Medical Summary & Transition Plan: Epilepsy Surgery & Devices

A simple summary to help families move from pediatric to adult care

Instructions for Families: *Copy and paste this text into a personal document. Fill it out with the help of your child's current pediatric care team, and give the final copy to your new adult doctor. You can delete any sections that don't apply to your child. Attach relevant legal, surgical, and emergency paperwork.*

1. Our Family & Legal Basics

Fill out the basic details about the patient and the people who help take care of them.

- **Patient Full Name** | Date of Birth | Current Age | *Age at Time of Official Transfer (if different)*
- **Primary Caregiver Name(s)** | Relationship to Patient | Email & Phone
- **Who makes medical decisions for the patient?** [ ] The patient (fully independent) [ ] Supported Decision-Making Agreement (family helps, but patient signs) [ ] Power of Attorney / Healthcare Proxy [ ] Full Guardianship / Conservatorship
- **What are your main goals with the new adult medical team?** (Examples: keeping seizures under control, managing device settings, reducing medication side effects, behavior/mood, etc.):
- **About Me:** *(Write a quick note about the patient's hobbies, interests, or what helps them feel comfortable at the doctor's office):*
- **Everyday Independence & Communication:** *This helps your new doctor understand how much support the patient needs with daily tasks and medical care.* **Can the patient reliably:**
    - Name their current medicines and what they do? ☐ Yes ☐ with help ☐ No
    - Take their own medications on time? ☐ Yes ☐ with help ☐ No
    - Explain their medical diagnosis? ☐ Yes ☐ with help ☐ No
    - Use an online patient portal or call the office? ☐ Yes ☐ with help ☐ No
    - Know when they need to go to the Emergency Room? ☐ Yes ☐ with help ☐ No
- **How does the patient communicate best?** *(Examples: speaks independently, uses an iPad or communication device, needs a parent to help translate, non-verbal):*
- **Mental Health & Learning Profiles** *(List diagnoses like Autism, ADHD, Anxiety, Depression, or developmental delays)*:
- **Behavior & Safety Alerts** *(Are there sensory triggers, a history of running away/wandering, or things that cause severe anxiety at the doctor? Describe here)*:

2. Emergency Safety & Seizure Plans

- 🚨**Seizure Action Plan (SAP)?:** ☐ YES *(attach official, signed, current emergency SAP)*
- **Primary Emergency Contact:** Name | Relationship to Patient | Phone | **Preferred Hospital/ER**
- **Warning Signs & Seizure Triggers** *(e.g., missing sleep, illness/fever, flashing lights, stress)*:
- **Allergies & Serious Drug Reactions** (*procedures & medications to AVOID & why*):
- **Typical Seizure** *(briefly describe what a typical seizure looks like, how long it lasts, and how long it takes them to recover)*:

3. PRIMARY TRANSITION TEAMS & PROVIDERS

- **Pediatric Epilepsy/Surgery Team:** Name | Primary Center / Institution | Phone / Email | Preferred Communication Method: ☐ Phone ☐ Email | Best Time to Reach
- **Other Key Specialists:** *(List names, specialties, contact phone/fax numbers; e.g., Neuropsychology, Epilepsy Monitoring, Psychiatry, Primary Care, Therapists, etc.)*

3. Epilepsy History, Surgeries, & Devices
This provides a quick history of the patient's epilepsy and the treatments they have tried.

- **Cause of seizures (etiology)** *(if known, such as a genetic reason, brain injury, stroke, or scar tissue):*
- **Age when seizures first started:**
- **Current Seizure Frequency:** * [ ] Seizure-free since: [date] [ ] Seizures happen less often, but still occur [ ] Seizures are ongoing and unchanged
- **Dates of most recent tests:** Last EEG: [date] | Last Brain Scan (MRI/PET): [date]
- **Brain surgery to remove a specific area:** (e.g., Temporal Lobectomy, Lesionectomy, Hemispherotomy) | Grid/Strip placement or sEEG / Invasive Monitoring | Shunt (hydrocephalus)
- **Neuromodulation Device Details:**
    - **Type of** Device: [ ] VNS (Vagus Nerve) [ ] RNS (Responsive) [ ] DBS (Deep Brain)
    - **Model & Serial Number**:
    - **Program Settings:** *(Ask your doctor for a printout of the current settings and add here):*
    - **Critical Safety Alerts & Device Quirks** *(Are there any specific programming quirks, warnings, or high-level safety guidelines the adult team must know?):*
    - **Who currently programs/monitors the device?** (Doctor/Clinic name):
    - **Is data tracked via a smartphone app or home monitor?** (e.g., MyRNS, LivaNova VNS App): [ ] Yes [ ] No. *List the name of the app used:*

4. Current Medications & Diets
- **Medication** Name | Dose (e.g., 500 mg) | When to take it (e.g., Morning / Night)
- **Medical Diet**: Is the patient on a special diet for epilepsy? *(e.g., Ketogenic or Modified Atkins):*
- **Critical Medications:** *(List any medications or rescue therapies that are absolutely mandatory and cannot be skipped or changed under any circumstances)*:
- **Past Medications Tried:** *(List any epilepsy medicines they tried in the past that did not work or caused bad side effects, and why they stopped taking them)*:

6. Medical Records & Potential Roadblocks Checklist
Adult care teams need the original files, not just summaries. Use this checklist to track what you have gathered, and note any issues you are having accessing them.

- [ ] Original Brain Scan Disks (MRI / PET / fMRI):
    - Status: [ ] Have it on CD/USB [ ] Shared digitally [ ] Having trouble getting this
    - Notes/Roadblocks: _____
- [ ] EEG Reports & Raw Data: (The actual wave recordings, especially baseline and post-surgery results)
    - Status: [ ] Have reports [ ] Have raw data [ ] Having trouble getting this
    - Notes/Roadblocks: _____
- [ ] Surgery & Pathology Reports: (The specific operating room notes and tissue lab reports from past brain surgeries)
    - Status: [ ] Have copies [ ] Having trouble getting this
    - Notes/Roadblocks: _____
- [ ] Legal Paperwork: (Guardianship documents, Power of Attorney, or Decision-Making forms)
    - Status: [ ] Signed and ready [ ] In progress [ ] Need help finding the right forms
- [ ] Pending Workups: (List any tests, like neuropsychological testing or blood work, that are currently scheduled or waiting for results): _____