

## Caregiver Assessment on Medical Transition Readiness

As we discussed in the C.A.R.E. Binder Guide, many families ask, “When should I start planning?” While this guide targets age 13 as a starting point for transition planning, if your loved one is younger than 13 years old, you can still start the planning process. It’s really never too early to start planning.

When you start to think about the different tasks of each phase of the transition process and the medical transition piece, you may be wondering when the best time is for your child to make that physical transition from the pediatric care team to an adult care team. There is no right or wrong answer here, since every family’s situation is unique.

**TIP:** Consider starting the search for those additional adult providers who will become more frequent in your child’s healthcare journey early in the process. It is important to initiate an encounter (visit) before transitioning your child to an adult care team. The identified adult provider(s) can continue to be included in subsequent visits until the handoff of clinical care has shifted. Note, if not possible to include the adult provider during your child’s visit with their pediatric provider, you can make separate appointments to ensure you begin to build a relationship prior to transitioning to an adult care team.

Some families may focus on a specific age as a target to start or complete the medical transition. This is important because our children will eventually age out of pediatric care facilities. It may also be helpful as you approach this process to consider your child’s medical stability when you think about timing. When it comes to transitioning your child’s medical care from the pediatric care team to an adult care team, it can be less challenging to target this change when your loved one with rare epilepsy has some stability related to their current medical care. For example, if your child is currently experiencing frequent status events, that may be a difficult time to transition the medical care from their pediatric care team to an adult care team. Transitioning your medical care team can be more challenging when your loved one is in constant crisis. That’s not to say it cannot or should not happen—it may be a necessity based on the age of your loved one and the policy of the pediatric facility where your care team is located, but you may be more successful if you try to time this phase of the transition when your child with rare epilepsy is more stable. Note that stability for each family can have different meaning.

**TIP:** Work with your child’s care providers. Having discussions early and often with your pediatric care team is a great way to work collaboratively to minimize the challenges that often come with medical transition to the adult care system. In this C.A.R.E. Binder, you’ll find an [Epilepsy Living & History Form](#). Completing this form with your child’s neurologist or epileptologist is an important first step as you will need to ensure you have all your child’s medical information summarized to share with new adult care providers. We also include resources on how to discuss this topic with healthcare professionals as well as template form letters to help facilitate the introduction of your child to the new potential adult care providers.

The [Medical Transition Readiness Assessment Form](#) below may be able to help facilitate discussions with your child’s healthcare professional to determine the timing that works best for your loved one with rare epilepsy. Every family will encounter challenges during this process, but you can be successful. Please keep in mind, the form below is only meant to be a guide. Only you know what is best for you, your child, and your family.<sup>2,3</sup>

# Medical Transition Readiness Form

**TIP:** Review progress on this form every 6-12 months. The key is to work collaboratively with your child's care team and if possible, target medical transition when your loved one with rare epilepsy is as stable as possible.

As you target the best time for your child to begin their medical transition to adult care, consider the following and evaluate the stability of your child:

- In their current medical care
- In their current daily home routine
- In their current school or day program

Go through the questions/checklist below to help you determine if your family is ready to begin the medical transition process from your child's pediatric care team to their adult care team

**TIP:** You do not need to transition all of your child's medical team at the same time. You may have many members on the care team including physical therapists and others who provide medical care for your child. Consider establishing relationships with an adult primary care provider and neurologist/epileptologist first before transitioning other providers to your child's adult care team. As they get to know you and the needs of your loved one with rare epilepsy, they may be able to help identify other adult providers who may work best to provide the level of care your child requires. **Note:** This approach will only work if you allow sufficient time to settle in with the new adult care providers before your child ages out of their pediatric care facility.



What areas would you like to see more stability prior to medical transition? (Check all that apply.)

☐ Medical care:

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☐ Daily home routine:

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☐ School or day program routine:

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## Medical Provider Transition Checklist:

☐ Find out if there is an age cutoff for any of the therapies your child receives. If so, begin seeking recommendations for providers working with adults.

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- ☐ Medical Records are organized
- ☐ Complete [Epilepsy Living & History Form](#) in this C.A.R.E. Binder with assistance of current pediatric neurologist/epileptologist
- ☐ [Seizure Action Plan](#) for your child is established and up-to-date
- ☐ Identify adult primary care provider (PCP) for your child:

Adult PCP name: \_\_\_\_\_

Adult PCP contact info: \_\_\_\_\_

- ☐ Pediatric/current PCP has discussed your child's history and current status with the identified adult PCP
- ☐ Have at least one in-person engagement with identified adult PCP
- ☐ Identify adult neurologist and/or epileptologist for your child:

Adult neurologist/epileptologist name: \_\_\_\_\_

Adult neurologist/epileptologist contact info: \_\_\_\_\_

- ☐ Pediatric neurologist/epileptologist has discussed your child's history and current status with the identified adult neurologist/epileptologist
- ☐ Have at least one in-person engagement with identified adult neurologist/epileptologist

### Insurance Coverage Considerations Checklist

- ☐ If your child has private insurance, review the policy regarding your child's coverage after the age of 18. Under the 2010 Patient Protection and Affordable Care Act ("Obamacare"), private insurance policies typically cover children under your policy until age 26, but with proof of disability your child can remain on your policy after age 26.

- ☐ If your child already receives Medicaid, understand which programs may change at age 18.

- ☐ If your child does not already receive Medicaid, consider applying after obtaining Supplemental Security Income (SSI). In most states, if you are an SSI recipient, you may automatically be eligible for Medicaid.

**What other criteria is important to your family situation? Is there anything else you need to consider to feel prepared to initiate your child's medical transition from pediatric to adult care providers?**

Note that information below to ensure the needs of your loved one with rare epilepsy and your family are addressed.

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