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