

Feeding & Nutrition Needs

Many of our loved ones with rare epilepsy have very specific nutrition needs. Some may have a G-tube, need a thickening agent, and/or be on a ketogenic diet. Certain foods may interact with their medications, cause GI or other issues, or simply aren't tolerable for various reasons. Feeding our loved ones with rare epilepsy may be very challenging at times, and ensuring they receive adequate nutrition can sometimes be difficult. It is important to provide as much detail as possible so that others providing care assistance for your loved one can maintain the feeding and nutrition plan you've thoughtfully developed for your child.

If your loved one with rare epilepsy has a nutritionist, dietician, and/or is on a medical diet (such as the ketogenic diet), please provide the healthcare professional's name and contact information below.

Check all that apply:

- ☐ A nutritionist or dietician is part of our care team
- ☐ Ketogenic Diet
- ☐ G-tube
- ☐ Uses a food thickener to help prevent aspiration
- ☐ Takes medication with meals (Please refer to the [Medication Schedule](#) section of this C.A.R.E. Binder.)

TIP: If your child is G-tube fed or on a ketogenic diet, be certain to print out the information/documentation necessary to follow your specific instructions and include with this C.A.R.E. Binder.

Healthcare Professional Contact Details (if applicable):

Name:

Address:

City:

State:

Zip:

Phone:

Mobile:

Email:

Please indicate the level of independence and joy your loved one with rare epilepsy has when it comes to feeding themselves. 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.

Check all that apply:

- ☐ My child can eat without assistance
- ☐ My child can eat with minimal assistance
- ☐ My child can eat with moderate assistance
- ☐ My child can only eat with complete assistance
- ☐ My child loves to eat
- ☐ My child loves to eat a little too much, please monitor
- ☐ My child likes to eat, but won't eat on command
- ☐ My child doesn't enjoy eating so it takes a bit of coaxing
- ☐ My child is a picky eater

Additional Information:

Mealtime Routines

TIP: It's important to make note when your loved one experiences changes in appetite. It could be that your child is just being picky about their food—or it could be an indication that something is wrong, such as GI distress or dental issues. Capturing details about your loved one's likes/dislikes and other mealtime routines can help others caring for your child better able to recognize changes that may need to be addressed.

This is what mealtime looks like for us:

What does your loved one like to eat/drink?

What do they dislike?

Do they have any allergies? ☐ YES ☐ NO Details:

Is there a special song you sing or ritual you both enjoy that sets your loved one up for success when it comes to mealtime? ☐ YES ☐ NO
Details:

Do you have a special tabletop mat, dish, cup, or eating utensil that makes mealtime fun? ☐ YES ☐ NO Details:

What are the must-haves, nice-to-haves, and absolute no-no's?

Does your routine change depending on the time of day or day or week? ☐ YES ☐ NO Details:

How does your routine change when dining outside the family home?

Use the additional space below to share/describe more details of your mealtime routine:
