

LONG-TERM CARE PLANNING FOR ADULTS WITH RARE EPILEPSY

Caring for Adults with Rare Epilepsy  
**C.A.R.E. Binder**  
*Sibling Companion Guide*

A supportive tool to help you implement a future C.A.R.E. plan



Inspired by **patients.**  
Driven by **science.**



# Welcome to the C.A.R.E. Binder Sibling Companion Guide, a resource aimed to help support adult siblings or others who may temporarily or permanently assume the role of primary caregiver for an individual with a rare epilepsy.

The C.A.R.E. Binder is a comprehensive resource that provides support for families when caring for an adult with a rare epilepsy. It addresses complex challenges, such as transitioning loved ones from the pediatric care setting to adult providers, planning for long-term care after age 22, and planning for the time when caregivers are no longer able to provide primary caregiving for their loved one. The C.A.R.E. Binder is a wonderful resource, but it may also be intimidating for those who suddenly find themselves stepping into the shoes of a primary caregiver of an individual with a rare epilepsy. When a transfer of primary caregiving is necessary, it's important, when possible, to keep schedules and routines the same to minimize disruption. Individuals with a rare epilepsy have complex needs. Patience, love, and care will be necessary to ensure the loved one with a rare epilepsy **is** safe—and **feels** safe—during a transfer of primary care.

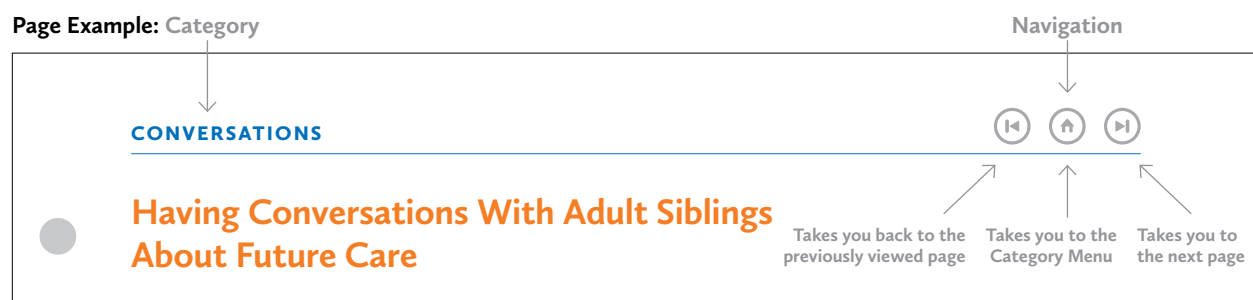
This Companion Guide was developed by a team of rare epilepsy adult siblings to guide you through the C.A.R.E. Binder resource with insights and practical tips to support you with the task of primary caregiving. We hope this Companion Guide will be helpful as you dive into the C.A.R.E. Binder and that it will provide a source of comfort through this potentially challenging time!

## How To Use This Companion Guide

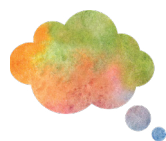
This guide provides an overview of each section of the C.A.R.E. Binder. The discussion topics are broken down into categories. Each category is described in detail with helpful tips included for implementing the daily living and long-term care plan for the individual with a rare epilepsy.

Categories are displayed across the top of the page. On the right of each header are navigation buttons to help you easily access the information.

Page Example: Category



Links found throughout will take you to different sections of this document. To return to the previously viewed page within this document, simply click the back arrow as shown above. You will also find links that will take you to external websites to access additional resources. The HOME button will allow you to jump back to the table of contents on the next page to quickly access the specific topic that interests you.



**Whenever you see this thought cloud icon**, you can read the thoughts of another adult sibling who has walked in your shoes. Even though every person's situation is different, you all share many of the same experiences and challenges. Sometimes just knowing you are not alone on this journey can be comforting. If you get stuck and need assistance, reach out to the patient organization that supports your specific rare epilepsy community. If you're feeling overwhelmed and anxious, it might be helpful to reach out to a healthcare professional to seek support. You don't have to take this on alone. There are many resources available to you—you just need to reach out to ask for help.

Click below to reference the different sections of the online **C.A.R.E. Binder**:

## C.A.R.E. Guide

### Conversations

### Daily Living

### Disease Management

### Long-Term Care Planning

### Medical Transition: Peds to Adult

### Resources

**TIP:** The links to the C.A.R.E. Binder contained in this document will take you to the online version of the C.A.R.E. Binder and are intended to provide reference only. Connect with your parents or other guardians/caregivers to access the version of the C.A.R.E. Binder they have downloaded and completed with the information you'll need, specific to your sibling with rare epilepsy.

Click the links below to skip to the pages in this **Companion Guide** that interest you most.

### Conversations

[Having Conversations With Adult Siblings About Future Care](#)

[Having Conversations With Extended Family Members](#)

[Having Conversations With Healthcare Professionals](#)

[Having Conversations With Others in your Community](#)

### Daily Living

[Activities of Daily Living \(ADLs\): Bathing & Personal Hygiene, Dressing, Feeding & Nutrition Needs, Sleeping Arrangements & Bedtime Routine, Toileting](#)

[Living Arrangements, Mobility, Safety, Crisis Planning, Respite](#)

[Appt. Schedule & Checklist, Day Programs, Supportive Employment](#)

[Communication Needs, Summary Introduction to My Loved One](#)

### Disease Management

[Medical Insurance Information](#)

[Medication Refills & Schedule, Medical Equipment & Supply Refills](#)

[Seizure Action Plan, Things to Avoid](#)

### Long-Term Care Planning

[C.A.R.E. Guide](#)

[Developing a Lifelong Support Network](#)

[Financial Information Form, Legal Checklist](#)

[Long-Term Residential Living](#)

### Medical Transition: Peds to Adult

[Caregiver Assessment on Medical Transition Readiness](#)

[Epilepsy Living & History Form](#)

### Resources

[Acknowledgments](#)

[Glossary of Terms](#)

[Resources](#)

This guide can help you get organized but should not be considered as a substitution for legal, financial or medical advice. It is meant to provide support and guidance only. UCB is not responsible for the content of the resources noted throughout. The resources were updated at the time these documents were finalized (February 2024) and can change at any time. You will need to conduct your own research and seek professional advice. Only you know what is best for your unique family situation.

Note that every situation and family is unique. You, your family, and those closest to you are the ones who know what is best for your loved one with rare epilepsy. The information contained here is intended to provide support as you navigate a transfer of primary (or supportive) caregiving (temporary or permanent). Only you know how best to implement your loved one's daily care and long-term care plans based on your own situation.

## *Dear Adult Sibling,*

Life as a sibling of someone with a rare epilepsy is one filled with love, challenges, and a unique kind of strength that we've all cultivated over the years. Growing up this way is a deeply personal experience, and even though adult sibs share so much in common with one another, each of our journeys is still uniquely our own.

We've seen moments of joy in the smallest victories—whether it's a smile, a laugh, or learning a new skill. But we've also faced the weight of uncertainty and confusion, the struggle of watching our sibling in pain, and the heartache of any setback they face. And though this has likely affected each of us differently, I'd venture to say that most sibs would agree that their brother or sister played a large part in shaping them into who they are today.

As we've grown older, the responsibilities we carry have evolved. As adults, we find ourselves thinking more about the future—about a time when we may need to step into the primary caregiving role for our siblings whether temporarily or permanently. It's a daunting thought, one that comes with a mix of love, duty, and apprehension. For many of us, our parents have been the ones navigating the complexities of our sibling's care for the majority of our lives, but we've always been aware that there may come a time when that responsibility, either directly or indirectly will fall on us.

The idea of taking over the caregiving for our siblings can feel daunting. It's not just about the possibility of physically caring for them, though that's a significant part; it's also about managing the medical decisions, the day-to-day routines, and ensuring that they continue to live a life filled with dignity and love. It's about being their advocate, their protector, and their constant source of support.

*We want you to know that you're not alone in these thoughts and fears. The transition to becoming our sibling's caregiver is one that many of us will face, and it's okay to feel uncertain or anxious about it. It's a huge responsibility, but it's also a continuation of the love and commitment we've always had for them.*

As you prepare for the future and the possibility of taking on this role, whether temporarily or permanently in whatever capacity that may look like for you, it's important to seek out resources, create a plan, and build a network of support. Talk with your parents and with others who have walked this path, and use this guide as a tool to initiate uncomfortable conversations. Understanding the logistical components of caregiving and having a plan in place will hopefully help ease the transition when the time comes.

And remember, as we plan for the future, it's crucial to take care of ourselves first. It's okay to set boundaries, to seek support, and to prioritize our own needs. In doing so, you're not only helping yourself, but you're also ensuring that you can move forward ready for whatever the future of caregiving for your sibling may look like.

**Sophie** (older sister to a brother with Dravet syndrome)

**Jessica** (younger sister to a brother with Lennox-Gastaut Syndrome)

**Murphy** (younger brother to a sister with Dravet syndrome)



## C.A.R.E. Guide

If you are an adult sibling, you have watched your parents care for your brother or sister with a rare epilepsy all of your life. You know how challenging it can be. The C.A.R.E. Guide is meant to be a road map to help your parents with medical transition and long-term care planning. Some of you may already be included in the future care plan for your sibling, while others may not have started this conversation with their family yet or are even actively avoiding it. Wherever you are in this journey, the C.A.R.E. Guide can provide you with valuable information to help with your current situation as well as future planning. Below are a few important things to consider as you read through the guide as well as insights from rare epilepsy adult siblings.

### Transition Planning

Transition Planning takes place over many years. When you begin to engage in the future planning of your brother or sister with rare epilepsy depends on your age and how you feel about being involved. Though your parents may start planning for your sibling with rare epilepsy as young as age 13, you might not be ready then, and that's okay. You may not feel ready at any age, but if you're reading this companion guide, chances are you've already decided to have some level of involvement in your sibling's future care.

Start by reading through the introduction of the [C.A.R.E. Guide](#) and review the [check lists](#) provided for each year. As you read through each checklist, try to think about the timing you feel most comfortable to begin engaging. What tasks on the checklist (if any) would you be interested in to support your parents? If you are ready to take the next step, this might be a good way to start your involvement with your sibling's care either now or in the future.

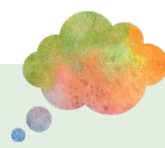
Wherever you are now and how you think about the future is important to discuss with your parents, even if it feels awkward. It can be difficult—no one wants to think about a time when a family member may become incapable of taking care of each other or themselves. The truth is that all families, not just those with special needs, will have to think about future care of a family member at some point in their lives. Being as prepared as you can to face this challenge will help since your sibling with rare epilepsy's needs are complex.

### Long-Term C.A.R.E. Planning

Taking a Deeper Dive into Long-Term C.A.R.E. Planning can be difficult as at first glance, it seems complex, but remember, these tasks happen over time. Breaking down the plan into smaller bites will make the overall task of creating a long-term care plan much more manageable.


At some point in our lives, we will all need to think about the future care for ourselves, our partners/spouses, our parents, and for some families, our children or siblings, especially those with family members who have complex medical or support needs. For siblings with a rare epilepsy, the long-term care planning can be complicated, so it's important to think about what you and your parents want for your sibling well in advance, and hopefully before something happens that puts you in crisis mode.

There are multiple aspects of long-term care planning. As you may have noticed when you reviewed the check lists, there are many tasks included that address your sibling's medical, financial, legal and future housing needs as well. Let's take a deeper dive into each of these topics.



**“Engaging with family in natural conversations as they come up has taken the emotions and heaviness out of transition planning for us. I like to use the phrase ‘How do you eat an elephant? One bite at a time.’ You can’t take on the process all at once. One bite at a time transition planning is much less daunting.”**


**—Adult Sibling**



**“Many parents may be hesitant to involve siblings in these conversations because they don’t want us to feel obligated and want to give us the space to live our own lives. What they might not realize is that we’re often already thinking about it and worrying on our own, likely at a much younger age than they’d expect. If the conversation hasn’t happened yet, it might take YOU bringing it up first. Letting them know that you want to be included can open the door to important discussions and help ease the uncertainty for everyone.”**

**—Adult Sibling**

**“For our loved ones with rare epilepsy. The care plan process can be much more intense than other medical conditions. The impact on our future lives can feel very daunting. The checklist seems long, but you are not alone. Others have walked the path before you and just remember, your loved one with rare epilepsy is right beside you. In all decisions keep them at the forefront because sometimes it feels like they can get lost in the paperwork and minutia. Also through the process, don’t forget to take care of you!” —Adult Sibling**



## Legal


As your parents prepare for the future of your sibling with rare epilepsy, it will be important for them to ensure the appropriate legal paperwork is filed to allow them to act as legal guardian once your sibling turns 18 years old. This is critical to being able to ensure your brother or sister maintains medical and other necessary care. If this does not occur by the time your sibling is 18, it can cause significant issues. If there is one thing you want to make sure you work with your parents on as you plan for the future, it is making sure legal guardianship is established. Read through the sections on [Guardianships and Conservatorships](#) and [Alternatives to Guardianships](#). Also encourage your parents to set up a [Letter of Guidance](#). You may even want to be involved in the process, especially if you may be the one taking care of your brother or sister in the future. Taking these steps at the appropriate time as your sibling ages will be very important. You and your parents may want to consider including you as a guardian along with your parents.

Under federal law, siblings are not eligible for FMLA to care for the sibling unless they are also Legal Guardians. Also, every state has different laws regarding guardianships, so it's important to seek legal advice to ensure you know what is required and when the deadlines are for filing.

## Medical

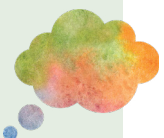
In addition to planning for the medical transition from pediatric providers to an adult care setting, there are other aspects of your sibling’s medical care as you focus on long-term care plans. It’s not something we like to think about, but [Advance Decision Making](#) is important to consider. Understanding what you and your family desire for your sibling before you are in crisis can help when you are facing medically challenging situations. After reading this section of the C.A.R.E. Guide on your own, set up time to sit down with your parents and review together. Take time to talk about what you want for your loved one with rare epilepsy and how you would like them to be treated in the event of a crisis. Having conversations now can really help during what will undoubtedly be a very emotional time for everyone.

**“One thing that has really helped in our family has been actively participating in medical conversations and decisions throughout the rare epilepsy journey. At medical crossroads, surgical decisions, pharmaceutical decisions, etc., we always discussed pros and cons as a family. When I was younger I listened to the conversations and now as an adult I am an active participant. This has helped my understanding of the medical complexity and decision making process which will eventually be my own.”**



**—Adult Sibling**

**“When my brother recently stayed for a week in my home without our parents, I felt confident that I had all the information I needed to care for him. But when a crisis hit and we had to call 911, I quickly realized how much I still relied on them for support. They know his entire medical history in a way I just don’t—they can give a clear, digestible rundown of his diagnosis in seconds, recall every medication he’s had a negative reaction to in relation to his daily meds, and remember all the little details of his medical history that I haven’t fully absorbed. Thankfully they were just a phone call away, but it was a stark reminder of how complex his care truly is. That experience reinforced how important it is to have everything clearly documented so that when the time comes, I have the right information at my fingertips and don’t need to scramble in an already high-stress moment.”**



**—Adult Sibling**

## Financial

This is a section that leaves many adult siblings feeling anxious and stressed. How will you possibly manage the financial demands, ensuring your brother or sister is able to maintain the same level of care your parent(s) has provided? It's something we hear often from adult siblings who may be taking over the care of their brother or sister with rare epilepsy. Again, planning will be key. It's also important to discuss your long-term financial plans with a licensed professional, preferably someone who specializes in special needs trusts and/or long-term care planning. With so many different laws to follow, federal and state, it's important to work with professionals with experience in this area. Read the [Financial and Estate Planning](#) section and make sure you go back to [the checklist](#) to highlight the tasks associated with finances. In addition to what your parents may set up, your sibling may have access to public benefits, such as Supplemental Security Income (SSI) and Medicaid; therefore, there are some decisions that need to be made in advance and actions necessary to ensure your sibling with rare epilepsy maintains the services and benefits they need to continue care long term. Many siblings want to shy away from this topic, but please don't. It can be awkward talking to your parents about money, but it's important. You'll be glad you did.

## Housing

Thinking about where your sibling with rare epilepsy will live is likely top of mind as you consider their future. As you and your family plan, you may explore different possibilities—whether that means bringing them into your home, overseeing their care while they live elsewhere, or coordinating support in another way. If you are grown with a family of your own, and even more so if your sibling has behavioral issues, you may experience increased anxiety around this decision. Remember that there are many ways to create a plan that honors both your sibling's needs and your own household. One such option is to establish a plan that includes some type of residential housing for your sibling. Every family's situation is unique. It may depend on the level of care needed for your brother or sister. It may depend on where you live geographically. It may depend on options available and for some, might be limited. Your sibling may be waiting for years on a waitlist to secure appropriate long-term care housing. Refer again to your [checklist](#) and make sure your parents have put your sibling on all necessary waitlists.

You may also elect to have someone in your home caring full time for your sibling. There are many options and considerations to think about as you discuss what you and your family wish for your loved one, combined with what is available for your situation. Planning well in advance will be necessary.



**“As a child, I was certain that my brother would live with me when we both grew up. I couldn't imagine it any other way. But now, with a family of my own, the answer is less clear cut. While I'm still open to the idea, it's become more complicated. Like many of our brothers and sisters with a rare epilepsy, my brother's care is complex, and at times he goes through stages where his behavior can be quite aggressive. With a young child of my own, I have to ensure that if my brother does live with us, we can provide him with the care and support he deserves while also ensuring the safety of my own family. We don't have all the answers yet, and we're open to many possible outcomes. But I've come to realize that it's important to approach this situation (and really all aspects of his future care) with flexibility. Things can change quickly, and it's essential to know all your options.”**

**— Adult Sibling**



**“The plan here may be fluid and in our family we are dabbling into a spectrum of options as we work on putting the plan together. It's possible my brother may live full time with me in my house, we may sell our house and move into my parents house, or possibly we would find some sort of care facility for him to live in. The goal is for us to know what options are out there and available before the time comes.”**

**— Adult Sibling**



## Conversations

It can be difficult to know how to start conversations that concern your brother's or sister's future. It can be uncomfortable for you and your parents. Most parents don't want to put the responsibility of the future care of their child with rare epilepsy on their other children (or extended family if there aren't siblings). Some siblings want and plan for this time all their lives—they know right from the start that they will be the future primary caregivers for their brother or sister. Some will shy away from conversations and dread the thought of taking on this responsibility. And many are somewhere in between. Wherever you are, whatever you are capable of offering, it's important to have the conversation with your family.

**The C.A.R.E. Binder has a special section to address these difficult conversations.** [Review this section](#) before setting up time to discuss with your family. The conversations about the current and future care of your sibling with a rare epilepsy may happen with medical professionals, your family, including extended family members, and others within your circle of support. There are nuances to approaching conversations with each of these different groups. Let's dive in a bit deeper.

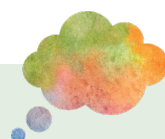
### Having Conversations With Adult Siblings About Future Care

This section provides guidance for your parents in how to approach conversations with **you** and if you are using this resource together, it may help you both feel more prepared to discuss your brother's or sister's future care. Remember, there are many different ways to support the future care of your sibling. Each adult sibling will feel differently about how they want or are capable of being involved. There is no one answer or pathway. And what if there are several adult siblings or willing family members, how will you divide the responsibility? Is that even possible? If your family is spread out geographically, it may be more challenging, but certainly not impossible.

This topic is complex, and it will take many conversations over time to create a thoughtful long-term care plan for your sibling with rare epilepsy. Patience and understanding will be needed. It will also be important to know what future life your parents envision for your brother or sister. **What future life do you envision for yourself?** Making assumptions about what each other wants may cause conflict. Managing expectations on both sides will help with conversations and planning. [Use the conversation form](#) provided in this section to help guide your discussion to ensure you don't forget to talk about what is important to you.


### Having Conversations With Extended Family Members

As you may have already experienced, not all extended family members may be willing to support your sibling's future care plan. Many families do not even have extended family to lean on for support. And for those who do have extended family that is willing to provide support, they may not know and/or may not fully understand the complex care your loved one with rare epilepsy requires. [Preparing for conversations](#) you have with extended family can be helpful to share information about your family's future care plans. As with any of these conversations, use caution in how much information you share to avoid overwhelming the person you're talking to. How much is this person



**"No matter how uncomfortable you are feeling about this conversation, it is guaranteed that your parents are feeling more uncomfortable. They have been worrying about your sibling's future for his or her entire life. Coming to the table to have the conversation is the first big step. You've got this!"**

**—Adult Sibling**



**"My brother currently lives with my parents in a different state, where he's on a waitlist for their state waiver program. If he were to move in with my husband and me at some point, he'd have to restart this wait in a new state and would lose access to the programs and support he'll eventually be set up to receive (unless, of course, we uprooted and moved to him). Over the years, my husband and I have discussed the possibility of moving to various states, but we've always been acutely aware that some states have much weaker waiver programs or long waitlists. This has become a factor in our decision-making, one that most people our age don't typically have to think about. It's a complex issue that really makes us question our own living situation and how we can ensure we're able to care for my brother in the future while also meeting our own family's needs and desires."**

**—Adult Sibling**



already involved in your sibling's life? What is their knowledge of your sibling's condition? Considering this history of your family member and tailoring the discussion to their experience may help you prepare for this conversation. Having patience and managing your expectations of what this person is willing to do to support you in the future care of your sibling with rare epilepsy will be important. At the conclusion of your conversation, the answer you hear may not be the one you had hoped for. This is a real possibility, so be prepared to hear "no." This does not mean your family does not care. Some family members will simply be uncomfortable providing care or support or may not have the capacity. Try not to take this personally. You don't want anyone on your care team who isn't truly invested in caring for your sibling, so if someone you ask to help declines, in the long run, it may be for the best.

## Having Conversations With Others In Your Community

The other people within your community who provide some level of support to you and your family likely are not as knowledgeable about your sibling's rare epilepsy as your family. They may need additional background information to help them understand how to better support you. The [Summary Introduction to My Loved One](#) from the C.A.R.E. Binder as well as the [My Family Is Living With A Rare Epilepsy](#) sections may be helpful.

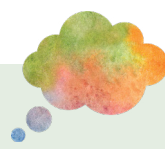
These individuals in your community may not be directly related to the care of your brother or sister, but still provide some level of support and engagement with you, your sibling with rare epilepsy, or another member of your family. While those individuals who fall into this category may not be lending support to the direct care of your sibling, they are still important. They may be friends, neighbors, teachers from school, the person you stop by to see every day at your favorite coffee shop, or others in your community. The support they provide may be directed toward you personally, to your children, if you have any, or other family members. As you will learn later in this guide, [developing a life-long support network](#) is important and will take effort on your part. Your parents likely have already started this process.

The approach to these conversations may be slightly different and the [guide in this section](#) can help you prepare and keep track of those who fall into this category.

## Having Conversations With Healthcare Professionals

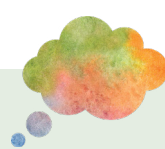
If you are reading this guide, you may already be of the age where you are managing your own healthcare. Even when you do not have any medical concerns, it still takes a lot of effort to keep up with doctor's appointments, manage insurance, and organize everything you need to do to stay healthy. Being able to discuss concerns with your physician is important to your own well-being. You may already have experience working with healthcare professionals to advocate for another person's well-being such as a child (if you have any), your parents, and even your sibling with rare epilepsy. One of the areas where some parents struggle as they tackle the pediatric to adult medical transition is in finding new ways to work with adult healthcare providers who may be used to dealing directly with their patients, not their patients' parents or other guardian. There can be a learning curve on both sides as this process is navigated. Even if you have experience advocating for another individual's medical care, the complex care your brother or sister with rare epilepsy requires can make this a bit trickier to navigate.

Review the [Having Conversations With Healthcare Professionals](#) section in advance of each appointment. Because time in the HCP's office is often limited, it will be important for you to be prepared in advance and determine 1) what is your goal for this appointment? 2) what is outstanding? 3) what concerns do you have today? Using the forms in this section to make sure you stay on track with tasks that need to happen throughout the medical transition journey may be helpful and help guide conversations.



**"One theme that we have found in my family is that people say "let us know what we can do to help" or "we are happy to help" however they don't actually know what to do to help. In times of stress we have tried to come up with small tasks that family can help with, such as running errands or picking up groceries that help to lighten the load. Even something as simple as coming over to spend time with my brother and read him stories can take away some of the emotional load."**

**— Adult Sibling**



**"Have a conversation with someone in the community that you trust and will tell you their opinions. They may provide helpful insight into how you are taking care of your sibling. It may result in you changing some things for the better."**

**— Adult Sibling**

## Daily Living

Many adult siblings who may take on the primary caregiving for their brother or sister with rare epilepsy will likely find the aspects of daily living the most challenging. Since many individuals with rare epilepsy require 24/7 care, even if you are used to taking care of your sibling, caring for your sibling full time while also managing your own life (work, home, health, partners, friends, hobbies, etc.) may be more difficult in the beginning when you are getting used to this new normal. You have grown up with your sibling and have probably been helping to care for your brother or sister for many years. Despite that, it can be a big adjustment taking on the role of primary or supportive caregiver for your sibling with rare epilepsy full time. The [Daily Living](#) section of the C.A.R.E. Binder was developed for families to help manage and document the care routines for their loved one with rare epilepsy. This resource can be invaluable in providing all the information you need. But how do you take this care plan and implement it into your daily life? While it will be different for each individual, below is some guidance to support you in this journey.


### Activities of Daily Living (ADLs):

#### Bathing & Personal Hygiene, Dressing, Feeding & Nutrition Needs, Sleeping Arrangements & Bedtime Routine, Toileting

Each of our sibling's needs with rare epilepsy are unique, however, most do require some level of support when it comes to activities of daily living. If you have been helping your parents with your brother or sister throughout your childhood and into your young adult years, then you are probably pretty familiar with your sibling's routine. But even if that is the case, if you are taking over the primary care of your loved one with rare epilepsy and are preparing to implement their daily care into your life full time, finding a way to provide the level of care your sibling requires may be challenging. This can be especially challenging for those adult siblings who may already have families of their own, and even more so if your sibling requires significant support or has behavioral issues.


The C.A.R.E. Binder provides guidance and forms for your parents, or primary caregiver, to document all aspects of your sibling's ADLs. This step is critical in creating a blueprint for you and others in your family's support circle. It may seem silly to document ADLs with the level of detail contained in the forms, but these details provide information necessary to the care your sibling needs to thrive and the details you need to maintain consistency of care. [This section of the C.A.R.E. Binder](#) may save a lot of time and heartache because this plan was thoughtfully created over the course of your sibling's life by your parents and any deviations in this plan may potentially cause stress to your brother or sister, which in turn will cause you stress. If your parents (or primary caregiver) have not completed this section, it will be in your best interest to ensure they do this sooner rather than later.

If you're not familiar with providing daily care for your sibling, if possible, practice going through your sibling's routine prior to assuming the role of primary or supportive caregiver. Take a day or a few days at a time to spend in your family home, acting as primary caregiver. As you go through the different routines, think about how your sibling's routine might work in your own home (if applicable). What are the things you'll need to adjust to



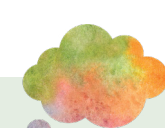
**"If you are not familiar with your sibling's daily routine and don't know where to start, think about what you do for your daily routine and simplify it for your sibling."**

**—Adult Sibling**



**"My adult brother has very scripted and set routines. The ultimate goal would be for these routines to remain as unchanged as possible, but ultimately many things will change when my husband and I become his primary caregivers. We have had many conversations about how we will blend his routine into our routine and how to make them work together. Ultimately some changes will have to be made on both sides. Flexibility is key and I'm sure it will ebb and flow over time."**

**—Adult Sibling**



**"This is something that you may have to learn on the fly and that is totally okay. The first few times don't have to go smoothly and will get better as you continue to work with your sibling."**

**—Adult Sibling**

accommodate the time and space it takes? Ask yourself questions like, can I do this alone? Do I need to hire another caregiver to help me with these tasks? Is my home (if applicable) set up to care for my sibling? Make sure you include this information in your sibling's long-term care plan. We mentioned that deviations in your sibling's care plan may potentially cause stress, but there are many things to think about and you won't be able to consider all the scenarios in advance. You may have the best plan created only to find out that when the time actually arrives, aspects of the plan don't fit for some reason, and you need to pivot and come up with a revised approach.

It's important to be as prepared as possible while also being willing to be flexible and adapt to your sibling's changing needs, as well as your family's unique situation. Implementing your sibling's activities of daily living into your own daily care routine will require patience.

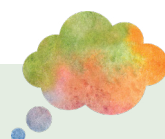
## Living Arrangements, Mobility, Safety, Crisis Planning, Respite

Where does your sibling with rare epilepsy currently live? Do they live in the family home? Or maybe in a residential facility? Some individuals with a rare epilepsy may have a primary and secondary residence. [Make sure your parents or the current primary caregiver has this information documented in the C.A.R.E. Binder.](#)

It's also important to understand your sibling's mobility limitations. Does your brother or sister with a rare epilepsy use a wheelchair or other mobility device? It's important to think about details like this and have a plan in place before it is needed.

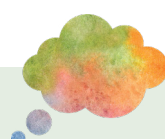
Safety for individuals with a rare epilepsy is something families think about often, especially for those who require 24/7 care. The [Safety](#) section of the C.A.R.E. Binder includes lots of helpful details that describe how your parents or primary caregiver keeps your brother or sister safe in the home where your sibling lives now. And it's not just safety inside the home you'll need to consider. How do you keep your sibling safe in the car or at school? What routines are in place for your brother or sister when they travel with your family into a store or restaurant? If the plan includes your sibling with a rare epilepsy coming to live in your home with you one day, it might make sense to begin making adjustments to your own home in phases over time so that when the time comes for you to become the primary caregiver, you have already begun the process of making your home a safe place for your sibling.

Some individuals with a rare epilepsy have behavioral issues. It may be a non-compliance issue—maybe your sibling refuses to cooperate at times. For some families, it's much more complicated. Some individuals with a rare epilepsy may exhibit behaviors that may cause potential injury to themselves or to someone in the family. This is not an easy issue to manage. You may need help if your sibling with rare epilepsy displays aggressive behavior. Make sure [this section of the C.A.R.E. Binder](#) is completed and that you have documentation to support the plan. Reading this section of the binder and educating yourself is a great way to prepare for these potential challenges. There are even courses you can take on how to de-escalate a situation in the event of a crisis. If behaviors are a concern for you, don't wait until you are in a crisis situation to reach out for help. You can take proactive measures by reaching out in advance to [NAMI \(National Alliance on Mental Illness\)](#). They have excellent resources and toolkits on how to prepare for a mental health crisis. Of course, if you find yourself in a life-threatening situation, go to your nearest psychiatric emergency room or call 911.



**"It has been critically helpful for me to step in as primary caregiver for just short periods of time for my brother—not just for me but for him. He is so set in his routines and when things are done slightly differently it can really throw him off. Having other people, myself included, help him through his routines can be really beneficial to him as well as me. Serving as temporary caregiver for even just an afternoon or evening can be really eye opening to some of the challenges and barriers that may pop up in the future."**

**—Adult Sibling**



**"We all get frustrated from time to time. Just remember to stay calm and remember that your sibling is not doing it on purpose."**

**—Adult Sibling**



Within the Daily Living section, you'll also find a [Crisis Planning Guide](#). As a sibling with a brother or sister with a rare epilepsy, you likely are familiar with being in crisis. We know that the best time to plan for a crisis is when we are not actively in crisis. For this reason, we included a section on crisis planning. This is a difficult topic to consider but it's important to think about and have advance discussions with your parents or primary caregiver of your sibling with a rare epilepsy. Try to carve out some quiet time to talk about the different scenarios that could happen with your brother or sister. Crisis planning includes talking about acute decision making when faced with a life-or-death situation. It includes discussing hospice and other options. And it also includes crisis planning for the primary caregiver. What do you do when suddenly the primary caregiver of your brother or sister with a rare epilepsy is either temporarily or permanently incapacitated and can no longer care for your sibling? In that unfortunate situation, what needs to be done on day one? What needs to be done the first week? What are the priorities to ensure continuity of care for your brother or sister with a rare epilepsy? In the Crisis Planning section of the C.A.R.E. Binder, you'll find a guide with checklists, to help you and your family plan. Make sure you find time to discuss this section with your parents or the primary caregiver. Make sure you document this plan so that you, or anyone else in your family's support circle, can step up to provide the care required for your sibling.

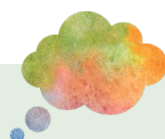
And last, but probably more important, the Daily Living section of the C.A.R.E. Binder includes information on [Respite & Self-Care](#). Please don't skip this section. If you are going to be a supportive or primary caregiver for your brother or sister with a rare epilepsy, you will need to take care of yourself. Please take time to read this section and put your own self-care plan in place. This guide will help you find ways to prioritize yourself as well as identify signs of caregiver burnout. Revisit this section from time to time to ensure you aren't finding yourself in the "struggling" zone. If you are, stop and take a moment to breathe. Reach out to those in your own support circle. Don't be afraid to ask for help.

You are strong and amazing, but you are also human. You cannot do this alone, so please don't try to. It's important to develop your [Lifelong Support Network](#) (which we'll discuss in the [Long-Term Care Planning](#) section). This is your circle-of-support lifeline; however, if you feel an immediate threat to yourself or others, please call 911 immediately for assistance. If you are having suicidal thoughts, please call the National Suicide Prevention Lifeline at 1-800-273-8255.

## Appointment Schedule & Checklist, Day Programs, Supportive Employment

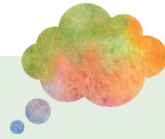
Preparing for and keeping track of appointments will go more smoothly if you have a system in place. Contained in the C.A.R.E. Binder are several forms to help you and your family keep this information organized. The information will also help you prepare for healthcare appointments to ensure all of your sibling's care needs are met. It's important to the supportive or primary caregiver and for anyone who may need to step in to help maintain a consistent level of care for your brother or sister—and keep you organized.

[Day Programs](#) are really important for your brother or sister with a rare epilepsy. Providing opportunities for learning and engagement, no matter your sibling's level of abilities, contributes to their quality of life. Yet it can be difficult to find suitable day programs for your sibling once they age out of the system. Have conversations with your parents or primary caregiver to ensure your brother or sister has been placed on waitlists for programs offered in your area. Please do this as early as possible since it can take *many* years.



**"As a highly sensitive person, planning for potential crisis can be a very difficult conversation for me. My parents were told that my brother wouldn't live past the age of five and now he is almost 40 years old. Crisis planning has been on our parents' minds for our sibling's entire lives. The chats are very emotional but my best advice is to let your parents be your support system through the conversation."**

**—Adult Sibling**



**"Being the primary caregiver for a sibling is tough and you may want to be there 100% of the time, but it is important to take small breaks or find things that you enjoy to do outside of being with your sibling."**

**—Adult Sibling**

## Communication Needs, Summary Introduction to My Loved One

Communicating with individuals with a rare epilepsy can be challenging for those who may not be as familiar with your sibling and the way your brother or sister communicates may change over time. The best place to start is by reviewing the [Communication Needs](#) section of the C.A.R.E. Binder. If you find this section hasn't been completed yet, please have a conversation with your parent (or primary caregiver for your sibling). Not only will be it frustrating for you or others who may be stepping in to care for your sibling, it will be frustrating for your brother or sister if they are not able to communicate their needs. And sometimes, frustration may be expressed through disruptive behaviors which can create additional challenges. Being able to determine when your sibling is happy or sad, frustrated, angry, hungry, scared, in pain, etc. is critical to maintaining their health and wellbeing. And it's important to your health and wellbeing, too.



## Disease Management


Unfortunately, the US healthcare system was not built for individuals with life-long chronic illnesses. Even for healthy individuals, navigating the complexities of healthcare can be difficult and at times, frustrating. If you are planning to provide primary or supportive care to your brother or sister with a rare epilepsy at some point, it will be helpful to stay organized, ensuring consistent care to keep your sibling as medically stable as possible. That's not to say if you stay organized your sibling will remain medically stable, but maintaining medication schedules, doctor's appointments, and other therapies will be helpful in providing a consistent level of care for your sibling. As we all know, with rare epilepsy things may sometimes be unpredictable.

### Medical Insurance Information

It is vital to keep your sibling's medical insurance information up to date, returning any required forms or documents timely, before annual deadlines. Many individuals with rare epilepsy have multiple types of insurance such as private insurance, Medicaid, Medicare or other types of medical insurance. Review the [Medical Insurance Information](#) forms found in the C.A.R.E. Binder with your parents or the primary caregiver of your brother or sister to ensure the information documented is accurate and current. Be certain to update this information every year as policies renew. A lapse in coverage can result in significant out-of-pocket cost.


### Medication Refills & Schedule, Medical Equipment & Supply Refills

You are likely already aware of the numerous medications your sibling may be taking for their rare epilepsy and all the related conditions your brother or sister may be experiencing. You also know how important it is to stick to their [medication schedule](#) as closely as possible. Some medications will be taken on a regular schedule. Some medications may be taken as needed. It's important to document your sibling's medication schedule and to keep this information easily accessible. It can be a lot to manage—keeping track of the schedule, making sure [refills](#) are completed/received on time. You may have to manage several different pharmacies as some medications are not available through your local pharmacy. Some medications are only distributed through specialty pharmacies, which may be delivered via FedEx or other delivery services. Your brother or sister with a rare epilepsy may also require medical equipment such as a g-tube. In addition to keeping up with the equipment, making sure it remains clean and in good working order, you may need to order supplies for the equipment. Keeping track of [medical equipment and supplies](#) is just as important as maintaining your sibling's medication needs. Every aspect of your sibling's care contributes to their wellbeing. There are many details to manage, so again, documenting this information is important. The C.A.R.E. Binder has a [section](#) that contains forms to help you stay organized. Work with your parents if these forms have not been completed or documented in some manner that is readily accessible to you. This also applies to other [supplies](#) your sibling may need such as diapers and other items. Working in partnership with your parents to ensure this information is included with all of the other documentation required for the care of your brother or sister is critical to ensure you and/or others in your family's support circle are able to provide the care your sibling requires. When the time comes for you to step in, you'll be glad you took the time to ensure this information is complete.




**“Over time we have learned that navigating medical insurance can be just as complicated as navigating medical issues. I have found it helpful to talk to my parents about my brother’s insurance and how they have navigated challenges in the past to ensure his needs are met.”**

**— Adult Sibling**



**“Managing medication and equipment can quickly become a full-time job. Make friends with your local pharmacist! They are there to help you and can often work around some things to make something easier for you or give you a great tip. Use the resources around you!”**

**— Adult Sibling**



**“I find keeping a separate calendar and setting alarms helps keep track of when medications need to be taken and refilled.”**

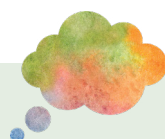
**— Adult Sibling**



## Seizure Action Plan, Things to Avoid

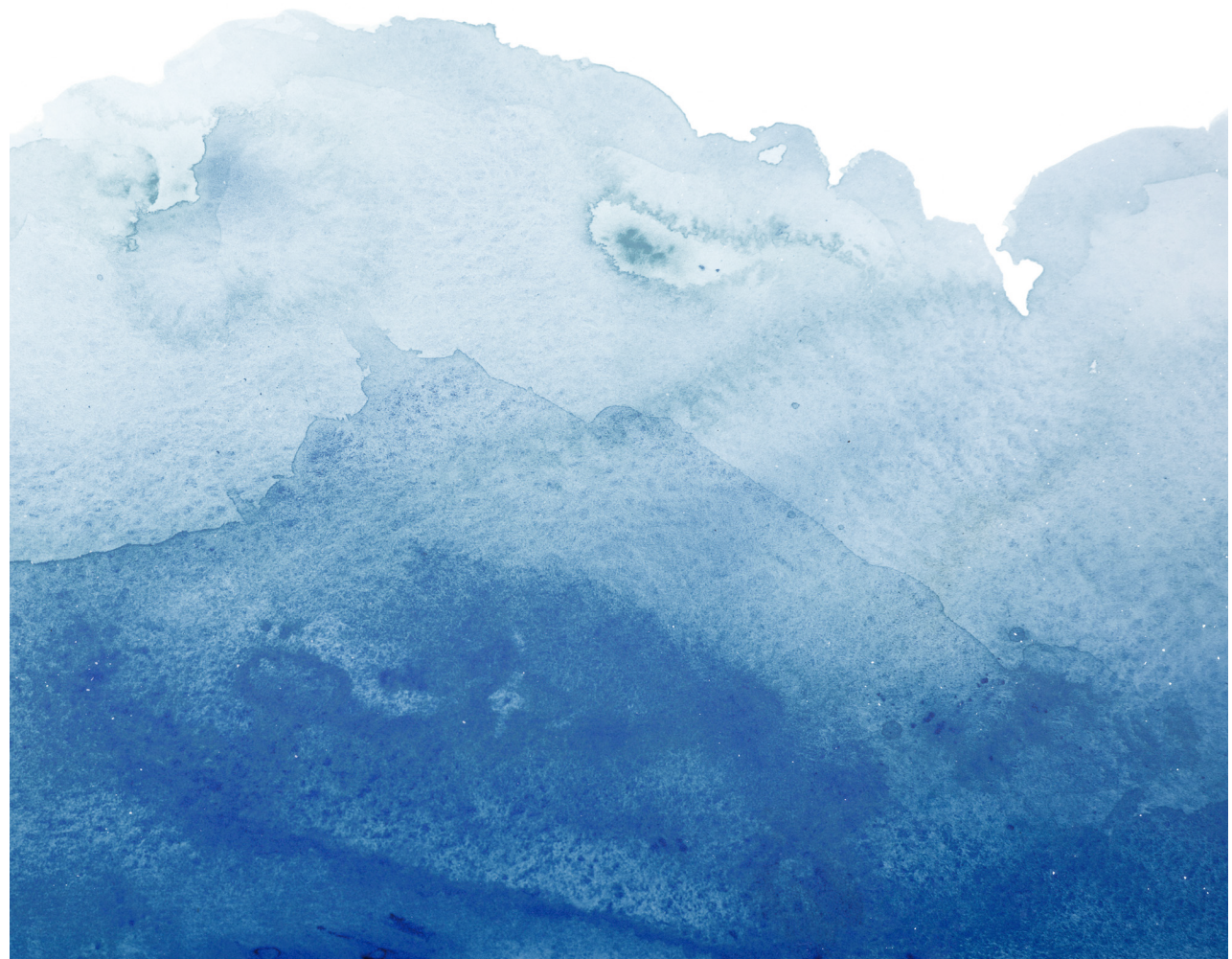
Many families skip the step of creating a seizure action plan. Please make sure your sibling has one that is easily accessible. Caregivers and parents who have cared for their child with rare epilepsy for a long time have their seizure action plan memorized. But others don't. In the case of a seizure emergency, it's critical that others know what to do. It's different for every individual with rare epilepsy—there is no one standard plan. This information is crucial for you and others who may be caring for your sibling and for anyone who is part of your lives—teachers, neighbors, EMS personnel, etc. And this document must be kept up to date as medications and conditions with your sibling change over time. If this hasn't been done, please reach out to your parents or the primary caregiver of your brother or sister and arrange a time to work together to complete a [seizure action plan](#) as soon as possible.

Many individuals have [triggers or things they must avoid](#). Some have food allergies or other sensitivities. Those with a rare epilepsy may be even more sensitive to triggers so it's important to identify what those triggers are and to document the information for anyone who is providing care for your sibling. What happens to your sibling when they are triggered? What should you do? Make sure this information is documented as well. There is not a standard protocol for a trigger response so capturing the information that is specific to your brother or sister is necessary and will help anyone who cares for your sibling ensure their safety and well-being.



**“It is important to go through the seizure plan with each caregiver that is helping your sibling out. Unfortunately, they are not always trained on how to deal with seizures properly.”**

**—Adult Sibling**



## Long-Term Care Planning

There are many different aspects to [long-term care planning](#). Sometimes families delay the planning process because they don't know where to start. Some families think they need to have the whole plan worked out before they can discuss with whomever is identified to step into the primary caregiver's shoes if temporarily or permanently unable to provide the level of care needed for your sibling with rare epilepsy. Some siblings may experience these feelings and/or concerns as well. Creating a plan and transitioning your brother or sister throughout the different phases of their rare epilepsy journey is a process that takes years. No plan will ever be perfect and even the best laid plans can change. Having regular conversations to keep the plan moving is important. It will all come together in time. Each section described below will provide some of the guidance and support you'll need during this process.

### C.A.R.E. Guide


As mentioned at the start of this C.A.R.E. Binder: Sibling Companion Guide, the C.A.R.E. Guide is meant to be a road map to help your parents with medical transition and long-term care planning. Some of you may already be included in the future care plan for your sibling while others may not have started this conversation with your family yet or are even actively avoiding it. Wherever you are in this journey, the C.A.R.E. Guide can provide you with valuable information to help with your current situation as well as future planning. Make sure you start by reviewing the [C.A.R.E. Guide](#) first. Within the [Long-Term Care Planning](#) section of the C.A.R.E. Binder are other important sections that will support you and your family as you work together to develop a long-term care plan for your brother or sister with rare epilepsy.

### Developing a Lifelong Support Network

Growing up with a sibling with a rare epilepsy, you have gained an understanding of the challenges and level of care required for your brother or sister. Caring for an individual with a rare epilepsy is tough to manage on your own. Developing a circle of support throughout is critically important. Developing a lifelong support network and documenting that information can be helpful throughout every phase of the rare epilepsy journey. From your sibling's first seizure, through childhood, adolescence, and into adulthood, your circle of support can provide a lifeline to you and to your family. If this section hasn't been completed by your parents, make time to discuss with them. Take this opportunity to think about the future and the needs of your sibling (as well as your own needs). And make sure that anyone who you have noted in your [Lifelong Support Network](#) knows they are included on the list. Have conversations with them about how they are able and willing to help.


### Financial Information Form, Legal Checklist

This section provides forms you and your family can use to document all your sibling's financial information including any accounts, trusts, insurance policies, other financial resources, and a legal checklist. The section also provides space to note where documents can be located and legal contact information. Make sure this section is completed, updated annually, and that you know where/how to access when needed.




**"Share your care plan and the basics with trusted people around you who understand your situation so they can help out in a pinch."**

*—Adult Sibling*



**"The care guide is a great resource to always fall back on. It is helpful to talk through ideas with others such as friends and family."**


*—Adult Sibling*



**"Always be looking for new and qualified people to help out with your sibling. You can never have too many. A great place to start is universities in your area that have special ed, education, behavioral health, psychology, and teaching programs. From my experience those students seem to be more willing and qualified to engage with you and your sibling."**

*—Adult Sibling*

Long-term residential living may be one of the most challenging to plan for. You don't know when or if your brother or sister may need this type of living arrangement and it can be a frustrating process finding facilities that are able to provide the level of care your sibling requires. Most have years-long waiting lists. It's best to conduct research and get your sibling on a waiting list as early as possible (you can do this when your sibling is still very young). Your family may have decided to provide care within the family home for your brother or sister as long as possible, but you don't know what the future holds. Even if you don't think you'll need it, talk with your parents about getting your sibling on the waiting list (or several waiting lists). In the [C.A.R.E. Binder](#), you'll find a form that provides guidance on what to look for when researching different residential options that you may find helpful as you think about the future care of your sibling.



## LONG-TERM CARE PLANNING

**A. Describe staff training, as well as any ongoing training that you receive.**

**Details:**

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**B. The [survey](#) offers links to Direct Support Professionals (DSP) training. Some of the trainings to look for in the staff may include CPR/BLS first aid and basic nursing, infection disorders, and lifting for DSPs.**

**C. Are there consent and/or release monitored if it's how are they monitored/documented?**

**(11-16) (11-16) Details:**

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**D. How would the right staff monitor nutritional status?**

**Details:**

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**E. Who supervises the staff? Do you have any input in the staff evaluation?/filing?**

**Details:**

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**VEHICULAR CONSIDERATIONS**

**A. Are there any restrictions on utilization?**

**(11-16) (11-16) Details:**

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**B. Is there an open-door policy for family?**

**(11-16) (11-16) Details:**

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**MEDICAL & ACCESSIBILITY CONSIDERATIONS**

**A. Do they have a nurse or other medical personnel on staff?**

**(11-16) (11-16) Details:**

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**B. How are medications handled? Where are the medications stored? Is in a locked cabinet?**

**Details:**

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**C. How do they handle safety with eating, drinking, locking doors, danger, fires, etc.?**

**Details:**

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**D. Are there meals and meal planning "handoff" Ask for sample menu. Do they have a nutritionist on staff? (11-16) (11-16)**

**Details:**

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LONG-TERM CARE PLANNING		20	21	22
<b>6.</b>				
Death				
<b>7.</b>				
Death				
<b>8.</b>				
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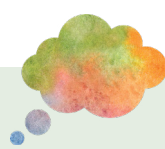


## Medical Transition: Peds To Adult

You may have heard your parents talking about finding care outside the pediatric system once your brother or sister with rare epilepsy ages into adulthood. Most pediatric doctor's offices or clinics and hospitals have a specific age cut-off. We've had adult siblings tell us that this aspect of preparing for the future gives them feelings of anxiety when it comes to the possibility of them taking on the primary caregiver role for their brother or sister. The process of medical transition from peds to adult care is difficult. Caregivers report that one frustrating aspect is finding adult care providers who are willing to accept a patient with a rare epilepsy that has complex medical needs. For these (and many more) reasons, working with your parents to ensure your sibling successfully completes their transition from the pediatric care system to adult healthcare providers before you may potentially take on the role of primary caregiver or even supportive caregiving will be very helpful. Some families start thinking about this process early on and some will wait until it's absolutely necessary. It's hard to know when the right time is to make the transition, but the tools contained in the [C.A.R.E. Binder](#) may be helpful in evaluating and planning for what is in the best interest of your loved ones with rare epilepsy. Have this conversation with your family and if you are able, you might consider offering your help through this process. Your parents will be grateful for your support, and you'll feel better knowing the medical transition has been completed.

### Caregiver Assessment on Medical Transition Readiness

When you do have that conversation with your parents about the peds to adult medical transition for your sibling, you can start by pulling out the [Caregiver Assessment on Medical Transition Readiness](#) section of the C.A.R.E. Binder. This document provides helpful and practical information on what to think about as you consider when and how to tackle medical transition. The needs of your brother or sister with rare epilepsy are complex. Generally speaking, the adult care provider system wasn't designed to care for individuals with intellectual disabilities and/or complex medical needs. And adult providers are used to working with their patients directly, not their patients' caregivers so that can also prove to be challenging. If possible, when parents do have the option to decide when, it's generally best to consider timing medical transition during a period when the individual with rare epilepsy has some medical stability. It can be very challenging to go through the peds to adult medical transition of care when a person is in crisis. Most families will want to keep their loved one in the pediatric care environment as long as possible, which is understandable, but considering transition during a period of medical stability, even if the individual hasn't aged out of the pediatric system, may be helpful and potentially result in a smoother transition. It's important to have these conversations within your family and with your sibling's healthcare team. The Caregiver Assessment on Medical Transition Readiness Form helps provide guidance on what to consider, contains important checklists, and has space to document the process, keeping you organized and on track with your family's long-term care plans for your brother or sister with rare epilepsy.




**“One challenge our family has not anticipated in the adult medical world is the hospital systems policies in regards to individuals with intellectual disabilities and/or complex medical needs. In the midst of a medical emergency, my parents discovered that they were unable to stay overnight in the hospital with my brother; however he is also not able to stay alone due to his complex needs. This created a major issue and stressor during an already intense situation. It may be helpful to look into your local hospital's policies in regards to caregivers and individuals with intellectual disabilities/complex medical needs.”**

**— Adult Sibling**

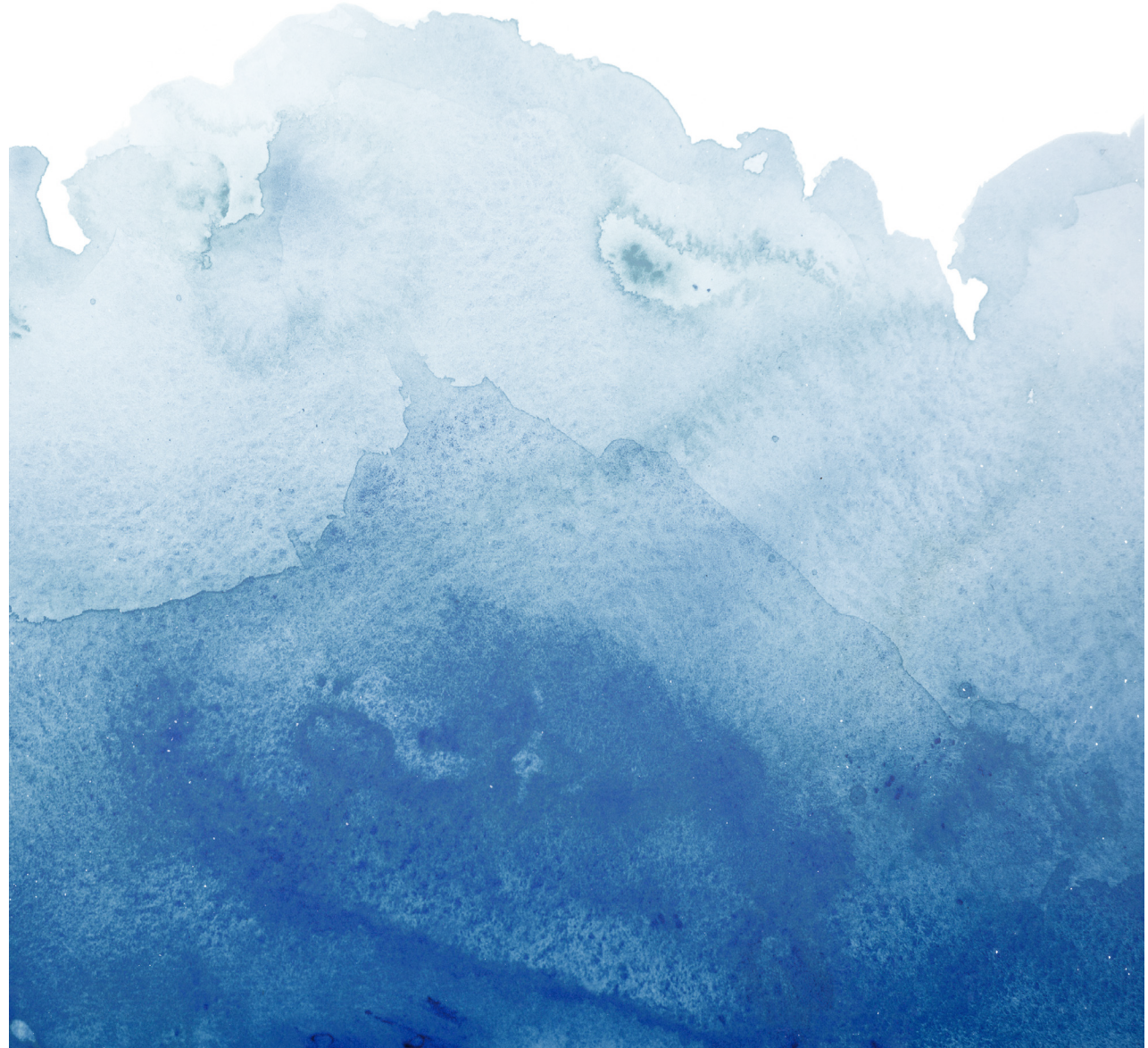
## Epilepsy Living & History Form

Throughout the years, your family has collected many reports and records, documenting the care of your sibling. This is all important history and information that helps families make decisions to provide the best care possible for their loved one with rare epilepsy. And while valuable information, when it comes time for the peds to adult medical transition, families will need a much more consolidated summary to provide to your sibling's new care team of adult healthcare providers. The [Epilepsy Living & History Form](#) was created in collaboration with clinicians and caregivers. It captures all the necessary information required for a medical transition of care. While it is wonderful that you have the C.A.R.E. Binder and many other records your family has collected over the years, it's best to ensure the Epilepsy Living & History Form is completed. Work together with your parents and your sibling's healthcare provider to ensure this form is completed prior to reaching out to potential adult care providers.



**"If the cause of your sibling's rare epilepsy is not known, you may want to talk with your brother's or sister's healthcare team on doing genetic testing and counseling. This can help you determine how you want to move forward with starting a family of your own."**

**—Adult Sibling**





## Resources

The C.A.R.E. Binder also has a [Resources](#) section, which contains additional information you may find helpful. A few notable categories can be found in the table below.

[Acknowledgments](#)[Resources](#)[Glossary of Terms](#)[Yellow Dot Program](#)

Thank you for investing the time to read through this guide. We hope you've found it helpful. As mentioned, thinking about the long-term goals and plans for your brother or sister earlier, rather than later, can be very helpful. If the plan includes a future transfer of primary caregiving to you or another person in your family's circle of support, or if you will be serving in a supportive role in the future care of your sibling, think about ways you can support your family now. What tasks can you be involved with that will help put a future care plan in motion? What tasks can you help your parents complete that helps you feel more confident and prepared to take on the future role of primary or supportive caregiver to your brother or sister? Give it some thought and let your parents know what's on your mind. Don't shy away from these conversations, even though they may be tough at times. Having a brother or sister with a rare epilepsy has given you special gifts. Your experience growing up with your sibling with rare epilepsy made you into this amazing person you are today. You've got this!

While the C.A.R.E. Binder and C.A.R.E. Binder Sibling Companion Guide are comprehensive resource tools, the best support can often be found within your own rare epilepsy community. Connecting to other rare epilepsy caregivers, siblings and others is a great place to start. Reaching out to those who have gone through this journey can be very comforting. Don't hesitate to reach out to the rare epilepsy organization that supports your community to ask for help!

**You are  
not alone!**

**You've  
got this!**

**Don't hesitate  
to reach out  
for help!**