

Communication Needs



We all know how important it is to be able to communicate. Some of our loved ones are able to verbally express their needs and wants; however, many of our loved ones struggle to communicate. As the caregiver, you probably know exactly what your child needs—when they are happy, when they are hurting, when they are frustrated, and when they are excited. Many families have their own language and communication methods to engage with their loved one with rare epilepsy. Sometimes our loved ones are able to speak in complete sentences, some a few words, others may express how they feel using facial expressions, sounds, or physical movements. Sometimes our loved ones use an electronic device to communicate. Every family has implemented what works best for them. When a new person steps into the picture, who may not be familiar with your daily living routines, they may need assistance learning how your loved one and family communicate with each other. Please use the guide below to document with as much detail as possible, how communication with your loved one works in your family, so that others will be able to understand and communicate in a way that your loved one with rare epilepsy will understand.

Things always seem to be changing with our loved ones; therefore, feel free to come back to this form and update anytime you feel the need.

How does your child communicate?

Check all that apply.

My child speaks:

☐ using single words ☐ using 3-5 words only ☐ using short sentences ☐ using long sentences or speaks fluently

My child communicates:

☐ using facial expressions

☐ using gestures: ☐ pointing ☐ using hands ☐ signs ☐ touch ☐ sound(s) ☐ eye contact

☐ through writing

☐ through drawing

☐ using equipment: ☐ text message or computer/iPad ☐ AAC (Augmentative and Alternative Communication) device

Below, please capture how your loved one with rare epilepsy communicates when they feel:

Happy

Sad

Frustrated

Angry

Embarrassed

Uncomfortable

Shy

Scared

Hungry

Pain

Other emotions

How does your child communicate?

Use the space below to provide additional details that may help others best communicate with your loved one with rare epilepsy.

Use the space below to provide pictures of your loved one expressing how they feel:

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here

Optional:
Upload Photo Here