



**RAReST**

Rare Disease  
Awareness, Education,  
Support, and Training



## Key learnings from Rare Disease Project ECHO®

Series 1: Session 2 – 2<sup>nd</sup> November 2022

### Opening presentation

Louise Healy, Education and Advocacy Manager, for [Rare Voices Australia](#) spoke on the topic of ‘Mental Health and Wellbeing: Unique Needs and Resources and Pathways’.

[A recording of the presentation can be found here](#)

### Discussion after the presentation

A rich discussion followed centring on practical steps of how to support families with a suspected or diagnosed rare disease. Louise’s top 10 tips for supporting mental health and wellbeing are summarised in [Lesson 3 of Rare Disease 101 Australia](#).

### How to connect families with the ‘right’ psychologist

It was raised that many people with a rare disease feel that they need to find a psychologist with practical experience of their rare disease. However, this is not possible with over 7,000 individually rare diseases. It is key to help explain to people living with a rare disease that the more important thing is finding a psychologist that ‘clicks’ with them. There are handy search tools such as the [APS website](#) where you can filter on the psychologists’ expertise that may be most relevant to a particular person or family such as skills in supporting people going through chronic traumatic stress, or family based and [strengths based approaches](#).

- ✓ **The importance of destigmatising discussion about mental health and wellbeing with people living with a rare disease: bring it up often and early!**

The importance of bringing up mental health and wellbeing early in the patient-provider relationship, talking about proactive mental health and wellbeing resources and destigmatising mental health impacts was emphasised. For example, checking in at each appointment and talking about mental health and wellbeing digital resources, such as those listed on [Head to Health](#). Using a strengths-based approach – i.e., helping the person and family identify their own resources and strategies that have helped for them before, and which resources or strategies they would like to strengthen with support can be very empowering.

- ✓ **Knowing your ‘go to’ support organisations and referral pathways**

The third e-learning lesson, ‘Mental Health and Wellbeing’, is now live on the Medics 4 Rare Disease Australia module, accessible via [this link](#). This includes practical information and guidance on referral pathways and approaches to supporting mental health and wellbeing. It provides links to great peer-peer support organisations including:

- those that specialise in supporting all members of the family,
- culturally safe and appropriate resources and organisations for people from culturally and linguistically diverse and Aboriginal and Torres Strait Islander communities,
- accessible resources for those with lower health literacy and learning differences.

## Case-based discussion

**Presentation:** A GP (General Practitioner) presented a case of a family where a little boy was investigated for mild developmental delay and hearing loss. His ENT specialist raised with the family that he thought the child had a rare (and life limiting) metabolic condition, [mucopolysaccharidosis](#). The family went through many months of significant anxiety until that condition was eventually thought to be unlikely. The presenter asked for advice on how to communicate possible (even if unlikely) rare diagnoses with families during the diagnostic process.

### The discussion covered:

- different approaches to supporting people through the diagnostic odyssey, and the importance of being humble and explaining that raised diagnoses may turn out to be wrong,
- how important building rapport is and trying to establish what sort of approach patients and families want – for example, their level of health literacy and information seeking style, so that you can meet that as a true partnership,
- that the internet can be a scary place, and often biased to people who are having particularly challenging times. So, guidance on reliable websites can be helpful as well as pointing out that people can come back to you as their health professional to ‘check in’ about information they have found online that worries or confuses them – a follow up appointment can be helpful here if practical.

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

- Talk about mental health and wellbeing impacts openly and proactively from an early stage of the health professional – person/ family relationship.
- Manage expectations about mental health supports, including that although it will be unlikely the psychologist or counsellor will know about an individual’s particular rare disease, they can still support that individual in a person-centred manner.
- Rather than saying ‘don’t Google this’ when a diagnosis or a test is raised, check if they are likely to look online and suggest some credible sources. A follow up appointment with you, or a point of contact if they want to ask questions about what they find online, can provide a helpful safety line.

**Some key resources** discussed over this ECHO® session were:

- [National Strategic Action Plan for Rare Diseases](#)
- [Rare Voices Australia](#) website which includes information about the [RARE Portal](#)
- [RD \(RARE DISEASE\) 101 Australia](#): e-learning platform for rare disease training for medical professionals: Lesson three on mental health and wellbeing is live now
- [Carer’s Gateway](#): free emotional, practical, and financial support for carers
- [Siblings Australia](#): support for siblings of people with chronic conditions
- [Kalparrin](#) and [Kindred](#): peer-peer support organisations, which help support families of children with chronic conditions, including tips to navigate the disability and health sectors
- [Livewire](#): a free online and safe community connecting teens living with illness or disability, and their siblings, in Australia or New Zealand
- [Strengths-Based Nursing and Health Care](#)

Thank you to all who attended. Please do not forget to let us know how we did so we can continue to improve [via this link](#) and please let us know about any of your 'go to' resources you would like to share by emailing us at [RAREST@unsw.edu.au](mailto:RAREST@unsw.edu.au)