



# Dravet Syndrome Foundation

## Developing a Lifelong Support Network

Using the table below, identify potential lifelong support network members. List everyone who comes to mind as a starting point.

	Name(s)	Strengths they can offer <i>(for instance, legal or medical background)</i>
<b>Who are the people who are closest to your loved one, those they will rely on every day and those who know them best?</b> <ul style="list-style-type: none"><li>• Are there siblings, and are they able and willing to be involved?</li><li>• Are there extended family members or friends who know your child well?</li></ul>		
<b>Who are the people who regularly interact with your loved one, who have some common interests or associations? Such as:</b> <ul style="list-style-type: none"><li>• Neighbors</li><li>• Teachers</li><li>• People where you worship.</li></ul>		
<b>Who are the people in your loved one's life who are providing a paid service? Such as:</b> <ul style="list-style-type: none"><li>• Doctors</li><li>• Therapists</li><li>• Support providers</li><li>• Attorneys</li></ul>		

### **After completing your list, consider:**

- Who will be the lead network member(s)? The lead(s) will be in charge of the primary decision making for your adult child with Dravet syndrome.
- Develop a list of other network members who can offer professional advice to the lead member(s). These will be supporting network members that the lead members can call on for their expertise. For instance, teachers or therapists may have suggestions on local day programs or housing placements that would be appropriate for your child.
- You may want to also consider temporary team members. For instance, if a sibling will eventually be taking over care decisions, but is currently too young, you could elect another network member to take a lead role in care, should the sibling end up in charge of care decisions before they are ready.
- There is no magic number for your network. In some cases, one individual may be comfortable in handling all of the decisions for your child's care. Regardless of the number of members on your team, it is important that they have as much information on your child as possible.

### **After selecting your network:**

- Set up an initial meeting to discuss the Letter of Guidance with each of the network members, and what you anticipate their role will be. For instance, "If I am unexpectedly hospitalized, I would ask you to manage daily care - including daily medication administration and transportation to day programs and therapies - until I am able to once again resume those duties." Or, "If I pass away unexpectedly, I would ask you to help the lead network member explore housing placement options."
- Find out what other information would be helpful for each team member and what questions they have.
- Compile a list of all of the members and their contact information for the lead member(s).
- After developing your Letter of Guidance, if you don't already have a Special Needs Trust established for your child you should speak with an attorney specializing in this area of law in your state. A Special Needs Trust allows for a disabled person to maintain his or her eligibility for public assistance benefits (such as SSI or medicaid), despite having assets that would otherwise make the person ineligible for those benefits.
- Establishing this Letter of Guidance and Lifelong Support Network for your child will also help you in selecting the trustees who will oversee your child's Special Needs Trust, as well as who you might select to act as your child's guardian when you are no longer able to.
- Be sure to connect with other families to share advice and ask questions.