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:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

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:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

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

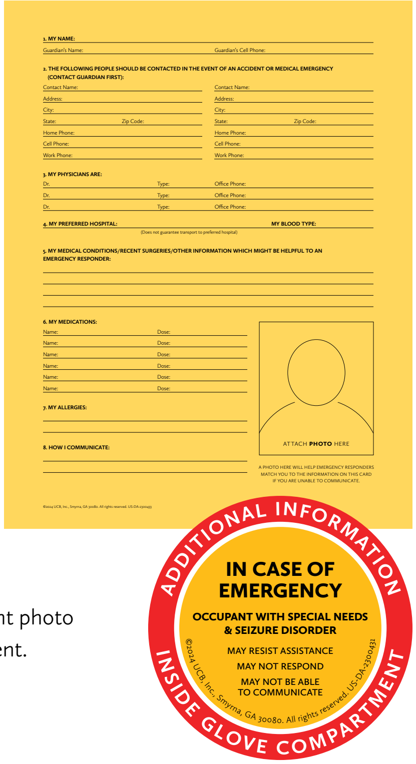
The Yellow Dot program was developed in cooperation with the New York State Sheriffs' Association.[6]

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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ADDITIONAL INFORMATION INSIDE GLOVE COMPARTMENT

IN CASE OF EMERGENCY

OCCUPANT WITH SPECIAL NEEDS & SEIZURE DISORDER

MAY RESIST ASSISTANCE

MAY NOT RESPOND

MAY NOT BE ABLE 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