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# Parent Support Program

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## About Our Program

It's no surprise that research shows that mothers of children with drug-resistant seizures experience high levels of stress and isolation. Children with drug-resistant seizures are at great risk of mood and behavioral problems as well as sleep disorders, which puts stress on the parent/child relationship. Caring for a child with epilepsy often makes spending time with friends and family very difficult, and may require one parent to abandon their own career and interests, all of which leads to isolation. Family members, such as grandparents, need information and support, too.

For many families, stress doesn't magically go away even after successful epilepsy surgery, especially if the child is exhibiting behavioral challenges or is older when they had surgery. It may take a few years for the stress to go away. The stress and isolation can feel suffocating at times, especially when no one understands what you're going through.

If your child is anywhere on the epilepsy surgery journey, you know that it can be an incredibly stressful and isolating experience to parent a child with drug-resistant seizures.

*Caregivers and parents find it very helpful to connect with other parents who are on the same journey. Our parent supporters share their personal experiences, answer questions, and provide self-help strategies. We provide community and a chance for parents to talk to someone "who gets it."*

## **What are the goals of the program?**

Our Parent Support Program is intended to improve family quality of life at any point on the epilepsy surgery journey by providing evidence-based information, emotional support, and personal empowerment.

The specific goals of this program are to:

- increase knowledge of surgical evaluation, treatment options, education rights, and support services throughout the lifespan;
- remove information barriers to care; and,
- reduce feelings of isolation.

When met, these goals promote full and meaningful participation in shared decision-making.

## **What is the role of a parent supporter?**

- helping the parent/caregiver manage grief, isolation, fear, misconceptions, expectations, and increase emotional well-being and sense of purpose;
- helping the family navigate the healthcare system and learn about their child's epilepsy, underlying condition(s), and relevant surgical options;
- providing evidence-based and unbiased information;
- ensuring that information is accessible to families, with consideration for racial, ethnic, language, education, and socioeconomic barriers;
- helping the caregiver identify resources available in their community;
- coaching families as they navigate complex systems;
- promoting effective communication and partnership with healthcare, education, service agencies, and other professionals to ensure collaborative shared decision-making;
- imparting compassionate relational support from an experienced parent to empower the caregiver or family member;
- enabling caregivers to candidly share fears and worries; and

- offering ongoing support reflecting the lifelong impact of epilepsy surgery on the entire family.

## **Qualities and Prerequisites**

Parent supporters are volunteers who:

- are the parent or primary caregiver of a child who has had epilepsy surgery (at least one year out from surgery); grandparents who seek to provide parent support to other grandparents will be considered as well;
- are out of the “surviving” stage of the Four Stages of Adaptation (see below);
- are ready to “pay it forward”;
- have sufficient time and bandwidth to provide parent support;
- consent to the application and training process (see below);
- commit to the Pediatric Epilepsy Surgery Alliance’s Parent Support Program rules and standards as outlined in this document;
- collaborate with the Pediatric Epilepsy Surgery Alliance staff, other parent supporters, and partners to assist individuals and/or families in reaching their goals;
- understand the purpose and limitations of the parent supporter role; and,
- are resourceful, flexible, non-judgmental, open-minded, empathetic, respectful, honest, hopeful, and encouraging.

*Being a parent supporter is hard work;  
it can be emotionally draining.*

*Your primary motive for joining this program  
must be to provide support to someone else.*

Parent Supporters are NOT those who:

- want to convince others that their way is right;
- are seeking personal gain, comfort, status, or validation through the Program;
- intend to offer legal or medical advice; or,

- Intend to advocate for or on behalf of the parent.

The Pediatric Epilepsy Surgery Alliance reserves the right to reject any applicant at its sole and absolute discretion.

## **Training Requirements**

Our volunteer parent support specialists are trained in evidence-based peer support practices to help parents anywhere on their child's epilepsy surgery journey and receive certification at the end of their training.

Approximately twenty hours of training in evidence-based core competencies are required as follows:

### **Parent support best practices**

Parent to Parent USA is a national non-profit organization whose mission is to promote access and quality in parent-to-parent support for all families who have children or adolescents with special health needs, mental health issues, or disabilities.

Parent to Parent's virtual training includes:

- an overview of the parent support program: how to handle referrals, matching, follow-up, and evaluation processes;
- setting expectations;
- active listening and communication skills;
- self-reflection and self-awareness;
- role-play;
- adjustment and adaptation processes;
- cultural diversity;
- connecting to national, state, and community resources;
- positive philosophy;
- advocacy;

- leadership; and,
- confidentiality.

## The Four Stages of Adaptation

All parent supporters must understand the Four Stages of Adaptation in special needs parenting, be able to identify where the matched parent is on their own journey in adaptation, and meet parents “where they are” as discussed in *Nobody’s Perfect: Living and Growing with Children Who Have Special Needs* by Nancy S. Miller.

The stages can be cyclical and you can be in more than one stage at a time or jump to different stages unexpectedly or when things change in your child’s health.

*There is no right or wrong way to go through each stage of adaptation. Every journey is different with its own set of unique circumstances. Your role as a parent supporter is not to move a parent into another stage; your role is to meet the parent where they are with empathy and grace.*

A very brief overview of the stages are:

- Stage 1: Surviving: “Surviving is what you do to keep going when you feel completely overwhelmed because something totally out of your control has taken away your child’s equal chance at life.”\*
  - Coping: just getting by, they may feel like they are underwater; they can’t stop crying; they can’t process; they are suffering.

- Reacting: draining and exhausting. symptoms of shock and stress: self-doubt, denial, anxiety (I can't handle this), fear (fight or flight)
- **Stage 2: Searching:** moving forward from the reactive phase and beginning to search for answers, therapy, treatments, etc. Caregivers experience outer searching and inner searching.
- **Stage 3: Settling In:** accepting things as they are; moving beyond the intense emotions of the Surviving stage or the anxiety and panic of the Searching stage.
- **Stage 4: Separating** – “Separating includes both emotional separation between you and your child, and physical separation, which may happen earlier or later than typical for children who do not have a disability. When Separating becomes a focus, there is an increased emphasis on teaching your child skills for community living and on preparing yourself to let go.”<sup>1</sup>

## Epilepsy self-management training

Evidence-based [epilepsy self-management training](#) from the [Managing Epilepsy Well Network](#). This training is generously provided at no charge by Dr. Elaine Kirakopoulos from the Dartmouth-Hitchcock Epilepsy Center, a coordinating center for the Managing Epilepsy Well Network (MEW). The Managing Epilepsy Well Network, a multi-state initiative funded by the Centers for Disease Control and Prevention, works to develop, scientifically test, and then share interventions and self-management tools for people with epilepsy. Even after epilepsy surgery, many patients continue to have seizures and take seizure medications; therefore, understanding these areas is essential.

This overview training helps participants understand:

- epilepsy, seizures, and how epilepsy is treated;
- current terms for the most common types of seizures and how to describe epilepsy;
- common morbidities in epilepsy;
- physical, mental, and psychosocial challenges associated with living with epilepsy;

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<sup>1</sup> <https://www.parentcompanion.org/article/the-4-stages-of-adaptation-stage-1-surviving>

- the benefits of epilepsy self-management and pathways for referral to a self-management program;
- key epilepsy self-management domains to help people control their seizures, prevent injuries, make healthy lifestyle choices, and improve quality of life;
- seizure first-aid (understand rescue meds, requirements of schools and workplaces, seizure action plans); and
- ways to provide resources and connect patients with assistance available to people living with epilepsy.

## **The Pediatric Epilepsy Surgery Journey**

Lastly, parent supporters must review and understand epilepsy surgery as covered in our 9-part webinar series "[Let's Talk About Epilepsy Surgery.](#)"

This series provides a detailed overview of the powerful barriers to a prompt epilepsy surgery referral, the different types of epilepsies, epilepsy surgeries, devices, tests and scans, and considerations for decision making. This knowledge is essential for parent supporters to understand many options as they are counseling families who may have had a surgery different than the one their child had.

Note that the role of the parent supporter in the surgical selection process is mainly managing expectations and supporting them through the decision-making process without making the decision for them.