LONG-TERM CARE PLANNING FOR ADULTS WITH RARE EPILEPSY

Caring for Adults with Rare Epilepsy

C.A.R.E. Binder

An organizational tool to help you create a future C.A.R.E. plan

Caring for an individual with a rare epilepsy takes a village. It also takes a village to develop tools to support individuals and the families that care for them. **Please click here** to learn more about the amazing contributions from UCB's collaborating partners.

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

Welcome to the C.A.R.E Binder, a Resource for Families Who Are Caring for Adults with a Rare Epilepsy

This interactive, fillable PDF resource has been created to support families as they begin to work through long-term adult care planning for their loved one with a rare epilepsy. It can guide you through some of the challenges families face as their loved one ages into adulthood.

We know this may not be a complete list, but hopefully it will be a helpful tool to understand what to consider, what to prepare for, and where to get support.

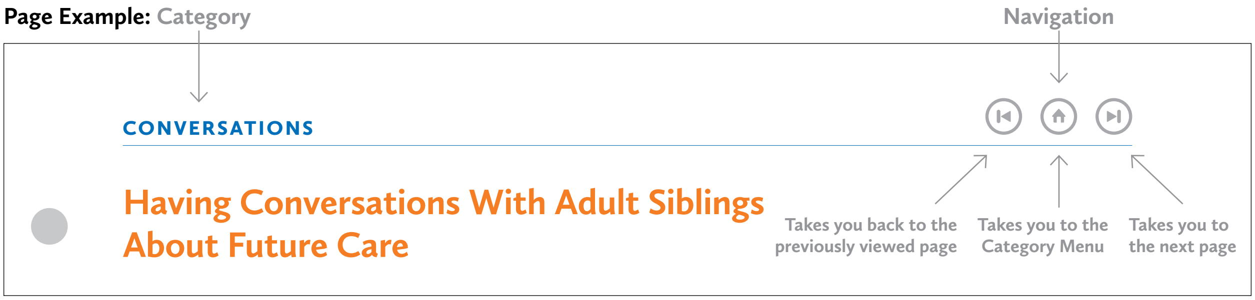
Rare epilepsy patient organizations like the Dravet Syndrome Foundation, Lennox-Gastaut Syndrome (LGS) Foundation, TSC Alliance, and others provide a lifeline to families in their communities and can help you navigate this complex journey. As you work your way through this C.A.R.E. Binder, don't hesitate to reach out to the rare epilepsy patient organization that supports your community to ask for help!

How To Use This C.A.R.E. Binder

The discussion topics are broken down into categories. Each category is displayed across the top of the page.
On the right of each header are navigation buttons to help you easily access the information.

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 below. You will also find links that will take you to external websites to access additional resources. The HOME button will allow you to jump to the Category Menu page to quickly access the specific topic that interests you.

Page Example:



TIPS:

- Changing the order of the pages in this document may cause broken links. It is recommended that you utilize the SAVE AS option when saving this document for editing.
- Interactive links and fillable fields will not work when using printed copies of this document.
- You may use the fillable fields within the electronic PDF and update the data whenever your child's information changes.
- You can save these files on your personal computer, handheld or other device. Conveniently formatted to fit a three-ring binder or other file system, you may also choose to print your completed documents and forms to help stay organized.

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.

How To Use This C.A.R.E. Binder *(continued)*

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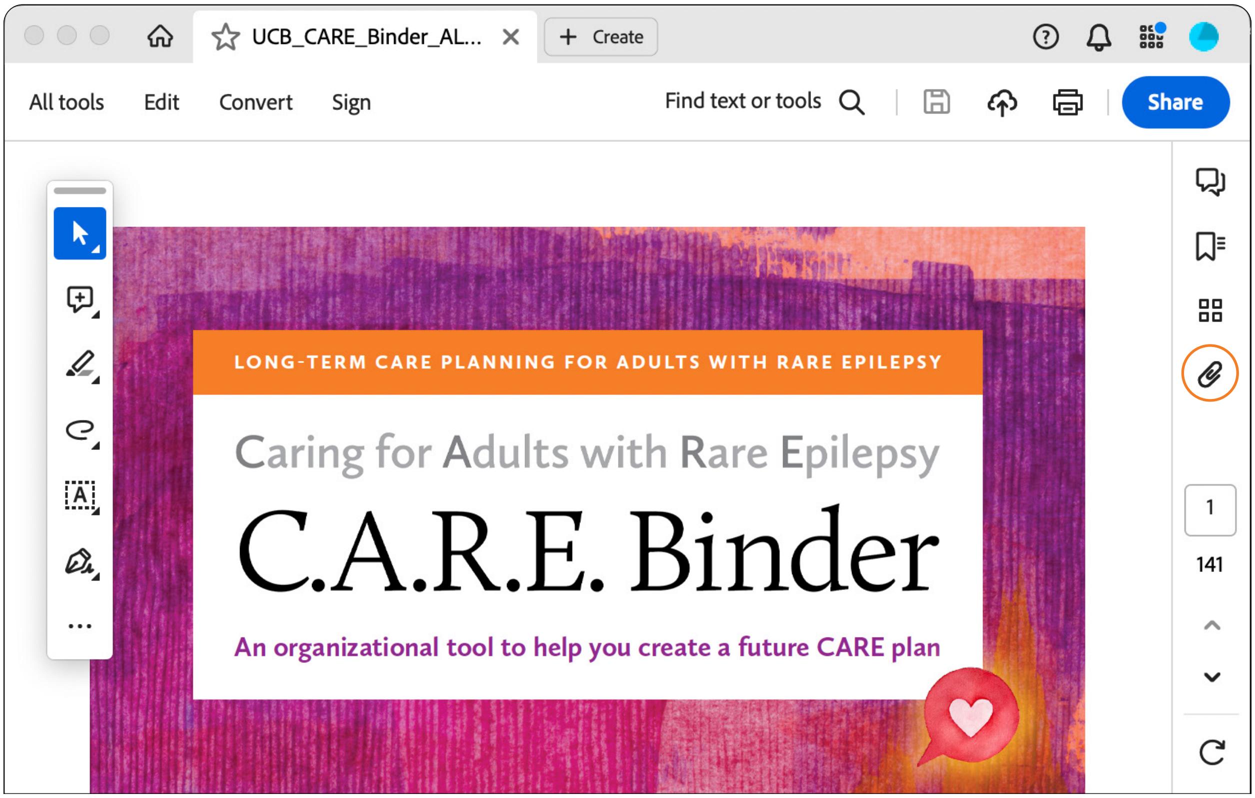


LONG-TERM CARE PLANNING FOR ADULTS WITH RARE EPILEPSY

Caring for Adults with Rare Epilepsy

C.A.R.E. Binder

An organizational tool to help you create a future CARE plan

TIP: In the toolbar of your PDF reader, click on the **Paperclip icon** to access the Attachments section of these resources to add pages as needed. Note, depending on the version of PDF reader you are using, the Paperclip icon may appear on the left of your screen.

Wherever you see this heart icon, click to view a short video message from someone who has walked in your shoes. No one understands better than another rare epilepsy parent or caregiver about the transition challenges you will face on this journey as your child with rare epilepsy ages into adulthood. Click on the heart to hear encouraging messages of inspirations. You are not alone.

Whenever you see this HCP icon, you can click on it to view a short video message from a healthcare professional who cares for families just like yours. While families will drive the planning process for long-term care for their loved ones, your child's healthcare provider team is there to support you. These short insights from caring professionals may provide encouragement and guidance on collaborating with your child's care team as you navigate this phase of your family's rare epilepsy journey.

Be sure to review the C.A.R.E. Guide before diving into the other content as the Guide provides helpful background information and is an important first step toward putting a long-term care plan in place for your loved one with rare epilepsy.

We hope you find these tools helpful!

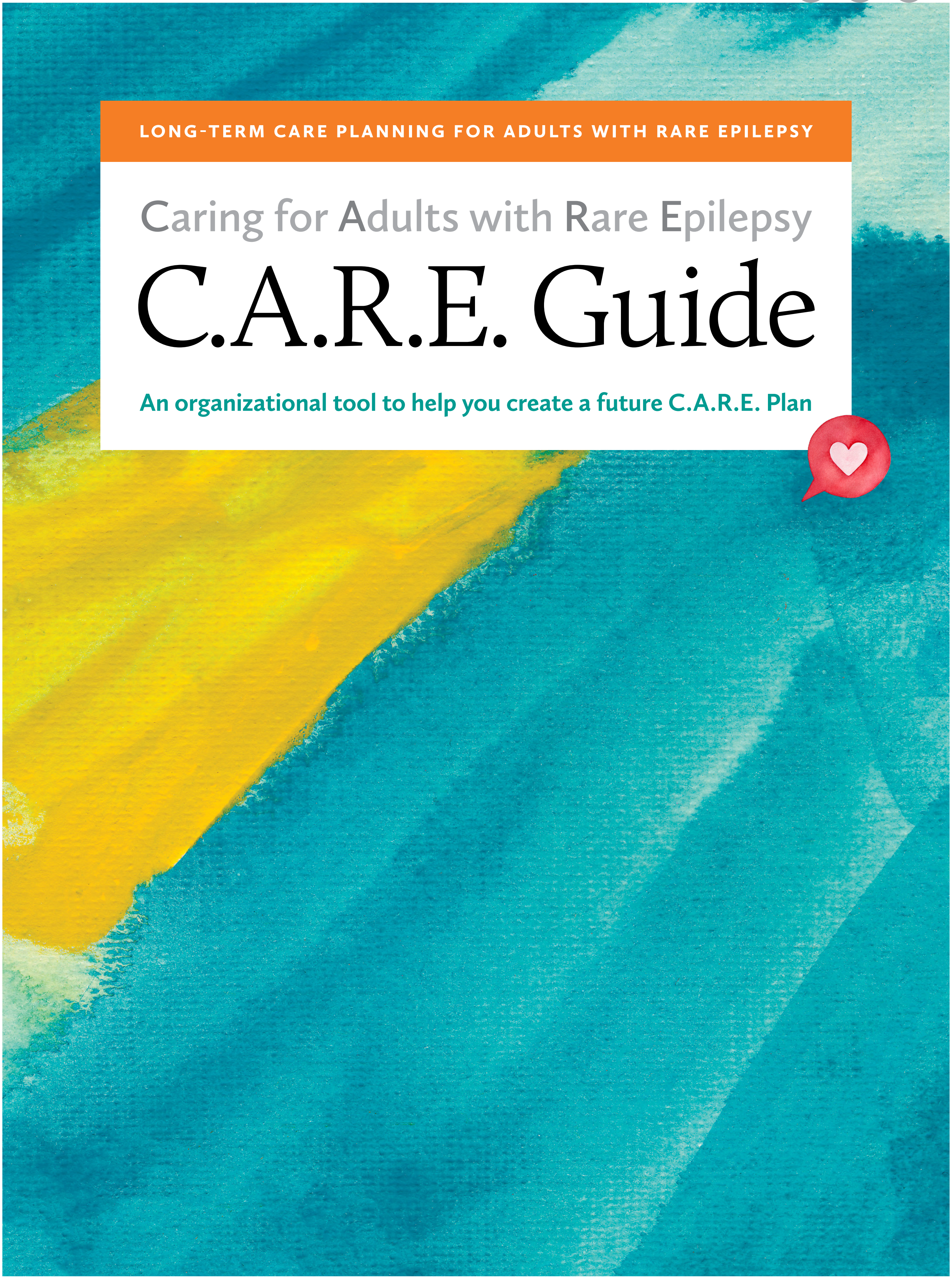
This C.A.R.E. Binder contains forms that allow you to fill in sensitive information. Should you choose to do so, we recommend that you ensure it is stored securely—using strong passwords, trusted devices or cloud storage services, and only share this with trusted individuals.

LONG-TERM CARE PLANNING FOR ADULTS WITH RARE EPILEPSY

Caring for Adults with Rare Epilepsy

C.A.R.E. Guide

An organizational tool to help you create a future C.A.R.E. Plan



C.A.R.E. Guide

Planning for care for your loved one with rare epilepsy or a developmental and epileptic encephalopathy (DEE) may feel daunting at times. If you have feelings of concern or anxiety as you prepare for your loved one's future, rest assured, this is normal.

This guide was created to help you approach the task with the reassurance of knowing, while it may feel that you are on your own during this next phase of your family's rare epilepsy journey, **you are not alone**. There are resources available to you such as patient organizations who offer many types of support services, including connecting you with other patient families who have gone through this process. Patient organizations like the Dravet Syndrome Foundation, Lennox-Gastaut Syndrome (LGS) Foundation, TSC Alliance, and others provide a lifeline to families in their communities. Don't hesitate to reach out to the rare epilepsy patient organization that supports your community to ask for help!

To get started, there are a few phases in the journey ahead as you approach long-term care planning that you'll need to consider for your loved one with rare epilepsy:

Transitioning your loved one from the pediatric care setting to adult care providers
At some point between 18-22, your loved one will age out of pediatric clinic and hospital systems, as well as the public school system. Preparing for and completing this transition is critical as you plan for long-term care for your loved one with rare epilepsy.

Planning for long-term care after age 22 and beyond as your loved one ages
There are several aspects to consider and plan for such as medical, housing options, financial, and legal.

Planning for the time when you are no longer able to provide primary caregiving for your loved one
Crisis planning for unexpected situations + long-term transfer of primary caregiver planning.

Transition Planning[1]

Transition to adulthood is a complex, confusing, and often emotional process. It's also the first important step to plan for as you consider the long-term adult C.A.R.E. Plan for your loved one. For each family, the process can look and feel very different, because our wants and needs for our young adult can differ.

The following information can provide guidance and assist parents through the often intimidating process of transitioning out of young adult care into the world of adult services. Life is challenging enough when caring for a loved one with a rare epilepsy, and our hope is that this information will provide some helpful and timely guidelines to make the process more manageable.

It's important to recognize that not only are each of our experiences different, but each state/county we live in has different rules, timelines, and disability entitlement programs. Please understand this document is just a guide, and some topics will require outside legal or financial assistance. You will also need to research your individual state programs and eligibility. If possible, connect with parents in your community to learn from their experience. Create a team including school teachers, therapists, a case management agency contact in your state, and anyone else who knows and understands your young adult with rare epilepsy.

We encourage you to lean on family, friends, patient organizations, and the broad rare epilepsy and DEE community to help you navigate this new journey. And please share your experiences and learnings with the patient community you are connected to!

TIP: Consider, realistically, how much family, friends, and others are willing and/or able to assist with the care of your loved one now and in the future. Paid life planning professionals can help with these steps if that is an option available to you.

Many families ask, "When should I start planning?" Some families may be feeling they are already behind in the process and are wondering, "Is it too late to 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 thinking about the planning process. If your loved one is older than age 13 and you haven't started discussions with your child's medical team, you can still be successful in transitioning your child. It is important to note that once your child becomes a legal adult at age 18, you may encounter additional obstacles that may be avoided if you complete certain tasks prior to your loved one's 18th birthday.

Starting to think about the following items prior to each phase of the transition process can help you feel more confident and prepared as you enter this part of your loved one's journey. Read through and consider each task. Which tasks are you capable of managing on your own and which tasks will you require assistance to complete? Knowing that upfront will be helpful.

TIP: Click the interactive links to dive into the details and learn more about available resources specific to each task. *Note, not all available resources are noted in this guide. You may need to conduct your own additional research and/or seek professional assistance.*

Age 13

☐ Begin 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 and the hospital in your current healthcare system.

TIP: Make a note to check in annually to discuss your child's medical transition plan with their primary care physician and neurologist or epileptologist.

Age 14

☐ Have your annual medical transition discussion with your child's primary care physician and neurologist or epileptologist.

☐ Contact the rare epilepsy patient organization that supports your community to learn ways to get connected with other rare epilepsy families starting this transition process.

Age 15 (Freshman Year/Grade 9)

☐ Have your annual medical transition discussions with your child's primary care physician and neurologist or epileptologist.

☐ Review the Caregiver Assessment on Medical Transition Readiness Form. Research/Connect with parent disability groups in your community to start to build a network of resources to help you with the transition process.

☐ Consider a Special Needs Trust and/or ABLE account in order to protect assets saved in your child's name and ensure eligibility for Supplemental Security Income (SSI) and Medicaid.

☐ Review bank accounts and financial planning. Money being saved in your child's name may impact access to future financial resources. Check with your financial advisor to be prepared when it's time to submit an SSI application when the child turns 18.

☐ If your child is already enrolled in a state waiver program, begin discussions on what changes to programming may take place after age 18 with your state agency case manager.

☐ If not in a waiver program, complete or update applications with your state disability services agency for adult disability waivers or programs.

☐ Begin exploring day programming and housing options because waiting lists can be several years long.

☐ Explore recreational opportunities or special rec programs in your area, including Special Olympics, Best Buddies, art, music, and/or theater programs.

☐ If you do not already have respite providers, explore options either through your waiver program or other community services.

☐ Make sure your child is receiving life skills planning, and if appropriate, vocational training as a part of their Individualized Education Program (IEP)/transition plan.

☐ If you haven't already, contact the rare epilepsy patient organization that supports your community to learn ways to get connected with other rare epilepsy families starting this transition process.

Age 16 (Sophomore Year/Grade 10)

☐ Have your annual discussion with your child's primary care physician and neurologist or epileptologist. Ask for recommendations for adult primary care provider and adult neurologist and/or epileptologist to begin the process of identifying an adult primary care provider and adult neurologist or epileptologist for your child.

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

TIP: A critical piece is to start searching for those additional adult providers who will become more frequent in your child's healthcare journey. It is important to initiate an encounter (visit) during this age. Adult providers 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.[2,3]

☐ Review the Caregiver Assessment on Medical Transition Readiness Form.

☐ Obtain a state ID from your local Department of Motor Vehicles (DMV).

☐ Review your estate plan to evaluate eligibility for governmental benefits, including Special Needs Trust and/or ABLE account.

TIP: Dependents of military families may be entitled to additional benefits through the Department of Defense. It will be important for these families to secure a disabled ID card for their child with rare epilepsy and to understand what benefits may be offered. You can visit the Survivor Benefit Program Children Only web page on defense.gov to learn more. When working with a financial advisor, it may be beneficial to find someone who understands military family benefits and how those benefits may impact other federal and state programs your child may be entitled to.

☐ Review parents' wills (or other family members' wills) if appropriate, to consider any inheritance money put aside for the child. The method of receipt may affect the child's access to public benefits, such as Supplemental Security Income (SSI) and Medicaid.

☐ Begin to identify professionals needed to allow you to complete guardianship and/or power of attorney paperwork (physician, social worker, and clinical psychologist). Consult with your state agency case manager/educational team for guidance, including who should be guardian. You may also want to discuss this with healthcare providers.

☐ Check with your attorney to see if a healthcare proxy, also known as a durable medical power of attorney, is recommended or required in your state.

☐ Familiarize yourself with the educational process in your school district once your child completes the traditional high school program (post high school programs will vary by age and scope for each state).

☐ Discuss with your child's educational team the timing to complete a neuropsychological evaluation, behavioral testing, and other tests needed for guardianship.

☐ Work with your educational team to start to create peer mentor relationships with high school students. These students can sometimes become great respite workers, in the long term.

☐ Begin to discuss day programming, residential, and work program options with educational staff for their input and suggestions.

☐ Identify community programs and services in your area and state.

☐ Connect with your patient community's online support group to learn from other parents and share advice. They may even offer a group specific to caregivers of adults.

Age 17 (Junior Year/Grade 11)

TIP: This is an important year as there may be tasks that must be completed by the time your child reaches age 18. You may encounter issues if certain tasks are not completed this year. Seek advice from medical, legal, and financial professionals to ensure you and your family are prepared.

☐ Review the Caregiver Assessment on Medical Transition Readiness.

☐ 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. Some patients will age out at 18 years old. If this applies to your child, you must complete the medical transition before your child's 18th birthday.**

☐ Continue the process of working to identify an adult primary care provider and adult neurologist or epileptologist for your child. This is especially critical this year if your child will age out of their current providers' practices at age 18.

☐ Work with your child's neurologist or epileptologist to complete the Epilepsy Living & History Form.

☐ Identify professionals needed to allow you to complete guardianship and/or power of attorney paperwork (physician, social worker, and clinical psychologist).

☐ Complete guardianship and/or power of attorney for financial and medical decisions. You will not be able to petition the court for guardianship until the date of your child's 18th birthday. Forms will expire, so you may not be able to complete them more than 180 days in advance. This can vary by state.

☐ Begin to tour post-high school day and residential programs, and get on waiting lists if necessary, for when your child ages out of their school system (this varies state to state).

☐ Organize all of your child's medical records and other important documents (social security card, birth certificate, IEP, behavior plans, trust documents, SSI papers, guardianship papers, care plan, etc.)

☐ Complete a neuropsychological evaluation, behavioral testing, and any other tests required for guardianship, SSI and/or day program placement.

☐ 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, be aware that some programs change at age 18.

☐ Setup respite services in your home to begin acclimating your child to support being provided in the home by someone other than a parent or family member.

☐ Work with your child's educational team (and your state disability/vocational service agency) to begin to understand potential vocational opportunities and job coaches.

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

☐ Keep detailed notes of your child's seizure activity and care requirements throughout the day. Documenting their multiple daily needs can support your SSI application and waiver programs.

☐ Check with durable medical equipment vendors and home care agencies to see if there are age cutoffs, and if so, determine what agencies can continue to provide the necessary care.

☐ If required by your state, begin the Certified Family Home process if your child will be receiving residential funding for in-home care.

☐ For military families - make sure your child has a military ID card, that it is updated as service status changes, and that you add the disabled dependent to your military survivor benefits.

Age 18 (Senior Year/Grade 12)

☐ Apply for SSI and Medicaid the month **after** your child turns 18 years of age, if applicable. If previously on SSI, complete phone interview.

TIP: If you apply for SSI during your child's birthday month, it will still be considered the parent income and therefore your request will be denied. Check the Compassionate Allowance List for SSI because if your child's diagnosis is on that list it can speed up the approval process.

☐ Set up a joint bank account to hold and track SSI payments. Ask your bank to help you set up a Representative Payee Account, where the account is for the child but actually has the parent name on it. This is a very specific type of account needed for SSI payment. Begin to track SSI spending as required by your state.

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

☐ Contact your state's disability agency - ask your school for a referral to determine eligibility. If approved, work to secure funding and programming. Inquire if agency has transition coordinators on staff.

☐ If your child qualifies for adult services through your state, consider whether you would qualify as a primary care provider and should be compensated (if that is an option in the state where you live). Consider adding another adult in household (could be a sibling or grandparent), in addition to parents, as a primary care provider.

☐ Share guardianship paperwork with schools, health care providers, etc. Also add a copy to your estate and financial files.

☐ If you have a son, he must register for Selective Service, regardless of disability. He may register at the post office or online at www.sss.gov.

☐ If you have a daughter, her primary care physician may recommend for her to have a gynecological exam. If so, arrange with a gynecologist who understands patients with intellectual disabilities and DEEs.

☐Consider getting on a housing waitlist. Section 8 waitlists are long and can be up to 10+ years. This includes Adult Family Homes (A.F.H.s) which are residences where three or four adults who are not related to the operator reside and receive care, treatment or services that are above the level of room and board. They adhere to state regulations and are built or modified with accommodations including but not limited to wheelchair ramps, wider doorways, and lower countertops.

☐Review the Caregiver Assessment on Medical Transition Readiness.

☐If still needed, continue the process of identifying an adult primary care provider and adult neurologist or epileptologist for your child.

Age 19-22 (Transition Services)

☐Research and work with your state agency case manager to identify potential vocational opportunities and day programming options.

☐Work with your child's transition team at their school to finalize IEP/transition goals to ensure focus on skills needed for adult life.

☐ Complete the Caregiver Medical Transition Readiness Form. If ready to proceed, move to the next step below.

☐ Start the process of transitioning your child from their pediatric primary care provider and neurologist or epileptologist. Find adult medical providers and start your outreach to replace all of your child's other current pediatric care team providers.

TIP: All patients will experience transitioning from pediatric to adult care after age 18, even if they have not yet transitioned to adult care providers. The healthcare sector changes, as well as healthcare insurance and the liability and scope of practice of many pediatric providers. Having a solid understanding of what this transition looks like and what you can do to prepare yourself and your child is the best approach to ensuring high quality care across the lifespan. Learning the adult health care system still applies even if your loved one's medical team will not change. As your child becomes an adult, it is important to establish a primary healthcare provider. Internal medicine or comprehensive/complex care management providers (dually certified in pediatrics and internal medicine, known as "Med-Peds certified") are two great places to start as you transition from a pediatrician to adult focused care.[2,3]

☐Create a Letter of Guidance that documents your desires and long-term plans for your child's daily care, finances, medications, caregivers, housing, etc.

☐Begin dialogue with immediate family members on goals/plans for your adult child's future and family involvement in this process.

☐Continue to monitor the waitlists for day programming and residential services that you are interested in.

☐Contact your state disability agency to ensure all adult entitlements are in place. If your state has an adult disability registry, ensure your case manager knows the criticality of receiving any services that may be offered through these programs.

☐Participate in informational sessions/presentations for services for adults with disabilities, often presented by local non-profit disability awareness agencies (such as The Arc) or centers for independent living.

☐Address transportation needs and explore options.

☐ Complete annual guardianship report, as required by your state.

☐ If your child is receiving SSI, track spending and submit an annual SSI report, as required by your state.

☐ At the beginning of the last year of transition, begin moving into adult programs. Complete necessary paperwork for transition and develop overall strategy for transition.

☐ 3-6 months prior to aging out of educational services, finalize your child's overall schedule, which may include day programming, vocational opportunities, volunteer options, and/or recreational programs.

☐ Begin to consider long-term housing options.

☐ Assess medical alert notification devices, if appropriate for your child.

NOTE: For Parent(s) Approaching Age 62 Years—
You will need to make a decision regarding the best age for you to begin receiving social security benefits. Consider the pros and cons for the parent and the child. It is very important for the parent to review his/her social security statement (info can be found on the Social Security Administration website).

Aging Caregiver [2,3]

Growing old is an inevitable part of life, but it can be especially daunting for those who care for individuals with a rare epilepsy. Life as a caregiver (e.g., cooking, managing medicines, medical appointments, therapy, etc.) can lead to decreased attention to your own personal needs, physical wellness and mental health. According to studies on aging caregivers, these significant barriers increase your risk for health problems, decrease quality of life and may cause early death. Caregivers older than 65 have a 63% higher risk[4] of serious health issues due to prolonged emotional and physical stress.

As caregivers age, they may feel haunted by difficult questions ("I'm not going to live forever so who is going to care for my loved one when I am gone?" or, more simply, "Will my loved one be okay?"). These questions are absolutely normal, particularly when confronting mortality. Contemplating this reality as a caregiver is difficult and can awaken some all-too-familiar feelings of fear, worry, loneliness, and isolation.

Your love and dedication as a caregiver to an affected individual with a rare epilepsy is an inspiration and has helped improve quality of care and life for all who are affected by the disease. To help you in your journey as a caregiver, these assembled resources can help you navigate this particularly challenging part of caring for someone with a rare epilepsy. The goal is to help you cope and focus on a practical, actionable care plan for your loved one, while also being vigilant regarding your own personal health and how to identify and mitigate stress brought on by your dedication to care. Please refer to the Respite & Self-Care section of this guide for reminders and supportive information about your own self-care as you care for your loved one with rare epilepsy.

Let's Take a Deeper Dive
into Long-Term C.A.R.E. Planning

Creating a Long-Term C.A.R.E. Plan

Thinking about the future of your adult child with rare epilepsy when you are gone can be challenging and emotional. Some families might feel that planning is not available to them, because they can't afford a lawyer or an estate planner. But, there are many aspects to the planning process that aren't related to money. Regardless of your financial resources, it is important for families to begin by creating a Letter of Guidance and a Lifelong Support Network to ensure your child's quality of life in case you are ever unexpectedly incapacitated or for when you can no longer act as the primary caregiver.

Consider starting with a Letter of Guidance

The Letter of Guidance, written on the premise that no one knows a child better than a parent, contains important information about your loved one's history, likes, dislikes, current health, future needs and emotional status. This letter is a summary or cover letter and is not a legal document but provides key information and instructions about your adult child's preference and routines, and provides guidance to the trustee regarding the family's wishes for your loved one's future.

Completing the Letter of Guidance and attaching all of the appropriate supportive documents should be done as soon as possible and updated regularly to reflect any changes in the loved one's health status or situation. This ensures the letter is ready at any moment should a parent or primary caregiver become ill, become disabled, or die. To help guide your planning, first ask: "During a life transition, what would my child need so his or her daily routine is maintained?" Next, create a vision for your child's life after the transition, including your wishes for future care. You should review and update this document every two years.

TIP: Identify future advocates or guardians – people who will ensure your wishes are carried out.

Documents you should include are listed below:

☐ Identified caregivers / long-term care team

☐ Current medical providers

☐ Contact information for those who are actively involved in your loved one's life (extended family, friends, dentist, social worker, therapists, respite workers, etc.)

☐ Living arrangements (including what supports will be needed)

☐ Medical decisions (including copies of advance directives or end of life orders)

☐ Finances (including the family and patient's public benefits, assets, incomes, trusts, insurance policies, copies of guardianship documents, etc.)

☐ Doctors' contact information and information about the person's medical history (including previous medications used, as well as food or medication allergies)

☐ Current medication list, doses, and administration schedule

☐ List of local and specialty pharmacies and how and when to reorder medications

☐ Day programs / community activities

☐ Support needs in a particular environment (school/day programs, social activities, hospital, home, etc.)

☐ Summary profile on likes/dislikes (what are their favorite things to do; how they react when scared or stressed; things that soothe them in times of distress; etc.)

☐ Daily routines, needs, and supports (including a daily schedule, feeding, toileting, sleep, transportation, and the support/equipment needed for each)

☐ Adaptive equipment needs and vendors (such as seating, special utensils, toothbrush, orthotics, incontinence supplies, seizure monitors, oxygen, etc.)

☐ Details about the person's leisure activities (including religious beliefs, behaviors, interests, friendships, and other important relationships)

☐ List of primary safety concerns (specific situations where extra caution is needed)

☐ Important documents (birth certificate, passport, guardianship papers, wills, trusts, etc.)

☐ Accounts and passwords (for patient portals, SSI, and/or other accounts related to your loved one with rare epilepsy)

TIP: Click here to view an example Letter of Guidance.

Financial and Estate Planning[2,3]

What is financial and estate planning? This topic can seem overwhelming with the breadth of information available. Estate and financial planning typically go hand-in-hand, but they are distinct from each other.

- Financial planning focuses on addressing long-term financial goals. Examples of financial planning include ABLE accounts and Special Needs Trusts. A skilled financial planner can help customize your unique goals while mapping out a financial road map to achieve your goals.
- Estate planning, when conducted with the assistance of an estate planning attorney, helps protect the parents' and patient's assets. An ideal estate plan should include a trust and living will.

TIP: Work with an attorney who specializes in special needs estate planning. Having the proper wills and Special Needs Trust established will assure that current resources and those in the future will not interfere with access to governmental benefits and can provide supplemental income.

It is never too early to start planning for your or your loved one's future. All estate and financial journeys are unique. Some trusts could potentially affect you and your loved one's eligibility for benefits (e.g., Medicaid, Social Security Income, etc.), leaving you or your loved one without a secure financial future, while others can be accessed for service reimbursement. Having a firm understanding will empower you to initiate the process and examine essential questions to help guide and reach your future goals, giving you peace of mind when you are no longer available to care for your loved one.

Achieving a Better Life Act (ABLE)[2,3]

The ABLE account allows families to create tax-free saving accounts that would cover qualified expenses associated with the individual's disability without losing eligibility for public benefits.

Special Needs Trust (SNT) A SNT is a trust that will preserve the individual's eligibility for government-based programs such as Medicaid and Social Security Income (SSI). This happens because the individual, or beneficiary, does not own the assets in the trust, so he/she remains eligible for the benefits. The trustee of the account is able to supplement the beneficiary's government-based benefits but not replace them. An example of these supplemental needs includes sitters, companions, dental and medical expenses that are not covered by either Medicaid or Medicare.

Guardianships and Conservatorships[2,3]

The definition and rules governing Guardianship vs. Conservatorship can vary from state to state; therefore, please seek legal advice for details on your specific state laws and what type of guardianship or conservatorship your loved one will require.

A guardianship – or conservatorship depending on the state – is a legal action that grants an adult legal power to make decisions for another person. Guardianship is a legal means for protecting adults who cannot take care of themselves, make decisions that are in their own best interest or handle their assets.

Generally, the natural guardianship of a minor child terminates at the age of 18, when the parent is no longer the child's legal guardian regardless of a disability. Adults with DEEs are not likely able to give reasoned and well-informed consent when making a decision. Most likely, setting up a guardianship will be necessary for their safety and well-being.

However, keep in mind guardianships can be relatively inflexible as compared to less intrusive options such as trusts. When considering the different types of available financial planning tools, families will need to consider some of the following questions:

- Will your loved one with rare epilepsy now or in the future need residential care? Can your loved one live with a relative, friend, or group home in the future? What are the estimated costs of these arrangements?
- What are your loved one's recreation, leisure time and social needs?
- Does your loved one's disability involve the possibility of declining health with age and potentially more involved healthcare needs and cost?
- What will the transportation costs for this individual be now and in the future? For instance, is a handicapped accessible van needed for their transport?

The following is a brief description of the types of guardianships generally available:

- A Guardian of the Person would be responsible for monitoring the care of your loved one.
- A Guardian of the Estate or Conservatorship should be considered for loved ones with disabilities who are unable to manage their finances and who have income from sources other than benefit checks or have other assets and/or property.
- A Limited Guardianship may limit the guardian's decision making to certain areas, such as decisions about medical treatment, to allow your loved one to continue making his/her own decisions in all other areas. This will not be an option for the majority of our loved ones with rare epilepsy.

- A Temporary Guardian or Conservator may be appointed in an emergency when certain decisions must be made immediately.
- A Letter of Guidance with supportive documentation is an important accompanying document for guardianships.

Alternatives to Guardianships [2,3]

The definition and rules governing Alternatives to Guardianship can vary from state to state; therefore, please seek legal advice for details on your specific state laws and what type of alternative guardianship your loved one will require.

Parents, family members and/or other potential caregivers must carefully consider your loved one's circumstances, including strengths/weaknesses, needs and interests, before deciding to seek guardianship. If your loved one with rare epilepsy is capable of making some but not all decisions, some less-intrusive alternatives to guardianship listed below may be considered:

- A Representative Payee (often a family member, friend, or nonprofit agency) can be named to manage the funds of a person with a disability who receives government benefits checks, such as SSI and SSDI (Social Security Disability Insurance).

TIP: The Social Security Administration (SSA) has two excellent resources to help you apply for SSDI: Child Disability Starter Kit and Adult Disability Starter Kit. It is also possible to hire someone at a law firm, or other individual who offers these services, who can work with you to obtain the needed information and to act as a representative for your child to complete this paperwork.

- A Durable Power of Attorney for Property is useful for individuals with mild or moderate disabilities who are capable of choosing another person to handle their money.
- A Durable Power of Attorney for Health Care or Medical Power of Attorney, also known as a Health Care Proxy, should be considered for individuals who are disabled and who can make some, but not all health care decisions. This is a legal document that enables a competent individual (the "principal") to designate a health care agent to make health care decisions should the individual become incompetent to make them.
- An Appointment of Advocate and Authorization is a customized power of attorney that allows an individual with a disability to designate an agent to advocate on his/her behalf with administrative agencies such as your state's Department of Developmental Services, Department of Human Services, Medicaid, local education authorities and any other state or federal agency from which an individual is receiving services.

As individuals and their families consider the different legal planning tools that work best for their situation, keep in mind the Social Security Administration (SSA) will only speak with a representative payee with regard to a person's benefit checks and will not speak with an agent who has been designated as a durable power of attorney for health care or advocate for the individual with a disability.

Legal assistance is sometimes needed to assist with certain barriers or challenges that are unique to your situation for appropriate resolution. We cannot endorse an individual or organization.

Housing Considerations[2,3]

Caring for your loved one at home

Caring for an individual with complex medical needs can be emotionally and physically exhausting for the caregiver. Depending on the needs, the countless doctor appointments, therapy services, medicines and personal care requirements may create constant worry and stress for the caregiver. Even with the best support system, this can be overwhelming. Depending on your insurance benefits, home health services may be an option. For more information about home health services, contact your local Department of Health and Human Services and request a caseworker, if you don't already have one.

What are home health services?

Home health services are available 365 days a year, 24 hours a day to qualified individuals based on what the needs are and what insurance is willing to cover. Knowing that each case and individual has different needs, home health services can vary from qualified nurses, physical therapists, occupational therapists, speech therapists and even social workers. If your loved one does not need nursing care, home health services can also provide personal care services with daily activities such as bathing, toileting, eating, dressing, exercise and even playing. Home health care professionals can also assist with family outings, school activities and even respite care for the parents.

How do I pay for these services?

Some insurance companies will help with the cost of home health services depending on the disability. State insurances, like Medicaid, may also cover up to a certain number of hours/days per week or a specific monetary allotment. In addition, each state differs in hours, wages, hiring and services that home health services can provide. Please note there is a difference in Medicaid coverage by state. It is best to contact your local Department of Health and Human Services for more information.

Where do I find home health services?

The first step will be to contact your state's Department of Health and Human Services and request a caseworker if you do not already have one. During this conversation make sure you are clear about your particular situation, needs, and struggles. A caseworker will come to assess the environment, needs, and situation. Once this is completed and approved you will be given a list of home health care agencies to contact. In some cases, states will allow you to hire someone yourself and submit for payment. And some states will even allow **you** to be the caregiver that provides this service for your loved one, including being compensated for providing this service. In either case, please make sure to thoroughly vet the agency and/or individual to ensure they are the best fit for your loved one. Make sure to ask about accreditation, required training, background checks, screening, experience, and reliability when you are researching different providers and agencies.

Residential programs

During the transition phase and estate planning, individuals and families should consider housing options that best serve the needs of the adult with rare epilepsy. These needs can vary between each individual and family. It is important to research the options available in your state before the time they are needed. While all states receive federal funding to provide these services, options vary from state to state, and many have long wait lists.

There are many things to consider when thinking about housing options such as independent living, semi-independent, and residential housing communities that may include 24-hour care facilities including nursing homes and long-term living facilities. For those who will live at home, other options are available such as skill development and adult day programs.

Public housing

Through the Section 811 Supportive Housing for Persons with Disabilities program, the U.S. Department of Housing and Urban Development (HUD) provides funding to develop and subsidize rental housing with the availability of supportive services for very low- and extremely low-income adults with disabilities.

Section 811

The newly reformed Section 811 program is authorized to operate in two ways: (1) the traditional way, by providing interest-free capital advances and operating subsidies to nonprofit developers of affordable housing for persons with disabilities; and (2) providing project rental assistance to state housing agencies.

Advance Decision Making[2,3]

Advance decision making is a process in which you can proactively plan out your or your loved one's wishes on end-of-life treatments and interventions, sometimes called an "advance directive." Ideally, this should be planned or discussed with your child's physician before it becomes medically urgent. Advance directives provide a roadmap of how to carry out difficult tasks during a difficult situation. These directives can provide peace and comfort to those who have to act in the best interest of their loved ones. An advance directive is a legal document that should be part of your estate planning. The difference between legal documents and living wishes can both be honored in a time of need.

Having an advance directive in place is especially important when caring for someone with special needs.

It's normal to experience many emotions including fear, doubt and guilt during this process. Thinking ahead proactively about these difficult choices can help avoid stress when emotions and doubt threaten to drive decision making. It is important for the caregivers to have a clear understanding of their loved one's baseline behaviors and quality of life. If your loved one has physical and/or cognitive disabilities, it is incredibly helpful to your healthcare team if you create a plan that outlines the best ways to communicate with your loved one should he/she be admitted to a hospital.

It's important to understand you are not alone during this time. It feels wrong to accept loss, but there's also a great act of kindness in helping your loved one pass with dignity. Deciding to have these difficult conversations earlier might be hard, but it is much harder to think clearly during a crisis. Having a plan in case of a serious illness is okay and can look different for each family. If your loved one is younger, it may be better to discuss only one or two topics at a time.

As you process and navigate this phase, remember all decisions including hospice and do-not-resuscitate (DNR) orders can be revoked at any time. Having a plan in place doesn't mean you're irreversibly committed to each decision – it is essentially a starting place meant to provide support, not stress, and it can be adjusted appropriately according to your situation.

Advance decision making planning considerations

Take the time to develop a care plan for current and possible future challenges. The purpose of planning is to help guide your decisions in the event of an acute situation in a stressful time when emotions, fears, doubts and guilt can take over and cloud your judgement. NO decision is permanent, so if you choose to change your decision at any given time along the healthcare journey, all prior decisions can be revoked if you are the legal caregiver or guardian.

Those who have legal medical power of attorney or conservatorship/guardianship would be the legal representative to make end-of-life decisions and carry out wishes that have already been discussed, which can offer comfort to those responsible during these times.

This plan helps identify the decision making process for the entire caregiver team. It is important to understand the development of the plan is a process, because not all situations are relevant and can be addressed over time. The plan is unique to the caregiver's personality and the loved one's condition. There are no right or wrong decisions. It is never too early to discuss these difficult situations.

Things to consider to be a part of a legal document or discussed with the caregiver team (family) include:

Nutrition, food and hydration

- Situations where alternative routes include a nasogastric tube or more permanent PEG-tube. These are both invasive, yet minor procedures. Both are performed at the bedside. Once your loved one has recovered, these can both be removed and typical nutrition feeding routes can be resumed.
- Situations involving decisions of withholding certain nutrition interventions. This is more common during irreversible situations when the end of life is being discussed. During the dying transition, the desire or metabolic needs for food or water change. It is important not to force food or water during this time. Allow the person to decide the timing and amount of food consumed. It is about comfort, not nutrition. Forcing food can have unfortunate consequences such as aspiration (food accidentally goes down airway).

Symptom control and management

- **Physical areas**
  - **Pain regimen:** How to identify pain – is it verbalized or through facial or body cues? What is acceptable and safe? When is comfort your main priority over treatment? Under some situations pain medication can be withheld to maintain basic life function. There is never a "giving up" period. Care goals change based on all the information in specific, unique situations.
  - **Infection treatment and management:** Are there situations during care where you would not want antibiotics, wound therapy, surgical debridement, wound vacs, etc.?
  - **Acute issues such as breathing and neurological function:** Are there situations where you would not want advanced life support?
  - **Blood transfusions:** Is this acceptable treatment or are there religious or personal beliefs that restrict this option?
- **Psychological areas**
  - How to provide comfort and support especially if your loved one is nonverbal during difficult times?
  - What is a source of comfort for your loved one, such as a special blanket, pillow, stuffed animal or book?
- **Spiritual support areas**
  - Are there spiritual needs necessary during difficult times?

Resuscitation/"life support" interventions

- **Do not resuscitate/do not intubate (DNR/DNI):** This means there will be no medical interventions by medical personnel if core basic functions have stopped such as no longer having a heartbeat or absence of breathing.
- **Full code:** This is where all life-saving interventions would be completed by medical personnel in the event the heart or breathing stopped. These interventions include chest compressions (pumping on the chest wall), intubation (a breathing tube), defibrillation (shocking with electric pads) and medications (given in efforts to reverse fatal arrhythmias, or to regain a heartbeat).
- **Partial code:** This is when a family/patient requests less than the full code protocol for a cardiopulmonary arrest.
- **Chemical code:** This means only allowing medications. The patient's family doesn't want CPR and doesn't want their loved one to be intubated and kept on a ventilator. However, they want all their loved one's conditions to be treated with pharmacotherapy and other forms of therapy as best as possible.

- **Acute dialysis:** This intervention can be done due to an acute illness in someone who is susceptible to kidney failure. However, this can also occur in situations where the body has started to shut down and the kidneys are no longer processing in a way to sustain life. It would be important to understand the situation to be able to navigate if this intervention should occur. Regardless, there are some who might feel this option would not be in the best interest of their loved one regardless of the etiology. All decisions are unique and should never be compared to others even with the same rare disease or other diagnosis.

These interventions can be unique and specific to you or your loved one. These interventions can be all of the above, none or certain in-between varieties based upon your wishes. You have the right to use a full code (all elements above carried out) or a partial code where you can select which elements you do and do not want carried out. You can also just request a chemical code, where life-saving medications would be pushed through an IV to attempt to restart the heart in the event the heart stops. You can also request chest compressions only.

It is important to understand these decisions can be reversed at any time. Having a plan in place or having discussions with another caregiver regarding these difficult conversations can change throughout your journey. Adapt accordingly. Empowered decisions are best made with those who are knowledgeable about all the options so you can make the best choices for your loved one.

It is critical that you have your loved one's Advance Decision Planning document completed before you are in a crisis. For guidance on what to consider and questions to ask during an active crisis involving hospitalization for your loved one with rare epilepsy, please refer to the Crisis Planning Guide in this C.A.R.E. Binder.

Congratulations on taking the first important steps toward putting a Long-Term C.A.R.E. Plan in place for your loved one with rare epilepsy. Don't forget, patient organizations like the Dravet Syndrome Foundation, Lennox-Gastaut Syndrome (LGS) Foundation, TSC Alliance and others provide a lifeline to families in their communities.

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

CATEGORY MENU (WITH COMPLETE LIST OF TOPICS)

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

- Appointment Schedule & Checklist
- Bathing & Personal Hygiene
- Communication Needs
- Crisis Planning Guide
- Day Programs
- Dressing
- Feeding & Nutrition Needs
- Living Arrangements
- Mobility
- Respite & Self-Care
- Safety
- Sleeping Arrangements & Bedtime Routine
- Summary Introduction to My Loved One
- Supported Employment (for the few who may qualify)
- Toileting

Disease Management

- Individualized Seizure ACTION Plan (I-SAP)
- Medical Care Team Contact Information
- Medical Equipment
- Medical Insurance Information
- Medication Information
- Medication Refills
- Medication Schedule
- Seizure Action Plan
- Supply Refills
- Things to Avoid

Important Contacts

- Emergency Contacts

Long-Term Care Planning

- C.A.R.E. Guide
- Developing a Lifelong Support Network
- Financial Information Form
- Legal Checklist
- Long-Term Residential Living

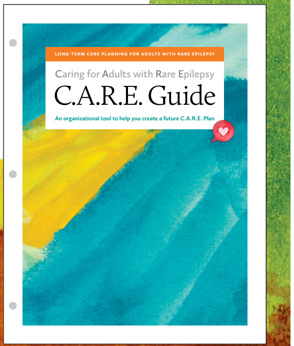
Medical Transition: Peds to Adult

- Caregiver Assessment on Medical Transition Readiness
- Epilepsy Living & History Form
- HCP to HCP Letter of Introduction (Template)

Resources

- Acknowledgments
- Glossary of Terms
- Resources
- Letter of Guidance (Sample)
- Yellow Dot Decal - Automobile Version
- Yellow Dot Decal - Home Version
- Yellow Dot Form
- References
- Appendix

Click here to access the C.A.R.E. Guide



CLICK HERE FOR HELP ON HOW TO USE THIS GUIDE.

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

It’s easy to navigate each section – simply click on the link to access the information that interests you.

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.

Having Conversations With Healthcare Professionals[2,3]

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?

10
11

12 ____________________

13 ____________________

14 ____________________

15 ____________________

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.

☐ ____________________
☐ ____________________
☐ ____________________
☐ ____________________

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.

Adult Care Team Provider Referral Form

The next conversations can be around connecting your current care team with the new care team to ensure your new adult care team has all the information and history they need to continue the best possible care for your loved one with rare epilepsy. Consider starting with your child's primary care provider and neurologist or epileptologist. Once you have this task completed, depending on your experience thus far, you may choose to alter the list of questions identified above or adjust the process to accommodate the needs of your loved one with rare epilepsy. Ask your child's adult neurologist or epileptologist and adult primary care provider, as well as your child's other medical care team, to provide you with recommendations for the rest of the specialists and others who care for your child. Make note of the information using the form below. Refer to the Attachments section for additional referral forms.

Specialty:

Provider Name: Hospital Affiliation:

Address:

City: State: Zip:

Phone: Mobile:

Email:

Does this adult physician have a collaborative working relationship with your pediatric provider? ☐ YES ☐ NO

Note your observations/notes below about this provider after you connect with them.

Specialty:

Provider Name: Hospital Affiliation:

Address:

City: State: Zip:

Phone: Mobile:

Email:

Does this adult physician have a collaborative working relationship with your pediatric provider? ☐ YES ☐ NO

Note your observations/notes below about this provider after you connect with them.

Specialty:

Provider Name: Hospital Affiliation:

Address:

City: State: Zip:

Phone: Mobile:

Email:

Does this adult physician have a collaborative working relationship with your pediatric provider? ☐ YES ☐ NO

Note your observations/notes below about this provider after you connect with them.

Specialty:
Provider Name: Hospital Affiliation:
Address:
City: State: Zip:
Phone: Mobile:
Email:
Does this adult physician have a collaborative working relationship with your pediatric provider? ☐YES ☐ NO
Note your observations/notes below about this provider after you connect with them.

Specialty:
Provider Name: Hospital Affiliation:
Address:
City: State: Zip:
Phone: Mobile:
Email:
Does this adult physician have a collaborative working relationship with your pediatric provider? ☐YES ☐ NO
Note your observations/notes below about this provider after you connect with them.

Specialty:
Provider Name: Hospital Affiliation:
Address:
City: State: Zip:
Phone: Mobile:
Email:
Does this adult physician have a collaborative working relationship with your pediatric provider? ☐YES ☐NO
Note your observations/notes below about this provider after you connect with them.

Having Conversations With Others in Your Community

Your family interacts with many different people within your community. Some may be close to your family, helping to provide care to your loved one with rare epilepsy or to your other children, if any. Some may be a part of your Lifelong Support Network. Some may only be in your life temporarily, such as school personnel or others in your community. They may or may not be considered part of your support circle, but you and your child with rare epilepsy may have somewhat regular interactions with them.

For this specific group of people, it may be helpful to provide a little background information on what rare epilepsy is and how they can help. Most people want to help, but they don't know how. If your loved one with a rare epilepsy has siblings, it will be important for you to first consider completing and sharing the My Family Is Living With a Rare Epilepsy form that can be found on the next page. This form will also contain important information on who to contact in case of emergency.

Another very helpful document to share is the Summary Introduction to My Loved One that provides important information about your loved one with a rare epilepsy.

Once you share these resources, follow up by offering to answer any questions they may have. Assure them that no question is silly or stupid. And don't forget to express your appreciation for the interest they have taken in your child (or children) and for the care they provide.

TIP: Make a list of those in this group who you provide these resources to so that if your family experiences a crisis, whoever is stepping in to provide care for your loved one with rare epilepsy, will have the complete list of those in your community that may be impacted by a change of primary caregiver for your child, even if only temporary.[2,3]

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My Family Is Living With a Rare Epilepsy

has a sibling with a rare epilepsy.

What are rare epilepsies?

Rare epilepsies are severe forms of epilepsy that cause frequent seizures or seizures that happen for a long time as well as many other complex health conditions. Rare epilepsy can begin as early as the first year of a child's life and lasts throughout their entire life.

Rare epilepsies can have a huge impact on a family's quality of life. The extra care that a child with a rare epilepsy needs and the unpredictable nature of seizures can disrupt family life. For this reason, siblings are at a greater risk for anxiety and depression. They can also experience feelings of sadness, stress, isolation, fear, worry, and fatigue.

Why rare epilepsies make life unpredictable

Seizures can happen at any time. Emergencies at any time of day or night are a "normal" part of life. Because of this unpredictability, siblings may:

- Feel emotionally "off" or distracted
- Arrive late to school or other events or cancel last minute
- Be tired from lack of sleep
- Fall behind on assignments or projects

How you can help

My child is doing their best to navigate an extremely difficult situation—but your support can make a big difference.

- If you notice any changes in my child's mood or behavior, please feel free to reach out anytime.
- If my child is late, unprepared, or distracted, it would be helpful if you could share that with me.
- If you sense my child is struggling or falling behind, some words of encouragement can go a long way.
- If possible, please provide feedback on how my child is doing, including how well they're able to connect with you.

Our family's emergency plan

Here is our plan for when their sibling has a medical emergency:

During school or practice:

In the evening:

During the weekend:

In the middle of the night:

My contact info

Name: Phone:

In case you can't reach me, please call:

Name: Phone:

Relationship to child:

Name of local hospital: Name of PCP/Nurse:

Street Address:

Office Phone: Mobile Phone (if applicable):

Thank you for everything you do to help support and encourage my child.

Daily Living

It's easy to navigate each section – simply click on the link to access the information that interests you.

Appointment Schedule & Checklist[2,3]

Having a checklist prepared in advance of your loved one's appointments can help ensure you don't forget important topics and can help to minimize additional follow-ups. Below are some prompts and tips to help you prepare for a successful appointment.

1. What are my top concerns to address at this appointment? (Write down questions and topics to discuss in the space below.)

2. Do I have any videos to show of seizures or any other strange behaviors/occurrences? ☐YES ☐NO

TIP: Queue any videos up before your appointment so you don't have to spend time scrolling through your phone to find them. Consider creating an album or folder on your phone to keep important videos.

3. Do you know who you should contact at your physician's office if you have any follow-up questions or concerns?

4. Make sure to jot down any key steps for you to take following this appointment.

Next scan (MRI, EEG, CT, etc.):

Next lab work:

Are there any forms you need to fill out before scheduling tests? ☐YES ☐NO

Does your loved one need any tests or bloodwork to monitor any of their medications? ☐YES ☐NO

5. Make note of any test results that are shared with you at the appointment and make sure you're able to access them via a secure web portal or by asking for a paper copy.

6. Make a plan for your loved one's next appointment – when and how to schedule it.

7. What medications does this doctor prescribe?

Medication: How many refills are left?

Will these refills last until the next appointment? ☐YES ☐NO

Medication: How many refills are left?

Will these refills last until the next appointment? ☐YES ☐NO

Medication: How many refills are left?

Will these refills last until the next appointment? ☐YES ☐NO

Medication: How many refills are left?

Will these refills last until the next appointment? ☐YES ☐NO

Medication: How many refills are left?

Will these refills last until the next appointment? ☐YES ☐NO

Medication: How many refills are left?

Will these refills last until the next appointment? ☐YES ☐NO

Medication: How many refills are left?

Will these refills last until the next appointment? ☐YES ☐NO

Medication: How many refills are left?

Will these refills last until the next appointment? ☐YES ☐NO

At-A-Glance Annual Appointment Schedule[2,3]: January – June

APPTS/HCP	JAN	FEB	MAR	APR	MAY	JUN
Example: Pediatrician	1/20 @ 2P		3/20 @ 4P		7/30 @ 12N	

At-A-Glance Annual Appointment Schedule[2,3]: July – December

APPTS/HCP	JUL	AUG	SEP	OCT	NOV	DEC
Example: Pediatrician	1/20 @ 2P		3/20 @ 4P		7/30 @ 12N	

Bathing & Personal Hygiene

Bathing your child can be a fun ritual filled with bathtubs full of bubbles, toys, and laughter, but it can also be a challenge. Some families may find it difficult to help their loved one with rare epilepsy perform basic tasks such as brushing teeth or washing hands. Some of our loved ones may not have the motor function to perform these tasks. Each family determines their own plan to care for their loved one. There is no right or wrong—there is only what works for your family.

Please use the guide below to document your loved one's daily bathing and personal hygiene plan. (Things always seem to be changing with our loved ones; therefore, feel free to come back to this form and update anytime you feel the need.)

TIP: Bathrooms can be a dangerous place for our loved ones. Filled with hard surfaces, a fall in the bathroom can cause serious injury. Please refer to the Safety In The Home section of this C.A.R.E. Binder for safety guidance.

Check all that apply:

☐ My child is unable to perform any of these tasks independently

☐ My child can bathe and perform basic hygiene tasks independently and safely without physical assistance
☐ My child can bathe and perform basic hygiene tasks independently and safely without physical assistance, but requires supervision

☐ My child requires coaxing with one or more of these tasks:
☐ My child can brush teeth independently
☐ My child can brush teeth with assistance
☐ My child can wash face independently
☐ My child can wash face with assistance

☐ My child can shave independently
☐ My child needs assistance with shaving

☐ My child can brush/comb hair independently
☐ My child can brush/comb hair with assistance
☐ My child can bathe/shower independently
☐ My child can bathe/shower with assistance

☐ My child can trim fingernails/toenails independently
☐ My child requires assistance to trim fingernails/toenails

☐ My daughter has a monthly period and can attend to these needs independently
☐ My daughter has a monthly period and requires assistance to tend to these needs

Daily Bathing and Hygiene Routine

Use the space below to describe your loved one's bathing and hygiene routine.

Hair Cuts

Where does your loved one with rare epilepsy get their hair cut?

Provider/Company Name:

Specific Stylist (or n/a): Phone:

Frequency:

Helpful Tips: (Include any tips that may be helpful to the person providing this care for your loved one. For example, "He can be distracted by a certain toy or snack" or "She tries to reach for the scissors so be on the lookout for that.")

Shaving (if applicable): Do you use: ☐ an electric razor ☐ shaving cream and razor

Additional Details:

Nail Trim

Who cuts the nails of your loved one with rare epilepsy?

Provider/Company name:

Specific manicurist (or n/a): Phone:

Frequency:

Helpful Tips: (Include any tips that may be helpful for the person providing this care for your loved one. For example, “Trim their nails after a seizure when they’re too tired to squirm.”)

Consider details that help these tasks go more smoothly:

How much time needs to be dedicated to these tasks? Details:

Do you physically assist your child? ☐ YES ☐ NO Details:

Does your child have a special toothbrush or other items that provide comfort? ☐ YES ☐ NO Details:

Does your child prefer: ☐ Bathtub ☐ Shower

In the shower, do they: ☐ Sit ☐ Stand If sitting, do they have a special seat they use? ☐ YES ☐ NO

Also make note of any symptoms your loved one may have related to products used for these tasks.

TIP: It’s important to perform regular skin assessments to identify any irritated spots or infected bumps. (Be sure to check for irritation from equipment like AFOs (ankle-foot orthosis)/orthotics blisters or red marks, chafing on the waist from gait belts or support harness, etc.)

Supportive Supplies Required (See the Supply Refills section of this C.A.R.E. Binder.)

☐ Shampoo/Conditioner:
☐ Toothpaste:
☐ Bodywash/Soap:
☐ Washing utensils:
☐ Helmet:
☐ Other:
☐ Other:
☐ Special toy or other item of comfort:

Additional Information:

Communication Needs

We all know how important it is to be able to communicate. Some of our loved ones are able to verbally express their needs and wants; however, many of our loved ones struggle to communicate. As the caregiver, you probably know exactly what your child needs—when they are happy, when they are hurting, when they are frustrated, and when they are excited. Many families have their own language and communication methods to engage with their loved one with rare epilepsy. Sometimes our loved ones are able to speak in complete sentences, some a few words, others may express how they feel using facial expressions, sounds, or physical movements. Sometimes our loved ones use an electronic device to communicate. Every family has implemented what works best for them. When a new person steps into the picture, who may not be familiar with your daily living routines, they may need assistance learning how your loved one and family communicate with each other. Please use the guide below to document with as much detail as possible, how communication with your loved one works in your family, so that others will be able to understand and communicate in a way that your loved one with rare epilepsy will understand.

Things always seem to be changing with our loved ones; therefore, feel free to come back to this form and update anytime you feel the need.

How does your child communicate?

Check all that apply.

My child speaks:

☐ using single words ☐ using 3-5 words only ☐ using short sentences ☐ using long sentences or speaks fluently

My child communicates:

☐ using facial expressions

☐ using gestures: ☐ pointing ☐ using hands ☐ signs ☐ touch ☐ sound(s) ☐ eye contact

☐ through writing

☐ through drawing

☐ using equipment: ☐ text message or computer/iPad ☐ AAC (Augmentative and Alternative Communication) device

Below, please capture how your loved one with rare epilepsy communicates when they feel:

Happy

Sad

Frustrated

Angry

Embarrassed

Uncomfortable

Shy

Scared

Hungry

Pain

Other emotions

How does your child communicate?

Use the space below to provide additional details that may help others best communicate with your loved one with rare epilepsy.

Use the space below to provide pictures of your loved one expressing how they feel:

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Crisis Planning Guide[2,3]

When you or your loved one with rare epilepsy is in crisis, everyone in the family is in crisis and it's very difficult to know what to do. Having a plan in place that ensures continuity of care can help provide comfort and guidance for all in your support circle during a very difficult situation. There are different types of crises that can happen at any time. You may have situations where your loved one with rare epilepsy experiences a crisis that requires immediate action. Are you, and those in your support circle, prepared for your loved one's inevitable medical emergencies? Throughout this guide we've been discussing the care of your child with rare epilepsy, but we also need to talk about what would happen if you, the primary caregiver, experience a crisis that prevents you from managing your normal daily tasks. What if you get sick or become injured and are temporarily unable to care for your loved one? What if that temporary situation became permanent? Who would care for your child? Would those in your support circle know how to immediately step in to provide the daily care your loved one with rare epilepsy requires? Having plans in place that address what happens when your loved one is in crisis and provides guidance should something happen to you, the primary caregiver, will be critical to ensure continuity of care.

While these are tough scenarios to consider, thinking about them when you are not in crisis can help make sure you are preparing for the most difficult situations when you are at your best, instead of when your family is under duress.

TIP: Make sure you have your child's Advance Decision Directive in place before your family is in crisis. Please refer to the Advance Decision Making section of the C.A.R.E. Binder Guide for guidance on what to consider. And remember, it's important to note that **decisions can be reversed at any time**. Having a plan in place doesn't mean you're irreversibly committed to each decision – it is essentially a starting place meant to provide support, not stress, and it can be adjusted appropriately according to your situation.

Crisis Planning for Your Loved One With Rare Epilepsy

What happens when your loved one with rare epilepsy is in a crisis? While you cannot prepare for every crisis scenario, knowing what questions to ask when you are faced with making decisions about your loved one's care, may help during difficult situations. The information below may be useful, when you are presented with options during your discussions with your loved one's healthcare or medical team during a challenging time or emergency.

Medical Interventions and Procedures

It is impossible to cover all options, but the main objectives will always remain the same. The type of questions you would want to ask yourself include:

- What is the purpose of this intervention or procedure?
- Will this fix the current issue or relieve stress?
- What is the benefit of this procedure?
- Is this a temporary fix or will this procedure or intervention need to be repeated and if so, what does that look like?
- What is the risk of these procedures?
- Will this intervention be long term?
- Does this intervention change our quality of life?
- What are the added barriers if we carry out this intervention?
- Is this a sustainable option? How long could this be feasible for the family dynamic?

Difficult situations can provoke emotions due to different points of view in families. Be open and compassionate to each other during these discussions and keep the overall goal centered on the loved one you all care about.

During transition phases in caregiver roles such as an aging parent transferring primary care to an adult sibling, consider including the adult sibling in the discussions as an equal part of the process, where the circumstances allow. If these conversations need to be addressed but you feel it will cause issues within a family dynamic, consider reaching out to a local counselor, clergy or palliative care service to help moderate these difficult talks. Remember, you are not alone during these times.

Acute decision-making planning considerations

The following considerations about acute care decision-making can help you navigate the very difficult questions that arise during these times. These considerations can help you understand your options using a very generalized approach. We hope going through this example can empower you and provide direction when planning your loved one's care.

Initiate a meeting to establish (and update) a care plan

- Request a meeting to discuss and develop family goals for care – consider including professionals such as the attending physician, nurse practitioner, nurse manager, social worker, case manager, other key healthcare team members and other specialists.
- This is a forum to discuss any issues in care, expectations of care, or interventions that could or should be carried out, can be held as often as possible and is typically arranged by the unit or floor social worker or case manager.
- You can request to have outside services or advocates such as a family member, patient advocacy representative or outpatient provider. These participants can help you better understand the discussion and articulate your thoughts to the medical team. Often these participants are on the phone.

Discussion topics to consider with your healthcare team

- What is the acute illness (reason for admission) and is it reversible?
  - How long will this acute illness last with the current care plan?
  - What to expect on "good" and "bad" days
  - What does it mean if there are not any changes in symptoms? Would that be expected, or is that a sign of something else that might require additional intervention?
- What are the underlying comorbidities that might increase the chance of a poor outcome?
  - Are those underlying issues worsening during this acute illness?
- Will any of the comorbidities permanently affect the quality of life?
  - This is always difficult in critical care as "time" is usually the only indicator if one will improve or not.
  - Remember: At baseline, your loved one has an incurable disease, and some healthcare providers might not understand goals of care and what is an acceptable change from this baseline. NOTE: It is very important to have a clear established understanding with your healthcare team of what is the ongoing quality of life that is effective and appropriate for your loved one.
- Are pain and quality of life being balanced?
  - Those who have loved ones who are nonverbal or with a lower cognitive function can find the lack of communication more difficult during an acute situation. Having a discussion with your healthcare team on understanding the patient's verbal and non-verbal cues regarding distress or pain is very important to the bedside nurses, as well as the overall healthcare team.
  - Resources such as communication boards or a quick reference guide (e.g., a poster board to hang on the wall that shows certain types of verbal sounds or movements your loved one makes when in distress or pain) is invaluable to the medical team and should be discussed as soon as admitted. You can also share the completed Communication Needs section of this C.A.R.E. Guide with your child's medical team.
- What is the risk of death if changes are not implemented?
  - EXAMPLE: Is a breathing tube or other form of life support required to maintain life? This can be a very difficult question, and the younger the age the more difficult it is to talk openly with parents from a healthcare perspective.
  - If you are faced with end-of-life considerations, medical professionals (e.g., hospice team, pain management team) are available to assist during these times. These teams typically include a physician, nurse practitioner, nurse and social worker.
  - Remember not all palliative care is hospice, but all hospice is palliative.
  - If you are faced with a situation involving difficult scenarios and difficult choices, always consult the attending medical doctor or team – you are not alone in this journey.

- What are the hospital visitation restrictions? For example, the COVID-19 pandemic has created many challenges in medical facilities.
  - Due to the complex changes, many institutions have been inconsistent and unpredictable with visitation policies.
  - Ask up front about visitation policies. Depending on the state, Title III of the ADA does require hospitals to provide including to whom these accommodations must be provided.
- Does the facility accommodate one support person to always remain at the bedside?
  - This does change depending on the higher level of care needed, such as an intensive care unit, which might be different from the the accommodation that you might've had in a another setting of the same hospital.
  - If you are found in this situation it is best to speak with the intensive care nurse manager, palliative care nurse, social worker, or case manager to discuss a family intervention plan. Despite clear and direct communication, you might still find yourself in a situation where you do not feel like your voice is being heard or the needs of your loved one are being met. If that is the situation, the following steps may help expedite your concerns and increase resolution.
    - Communicate directly with the bedside nurse.
    - Discuss care expectations with the nurse manager.
    - Repeat these steps as necessary during a hospitalization. If you still do not feel you are being heard or interventions are not being carried out at any point in this process, you can contact the hospital patient advocate or liaison. This can occur at any stage of the hospitalization including in the emergency department. If things continue to not go well and you need to expedite care, you can always reach out to the chief medical officer or, depending on the issue, request an ethics committee consultation. It is best to try to resolve any conflict prior to those steps, but all situations are unique and understanding your options can help empower you to have a sense of direction during the most difficult circumstances.

If you decide to have a family meeting, it's always best to have a written agenda with your concerns and questions you want addressed. Don't be afraid to speak up. Don't be afraid to have an advocate who is removed emotionally from the situation to make sure your objectives are being carried out and you have a clear picture of what is going on, given the current barriers and restrictions.

If you are alone but would like to express your wishes in writing, ask the unit security or bedside nurse to make a copy of your agenda so each person attending the meeting can read it themselves, thus putting less pressure on you. Another key person to consider having present is a chaplain, clergy, or religious leader (the hospital can help you connect if you don't have one in mind) for moral support for you and who can moderate the discussion if it becomes difficult between you and the healthcare team.

Hospice Care

What is hospice?

Hospice care is medical care for individuals who have experienced a sudden decline in their health or have received a terminal diagnosis. The life expectancy is six months or less and the intention is to focus on aggressive care management to optimize comfort and quality of life for the time that remains. The hospice care team includes medical professionals trained to address the needs of the individual at this stage. This can mean anything from pain management to physical, psychosocial, and spiritual needs, as these become the focus of care with less emphasis on the disease.

For those who have outlined an advance decision-making plan, the hospice process is usually a by-product of your loved one not responding to current medical interventions.

Understanding what options and interventions you want your loved one to receive before an acute episode does help minimize some of the emotions; however, this is still a very emotional and difficult decision to make regardless of the loved one's age. For those who have outlined interventions that are not wanted, hospice services are an excellent option to offer the loved one a higher quality of life for the remainder of their lives.

How does hospice care work?

Hospice can be provided in multiple types of settings – in the home or at a facility, such as a hospital, nursing home, or hospice center. Acute hospice options are also available, which are usually within the acute care setting (inpatient) when care is being withdrawn or de-escalated to allow time and interventions to be set up at one of the previous options. Depending on your needs, some of these options might not be offered. If you find yourself in this situation, most hospitals have hospice coordinators who you can discuss your unique needs with to align with the best option for your loved one.

How do I find hospice care?

Once it is determined your loved one qualifies for hospice, hospice care can be initiated within the inpatient or outpatient setting. Depending on the overall situation, goals of care, resources, and needs, your local provider or your primary hospital provider (the doctor you are admitted under) can help initiate this process. It is important to know that the Centers for Medicare & Medicaid Services (CMS) require that option/agency that provides care in your area is offered to you as the family. Most families defer to an agency suggested by their healthcare provider, but if you want to know all options, you have that as a right. The final decision is yours. It is strongly recommended, if time allows, to visit any hospice facility or long-term care facility that offers hospice agencies prior to your loved one being discharged.

Who pays for hospice care?

The cost of hospice is dependent on your insurance. Medicaid or Medicare typically pay for 100% of hospice services, which include the medical team, therapy, medications and supplies needed. Commercial insurance still offers hospice benefits but can be slightly different than those who qualify for CMS support covered by Medicare Part A. Depending on the location of hospice, such as a hospice house or skilled nursing facility, other charges can accrue. Some insurances will cover the full cost, while others have a daily fee. If you are exploring these options in a non-acute situation, your case manager, health benefits managers, or appointed personnel through human resources would be the best resources to understanding your hospice benefits. If you are in an acute situation, the best option would be to discuss these questions with the hospice coordinator at the agency of choice, the hospital's hospice coordinator or your social worker/case manager.

Hospice Services

Organization	Description	Website
Hospice Foundation of America	Educates the public and health care professionals about death, dying, and grief	www.hospicefoundation.org
National Hospice and Palliative Care Organization (NHPCO)	Works to expand access to a proven person-centered model for healthcare; one that provides patients and their loved ones with comfort, peace, and dignity during life's most intimate and vulnerable experiences	www.nhpco.org
National Association for Home Care & Hospice	Promotes, protects, and advances the highest quality health care at home.	www.nahc.org

Crisis Planning for You, the Primary Caregiver[2,3]

You have been caring for your loved one with rare epilepsy for their whole life, and because of that, you know exactly what to do and what is needed. Handing over care of your loved one to someone who isn't used to being their primary caregiver, even if only temporarily, may be quite daunting—even if you have this entire guide completed and easily accessible, and all your documents organized. Implementing your care plan no matter how expertly prepared can be challenging, so tackling what needs to be done in phases may help those in your circle of support step into the caregiver role with confidence. To accomplish this, we'll break down this section of the Crisis Planning Guide into smaller sections for your designated back up to ensure the most critical needs are addressed first, allowing your loved one with rare epilepsy to continue receiving continuity of the best care possible.

This guide is broken down in three sections: 1) Actions to take immediately; 2) Actions to take within the next week; 3) Actions to take in the next month and beyond.

There can be different guidance to follow based on a temporary or permanent change of primary caregiver. Even for temporary care, it may be difficult to step into your shoes, especially if it is unknown how long the primary caregiver will be incapacitated. Depending on this situation, and duration of care, it may be necessary to make adjustments. Please feel free to use the plan that provides the best guidance for the specific situation. Also note, the information below contains suggestions to help navigate a challenging situation. Only you know what is best for your family and your loved one with rare epilepsy. Before a crisis occurs, provide this plan and checklist with those designated to step in and care for your loved one with rare epilepsy. Make sure they know where to locate the referenced documents and that you have provided your back-up caregiver with the authorization in advance that they will need to step in during an emergency.

Crisis Planning Checklist for Temporary or Backup Caregiver

When a crisis occurs that prevents the loved one's primary caregiver from providing care to their child, the most important thing you can do is to ensure the individual with rare epilepsy **is** safe and **feels** safe. Losing care from the primary person in their life, even if only temporary, may be unsettling for the loved one with rare epilepsy. Patience, love, and care will be necessary. To maintain as much consistency as possible, many families use a very structured care schedule. **When possible, try to keep the schedule and routines the same to minimize disruption.**

Crisis Planning Day 1 Checklist – Actions to take immediately

☐ Emergency Contact List – review the list for each person's assigned role and alert them of the situation.

☐ Living Arrangements – this document contains the most current information on the loved one's living arrangements.

☐ Review Safety section – make sure you understand how the individual with rare epilepsy is kept safe within their current living arrangements.

☐ Review Summary Introduction to My Loved One – this document provides important information on what the individual with rare epilepsy likes, dislikes, what brings them joy and what areas are most challenging. This important document is necessary to review, even if you are very familiar with this individual since things can change over time.

☐ Contact key Medical Team members

☐ Contact Social Worker/Coordinator (if applicable)

Medication List

☐ Refer to the Medication Schedule document contained in this C.A.R.E. Binder for daily medication schedule.

☐ You can also access the Detailed Medication Information and Medication Refills sections for details on dosing and more.

Crisis Planning Day 2-7 Checklist

Carefully review each section noted below of this C.A.R.E. Binder to familiarize yourself with the individual with rare epilepsy.

☐ Things to Avoid (i.e. allergies, seizure triggers)

☐ Seizure Action Plan (found in the Attachments section of this C.A.R.E. Binder)

☐ Daily Living Section—these documents contain details on Living Arrangements, Sleeping Arrangements & Bedtime Routines, Feeding/Nutrition Needs, Toileting, Bathing and Personal Hygiene, Dressing, Communication Needs, Mobility Needs, and more.

☐ Appointment Schedule

☐ Day Programs

Crisis Planning Day 30+ Checklist

Note: In the event of death of the primary caregiver, or if the temporary situation becomes permanent, refer to the following sections of this C.A.R.E. Binder.

☐ Legal Information Plan

Contact Name:

Phone: Mobile:

Email:

☐ Financial Information Plan

Contact Name:

Phone: Mobile:

Email:

Document the information below for those who will be able to provide care and support in the event you are no longer able to care for your loved one with rare epilepsy.

☐ Temporary Caregiver

Contact Name:

Phone: Mobile:

Email:

☐ Long-term Caregiver

Contact Name:

Phone: Mobile:

Email:

Review the remaining C.A.R.E. Binder Documents over the next 30 days and beyond, or as needed:

☐ Conversations
☐ Developing a Life-Long Support Network
☐ Long-Term Care Planning
☐ Resources

Day Programs

Use the space below to document Day Programs your loved one with rare epilepsy attends. Additional pages can be added by going to the Attachments section of this C.A.R.E. Binder.

Does your loved one with rare epilepsy attend a Day Program? ☐ YES ☐ NO

Day Program 1

Name of Program:

Contact Name: Phone:

Address:

City: State: Zip:

Day(s) of the Week: ☐ Monday ☐ Tuesday ☐ Wednesday ☐ Thursday ☐ Friday ☐ Saturday ☐ Sunday

Hours:

Transportation to/from Day Program:

Does your loved one stay in one location all day for this day program? ☐ YES ☐ NO

Is this a community-based program where they go on outings? ☐ YES ☐ NO

If YES, how is transportation provided for these outings?

How is this program funded?

If funded by the state, does the state also pay for transportation? ☐ YES ☐ NO

Day Program 2

Name of Program:

Contact Name: Phone:

Address:

City: State: Zip:

Day(s) of the Week: ☐ Monday ☐ Tuesday ☐ Wednesday ☐ Thursday ☐ Friday ☐ Saturday ☐ Sunday

Hours:

Transportation to/from Day Program:

Does your loved one stay in one location all day for this day program? ☐ YES ☐ NO

Is this a community-based program where they go on outings? ☐ YES ☐ NO

If YES, how is transportation provided for these outings?

How is this program funded?

If funded by the state, does the state also pay for transportation? ☐ YES ☐ NO

List of Current Day Program Care Providers

Name	**Role** (parent/sibling/teacher/driver/etc.)	**Phone**	**Email**

Dressing

Dressing your child can be challenging. Does your loved one with rare epilepsy like to pick out their own clothes? Some of our loved ones do not like getting dressed at all—some even prefer to be in various stages of undress. Whatever your situation at home, completing the information below can help those in your support circle provide the best experience possible when they are stepping into your shoes to assist with the care of your loved one with rare epilepsy.

TIP: Some of our loved ones have sensitivities to certain fabrics that can create difficulties with the dressing experience and can also cause distress for your loved one throughout the day. If your child is unable to communicate their distress, this may cause frustrations for them. If your child has any sensitivities, please be sure to note it below.

Things always seem to be changing with our loved ones; therefore, feel free to come back to this form and update anytime you feel the need.

Check all that apply:

☐ My child can dress independently and safely without physical assistance
☐ My child can dress independently and safely without physical assistance, but requires supervision
☐ My child can dress independently and safely but needs assistance with fine motor tasks (such as buttons or zippers)
☐ My child can select their own clothing
☐ My child can select their own clothing, with supervision
☐ I select a few options for my child to choose from each day
☐ I select my child's clothing each day
☐ My child cooperates while getting dressed
☐ My child requires coaxing to get dressed each day
☐ My child frequently refuses to get dressed for the day
☐ My child will frequently undress
☐ My child requires full assistance getting dressed

Daily Dressing Routine

Use the space below to describe your loved one's dressing routine. Consider details that help this task go more smoothly. How much time does it take your child to dress? Do you physically assist your child? Does your child have a favorite color or outfit? Do they like matching or mis-matched socks? Details like that might seem silly, but those types of details may provide comfort to your loved one and having that information documented is important. Those assisting with the care of your child will really appreciate being able to provide the same level of thoughtful care that you do on a daily basis.

Optional:
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Additional Information:

Feeding & Nutrition Needs

Many of our loved ones with rare epilepsy have very specific nutrition needs. Some may have a G-tube, need a thickening agent, and/or be on a ketogenic diet. Certain foods may interact with their medications, cause GI or other issues, or simply aren't tolerable for various reasons. Feeding our loved ones with rare epilepsy may be very challenging at times, and ensuring they receive adequate nutrition can sometimes be difficult. It is important to provide as much detail as possible so that others providing care assistance for your loved one can maintain the feeding and nutrition plan you've thoughtfully developed for your child.

If your loved one with rare epilepsy has a nutritionist, dietician, and/or is on a medical diet (such as the ketogenic diet), please provide the healthcare professional's name and contact information below.

Check all that apply:

☐ A nutritionist or dietician is part of our care team
☐ Ketogenic Diet
☐ G-tube
☐ Uses a food thickener to help prevent aspiration
☐ Takes medication with meals (Please refer to the Medication Schedule section of this C.A.R.E. Binder.)

TIP: If your child is G-tube fed or on a ketogenic diet, be certain to print out the information/documentation necessary to follow your specific instructions and include with this C.A.R.E. Binder.

Healthcare Professional Contact Details (if applicable):

Name:
Address:
City: State: Zip:
Phone: Mobile:
Email:

Please indicate the level of independence and joy your loved one with rare epilepsy has when it comes to feeding themselves. Things always seem to be changing with our loved ones; therefore, feel free to come back to this form and update anytime you feel the need.

Check all that apply:

☐ My child can eat without assistance
☐ My child can eat with minimal assistance
☐ My child can eat with moderate assistance
☐ My child can only eat with complete assistance
☐ My child loves to eat
☐ My child loves to eat a little too much, please monitor
☐ My child likes to eat, but won't eat on command
☐ My child doesn't enjoy eating so it takes a bit of coaxing
☐ My child is a picky eater

Additional Information:

Mealtime Routines

TIP: It's important to make note when your loved one experiences changes in appetite. It could be that your child is just being picky about their food—or it could be an indication that something is wrong, such as GI distress or dental issues. Capturing details about your loved one's likes/dislikes and other mealtime routines can help others caring for your child better able to recognize changes that may need to be addressed.

This is what mealtime looks like for us:

What does your loved one like to eat/drink?

What do they dislike?

Do they have any allergies? ☐ YES ☐ NO Details:

Is there a special song you sing or ritual you both enjoy that sets your loved one up for success when it comes to mealtime? ☐ YES ☐ NO
Details:

Do you have a special tabletop mat, dish, cup, or eating utensil that makes mealtime fun? ☐ YES ☐ NO Details:

What are the must-haves, nice-to-haves, and absolute no-no's?

Does your routine change depending on the time of day or day or week? ☐ YES ☐ NO Details:

How does your routine change when dining outside the family home?

Use the additional space below to share/describe more details of your mealtime routine:

Living Arrangements

Every rare epilepsy family has their own unique situation; therefore, each family can have their own unique living arrangements. There is no right or wrong—your plan is the best plan for your family. The goal of this document is to capture the details of your loved one's living arrangements so that anyone who may assist you with care has all the information they need to provide the best care possible for your child with rare epilepsy.

TIP: Please provide additional detail about your loved one's residence(s) that may help others care for your child. For example, if your loved one has more than one residence, you may want to document what days/times of the week they live in their primary residence and how transportation is provided when traveling to secondary residence.

Primary Residence: My child lives...

Optional:
Upload Photo Here

☐ **in the family home.** Please list the names and relationships of those living in the family home:

☐ **in a group home**

☐ **other assisted living facility or institution** (If this option is selected, please also complete the Living Arrangements Additional Information form.)

On-Site Primary Caregiver(s):

Address:

City: State: Zip:

Phone: Mobile:

Emergency Contact Name: Phone:

Additional Details:

Secondary Residence (if applicable): My child lives...

Optional:
Upload Photo Here

☐ **in the family home.** Please list the names and relationships of those living in the family home:

☐ **in a group home**

☐ **other assisted living facility or institution** (If this option is selected, please also complete the Living Arrangements Additional Information form.)

On-Site Primary Caregiver(s):

Address:

City: State: Zip:

Phone: Mobile:

Emergency Contact Name: Phone:

Additional Details:

Living Arrangements: Additional Information

If your loved one lives in a group home or other facility outside the family home, please use this form to share additional information to aid anyone assisting you with the care of your loved one with rare epilepsy.

Facility/On-Site Contact(s):
Address:
City: State: Zip:
Phone: Mobile:
Emergency Contact Name: Phone:

How close is the facility to where the family lives? Number of Miles:

How is communication between the staff and family handled? Details:

What kind of activities are offered? Details:

How does the night staff monitor for nocturnal seizures? Details:

Are there cameras on site? If so, how frequently are they monitored? ☐ YES ☐ NO Details:

Are there any restrictions on visitation times? ☐ YES ☐ NO Details:

Does the facility have a nurse or physician on staff? ☐ YES ☐ NO Details:

How are medications administered?

What is the accessibility for getting around in the home, bathing, etc.? Details:

How are challenging behaviors handled? Details:

Does the facility provide the following basic needs?

Shaving: ☐ YES ☐ NO Details:

Bathe and wash daily? ☐ YES ☐ NO Details:

What is the protocol in the event of a natural emergency? (for example, earthquakes, fires, tornadoes, etc.) Details:

What happens on **holidays?** Details:

How is transportation handled? Does the home have its own van/car? ☐ YES ☐ NO Details:

Use the space below to provide pictures and detailed information of your loved one's living arrangements:

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Mobility

We will all likely need some sort of assistance with mobility over the course of our lives. Most of our loved ones with rare epilepsy will also require assistance during certain situations and/or assistance at some point in their lives as gait issues develop, and some may require 100% mobility assistance. Families adapt their homes and lives to accommodate their loved one with rare epilepsy to ensure they are able to move about as freely and safely as possible (please refer to the Safety section of this C.A.R.E. Binder for more information).

TIP: Some of our loved ones have the ability to move around independently; however, may still use a wheelchair during certain situations such as going out in public. This may be to maintain safety for our loved one or to control their behavior. Make sure you include details in the section below.

Things always seem to be changing with our loved ones; therefore, feel free to come back to this form and update anytime you feel the need.

Check all that apply:

☐ My child requires walking assistance for short distances (around the house)
☐ My child requires assistance walking up/down the stairs
☐ My child requires assistance when walking on surfaces that are not level
☐ My child requires walking assistance for longer distances/walking outdoors
☐ My child requires a wheelchair or other adaptive equipment
☐ My child requires a wheelchair only for certain situations (such as after a seizure) —details noted below.

My child uses the following mobility support:

☐ Adaptive stroller ☐ Other equipment:

☐ Walker ☐ Other equipment:

☐ Wheelchair ☐ Other equipment:

TIP: Please refer to the Medical Equipment section of this C.A.R.E. Binder for a full list of equipment required with details on who provides the equipment and how it is funded.

☐ An adapted vehicle/van is used to transport my child
☐ Our family provides 100% of my child's transportation needs

Other transportation providers
(Note: additional transportation details for Day Program activities are noted in the Day Programs section of this C.A.R.E. Binder.)

☐ My child takes a bus to school. Provide details below:

☐ Other transportation. Provide details below:

Daily Mobility Routine

Use the space below to describe your loved one's daily mobility routine. Consider details that help your loved one move safely around inside your home and outside the home. What are all the different mobility tools you use daily? Describe how you transport your loved one with rare epilepsy to school, doctor's appointments, family outings or other activities that require transportation. Having this detailed information documented will be important for those assisting with the care of your child to provide the same level of thoughtful care that you do on a daily basis.

Use the space below to provide pictures of your loved one in action:

Optional:
Upload Photo Here

Optional:
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Respite & Self-Care[2,3]

Caregiver Mental Health

Being a caregiver can be equally rewarding and overwhelming at the same time – it is completely normal to feel this way. Many caregivers start this journey as parents, yet others might be relatives (grandparents, siblings, etc.) or close family friends who are all essential parts of the "village" that cares for someone with a rare epilepsy. Western society often considers the village as solely for the loved one who needs assistance; however, the reality is the village is the support system for the primary caregiver in addition to the loved one with a rare epilepsy.

Caring for a loved one with a rare epilepsy means having to work especially hard at finding balance. It is all too common for caregivers in our community to find themselves without a sense of balance in their lives. Too often, caregivers can find themselves exhausting their minds and bodies in an effort to provide the absolute best care for their loved ones while neglecting their own basic needs.

Mary Anne Meskis, Executive Director of the Dravet Syndrome Foundation reminds us in the *Decoding Dravet Blog*, that "Self-Care is Not Selfish."[5]

"Caring for a child or adult with a rare epilepsy is challenging. It is a lot of work, mentally and physically. Our caregiver community frequently talks about feelings of isolation, depression about the diagnosis, and anxiety over what their child's future looks like. On top of that they are overworked and exhausted from managing their child's medical, educational, and emotional needs. They are left with little or no down time when they can relax, rest, or have fun.

I understand how it feels to try to keep up this pace day after day, hour after hour, with no real break in sight. While love is a limitless resource, energy is not. I have looked around some days, wondering how this chaos became my life. I have felt my nerves fraying and I have fought the urge to walk out the door and keep going. Those are not feelings that we as parents are comfortable with or want to admit to ourselves. We feel guilty thinking them and want to fight them off. But we should recognize that these are signs that we are in desperate need of self-care.

The extremes in your day-to-day lives as a caregiver for someone with a rare epilepsy can and will wear you down. It is important to remember to take care of yourself. You need to focus on eating well, moving your body, and taking time for things that bring you joy. Caregivers typically don't get to just "turn off," so it is important to realize when you're overwhelmed and to establish coping mechanisms and a plan. Whatever you need to do, prioritize yourself and make it happen. Let go of the idea that good caregivers don't need breaks. **It is regular breaks that will keep you from breaking.**

Prioritize yourself

I realize that me telling you to take care of yourself feels like one more thing on your never-ending To Do list. But, here is the good news – it sometimes doesn't take much to make a huge difference. Purposely doing something that brings you joy will be restorative – get in a workout, indulge in a hobby, take a nap, schedule a spa day – whatever you need. No one is going to force you to take a break, so you have to give yourself permission and make yourself a priority. Only you can shape the life you want to live, even with the many challenges you face as a caregiver. I know it's hard, but you will be amazed that a little bit of time to yourself can significantly change your outlook.

- **Say no.** With the additional needs of your child your time is extremely limited. If something adds stress to your life, say no. Say yes to those things you find fulfilling.
- **Consider counseling.** It is never too early or too late to get counseling. This is a lifelong condition you will be dealing with, and it is important to maintain your mental health.
- **Do something that brings you joy.** Give yourself permission to make time for something you enjoy. Take a class, go to a museum, meet up with a friend – just do something that makes you happy.
- **Take alone time for yourself.** Whether it's just in your own home for an hour or it's an entire weekend away, mark it on your calendar. Consider setting a long-term goal that forces you to make time for yourself. For instance, training for a 5K or committing to a weekly class."

That being said, we understand that in the midst of being overwhelmed, it can also be challenging to even know where to start, how to recognize if you are close to "burning out" and what action steps you can take to create healthy boundaries so you can live your fullest life. The information below covers some signs and symptoms of caregiver burnout. If you or another caregiver is experiencing these symptoms, we recommend reaching out to your local provider or therapist to work through your unique situation and provide you with a plan that meets your needs.

TIP: Take time to listen to this Raring to Listen podcast episode that focuses on the importance of self care. The TSC Alliance's TSC Navigator also offers a wide range of great resources

Signs and symptoms of caregiver burnout

If you find yourself identifying with a lot of these feelings, please bring the following information to your local primary healthcare provider (PCP) or mental health provider.

- Physical
  - No energy, "run down" feeling
  - Changes in your body weight
  - Chronic or acute pain and fatigue
  - Sleep cycle disturbances
  - Nausea (with or without vomiting)
  - Changes in bowel movements (diarrhea or constipation)
  - Frequent cold-like illness or congestion
- Emotional
  - Mood swings and/or stronger-than-usual emotions (anger, crying, etc.)
  - Emotional numbness
  - Lack of focus/concentration
  - Constant state of feeling overwhelmed or worried
  - Frequent emotions of guilt and/or resentment
- Behavioral
  - Neglecting your own basic health needs (appointments, screenings, hygiene)
  - Not enjoying the things that you used to
  - Avoiding your friends and family
  - Detachment from loved ones
  - Increased use of alcohol, drugs, and/or prescription medications

If you feel an immediate threat to yourself or others, please call 911 for immediate assistance.
If you are having suicidal thoughts, please call the National Suicide Prevention Lifeline at 1-800-273-8255.

Respite care

For families of a loved one with a rare epilepsy, respite care is a support service that may be required from time to time. Several types of respite care exist, but the two main models of respite care are in-home and out-of-home options. Some community-based programs offer respite care that may be as simple as providing a substitute caregiver for a few hours each week. Others provide more major interventions, like temporarily placing your loved one in a special respite home that can accommodate their needs. The National Respite Locator Service helps individuals, parents and caregivers find respite services in their state and local area. Please note: Respite care and services vary by state and region.

Caregiver Zone Guide

The rare epilepsy journey can often bring ups and downs given the uncertainties that exist during non-conflict or non-crisis times, so understanding your caregiver zone can help you gauge the amount of stress you are currently under. Stress levels constantly ebb and flow – you may have seasons where you fluctuate between the different **Caregiver Zones**. This is normal and to be expected. Once you have had time to implement this you can start to uncover trends in your life and start proactively empowering strategies that work for you and your family dynamic. It is not about surviving this life; it is about uniquely thriving the best you can with the resources you have.

Finding Your Caregiver Zone[2,3]

This chart can help you identify where you need help. You'll find yourself moving between zones, which is completely normal. Try to track this monthly and share with close friends and family so they, too, can help you to recognize signs of burnout.

	Thriving	Surviving	Struggling	Crisis
Emotion	Emotions are steady with only minor swings.	Increased emotional fluctuations – nervous, sad, anxious, etc.	Constant thoughts of intense emotions – fear, panic, sadness, anger, hopelessness, etc.	Unable to regulate any emotions. Numbness, complete loss of control, easily aggressive or emotional.
Focus	Able to focus on and execute plans.	Inconsistent focus but still able to execute plans.	Decision fatigue, unable to focus or make decisions.	Extreme inability to focus on any decisions for yourself or others.
Social	Able to communicate effectively and adjust to changes within reason.	Difficult to communicate and adjust plans, easily overwhelmed, irritated, or emotional.	Increased difficulty with communication and adaptation. Avoidance of friends, family, work, etc.	Unable to communicate or adapt. Frequent isolation from others – emotionally and/or physically.
Appetite	Normal appetite.	Inconsistent appetite.	Emotional eating or restriction.	Out of control eating/ restriction.
Sleep	Normal sleep habits.	Trouble falling asleep or staying asleep.	Frequent restlessness and disruption of sleep (more often than not).	Complete inability to sleep, with restlessness and disrupted sleep nightly.
Daily Activities	Feeling consistent with daily performances.	Inconsistent with daily performances but still able to achieve most on your "to-do" list. No time for hobbies.	Increased inconsistency, more frequently unable to achieve daily tasks, no time for hobbies.	Complete inability to get any daily tasks done. Withdrawn from friends/family and tasks/ hobbies.
Self-Care	Providing daily self-care.	Inconsistent, but still providing self-care a few days a week.	Increased inability for self-care, except for very randomly throughout a month.	Inability to perform any self-care or meet basic needs for oneself or others. Self-medicating with drugs, alcohol, prescription medications, food, and other stimuli.

References:
1. https://www.caregiver.org/resource/taking-care-you-self-care-family-caregivers/
2. http://www.njni.org/programs/njni-supporting-stress-first-aid-for-nurses/
3. https://www.firefightermentalhealth.org/system/files/Stress%20First%20Aid%20Student%20Manual.pdf

If you feel an immediate threat to yourself or others, please call 911 for immediate assistance.
If you are having suicidal thoughts, please call the National Suicide Prevention Lifeline at 1-800-273-8255.

How to Help Me Guide[2,3]

Another resource is the **How to Help Me Guide** where you will find a list of examples that you can customize to fit your own needs. As caregivers going through challenging times, you often get asked, "How can I help you?" Yet, you might not even know that because you are already in a crisis and decision fatigue is setting in. Having a go-to list you can show to others not only helps you, but it also helps those in your inner circle to know how to truly help you.

	Thriving	Surviving	Struggling
Emotion	Reach out to someone close to schedule a regular phone call or lunch. (A person you feel safe with in case you need to discuss life situations.)	Reach out to someone close to discuss. (Counselors, clergy, primary care providers are also helpful resources.)	Reach out for immediate assistance. Develop a crisis plan with a friend for this type of scenario. (Counselor, clergy, Suicide Hotline, or seeking emergency care.)
Focus	Set a daily goal to stay focused. (There are apps for that!)	Can you help me make a task list and prioritize my tasks?	Can you help me by making a plan for daily check-ins with myself or someone else?
Social	Participate in organization groups or focus groups. Plan one event per week that is for YOU.	Can you watch my loved one with rare epilepsy so I can take my other kid(s) out to do something fun?	Discuss strategies and resources with a close friend or group to help examine priorities. Do not overcommit. Prioritize.
Appetite	Can you come grocery shopping with me this week?	Can you help me plan my meals/grocery shop for me?	Can you help me make sure I have dinners made for the next few nights?
Sleep	Can you provide respite care by watching my child on this night so I can stay at a local hotel and get a much-needed break?	Take a shower or try to meditate.	Have friends clear your nighttime responsibilities for you for a few nights so you can sleep.
Daily Activities	Create a list of grounding activities like walking, painting, music, etc.	Ask a friend to help with a chore or task to help focus on priorities. Ask for help with laundry. Ask a friend, "Can you pick up these prescriptions at this pharmacy?"	Can you please help me run a few errands? (The more specific you are, the better – would a clean kitchen help clear your mind? Or picking up groceries? Taking another kid to the dentist?)
Self-Care	Can we do an at-home spa day?	Can you absorb some of my responsibilities for 20 minutes, 3 days a week so I can take a luxurious shower, attend a workout class, meditate?	Can you come over at ___ time and do ___ so I can take a shower, meditate, take a nice walk, etc.?

References:
1. https://www.caregiver.org/resource/taking-care-you-self-care-family-caregivers/
2. http://www.njni.org/programs/njni-supporting-stress-first-aid-for-nurses/
3. https://www.firefightermentalhealth.org/system/files/Stress%20First%20Aid%20Student%20Manual.pdf

If you feel an immediate threat to yourself or others, please call 911 for immediate assistance.
If you are having suicidal thoughts, please call the National Suicide Prevention Lifeline at 1-800-273-8255.

Make Your Own How to Help Me Guide[2,3]

We gave you some suggestions for your **How to Help Me Guide**. You can also use the template below if you would like to create your own How to Help Me worksheet based on your individual needs.

	Thriving	Surviving	Struggling
Emotion			
Focus			
Social			
Appetite			
Sleep			
Daily Activities			
Self-Care			

Safety

Every caregiver knows the most important thing you can do is to ensure that your loved one with rare epilepsy is safe…and feels safe. Depending on the temperament of your loved one, side effects of medication and other variables, behavior may be a challenge. Especially when communication is challenging, our loved ones may show aggression towards us that can be very difficult to handle. When behavioral outbursts happen, it can be frustrating, and sometimes even frightening, but even during these difficult situations, it's still our priority to keep our loved one with rare epilepsy safe, as well as ourselves and other family members.

To maintain safety, there are several important areas to address and document for those who may care for your loved one with rare epilepsy. **And remember, if you or your loved ones ever feel unsafe, contact emergency services or call 911 for assistance.**

- How your home is set up to keep your loved one safe
- How to keep your loved one safe outside the home
- How to keep your family safe when aggressive behaviors are displayed
- How to keep your loved one safe from other people

TIP: Please print the Summary Introduction to My Loved One and keep in a visibly accessible location where it can be quickly found in the event of emergency.

Included with this C.A.R.E. Binder are two Yellow Dot decals and a personal information form. The bright yellow dot alerts EMS about your loved one with rare epilepsy and provides additional information/direction to help keep your loved one safe.

Note: The Yellow Dot form can be found in the the Attachments section of this C.A.R.E. Binder. You can also find the decal file in the Attachments section, print and tape them to your car/home windows.

About Yellow Dot

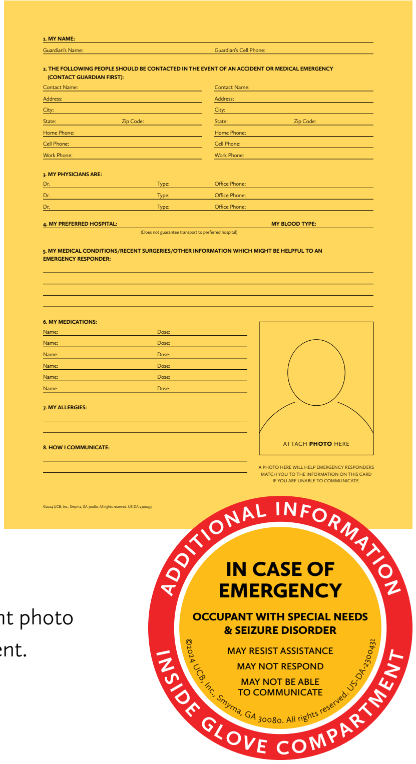
The Yellow Dot program was developed in cooperation with the New York State Sheriffs' Association.[6]

Yellow Dot is a free program designed to help first responders provide life-saving medical attention during that first "golden hour" after a crash or other emergency. A Yellow Dot in the driver's-side rear window of your vehicle will alert first responders that vital medical information is stored in the glove compartment.

How Yellow Dot Works

Yellow Dot kit contains a personal information card and a Yellow Dot decal.

- Complete both sides of the personal information card as fully as possible. Attach or upload a recent photo of your loved one with rare epilepsy and place it in a visible location in your car's glove compartment.
- Place the Yellow Dot decal on the rear driver's side window to alert first responders to look in the glove compartment for your loved one's medical information.
- Update the personal information form annually. If you sell your car, remove the Yellow Dot decal.
- Yellow Dot Program provides your loved one's vital medical information to first responders.



1. MY NAME:

Guardian's Name: Guardian's Cell Phone:

2. THE FOLLOWING PEOPLE SHOULD BE CONTACTED IN THE EVENT OF AN ACCIDENT OR MEDICAL EMERGENCY (CONTACT GUARDIAN FIRST):

Contact Name:	Contact Name:
Address:	Address:
City:	City:
State: Zip Code:	State: Zip Code:
Home Phone:	Home Phone:
Cell Phone:	Cell Phone:
Work Phone:	Work Phone:

3. MY PHYSICIANS ARE:

Dr.	Type:	Office Phone:
Dr.	Type:	Office Phone:
Dr.	Type:	Office Phone:

4. MY PREFERRED HOSPITAL: **MY BLOOD TYPE:**

(Does not guarantee transport to preferred hospital)

5. MY MEDICAL CONDITIONS/RECENT SURGERIES/OTHER INFORMATION WHICH MIGHT BE HELPFUL TO AN EMERGENCY RESPONDER:

6. MY MEDICATIONS:

Name:	Dose:
Name:	Dose:
Name:	Dose:
Name:	Dose:
Name:	Dose:
Name:	Dose:

7. MY ALLERGIES:

8. HOW I COMMUNICATE:

ATTACH **PHOTO** HERE

A PHOTO HERE WILL HELP EMERGENCY RESPONDERS MATCH YOU TO THE INFORMATION ON THIS CARD IF YOU ARE UNABLE TO COMMUNICATE.

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The Yellow Dot form can be accessed in the Attachments section of this C.A.R.E. Binder.

Use Yellow Dot at Home

A Yellow Dot decal and information form can also be used to alert those who respond to an emergency in your home. Simply place a Yellow Dot decal on or beside your front door and place a completed personal information form in a clear plastic freezer bag in a visible location in the freezer compartment of your refrigerator.

Safety in the Home

Please complete the following to help others who may provide care for your child in your home. Photos can be very helpful so feel free to upload as appropriate. Include details about equipment used, such as a helmet. Be sure to list any comfort items that help provide a sense of safety and security for your loved one with rare epilepsy.

Kitchen Safety			
Optional: Upload Photo Here		Optional: Upload Photo Here	

Main Living Room/Family Room Safety			
Optional: Upload Photo Here		Optional: Upload Photo Here	

Bedroom (of your loved one) Safety			
Optional: Upload Photo Here		Optional: Upload Photo Here	

Bathroom Safety			
Optional: Upload Photo Here		Optional: Upload Photo Here	

Safety Outside the Home

Please complete the following to help others who may provide care for your child outside your home and/or when traveling (even if only to the grocery store). Photos can be very helpful so feel free to upload as appropriate. Include details about equipment used, such as a helmet. Be sure to list any comfort items that helps provide a sense of safety and security for your loved one with rare epilepsy.

Automobile Safety

Optional: Upload Photo Here		**Optional: Upload Photo Here**	

School Safety

Optional: Upload Photo Here		**Optional: Upload Photo Here**	

Store/Restaurant Safety

Optional: Upload Photo Here		**Optional: Upload Photo Here**	

Other Safety

Optional: Upload Photo Here		**Optional: Upload Photo Here**	

Keeping Your Family Safe When Aggressive Behaviors Are Displayed[2,3]

The following is informational only and is not intended to give advice on what your family should do in the event of a mental health crisis. Please reach out to an experienced, licensed mental health professional who may assist you with putting a plan in place that addresses your specific concerns and challenges.

Unfortunately, many in the rare epilepsy community will experience a behavior or mental health crisis at some point in their lifetime. It is best to have a specific behavior/mental health crisis intervention plan in place before a crisis occurs to help guide your steps when the emotions of the situation can be very difficult to process. If you or your loved one suffer with any mental health condition, it is ideal to have a plan in place that was created during a non-conflict time. It can be as detailed as you feel is important. For those who know your loved one's triggers, situations or signs that usually proceed a crisis time, it is best to write those down for those in your inner circle to be aware of, and so that they can proactively intervene if possible.

National Alliance on Mental Illness (NAMI) provides excellent toolkits for you and/or your loved one on how to prepare for a mental health crisis and portable treatment records which include what behaviors to call 911 to seek emergency support for. They also provide a guide for navigating a mental health crisis.

If you or a loved one are having thoughts of self-harm or need immediate support, you can contact the National Suicide Prevention Lifeline (1-800-273-8255/TALK) or Crisis Text Line by texting "NAMI" to 741-741. In a life-threatening situation, go to your nearest psychiatric emergency room or call 911. NAMI also provides support groups and a helpline for additional support and encouragement at 1-800-950-6264.

Here are some other things you may want to think about—

- Have you identified triggers that may agitate your loved one? If so, please note them here—
- Does your loved one have an area within your home with soft furnishings that they can retreat to when in an agitated state where they can find comfort and feel safe?
- Do you and your family have your own safe room to protect yourselves from harm where you can retreat to when your loved one with rare epilepsy is agitated?
- Have you considered going through crisis prevention and de-escalation training? Ask the mental health professional you are working with to recommend an accredited training program.

Does your family already have a crisis plan? If so, attach to this C.A.R.E. Binder. If not, use the space below to capture your family's specific needs related to safety that are not already included in this Safety section.

Keeping Your Loved One With Rare Epilepsy Safe From Other People

Make sure the people who come into your home and those outside your home that care for your loved one with rare epilepsy can be trusted. That's important anyway, but it's even more critical when you're a caregiver for an individual with rare epilepsy. Don't let someone into your home or care for your child without proof they are who they say they are. That means identification at a minimum; never trust someone who does not show any credential. If you need to call the company while the healthcare worker waits outside, don't feel bad. You're performing your due diligence.

Healthcare providers, caregivers and even family members may pose potential dangers, too. For instance, people with cognitive disability, which is common in people from the rare epilepsy community, are four to ten times more vulnerable to abuse and four times more likely to be crime victims.[7] Children or adults with intellectual developmental disabilities are at even higher risk. Caregivers may never dream of others hurting your loved one, but healthcare caretaker burnout is a genuine thing that can lead some to act in uncharacteristic ways. It can happen to anyone. In case this happens, having another person of trust or talking to a trusted healthcare provider can be a good solution.

The ARC has excellent resources on this topic. The excerpt below is from their website:

> ***How Can I Tell if a Child with Disabilities is Being Abused?***[8]
>
> *"Children with and without disabilities share similar indicators of abuse. Along with physical signs (bruises, broken bones, head injuries, or other outward marks) two primary indicators are reports from the child that abuse has occurred and changes in the child's behavior. Children with disabilities face greater risk of abuse going unnoticed if their behavior change can be attributed to their disability instead of the abuse. Also, children with intellectual disabilities may be viewed as easily suggestible or untrustworthy, especially when the report involves abuse that seems improbable. Any time abuse is suspected, it is the adult's responsibility to carefully monitor the child's behavior, ask the child about his or her safety and follow through by reporting any suspected abuse. State laws vary regarding who is considered a mandated reporter, although usually professionals who have regular contact with children are included, such as teachers, physicians, dentists, speech pathologists, etc."*

Below are a few resources that may help as you think about and navigate these very challenging situations.

Organization	Description	Website
NeuroRestorative	NeuroRestorative is a leading provider of subacute and post-acute rehabilitation services for people of all ages with brain, spinal cord and medically complex injuries, illnesses, and other challenges.	www.neurorestorative.com
National Alliance on Mental Illness (NAMI)	Provides advocacy, education, support and public awareness so that all individuals and families affected by mental illness can build a better life. **Notable Article:** Being Prepared for a Crisis	www.nami.org
Child Mind	Child Mind is dedicated to transforming the lives of children and families struggling with mental health and learning disorders by giving them the help they need.	www.childmind.org
Centers for Disease Control and Prevention (CDC)	The CDC has compiled data, research and programming specifically for people living with a disability. **Notable Resource:** Disability and Health Promotion	www.cdc.gov

Sleeping Arrangements & Bedtime Routine

Most families with loved ones with rare epilepsy struggle to get the sleep needed each night. This can be very stressful for everyone in the family. Not getting proper sleep makes it difficult to function. You must get up every morning (or several times a night) and keep pushing forward. Doing what we can to standardize bedtime routines can be helpful to obtain the best rest possible. We've said it multiple times throughout this C.A.R.E. Binder because it's true—every family will have their own routines that work best for their family. There is no right or wrong, only what works best for you. The purpose of this form is to document what your family routine entails so that anyone else providing care for your loved one can do their best to care for your loved one as you would.

TIP: Some of our loved ones are prone to nighttime seizures. Make sure you document that information below. Also make sure your Seizure Action Plan (which can be found in this C.A.R.E. Binder) is readily accessible.

Things always seem to be changing with our loved ones; therefore, feel free to come back to this form and update anytime you feel the need.

Check all that apply:

☐ My child sleeps in their own bedroom.

☐ My child co-sleeps with another member of the family. Describe below:

☐ My child requires nighttime seizure monitoring (see Medical Equipment section of this C.A.R.E. Binder for more details)

☐ My child requires other equipment at night. Describe below:

☐ My child wears diapers at night.

☐ My child needs to sleep on a mattress protector or Chucks disposable underpad because of incontinence issues.

Bedtime Routine

Use the space below to describe your loved one's bedtime routine. Consider details that help this task go more smoothly. Does your loved one enjoy bedtime or do they fight you when it's time to say goodnight? Does your child require safety or seizure monitoring at night? Does your child have a favorite set of pajamas or special stuffed toy or blanket they like to cuddle up with? Is there a special book you enjoy reading or song you like to sing? What other nightly rituals do you practice with your loved one that makes bedtime special? Details like this might seem silly, but these types of details may provide comfort to your loved one and having that information documented is important. Those assisting with the care of your child will really appreciate being able to provide the same level of thoughtful care that you do on a daily basis.

Bedtime routine details continued...

Use this space to insert a picture(s) and additional information of your loved one's bedtime routine:

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Summary Introduction to My Loved One

Your loved one with rare epilepsy is a very special person with many positive qualities and gifts. Use the form below to tell others what makes your loved one laugh and smile, what activities bring them joy, what is challenging for them, and of course, information about their medical challenges. Providing this important information is needed to help others to provide the very best care with dignity, respect, and appreciation for all your loved one has to offer.

Insert pic of loved one here

Say HELLO to: !

is years old and has .

A little about me…

My family:

My favorite people are:

My favorite places are:

My favorite thing to do is:

What others like about me:

Things that bring me joy:

Things that are difficult for me:

Things that make me feel frustrated:

Things that help me feel safe and loved:

How to support me when I am stressed, sick, or hospitalized:

Now that you are better acquainted with ______________________________ , here is a summary of the most challenging aspects of their life.

Mobility	
Communication	
Bathroom procedures	
Behavior	
Shower/bath time	
Dental hygiene	
Bedtime/sleep	
Mealtime/eating/ snacks	
Allergies	
Seizure triggers	
Seizure types and rescue protocol	

Use this page to insert a picture(s) of your loved one, family, or anything else you may want to share:

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Supported Employment *(for the few who may qualify)*[2,3]

We all want to provide the most enriching life we can for our loved ones with rare epilepsy, and we do that through different activities such as Day Programs. While we acknowledge that the majority of our loved ones will not qualify for supported employment, we wanted to include information in this guide for those caregivers with loved ones who may qualify.

Employment rights

The Americans with Disabilities Act (ADA) is a federal mandate that prohibits discrimination based on disability in the areas of employment, housing, public accommodation, transportation, and telecommunication services. Title I of the ADA states employment practices cannot discriminate against a person with a disability who is qualified for the job. A person with a disability who can complete the essential functions of the job is considered qualified. The law also requires an employer to provide "reasonable accommodations" or modifications to a work environment to guarantee the person can effectively perform their job, such as providing wheelchair accessibility. For more information, please visit www.eeoc.gov.

Vocational/rehabilitation programs, jobs and employment

For some people, participating in a vocational, educational, or other type of activity can be empowering and may provide purpose. Vocational and rehabilitation options for people with disabilities range from positions that provide high levels of assistance to competitive employment without additional accommodations. Experience provided through work, job training or other enrichment activities may add to the quality of life and increase a person's self esteem. Additionally, social interactions with coworkers may enhance a person's integration into the community. Often the challenge is not in performing the job, but in finding the job that best suits an individual's interests, strengths and personality. One of the best places to begin a job search is with your state vocational rehabilitation (VR) agency. State VR agencies coordinate and provide several services for people with disabilities looking for a job. These services may include counseling, skills evaluation, training, job placement, coaching and support. Services provided vary by state, but most agencies will assign a vocational counselor to work with an individual with a disability to identify and locate employment options that best suit their capabilities, needs and interests. State VR agencies work with non-profit organizations and private employers that may provide a wide range of employment options in a variety of settings. You can find your state or local VR agency by checking your state government websites or by visiting the Job Accommodation Network.

Federal employment and support programs

Ticket to Work is a nationwide initiative that offers Social Security Administration (SSA) disability beneficiaries greater choice in obtaining services they need to help them go to work. To qualify, you must be a SSA disability beneficiary. This program may be able to assist you in finding employment, vocational rehabilitation and other support services from public and private providers.

The Job Accommodation Network (JAN) is a free consulting service of the U.S. Department of Labor Office of Disability Employment Policy that provides information about job accommodations, the Americans with Disabilities Act and the employability of people with disabilities. JAN is not a job placement service; however, it does provide services that assist people with disabilities to become informed about their educational rights, acquire accommodation options and learn about other government and placement agencies.

Association of University Centers on Disabilities (AUCD) hosts a nationwide network of interdisciplinary centers advancing policy and practice for and with individuals with developmental and other disabilities, their families and communities. At least one center per state provides a wide range of community outreach and assistance in the areas of special education, employment and housing programs. All centers are part of universities or medical centers and serve as a link between the university and community. Services provided by each center can vary. For example, some provide more services to adults with disabilities. In some instances, centers may work with the local Developmental Disability Planning Council in providing services and information.

Developmental Disability (DD) Planning Councils are assisted by the U.S. Department of Health and Human Services (HHS) and provide information on disability-related organizations in your state. The information offered by each council differs by state. To find the DD council in your state, visit www.nacdd.org.

Supported Employment Resource List

Organization	Description	Website
Job Accommodation Network (JAN)	A source for free, expert, and confidential guidance on job accommodations and disability employment matters.	www.askjan.org
Employer Assistance and Resources Network (EARN)	EARN provides resources for employment seekers and job training for those looking to gain and build skills necessary to succeed in the workforce.	www.askearn.org
abilityJOBS	Works with companies, government and nonprofit agencies to employ people with disabilities.	www.abilityJOBS.com
Equal Opportunity Publications, Inc. (EOP)	EOP is an online publication that publishes career guidance and recruitment magazines for women, members of minority groups and people with disabilities.	www.eop.com
Bender Consulting	Consulting firm that specializes in recruiting and hiring people with disabilities for full-time, competitive employment opportunities.	www.benderconsult.com

Toileting

Toileting can be a tricky and challenging endeavor for many of our loved ones with rare epilepsy. Some of our loved ones are able to toilet independently, some use the toilet with assistance, and some will use diapers throughout childhood and into adulthood. Please use the guide below to document the level of independence your child has when it comes to toileting. Things always seem to be changing with our loved ones; therefore, feel free to come back to this form and update anytime you feel the need.

Check all that apply:

☐ My child can toilet independently (can recognize the urge to go, alert me, and perform all tasks independently)

☐ My child can toilet with minimal assistance
☐ My child can toilet with moderate assistance
☐ My child can toilet with complete assistance
☐ My child cannot independently toilet

☐ Can recognize the urge to go and alert me
☐ Needs assistance with clothing
☐ Needs assistance with performing the task
☐ Needs assistance with wiping

☐ My child requires diapers, some of the time
☐ My child requires diapers all the time
☐ My child experiences incontinence during a seizure

☐ Requires diapers at night
☐ Requires diapers in certain situations – such as traveling
☐ My child needs a mattress protector and/or disposable underpad (such as Chucks underpad)

TIP: It's important to make note when your loved one experiences changes in frequency of bowel movements and/or skin changes, such as rashes or other irritations. Capturing details about your loved one's normal toileting routine can help others caring for your child better able to recognize changes that may need to be addressed.

Toileting Routine

Use the questions below to describe your loved one's toilet routine.
Consider details such as how your child alerts you when they feel the urge to go.

Do you go into the bathroom with them? ☐ YES ☐ NO Details:

Do you physically assist your child? ☐ YES ☐ NO

Does your child like to flush? ☐ YES ☐ NO

Does this routine change when they are at school or somewhere else outside the home (in someone else's care)? ☐ YES ☐ NO Details:

Describe any symptoms your loved one may have related to rashes or other skin irritations:

Is there a routine you follow such as using ointment or any other preventative or reactive topical medication to keep your loved one healthy and comfortable? ☐ YES ☐ NO Details:

If your child requires diapers, what is the routine you follow? Details:

What environment is required to provide this care to your child and maintain their privacy and safety? Details:

Supportive Supplies Required (See the Supply Refills section of this C.A.R.E. Binder.)

☐ Ointment:

☐ Wipes:

☐ Toilet paper:

☐ Hand soap:

☐ Diapers (brand/size, if not using a service*):

☐ Changing mat:

☐ Other:

☐ Special toy or other item of comfort:

*If using a diaper service, please provide the following information:

Incontinence Service for Diapers and Pads

Company Name:

Contact Name (if applicable):

Email:

Phone:

Billing Options: ☐ Medicaid ☐ Insurance

Billing Info: ☐ Auto Pay by Bank Account ☐ Auto Pay by Credit Card ☐ Monthly Invoice, Manual Pay

Ordering Frequency: ☐ Monthly ☐ Quarterly ☐ Other

Disease Management

- Medical Care Team Contact Information
- Medical Equipment
- Medical Insurance Information
- Medication Information
- Medication Refills
- Medication Schedule
- Seizure Action Plan
- Supply Refills
- Things to Avoid

It’s easy to navigate each section – simply click on the link to access the information that interests you.

Medical Care Team Contact Information

It's important to keep your child's medical care team contact information up to date. Print a copy for your C.A.R.E. Binder and also put a copy somewhere easily accessible to others. See the Attachments section of this C.A.R.E. Binder to add pages as needed.

Primary Medical Care Team

Hospital/Clinic/Physician: Contact:
Address:
City: State: Zip:
Phone: Mobile:
Email:
Comments:

Specialty Medical Care Team

Hospital/Clinic/Physician: Contact:
Address:
City: State: Zip:
Phone: Mobile:
Email:
Comments:

Support Care Team

Hospital/Clinic/Physician: Contact:
Address:
City: State: Zip:
Phone: Mobile:
Email:
Comments:

Additional Care Team

Hospital/Clinic/Physician: Contact:
Address:
City: State: Zip:
Phone: Mobile:
Email:
Comments:

Additional Care Team

Hospital/Clinic/Physician: Contact:
Address:
City: State: Zip:
Phone: Mobile:
Email:
Comments:

Additional Care Team

Hospital/Clinic/Physician: Contact:
Address:
City: State: Zip:
Phone: Mobile:
Email:
Comments:

Additional Care Team

Hospital/Clinic/Physician: Contact:
Address:
City: State: Zip:
Phone: Mobile:
Email:
Comments:

Additional Care Team

Hospital/Clinic/Physician: Contact:
Address:
City: State: Zip:
Phone: Mobile:
Email:
Comments:

Medical Equipment

Our loved ones with rare epilepsy may have a variety of different types of equipment and devices to support their care and wellbeing. Please use the chart below to list any adaptive equipment, devices and durable medical equipment (i.e., walker, wheelchair, car seat/harness, C-pap machine, orthotics, iPad communication device, glasses, etc.).

TIP: Sometimes durable medical equipment also requires disposable medical supplies for use. See the Supply Refills section of this C.A.R.E. Binder. See the Attachments section of this C.A.R.E. Binder to add pages as needed.

Adaptive Equipment/Device	Who is involved? (for example, prescription from doctor or therapist)	How is it funded?	How often can/should it be replaced?	Is it owned or rented?	Company providing it and/or who to call for repairs/replacement	Additional Information

Medical Insurance Information

TIP: Include copies of all insurance cards, print and store in your C.A.R.E. Binder. Make sure you update this information each year when your policies renew.

Insurance Coverage

Does your loved one with rare epilepsy have any of the following:

Private Insurance ☐YES ☐NO

If yes, Policy Name:

Member ID Number:

Group Number:

Claims Address:

City: State: Zip:

Customer Service Phone:

Subscriber Name (Policy Holder):

Subscriber (Policy Holder) Date of Birth:

Online access, if applicable: Site link:

Username: Passcode:

Secondary Insurance (such as Tricare, if military, or other) ☐YES ☐NO

If yes, Policy Name:

Member ID Number:

Group Number:

Claims Address:

City: State: Zip:

Customer Service Phone:

Subscriber Name (Policy Holder):

Subscriber (Policy Holder) Date of Birth:

Medicaid ☐YES ☐NO

If yes, Policy Name:

Member ID Number:

Group Number:

Claims Address:

City: State: Zip:

Customer Service Phone:

Subscriber Name (Policy Holder):

Subscriber (Policy Holder) Date of Birth:

Case/Social Worker/Coordinator Name:

Medicare ☐ YES ☐ NO

If yes, Policy name:

Member ID Number:

Group Number:

Claims Address:

City: State: Zip:

Customer Service Phone:

Subscriber Name (Policy Holder):

Subscriber (Policy Holder) Date of Birth:

TIP: Visit Medicare for additional information on how to lower your Medicare prescription costs.

Part D Coverage ☐ YES ☐ NO

If yes, Policy name:

Member ID Number:

Group Number:

Claims Address:

City: State: Zip:

Customer Service Phone:

Subscriber Name (Policy Holder):

Subscriber (Policy Holder) Date of Birth:

Dental ☐ YES ☐ NO ☐ Covered under another policy

If yes, Policy name:

Member ID Number:

Group Number:

Claims Address:

City: State: Zip:

Customer Service Phone:

Subscriber Name (Policy Holder):

Subscriber (Policy Holder) Date of Birth:

Vision ☐ YES ☐ NO ☐ Covered under another policy

If yes, Policy Name:

Member ID Number:

Group Number:

Claims Address:

City: State: Zip:

Vision *(continued)*

Customer Service Phone:

Subscriber Name (Policy Holder):

Subscriber (Policy Holder) Date of Birth:

Waivers

Is additional insurance provided by a Deeming Waiver (Katie Beckett or other)? ☐ YES ☐ NO

If YES, summarize the renewal process below, including as much information as possible about this process.
(You can also attach separately to C.A.R.E. Binder.)

Is your loved one accessing Medicaid through a Supplemental Security Income (SSI) Waiver? ☐ YES ☐ NO
If YES, please see the Financial Information form in this C.A.R.E. Binder.

Are there any regular meetings in regard to insurance and/or waivers? ☐ YES ☐ NO

If YES, please provide details:

Medication Information[2,3]

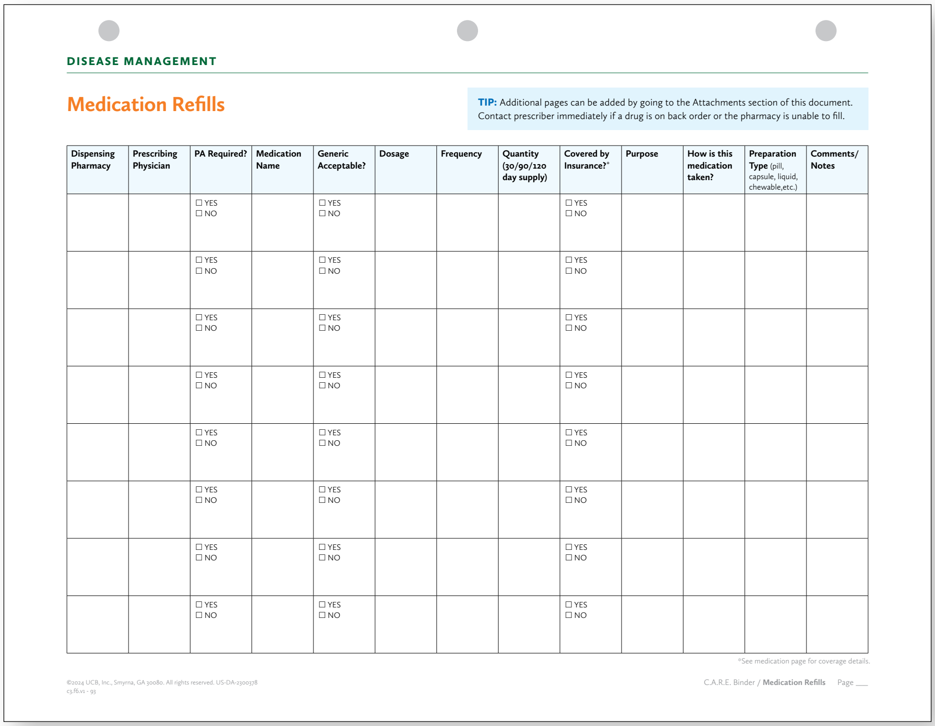
Use the summary page to document your loved one's medications.

Below are some helpful tips to keep in mind as you manage your loved one's medications.

- Does this medication require a prior authorization (PA)?
- Make a note of the following important information for your prescription, such as pharmacy name/contact info.
- Have a point of contact at your provider's office in case anything goes awry with filling your prescription.
- Determine what the estimated turnaround time is for prescription requests – especially if it's different for submissions via a secure web portal vs. requests by phone.
- Contact prescriber immediately if a drug is on back order or the pharmacy is unable to fill.

TIP: Request as soon as you can to refill a prescription (retail or specialty) – if it's too soon to refill, ask the pharmacist when is the soonest you can make a request. It's especially important to manage your loved one's anti-seizure medications (ASMs) to ensure they don't run out. If possible, it may help to ask for the medication to be put on an automatic refill. Also, pay attention to weekends and holidays and try to avoid needing a refill around those times, when possible.

The Medication Refills Chart (sample shown at right) has been included in the C.A.R.E. Binder for your convenience. Use the summary page to document your loved one's medications.



DISEASE MANAGEMENT

Medication Refills

TIP: Additional pages can be added by going to the Attachments section of this document. Contact prescriber immediately if a drug is on back order or the pharmacy is unable to fill.

Dispensing Pharmacy	Prescribing Physician	PA Required?	Medication Name	Generic Acceptable?	Dosage	Frequency	Quantity (30/90/120 day supply)	Covered by Insurance?*	Purpose	How is this medication taken?	Preparation Type (pill, capsule, liquid, chewable,etc.)	Comments/ Notes
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				

*See medication page for coverage details.

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C.A.R.E. Binder / **Medication Refills** Page ___

Detailed Information on Medication

TIP: Additional pages can be added by going to the Attachments section of this document.

Medication Name:

Purpose:

Generic Acceptable? ☐ YES ☐ NO Does this medication require a prior authorization (PA)? ☐ YES ☐ NO

PA renewal date:

TIP: Set a reminder on your phone to go off at least two weeks before the prescription expires to remind you to start the PA process.

RX Number: Dosage:

Frequency: Quantity:

Prescribing Physician Name:

Phone: Fax:

Email:

Dispensing Pharmacy: ☐ Local Pharmacy ☐ Specialty Pharmacy

Contact Name:

Address:

City: State: Zip:

Phone: Fax:

Email:

Please indicate if identification is required when picking up this medication from the pharmacy. ☐ YES ☐ NO

TIP: You may have different medications that are dispensed by different pharmacies. Indicate the list of medications each pharmacy provides.

Covered by insurance ☐ YES ☐ NO

Co-pay cost:

Prescription or Co-Pay Assistance Program Available? ☐ YES ☐ NO

Name/Info for Assistance Program(s):

Phone: Fax:

How is this medication taken?

Preparation Type (pill, capsule, liquid, chewable, etc.)?

Additional Comments/Notes:

Medication Refills

TIP: Additional pages can be added by going to the Attachments section of this document. Contact prescriber immediately if a drug is on back order or the pharmacy is unable to fill.

Dispensing Pharmacy	Prescribing Physician	PA Required?	Medication Name	Generic Acceptable?	Dosage	Frequency	Quantity (30/90/120 day supply)	Covered by Insurance?*	Purpose	How is this medication taken?	Preparation Type (pill, capsule, liquid, chewable,etc.)	Comments/ Notes
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				
		☐ YES ☐ NO		☐ YES ☐ NO				☐ YES ☐ NO				

*See medication page for coverage details.

Medication Schedule

TIP: Keep a copy of this document in your C.A.R.E. Binder and print an extra copy to post somewhere easily accessible, such as on the refrigerator. Refer to the Medication Refills document in this C.A.R.E. Binder for details on dosage and how to administer. Additional pages can be found in the Attachments section of this C.A.R.E. Binder.

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday	PRN (As Needed Meds)
☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	Medication Name: Use as needed for:
☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	Medication Name: Use as needed for:
☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	Medication Name: Use as needed for:
☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	Medication Name: Use as needed for:
☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	Medication Name: Use as needed for:
☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	Medication Name: Use as needed for:
☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	Medication Name: Use as needed for:
☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	☐ AM ☐ MIDDAY ☐ PM Medication Name:	Medication Name: Use as needed for:

Seizure Action Plan[2,3]

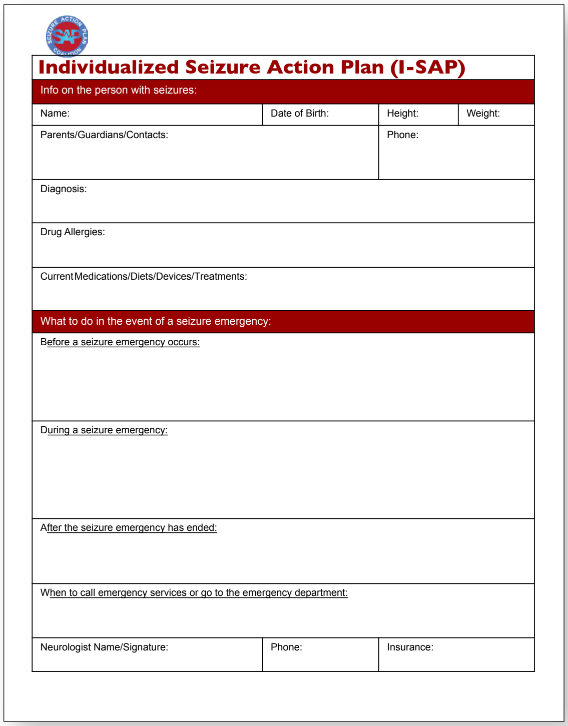
For all individuals who experience seizures, it is important to provide your child's school and others who care for your loved one with a Seizure Action Plan (SAP). An SAP helps organize all the individual's seizure information to guide on what to do in an emergency. There are some great resources available from the Seizure Action Plan Coalition and the Epilepsy Foundation. In addition, those within your inner circle (friend, family, school staff) can complete training on seizure safety for an extra layer of confidence to help ensure your loved one receives high quality seizure support in the event it is needed.

Included in this C.A.R.E. Binder is the Individualized Seizure Action Plan (I-SAP)[9]; however there are additional seizure action plan forms and templates on the Seizure Action Plan Coalition and Epilepsy Foundation websites noted above.

Instructions for using the Individualized Seizure Action Plan (I-SAP):

- This I-SAP is a tool that may prepare caregivers and others for what to do if a seizure emergency occurs or is likely to occur. It was created by caregivers of children and adults with severe epilepsy.
- This I-SAP should be discussed and agreed upon with a neurologist who understands seizure emergencies and rescue medication use.
- This I-SAP, once filled out with your doctor, can be handed to emergency personnel to get the facts to them, in writing, as quickly as possible if needed.
- The below document is meant to be an interactive form where you can add or delete spaces in each section as needed. Read the suggested comments in gray and then delete them once you add your own loved one's information. It is suggested that you print your I-SAP and hang it on the wall for emergency use.

TIP: Be sure to print a second copy to keep in your C.A.R.E. Binder so all your loved one's information can be accessed in one place.



Individualized Seizure Action Plan (I-SAP)

Info on the person with seizures:

Name:	Date of Birth:	Height:	Weight:
Parents/Guardians/Contacts:		Phone:	
Diagnosis:			
Drug Allergies:			
Current Medications/Diets/Devices/Treatments:			

What to do in the event of a seizure emergency:

Before a seizure emergency occurs:

During a seizure emergency:

After the seizure emergency has ended:

When to call emergency services or go to the emergency department:

Neurologist Name/Signature:	Phone:	Insurance:

The fillable I-SAP form can be found in the Attachments section of this C.A.R.E. Binder.

Supply Refills

Use the summary page below to document your loved one's necessary supplies. This includes things like diapers, medical supplies and even durable medical equipment and accessories. Sometimes durable medical equipment also requires disposable medical supplies for use. Below are some helpful tips to keep in mind as you manage your loved one's supplies.

TIP: Set a reminder on your phone to go off at least two weeks before supplies run out to remind you to start the order process. Adjust the reminders as needed depending on processing time for each of the needed supplies. Also, pay attention to weekends and holidays and try to avoid needing a resupply around those times, if possible. Additional pages can be added by going to the Attachments section of this document.

Item (Name and item #/model)	Size	Quantity	Vendor Name/ Point of Contact	Website link to product page	Login/PW	Order Frequency	Last Order Date	Comments/Notes

Things to Avoid

In addition to seizures, our loved ones with rare epilepsy may have several comorbidities, including GI issues or allergies to certain substances such as seasonal allergies or medication allergies. They may also have sensitivities to things like fabric, food, light or patterns. Sometimes our loved ones may have a reaction for an unknown reason to sounds or other things in our environment. These sensitivities can sometimes trigger seizures, challenging behaviors, or other reactions. It's important to document all your child's allergies and triggers to alert others. This document can be helpful to those who may assist with the care of your loved one, but this can also be useful in everyday situations.

TIP: After completing the information below, print an extra copy. Put one in your C.A.R.E. Binder and keep one out in plain sight for quick and easy access. Also, make sure you share this list with anyone who provides care for your loved one with rare epilepsy. See the Attachments section of this C.A.R.E. Binder to add pages as needed.

Trigger Type	Trigger Response	Trigger Details	Immediate Action Required	Additional Helpful Info to Resolve
☐ **Heat** ☐ **Excitement** ☐ **Light** ☐ **Flashing light** ☐ **Patterns** ☐ **Allergy** ☐ **Food** ☐ **Sound**	☐ **Seizure** ☐ **GI-Stomach** ☐ **GI-Bowels** ☐ **Skin Rash/Hives** ☐ **Wheezing** ☐ **Behavior Change** ☐ **Lethargy**		☐ **Call 911** ☐ **Seizure Rescue Meds** ☐ **Behavior Rescue Meds** ☐ **Administer EpiPen** ☐ **Administer Oxygen** ☐ **Other:**	
☐ **Heat** ☐ **Excitement** ☐ **Light** ☐ **Flashing light** ☐ **Patterns** ☐ **Allergy** ☐ **Food** ☐ **Sound**	☐ **Seizure** ☐ **GI-Stomach** ☐ **GI-Bowels** ☐ **Skin Rash/Hives** ☐ **Wheezing** ☐ **Behavior Change** ☐ **Lethargy**		☐ **Call 911** ☐ **Seizure Rescue Meds** ☐ **Behavior Rescue Meds** ☐ **Administer EpiPen** ☐ **Administer Oxygen** ☐ **Other:**	
☐ **Heat** ☐ **Excitement** ☐ **Light** ☐ **Flashing light** ☐ **Patterns** ☐ **Allergy** ☐ **Food** ☐ **Sound**	☐ **Seizure** ☐ **GI-Stomach** ☐ **GI-Bowels** ☐ **Skin Rash/Hives** ☐ **Wheezing** ☐ **Behavior Change** ☐ **Lethargy**		☐ **Call 911** ☐ **Seizure Rescue Meds** ☐ **Behavior Rescue Meds** ☐ **Administer EpiPen** ☐ **Administer Oxygen** ☐ **Other:**	
☐ **Heat** ☐ **Excitement** ☐ **Light** ☐ **Flashing light** ☐ **Patterns** ☐ **Allergy** ☐ **Food** ☐ **Sound**	☐ **Seizure** ☐ **GI-Stomach** ☐ **GI-Bowels** ☐ **Skin Rash/Hives** ☐ **Wheezing** ☐ **Behavior Change** ☐ **Lethargy**		☐ **Call 911** ☐ **Seizure Rescue Meds** ☐ **Behavior Rescue Meds** ☐ **Administer EpiPen** ☐ **Administer Oxygen** ☐ **Other:**	

Important Contacts

Emergency Contacts

It's easy to navigate each section – simply click on the link to access the information that interests you.

Emergency Contacts

TIP: Print two copies of your completed form—one for your C.A.R.E. Binder and one to put in plain view (such as on the refrigerator) for easy access during emergencies. Also consider making copies for everyone noted on this list so that all of your emergency contacts have each other's information. Additional pages can be found in the Attachments section of this C.A.R.E. Binder.

Contact Name: Relationship:
Phone: Email:

When to contact:
☐ Weekdays, 9-5P ☐ Weekends/Holidays ☐ Nighttime ☐ Other:

Authorization(s):
☐ House access/has key ☐ Can watch sibs at home ☐ Take siblings to their home ☐ Pickup/Dropoff siblings from home or other locations
☐ Pickup/Dropoff siblings from/to school ☐ Temporary Caregiver ☐ Long-Term Caregiver ☐ Power of Attorney
☐ Other:

Contact Name: Relationship:
Phone: Email:

When to contact:
☐ Weekdays, 9-5P ☐ Weekends/Holidays ☐ Nighttime ☐ Other:

Authorization(s):
☐ House access/has key ☐ Can watch sibs at home ☐ Take siblings to their home ☐ Pickup/Dropoff siblings from home or other locations
☐ Pickup/Dropoff siblings from/to school ☐ Temporary Caregiver ☐ Long-Term Caregiver ☐ Power of Attorney
☐ Other:

Contact Name: Relationship:
Phone: Email:

When to contact:
☐ Weekdays, 9-5P ☐ Weekends/Holidays ☐ Nighttime ☐ Other:

Authorization(s):
☐ House access/has key ☐ Can watch sibs at home ☐ Take siblings to their home ☐ Pickup/Dropoff siblings from home or other locations
☐ Pickup/Dropoff siblings from/to school ☐ Temporary Caregiver ☐ Long-Term Caregiver ☐ Power of Attorney
☐ Other:

Contact Name: Relationship:
Phone: Email:

When to contact:
☐ Weekdays, 9-5P ☐ Weekends/Holidays ☐ Nighttime ☐ Other:

Authorization(s):
☐ House access/has key ☐ Can watch sibs at home ☐ Take siblings to their home ☐ Pickup/Dropoff siblings from home or other locations
☐ Pickup/Dropoff siblings from/to school ☐ Temporary Caregiver ☐ Long-Term Caregiver ☐ Power of Attorney
☐ Other:

Long-Term Care Planning

It’s easy to navigate each section – simply click on the link to access the information that interests you.

Developing a Lifelong Support Network[10]

As we all know, it takes a village of many caring individuals around us to help support our loved one with rare epilepsy and our families. That's why it is so important to take time to develop a lifelong support network. It's also important to document who is in your network to share with others who support your family.

Using the table below, identify potential lifelong support network members. List everyone who comes to mind as a starting point.

Considerations	Name(s)	Strengths they can offer
Who are the people who are closest to your loved one, those they will rely on every day and those who know them best? • Are there siblings, and are they able and willing to be involved? • Are there extended family members or friends who know your child well?		
Who are the people who regularly interact with your loved one, who have some common interests or associations? Such as: • Neighbors • Teachers • People where you worship		
Who are the people in your loved one's life who are providing a paid service? Such as: • Doctors • Therapists • Support providers • Attorneys		

After completing your list, consider:

- Who will be the lead network member(s)? The lead(s) will be in charge of the primary decision making for your adult child with rare epilepsy.
- Develop a list of other network members who can offer advice to the lead member(s). These may be supporting network members that the lead members can call on for their expertise. For instance, teachers or therapists may have suggestions on local day programs or housing placements that would be appropriate for your child.
- You may want to also consider temporary team members. For instance, if a sibling will eventually be taking over care decisions, but is currently too young, you could elect another network member to take a lead role in care, should the sibling end up in charge of care decisions before they are ready.
- There is no magic number for your network. In some cases, one individual may be comfortable handling all of the decisions for your child's care. Regardless of the number of members on your team, it is important that they have as much information on your child as possible. Make sure they know where this C.A.R.E. Binder and other important information can be accessed.

After selecting your network:

- Set up an initial meeting to discuss the Letter of Guidance and Crisis Planning Guide section of this C.A.R.E. Binder with each of the network members, and what you anticipate their role may be. For instance, "If I am unexpectedly hospitalized, I would ask you to manage daily care - including daily medication administration and transportation to day programs and therapies - until I am able to once again resume those duties." Or, "If I pass away unexpectedly, I would ask you to help the lead network member explore housing placement options."
- Find out what other information would be helpful for each team member and what questions they have. Explore the Conversations section of this C.A.R.E. Binder for helpful tips on having difficult conversations.
- Compile a list of all of the members and their contact information for the lead member(s). Ensure those who will serve as your primary supporters during a crisis are listed in the Emergency Contacts document section of this C.A.R.E. Binder. Print and share copies of the Emergency Contacts with your lead team members.
- The Letter of Guidance should include supporting documents (see C.A.R.E. Guide for more information). After developing your Letter of Guidance, if you don't already have a Special Needs Trust established for your child you should speak with an attorney specializing in this area of law in your state. A Special Needs Trust may allow for a disabled person to maintain his or her eligibility for public assistance benefits (such as SSI or Medicaid).
- Be sure to connect with other families to share advice and ask questions.

TIP: Be sure to review this list annually and update as needed and when you do, make a note below of the date last updated:

____

Financial Information Form

Include any account or financial information that directly impacts your loved one with rare epilepsy.

Do you have a financial advisor? ☐ YES ☐ NO

Financial Institution/Firm:

Address:

City: State: Zip:

Advisor Name:

Phone: Email:

ABLE Account (For more information, visit: https://www.ssa.gov/ssi/spotlights/spot-able.html)

Name(s) on Account:

Banking Institution:

Account Number: Routing Number:

Beneficiary(ies):

Online Link to Account:

Online Login: Passcode:

TIP: Rules of an ABLE account vary by state—especially maximum deposit limits AND what it can be used for. Be sure to review the rules for your specific state. The ABLE National Resource Center highlighted on the Social Security Administration's website provides resources on state specific information.

Special Needs Trust

Name(s) on Trust:

EIN:

Rules Related to Trust (what it can be used for and tax information):

Accountant Name(s):

Accountant Phone: Accountant Email:

Attorney Name(s):

Attorney Phone: Attorney Email:

Social Security (SS)/Supplemental Security Income (SSI)

Amount deposited each month: Where is SS/SSI Deposited:

Rules for SS/SSI Direct Deposit:

Name of Representative Payee:

Online Social Security Account Link:

Online Login to SS/SSI Account: Passcode to SS/SSI Account:

TIP: To qualify for SS/SSI, certain waiver programs, and Medicaid, the balance for bank/savings accounts may need to remain below a certain amount. For more information, visit: https://www.ssa.gov/benefits/ssi/

Insurance Policies (Life, Disability, Long-Term Care, Liability, etc.)

Insurance Type:

Company Name:

Address:

City: State: Zip:

Contact Name:

Phone: Email:

Policy Effective Date: Expiration Date:

Monthly Premium:

Person Responsible for Making Payments:

Online Account Link:

Online Login: Passcode:

How is policy paid? ☐ Check by Mail ☐ Manual Online Pay from Bank Account ☐ Auto-deduction from Bank Account ☐ Auto-pay to Credit Card

Insurance Policies (Life, Disability, Long-Term Care, Liability, etc.)

Insurance Type:

Company Name:

Address:

City: State: Zip:

Contact Name:

Phone: Email:

Policy Effective Date: Expiration Date:

Monthly Premium:

Person Responsible for Making Payments:

Online Account Link:

Online Login: Passcode:

How is policy paid? ☐ Check by Mail ☐ Manual Online Pay from Bank Account ☐ Auto-deduction from Bank Account ☐ Auto-pay to Credit Card

Other Financial Resources:

Anticipated Inheritance Gifts (If expected, please add details below.)

Taxes/Tax Returns

Accountant Contact Name:

Address:

City: State: Zip:

Phone: Email:

Location where the noted documents can be found:

Account Statements:

Policies In Effect:

Tax Returns:

TIP: If helpful, you may use the space below to add any other relevant financial details for your loved one's specific information.

Bank/Checking Account (Include any account that directly impacts your loved one with rare epilepsy)

Name(s) on Account:

Banking Institution:

Account Number:

Routing Number (or attach voided check):

Online Link to Account:

Online Login: Passcode:

Bank/Savings Account (Include any account that directly impacts your loved one with rare epilepsy)

Name(s) on Account:

Banking Institution:

Account Number:

Routing Number (or attach voided check):

Online Link to Account:

Online Login: Passcode:

Who manages account(s)?

Name:

What are the asset limits to this account(s)?

Amount:

Specific banking location that you currently use:

Address:

City: State: Zip:

Specific contact info for person you work with at the bank (if applicable):

Name:

Phone: Email:

REMINDER TIP: To qualify for Social Security (SS)/Supplemental Security Income (SSI), certain waiver programs, and Medicaid, the balance for bank/savings accounts may need to remain below a certain amount.

Legal Checklist

Below is a check list of the documents to keep on file and keep maintained for your loved one with rare epilepsy. This is a suggested list, not legally required, and not intended to be complete. **It's important to ensure all legal paperwork is safely stored in one location and to safeguard your documents, account information, logins, and passwords.**

☐ **Original Birth Certificate**
☐ **State Issued ID Card** State Issued ID Expiration Date:
☐ **Passport** Passport Expiration Date:
☐ **Social Security Card** Social Security Number:
☐ **Copies of Will for Parents/Primary Caregiver**
☐ **Guardianship Paperwork**
☐ **Medical Power of Attorney (POA) for Parents/Primary Caregiver** POA Name:
☐ **Advance Directives for your loved one with rare epilepsy**
☐ **Special Needs Trust documents and other information that benefits your loved one with rare epilepsy**
☐ **Prior Years' Tax Returns**
☐ **Copies of Waiver Documents**

Document Storage

Physical Location of Legal Documents:
Electronic Location of Legal Documents:
Account Link (if stored online):
Online Login: Passcode:

Legal Team Contact Information:

Estate Attorney Name:
Address:
City: State: Zip:
Phone: Email:

General Legal Counsel Name:
Address:
City: State: Zip:
Phone: Email:

Other Contact Name:
Address:
City: State: Zip:
Phone: Email:

Long-Term Residential Living

Planning for future living arrangements for your loved one with rare epilepsy can be challenging. During the process of evaluating your loved one's needs, some families may consider long-term residential care. With this option comes many questions and details to sort through. The following information can help guide you in asking questions to obtain the information you need to make an informed decision on the type of facility that can best support your vision for the long-term care plan that reflects your future wishes while addressing the needs of your loved one with rare epilepsy. Even if residential living arrangements are not the first choice for your loved one, investigating what options are available may be helpful if future care situations change.

Print and bring this list with you when you visit potential facilities. Space is provided to allow you to capture the information you gather from each facility you may research or visit. Also included is additional space to add your own questions unique to the individual needs of your child. You can use this document as a guide to refer back to later as you consider what options best align with your vision of future long-term care for your loved one with rare epilepsy.[2,3]

Researching & Touring Facilities for Long-Term Care: Questions & Worksheet/Checklist

Name of Facility Being Evaluated:

GENERAL QUESTIONS FOR CAREGIVERS

1. Do you have an advocate that can help you with transition to adult services and benefits that may be available?

☐ YES ☐ NO Details:

2. Is there a day or work program near your residence?

☐ YES ☐ NO Details:

3. Is there medical support close by?

☐ YES ☐ NO Details:

4. How close is the facility to where the family lives?

Number of miles:

5. Are staff making eye contact with you, smiling, speaking kindly to the residents—do staff look happy?

Observations:

FACILITY CONSIDERATIONS

6. Is the home co-ed?

☐ YES ☐ NO Details:

7. How is communication between the staff and family handled? How do I keep up with what is going on in my loved one's life?

Details:

8. What level of support do the other residents require?

Details:

9. What kind of activities are offered?

Details:

10. What are the recommendations for transitioning to the home?

Details:

11. What is the staff's experience with rare epilepsy? With developmental delay?

Details:

12. What is the facility's protocol in the event of an emergency? (for example, earthquakes, fires, tornadoes, etc.)

Details:

STAFFING CONSIDERATIONS

13. Is there a place where I can find data about the facility? Ratings, staff retention, previous complaints?

Details:

14. What is staff-to-resident ratio? Does this number change on weekends and holidays? ☐ YES ☐ NO

Details:

15. What is the staff turnover rate? Are you fully staffed or are there openings?

Details:

16. Describe staff training, as well as any ongoing training that they receive.

Details:

TIP: This website offers ideas for Direct Support Professionals (DSP) training. Some of the trainings to look for in the staff may include CPR, basic first aid, basic nutrition, seizure disorders, safe lifting for DSPs.

17. Are there cameras and/or seizure monitors? If so, how are they monitored/documented?

☐YES ☐NO Details:

18. How would the night staff monitor nocturnal seizures?

Details:

19. Who supervises the staff? Do you have any input in the staff evaluations? Hiring?

Details:

VISITATION CONSIDERATIONS

20. Are there any restrictions on visitation?

☐YES ☐NO Details:

21. Is there an open-door policy for family?

☐YES ☐NO Details:

MEDICAL & ACCESSIBILITY CONSIDERATIONS

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

☐YES ☐NO Details:

23. How are medications handled? Where are the medications stored? Is it in a locked cabinet?

Details:

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

Details:

25. How are meals and meal planning handled? Ask for sample menu. Do they have a nutritionist on staff? ☐YES ☐NO

Details:

26. What are the accessibility options in the facility for mobility, bathing, etc.?

Details:

27. Can your loved one get up and go to bed as she/he wishes? Or is there a bedtime and wake up time that is set?

☐YES ☐NO Details:

28. Can your loved one have electronic devices like iPads?

☐YES ☐NO Details:

29. How are challenging behaviors handled? Do they have a behavior specialist available to consult on challenging behaviors?

Details:

30. Are physical restraints ever used? If so, when?

Details:

31. What is in place for fall prevention and to reduce the chance of injury when falls happen?

Details:

32. What is the condition of beds/floor mats, etc?

Observations:

FINANCIAL CONSIDERATIONS

33. How will the money be handled? Cash, debit card?

Details:

34. Can you pay the room and board, or do they require that the agency be the representative payee?

☐YES ☐NO Details:

HYGIENE CONSIDERATIONS

35. Will they shave residents when needed?

☐YES ☐NO Details:

36. Do they bathe and wash residents daily?

☐YES ☐NO Details:

37. How often do they brush residents' teeth?

Details:

38. Do they have standards of care that they follow?

☐YES ☐NO Details:

ADDITIONAL OBSERVERVATIONS

39. Are there younger residents?

☐YES ☐NO Details:

40. What are residents doing?

Details:

41. Do residents look happy?

☐YES ☐NO Details:

42. Does the food look and smell appetizing?

☐YES ☐NO Details:

43. How is transportation handled? Does the home have its own van/car?

Details:

44. Do they have someone on staff who is able to accompany your loved one to doctor appointments? ☐YES ☐NO

If so, will they ensure this person brings with them any appropriate information/documentation required for a successful appointment?

☐YES ☐NO

ADDITIONAL QUESTIONS UNIQUE TO MY LOVED ONE WITH RARE EPILEPSY

45.

Details:

46.

Details:

47.

Details:

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Details:

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Details:

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Details:

Medical Transition: Peds to Adult

Caregiver Assessment on Medical Transition Readiness

Epilepsy Living & History Form

HCP to HCP Letter of Introduction (Template)

It's easy to navigate each section – simply click on the link to access the information that interests you.

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.[2,3]

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:

☐ Daily home routine:

☐ School or day program routine:

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.

☐ 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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Epilepsy Living & History Form

This form can be used for pediatric-to-adult medical transition for any childhood-onset epilepsy. While this form is intended to be filled out with the assistance of your child's pediatric neurologist/epileptologist prior to the transfer of care to an adult neurologist, we encourage you to complete as much information as you can on your own before you bring to your child's healthcare provider for their input.

TIP: Although this form does not need to be completed prior to entering the pediatric-to-adult medical transition, if you would find it helpful in managing your loved one's medical records, you may wish to complete the form earlier and update it on an annual basis. Sometimes it's easier to pick a date that is easy to remember, such as your loved one's birthday.

Name of current neurologist/epileptologist:

Address:

City: State: Zip:

Phone: Email:

Name of caregiver or individual completing the form with clinician:

Date this form was last completed/updated:

Patient Name: Current Age:

Date of Birth: Sex:

Epilepsy history

1. Epilepsy diagnosis:

2. Is the cause of the patient's diagnosis known? For example, does the patient carry a genetic variant? ☐YES ☐NO

Details:

3. Age at first seizure:

a. Was the first seizure febrile or afebrile? ☐YES ☐NO ☐UNSURE

b. Was the first seizure infantile spasms? ☐YES ☐NO ☐UNSURE

Details:

4. **Seizure types.** Please note whether this is a prior history as well as the current seizure type the patient experiences.

Seizure Type	Current/Prior	Description	Frequency	Date of Last Seizure
☐ **Tonic-clonic**	☐ Currently Experiences			
	☐ Prior History			
☐ **Hemiclonic**	☐ Currently Experiences			
	☐ Prior History			
☐ **Myoclonic**	☐ Currently Experiences			
	☐ Prior History			
☐ **Focal Unaware**	☐ Currently Experiences			
	☐ Prior History			

Seizure Type	Current/Prior	Description	Frequency	Date of Last Seizure
☐ **Focal Aware**	☐ Currently Experiences			
	☐ Prior History			
☐ **Focal to Bilateral Tonic Clonic**	☐ Currently Experiences			
	☐ Prior History			
☐ **Typical Absence**	☐ Currently Experiences			
	☐ Prior History			
☐ **Atypical Absence**	☐ Currently Experiences			
	☐ Prior History			

Seizure Type	Current/Prior	Description	Frequency	Date of Last Seizure
☐ **Tonic**	☐ Currently Experiences			
	☐ Prior History			
☐ **Atonic**	☐ Currently Experiences			
	☐ Prior History			
☐ **Other**	☐ Currently Experiences			
	☐ Prior History			

5. List known seizure triggers:

6. Seizure free period(s):

a. Longest length of time seizure-free:

b. Approximate dates:

7. Please detail the patient's history of status epilepticus (SE), defined here as a seizure lasting more than 30 minutes:

Type of SE	Date(s) of Event(s)	Successful Treatments	Additional Details
☐ Convulsive			
☐ Non-convulsive			
☐ Intermittent/ Seizure Cluster			

8. Family history of epilepsy or other relevant neurologic conditions:

Treatment(s)

9. Current antiseizure medications (ASMs):

Current ASM	Dose	Duration of Time on Therapy

10. Rescue ASMs:

Current ASM	Dose	Duration of Time on Therapy

11. Seizure Emergency Protocol (brief description, please attach full Seizure Action Plan to report):

12. Vagus nerve stimulation (VNS) or other neuromodulation device:

Device	**Settings**	**Date of Placement**

12a. Has the VNS (or other device) battery been replaced?

Device	**Date of battery replacement**	**Did seizures worsen when battery life ended?**

13. Prior/failed ASMs:

Prior ASM	**Highest dose**	**Duration**	**Reason discontinued**

14. Epilepsy surgery (excluding neuromodulation, if already noted above):

Procedure type	Date of surgery	Details

15. Ketogenic or other dietary therapy for epilepsy:

Prior/Failed Dietary Therapy	Dates	Reason Discontinued

Current Dietary Therapy	Date Initiated	Details and Future Plans for Continuation

16. Other current medications or supplements (Please include psychiatric or behavior drugs, contraceptives, calcium/vitamin D, folic acid, etc.):

Medication/Supplement	Dose	Duration of Time on Therapy

17. Please list any allergies or contraindicated medications with details:

Epilepsy History

18. Intellectual evaluation: ☐ Normal cognition ☐ Mild intellectual disability ☐ Moderate or severe intellectual disability

Evaluation determined by: ☐ Pediatrician ☐ School Reports ☐ Psychiatrist ☐ Psychologist

☐ Other (please explain):

19. Psychiatric comorbidities: (please select all that apply) ☐ None ☐ Depression ☐ Anxiety ☐ Autism Spectrum Disorder ☐ Psychosis
☐ Other (please explain):

Evaluation determined by:

20. Gait, motor, and/or skeletal abnormalities (please describe any interventions):

20a. Is patient currently followed by a specialist for these issues? ☐ YES ☐ NO

Please include name of specialist:

21. Sleep disruptions or apnea (please specify dates and findings from sleep studies):

21a. Is patient currently followed by a specialist for these issues? ☐ YES ☐ NO

Please include name of specialist:

22. Please list any other non-epilepsy surgeries (include dates):

Procedure Type	Date of Surgery	Details

23. List other significant medical conditions/comorbidities (please include name of specialist, if relevant):

Neurologic Exam

24. Neurologic exam: ☐Normal ☐Abnormal

Please describe abnormal exam findings:

Tests

25. Neuroimaging procedures and findings:

Procedure Type	Exam Date(s)	Relevant Findings
☐ CT head		
☐ MRI brain		
☐ PET		
☐ SPECT		
☐ Other:		

26. Electrophysiology/EEG:

Procedure Type	Most Recent Procedure Date(s)	Relevant Findings from Current or Past Procedures
Routine EEG		
Inpatient video- EEG (in Epilepsy Monitoring Unit)		
Inpatient video- EEG (not in Epilepsy Monitoring Unit)		
Outpatient prolonged video EEG (ambulatory EEG with video)		
Outpatient prolonged EEG (ambulatory EEG without video)		
MEG		
Other:		

27. Genetic tests:

Test Type	Date(s)	Lab or Company Name	Relevant Findings
Epilepsy gene panel			
Karotype			
Microarray			
Whole exome sequencing (WES)			
Whole genome sequencing (WGS)			
Other:			

28. Metabolic tests (please include exam date(s) and relevant findings):

Test Type	Date(s)	Lab or Company Name	Relevant Findings

This Epilepsy Living & History Form was developed from the following resources:

- Nascimento FA, Gurnett CA. Epilepsy Transition Program– Washington University School of Medicine. St. Louis, MO, USA.
- Li W, Schneider AL, Scheffer IE. Defining Dravet syndrome: an essential pre-requisite for precision medicine trials. Epilepsia. 2021;62(9):2205-2217. https://doi.org/10.1111/epi.17015
- Andrade DM, Bassett AS, Bercovici E, Borlot F, Bui E, Camfield P, et al. Epilepsy: Transition from pediatric to adult care. Recommendations of the Ontario epilepsy implementation task force. Epilepsia. 2017; 58(9):1502–17. https://doi.org/10.1111/epi.13832
- Andrade DM, Berg AT, Hood V, Knupp KG, Koh S, Laux L, et al. Dravet syndrome: a quick transition guide for the adult neurologist. Epilepsy Res. 2021;177:106743. https://doi.org/10.1016/j.eplepsyres.2021.106743
- Dravet Syndrome Foundation https://dravetfoundation.org/

HCP to HCP Letter of Introduction[11]

TIP: You should already have the attached documents completed as a part of your C.A.R.E. Binder so all you need to do is print and include with this letter of introduction. An editable word version of this letter template can be found in the Attachments section of this C.A.R.E. Binder.

Dear ________________________________ ,

____________________________ is a(n) ___ year-old patient of our pediatric practice who is interested in transferring to your care. Their primary diagnosis is ________________________. As a result of __________________, ___________________ also has other associated health issues which need medical management. Enclosed with this letter is a complete Epilepsy Living & History Form, medication schedule chart, medical insurance information, and seizure action plan.

____________________________ is the primary caregiver and guardian for ___________________________ .

Guardian information

Name:

Address:

City: State: Zip:

Phone: Email:

Also enclosed is an Intro Summary of ______________________ to help you get to know them.

The needed next steps in ________________________’s plan of care are:

___

___

___

I have had ____________________________ as a patient since age _____ and am very familiar with their health condition, medical history, and specialists. Our practice will provide care for them, such as refilling medications, until they come to the first visit in your practice. Please send us a note or call when _________________________ has attended their first appointment in your practice. I would be happy to provide any consultation assistance to you during the initial phases of ____________________________’s transition to your practice. Please do not hesitate to contact me by phone or email if you have any questions.

Thank you very much for your willingness to care for __________________________.

Sincerely,

____

Phone: Email:

Resources

It’s easy to navigate each section – simply click on the link to access the information that interests you.

Acknowledgements

Caring for an individual with a rare epilepsy takes a village. It also takes a village to develop tools to support individuals and the families that care for them. These resources contain a combination of original content and content created by others. We are incredibly grateful to the organizations listed below for the unrelenting support they provide the families they serve. Each of these organizations graciously contributed resource tools and programs to this C.A.R.E. Binder and generously authorized us to adapt for the rare epilepsy community.

Thank you for your collaboration!

Organization	Mission/Description
Dravet Syndrome Foundation	The mission of Dravet Syndrome Foundation (DSF) is to aggressively raise funds for Dravet syndrome and related epilepsies; to support and fund research; increase awareness; and to provide support to affected individuals and families.
epilepsy ALLIANCE AMERICA	Epilepsy Alliance America is a growing national organization representing like-minded local, regional, statewide, and even other national agencies dedicated to serving the everyday needs of people who live with seizures and epilepsy every day.
got transition®	Got Transition® is the national resource center on health care transition (HCT). Its aim is to improve the transition from pediatric to adult health care through the use of evidence-driven strategies for clinicians and other health care professionals; public health programs; payers and plans; youth and young adults; and parents and caregivers.
LGS FOUNDATION® LENNOX-GASTAUT SYNDROME	The mission of the Lennox-Gastaut Syndrome (LGS) Foundation is to improve the lives of those impacted by LGS through research, family support programs, and education.
NEW YORK STATE SHERIFFS' ASSOCIATION NYSSA Est. 1934	The New York State Sheriffs' Association is a not-for-profit corporation formed for the purpose of assisting sheriffs in the efficient and effective delivery of services to the public. It comprises all 58 elected and appointed sheriffs of the State of New York. Since 1934, the Sheriffs' Association has helped New York's sheriffs to serve and protect the citizenry through member-supported training programs, accreditation, legislative advocacy, and public safety programs.
TSC Alliance®	The TSC Alliance is an internationally recognized nonprofit that does everything it takes to improve the lives of people with TSC. We drive research, improve quality care and access and advocate for all affected by the disease. The TSC community is our strongest ally. The collaboration of individuals and families, along with the partnership of other organizations, fuels our work to ensure people navigating TSC have support—and hope—every step of the way.

Thank you to all the individuals who spent countless hours conducting research, participating in 1:1 interviews and focus groups, providing insight and expertise, collating, writing, and editing the C.A.R.E. Binder!

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DSF: Mary Anne Meskis
DSF: Veronica Hood, PhD
LGSF: Jennifer Griffin
LGSF: Tracy Dixon-Salazar, PhD
TSC: Ashley Pounders, MSN, FNP-C
TSC: Shelly Meitzler

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Kelli Stanley, PA
Kristin Krumm
Murphy Penwell
Sophie Meskis, MSpEd

Glossary of Terms

ABLE Accounts: Tax-advantaged savings accounts for individuals with disabilities and their families were created as a result of the passage of the Stephen Beck Jr., Achieving a Better Life Experience Act of 2014 or better known as the ABLE Act. Currently you can deposit $15,000 per year for a maximum of $350,000.

Americans With Disabilities Act of 1990 (ADA): A law that was implemented in 1990 prohibiting discrimination based on disability. The ADA is the most important piece of civil rights legislation for people with disabilities in the Unites States, promising equal opportunity for individuals with disabilities in employment; public accommodations, transportation, state, local government and telecommunications.

How does the ADA define "disability"? To be protected by the ADA, a person must have one of the following:
1. A physical or mental impairment that substantially limits one or more major life activities of the individual.
2. A record of such impairment.
3. A perception by others as having such an impairment.

The ADA further requires that reasonable accommodation be made to provide individuals with disabilities equal opportunities. Federal agencies and departments charged with enforcing the ADA include the Equal Employment Opportunity Commission (EEOC) and the Department of Justice. Specific titles of the ADA (I-IV) address specific rights regarding employment; state and local government activities; public transportation; public accommodations; and telecommunication relay services. States may pass disability statutes so long as they are consistent with the ADA.

Beneficiary: One who is lawfully entitled to the proceeds of property, the title to which is vested in another, such as a trustee or an executor.

Cognitive Function: Brain-based skills that are used to acquire knowledge, think, and remember.

Comorbidities: A medical condition that is present simultaneously with another.

Daily Living Skills: Skills/activities that are required for day-to-day functioning within the home and the community.

Department of Health and Human Services (HHS): This is the federal agency that oversees the federal Medicare and Medicaid programs. Most families will work with their State Department of Human Services for funding from these programs.

Developmental Delay: A delay in the development of skills expected of child, compared to others of the same age.

Durable Medical Equipment (DME): Equipment and supplies ordered by a healthcare provider for everyday or extended use. This may include oxygen, wheelchairs, walkers, adaptive/hospital beds, etc.

Epilepsy: Chronic noncommunicable disease of the brain that affects around 50 million people worldwide. It is characterized by recurrent seizures, which are brief episodes of involuntary movement that may involve a part of the body (partial) or the entire body (generalized) and are sometimes accompanied by loss of consciousness and control of bowel or bladder function.

Epilepsy Syndrome: A disorder defined by seizure type, age of onset, clinical and EEG findings, family history, response to therapy, and prognosis.

Epileptologist: A neurologist with specialty training in epilepsy.

Estate Planning: The process of creating and preserving one's property during one's lifetime and arranging for its transfer at one's death. Most frequently, the term is associated with advantageous investment and tax planning that does not sacrifice personal/family security and welfare.

Guardian: A person appointed by the court to control and manage another person's affairs and/or property. Most typically, a guardian is appointed by the court to control and manage the affairs of a minor or an adult who is incapable of looking after his/her own affairs.

Health Care Proxy: Also known as a durable medical power of attorney, this is a document that allows you to appoint another person(s) as your health care agent to make health care decisions on your behalf if you are no longer able to do so. You may give your health care agent authority to make decisions for you in all medical situations if you cannot speak for yourself. Thus, even in medical situations not anticipated by you, your agent can make decisions and ensure you are treated according to your wishes, values and beliefs.

IDEA: Individuals with Disabilities Education Act: The most important US law regarding the education of students with disabilities. The law ensures that eligible children with disabilities have a free, appropriate public education in the least restricted environment.

Inclusion: The act or practice of including people with disabilities with the general population.

Intellectual Disability: A disability characterized by significant limitation in both intellectual functioning and adaptive behavior that is present before the age of 22. It replaced the older, outdated term of mental retardation and was signed into law in 2010 (Rosa's Law).

Job Coach: A person who trains persons with disabilities on the job. Coaches have special training to help them both instruct the person with disabilities on the job and to aid him/her to become fully integrated in the workforce.

Letter of Guidance: A "letter of guidance" or "letter of instruction" is a document that ensures your trustee knows your child's functional abilities, routines, interests, and particular likes and dislikes. In addition to describing your special child, the letter of intent identifies specific doctors, services and resources that can help your child enjoy the highest level of independence and self-reliance. The document is a valuable tool that communicates knowledge only parents may know, including specific hopes and desires for their child's future wellbeing, to the very people who will be caring for the child after the parents are no longer able to do so.

Medicaid: A state-administered medical assistance program for those individuals who are 65 years or older, blind or disabled and eligible for Supplemental Security Income (SSI), or a recipient of Aid to Families with Dependent children (AFDC).

Medicaid Waiver: State-developed home- and community-based services waivers (HCBS Waivers) that meet the needs of people receiving long-term care services and supports in their home or community, rather than in an institutional setting. States can waive certain Medicaid requirements under HCBS waivers.

Medicare: National social insurance program administered by the US Federal government. It provides healthcare for Americans age 65 or older who have worked and paid into the system through the payroll tax. It also provides health insurance to younger people with some disability status as determined by the Social Security Administration.

Occupational Therapy (OT): A therapist who helps people across the lifespan participate in the things they want and need to do through the therapeutic use of everyday activities (occupations). Examples include self-care routines like getting dressed; writing, holding a pencil; self-regulating; and sensory processing.

Physical Therapy (PT): Therapy utilizing exercises for the preservation, enhancement, or restoration of movement and physical function impaired or threatened by disease, injury, or disability.

Power of Attorney: Legal document that gives one person the power to act for another person in property, financial, or medical matters.

Related Services: Supportive and therapeutic activities and services during and after high school to achieve and maintain post-school goals and rehabilitation. Can include transportation, physical therapy, occupational therapy, rehabilitative counseling, etc.

Respite Care: Provides temporary relief for caregivers from the ongoing responsibility of caring for an individual of any age with special needs.

Supplemental Security Income (SSI): The SSI program provides monthly payments to adults and children with a disability or blindness who have income and resources below specific financial limits.

Social Security Disability Insurance (SSDI): Social Security benefits payable to an individual with a work history, or their family, in the event the individual becomes disabled. It is a federal insurance program of the United States government, managed by the Social Security Administration.

Special Needs Trust: Special needs trusts are made specifically for the benefit of disabled or mentally ill beneficiaries who lack the mental capacity to manage their own finances. The trust is created with the specific needs, lifestyle, and future of the beneficiary in mind. Oftentimes these trusts are used to ensure that the beneficiaries don't lose government benefits they are receiving. The trustees of special needs trusts can be family members, or if an appropriate and trustworthy family member is unavailable, a third party will be appointed by the court.

Status Epilepticus: A prolonged seizure (usually defined as lasting longer than 5 minutes) or a series of repeated seizures without regaining consciousness. Status epilepticus is a medical emergency and medical help should be obtained immediately.

Resources

Organization	Description	Website
AAPM&R Directory of Sports Organizations for Athletes with Disabilities	This directory contains resources for athletes with disabilities who wish to engage in sports competitions and activities and for physiatrists and the general public who would like to volunteer with these organizations.	www.aapmr.org
abilityJOBS	Works with companies and government and nonprofit agencies to employ people with disabilities.	www.abilityJOBS.com
ABLE National Resource Center	Connecting people with disabilities, their families and those who support them to information about ABLE.	www.ablenrc.org
Angelman Syndrome Foundation: State Insurance Guide (2022)	The ASF State Insurance Resource Guide is a state-by-state list of insurance information about government agencies, waivers, contact information and more.	www.angelman.org
The Arc	Promotes and protects the human rights of people with intellectual and developmental disabilities and actively supports their full inclusion and participation in the community throughout their lifetimes.	www.thearc.org
Bender Consulting	Consulting firm that specializes in recruiting and hiring people with disabilities for full-time, competitive employment opportunities.	www.benderconsult.com
Bounce Out the Stigma	Using basketball, the primary charter of Bounce Out the Stigma is to empower special needs children and young adults with motor skill sets, self-confidence, peer support, and a unique message to meet the challenges they face. They have carefully constructed their entire platform of programs and events to meet the changing landscape of special needs kids.	www.bounceoutthestigma.org
Center for Parent Information and Resources	Family-friendly information and research-based materials on key topics, this is a hub of information and products for the use of Parent Centers who serve families of children with disabilities.	https://www.parentcenterhub.org/resourcelibrary/
Centers for Disease Control and Prevention (CDC)	CDC is the nation's leading science-based, data-driven, service organization that protects the public's health. The CDC has compiled data, research and programming specifically for people living with a disability. **Notable Resources:** SUDEP Information for Parents of Children with Epilepsy; Disability and Health Promotion	www.cdc.gov www.cdc.gov/ncbddd/disabilityandhealth/national-programs.html
Centers for Medicare and Medicaid Services (CMS)	Provides an extensive list of state-based resources on its website.	www.medicare.gov/care-compare/
Challenged Athletes Foundation(CAF)	It is the mission of the Challenged Athletes Foundation (CAF) to provide opportunities and support to people with physical challenges, so they can pursue active lifestyles through physical fitness and competitive athletics.	www.challengedathletes.org
Charlie Foundation	Dedicated to advancing the awareness of ketogenic therapeutics to help with seizures. Was founded in 1994 to provide information about diet therapies for people with epilepsy, other neurological disorders, mental health conditions and select cancers. **Notable Article:** Ketogenic Therapies & Resources	www.charliefoundation.org

Organization	Description	Website
Chelsea Hutchison	A non-profit to provide help and support to individuals who have epilepsy. **Notable Section:** Helpful Links: Monitoring Devices Helpful Link: Service Dogs Helpful Links: Other	www.chelseahutchisonfoundation.org
Child Mind	Child Mind is dedicated to transforming the lives of children and families struggling with mental health and learning disorders by giving them the help they need.	www.childmind.org
Children's Health Insurance Program (CHIP)	Provides information about Medicaid and Children's Health Insurance Program (CHIP) services for families who need health insurance coverage. **Note:** All CHIP programs are state-based, and procedures may vary.	www.insurekidsnow.gov
The Connected Parent	A free search platform connecting parents and caregivers to the local and national disability resources they need. This one-stop hub includes crowdsourced recommendations and detailed reviews of therapists, advocates, recreational activities, independent living options, camps for children and adults and other hard-to-find services. The easy-to-use interface allows families to search by specific need or browse all the categories by location, read honest reviews and build a curated and organized list of resources they can update and share as needed.	www.theconnectedparent.net
Council for Exceptional Children	The Council for Exceptional Children (CEC) is the largest international professional organization dedicated to improving the success of children and youth with disabilities and/or gifts and talents. CEC advocates for appropriate governmental policies, sets professional standards, provides professional development, and helps professionals obtain conditions and resources necessary for effective professional practice.	www.exceptionalchildren.org
Courageous Parents Network (Available in English and Spanish)	Empowers, supports and equips families and providers caring for children with serious illnesses.	www.courageousparentsnetwork.org
Danny Did Foundation	A resource to help prevent deaths caused by seizures **Notable Section:** Devices + Technology	www.dannydid.org
Department of Education	Our mission is to promote student achievement and preparation for global competitiveness by fostering educational excellence and ensuring equal access. **Notable Resources:** Office of Vocational Rehabilitation; A Transition Guide: to postsecondary education and employment for students and youth with disabilities	www.ed.gov
Employer Assistance and Resources Network (EARN)	EARN provides resources for employment seekers and job training for those looking to gain and build skills necessary to succeed in the workforce.	www.askearn.org
Epilepsy Foundation	Connects the people, data and resources needed to address challenging health problems associated with seizures and epilepsies — and promotes education, policy, research and systemic change that will improve the life of those living with epilepsy. Their mission is to lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.	www.epilepsy.com

Organization	Description	Website
Equal Opportunity Publications, Inc. (EOP)	For more than 50 years, EOP has been the leading publisher of diversity career and recruitment digital and print magazines, and host of several nationally recognized online career expos. EOP's seven publications for women, veterans, members of minority groups and diverse cultures, and people with disabilities include *CAREERS & the disABLED* magazine.	www.eop.com
Financial Assistance and Support Services for People with Disabilities	This government listing provides resources on a wide range of tools for people with disabilities to apply for financial assistance with medical treatment, as well as housing resources and tax help. **Notable Resource:** Financial Assistance and Support Services for People with Disabilities	www.usa.gov
Got Transition	Got Transition aims to help youth and young adults move from pediatric to adult health care.	www.gottransition.org
HUD U.S Department of Housing and Urban Development	**Notable Section:** Disability Overview	www.hud.gov
Individuals with Disabilities Education Act (IDEA)	Access from the U.S. Department of Education website	www.sites.ed.gov/idea/
Job Accommodation Network (JAN)	A source for free, expert, and confidential guidance on job accommodations and disability employment matters.	www.askjan.org
Kaiser Family Foundation (KFF)	Dedicated to filling the need for trusted information on national health issues.	www.kff.org/statedata/
Kids' Waviers	Kids' Waivers is a compilation of information about Medicaid waivers, Katie Beckett or TEFRA programs, and other programs for children with disabilities or medical needs. This website is the product of years of ongoing research on these programs.	www.kidswaivers.org
Learning Disabilities Association of America (LDA)	LDA's mission is to create opportunities for success for all individuals affected by learning disabilities through support, education, and advocacy.	www.ldaamerica.org
Medication Assistance Tool (MAT)	MAT is a free-to-use search engine that focuses its searches on patient assistance resources available to eligible patients.	www.mat.org
Miracle League	Even the most disabled individuals deserve a chance to play sports. The Miracle League is a great opportunity for those who have mobile disabilities to have the chance to play baseball. Parents or "buddies" accompany the individual on the field sometimes as an aide and other times assisting them with the bat.	www.miracleleague.com
National Alliance on Mental Illness (NAMI)	Dedicated to improving the lives of millions of American affected by mental illness. **Notable Resource:** People with Disabilities	www.nami.org www.nami.org/beprepared
National Council of State Housing Agencies (NCSHA)	Assist the Housing Finance Agencies' efforts to provide affordable housing to those who need it. **Notable Article:** Special Needs Housing	www.ncsha.org
National Law Review	The National Law Review is a free database of legal and business articles. **Notable Article:** Understanding Special Needs Trusts	www.natlawreview.com

Organization	Description	Website
National Technical Assistance Center on Transition (NTACT)	Is a Technical Assistance Center co-funded by the U.S. Department of Education's Office of Special Education Programs (OSEP) and the Rehabilitation Services Administration (RSA) which provides information, tools, and supports to assist multiple stakeholders in delivering effective services and instruction for secondary students and out of school youth with disabilities. **Notable Resources:** Postsecondary Education VR Transition Services; Pre-Employment Transition Services Instruction in Self-Advocacy	www.transitionta.org
Needy Meds (Available in English and Spanish)	NeedyMeds connects people to programs that will help them afford their medications and other healthcare costs.	www.needymeds.org
NeuroRestorative	NeuroRestorative is a leading provider of subacute and post-acute rehabilitation services for people of all ages with brain, spinal cord and medically complex injuries, illnesses, and other challenges.	www.neurorestorative.com
Office for Civil Rights (OCR)	Access from the U.S. Department of Education website. The mission of the Office for Civil Rights is to ensure equal access to education and to promote educational excellence throughout the nation through vigorous enforcement of civil rights.	www.ed.gov/about/offices/list/ocr/aboutocr.html
Our Place	A community where you can learn from others, connect with others in your same situation and find services.	www.joinourplace.com
PAME: Partners Against Against Mortality in Epilepsy	PAME's mission is to convene, educate and inspire all stakeholders to promote understanding and drive prevention of epilepsy-related mortality. PAME hosts an annual conference and webinars for bereaved family members, people living with epilepsy, and health care professionals to learn about sudden unexpected death in epilepsy (SUDEP), grief, and other topics related to epilepsy-related death.	www.pameonline.org
Parents Helping Parents (PHP)	Supports, educates, and inspires families and the community to build bright futures for youth and adults with special needs.	www.php.com https://www.php.com/transition-to-adulthood/
Parent to Parent USA	Provides emotional and informational support to families of individuals with disabilities or special health care needs.	www.p2pusa.org
Patient Advocate Foundation (PAF)	Provides professional case management services to patients with chronic, life-threatening and debilitating diseases.	www.patientadvocate.org
RxAssist	RxAssist offers a database of patient assistance programs and a prescription drug savings/discount card at no cost.	www.rxassist.org
Seizure Action Plan Coalition	This collaborative effort is designed to raise awareness of what a Seizure Action Plan (SAP) is, the importance of an SAP in the health management of those with epilepsy, and resources to develop an individualized SAP. **Notable Resource:** School Staff: how to respond to a Seizure Action Plan, First Aid Training for School Nurses and Personnel	www.seizureactionplans.org
Seizure Tracker	Founded by parents of a child with TSC who were struggling to understand their son's seizure activity, SeizureTracker™ has become a valuable tool for parents, doctors, and researchers alike.	www.seizuretracker.com

Organization	Description	Website
Social Security Administration	Provides information about eligibility and application requirements. The SSA website provides answers to frequently asked questions, forms, and online tools to help determine eligibility for certain benefit programs. **Notable Resource:** Spotlight on Achieving a Better Life Experience (ABLE)	www.ssa.gov www.ssa.gov/disability/
Special Needs Alliance (SNA)	National alliance of attorneys for special needs planning. **Notable Resource:** Life Care Planning Special Needs Trust ABLE Accounts	www.specialneedsalliance.org
Special Needs Project	Comprehensive directory of various special needs resources, providing books about disabilities that serve individuals, families, and professionals with a large collection of disability-related materials, including titles about autism, ADHD, independent living and full inclusion.	www.specialneeds.com
Special Olympics	The Special Olympics is a worldwide organization offering a variety of sports opportunities to individuals with intellectual disabilities. With over 30 Olympic-style sports offered, there are countless opportunities for individuals to participate.	www.specialolympics.org
TSC Navigator	An easy-to-use online tool from the TSC Alliance to help guide individuals and families through the complexities of tuberous sclerosis complex (TSC) across the lifespan, proactively manage their care, and live their fullest lives. **Notable Resource:** TSC Navigator	www.tscalliance.org/tscnavigator
Understood	A guide to help those who learn and think differently. **Notable Resource:** IEP Transition Planning Sample IEP Transition Plan and Goals (from the Understood.com website)	www.understood.org
U.S. Department of Justice - Civil Rights Division	A guide to disability rights laws	www.ada.gov/cguide.htm
US Department of Labor (DOL) Office of Disability Employment Policy (ODEP)	Provides fact sheets regarding disability issues, discrimination, and legal rights	www.dol.gov/odep
Veterans Affairs	Cares for those who have served in our nation's military and for their families, caregivers, and survivors. **Notable Section:** Family and Caregiver Health Benefits	www.va.gov/health-care/family-caregiver-benefits/
Volunteers of America	This site contains resources for affordable housing, employment, and behavioral health services. **Notable Resource:** People with Disabilities	www.voa.org

Letter of Guidance *(Sample)*

October 24, 2024

To Whom It May Concern:

My child, Jane Smith, is diagnosed with Dravet Syndrome. She is beautiful, funny, mischievous and an incredible joy to have in our lives. Below is a summary of what I envision for Jane as she ages into adulthood and beyond. It is my wish that Jane's current level of care continues with as little disruption as possible. Details on her emotional, physical, and logistical support needs can be found in the attached documents contained within Jane's C.A.R.E. Binder and include the following.

☐ Identified caregivers / long-term care team
☐ Current medical providers
☐ Contact information for those who are actively involved in our loved one's life (extended family, friends, dentist, social worker, therapists, respite workers, etc.)
☐ Living arrangements (including what supports will be needed)
☐ Medical decisions (including copies of advance directives or end of life orders)
☐ Finances (including the family and patient's public benefits, assets, incomes, trusts, insurance policies, copiesof guardianship documents, etc.)
☐ Doctors' contact information and information about the person's medical history (including previous medications used as well as food or medication allergies)
☐ Current medication list, doses, and administration schedule
☐ List of local and specialty pharmacies and how and when to reorder medications
☐ Day programs / community activities
☐ Support needs in a particular environment (school/day programs, social activities, hospital, home, etc.)
☐ One-page profile on likes/dislikes (what are their favorite things to do; how they react when scared or stressed; things that soothe them in times of distress; etc.)
☐ Daily routines, needs, and supports (including a daily schedule, feeding, toileting, sleep, transfers, and the support/equipment needed for each)
☐ Adaptive equipment needs and vendors (such as seating, special utensils, toothbrush, orthotics, incontinence supplies, seizure monitors, oxygen, etc.)
☐ Details about the person's leisure activities (including religious beliefs, behaviors, interests, friendships, and other important relationships)
☐ List of primary safety concerns (specific situations where extra caution is needed)
☐ Important documents (birth certificate, passport, guardianship papers, wills, trusts, etc.)
☐ Accounts and passwords (for patient portals, SSI, and/or other accounts related to the patient)

Your first point of contact with any questions about this information can be directed to my husband, Bob Smith. Thank you for doing your best to continue the current level of care for my daughter, Jane.

With sincere gratitude,

Mary Smith

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Appendix

Conversations

Daily Living

Disease Management

Important Contacts

Long-Term Care Planning

Medical Transition – Peds to Adult

Resources

A Very Special Thank You

The following organizations made significant contributions to the C.A.R.E. Binder. The development of the these resources would not have been possible without collaboration from our friends at the Dravet Syndrome Foundation, Lennox-Gastaut Syndrome (LGS) Foundation, and the TSC Alliance.

Dravet Syndrome Foundation

LGS FOUNDATION®
LENNOX-GASTAUT SYNDROME

TSC Alliance®

Thank you to these additional contributors:

epilepsy ALLIANCE AMERICA

got transition.

NEW YORK STATE SHERIFFS' ASSOCIATION
NYSSA Est. 1934

We'd love to hear your feedback on the C.A.R.E. Binder! Please check here to share your insights.

ucb Inspired by patients.
Driven by science.