



Supporting Siblings Through the Epilepsy Surgery Journey

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The sibling
relationship is
unique in that
it lasts the
longest of all
human
relationships.

(Cicirelli, 1995)



Epilepsy Affects the Whole Family

- Unpredictability of seizures
- Risk of injury and medical emergencies
- Social stigma and misunderstanding
- Repeated hospitalizations and procedures
- Lasting disabilities / ongoing care needs
- Caregiver stress and financial challenges
- Stress often continues after surgery

What Siblings Are Really Experiencing

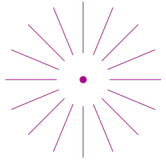
- Fear and anxiety around seizures and procedures
- Jealousy over time and attention
- Guilt for being healthy
- Confusion about epilepsy and surgery
- Social isolation or embarrassment



this. is. trauma.

(Kazak et al., 2006)





Traumatic Stress Reactions

- Nightmares or intrusive memories
- Avoiding thinking/talking about it
- Anxiety / Irritability
- Somatic complaints
- Withdrawal or emotional numbing
- Feeling jumpy or easily startled
- Difficulty sleeping / concentrating
- Fatigue
- Hypervigilance
- New fears related to event
- Change in appetite
- Isolating at home or at school

(Bailey et al., 2020)



What Helps

- Name and normalize
- Help them make sense of what happened.
- Offer predictable routines
- Seek extra help if distress continues

Sibling Support Pilot & SibShops

- PESA's sibling support group (pilot project)
- Hosted by a trained **SibShops** facilitator
- Siblings met regularly to:
 - Share experiences
 - Learn coping skills
 - Realize they are not alone
- **SibShops** is a fun, peer-based space for siblings to:
 - Play, connect, and talk
 - Learn about their sibling's condition
 - Express feelings in a safe, supported environment





Key Themes from the Sibling Pilot

- Communicating with parents
- Wanting to be involved and in the know
- Helping out at home
- Learning life skills earlier than peers
- Navigating judgment and bullying
- Loneliness and feeling different
- Fears and worries about their sibling
- Building and repairing the relationship with their sibling

the “glass child”

(Hames & Appleton 2009)



Development Matters: Young Children

- Distress shown through behavior
- Regression, clinginess, new fears
- Somatic complaints
- Acting out or “perfect child” behavior

What they need:

- Simple explanations, reassurance, 1:1 time





Development Matters: School-Age Children

- Embarrassment or over-protectiveness
- Noticing different rules
- Minimizing own achievements

What they need:

- Language for peers, validation, celebration of their successes

Development Matters: Adolescents & Young Adults

- Future worries: What will happen to my sibling?
- Guilt about independence and their own life
- Family responsibility vs. personal identity

What they need:

- Inclusion in real conversations with honest information and space for autonomy





When Siblings Have Disabilities Too

Common experiences:

- Comparison – “Who has it harder”
- Feeling invisible
- Pressure to minimize their own needs

What they need:

- Acknowledgment that their challenges are real
- Opportunities to be seen for who they are, not just as “the sibling of...”
- Inclusion in family conversations in accessible ways

The Strengths We Often Overlook

- Deep empathy and emotional insight
- Flexibility and adaptability
- Strong sense of justice and advocacy
- Lifelong companions and allies
- Pride in watching their sibling recover and grow

(Kroner et al., 2018)





What Siblings Need Most

- Honest, age-appropriate communication
- Validation of their feelings
- Inclusion – with clear boundaries
- Protected space to be a child

(Meyer & Vadasy, 2008; Haukeland et al., 2020)



The Lifelong Sibling Bond

- Childhood companions → adolescent witnesses → adult partners
- Future roles: health advocates, caregivers, decision-makers
- Supporting siblings now strengthens that future relationship





Parent Panel

Hear from families with lived experience:

- Balancing multiple children
- Making space for siblings
- What worked, and what didn't