

LIVED EXPERIENCE: Maternity, Carer: Rare Disease, Bereavement, NICU Palliative Care



Sarah's life transformed when she became the mum of Jay, an incredibly loved, charismatic and joyous son who is one of the few babies in the world to have had this condition. Sarah's pregnancy was classified as high risk after Jay's rare condition was identified in-utero at 20 weeks, however despite this identification Jay's prognosis was not understood. Once Jay was born via emergency caesarean, Sarah and her Canadian partner were faced with the reality that their son wouldn't live past life as a baby, passing away at 6.5 weeks old. In his short life, Jay faced many challenges and charmed everyone who met him and even those who saw his photo. Sarah has a unique lived experience - of something so joyful like the birth of a new child being compounded by the isolation of requiring a trigger warning before sharing her story with others - as it saw her and her family get to know Jay from the Neonatal Intensive Care Unit (NICU) where he received palliative care. After Jay's passing, Sarah compiled a website in memory of Jay, began to build the beginning of his legacy and created a survival guide. She recognises that society does not know how to respond to bereaved parents grieving in diverse ways, and often there aren't adequate holistic supports - one of the motivations behind creating the survival guide, and something Sarah wants to teach. Sarah's journey of motherhood continues in a unique way - through her advocacy; for a better maternity sector - especially for high risk pregnancies, for improved support for congenital disabilities and rare conditions. Sarah is also passionate to create a family-centred 'gold standard' for NICU and paediatric palliative care, modelled off her experience with Jay to ensure people around the world receive the care and memory-making ideas they did at NICU. Even though Sarah's experience has been as a bereaved mother, her understanding of concepts like self-advocacy, loss, grief, radical acceptance, trauma, personal resilience and mindset are transferable to many settings. Sarah is on a mission to use her lived experience to make an incredible global impact.

KEY INFORMATION

Place of Birth: New Zealand
 Current location: Carterton, Wellington Region, New Zealand
 Age: 36 years old
 Cultural Background: New Zealander and Irish
 Language/s: English only
 LGBTQIA+: No
 Diagnoses: High risk pregnancy (Sarah), Rare genetic disorder (Jay)
 Healthcare Access: Primary Health Care, Mental Health, Secondary, Tertiary and Quaternary care

LINKS

- [Jay Mac's Journey](#) - Website in memory of Sarah's son Jay
- [Marketing by Sarah Mac](#) - Sarah's professional marketing and communications website

ACHIEVEMENTS AND EXPERIENCE:

- A Marketing and Communications Specialist.
- Sarah created a website in memory of her son Jay - shared organically and not on social media - and it's been viewed in 16 countries since November 2021.
- Created 'our survival guide' - a support resources for parents and medical professionals navigating rare journeys.
- Raised \$2,145 for The Neonatal Trust for Sarah's birthday (via The Good Registry) in 2021. Sarah is aiming for a goal of \$5000 by the end of 2022.
- Interviewed by Stuff NZ for a feature story about Jay's life and legacy - topics include pregnancy, NICU life and grief. Due to be published April 2022.