Key learnings from Rare Disease Project ECHO®

Series 4, Session 4
From Crisis to Confidence: Rebuilding Trust with Rare Disease Families After Medical Trauma
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Presentation 1: Rebuilding Trust with Rare Disease Families After Medical Trauma

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Belongside Families is a not-for-profit organisation supporting families of children with disability, developmental delay, Autism, rare and genetic conditions. Their approach is shaped by families' real experiences and needs, offering workshops, peer groups, webinars and resources.

Defining medical trauma

Medical trauma refers to the psychological and physiological response to distressing experiences in healthcare settings.

- **'Big T' Trauma**: acute medical events such as severe injury, life-threatening illness, traumatic childbirth, intensive care stays, or witnessing resuscitation.
- **'Little T' trauma**: cumulative experiences including dismissive provider relationships, repeated painful procedures, loss of autonomy, chronic illness management, or systemic failures.

The parental experience of medical trauma

"All of my children are pieces of my heart walking around outside my body. When things happen to them, by default they happen to me too."

- **Advocacy fatigue**: constant vigilance, repeated dismissal, emotional exhaustion.
- **Witnessing trauma**: parents experience trauma alongside their children.
- **Family strain**: balancing medical needs with siblings, spouses, and household responsibilities.
- **Systemic barriers**: financial stress, fragmented care, lack of trauma-informed practice.
- **Societal expectations**: families are expected to recover immediately after crises, often only given fleeting space to process trauma. This is inadequate for the depth of what they've witnessed.
- **Trust–fear balance**: parents must hand their child to the very clinicians who may have previously dismissed them, relying on those same people to provide care despite lingering mistrust.
- **Advocacy as "difficult" behaviour**: when parents push back or escalate concerns, it is not obstruction but a reflection of their role as their child's voice; reframing this helps professionals understand advocacy as expertise.

What makes a difference?:

- **Compassionate clinicians**: those who check in with parents as well as children, acknowledging the whole family's experience.
- **Trauma informed care**: approaches that slow the pace, use calm communication, validate feelings, and offer choice and control.
- **Accessible primary care**: A GP who consistently bulk bills removes financial barriers, ensuring families never delay seeking help because of cost.
- **Respectful paediatric care**: A paediatrician who actively seeks the parent's perspective before decisions, and teaches medical students that parents are the experts, builds trust and validates lived knowledge.
- **Holistic rehabilitation teams**: Services that recognise the interconnections between conditions (for example, scoliosis and respiratory issues) provide integrated care rather than treating problems in isolation.
- **Care coordination support**: Coordinators who manage administrative burdens and medical jargon allow parents to focus on love, connection, and the positive aspects of family life.

Case presentations and discussion

Kelly's son

- Born with a rare congenital condition, with limited guidance provided to parents at birth.
- Underwent surgery at 5 weeks and again at 9 months; endured biweekly casting that caused extreme distress.
- Experienced repeated invasive procedures (imaging, nerve conduction tests, physiotherapy) from infancy.
- **Trauma trigger**: a failed cannulation during surgery at age 4 left him terrified of treatment rooms and anaesthetic masks, creating long-term avoidance behaviours.
- **Family impact**: juggling medical appointments with the needs of older siblings, leading to guilt and emotional strain.

Kelly's daughter

- A finger injury at age 15 escalated into prolonged hospitalisation
- Experienced repeated complications: infected PICC lines, heavy antibiotics, and eventual epilepsy diagnosis.
- Schooling disrupted during critical senior years (Years 11–12), with seizures and cyclic vomiting compounding exhaustion.
- Faced exclusion from appointments due to age-based consent rules, leaving her to navigate complex medical decisions alone.
- **Diagnostic odyssey**: multiple misdiagnoses, delayed referral to dermatology, and eventual rare condition diagnosis after more than a year.
- **Family impact**: overlapping surgeries for siblings in the same week, compounding stress and logistical challenges.

Pam's son

- Experienced 8–12 hospital admissions per year in early childhood, mostly respiratory, each lasting 4–7 days.
- Required repeated IV antibiotics, oxygen, chest physio, and suctioning due to aspiration pneumonia.
- **Feeding challenges**: NG tube caused distress and refusal of oral intake; PEG insertion followed, but he frequently pulled the tube out, requiring repeated hospital visits.
- Underwent multiple major surgeries, including bilateral femoral osteotomy at age 4. Recovery was prolonged and traumatic, with pain avoidance leading to refusal to move for months.
- **Trauma triggers**: small white rooms with curtains and heightened emotions, linked to NG tube reinsertion experiences.
- **Communication challenges**: non-verbal, relies on parents' advocacy and understanding his cues.
- **Critical incident**: post-surgery cast caused a pressure sore nearly reaching the kneecap; parental insistence on further investigation prevented a life-threatening infection.
- **Family impact**: advocacy became a survival skill, with parents needing to push back against dismissive advice to protect their child's life.

Discussion

The audience responded strongly to the lived experiences shared, with reflections highlighting both the emotional impact and practical strategies for improving care.

- Parents emphasised the need for children with complex needs to be prioritised, and for empathy and compassion to be embedded in every interaction.
- Several noted that while they had supportive GPs and paediatricians, hospitals often remained the most distressing and inconsistent part of the system.
- Cannulation protocols: Participants discussed the “two attempts” rule in paediatrics, with escalation to senior clinicians or anaesthetic registrars if needed. Parents valued knowing they could request this upfront.
- Trauma-informed pathways: The “quiet pathway” program for neurodiverse children was highlighted as a promising initiative, reducing sensory overload and distress in hospital settings.
- Clinicians were reminded of the importance of getting down to a child’s level, explaining procedures clearly, and even demonstrating on parents first (e.g., oximeters, ear checks) to build trust.
- Families often leave appointments traumatised when diagnoses are poorly explained. The group stressed the value of bringing an advocate, support worker, or even a trusted friend to appointments to take notes and help process information.
- Participants reinforced that what may be perceived as “difficult” behaviour from parents is often advocacy in action, a necessary safeguard for their child.
- Mothers are frequently dismissed as "just anxious." Some later discover legitimate medical conditions (perimenopause, thyroid) after being told symptoms were psychological. Need for medical education addressing gendered experiences.

Further resources

Links to supportive organisations and resources:

- Belong Side Families (https://belongsidefamilies.org.au/)
- KIIND WA (https://www.kiind.com.au/)
- Quiet Pathway policy (Sydney Children’s Hospitals Network – Westmead
- Trauma-informed care guidance for people with intellectual disability

Educational resources to support timely diagnosis from the RArEST project including:

- National Recommendations for Rare Disease Health Care: recommendation 2 which includes Red Flags for Rare Disease and AI assisted diagnostic platforms
- Rare Disease 101 Australia, an RACGP accredited e learning module
- RACGP check on Rare Diseases [Unit 607]

Read previous summaries of presentations from the Rare Disease Project ECHO series here.

Send us questions, discuss presenting a case, or let us know your go-to resources by emailing us at RareDiseasesNSW@unsw.edu.au.