Having Conversations With Adult Siblings About Future Care

Some conversations are tough to have when you don't know where to start. And especially when it comes to talking to siblings about the topic of Long-Term Care Plans for their brother or sister with a rare epilepsy. Below are insights shared by rare epilepsy caregivers and adult siblings on the topic of Having Conversations About Future Care.

"Some things have been discussed and some not—it depends on the topic. The big thing for me is the financial thing and when my dad brings it up, I don't want to talk about it. I don't want to learn anything about the financial plan right now. I don't consider myself competent in this area and I know I should learn, but at the same time, I want to avoid it." — *Adult Sibling*

"I know the discussion needs to happen, but it hasn't with my parents. I know my parents have financial (and other) plans, but they haven't shared it. I want to have the conversation now rather than waiting until something happens and having it dumped on me. Even though they've been open about the topic, they have yet to have a conversation about it." — *Adult Sibling*

"I don't want the sibling to take their sibling with rare epilepsy full-time in their own homes." — *Caregiver*

"I'm the older sibling and I already have caregiving responsibilities for my loved one with rare epilepsy yet have not had the conversation about future care. Each day, I don't know what to expect or what will happen, so we live day-to-day. It doesn't even occur to me to think about the future." — *Adult Sibling Caregiver*

Caregivers and adult siblings both agree, it would be so much easier to talk to siblings about the future care of our loved ones with rare epilepsy if there was a list to help get them started. Completing this C.A.R.E. Binder is a great place to start. We've also created an Adult Sibling version of the C.A.R.E. Binder to help introduce different aspects of care for your loved one with rare epilepsy, creating a pathway for more manageable conversations. If a crisis occurs, you will need to have these conversations much sooner.

One caregiver says, if we have a conversation without having the solution, it will just transfer the stress and anxiety downward. The anxiety is paralyzing.

Family members can be unrealistic when they visualize their loved one's future. Primary caregivers feel it's all on them to make the plan.

Parents feel they don't even understand what the future looks like so how can they have this conversation with the sibs?

Parents feel there's no reason to have a conversation without having a solid plan in place first, but the problem is the plan is never solid.

TIP: What else can you do? Reach out to the rare epilepsy organization that serves your community. There are many others who have walked in your shoes. They understand the complex rare epilepsy journey. You may want to join a private rare epilepsy Facebook group that allows caregivers and adult siblings to communicate safely with each other to share ideas. Also think about attending a conference or workshop, if offered in your specific rare epilepsy community. Meeting other caregivers and siblings in person and sharing your journey together can really make a difference.

Caregivers

Caregivers should be the one to bring it up even though the sibling may have been thinking of it long before the conversation starts.

Consider starting the conversation with the caveat that the caregiver doesn't expect the sibling to be the full-time caregiver so the sibling has that out. Especially if their loved one has significant support needs, it can scare the sibling away to think about it and want to avoid discussing.

Caregivers may ask siblings, "How involved do you want to be?"

Explain that the family needs to think about what the future looks like, but that the sibling does not have to personally be the one who is providing the care or making the decisions.

Or, caregivers could start with asking, "Have you thought about it?" The sibling will likely say "yes." Then caregiver can follow up with "What are you envisioning?"

Siblings

Siblings could ask caregivers, “What do you visualize for the future care of my rare epilepsy sibling?"

You can never plan for when things are going to happen, and the plan can be different depending on the "when," but you can have the discussion to get ideas.

As your rare epilepsy loved one ages, comorbidities increase and the burden of planning and care continues to grow on the primary caregiver. Bringing the sibling into that conversation often induces anxiety in the parent.

Often even spouses don’t really understand the care of the loved one with rare epilepsy.

Some siblings are saying, “Don’t worry about the plan, I’ll figure it out,” but parents may not be comfortable with that.

Siblings acknowledge the difficulty in making a plan stating parents don’t have one because there is so much uncertainty. Parents don’t know how to plan. Despite that, siblings want to have the conversation and they want the parents to start the conversation.

Having a list of questions or discussion prompts can help when having difficult conversations. Use the Sibling Discussion Form on the next page to help get your thoughts together beforehand. Bring the form with you to use as a reminder of what you want to say. These types of conversations can be emotional, and so it may be easy to forget to bring up important topics that might be on your mind.

Adult Sibling Discussion Form

This is intended to help prepare or guide the conversation, but is just a suggestion. Only you know what is best for your family.

TIP: Take some time to think about and complete this form prior to each important conversation about the future care for your loved one with rare epilepsy that you have with their sibling. Try to arrange for a quiet place to have your conversation, free of disruption.

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

What resources do I need to share during the discussion? (There may be specific sections of the C.A.R.E. Binder or other resources that you'll want to have handy.)

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 keep the sibling from feeling overwhelmed.

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

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.

Is there any follow-up you owe the sibling 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 the sibling agree to complete as a result of this conversation.

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Having Conversations With Extended Family Members (Or Other People in Your Lifelong Support Network)

Some caregivers are fortunate to have supportive family members nearby to help them care for their loved one with rare epilepsy and their siblings (if any). Some caregivers may have supportive family members, but they live far away so may not be quite as available to provide support. Some families may have family near or far, but their family isn't supportive. Some caregivers may be flying solo with a single primary caregiver and no family support at all. No matter your particular family situation, it's still important to have conversations regarding the long-term and crisis planning for your loved one with rare epilepsy.

TIP: This Having Conversations guide can also be helpful in having conversations outside of your extended family, such as those in your Lifelong Support Network.

As with other future planning, it's best to think about options for your loved one when your family is not in crisis. We discuss putting plans in place in the Crisis Planning Guide in this C.A.R.E. Binder. Once you have a plan, how do you talk about that plan with others in your life?

Consider starting by making a list of those you want to have conversations with about your loved one with rare epilepsy's future care. As you conclude your discussions, check them off the list so you have record of who you need to speak with and who you still need to reach out to.

TIP: As life changes during your family's rare epilepsy journey, the list can change. Feel free to come back to the list at any point to add to or edit it.

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TIP: Beginning by expressing your appreciation for their support is a good way to get your conversation off to a positive start. Taking care of any child takes a village, and this is especially true when that child has a rare epilepsy.

Extended Family Discussion Form

Having a list of questions or discussion prompts can help when having difficult conversations. Use the Extended Family Discussion Form on the next page to help get your thoughts together beforehand. Bring the form with you to use as a reminder of what you want to say. These types of conversations can be difficult so it may be easy to forget to bring up important topics that you want to share.

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.