



RAReST

Rare Disease
Awareness, Education,
Support, and Training



Key learnings from Rare Disease Project ECHO®

Series 1: Session 6 – Whole of life care

Opening presentation

Danielle Headland spoke on cultural safety in rare disease care. She is a Senior Health Promotion Officer at WA Health, Aboriginal Research Officer at Telethon Kids Institute, and Language Champion at Lyfe Languages.

You can find a recording of the presentation [here](#).

For more on whole of life care, check out Lesson 6 in our **Rare Disease 101 Australia module**. Tips on culturally safe care throughout the module. You can register for this short, free CPD on the [Medics for Rare Disease](#) website.

Opening presentation discussion

Discussion was included:

- The importance of:
 - Facilitating people bringing who they want and need to an appointment
 - Being flexible with time, for example fitting in people who arrive early or late, offering appointments at times that suit families
 - Adjusting spaces, for example having welcoming consultation and waiting rooms : looking at alternatives such as large rooms where families can also connect and support each other
- How to assess who are the decision makers and who is doing day to day care in a family. For example, talking with patients ahead of time about who will attend an appointment and being open about wanting to make sure you are involving the important people.
- The importance of taking the time to build rapport

Case presentation

A transition care coordinator presented the case of a seventeen-year-old living in a regional area with Duchenne Muscular Dystrophy. They were preparing to move from paediatric care (in a metropolitan tertiary facility) to adult care (in another metropolitan tertiary facility plus a local hospital). They had six specialists to transition, along with a good general practitioner locally who was able to continue being a trusted, central point of care.

Challenges included:

- A late commencement of the transition process
- Fragmented care across two sites, including challenges sharing extensive medical records
- Needing to travel a long distance to access care
- Long wait times to see new specialists
- Needing specialist approval for key medications that were not previously stocked locally

Case discussion

The case discussion covered:

- How people are identified for transition services, including being referred by hospitals
- GPs are well placed to coordinate, refer, share documentation and advocate for people – however this can be challenging due to the number of people and systems involved, so dedicated transition services to support GPs, families and clinicians are very valuable
- GPs often see multiple members of a family, so are well placed to support everyone's emotional wellbeing as well as their physical health
- More services are now open to using telehealth, facilitating easier and more affordable care for people living far away
- Extra facets that might be considered if the young person was Aboriginal or Torres Strait Islander, including:
 - At Aboriginal Medical Services (AMS) screening is normally done proactively before a consultation which could be very beneficial approach for many rare conditions
 - Greater awareness of rare disease and genetics could be raised amongst both communities and health professionals working at AMS
 - Engaging with existing Aboriginal health services, who often focus on supporting people locally, can help families facing challenges like distance to receive care

Key recommendations that the Project ECHO® participants and experts shared at the end of this case-based discussion were:

- The importance of communication, not coming in with assumptions, taking time to build rapport, and having honest conversations with patients and other healthcare professionals
- There is a lot of room for innovation, such as having a different physical space that encourages community building, or different models of proactive, multidisciplinary care
- The whole family also needs to be thought of, as rare diseases are often multifaceted and last a lifetime, therefore impact many people beyond an individual patient

Useful resources for clinicians and patients include transition information and services in:

- [NSW](#)
- [WA](#)
- [VIC](#)
- [QLD](#), as well as a [nurse navigator](#) for children
- [SA](#)
- [TAS](#)

Thank you to all who attended. Please do not forget to let us know how we did via [a short survey](#), so we can continue to improve.

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