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# “FINDING A WAY”

## A world-first suite of positive psychology videos codeveloped with families of children with rare and severe neurodegenerative conditions

**S**evere neurodevelopmental conditions, with devastating comorbid psychiatric, behavioural, and medical challenges have profound impact on children and families.

Achieving a genetic diagnosis is critical for improving patient outcomes, as it can inform optimal therapies, provide early access to information about developmental comorbidities, and potential opportunities to participate in clinical trials.

Outside the specialist setting, these conditions are poorly understood, and our research has demonstrated that families can experience high levels of distress and uncertainty while undergoing genetic testing and receiving a genetic diagnosis for their child. Challenges can be manifold and include the highly emotional impact of new-onset life-threatening seizures, developmental comorbidities, coupled with an overwhelming amount of complex information families endeavour to absorb during this intensely emotional crisis period. There is a glaring lack of accessible psychosocial care and evidence-based psychological resources for families.

Between 2018 and 2022, a team at UNSW and Sydney Children’s Hospital partnered with families to conduct a translational, codesign program of work. The team

conducted several independent and sequential high-quality research studies including a systematic review, priority setting workshops, in-depth mixed-methods interviews. The research generated novel insights that were used to inform the scope and content of ‘Finding a Way’, a suite of positive psychology resources tailored to address specific psychosocial challenges families face. The current study describes an online mixed-methods pilot evaluation of the co-developed psychological resources.

The online pilot evaluation included the perspectives of 167 parents from 18 countries. Data showed that Finding a Way is highly acceptable and relevant to families’ experiences. The coping strategies recommended were considered practical and achievable. Families valued that ‘Finding a Way’ provided a balanced representation of their experiences. In both the quantitative and qualitative data, parents reported that the resources normalised their emotional experiences and provided helpful suggestions about managing their personal relationships, seeking support and accepting help from others.

“They put into words exactly how I felt through this journey. I actually nearly cried in the second video as I felt someone gets it. That’s me. I also loved how it describes how others cope with the diagnoses and gave me a better understanding of my husband’s role.”



“I was looking for answer on this topic since my son was born, but I couldn’t find them. I really appreciate there is enough money and effort for parent’s mental health.”

Our research revealed that the resources appeared to be of highest relevance to parents’ social-emotional support needs following their child’s initial diagnosis. Frequently reported emotional responses after viewing the resources included feeling “comforted”, “hopeful”, “connected” and “reassured”. Importantly, social support can empower individuals to maintain optimal mental health and parents noted that the content and the quotes in the resources validated their emotional experiences and provided them with a sense of social-emotional connection.

Our results offer preliminary evidence that framing adaptation to a genetic and rare neurodevelopmental condition as a shared challenge has the potential to increase parent and family social-emotional connection and to empower families who feel isolated following their child’s genetic diagnosis.

“I found myself very alone, very afraid and very distraught in the beginning and I still feel the same to some extent. There’s very little focus on helping the families cope. I find the advice in the videos very helpful and approachable”

“They were beautiful. I’m literally in tears as I write this, I wish I’d had access to something similar 4 years ago when we got our child’s diagnosis, but I’m grateful for them today, they’re still just as relevant today as they would have been back then.”

Insights provided by families highlighted the need to broaden the accessibility of psychological resources using a holistic lens, to support families throughout different stages of their child’s rare disease trajectory. Suggestions for improvement included increasing the accessibility of positive psychology resources, reducing barriers to implementation and embedding the resources with links to specialised family services and online platforms.

Psychological resources are increasingly being disseminated online and via smartphone applications as a strategy to improve the accessibility and sustainability of available psychological support. Studies consistently show that individuals are unlikely to engage in psychological resources that drive a notion of positivity without validating their experiences as real, relevant and painful. Finding a Way includes positive psychology resources tailored to satisfy parents’ social-emotional needs, while gently nudging them towards an adaptive solution, harnessing their cognitive abilities and perspectives.

Following family recommendations, Finding a Way is now freely accessible and available to families via the Paediatric Epilepsy Network New South Wales (PENNSW) website (<https://pennsw.schn.health.nsw.gov.au/families/resources/finding-way-video-series>).

PENNSW is an openly accessible website developed by specialists in epilepsy and paediatrics, embedded with educational resources designed to optimise the care of all children and families living with neurological conditions. Hosting the resources online improves the accessibility, enabling engagement with families living in rural or remote locations who are unable to access other services.

In view of the current research findings, we are conducting further research to investigate the feasibility and acceptability of incorporating ‘Finding a Way’ into clinical practice. This research has increased awareness and provided high-quality, innovative, and freely available psychological resources (<https://pennsw.schn.health.nsw.gov.au/families/resources/finding-way-video-series>) for families of children living with severe neurodevelopmental conditions. This family-led body of work suggests that positive psychology resources may prove valuable in the context of rare and multifactorial genetic conditions, when used to complement other treatments and the suite of existing clinical psychology services. Equipping clinicians with accessible evidence-based resources will promote the delivery of integrated and sustainable best practice care, paving the way for improved quality of life for these families.

Finding a Way can be accessed via this link: <https://pennsw.schn.health.nsw.gov.au/families/resources/finding-way-video-series>

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