

Caregiver & Siblings Tips and Resources to Promote Positive Coping

Holly Senn, CCLS III & Lauren Furtner, CCLS II

Inova Children's Hospital

Parent Reminders:

- Take care of yourself and build a support system. You have to be in a good mental and physical state in order to support others.
- Include the sibling and patient (when appropriate) in decision making. Not all decisions are appropriate to include everyone but it is important to do it when possible so everyone feels valued and part of the family "team."
- Talk openly and honestly with children on a developmentally appropriate level about the illness and treatments. This pertains to the child with Glut 1 deficiency and their siblings.
- Treat all children the same. Set expectations that are appropriate for that child's developmental level, not just their age.
- Do not minimize the problems of the sibling without Glut 1 Deficiency.
- Do not give siblings too much responsibility. They can help but they are still children.
- Acknowledge the variety of emotions that the sibling without Glut 1 Deficiency experiences and help them manage these in a safe and productive manner – journaling, sports, therapy, etc.
- Encourage siblings without Glut 1 Deficiency to have their own interests and activities so they can develop their own identity. Help them to keep those things routine.
- Spend time with each child individually. Verbally recognize their differences and strengths so they are aware of those things and know that they are appreciated by others.

Sibling Tips:

- Ask questions about your sibling with Glut 1 Deficiency – their illness, their needs, what changes might occur as they get older.
- Speak up about your needs, fears, and concerns regarding your sibling with Glut 1 Deficiency as well as speak up about your PERSONAL needs, fears, and concerns.
- Find a strong support system or person you can talk to when you feel like you need someone besides your parents. This could be an aunt, uncle, teacher, spiritual/religious guide, coach, or any other adult you trust.
- You do **NOT** have to be perfect! **Just be YOU!**
- Do not feel like you have to take on extra responsibilities or become another parent for your sibling with Glut 1 Deficiency. You might be asked to help at times but remember that you are not the parent.
- Know that you will experience a variety of emotions about yourself, your parents, your sibling with Glut 1 Deficiency, and your life in general. You can talk about these with people or you can find some other type of outlet like journaling, art, or exercise to help manage them.
- Spend some 1 on 1 time with your sibling with Glut 1 Deficiency to really get to know and understand them.
- Develop your own interests, dreams, and hobbies. **Be an individual and enjoy it!**

Resources:

University of Michigan, Michigan Medicine <http://www.med.umich.edu/yourchild/topics/specneed.htm>

Child Mind Institute <https://childmind.org/>

Kids Health by Nemours <https://kidshealth.org/en/parents/siblings-special-needs.html?ref=search>

Sibling Support Project www.siblingsupport.org

SuperSibs www.alexslimonade.org

Sibling Leadership Network www.siblingleadership.org

Facebook Groups:

SibTeen (monitored)

SibNet (adult siblings)