

Developing a Lifelong Support Network¹⁰

As we all know, it takes a village of many caring individuals around us to help support our loved one with rare epilepsy and our families. That’s why it is so important to take time to develop a lifelong support network. It’s also important to document who is in your network to share with others who support your family.

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

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

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 rare epilepsy.
- Develop a list of other network members who can offer advice to the lead member(s). These may 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 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. Make sure they know where this C.A.R.E. Binder and other important information can be accessed.

After selecting your network:

- Set up an initial meeting to discuss the [Letter of Guidance](#) and [Crisis Planning Guide](#) section of this C.A.R.E. Binder with each of the network members, and what you anticipate their role may 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. Explore the [Conversations](#) section of this C.A.R.E. Binder for helpful tips on having difficult conversations.
- Compile a list of all of the members and their contact information for the lead member(s). Ensure those who will serve as your primary supporters during a crisis are listed in the Emergency Contacts document section of this C.A.R.E. Binder. Print and share copies of the [Emergency Contacts](#) with your lead team members.
- The Letter of Guidance should include supporting documents (see [C.A.R.E. Guide](#) for more information). 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 may allow for a disabled person to maintain his or her eligibility for public assistance benefits (such as SSI or Medicaid).
- Be sure to connect with other families to share advice and ask questions.

TIP: Be sure to review this list annually and update as needed and when you do, make a note below of the date last updated:
