

Preparing for Discharge: A Guide for Seamless Transition

Navigating the journey from hospital to home can be daunting, but with the right preparation, you can ensure a smooth transition for your child. This comprehensive guide will equip you with the essential steps to make the most of your child's discharge and set the stage for a successful recovery at home.

Organize Your Medical Team

Collect Contact Information

Gather business cards for all doctors involved in your child's care, including Geneticist, Gastroenterologist, Neurologist, Pulmonologist, Dietician, and the Pharmacy. This will ensure you have easy access to your child's medical team when needed.

Maintain Medical Records

Keep digital and paper copies of genetic results, medical records, prescriptions, keto formula, and swallow studies. Having these documents readily available will be invaluable as you navigate your child's care at home.

Stay Connected with Case Manager

Obtain the contact information for your Case Manager at the hospital. They can provide valuable support and resources once you're home and have questions about your child's care.

Understand Seizures and Medications

1

Seizure Action Plan

Ensure you have a complete understanding of your child's seizures, what constitutes an emergency, and how to administer emergency medications before leaving the hospital.

2

Medication Management

Familiarize yourself with your child's medications, dosages, and schedules. Request a printout from the hospital to keep track of their medications effectively.

3

Medication Effectiveness

Start your own spreadsheet to monitor the effectiveness of your child's medications and any side effects. This will help you communicate with the medical team effectively.

Prepare for Home Services and Support

1

Home Health Services

Start the application process for home health services, Medicaid, medical supply companies, and therapy services before discharge. Your case manager can assist you with available resources.

2

Government Assistance

Speak with the hospital's social services or case management team to understand the process of enrolling in Medicaid (or other government assistance programs) to unlock financial support for your child's medical needs.

3

Hospice and Palliative Care

Even though it may sound daunting, ask about hospice (or palliative) care before discharge. Hospice for children can provide invaluable support, including 24/7 nursing care and a dedicated social worker.



Advocate for Your Child's Needs

Therapy Prescriptions

Advocate for your child's well-being by asking for prescriptions for Physical Therapy (PT), Occupational Therapy (OT), Audiology, Speech, Swallowing Therapy, and Vision therapy. These therapies can be vital in aiding your child's development and improving their quality of life.

Emergency Care Letters

Request a letter from your Neurologist stating your child's needs, as well as a letter to ER staff about your child's medical diagnosis and preferred medications. This will save you time and ensure your child receives the appropriate care in an emergency.

Medical Equipment

Work with the hospital to request necessary medical equipment for home use, such as a Pulse Ox, Oxygen tanks, Suction machine, Feeding pump, and Nebulizer. Having these on hand can help prevent future hospital stays. View our video tips!

Tips from Tammy

Types of Home Equipment

Tammy Williams, Mom and KCNT1 Parent Support Specialist

Tammy@KCNT1Epilepsy.org



▶ 06:54



Vimeo



Medical Equipment for Home

Tammy is the mother of Bailee, a young girl with KCNT1 -related epilepsy. She share the equipment she has in her home to help care f...

Communicate with Siblings



Open Conversations

Have open and honest conversations with your other children about the changes they might experience when their sibling comes home. Explain any new routines or adjustments that will be necessary.



Provide Support

Ensure your other children feel heard and supported during this transition. Encourage them to express their feelings and involve them in the caregiving process, when appropriate. Siblings ages 5 and older can attend our Sibling Support Circle. Check our Events page for the next session.



Manage Expectations

Set realistic expectations with your other children about the level of attention and care their sibling will require. Reassure them that their needs will also be met, even if the focus may shift temporarily.

Get Organized at Home



Establish a Calendar

Write down follow-up appointments and other essential dates related to your child's care to stay organized and avoid missing any crucial appointments.

Continue Daily Journal

Keeping a historical record of your child's progress and medication details is important and can help improve their care.

Set Up Monitoring

Install a baby monitor or camera to keep an eye on your child, especially during the night or times when you cannot be with them. Utilize medical equipment like oxygen monitors to ensure your child's safety.

Tips from Tammy

Ways to Organize Your Care Schedule

Tammy Williams, Mom and KCNT1 Parent Support Specialist

Tammy@KCNT1Epilepsy.org



▶ 05:26



Vimeo



4 ways to stay organized

Mom of a 12 yo child with KCNT1 -related epilepsy offers some tips for managing the care of a child with medically-complex needs. .



Be Prepared for Emergencies

▼ Pack an Emergency Diaper Bag

Prepare a bag with essential items like medications, a list of primary medical contacts, extra clothes, diapers, and anything else you may need if a trip to the Emergency Room becomes necessary. Include items that mom or dad might need, and label all of your child's equipment.

▼ Prepare for ER Visits

Discuss with your healthcare provider what situations warrant a trip to the ER and which hospital you should request. Prepare a medical history write-up with a letter from your doctor to hand to ER admissions, including details about your child's medications, diet, and any implanted devices.

▼ Register with Local Emergency Services

Introduce yourself to your local EMS and Emergency Services Department, explaining your child's medical diagnosis. They can add your child to a list for Emergency Evacuation or Emergency Resources in case of natural disasters or other emergencies.

Connect with Experienced Parents

Are you seeking guidance and support on your child's healthcare journey? Our parent support specialists are here to share their firsthand experiences and provide personalized advice. Send us an email at Support@kcnt1epilepsy.org to schedule a confidential consultation.



KCNT1 EPILEPSY

HOPE IS ON THE HORIZON