Preparing for Health Independence: An Action Workbook for Transitioning Young Adults and Families

Companion Tool for Epilepsy Surgery & Device Patients

Instructions: Copy, paste, and modify this worksheet. Use it to build self-advocacy skills during high school IEP planning, prepare for employment or adult programs, and map out daily health management before leaving pediatric care. Omit sections that do not apply to your journey.

Section 1: My self-care plan template

Use this section to create your personalized health plan. Practice writing this out in your own words so you can easily share your medical history, daily care needs, and device settings with new adult doctors, supervisors, or roommates.

- **My medical condition(s) & diagnosis in plain language:** *(e.g., "I have drug-resistant focal epilepsy. I had an epilepsy surgery [resection/hemispherectomy] in [Year] and have an implanted [RNS/VNS/DBS] device to help control my seizures.")*
- **My medications, accurate dosages, & strict schedule:** *(List all daily anti-seizure medications, vitamins, psychiatric medications, or other maintenance therapies here. Include the exact time of day each is taken.)*
- **My specific seizure triggers & warning signs:** *(e.g., Sleep deprivation, acute illness/fever, extreme stress, missed medication doses, specific flashing lights).*
- **My implanted device details & safety rules:**
    - **Device type:** (VNS, RNS, DBS, or Shunt)
    - **My device identification card:** *(Where do you keep your physical manufacturer device card? e.g., "In my wallet behind my ID," or "A digital photo is saved on my phone lock screen.")*
    - **Where my magnet/equipment is kept:** *(e.g., "VNS swipe magnet is always in the front pocket of my backpack.")*
    - **Critical device safety restraints:** *(e.g., "I cannot have a standard MRI because of my specific device model; the adult team must check my device card first.")*
- **What to do in an emergency (my seizure first aid):** *(Step-by-step instructions for people around you, including when to use your rescue medication or VNS magnet, and when to call 911).*
- **Contact info for my healthcare providers:**
    - Adult neurologist/epilepsy center:
    - Adult neurosurgery team:
    - Primary care doctor:
- **Questions I need to ask my doctor at my next appointment:** *(Keep a running list of questions about driving laws, independence, device battery life, or prescription refills).*
- **How I track my health, seizures, & side effects:** *(e.g., "I use the MyRNS app daily," "I keep a paper calendar in my room," or "My caregiver logs my episodes in a shared notes app.")*

Section 2: Health-related IEP & transition goals

For high school & transition planning: Work with your school nurse, case manager, or transition team to add these measurable medical independence goals to your official school or agency plan. Replace "[Youth]" with the individual's name.

- **Prescription independence:** By the end of the term, **[Youth]** will independently request a medication refill (via phone, app, or pharmacy counter) with 90% accuracy, as measured by caregiver/staff log.
- **Appointment scheduling: [Youth]** will independently call their neurology office, schedule one routine follow-up appointment, and prepare a written list of 3 questions for the provider.
- **Emergency plan sharing: [Youth]** will complete a written emergency plan and independently share and explain it to at least two trusted adults and one peer in their daily environment.
- **Condition disclosure: [Youth]** will demonstrate the ability to describe their specific epilepsy history, surgical site care, device purposes, and baseline needs using plain language to an unfamiliar adult.

Section 3: The independent living & community prep checklist

Navigating disability services, human services, & legal rights

- **Self-disclose early:** Unlike pediatric systems, adult environments will not seek you out. The young adult must formally register with the appropriate campus disability office, vocational program, or human services coordinator well before programs begin.
- **Secure essential accommodations:**
    - **In higher education:** Formally register with the disability office, submit your clinical summary/provider documentation, and secure accommodations such as extended test time, a quiet testing environment, flexible attendance for post-seizure flare-ups, and permission to record lectures.
    - **In workplace settings:** Submit a formal, written letter to Human Resources or your supervisor documenting your condition and requesting reasonable safety/task accommodations.
- **Sign privacy releases (FERPA & HIPAA):** Once the patient turns 18, parents do not automatically have access to medical or academic records. Sign a formal release form at your doctor's office if you want your family involved in health and financial discussions.
- **Advocate and escalate:** If an instructor or supervisor pushes back on approved accommodations, do not argue; the young adult should immediately escalate the issue to their assigned disability coordinator, HR representative, or institutional ADA compliance officer.

Medication & device proactivity

- **Map your pharmacy access:** Locate a local pharmacy near your daily environment or set up a reliable mail-order prescription system to ensure you never run out of medication. Keep a backup supply in a secure, designated place.
- **Rescue medication responsibility:** Ensure your emergency rescue medication is unexpired and carried with you at all times (e.g., in a designated backpack compartment or dedicated pouch).
- **Device management:** Identify the nearest adult comprehensive epilepsy center to ensure your specific VNS/RNS/DBS device or shunt can be reliably monitored, interrogated, or programmed in an emergency.
- **Set multi-layered alarms:** Program daily phone reminders and use physical pill organizers to maintain strict medication adherence amidst an unpredictable daily schedule.
- **Prioritize wellness:** Lack of sleep, high stress, and alcohol significantly lower seizure thresholds. Set firm boundaries around your sleep schedule to protect your post-surgical progress.

Safety & emergency preparedness

- **Share your seizure action plan (SAP):** Give a physical copy to roommates, supervisors, close friends, or instructors. Directly teach them how to spot your seizure types and use your emergency rescue medications or VNS magnet.
- **Map local emergency rooms:** Learn the location of the nearest hospital ER and write down the explicit local protocol for medical situations (e.g., calling campus/site security vs. dialing 911).
- **Consider wearable safety tech:** Evaluate specialized seizure-alert devices (e.g., smartwatches, the SeizAlarm app) and wear a clear medical ID bracelet that specifies your cranial implants.
- **Utilize safe transportation:** Identify how you will get to appointments. Use night-time safe-ride programs, public transit, or reliable rideshares to avoid traveling alone when fatigued.

Section 4: Roles & responsibilities for the transition team

For school nurses & transition coordinators

- **Assess health literacy:** Regularly quiz the youth on their medication names, surgical history, and device parameters to encourage self-advocacy.
- **Protect the routine:** Emphasize the absolute non-negotiable importance of sleep, consistent routines, and stress management in maintaining post-surgical seizure control.
- **Build practical self-management:** Guide the young adult in setting up durable calendar/planning systems, understanding medical record systems, structuring emergency protocols, and practicing navigating transportation logistics independently before high school ends.
- **Promote disclosure awareness:** Work with the student on how, when, and whom to educate (roommates, RAs, employers, health centers) about their emergency rescue plans.

For parents & caregivers

- **Guide from a distance:** Allow your young adult to speak first during doctor visits, manage their own pill boxes, and call in their own refills while you supervise. Teach them to advocate for themselves early.
- **Support housing accommodations early:** If your young adult needs a single room (for privacy during post-seizure recovery or device management), a lower floor, or specific air-conditioning modifications due to their surgical history, apply to housing offices exceptionally early, as extensive medical justification is often required.
- **Establish autonomy boundaries:** Set up structured, predictable weekly check-ins to discuss wellness, rather than micromanaging their daily routines, which allows them room to practice independent living.

Section 5: Supplemental checklist for young adults heading to college

Omit this section if it does not apply to your transition path.

College accommodations & legal rights

- **Understand the systemic shift:** Unlike K-12 education, colleges are not required to identify you for support. You must proactively self-disclose and register with Disability Services.
- **Remember re-request rules:** You may need to formally request your approved accommodation letters from the disability office every single semester; they do not always carry over automatically.
- **Utilize complete campus resources:** Schedule introductory visits with the student health center and campus counseling services *before* you experience a health flare-up or academic crisis.

Dorm & campus social safety

- **Educate your residential staff:** Schedule a brief meeting with your Resident Advisor (RA) and the Coordinator of Residential Life during move-in week to provide them with a physical copy of your seizure action plan.
- **Set strict lifestyle boundaries:** The sudden shift in routine, exam stress, pulling "all-nighters," and exposure to campus party culture are dangerous seizure triggers. Prioritize your routine.
- **Establish a public safety net:** Carry a medical ID card in your wallet, keep emergency contacts saved on your phone's lock screen, and make sure at least one close friend or peer in each class knows your seizure first aid.

Academic advocacy

- **Connect with professors on day one:** Visit your instructors during their first week of office hours to introduce yourself and confirm they received your approved accommodations.
- **Establish a post-seizure protocol:** Make sure your professors know exactly what to expect if you experience an absence, focal seizure, or generalized seizure during a lecture or exam.

Section 6: First adult visit: a simple checklist

Use this quick checklist to prepare for your very first appointment with the new adult neurology and neurosurgery team.

Before the first adult visit, try to:

- **Confirm adult healthcare coverage:** Verify that the new adult clinic accepts your specific adult health insurance plan, national health system coverage, or specialized community funding structure (which often changes drastically when legally becoming an adult).
- **Request pediatric records:** Ask the pediatric neurologist and neurosurgeon to send the following documents directly to the new adult office:
    - A recent comprehensive clinic note
    - Complete surgery summaries and device specification sheets
    - The current, exact medication list
- **Prepare a seizure summary:** Bring a simple, one-page summary of current seizure activity (how often they happen, what they look like, and how long they last).
- **Write down your top priorities:** Note your top 2–3 specific questions or immediate worries so you do not forget to bring them up during the appointment.

Possible questions to ask the adult team

Edit or add to this list based on your family's unique needs:

1. How will your team review and learn about my specific surgery history and device programming quirks?
2. Who is my direct point of contact if I experience a sudden problem with seizures, side effects, or my device/shunt?
3. What is your clinical protocol if my seizures get worse, or if I notice major changes in my mood or behavior?
4. How will you stay in touch with my previous pediatric team during this first transition year if questions come up?