



Transition Toolkit

**Epilepsy Alliance Florida
is dedicated to supporting
those impacted by epilepsy by
confronting the spectrum of
challenges created by seizures**



www.epilepsyalliancefl.com

This publication is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award funded by HRSA/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA/HHS, or the U.S. Government.



Transition Toolkit

Our Mission

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www.epilepsyalliancefl.com



Our Mission

Epilepsy Alliance Florida is dedicated to supporting those impacted by epilepsy by confronting the spectrum of challenges created by seizures.



Our History

Established in 1971 as a not-for-profit 501(c)(3), Epilepsy Alliance Florida (EFLA) is the principal agency for epilepsy programs and services sponsored by the State of Florida, servicing an estimated 500,000 Floridians who live with the condition. For most of our history we were known as Epilepsy Foundation of Florida but in July 2018 we formally changed our name as we co-founded Epilepsy Alliance America, a nation-wide network of community-based epilepsy organizations. EFLA also serves as the lead advocate for the rights and needs of people with epilepsy and seizures at the local, county, state and national level.

Dear Family,

Adolescence is a period of change, both physically and mentally and it can be especially trying for those with ongoing health problems when their care needs to be transitioned to the adult health care system. Transition is defined as a “purposeful planned process that addresses the medical, psychosocial, and educational/vocational needs of young people with chronic physical and medical conditions as they move from child-centered to adult-oriented health care systems.” This is a dynamic and structured process that involves a lot of careful planning, preparation and involvement of a skilled team to ensure a seamless continuation of care from pediatric to adult care.

We know that this can be a difficult time met with much nervousness as most young adults and their families have developed a relationship built on trust and friendship with their current provider. Your child’s transition care team is very educated on their epileptic condition and motivated in providing a safe and successful transition for them. It is important that you, as the parent or guardian, see the transition as a regular recurring process and not a single event and know that proper preparation is the key to its success.

Your teen faces many challenges including managing and learning about their epilepsy and as their parent that has been your job, until now. You have been the one managing their treatments, making their medical appointments and making sure they are there for them. You’ve also encouraged them to learn more about epilepsy so that they know about their condition and could educate others as well to lessen the stigma that surrounds it. As your child has learned more about their epilepsy, treatments and medications they slowly but surely have gained the responsibility needed to manage adulthood and their condition. This is why you all are ready to transition from pediatric to adult care.

Epilepsy Alliance Florida QIN team

Transition Readiness Checklist

Basic Knowledge: Health & Wellness

- I can explain my diagnosis and healthcare needs to others.
- I can provide my medical history when needed.
- I am aware of my symptoms that need quick medical attention.
- I can explain my medical emergency plan to others.
- I can explain how my healthcare needs may affect my daily living.
- I can name all my medications, the amount and times I take them.
- I know all my allergies and what to do if I have an allergic reaction.

Being Prepared: Health & Wellness

- I carry my medical insurance card daily.
- I carry my healthcare information with me.
- I provide my medical safety plan to my school and/or workplace.
- I carry a list of my emergency contacts.
- I keep a personal health history notebook and/or medical journal.
- I keep a personal seizure log.
- I know when it is time to reorder my medications.
- I know how to reorder my medications.

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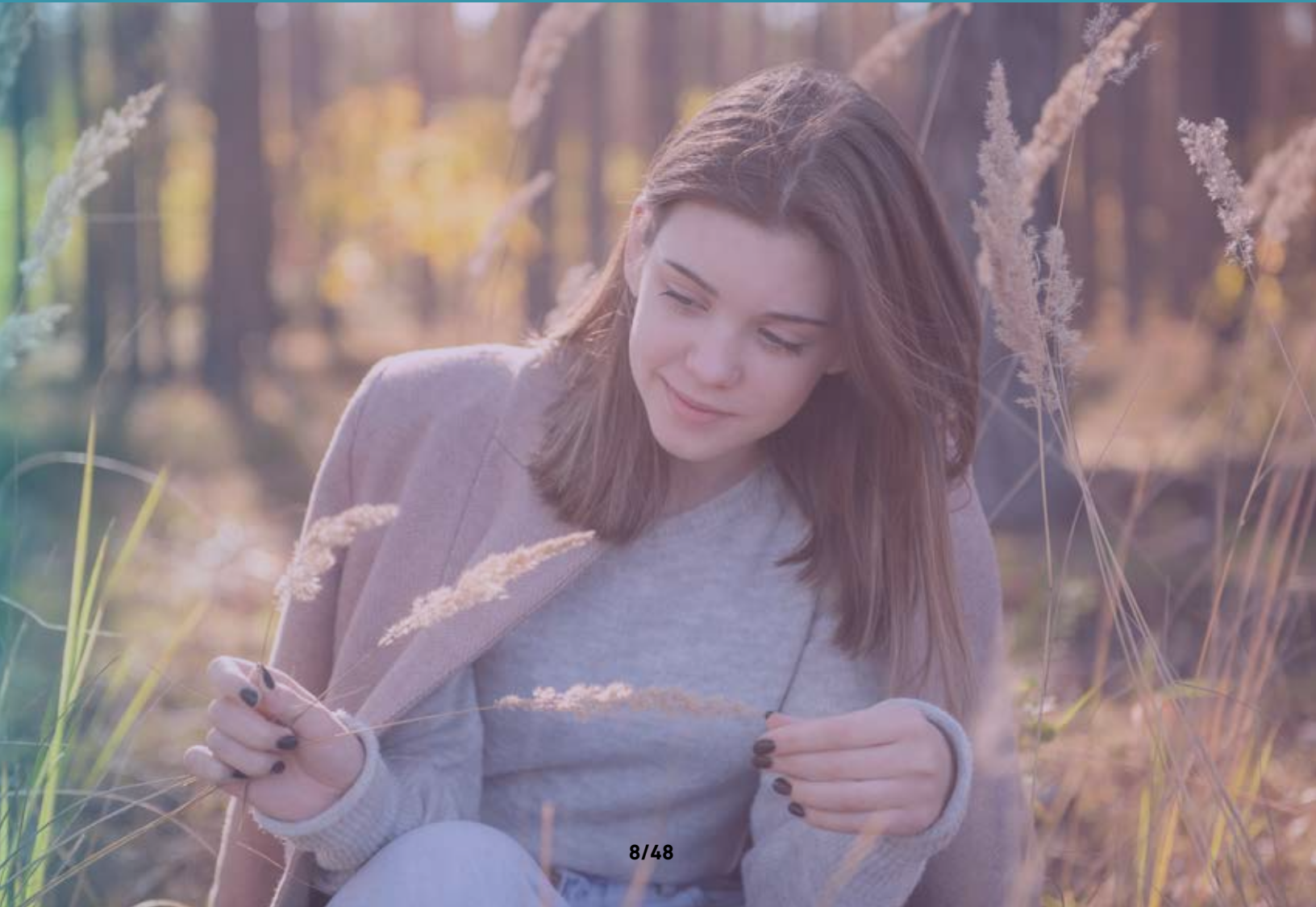
1

Taking Charge

a. About Me

b. Health Summary

c. Immunization Records



About Me

Name: _____ Date of Birth: _____

Born: (city/state/country) _____

My language preference is: _____

Living with me are: _____

My mother and/or father live: _____

My sister's names/ages are: _____

My brother's names/ages are: _____

Other half siblings or step siblings are: _____

My grandparents names are: _____

Are you currently in a relationship, if so with who: _____

Name of school:

Grade level:

GPA:

What is your highest level of education (college, tech/vocational school, certifications):

Special school services or accommodations I have now:

Are you currently employed, if so where:

Do you have a seizure response dog? Yes _____ No _____

Name: _____

Would you like one? Yes _____ No _____



My Favorites

Activities:

Sports:

Color:

Movies and/or TV shows:

Music:

Pet(s):

Three things I do well are:

Five positive words to describe me are:

I am most proud of:

The things that give me the most joy are:

My strengths are:

Names of people that I can depend on for emotional support and assistance are:

How I learn best is:

Special abilities and interests:

When I have a seizure, who do you want for support:

When I'm feeling sad I like to:

Things that comfort me are:

What makes me angry or stressed is:

When I'm angry, feeling stressed or upset, I handle these emotions by:

When I am finished with school, I would like to:

My Health Summary

My Name: _____ date of birth: _____

Address: _____ phone: _____

Parents or Guardian: _____

Address: _____ phone: _____

Emergency Contact

Name and relationship: _____

Address: _____ phone: _____

Do you currently have access to an Electronic Health Record system?

Yes _____ No _____

If yes, what is the name of the system? _____

If not, would you like help in signing up with one? Yes _____ No _____

"Benefits of using an electronic health record system helps provide accurate, up-to-date, and complete information about patients at point of care. Also it enables quick access to patient records for more coordinated efficient care and securely sharing electronic information with patients and other clinicians."

Primary Care Doctor: _____

Address: _____ phone: _____

Pediatric Epileptologist: _____

Address: _____ phone: _____

Adult Epileptologist: _____

Address: _____ phone: _____

Mental Health Provider (psychiatric and counseling)

Name: _____ specialty: _____

Address: _____ phone: _____

Name: _____ specialty: _____
Address: _____ phone: _____

Current Other Doctor/Specialists

Name: _____ specialty: _____

Address: _____ phone: _____

Name: _____ specialty: _____

Address: _____ phone: _____

Name: _____ specialty: _____

Address: _____ phone: _____

Name: _____ specialty: _____

Address: _____ phone: _____

Pharmacy: _____

Address: _____ phone: _____

Primary Medical Insurance Company _____

ID/Policy #: _____ group #: _____

Address: _____ phone: _____

Secondary Insurance Company _____

ID/Policy #: _____ group #: _____

Address: _____ phone: _____

Current Prescriptions/Medications List

Name: _____ dosage: _____

frequency: _____

Reason: _____ Time: _____

Name: _____ dosage: _____

frequency: _____

Reason: _____ Time: _____

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frequency: _____

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Reason: _____ Time: _____

Previously taken Prescriptions/Medications List

Name:_____ dosage:_____

frequency:_____

Reason:_____ Time:_____

Name:_____ dosage:_____

frequency:_____

Reason:_____ Time:_____

Name:_____ dosage:_____

frequency:_____

Reason:_____ Time:_____

Name:_____ dosage:_____

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frequency:_____

Reason:_____ Time:_____

Name:_____ dosage:_____

frequency:_____

Reason:_____ Time:_____

Name:_____ dosage:_____

frequency:_____

Reason:_____ Time:_____

Allergies:

Reactions to medications:

Vitamins/Supplements I take:

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

Current Diagnosis/Problem List:

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

Past Illnesses and/or Conditions:

<hr/>	<hr/>
<hr/>	<hr/>
<hr/>	<hr/>

Past hospitalizations (include surgeries, dates, hospitals, reason, doctors)

Dietary/Nutritional needs

Family medical history (mother, father, brother, sister, grandparents)

<hr/>	<hr/>
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Vision

Do you wear glasses? Yes _____ No _____

Doctor: _____

Address: _____ phone: _____



Medical equipment/supplies used

Equipment: _____

Supplier Name: _____

Address: _____ phone: _____

Equipment: _____

Supplier Name: _____

Address: _____ phone: _____

Additional medical equipment

Equipment: _____

Supplier Name: _____

Address: _____ phone: _____

Equipment: _____

Supplier Name: _____

Address: _____ phone: _____



Orthotics and Prosthetics

Supplier Name: _____

Address: _____ phone: _____

Supplier Name: _____

Address: _____ phone: _____

Supplier Name: _____

Address: _____ phone: _____

Supplier Name: _____

Address: _____ phone: _____

Address: _____ phone: _____

Supplier Name: _____

Address: _____ phone: _____

Seizure alert device

Type of device: _____

Special physical needs:

Transportation needs:

(transportation company/phone, family member/phone, friend/phone)

Cognitive/problem solving concerns:

Tobacco use:

Do you smoke? Yes _____ No _____ Frequency: _____

For how long? _____

Illicit drug usage: (include treatment program and dates, if any)

Yes _____ No _____ Frequency: _____

Treatment program: _____

Alcohol use and/or abuse: (include treatment program and dates, if any)

Yes _____ No _____ Frequency: _____

Treatment program: _____

Immunization Record

Immunization	Month/year

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Moving into Adulthood: Establishing Independence

a. Medical Journal

b. Seizure Information/Log



My Seizure Information

Date of first seizure: _____ **Date of diagnosis:** _____

Type(s) of seizures and brief description

Frequency of seizures per month (how often and how long do they last)

Date of last generalized seizure: _____



Current or future adult epileptologist

Name: _____

Address: _____ phone: _____

Past providers

Doctor's name: _____

Hospitals name: _____ dates: _____

Doctor's name: _____

Hospitals name: _____ dates: _____

Doctor's name: _____

Hospitals name: _____ dates: _____

Current seizure medications (names of medications, dosage, frequency, times given, oral or rectal)

Name: _____ dosage: _____

frequency: _____

Where: _____ Time: _____

Name: _____ dosage: _____

frequency: _____

Where: _____ Time: _____

Name: _____ dosage: _____

frequency: _____

Where: _____ Time: _____

Name: _____ dosage: _____

frequency: _____

Where: _____ Time: _____

Name: _____ dosage: _____

frequency: _____

Where: _____ Time: _____

Where: _____ Time: _____

Name: _____ dosage: _____

frequency: _____

Where: _____ Time: _____

Past medications and/or treatments that were NOT helpful and why

Past seizure medications that have caused MAJOR side effects

Name of medication: _____ side effect: _____

Name of medication: _____ side effect: _____

Name of medication: _____ side effect: _____

Name of medication: _____ side effect: _____

Name of medication: _____ side effect: _____

Name of medication: _____ side effect: _____

Name of medication: _____ side effect: _____

Name of medication: _____ side effect: _____

Name of medication: _____ side effect: _____

Name of medication: _____ side effect: _____

Name of medication: _____ side effect: _____

Name of medication: _____ side effect: _____

Name of medication: _____ side effect: _____

Name of medication: _____ side effect: _____

Name of medication: _____ side effect: _____

Other treatments or therapies being used

Safety precautions used

Special instructions

Special challenges



My Seizure Log

Date	Time	Duration	Type of seizure	Behavior post seizure	Injuries	Who was notified	Interventions used

Date	Time	Duration	Type of seizure	Behavior post seizure	Injuries	Who was notified	Interventions used

3

Moving into Adulthood: A Look into the Future

a. Helpful Information



Helpful Information

Useful resource for seizure tracking.
Download Seizure Tracker app

For iPhone:

- Go to App store
- Search "Seizure Tracker LLC" app
- Select "GET" to download

The screenshot shows the Mac App Store page for the "Seizure Log" app by Seizure Tracker LLC. The app is designed for iPhone, has a 4.7 rating from 89 reviews, and is free. The app icon features a red background with a white clapperboard and the text "track it!". A "View in Mac App Store" button is visible.

App Store Preview

Open the Mac App Store to buy and download apps.

Seizure Log 12+
Seizure Tracker LLC
Designed for iPhone
★★★★★ 4.7 • 89 Ratings
Free
[View in Mac App Store](#)

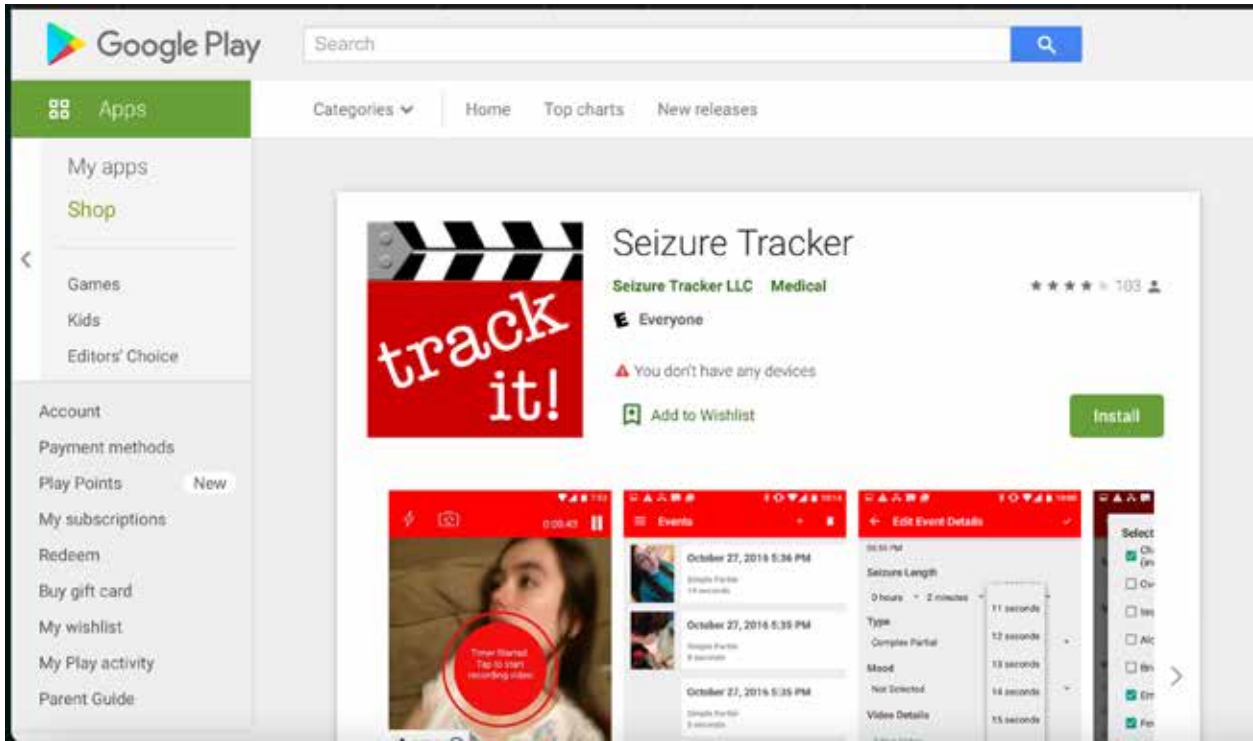
App Store Preview

Screenshots [iPhone](#) [Apple Watch](#)

The screenshots show the app's interface on an iPhone. The first screenshot shows a video recording of a person with a red overlay that says "Timer started. Tap to start recording video." The second screenshot shows the "Events" list with entries for September 2019 and August 2019. The third screenshot shows a "Sync" screen with a circular arrow icon and a "Sync" button. The fourth screenshot shows the "Rescue Meds" list with entries for September 2019 and August 2019.

For Android:

- Go to Google Play store app
- Search "Seizure Tracker LLC" app
- Select "Install" to download



- Download the seizure tracker app "EPSY"

For Iphone:

- Go to App store
- Search "EPSY" app
- Select "GET" to download

App Store Preview

Open the Mac App Store to buy and download apps.



Epsy: Seizure Log for Epilepsy (4+)

Seizure, Medications, Epilepsy

Livanova

Designed for iPhone

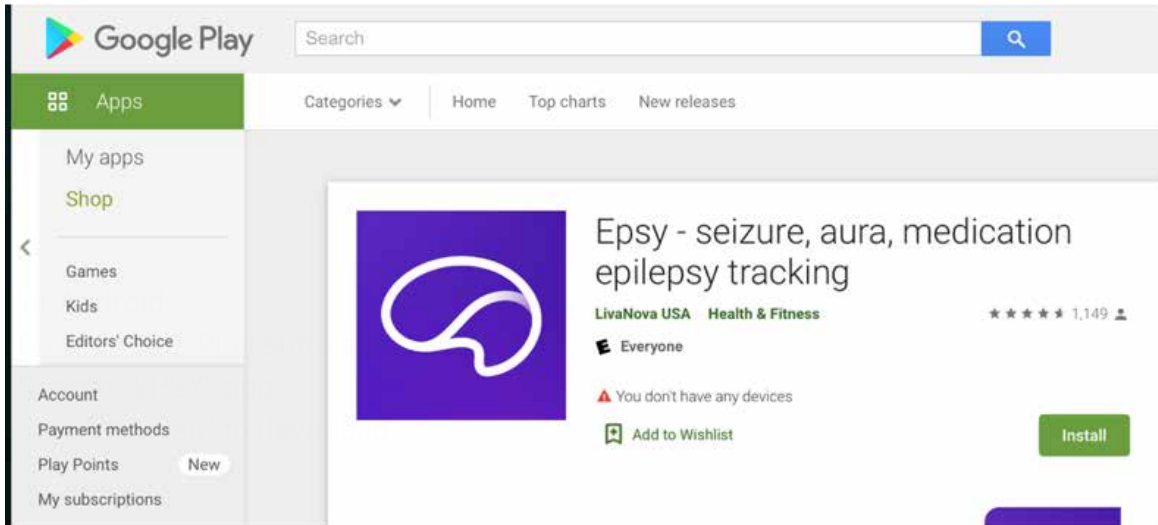
★★★★★ 4.8 • 675 Ratings

Free

[View in Mac App Store](#)

For Android:

- Go to Google Play store app
- Search "EPSY" app
- Select "Install" to download



Basic Seizure First Aid Training

By completing the course, you will be able to:

- Recognize three (3) common seizure types
- Describe three (3) basic seizure first aid steps to assist a person having a seizure
- Recognize three (3) key factors that would make a seizure a medical emergency
- Describe three (3) ways to support persons epilepsy

Register Here

Basic Seizure First Aid Training - Epilepsy Alliance Florida

How to request your medical records

Steps to obtaining your medical records:

1. Contact or visit your providers medical records department
2. Complete a medical records request form online or in person
3. Select your records



Records your provider may deny:

- Psychotherapy notes and other mental health notes that may lead to patient harm
- ER records that are specific to hospital or company procedure and not patient care
- Information involved in a lawsuit
- Records that include information about other people or a third party that may be harmed by the release of information
- Ongoing research that has not been completed
- Any records that may endanger patient safety

How long does this process take?

Providers have anywhere up to 30-60 days to process a request, but many facilities may process the request within 5-10 business days.

How much does it cost?

Please be advised to check your state's fees.

For Florida:

- **Limit on Fees Mandated by State Law**

- Yes

- **Search Fee/ Labor Charge/ Processing Charge**

- \$1.00 for each year of records requested

- **Copy Fees for First Pages**

- All pages for hospital records may not exceed \$1.00/page
- Physician records pages 1-25= \$1.00/page

- **Copy Fees for Additional Pages**

- Physician records pages 25+= \$0.50/page

- **Mailing Costs**

- Actual cost plus sales tax

- **Additional Fees and Costs**

- Labor, materials, and supply costs for x-rays and other special records.

- **Electronic Records**

- Non-paper records may not exceed \$2.00/page

- **Worker's Compensation**

- Fee rates: \$0.50/page

Video example: [How to Get Medical Records](#)

Source: <https://www.drugwatch.com/health/how-to-obtain-medical-records/>

Mental Health resources

Call 911 if you or someone you know is in immediate danger or go to your nearest emergency room.

Epilepsy Foundation

Call the toll-free helpline 1-800-332-1000; En español 1-866-748-8008
Visit the [Epilepsy Foundation's 24/7 Helpline page External](#) to learn more.

National Suicide Prevention Lifeline

Call 1-800-273-TALK (8255); En español 1-888-628-9454

Use Lifeline Chat on the web

The Lifeline is a free, confidential crisis service that is available to everyone 24 hours a day, seven days a week. The Lifeline connects people to the nearest crisis center in the Lifeline national network. These centers provide crisis counseling and mental health referrals.

Crisis Text Line

Text "HELLO" to 741741

The Crisis Text hotline is available 24 hours a day, seven days a week throughout the U.S. The Crisis Text Line serves anyone, in any type of crisis, connecting them with a crisis counselor who can provide support and information.

Disaster Distress Hotline

Call or text 1-800-985-5990

The disaster distress helpline provides immediate crisis counseling for people who are experiencing emotional distress related to any natural or human-caused disaster. The helpline is free, multilingual, confidential, and available 24 hours a day, seven days a week.

Federal Resources:

Some federal agencies offer resources for identifying health care providers and help in finding low-cost health services. These include:

- **Substance Abuse and Mental Health Services Administration (SAMHSA):** For general information on mental health and to locate treatment services in your area, call the SAMHSA Treatment Referral Helpline at 1-800-662-HELP (4357). SAMHSA also has a [Behavioral Health Treatment Locator](#) on its website that can be searched by location.
- **Health Resources and Services Administration (HRSA):** HRSA works to improve access to health care. The HRSA website has information on finding affordable healthcare, including health centers that offer care on a sliding fee scale.

- **Centers for Medicare & Medicaid Services (CMS):** CMS has information on its website about benefits and eligibility for mental health programs and how to enroll.
- **The National Library of Medicine (NLM) MedlinePlus:** NLM's website has **directories** and lists of **organizations** that can help in identifying a health practitioner.

National Agencies and Advocacy and Professional Organizations: Advocacy and professional organizations can be a good source of information when looking for a mental health provider. They often have information on finding a mental health professional on their website, and some have practitioner locators on their websites. Examples include but are not limited to:

- **Anxiety and Depression Association of America**
- **Depression and Bipolar Support Alliance**
- **Mental Health America**
- **National Alliance on Mental Illness**

State and County Agencies: The website of your state or county government may have information about health services in your area. You may be able to find this information by visiting their websites and searching for the health services department.

Insurance Companies: If you have health insurance, a representative of your insurance company will know which local providers are covered by your insurance plan. The websites of many health insurance companies have searchable databases that allow you to find a participating practitioner in your area.

University, College, or Medical Schools: Your local college, university, or medical school may offer treatment options. To find these, try searching on the website of local university health centers for their psychiatry, psychology, counseling, or social work departments.

Help for Service Members and Their Families: Current and former service members may face different mental health issues than the general public. For resources for both service members and veterans, please visit the MentalHealth.gov page **Help for Service Members and Their Families page** or the **U.S. Department of Veteran Affairs' mental health page**.

Source: https://www.nimh.nih.gov/health/find-help/#part_150430

College Resources

Scholarships

- [College Resources for Students with Disabilities the Ultimate Guide](#)
- [Disability Scholarships](#)

Nationwide Scholarship programs

American Association On Health And Disability

“Frederick J. Krause Scholarship on Health and Disability” is awarded annually to deserving college students with a disability who are pursuing undergraduate/graduate studies related to health and disability.

www.aahd.us/initiatives/scholarship-program

Federal Student Aid Information Center

Apply for federal financial aid for college or graduate school.

Washington, DC Tel: 1-800-433-3243

www.fafsa.ed.gov

FACES (Finding A Cure For Epilepsy And Seizures)

A program of NYU Langone Health, FACES provides partial financial support for the education of incoming freshmen or currently enrolled college students affected by epilepsy and seizure disorders.

faces.med.nyu.edu/events-programs/college-scholarship-program

HEATH Resource Center

Managed by The George Washington University, this center provides information on post-secondary education for students with disabilities, including information on financial aid resources. Write or telephone:

2121 K Street, N.W. Suite 220

Washington, DC 20037

www.heath.gwu.edu

Patient Advocate Foundation

“Scholarship for Survivors” program to honor these individuals by offering educational scholarships to individuals who have suffered (or are suffering) a life-threatening disease or chronic condition.

patientadvocate.org/connect-with-services/apply-for-a-scholarship

UCB Family Epilepsy Scholarship Program™

The program offers educational scholarships to people living with epilepsy, family members and caregivers to help them fulfill their dreams.

ucbepilepsyscholarship.com

Employment Resources

[Jobs and Education for People with Disabilities](#)

[Epilepsy in the Workplace and the ADA | US Equal Employment Opportunity Commission](#)



Acknowledgements

Dr. Edgar Andrade

Pediatric Epilepsy Specialty Care
Institute of Pediatric Neurosciences of Florida

Angela Miney

University of Florida Pediatric Pulmonary Center (PPC) Family Partner
Florida Family Leader Network Coordinator

Gloria Riefkohl, MD, MPH, MSHSA, FAAP

Gladys and Frederick Stewart Pediatric Care Center
Nicklaus Children's Hospital

Syndi Seinfeld, DO, FAAN

Director of Epilepsy Pediatric Neurologist and Epileptologist at Joe DiMaggio
Children's Hospital's Neuroscience Center

Kelley Avant McCallister, MPH

Epilepsy Alliance Florida Prevention & Education Intern

Credits and special thanks to Monica Gonzalez, Senior Director Programs Administration Epilepsy Alliance Florida; Judy Clauser, VP of Programs Epilepsy Alliance Florida; Dr. Zafar Qureshi MD MAHA Group; Patricia Dean, NP, Nicklaus Children's Hospital Brain Institute; Cecily Chundrlek, Youth & Family Engagement Specialist Epilepsy Alliance Florida; Diana Garcia, Data Analyst Epilepsy Alliance Florida; Janice Buelow, Project Evaluator Epilepsy Alliance Florida.

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This publication is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award funded by HRSA/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement, by HRSA/HHS, or the U.S. Government.