

Mental Health Support for Epilepsy Surgery Families

Families often reach out to us with questions like:

- Can you recommend a therapist for me as a caregiver?
- Do you know therapists who understand depression or anxiety in teens or adults who have had epilepsy surgery?
- How do I support siblings who have lived through years of seizures, hospitalizations, and uncertainty?

If you are asking these questions, you are not alone. Living with epilepsy and navigating brain surgery can affect the mental health of the entire family. Parents, siblings, and the child or young adult with epilepsy may all carry stress, fear, grief, or exhaustion long after the medical crisis has passed. This document is meant to help you find support that fits your family and your situation. It brings together resources families have found helpful, including clinicians, therapy options, and community support.

Understanding Medical Trauma

Medical trauma is more common than many families realize. Many parents and children experience trauma-related symptoms after serious or prolonged medical events. It does not always look the same. It can show up as anxiety, irritability, emotional numbness, trouble sleeping, constant worry, or feeling shut down. These reactions are often dismissed or explained away as “just part of caregiving.”

They are not personal failures. They are common responses to chronic stress, uncertainty, and fear. Trauma-informed care focuses on emotional safety, trust, and healing. Caregivers often put all their energy into supporting their child, but mental health matters, too, for the entire family.

Stress does not always end after surgery. For some families, it increases, especially when recovery is complicated or outcomes differ from what they hoped for. Parents, siblings, and even grandparents can feel the long-term effects of years of caregiving.

Learn More about Medical Trauma:

- [Coping with Medical Trauma](#): a blog post about medical trauma (Pediatric Epilepsy Surgery Alliance)
- [What is Medical Trauma?](#) A fact sheet that explains signs, symptoms, and support strategies in plain language. (International Society for Traumatic Stress Studies)

Emergency Mental Health Support

If you or someone in your family is in immediate distress, please reach out for help right away:

- [988 Suicide & Crisis Lifeline](#): (US): Dial or Text 988 (English & Spanish)
- [Crisis Text Line](#): Text CONNECT to 741741 (Free, 24/7 support in the US and Canada)
- [SAMHSA Helpline](#): 1-800-662-HELP for mental health and substance use support.
- [NAMI HelpLine](#): 1-800-950-NAMI (6264) for peer support and guidance.
- [Talk Suicide Canada](#): 1-833-456-4566.

Where to Start with Therapy

A therapist does not need to be an expert in epilepsy surgery to be helpful. What matters most is that they understand trauma, are open to learning, and are comfortable supporting families affected by medical complexity.

Therapy is not about reliving everything you have been through. For many people, it focuses on recognizing stress responses, calming the nervous system, and building tools to manage anxiety, grief, or burnout. When speaking with a potential therapist, you may want to ask:

- Are you trained in trauma-informed care?

- Do you have experience working with families affected by complex medical or neurological conditions?
- Are you open to learning about our child's medical history?

Mental Health Care for Children, Teens, and Adults With Epilepsy

Caregivers often tell us that finding mental health care feels harder when epilepsy, surgery, and emotional health intersect. Families frequently ask how to find support for a child or adult child with epilepsy or a history of epilepsy surgery who is experiencing depression, anxiety, or other mental health challenges.

Some individuals also have learning differences, intellectual or developmental disabilities, or borderline cognitive profiles. Others do not. Many share a complex neurological history that can affect mood, behavior, communication, and emotional regulation.

Mental health concerns are common in people with epilepsy, but they are sometimes missed or minimized. Mood changes, withdrawal, irritability, or behavior changes may be attributed only to epilepsy, medications, or cognitive differences rather than recognized as treatable mental health conditions.

Mental health providers who tend to be a good fit often:

- Are comfortable working with neurological conditions or brain injury histories
- Understand how epilepsy, medications, and surgery can affect mood and behavior
- Adapt therapy to match communication and cognitive needs
- Involve caregivers when appropriate, especially for teens and adults who still rely on family support

This can be especially important during transitions such as adolescence, returning to school, starting work, or adjusting to life after surgery. If you are seeking therapy for a child or adult child with epilepsy, it can help to ask providers directly about their experience with neurological conditions and their willingness to adapt treatment rather than assuming a standard mental health approach will be a good fit.

Common Therapy Approaches for Medical Trauma

The following approaches are commonly used to support caregivers, siblings, and individuals with epilepsy:

[Accelerated Resolution Therapy \(ART\)](#): A structured, gentle therapy that uses eye movements to reduce distress linked to traumatic memories. Often helpful for anxiety, nightmares, and sleep disruption. [ART Therapist Directory](#)

[EMDR \(Eye Movement Desensitization and Reprocessing\)](#): Uses bilateral stimulation to help process traumatic experiences. Supported by strong evidence for PTSD, anxiety, and depression. [EMDR International Association Therapist Finder](#)

Trauma-Informed Therapy: An approach rather than a single method. Focuses on emotional safety, trust, and the avoidance of re-traumatization.

Somatic Therapies: Body-based therapies, such as [Somatic Experiencing](#), that focus on calming the nervous system and addressing how trauma is held in the body. [Somatic Experiencing Practitioner Directory](#)

Cognitive-Based Therapies

- **Cognitive Behavioral Therapy (CBT)** reframes unhelpful thinking.
- **Trauma-Focused CBT (TF-CBT)** is a trauma-specific CBT approach for children and teens.
- **Cognitive Processing Therapy (CPT)** helps process and reframe trauma-related thoughts.
- **Prolonged Exposure Therapy (PE)** supports healing through gradual exposure to trauma-related situations or memories.

Some people benefit from a **combination** of *talk-based* and *body-based* approaches.

How to Find a Therapist

The following directories allow you to search by location, insurance, or therapy type:

- [Psychology Today – Therapist Finder](#)
- [Accelerated Resolution Therapy Directory](#)
- Amanda Griffith-Atkins has a wonderful resource listing professionals in the Americas and the UK: [Therapist Directory – Amanda Griffith-Atkins](#)
- [BetterHelp](#) matches you with a licensed therapist based on your location and preferences.
- [CBT Therapist Finder](#)
- [EMDR International Association](#)
- [The National Child Traumatic Stress Network](#) helps families find trauma-informed therapists and services. [Get Help Now](#)
- [Open Path Psychotherapy Collective](#) offers online or in-person therapy with a vetted therapist for \$40–70 per session, plus a one-time membership fee.
- [Rula](#) allows you to search for providers by insurance type, therapy focus, and more.
- [Somatic Experiencing Directory](#)
- [TF-CBT Directory](#)

You can also ask your primary care provider, neurologist, or epilepsy care team for referrals.

Therapists Familiar with Epilepsy Families

The following therapists have experience supporting families in our community:

Dr. Annelise Cunningham • Otterly Connected Psychological Services
Virtual for PSYPACT states | In-person in Charlotte, NC
otterly-connected.com
drc@otterly-connected.com | (773) 531-8738

Dr. Brynn Huyssen • Brookside Behavioral Wellness
Dr. Huyssen is the parent of a child who had epilepsy surgery.
Virtual for PSYPACT states | In-person in Northern VA
brooksidebehavioral.com
brynn@brooksidebehavioral.com | (703) 495-3999

Disclaimer: This list is provided for informational purposes only. The Pediatric Epilepsy Surgery Alliance does not endorse or recommend any specific provider. Families are encouraged to research and evaluate providers based on individual needs.

Coaching & Community-Based Support

Some families benefit from support outside of traditional therapy:

- [Alongside Network](#)'s Wellbeing Groups are research-based and designed for parents/caregivers of kids who have had significant medical experiences. Groups focus on validating experiences, building community, and increasing coping skills. They offer groups specifically for TBI / Medical Complexity parents/caregivers. All groups are six-weeks long, 90 minutes once per week, and offered at no cost to families. Here's the link to express interest and learn more: [Wellbeing Group Sign-up — Alongside Network](#)
- [Courageous Parents Network](#) offers parent-focused education and support for parents of children with medical complexity.
- [Eileen Devine, LCSW](#), offers brain-based parenting coaching, especially for caregivers experiencing chronic stress, behavioral challenges, or trauma.

- [HOBSCOTCH Program](#): Cognitive coaching for adults with epilepsy (or a history of epilepsy) to improve memory, organization, and confidence.
- [National Alliance on Mental Illness \(NAMI\)](#) offers peer-led support groups and education.
- [Pediatric Epilepsy Surgery Alliance](#) offers trained [Parent Support Navigators](#) who have been through epilepsy surgery. Peer support is available in multiple languages.
- [We Are Brave Together](#) is a supportive community specifically for moms raising children with disabilities or other unique needs. It provides a safe space where these mothers can find connection and strength through their shared experiences.

Online and in-person groups offer emotional support and practical advice (available through children's hospitals, local disability organizations, and similar organizations). Facebook groups or online support groups for specific conditions (epilepsy, epilepsy surgery, stroke, preemies, bereaved families, etc.) provide education and community.

Managing the Toll of Caregiving

Even after successful surgery, stress doesn't just disappear. Research shows that **parenting stress can continue or even increase** after surgery, especially if families had high hopes for full recovery. Children may still struggle with learning, fatigue, behavior, or social connections. Parents may feel depleted or uncertain about how to move forward.

That's why we partnered with several rare epilepsy organizations to offer a 3-part video series on managing the toll of caregiver trauma. These videos are not a substitute for therapy, but they are a starting point for naming what many of us experience and opening the door to healing.

- [Part 1 – The Toll of Caregiver Trauma](#)
- [Part 2 – Reframing Expectations and Coping Tools](#)
- [Part 3 – Healing and Moving Forward](#)

With insights from parent coach **Eileen Devine, LCSW**, and stories from real families, this series is a powerful starting point for validation and connection.

VIDEO: [Managing Post-Traumatic Stress Before and After Pediatric Epilepsy Surgery](#)

Dr. Brynn Huysen is a clinical psychologist specializing in the assessment and treatment of post-traumatic stress. She has over 15 years of experience providing evidence-based treatments for trauma to adults and adolescents in hospitals and outpatient clinics. Dr. Huysen has traveled extensively to train doctors and nurses around the world on how to support patients following trauma exposure and grief, and how to promote resilience. She also serves as a consultant to organizations that are working to become more trauma-informed. Dr. Huysen's most important role, however, is being a mom to a child with catastrophic epilepsy. Through her son's many hospitalizations and brain surgeries to stop seizures, she has had to implement the methods she teaches others, with unique and personal insight into the psychological and emotional impact of epilepsy surgery on children and their family members. Supplemental materials provided by Dr. Huysen can be found here: bit.ly/4f9mQPW

VIDEO: [Coping Strategies](#)

In this Power Hour, Eileen Devine draws on her experience as a Clinical Social Worker and her work with parents of children with a variety of brain-based differences to teach parents in these situations ways to manage the stress that comes with it. She explains to these parents that they are not alone on this journey, and that it is essential to worry not only about their children but also about themselves. (Eileen Devine, LCSW, and Founder of the [Brain First Parenting Program](#) and [The Resilience Room](#) for the [Pediatric Epilepsy Surgery Alliance](#))

VIDEO: [Making It to Monday – A Conversation on Medical Trauma, Resilience, and Community](#)

This powerful discussion explores how trauma shows up in families facing neurological illness and what healing can look like. Featuring personal stories, professional insights, and recovery tools, this Power Hour is a must-watch for caregivers and clinicians alike.

Additional resources:

- Coping Skills and Strategies for Managing the Stress of Special Needs Parenting (Jessica Sen, M.A.Ed., LPCC-S, CCHMC, and Holly Chalkwater, M.A., LPCC-S, Grow Well Cleveland for the [Pediatric Epilepsy Surgery Alliance](#), 2019)

- [Decision-Making for Parents of Medically Complex Children](#): Making constant decisions can feel overwhelming. This talk explores how understanding your own decision style and having provider support can reduce stress. Also introduces NeuroJourney, a tool to guide families facing severe neurological conditions. (Jennifer Siedman, MEd, Director of Community Engagement at [Courageous Parents Network](#) for the [Pediatric Epilepsy Surgery Alliance](#))
- [Depression in Parents of Children with Developmental Disabilities](#): Highlights the emotional toll on caregivers and ways to offer better mental health support. (CHOP Policy Lab)
- [Exploring the Meaning of Self-Compassion and Its Importance](#) (Self Compassion Institute, Dr. Kristin Neff)
- [MindBridge](#) offers a portal for young adults (ages 18–24) to help them find the right support as they move into adulthood. They are also working to fill a gap in therapy options for children who have both developmental disabilities and mental health needs.
- [Post-Traumatic Stress Disorder \(PTSD\) in Parents of Medically Fragile Children](#): blog post (Cincinnati Children's)
- The [Rare Life Podcast](#) explores real-life parenting and trauma
 - [Epilepsy | Unpredictability + Emotional Toll It Takes on Parents](#)
 - [EMDR Trauma Therapy](#)
 - [Medical Parent Trauma | Dealing with Triggers + Ongoing Trauma](#)
 - [Our Children's Medical Trauma](#)
- [Taking Care of Yourself | NAMI](#) (National Alliance of Mental Illness)
- [Understanding and Addressing Pediatric Medical Trauma](#): Dr. Meghan Marsac and Melissa Hogan explain how trauma affects both children and caregivers and share tips from their book, [Afraid of the Doctor](#), to help families cope and heal. ([Courageous Parents Network](#))

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