

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?*
- *How do I navigate grief and loss?*

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.

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.

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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)

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.

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?*
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- *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?*
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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/your child's primary care provider, neurologist, or epilepsy care team for referrals.

Knowledgeable Therapists

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](https://www.otterly-connected.com)
drc@otterly-connected.com | (773) 531-8738

Dr. Polina Eidelman • Redwood Center for Cognitive Behavior Therapy and Research
San Diego and Telemedicine throughout CA
Dr. Eidelman is the parent of a child who had epilepsy surgery.
[Polina Eidelman, Ph.D. \(San Diego; Telehealth\)](https://www.polinaeidelman.com)
eidelman@redwoodcbt.com | 858-926-7333

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](https://www.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.

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.

Other helpful videos:

- [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 that we are not alone on this journey, and that it is essential to worry not only about our children but also about ourselves.
- [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.
- [Managing Post-Traumatic Stress Before and After Pediatric Epilepsy Surgery](#): **Dr. Brynn Huyssen** is a clinical psychologist with over 15 years of experience in trauma treatment and international clinician training. As the mother of a child who underwent brain surgery for catastrophic epilepsy, Dr. Huyssen combines professional expertise with personal insight to guide families through medical trauma, grief, and emotional recovery. Supplemental materials provided by Dr. Huyssen can be found here: bit.ly/4f9mQPW

Peer support & community connection

Connecting with other caregivers through structured support groups, peer networks, and dedicated organizations helps reduce isolation and build a community of shared understanding.

- [Pediatric Epilepsy Surgery Alliance](#) offers trained [Parent Support Navigators](#) who have personally navigated the epilepsy surgery journey with their child. They provide one-on-one peer support in multiple languages.
- [Alongside Network](#) offers research-based Wellbeing Groups for parents/caregivers of kids who have had significant medical experiences, focusing on validating experiences, building community, and increasing coping skills. They offer groups specifically for TBI or Medical Complexity. ([Wellbeing Group Sign-up](#))
- [Courageous Parents Network](#) offers parent-focused education and support for parents of children with medical complexity.
- [Eileen Devine, LCSW](#), Founder of the [Brain First Parenting Program](#) and [The Resilience Room](#), offers brain-based parent coaching and specialized support for caregivers navigating chronic stress, trauma, or complex neurobehavioral challenges.
- [Love Your Brain](#) offers [caregiver retreats](#) for those caring for a child or adult living with brain injury.
- [National Alliance on Mental Illness \(NAMI\)](#) offers free, peer-led support groups and educational programs for individuals and family members navigating mental health challenges.
- [Raregivers](#): A nonprofit that supports the mental health of rare disease families through virtual support groups, gentle on-demand workout videos, and research-backed emotional guidebooks. Their [YouTube channel](#) also hosts dedicated conversation series for both moms and dads to help caregivers feel less alone.
- [We Are Brave Together](#) is a supportive community specifically for moms raising children with disabilities or other unique needs.
- *Hospital & condition-specific networks*: Local children's hospitals, disability organizations, and online caregiver groups (focusing on epilepsy, surgery recovery, stroke, or bereavement) offer practical guidance and a sense of community.

Self-Care Strategies

Practical, evidence-based coping practices designed to help caregivers process stress, release tension, and maintain emotional wellbeing:

- **Self-compassion & mindfulness:** Free guided audio practices and exercises can help navigate acute stress, lower self-criticism, and process feelings of caregiver guilt. (see [Exploring the Meaning of Self-Compassion and Its Importance](#) and [Self-Compassion Practices & Resources](#) from the Self Compassion Institute, Dr. Kristin Neff)
- **Nervous system grounding:** Practical breathing techniques (such as 4-7-8 or box breathing) and sensory exercises (like 5-4-3-2-1 grounding) to help down-regulate the nervous system during high-stress medical events. (see [13 Grounding Techniques To Help Calm Anxiety](#) – Cleveland Clinic Health Essentials)
- **Caregiver rest & boundary setting:** Practical tools for setting emotional boundaries, managing caregiver burnout, and scheduling brief, intentional 5- to 10-minute mental breaks throughout the day. (see [Understanding and Managing Caregiver Stress Syndrome](#), Caregiver Action Network and [Taking Care of Yourself](#), National Alliance of Mental Illness)
- **Somatic & physical release:** Gentle physical movements, restorative stretching, and progressive muscle relaxation to help discharge stored stress and physical tension from the body. (see [Somatic Self Care](#) – Johns Hopkins Medicine, Office of Well-Being)
- **Journaling & emotional processing:** Expressive writing and bullet journaling to track emotions, externalize overwhelming thoughts, and organize questions for the medical team. (see [The Power of Journaling: What Science Says About the Benefits for Mental Health and Well-Being](#), The Child Mind Institute)

Bereavement resources

Support for grieving children:

- [10 Things Grieving Children Want You to Know:](#) A quick guide with key tips on how to best comfort and support a child who is mourning.

- [Art with Heart](#): Uses creative writing and art books to help kids and teens express feelings and heal after a difficult loss.
- [The Dougy Center](#): Offers free grief support groups, resources, and a [program finder](#) to help you locate local support for your child.
- [The Eluna Network](#): Provides a [Resource Center](#) for parents and runs Camp Erin, a free, fun summer camp designed for grieving children and teens.
- [Helping Bereaved Siblings Heal](#): A helpful article explaining what children feel when they lose a brother or sister, and how parents can guide them through it.

Support for grieving adults:

- [The Center for Loss & Life Transition](#): Offers articles and advice to help adults understand their own grief or learn how to support a grieving child.
- [The Child Neurology Foundation](#): Offers the [Willow and Wind](#) community, which connects families who have lost a child to a neurological condition for mutual support.
- [The Compassionate Friends](#): Provides free, local support chapters across the country for parents and siblings who are grieving the loss of a child.
- [Courageous Parents Network](#): Offers videos, podcasts, and guides on [Coping with Loss](#) for families who have lost a child to a serious illness.
- [DannyDid Foundation](#): Provides a dedicated [Bereavement Support](#) network and counseling resources for families who have lost a loved one to epilepsy.
- [Electric Love](#) holds a retreat for moms who have experienced loss.
- [The Epilepsy Foundation](#): Offers a specialized [Support for Bereaved](#) page with grief resources and guidance for families mourning an epilepsy-related loss.
- [The MISS Foundation](#): Provides online forums, local support groups, and mentor programs specifically for parents and grandparents mourning the death of a child.
- [Partners Against Mortality in Epilepsy](#): Connects grieving families with specialized [Bereavement Resources](#) and supportive [Family Organizations](#) in the epilepsy community.
- [SUDEP Action](#) (UK): Offers a dedicated hotline, [Bereavement Support](#), and clear guides on [Understanding grief](#) for families who have lost someone to sudden unexpected death in epilepsy.

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)
- [HOBSCOTCH Program](#): Cognitive coaching for adults with epilepsy (or a history of epilepsy) to improve memory, organization, and confidence.
- [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](#)
- [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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