

# Top 10 Tips

## for **RARE** Healthcare Providers

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- 1 CHECK**

Ask parents/guardians if they are comfortable having discussions with their child present. They may have questions they simply don't want to ask at this stage in front of their child
  - 2 LISTEN & LISTEN AGAIN**

Help parents to feel that their opinions, experiences and information are valued. They are also an **expert** in the room so take time to listen to their research, observations, and questions. You may both learn from each other on this journey
  - 3 COMMUNICATE**

Be clear - be understood. Medical terminology is great but take the time to explain this terminology to your patient and explain its context in their or their child's care. Think also about appropriate language. Do you need a translator or sign-language interpreter? When talking with children, would social stories, visual timetables or mind maps help?
  - 4 BE HONEST**

Honesty is vital in building trust. This means sometimes admitting that you don't know the answer. Be transparent about research and its future for your patient, research gives hope, and it is your role to manage expectations while allowing patient to know their cause is not forgotten about
  - 5 UPDATE**

Silence can be alarming and frightening, and make patients feel lost. Keep patients up to date, even if it is to say you are still waiting or working on the answers. This can go a long way in alleviating anxiety which is experienced by many living with rare disease
  - 6 SIGNPOST**

Direct your patients to support groups and resources for extended reading. Patients almost universally crave information, make it your responsibility to guide them to reliable sources
  - 7 COORDINATE**

RARE families typically attend appointments with various consultants of which you are one, often telling and retelling their story. Try to work to coordinate appointments and locations to minimise financial/time stresses of attending appointments. Know your patient - remove the need for retelling
  - 8 COLLABORATE**

There is a wealth of information and content held by clinicians, support groups, and patients. Collaboration and the bringing together of this information is vital in providing families complete information - **collaboration is key!**
  - 9 RECAP**

Patients are absorbing a lot of information in any appointment. Be sure to recap, encourage note-taking, and follow up in a few days to ensure vital information is understood and any emerging questions don't have to wait until the next appointment
  - 10 SUPPORT**

Living with RARE can be extremely isolating, and your relationship with your patient is more important than you realise!  
**Treasure exceptions!**