“This is a good one, I mean this is my life story”

Understanding the experience of narrative storytelling for adults with acquired brain injury.

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PhD research
Why narrative storytelling?

We know that survivors of brain injury experience:

- **Long and complex recovery** *(Levin, Shum & Chan, 2014; Ponsford, Sloan & Snow, 2013)*
- **Social isolation** *(Douglas, 2013; Levack, Kayes & Fadyl, 2010)*
- **Identity loss** *(Badle et al., 2016; Coetzer, 2008; Levack et al., 2010)*

Yet....

- **Relationship between identity construction and narrative storytelling** *(Adler, 2012; Gergen & Gergen, 2014; McAdams, 2001; Nochi, 1998)*
What is the experience and impact of narrative storytelling following brain injury?
OUR AIM

WE AIM TO CREATE, LEAD AND DEMONSTRATE LONG-TERM SUSTAINABLE CHANGES THAT STOP YOUNG PEOPLE FROM BEING FORCED TO LIVE IN NURSING HOMES BECAUSE THERE IS NOWHERE ELSE FOR THEM.

RESEARCH
Research underpins the work of the Summer Foundation and provides an evidence base for policy and practice change. Read More

HOUSING
The Summer Foundation is building housing demonstration projects to provide concrete examples of alternatives for young people living in nursing homes. Read More

STORIES
Enabling young people and their families to tell their stories is a powerful tool to influence others and to effect change. Read More

NDIS CONNECTIONS
The NDIS is an exciting and significant part of the solution to resolve the issue of young people in nursing homes but it is not a silver bullet. Read More
Group Workshop

Individual meeting

1:1 storytelling

Written profile

Digital story

Interview 1

Data analysis

Interview 2 & 3
Storytellers

Communication: (dysarthria, speech generating devices)
Cognition: significantly impaired memory (1)
Age range: 30’s to mid 50’s;
Time since injury: 3 to 18 years
Accommodation: nursing home (3), on own with 24 hour support (4), with parents (1)
My lived experience

Sharing my story to help others

Finding storytelling therapeutic
- Feeling heard
- Releasing emotions

Re-visiting my story
- Reflecting and learning
Sharing my story to help others

Daniel: “People who felt like me in the nursing home, I give them the courage to go on”

Robert: “It is for me to let people know... if there are other people going through this, there is hope, light at the end of the tunnel

Bridget: “I want other people to watch it. And to get some answers... I’d like people to see that I’m a real person who has a disability”

Matt: “I can’t walk or talk yet, yet I still find it good to help others”
Kim: “Telling my story has been really huge for me. Summer Foundation was the only one that really listened at the time. I had a good social worker but she had to work a system that doesn’t work”

Bridget: I felt like I could explain... about me and my interests”

Daniel: “...talking to people who seemed to really care. Because I’ve not found everybody cares for other people”

Robert: “I like these people, they really know what they’re on about and they’re intelligent, they were willing to listen to me”
Finding storytelling therapeutic: Releasing emotions

Katherine: “I felt sad upon re-visiting the memory. Emptiness would be the exact word. And loneliness. Like being turned inside out. You feel every emotion”

Katherine: “I felt better to get it out. Yeah. I think being open helps. You let people in”

Bessie: “I just wanted to get it out there... unburden... off my chest”

Daniel: “I felt good and tired [after telling my story]. I got a lot of stuff off my chest”
Revisiting stories: Reflecting & learning

Daniel: “I’ve got more to achieve both personally and with other people”

Lucy: It’s a good one, because my face is good. That’s my life story”

Katherine: “But that’s acceptance of where I am at and I’m realistic, I can’t do what I used to ...acceptance it helps”

Matt: “I will always go back to my past, although I have very little chance to return so I just go to the next page and see what is there”
In summary

Feeling good about helping others

Feeling heard

Releasing emotions

Reflecting and learning about self

Narrative storytelling validates lived experience & helps build a positive identity
Thank you

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