

# Psychosocial Care of Hemispherectomy Families

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## Preparing, Adapting, and Thriving Together

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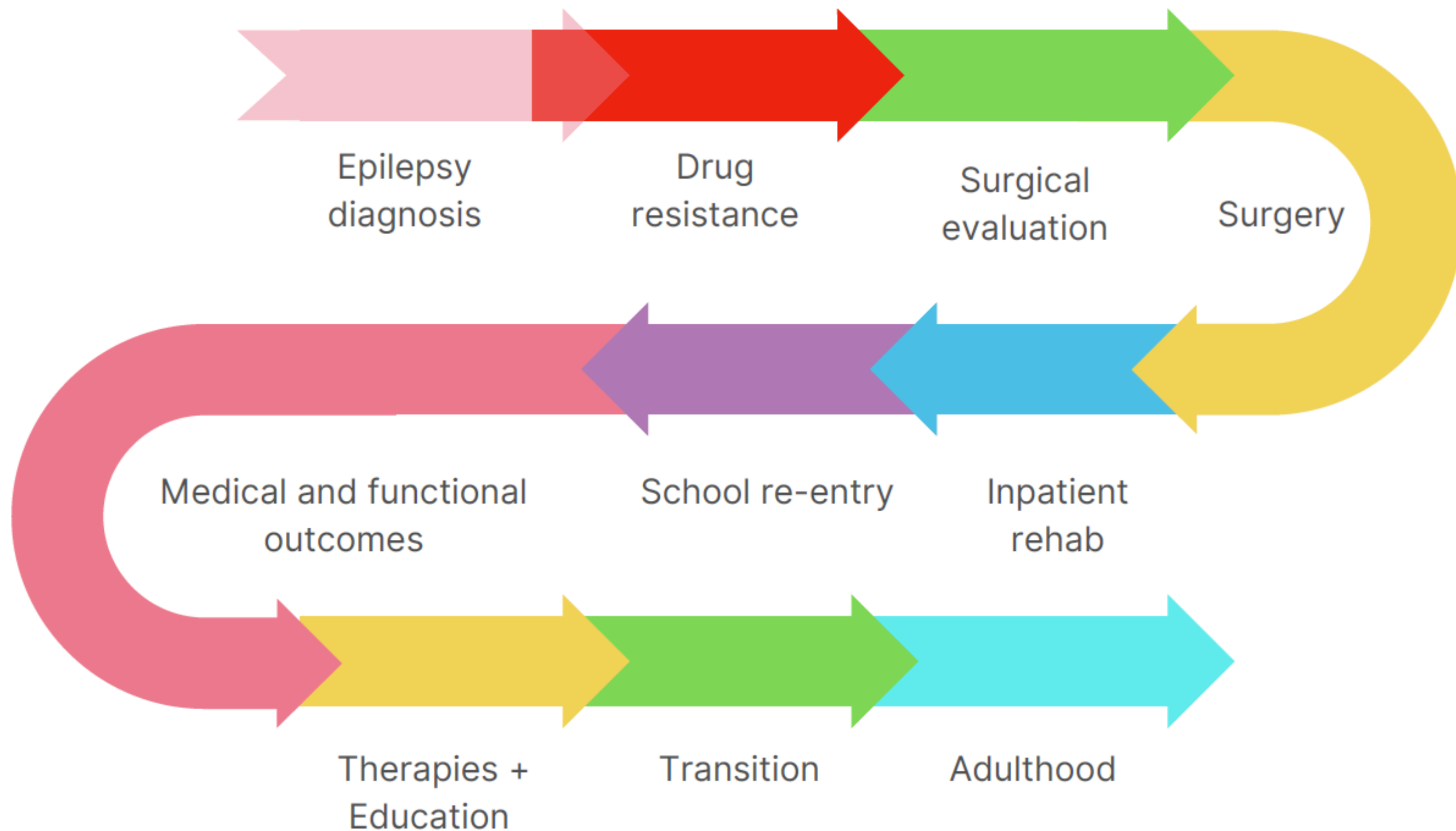
## **Our mission.**

We help children reach their full potential after surgery where part of the brain is removed, disconnected, destroyed, or stimulated to stop seizures by inspiring and funding research, providing emotional and financial support, and empowering families with research-based information and programs.

## **Our vision.**

A world where all children after epilepsy surgery have the opportunity for a high quality of life, including an appropriate education, gainful employment, meaningful social opportunities, and good health to the maximum extent possible regardless of where they are on the spectrum of outcomes.

# Pediatric Epilepsy Surgery Journey





# What we'll cover today

Preparing for surgery as a family

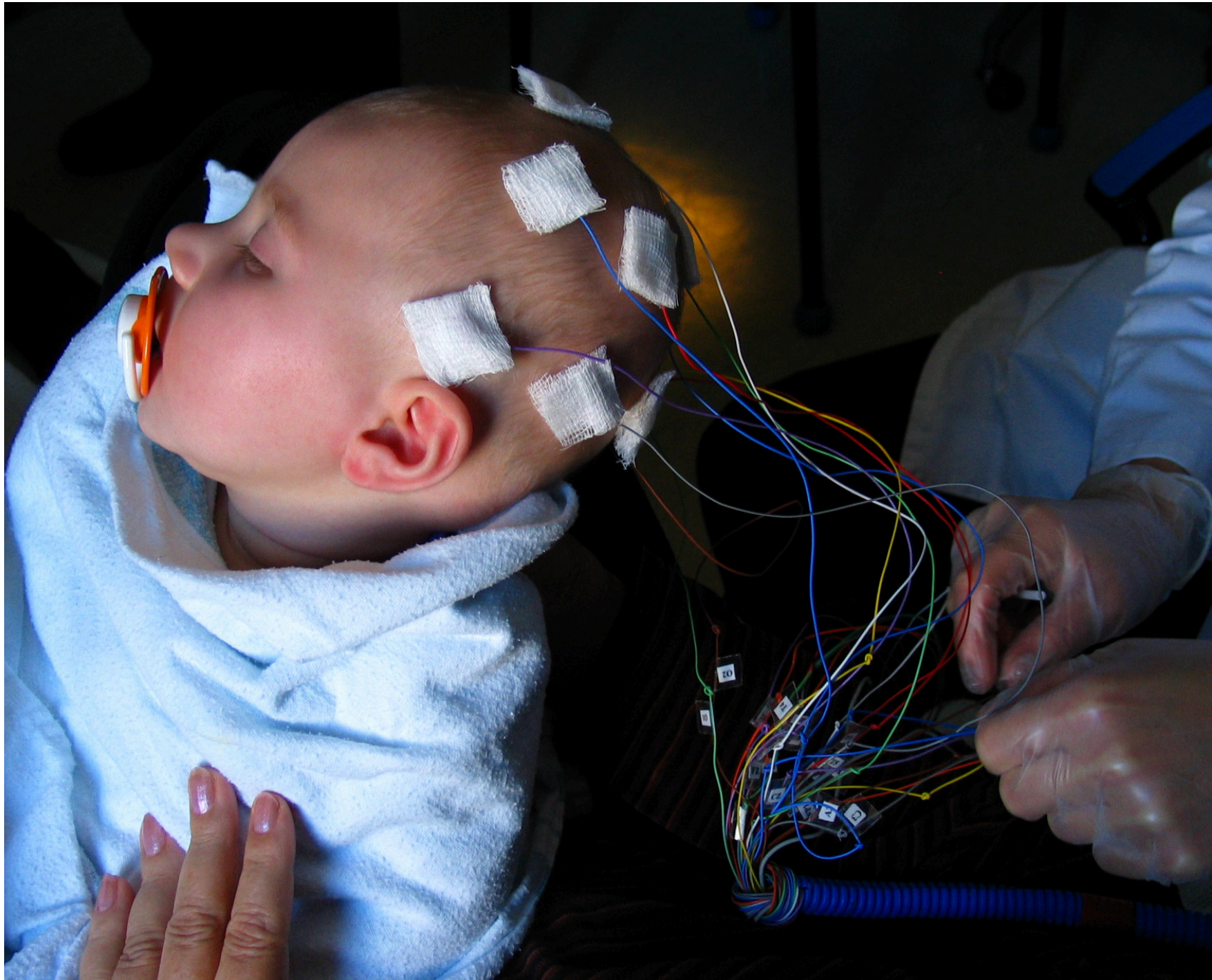
Adapting post-surgery

Thriving together in the long run





# Bennett's story







**Recovery takes time—  
but hope is real**







# Hemispherectomy: More Than Seizure Control

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- Lifesaving, life-changing
- Whole-child and family impact





# Why Psychosocial Care Matters

Psychosocial care refers to the support and interventions that address the psychological, social, and emotional well-being of individuals and their families

- Emotional needs are real
- Early support = better outcomes
- Support for the whole family
- Builds resilience



# Preparing for Surgery

*Hope for the Best, Plan for the Hard Parts*

- Set expectations early
- Prepare siblings and care networks
- You can grieve and hope at the same time





# What the Research Tells Us

- Cognitive & emotional needs often come first (even before seizures)
- Seizures are one piece of a bigger picture
- 30% of patients with epilepsy are at risk of anxiety or depression

*Cognitive and psychological dysfunction is present after a first seizure, prior to epilepsy diagnosis and treatment at a First Seizure Clinic (Pugh et al., 2024)*



# Assess Early, Reassess Often

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- Track development over time
- Inform school and therapy needs
- Advocate with data







# Recovery Isn't a Straight Line—And That's Okay

- Learning needs may persist
- Fatigue and frustration are real
- Social skills take support



# Supporting the whole family

- Caregivers need care
- Siblings carry invisible stress
- Community connection helps





# Planning for the Teen & Adult Years

- ★ — Start transition planning early
- ★ — Reassess mental health & learning needs
- ★ — Know your legal rights and resources





# You're Not Alone

Peer support fuels resilience

PESA + HFA = global connection

Community is healing







# Key takeaways

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- Medical recovery is only part of the journey
- Emotional and cognitive health matter too
- Families need and deserve support



# Thank you!



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epilepsy  
surgery  
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