

Extended Family Discussion Form

TIP: Take some time to think about and complete this form prior to each important conversation with your family or others in your [Lifelong Support Network](#) who will be included in the future care plan for your child. Try to arrange for a quiet place to have your conversation, free of disruption.



Think about what it is that you wish to ask of this person you are preparing to speak with as you complete the information below.

Who is the person you will be talking to about the future care of your loved one with rare epilepsy?

Write their name here:

• **What are the topics you would like to discuss during this conversation?** (Write down questions and topics to discuss in the space below.)

• **What resources do you want to share during the discussion?** There may be specific sections of the C.A.R.E. Binder (such as the Summary Introduction to My Loved One) or other resources that you'll want to have handy. If you are comfortable sharing the information, you can print a copy for them to keep.

TIP: Be mindful of bringing too much material or covering too wide a range of topics during your discussion. It's best to have multiple smaller conversations over time. This approach can help the person you are conversing with from feeling overwhelmed.^{2,3}

• **What questions or concerns does this person have?** (If you know before your conversation, note this information in the space below. You can also capture questions that come up that require follow up after this conversation.)

TIP: This conversation may be difficult for you both. Try to not to react quickly to any responses. Take time to let the information settle in. This person does not know what it's like to walk in your shoes. They may not know how to react so their initial reaction may seem off-putting to you, but this does not mean they do not care or want to support you and the initial reaction may not actually reflect how they truly feel. Give them space to process what you are discussing.^{2,3}



• Is there any follow-up you owe this person from the last conversation you had regarding the long-term care plan for your loved one with rare epilepsy? Note the outstanding items below.

Create a TO-DO list below with any tasks you and this person agree to complete as a result of this conversation.

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What about those outside your extended family and outside your [Lifelong Support Network](#)?

It's important to have conversations with anyone who will be a part of the future care of your child with rare epilepsy and just as important to have conversations with those who may not provide direct care but may be in your [Lifelong Support Network](#) or who may be in your general circle of support.

A good place to start is by having regular conversations about your loved one with rare epilepsy with others in your life. Share how you and your family are doing—what was something funny your child did today? What made them laugh? People who don't live with rare epilepsy don't understand your life. Only those that you are very close with can have an appreciation for the challenges your family faces every day. Having regular conversations with others helps them better understand and may also help them “normalize” rare epilepsy. The more you can talk about your loved one's rare epilepsy and share real-life family stories, the more comfortable people in your support circle will feel. And the better you will feel, too.