

Letter of Guidance (Sample)

October 24, 2024

To Whom It May Concern:

My child, Jane Smith, is diagnosed with Dravet Syndrome. She is beautiful, funny, mischievous and an incredible joy to have in our lives. Below is a summary of what I envision for Jane as she ages into adulthood and beyond. It is my wish that Jane's current level of care continues with as little disruption as possible. Details on her emotional, physical, and logistical support needs can be found in the attached documents contained within Jane's C.A.R.E. Binder and include the following.

- ☐ Identified caregivers / long-term care team
- ☐ Current medical providers
- ☐ Contact information for those who are actively involved in our loved one's life (extended family, friends, dentist, social worker, therapists, respite workers, etc.)
- ☐ Living arrangements (including what supports will be needed)
- ☐ Medical decisions (including copies of advance directives or end of life orders)
- ☐ Finances (including the family and patient's public benefits, assets, incomes, trusts, insurance policies, copies of guardianship documents, etc.)
- ☐ Doctors' contact information and information about the person's medical history (including previous medications used as well as food or medication allergies)
- ☐ Current medication list, doses, and administration schedule
- ☐ List of local and specialty pharmacies and how and when to reorder medications
- ☐ Day programs / community activities
- ☐ Support needs in a particular environment (school/day programs, social activities, hospital, home, etc.)
- ☐ One-page profile on likes/dislikes (what are their favorite things to do; how they react when scared or stressed; things that soothe them in times of distress; etc.)
- ☐ Daily routines, needs, and supports (including a daily schedule, feeding, toileting, sleep, transfers, and the support/equipment needed for each)
- ☐ 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 documents (birth certificate, passport, guardianship papers, wills, trusts, etc.)
- ☐ Accounts and passwords (for patient portals, SSI, and/or other accounts related to the patient)

Your first point of contact with any questions about this information can be directed to my husband, Bob Smith. Thank you for doing your best to continue the current level of care for my daughter, Jane.

With sincere gratitude,

Mary Smith