

The Next Step: Transitioning to Adult Neurology and Neurosurgery Care

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Case

- HISTORY: 27 yo right-handed amazing young man that loves building complex Legos transitioned to my Adult Epilepsy Colleague at 25 years
- He was born full term with normal early development.
- Sz. age of onset: 5 y/o w regression of prev. normal speech and poor socialization
- Seizure Description: Generalized or right sided stiffening; prolonged episodes of confusion with staring, isolated or full body jerks +/- falls.
- Frequency: Daily (often in sleep transitions or out of sleep)
- Epilepsy panel and WES: No abnormalities found
- Hospitalized several times as well as multiple ER visits
- **ASM's**: Lamictal, Lacosamide, and clobazam; VNS (2013 – 12 years old)
- **Prior ASM's**: TPM, OXC, VPA, PHT, ZNG, LVT, KLP, Clorazepate, RFN, CBD and high dose steroids
- EEG: Generalized activity; right > left frontal activity; slow spike and wave; GPFA
- MRI: Stated to be negative

Poor socialization

1. Less friends and poor socialization.
2. Stereotyped behavior
3. Poor sleep
4. Multiple days of missing school
5. Decrease focusing
6. Parents travelled to seek care.
7. family sleep deprivation.

Clinic related concerns: Insurance related issues; requests more clarity; difficulty with call back; ASM side effect frustration; honeymoon periods of up to 3 mths.....



How did it affect the family?

- His Mother was going to return to work but decided not to because of his complexity.
- There were concerns for sibling balanced attention engagement.
- Parents opened a business where he could work but it closed during COVID.
- There were hours spent in advocacy for multiple components of care delivery.
- Limited social outings for fear of acute seizures
- Seizures occurred mainly at night therefore less sleep for him and his family

Epilepsy affects
50-70 million
people worldwide
and **over 500
million extended
family members!!!**



Managing Drug Resistant Epilepsy



What seizure types does this patient have?

What is the underlying cause?

What are his comorbidities?

What are the side effects of these ASMs?

When do we change ASMs?

When do we think of a device?

Can he have other surgeries?

What does this have to do with his transition to adult care?

- Management
- School to vocation
- Learning to independence
- Socialization to family and quality of life



At 17 years old we met through referral to the EMU



He had features on EEG and observed seizures that suggested that the events were possibly starting from one area.

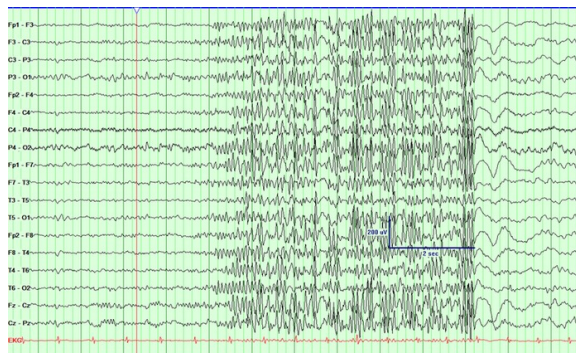
It was close to his speech area; therefore, we ablated just below and posterior to it and he was seizure free.

He was seen by another provider and after 3 years weaned the ASMs.

He unfortunately had another event.

We did further ablation at 21, still avoiding the language area and...

He is now doing well on 1 ASM and Clonazepam at night only and is 3 years seizure free.



- Why did it take 12 years to identify an underlying pathology?
- Should I have seen him at 17yo since he should have soon been transitioning to adult care?
- Why did he not go to an Adult neurologist earlier?
- Even after suggesting not to wean, it was done. Did the other Provider do the right thing?
- Should I have taken over his care again at 21 years old?
- Who is going to care for his device?
- What about his psychosocial well-being, future, and QOL?



What is access, and what are the impediments to access to transitional care?

Patient-centered access to health care: conceptualising access at the interface of health systems and populations.

Levesque JF, Harris MF, Russell G. Int J Equity Health. 2013 Mar 11;12:18.

- Dimensions of accessibility: 1) Approachability 2) Acceptability 3) Availability and accommodation 4) Affordability 5) Appropriateness.

- Dimensions of abilities: 1) Ability to perceive 2) Ability to seek 3) Ability to reach 4) Ability to pay 5) Ability to engage.

Less Adult Providers
Knowledge/Education
Family/peer pressure
Insurance/economics
Mistrust
Unconscious bias
Geography/Zip code
Race/Ethnicity
Language/linguistics
History/Culture
Stigma
Societal laws
Religion/Spirituality



Geographic Heterogeneity in Epilepsy Specialist Distribution

Gotlieb E, Lally A, Blank LJ, Jette N. Geographic Heterogeneity in Epilepsy Specialist Distribution. *Neurology*. 2025 Sep 23;105(6):e214035.

2,284 epilepsy certifications; 2,169 were active.

- Zero in Montana; 1 in Arizona, Vermont, and Wyoming.
- California, New York, and Texas had the highest #
- The South had the highest number of epilepsy cases and the highest patient-to-physician ratios.

Most epilepsy physicians were in metropolitan areas; many of these counties lacked any epilepsy-certified physicians.

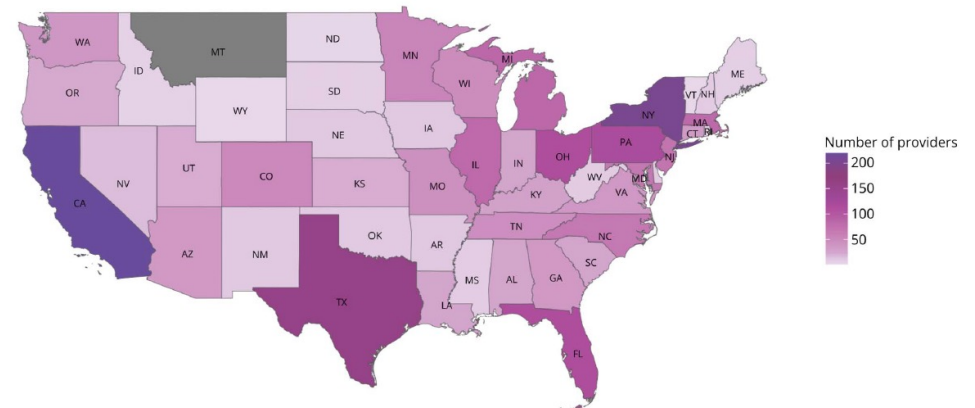
Counties with more physicians had lower ADI scores.

Worse access to care in areas with higher levels of socioeconomic deprivation.

^a There are no CDC data on number of active epilepsy cases in PR. There is no 2020 Area Deprivation Index (ADI) in the data set used.

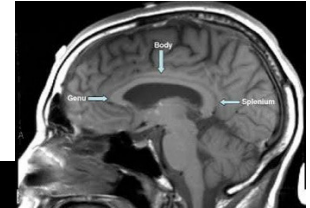
^b Because there are no registered epilepsy-certified physicians in MT, the number of patients with epilepsy per physician was not calculated.

Figure 1 Number of Epilepsy-Certified Physicians by State



The map excludes epilepsy-certified physicians in Puerto Rico (10), Hawaii (4), and Alaska (1). States in gray have zero epilepsy-certified physicians. Top 10 states by physician are California (220), New York (204), Texas (159), Pennsylvania (118), Florida (114), Ohio (113), Michigan (86), Illinois (84), Massachusetts (83), and New Jersey (72). Montana has 0 epilepsy-certified physicians.

Early treatment affects outcome!!! The ultimate outcome is the best QOL!!!



Early epilepsy surgery for non drug-resistant patients

Pelliccia V, Deleo F, Gozzo F, Giovannelli G, Mai R, Cossu M, Tassi L... Epilepsy Behav Rep. 2022 Apr 21;19:100542. doi: 10.1016/j.ebr.2022.100542. PMID: 35573058; PMCID: PMC9096667.

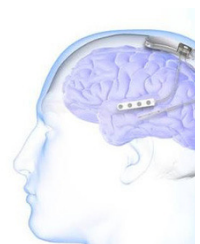
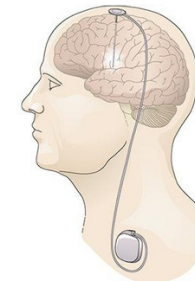
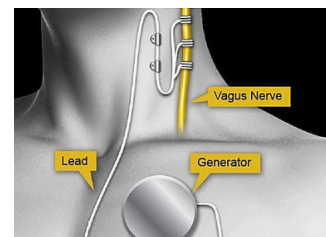
Table 2. The table reports the differences about age at epilepsy onset, epilepsy duration, age at surgery, initial seizure freedom period.

	NDR	DR	<i>p</i>
Age at epilepsy onset (years)	10 (IQR 5–21)	7.0 (IQR 2–14)	= 0.029
Epilepsy duration (years)	2 (IQR 1–5)	17 (IQR 9–28)	<0.001
Age at surgery (years)	16 (IQR 7–23)	30 (IQR 18–38)	<0.001
Initial seizure freedom period (months)	17 (IQR 9–36)	48 (IQR 24–84)	<0.001

Seizure outcomes or NDR patients were excellent:

- 71 (95.9%) had Engel class Ia and three patients were in class Ic outcomes
- DR patients, 111 (63.1%) were in class Ia, four (2.3%) class Ib, 25 (14.2%) class Ic, two (1.1%) class Id.

Who will do all of this in the Adult world?!?!



All hands-on deck!!!

Epilepsy Smart Schools: Educational intervention improves knowledge, attitude, and practices regarding epilepsy among school teachers. Sulena S et al. Epilepsy Behav. 2023 Apr;141:109138.

PESA

Improved availability and quality of care with epilepsy nurse practitioners. Chloe E. Hill, MD et al. Neurol Clin Pract 2017;7:109–11

EFA

The emerging role of the advanced practice epilepsy nurse: A comparative study between two countries. Manzanares I et al. J Clin Nurs. 2021 May;30(9-10):1263-1272.

> 8 mil PWE, Parents, Family, extended family

>5 Mil Nurses;
3.5 Mil Teachers

>800,000 Social Workers

>500,000 NP's/PA's

330,000 Pharmacists

>25,000 Neurology

>2,500 Epi

Effectiveness of a Self-Management Program to Improve Cognition and Quality of Life in Epilepsy: A Pragmatic, Randomized, Multicenter Trial. Streltsov NA et al. Neurology. 2022 May 24;98(21):e2174-e2184.

REN

Use of AANN Seizure and Epilepsy Certificate Program to Improve Neuroscience Nurses' Knowledge and Confidence. Bhatnagar S et al. J Neurosci Nurs. 2025 Jun 1;57(3):104-107.

EAA

Zaraa S, et.al. Using design thinking to strengthen the community pharmacist's role in epilepsy care. Epilepsy Behav 2024;150:109542

His mother became well informed and constantly advocated for his care.

- She engaged with our **Social worker** and Blue Bonnet Trail, and the Texas Work Commission was identified as sources of help.
- She went from business to business **educating** them about her son's condition, how much better he is doing, and their willingness to employ him.
- When she found a location that would higher him, the **TWC and Blue Bonnet Trails** helped to **train** him for the position.
- We **worked together** to identify an **Adult Epileptologist** that was versed in all 3 devices and Epilepsy Care
- I **communicated with my Adult Colleague** about his case and kept in **close communication** for questions from him and his Mother as she **navigated the course of care delivery**.
- How is the Social Worker, PCP, Neuropsychology +/- GI, +/-Counselor...care transferred?



What does this look like in the Pediatric space?

Nurse Practitioners

Neuropsychology



Epilepsy (EMU) Nurses



Neurosurgery



Cardiac

Neurosurgery Nursing

Physiatry



Clinic Nurses



Care Coordination



EEG Technologists

Epileptologists



Child life

Epilepsy Trainees

Social workers



Diet

Pulmonary

Hospital admin and Foundation



Physiatry

Adult transition integration!!!

Health care transition is a process



**TRANSITION planning ≠
TRANSFER alone.**

**TRANSITION =
planning, transfer, and
integration into adult care.**

[Six Core Elements of Health Care Transition](#) (Got Transition)



Why adult care feels different.





What families have told us.

- Transition starts too late.
- Families do too much alone.
- Adult care can be hard to find.

Bennett's Care Map

SCHOOL

Disability Services & Programs for Students (DSPS)
Computer Adaptive/Assistive Technology
Tutor
Course advisor
Counselor
Professors

EMPLOYMENT

Vocational Rehab Dept
Regional Center Employment Specialist
Service Agency
Career Counselor
Job Coach
Assistive Technology
Employer

PEDIATRIC PROVIDERS

Neurology – epilepsy specialist
Neurovascular specialist
Neurosurgery
Radiology
Genetics

THERAPIES

Occupational Therapy
Physical Therapy

ADULT PROVIDERS

Neurology – movement disorder specialist
Neurosurgery – hydrocephalus & shunt management
Primary care – wellness, Rx, labs, referrals, vaccinations, Urgent care/ED
Orthopedist
Physiatrist
Orthotist
Sleep specialist
Dermatologist
Urologist

DEVELOPMENTAL ASSESSMENTS

Neuropsychological
Mental Health

MENTAL HEALTH

Counseling
Crisis Management
Medication

VISION

Neuro-ophthalmology
Optometry
Developmental optometrist
Vision therapy

EDUCATION & EMPLOYMENT

HEALTH

Bennett

INSURANCE
Private Insurance
Medicaid
Dental
Vision

AUDIOLOGY

Assessment
Auditory training
Hearing aids?
SLP

DENTIST

Mom
Case Manager

RECREATION & COMMUNITY

Special Olympics
Lighthouse for the Blind
Best Buddies
Center for Independent Living
Dating coach
Financial coach
Transportation
Vacation travel

CONSERVATORSHIP

STATE & FEDERAL BENEFITS

SSI
Benefits Specialist
IHSS
Regional Center/SDP
Independent Facilitator
Medicaid Waiver
HCBS
DDS
Housing (Section 8 waitlists)

ABLE ACCOUNT

LEGAL & FINANCIAL

TRUST & ESTATE
Attorney
Financial Advisor

SUPPORT

PEOPLE
Family
Friends
Neighbors

THERAPISTS

Behavior coach
Executive function specialist
1:1 counseling
Family therapy
Music therapy
Bodywork
Massage

1:1 SUPPORT STAFF

Adaptive skills training
Behavior coach/BCBA
Social coach/personal assistant

GROUPS

Pediatric Epilepsy Surgery Alliance
DEE-p Connections
AS/ND List Serv
Support for Families
Epilepsy Surgery Support
Council of Parent Attorneys and Advocates
Stanford Neurodiversity Project

@ 2026 Pediatric Epilepsy Surgery Alliance

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Devices and Imaging Matter

Be the Keeper of Records:

Keep your own physical and digital copies instead of relying on hospital systems.

Get Raw Images & EEGs:

Request original data for MRIs and EEGs on disc, not just written reports.

Confirm Device Support:

Make sure the adult clinic actively manages and programs your child's exact device model – before your first visit!



Independence, with support

- **Surface Ready:** Some young adults appear fully prepared on the surface.
- **Hidden Gaps:** It is easy for them to miss subtle medical details, histories, or tracking routines.
- **Scaffold Success:** Structured parental support builds confidence without risking health control.



A portrait of a young man with curly brown hair and light green eyes, looking directly at the camera. He is wearing a grey t-shirt and a thin chain necklace. The background is a blurred outdoor scene with green foliage. A solid magenta square is in the top left corner of the image area.

Decision-making after age 18

- Privacy changes at 18.
- Some families need legal support.
- Plan before the crisis.





Access is a barrier

- Adult specialists can be hard to find.
- Complex histories raise the bar.
- Families need help connecting.





Transition toolkit



Medical Summary & Transition Plan

A simple summary of epilepsy surgery, devices, and history to share with the adult team. Includes an integrated contact tree.



Seizure Action Plan

A current, signed medical plan that tells caregivers, roommates, or friends exactly what to do in an emergency.



Self-Care Plan

A youth-written guide to daily care and independence, mapping out exactly where support is needed.



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):

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):



Some Favorite Health Care Transition resources

- [Adolescent without significant developmental disability](#) (plan for independence), a helpful guide that outlines a step-by-step timeline to prepare adolescents with epilepsy for a smooth and independent transition into adult medical care. (*American Epilepsy Society*)
- [Adolescent with significant developmental disability](#) (independence unlikely), a tailored guide that details a step-by-step timeline to navigate long-term medical care, guardianship, and supportive living transitions for adolescents with epilepsy who have significant developmental disabilities. (*American Epilepsy Society*)
- [Center for Transition to Adult Health Care for Youth with Disabilities](#): A national resource hub that provides tools, training, and guides to empower young adults, caregivers, and clinicians navigating the health transition process.
- [Educational Transition for Youth With Neurological Conditions](#): A practical guide that explains how to integrate healthcare skills into a child's school IEP, ensuring pediatric epilepsy surgery patients learn self-management for adulthood. (*Pediatric Epilepsy Surgery Alliance*)
- [Moving to Adult Health Care: A 6-Part Toolkit Series for Health Care Transition: A comprehensive toolkit series designed to help youth with intellectual and developmental disabilities learn, prepare, and take charge of their adult health care.](#) (*Center for Transition to Adult Health Care for Youth with Disabilities & The LifeCourse Nexus*)
- [Seizure Action Plan Coalition](#): A dedicated website that provides downloadable tools, templates, and expert resources to help families create and share individualized emergency seizure care plans.
- [Seizure Safe Schools Courses](#): A suite of training modules that equips school staff, students, and nurses with the essential skills to safely recognize and respond to seizures in the classroom. (*Epilepsy Foundation*)
- [Six Core Elements of Health Care Transition](#): A structured framework that defines the essential clinical steps needed for a seamless shift from pediatric to adult medical care models. (*Got Transition*)
- [The Almost Everything List](#): A curated resource guide that covers essential information on school support, adult life, financial assistance, family resources, and decision-making before and after epilepsy surgery. (*Pediatric Epilepsy Surgery Alliance*)
- [Transition of Care](#): A centralized platform that offers expert checklists, timelines, and educational materials to assist families in planning a smooth move to adult neurology care. (*Child Neurology Foundation*)
- [Transition Roadmap for Youth with Neurological Conditions](#): A free self-paced course that covers key transition milestones, including post-secondary education, employment, benefits, independent living, and adult healthcare. (*Pediatric Epilepsy Surgery Alliance*)
- [Transition to Adulthood Checklist](#): A step-by-step milestone tracking tool designed to help families organize medical, legal, and financial preparations as their child approaches legal adulthood. (*Pediatric Epilepsy Surgery Alliance*)
- Young Adults with Rare Disease: [YARR Healthcare Guide](#): A patient-led handbook that offers actionable tips, self-advocacy tools, and insurance guidance specifically for young adults living with rare health conditions. (*EveryLife Foundation for Rare Diseases*)

Thank you

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