

## 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 [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.<sup>6</sup>

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.

### 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.

The form is titled 'MY NAME' and includes fields for 'Guardian's Name' and 'Guardian's Cell Phone'. It is divided into several sections:
 

- THE FOLLOWING PEOPLE SHOULD BE CONTACTED IN THE EVENT OF AN ACCIDENT OR MEDICAL EMERGENCY:** This section has two columns for 'EMERGENCY GUARDIAN FIRST' and 'EMERGENCY GUARDIAN SECOND'. Each column includes fields for Name, Address, City, State, Zip Code, Home Phone, Cell Phone, and Work Phone.
- MY PHYSICIAN AND:** Fields for Name, Type, Office Phone, and Cell Phone.
- MY PREferred HOSPITAL:** Fields for Name, Type, and Office Phone.
- MY MEDICAL CONDITIONS, RECENT SURGERIES, OTHER INFORMATION WHICH MIGHT BE HELPFUL TO AN EMERGENCY RESPONDER:** A large text area for additional information.
- MY MEDICATIONS:** A table with columns for Name, Dose, and Frequency.
- MY ALLERGIES:** A text area for listing allergies.
- HOW I COMMUNICATE:** A text area for describing communication needs.
- ATTACH PHOTO HERE:** A designated area for a recent photo of the individual.



The Yellow Dot form can be accessed in the [Attachments](#) section of this C.A.R.E. Binder.

# 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:<br>Upload Photo Here |  | Optional:<br>Upload Photo Here |  |

| Main Living Room/Family Room Safety |  |                                |  |
|-------------------------------------|--|--------------------------------|--|
| Optional:<br>Upload Photo Here      |  | Optional:<br>Upload Photo Here |  |

| Bedroom (of your loved one) Safety |  |                                |  |
|------------------------------------|--|--------------------------------|--|
| Optional:<br>Upload Photo Here     |  | Optional:<br>Upload Photo Here |  |

| Bathroom Safety                |  |                                |  |
|--------------------------------|--|--------------------------------|--|
| Optional:<br>Upload Photo Here |  | Optional:<br>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:<br>Upload Photo Here |  | Optional:<br>Upload Photo Here |  |
|                                |  |                                |  |
| School Safety                  |  |                                |  |
| Optional:<br>Upload Photo Here |  | Optional:<br>Upload Photo Here |  |
|                                |  |                                |  |
| Store/Restaurant Safety        |  |                                |  |
| Optional:<br>Upload Photo Here |  | Optional:<br>Upload Photo Here |  |
|                                |  |                                |  |
| Other Safety                   |  |                                |  |
| Optional:<br>Upload Photo Here |  | Optional:<br>Upload Photo Here |  |
|                                |  |                                |  |

## Keeping Your Family Safe When Aggressive Behaviors Are Displayed<sup>2,3</sup>



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—

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- 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.

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## 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.<sup>7</sup> 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?](#)<sup>8</sup>

*"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  |
|---|--|--|
| <b>NeuroRestorative</b>                                 | 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.  | <a href="http://www.neurorestorative.com">www.neurorestorative.com</a> |
| <b>National Alliance on Mental Illness (NAMI)</b>       | Provides advocacy, education, support and public awareness so that all individuals and families affected by mental illness can build a better life.<br><b>Notable Article:</b> Being Prepared for a Crisis | <a href="http://www.nami.org">www.nami.org</a>                         |
| <b>Child Mind</b>                                       | 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.   | <a href="http://www.childmind.org">www.childmind.org</a>               |
| <b>Centers for Disease Control and Prevention (CDC)</b> | The CDC has compiled data, research and programming specifically for people living with a disability.<br><b>Notable Resource:</b> Disability and Health Promotion  | <a href="http://www.cdc.gov">www.cdc.gov</a>                           |