

## Having Conversations With Healthcare Professionals<sup>2,3</sup>

You may feel like you're just getting the hang of the pediatric care system when you have to start thinking about the medical transition from the pediatric care team to an adult care team for your loved one with rare epilepsy. It may seem like a daunting task—and it is, but you have thoughtfully provided care for your loved one for many years and have overcome many obstacles and you can also be successful with this new challenge.

We hope using this guide can provide you with some of the support you'll need. Throughout this C.A.R.E. Binder, we discuss many different aspects of preparing for the long-term care of your child as they age into adulthood. While it would make sense for the healthcare system to recognize the needs of those with severe disease as they age out of the pediatric system, the reality is that you, as the primary caregiver of your loved one with rare epilepsy, will need to drive the process. You will also likely need to drive the communications and conversation with your child's medical care team—on both sides of the medical transition process, pediatric and adult.

Below you'll find some helpful tips to initiate the process and get the conversation going. You'll also find suggestions on timing—it's just as important to know **what** to discuss as it is **when** to discuss. And as with the other areas we've focused on, planning and preparation are key. Finding time to work on your plans when your family is not in crisis can be helpful; however, even when in crisis, there are sometimes decisions that must be made to continue the care you've so thoughtfully provided throughout your child's journey.

**Timing—when is the best time to start the conversation with your pediatric care team?** You can start conversations around age 13 or even earlier if that is what works for you. It depends on your family's unique situation. Begin by having discussions with your child's primary care physician and neurologist or epileptologist on what to expect and how they can help support the medical transition process. Confirm when your child will age out of their practices, as well as the current medical institution(s) your child is treated at, well ahead of time to determine the timeline you need to follow.

### HCP Conversation Guide Checklist



**TIP:** Consider starting the conversation by letting your child's pediatric care providers know that you have been thinking about transition. Let them know you understand this will be a process that will need advance planning. Thank them in advance for supporting you through this transition process. You don't need to have all the details at this point. The goal for this first conversation is to gain an understanding of the basics so you know how to plan.

**Age 13** Consider starting the conversation by asking your child's primary care provider and neurologist or epileptologist the following:

At what age will my child age out of your practice?

At what age will my child age out of this hospital?

Does this facility have a transition clinic, transition resources or social worker available to me and my child? ☐ YES ☐ NO

How can you and your staff help support the medical transition process?

**Age 14** Check in with your child's primary care provider and neurologist or epileptologist on your child's medical transition plan. Write down any questions you want to discuss:

**Age 15** Check in with your child's primary care provider and neurologist or epileptologist on your child's medical transition plan. Review the [Caregiver Assessment on Medical Transition Readiness Form](#). Are there any areas your child's physician can assist you with? Make a list below:

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**Age 16** Check in with your child's primary care provider and neurologist or epileptologist on your child's medical transition plan. Review the [Caregiver Assessment on Medical Transition Readiness Form](#). Are there any areas your child's physician can assist you with? Make a list below.

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Ask your child's neurologist or epileptologist and primary care provider to provide you with recommendations for an adult neurologist or epileptologist and adult primary care provider and document the information using the [Adult Care Team Provider Referral Form](#).

Once you have some referrals, you are ready to begin your research on finding the best fit for your child. Hopefully, you will identify adult care providers right away, but it may take some time and several phone calls. Use the guide below to help you facilitate discussions with these potential new care providers.

**TIP:** Consider starting the conversation by acknowledging that you understand the adult care provider may be used to working directly with their patients (vs. working with a parent/caregiver). Thank them in advance for being willing to collaborate as a team with you on the care of your child.

**Suggested questions to ask potential new healthcare providers:**

- 1 Do you have experience managing patients with rare epilepsy?
- 2 Do you have experience working with adult patients with intellectual developmental disabilities?
- 3 What accommodations does your office make, if any, for patients with cognitive impairment?
- 4 Are you comfortable and available to join me and my child for an upcoming appointment with our pediatric care provider?  
*Please note, while this is the ideal situation, it can sometimes be a problem with insurance so check with your insurance provider prior to making these arrangements.*
- 5 Are you or your colleagues accessible after hours/weekends/holidays for emergencies?
- 6 Do you accept my child's health insurance or Medicaid/Medicare?
- 7 What are your office hours?
- 8 What is parking like at your office?
- 9 How long do I typically need to wait for an appointment?

Add your own questions here—what is priority to ensure the comfort and care of your child?

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**Age 17** Have your annual medical transition discussion with your child's primary care physician and neurologist or epileptologist. Reconfirm when your child will age out of their practices and the hospital in your current healthcare system to ensure policies you may have previously confirmed have not changed.

Review the Caregiver Assessment on Medical Transition Readiness Form. Are there any areas your child's physician can assist you with? Make a list below.

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Ask your child's neurologist or epileptologist the following and complete the tasks noted:



In preparation for my child's medical transition from a pediatric care team to an adult care team, can you please assist me with completing this [Epilepsy Living & History Form](#)? Have the form with you and offer to email it to the physician to complete at their convenience. Find out if there is additional information the physician needs you to provide. Be certain to respond to the physician's request for any information in a timely manner.

**TIP:** Some families only visit with their neurologist or epileptologist once or twice a year. Make sure you are giving them enough time to help you complete the [Epilepsy Living & History Form](#). Depending on when your child ages out of their practice, you may need to adjust the timing of completing this task.

**Age 18-21** For those loved ones who age out of the pediatric system at age 18, you should have already completed the process.

For all others, at this point, you should be starting, in the middle of, or close to completing the medical transition process. Since it is a process and not something that can happen overnight, it will take time and patience. The goal is to comfortably transition before your child ages out of the system. The target age can be different in each practice and hospital system so you may need to adjust the timing of having conversations and tasks depending on your situation.