



Creating a Long-Term Care Plan

Thinking about the future of your adult child with Dravet syndrome when you are gone can be challenging and emotional. Some families might feel that planning is not available to them because they can't afford a lawyer or an estate planner. But, there are many aspects to the planning process that aren't related to money. Regardless of your financial resources, it is important for families to begin by creating a Letter of Guidance and a Lifelong Support Network who can ensure the quality of life of your child in case you are ever unexpectedly incapacitated or for when you can no longer act as the primary caregiver.

Start with a Letter of Guidance

The Letter of Guidance, written on the premise that no one knows a child better than a parent, contains important information about your loved one's history, likes, dislikes, current health, and emotional status. This letter is not a legal document, but provides key information and instructions about your adult child's preference, routines, and wishes. To help guide your planning, first ask: *"During a life transition, what would my child need so his or her daily routine is maintained?"* Next, create a vision for your child's life after the transition, including your wishes for future care. You should update and review this document every two years.

Details should include:

Identified caregivers / long-term care team	
Current medical providers	
Others contact Information who are actively involved in your loved one's life (extended family, friends, dentist, social worker, therapists, respite workers, etc.)	

<p>Living arrangements (including what supports will be needed)</p>	
<p>Medical decisions (including copies of advanced directives or end of life orders)</p>	
<p>Finances (including the family and person's public benefits, assets, incomes, trusts, insurance policies, copies of guardianship documents)</p>	
<p>Doctors' contact information and information about the person's medical history (including any medications and food allergies)</p>	
<p>Medication list, doses, and administration schedule</p>	
<p>List of local and specialty pharmacies and how and when to reorder medications</p>	
<p>Day programs / community activities</p>	
<p>Support needs in a particular environment (school/day programs, social activities, hospital, home, etc.)</p>	
<p>One page profile on likes/dislikes (what are their favorite things; how they react when scared or stressed; things that soothe them in times of distress; etc.)</p>	
<p>Daily routines, needs, and supports (feeding, toileting, sleep, transfers, and the support/equipment needed for each) A daily schedule would be helpful to include.</p>	

Adaptive equipment needs and vendors (such as seating, special utensils, toothbrush, orthotics, incontinence supplies, seizure monitors, oxygen, etc.)	
Details about the person's leisure activities (including religious beliefs, behaviors, interests, friendships, and other important relationships)	
List of primary safety concerns (specific situations where extra caution is needed)	
Important Papers (Birth Certificate, passport, guardianship papers, wills, trusts, etc.)	
Accounts and Passwords (for patient portals, SSI, and/or other accounts related to the patient)	