



Young Stroke Project

"Support Crew" journey - Roundtable 3

Peers: Nichola Browning, Kasma Kasim, Maree Scale, Donna Maysey, Patricia Giacomini

Peer-Led research facilitated by Ian Rixon of genyus network, February 26, 2021

What Hindered your journey?

- Needed extra support for family
- Didn't know how to help / had to do research due to hereditary issues
- Needed to connect with other Supporters
- Guilt due to relationship 'separation'
- Had to make life-changing decisions
- Managing various mental health issues for survivor
- 2020 COVID = Huge hindrance. Rapid transfer of patient = separation & isolation
- Survivor's communication capacity was challenged = self-advocacy was impossible
- Digital capacity between Survivor and Supporter greatly challenged due to Survivor capacity (and never being trained up)
- ADHD/Aspergers condition requires extra care, but he is placed amongst confined older/restrictive environments exacerbating his condition
- Battles with the NDIA - trying to get funding for interdependent care in survivor's own space and eventual independence
- Mental health issues have been huge issue for sister survivor - only physical rehab not enough psychological support
- Hospital staff didn't ask about pre-existing conditions
- Health pro's need to be more inquisitive
- Had to advocate for my daughter - she was disempowered/disheartened about their engagement with her
- No one addressed mental health or follow up support
- Given generic 'stroke info pack' - nothing specific to survivor (too old!!)
- Peer-peer connection wasn't easy to find - "Nothing like this in neuro" "You need people to relate to!"
- Not enough connection to specialists (specific to young person)
- Everyone assumed my daughter was ok due to physical appearance (looking "recovered")
- No one has talked about NDIA (means tested = doesn't qualify which is a crock)
- Relationship between Supporters was impacted = everyone needs their space to grow and change and share
- Support coordination was really difficult - Stroke Foundation could take this on
- I had to be my sister's voice!
- Balancing my role as 'Supporter' 'Father' 'Mother' 'Spouse' etc was impossible
- Different stages = different challenges: I psychologically needed to physically be there for my own self-care
- Health professionals were always coming and going, but I needed to be there to relay/retain information
- Fight to get thickened water "What if I'm not here?!"
- I could tell my son's mental health was shifting, but I was worried if I wasn't, he would be disregarded.
- I had to be his voice as he was voiceless
- How the hell to let everyone know (in my son's social/work circle) was overwhelming to filter information
- Coordinating visitors was challenging - I had to look over his capacity and filter how many people could see him etc.
- Being lumped in with older people was really problematic for my son
- Felt like no one understood - challenging for my relationship with my partner
- My son is depressed, grieving old life - I fear this holds him back
- Balancing my job for income etc = Extreme burnout!



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What Helped your journey?

- Got lucky with having great GP
- Having a great support coordinator was so beneficial
- My own capacity as a nurse was hugely helpful for daughter
- Stroke Foundation helped with some connections to peers
- Strong good support in the family unit
- Hearing everybody's stories make you feel connected and not alone
- A fellow young survivor was the catalyst for me comprehending my son's new identity (without his guidance we would never have known)
- Connecting my son with Neuropsychologist (/me liaising with them)= imperative
- Supporting him during his appointments has been so important
- Being able to share "my story" with clients at work allowed for me to unburden myself (but not same for my wife)
- My own friends have been so helpful for my own support and mental health
- Very grateful for the NDIS support
- Occupational Therapy offered a wide variety of 'gifts' of support
- Raising funds with community was important
- Having a pay-it-forward mentality and to help others has been a blessing
- My workplace was great in the short-term (gave extra support)
- Jesse's workplace was wonderful/supportive (became a kind of 'foundation' \$\$\$!)
- Being involved in Clinical trials has been helpful/fortunately
- NDIS coordinator has been wonderful (found a really good one!)
- Big win = getting my son into his own unit!
- My son published his book / helped by getting a ghost writer - launched!
- Clinical trials advertised at Stroke Foundation/Enable me = really helpful!
- Advised to "spend energy dollar\$ on myself. WHOA OK!" = appreciated this nudge

What might the ideal "Support Crew" journey involve?

- Continued Psychological support for Supporters
- Great info accessed for a specific situation (not generic)
- A list of resources (numbers, support networks, preferred providers, self care!)
- Safe space to share openly (i.e. specific for male supporters etc)
- Connection with a similar aged Peer Mentor - ONGOING through all stages
- (if Aphasic) Connection with Peers to give realistic/empowering advice/guidance
- Peer connections = in a personal/social/supportive way!)
- Access to chaplain
- More information and journey progress notes given by Health Pro's
- List of services for carers
- Connection Supporters and Survivors on Zoom!
- Personal guidance on how to navigate NDIS
- Mental Health plan provided straight away
- Qualified experienced nurses employed to stroke wards!
- One voice of stroke (constant same approach)!
- Peer connection support DEFINITELY
- Awareness in community (capacity/understanding built)
- A PERSONAL APPROACH at every point of engagement from Health Professionals
- Social experiences - Face to Face for specific peers to connect!!



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- More specific therapies offered - keeping Support Crew informed at all points!
- EMPATHY TRAINING "LET'S ALL BE PART OF THE SOLUTION"!
- Professional Advocacy Service offered - facilitated by Professional (possibly via NDIA, even a carers organization, Stroke Foundation)