

# My Family Is Living with a Rare Epilepsy

## What are rare epilepsies?

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

Rare epilepsies can have a huge impact on a family's quality of life. The extra care that a child with a rare epilepsy needs and the unpredictable nature of seizures can disrupt family life. For this reason, siblings are at a greater risk for

## has a sibling with a rare epilepsy.

anxiety and depression. They can also experience feelings of sadness, stress, isolation, fear, worry, and fatigue.

## Why rare epilepsies make life unpredictable

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

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

## How you can help

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

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

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

## Our family's emergency plan

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

During school or practice:

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In the evening:

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During the weekend:

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In the middle of the night:

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## My contact info

Name:

Phone:

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

Name:

Phone:

Relationship to child:

Local hospital information:

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