How Can Practitioners Support Families of Children Who Have A Rare Disease?

Learning about and adapting to the life-long needs of a child with a rare disease can be overwhelming. Caregivers and their families have better outcomes when providers understand the range of stressors associated with the diagnosis, use capacity-building coaching to support the family, and encourage caregivers to access support and services, including emotional support as needed.

Help the family organize their priorities by using open-ended questions:

1. What information or support are you looking for?
2. How will you prioritize what you need?
3. What are you doing now to gathering the information and support you need?
4. What ideas do you have for finding information and support?

Support the family with making a plan for next steps. Try asking:

1. How will you decide what you want to do or try?
2. What will you continue doing? What will you adjust?
3. How will you evaluate what is helpful or not helpful?

Provide Caregivers with anticipatory guidance to make the journey smoother.

1. Help families manage health information. Many caregivers find that organizing test results, physician and specialist information, appointment dates and times, onset of new symptoms, and their questions is helpful.

2. Help families consider ways to streamline care. Caregivers may want to use a complete team of specialists, including a social worker or case manager, at one hospital.
3. Help families anticipate how they will clarify and remember instructions. Caregivers can become intimidated and overwhelmed by all the information they are given and may need strategies for getting it in writing and deciding what questions they have.
4. Help caregivers make informed decisions on all aspects of care for their child. Caregivers need all available information when making decisions, including respite and home health care resources.