Having Conversations With Others in Your Community

Your family interacts with many different people within your community. Some may be close to your family, helping to provide care to your loved one with rare epilepsy or to your other children, if any. Some may be a part of your Lifelong Support Network. Some may only be in your life temporarily, such as school personnel or others in your community. They may or may not be considered part of your support circle, but you and your child with rare epilepsy may have somewhat regular interactions with them.

For this specific group of people, it may be helpful to provide a little background information on what rare epilepsy is and how they can help. Most people want to help, but they don't know how. If your loved one with a rare epilepsy has siblings, it will be important for you to first consider completing and sharing the My Family Is Living With a Rare Epilepsy form that can be found on the next page. This form will also contain important information on who to contact in case of emergency.

Another very helpful document to share is the Summary Introduction to My Loved One that provides important information about your loved one with a rare epilepsy.

Once you share these resources, follow up by offering to answer any questions they may have. Assure them that no question is silly or stupid. And don't forget to express your appreciation for the interest they have taken in your child (or children) and for the care they provide.

TIP: Make a list of those in this group who you provide these resources to so that if your family experiences a crisis, whoever is stepping in to provide care for your loved one with rare epilepsy, will have the complete list of those in your community that may be impacted by a change of primary caregiver for your child, even if only temporary.[2,3]