

Epilepsy Living & History Form

This form can be used for pediatric-to-adult medical transition for any childhood-onset epilepsy. While this form is intended to be filled out with the assistance of your child's pediatric neurologist/epileptologist prior to the transfer of care to an adult neurologist, we encourage you to complete as much information as you can on your own before you bring to your child's healthcare provider for their input.

TIP: Although this form does not need to be completed prior to entering the pediatric-to-adult medical transition, if you would find it helpful in managing your loved one's medical records, you may wish to complete the form earlier and update it on an annual basis. Sometimes it's easier to pick a date that is easy to remember, such as your loved one's birthday.

Name of current neurologist/epileptologist:

Address:

City:

State:

Zip:

Phone:

Email:

Name of caregiver or individual completing the form with clinician:

Date this form was last completed/updated:

Patient Name:

Current Age:

Date of Birth:

Sex:

Epilepsy history

1. Epilepsy diagnosis:

2. Is the cause of the patient's diagnosis known? For example, does the patient carry a genetic variant? ☐ YES ☐ NO

Details:

3. Age at first seizure:

a. Was the first seizure febrile or afebrile? ☐ YES ☐ NO ☐ UNSURE

b. Was the first seizure infantile spasms? ☐ YES ☐ NO ☐ UNSURE

Details:

4. Seizure types. Please note whether this is a prior history as well as the current seizure type the patient experiences.

Seizure Type	Current/Prior	Description	Frequency	Date of Last Seizure
<input type="checkbox"/> Tonic-clonic	<input type="checkbox"/> Currently Experiences			
	<input type="checkbox"/> Prior History			
<input type="checkbox"/> Hemiclonic	<input type="checkbox"/> Currently Experiences			
	<input type="checkbox"/> Prior History			
<input type="checkbox"/> Myoclonic	<input type="checkbox"/> Currently Experiences			
	<input type="checkbox"/> Prior History			
<input type="checkbox"/> Focal Unaware	<input type="checkbox"/> Currently Experiences			
	<input type="checkbox"/> Prior History			

Seizure Type	Current/Prior	Description	Frequency	Date of Last Seizure
<input type="checkbox"/> Focal Aware	<input type="checkbox"/> Currently Experiences			
	<input type="checkbox"/> Prior History			
<input type="checkbox"/> Focal to Bilateral Tonic Clonic	<input type="checkbox"/> Currently Experiences			
	<input type="checkbox"/> Prior History			
<input type="checkbox"/> Typical Absence	<input type="checkbox"/> Currently Experiences			
	<input type="checkbox"/> Prior History			
<input type="checkbox"/> Atypical Absence	<input type="checkbox"/> Currently Experiences			
	<input type="checkbox"/> Prior History			

Seizure Type	Current/Prior	Description	Frequency	Date of Last Seizure
<input type="checkbox"/> Tonic	<input type="checkbox"/> Currently Experiences			
	<input type="checkbox"/> Prior History			
<input type="checkbox"/> Atonic	<input type="checkbox"/> Currently Experiences			
	<input type="checkbox"/> Prior History			
<input type="checkbox"/> Other	<input type="checkbox"/> Currently Experiences			
	<input type="checkbox"/> Prior History			

5. List known seizure triggers:

6. Seizure free period(s):

a. Longest length of time seizure-free:

b. Approximate dates:

7. Please detail the patient's history of status epilepticus (SE), defined here as a seizure lasting more than 30 minutes:

Type of SE	Date(s) of Event(s)	Successful Treatments	Additional Details
<input type="checkbox"/> Convulsive			
<input type="checkbox"/> Non-convulsive			
<input type="checkbox"/> Intermittent/ Seizure Cluster			

8. Family history of epilepsy or other relevant neurologic conditions:

Treatment(s)

9. Current antiseizure medications (ASMs):

Current ASM	Dose	Duration of Time on Therapy

10. Rescue ASMs:

Current ASM	Dose	Duration of Time on Therapy

11. Seizure Emergency Protocol (brief description, please attach full [Seizure Action Plan](#) to report):

12. Vagus nerve stimulation (VNS) or other neuromodulation device:

Device	Settings	Date of Placement

12a. Has the VNS (or other device) battery been replaced?

Device	Date of battery replacement	Did seizures worsen when battery life ended?

13. Prior/failed ASMs:

Prior ASM	Highest dose	Duration	Reason discontinued

14. Epilepsy surgery (excluding neuromodulation, if already noted above):

Procedure type	Date of surgery	Details

15. Ketogenic or other dietary therapy for epilepsy:

Prior/Failed Dietary Therapy	Dates	Reason Discontinued

Current Dietary Therapy	Date Initiated	Details and Future Plans for Continuation

16. Other current medications or supplements (Please include psychiatric or behavior drugs, contraceptives, calcium/vitamin D, folic acid, etc.):

Medication/Supplement	Dose	Duration of Time on Therapy

17. Please list any allergies or contraindicated medications with details:

Epilepsy History

18. Intellectual evaluation: ☐ Normal cognition ☐ Mild intellectual disability ☐ Moderate or severe intellectual disability

Evaluation determined by: ☐ Pediatrician ☐ School Reports ☐ Psychiatrist ☐ Psychologist

☐ Other (please explain):

19. Psychiatric comorbidities: (please select all that apply) ☐ None ☐ Depression ☐ Anxiety ☐ Autism Spectrum Disorder ☐ Psychosis

☐ Other (please explain):

Evaluation determined by:

20. Gait, motor, and/or skeletal abnormalities (please describe any interventions):

20a. Is patient currently followed by a specialist for these issues? ☐ YES ☐ NO

Please include name of specialist:

21. Sleep disruptions or apnea (please specify dates and findings from sleep studies):

21a. Is patient currently followed by a specialist for these issues? ☐ YES ☐ NO

Please include name of specialist:

22. Please list any other non-epilepsy surgeries (include dates):

Procedure Type	Date of Surgery	Details

23. List other significant medical conditions/comorbidities (please include name of specialist, if relevant):

Neurologic Exam

24. Neurologic exam: ☐ Normal ☐ Abnormal

Please describe abnormal exam findings:

Tests

25. Neuroimaging procedures and findings:

Procedure Type	Exam Date(s)	Relevant Findings
<input type="checkbox"/> CT head		
<input type="checkbox"/> MRI brain		
<input type="checkbox"/> PET		
<input type="checkbox"/> SPECT		
<input type="checkbox"/> Other:		

26. Electrophysiology/EEG:

Procedure Type	Most Recent Procedure Date(s)	Relevant Findings from Current or Past Procedures
Routine EEG		
Inpatient video- EEG (in Epilepsy Monitoring Unit)		
Inpatient video- EEG (not in Epilepsy Monitoring Unit)		
Outpatient prolonged video EEG (ambulatory EEG with video)		
Outpatient prolonged EEG (ambulatory EEG without video)		
MEG		
Other:		

27. Genetic tests:

Test Type	Date(s)	Lab or Company Name	Relevant Findings
Epilepsy gene panel			
Karotype			
Microarray			
Whole exome sequencing (WES)			
Whole genome sequencing (WGS)			
Other:			

28. Metabolic tests (please include exam date(s) and relevant findings):

Test Type	Date(s)	Lab or Company Name	Relevant Findings

This Epilepsy Living & History Form was developed from the following resources:

- Nascimento FA, Gurnett CA. Epilepsy Transition Program– Washington University School of Medicine. St. Louis, MO, USA.
- Li W, Schneider AL, Scheffer IE. Defining Dravet syndrome: an essential pre-requisite for precision medicine trials. *Epilepsia*. 2021;62(9):2205-2217. <https://doi.org/10.1111/epi.17015>
- Andrade DM, Bassett AS, Bercovici E, Borlot F, Bui E, Camfield P, et al. Epilepsy: Transition from pediatric to adult care. Recommendations of the Ontario epilepsy implementation task force. *Epilepsia*. 2017; 58(9):1502–17. <https://doi.org/10.1111/epi.13832>
- Andrade DM, Berg AT, Hood V, Knupp KG, Koh S, Laux L, et al. Dravet syndrome: a quick transition guide for the adult neurologist. *Epilepsy Res*. 2021;177:106743. <https://doi.org/10.1016/j.eplepsyres.2021.106743>
- Dravet Syndrome Foundation <https://dravetfoundation.org/>