

# My Family Is Living With a Rare Epilepsy

has a sibling with a rare epilepsy.

## What are rare epilepsies?

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

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

## Why rare epilepsies make life unpredictable

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

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

## How you can help

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

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

## Our family's emergency plan

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

During school or practice:

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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:

Name of local hospital:

Name of PCP/Nurse:

Street Address:

Office Phone:

Mobile Phone (if applicable):

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