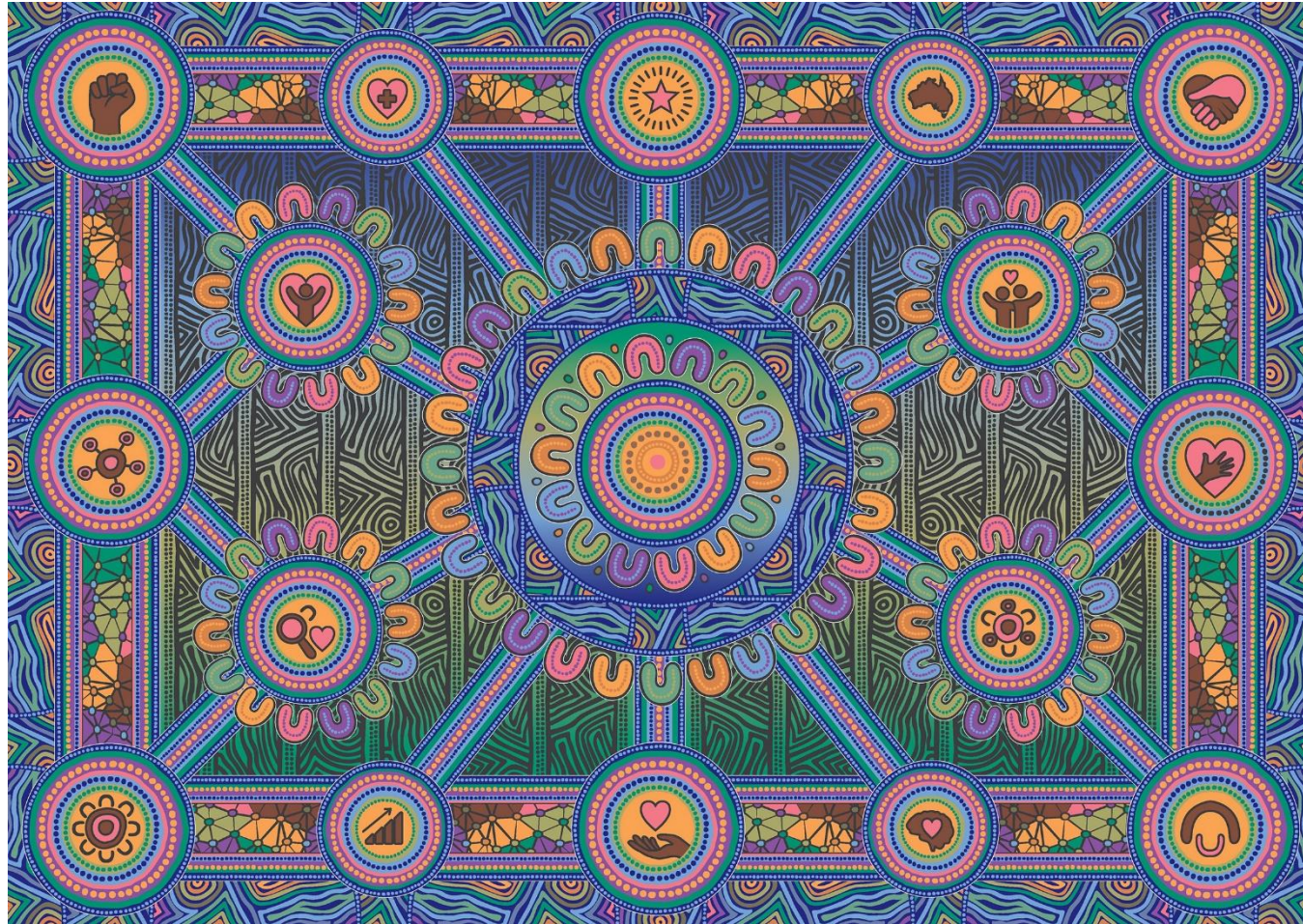


Childhood Stroke Project

Mardee Greenham, Childhood Stroke Coordinator
Tony Peacock, Lived Experience Advisory Group member
Amanda Clayton, Lived Experience Advisory Group member



Acknowledgement of Country



Carissa Paglino, 'Stronger Together' 2025, Digital Illustration.

Acknowledgement of lived experience



About Stroke Foundation

We are a national charity that partners with the community to ensure **fewer strokes, better outcomes, support and care for all.**

We are the voice of stroke in Australia.

- › We stand alongside survivors of stroke and their families, healthcare professionals and researchers.
- › We build community awareness and foster new thinking.
- › We support survivors on their journey to live the best possible life after stroke.



Childhood stroke



Up to **120 babies** and **400 children** have a stroke each year in Australia.



Among the **top ten** causes of **death** in **children**



More common in **newborns** and **young babies** than older children.



More than half have long term **neurological disability**

Childhood Stroke Project

Vision

Empower every child to achieve their full potential after stroke.

Mission

Centre the expertise of lived experience, and together develop resources, create awareness and advocate for survivors of childhood stroke and their families.



Consultation vs Co-design

	Consultation	Co-design
Role of lived experience	Asked for input after decisions are made	Involved from the start , shaping decisions
Power balance	Professionals hold the decision-making power	Shared decision-making between all parties
Process	One-off or occasional feedback	Ongoing collaboration over time
End result	May reflect professional priorities	Reflects real-life needs and lived realities
Ownership	Limited sense of ownership	Builds trust and shared ownership

Lived experience – why it matters

- Makes resources more relevant and practical
- Highlights what matters most to survivors and families
- Builds connection between health professionals and communities

“We’re the ones living it every day - so it makes sense to be part of creating something that could actually help others like us.”

- LEAG member



Amanda



Tony



Our co-design journey



From the
beginning

Joint decision
making

Equal value

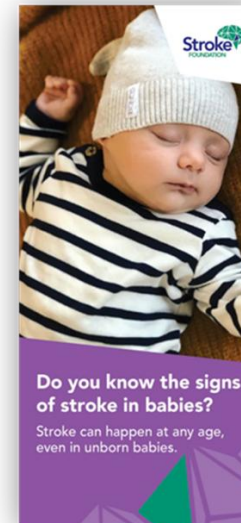
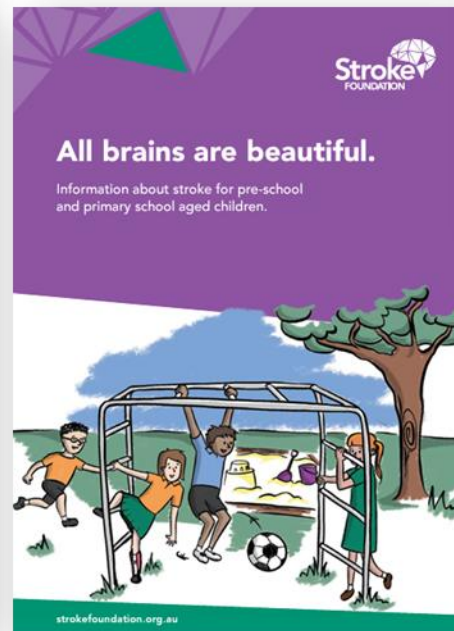
Messy

Flexibility

Feedback

Changes

Resources



What's next?



Information and support

- › Stroke Foundation website <https://strokefoundation.org.au/childhoodstroke>
- › Little Stroke Warriors Facebook group for families
- › Little Stroke Warriors Facebook public page

StrokeLine

StrokeLine is available 9am to 5pm, Monday to Friday, AEST.

1800 787 653

strokeline@strokefoundation.org.au



Questions?



childhoodstroke@strokefoundation.org.au

