeting Peers!
- Hunter Brain Injury Service (Newcastle) - amazing access to therapies! (mixed group led by fantastic case manager and therapists)
- Maitland Aphasia Group (peers) had amazing impact on connections and info
- Brain Injury Service (Hunter) helped with transitional aged care (12 weeks)
- Stroke Foundation led to Maitland group / aphasia group: helped initially
- Finding our people (our style) locally!
- NDIS has helped connecting to the community
- Antidepressants / Mood stabilizers (+ scotch, but in good measure)



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

- More intensive therapies (e.g. physio, speech pathology)
- More information for me to process at the beginning
- Being linked to peer groups to navigate journey together
- Promoting insight/understanding of survivor's experience early on
- Being linked with services to continue intense rehab as soon as you get home
- Capacity built for Carers/Supporters (training for Support/Assist/Partner)
- A stroke specific centre in each major area following clinical rehab
- A conduit between Individual and Government relations (case manager/paperwork navigator)
- Mental Health support for "Support Crew"