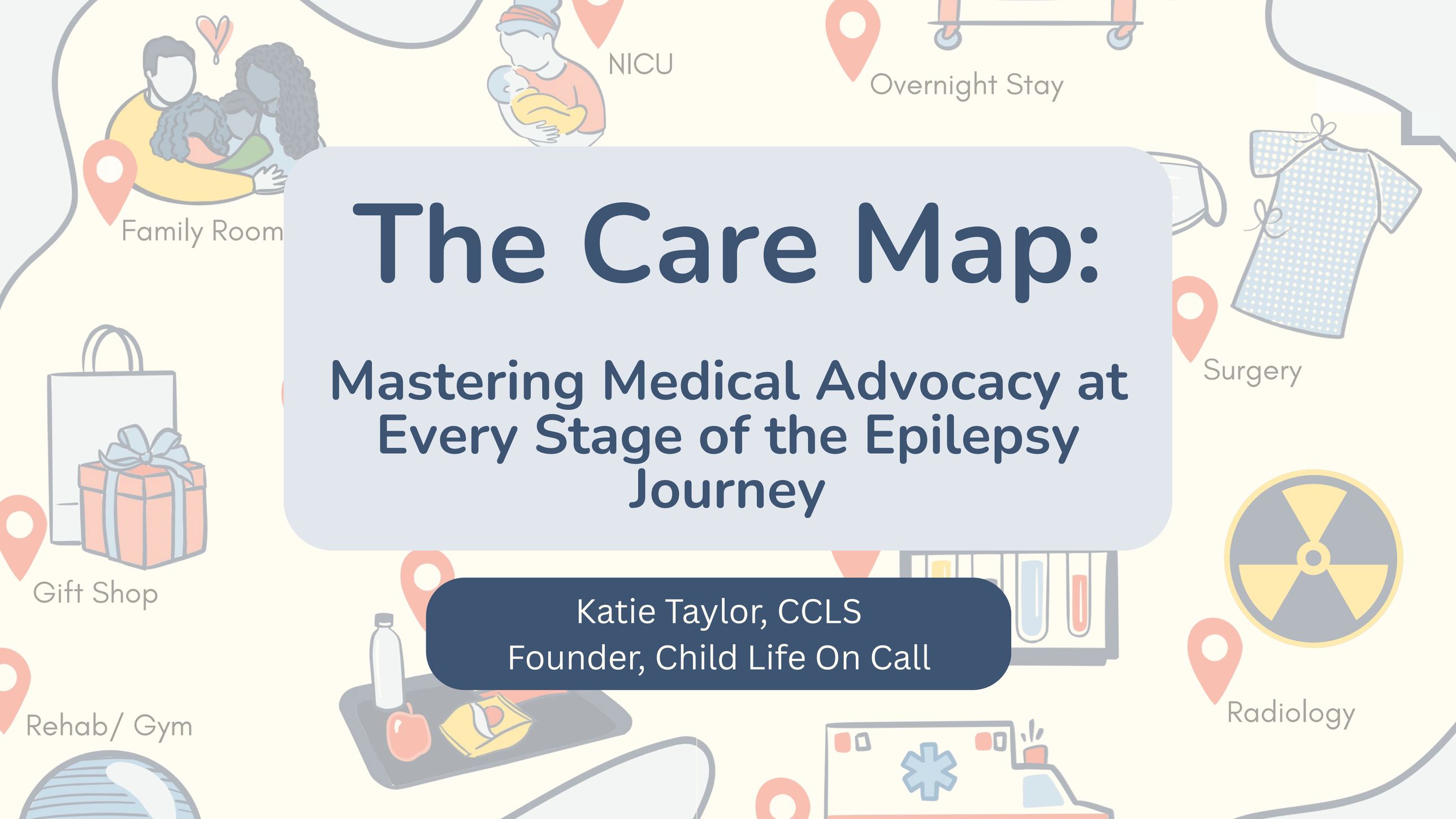


The Care Map:

Mastering Medical Advocacy at Every Stage of the Epilepsy Journey

Katie Taylor, CCLS
Founder, Child Life On Call

Objectives

- Build Bedside Agency and Multidisciplinary Alignment
- De-escalate the Anxiety of High-Stakes Surgical Decisions
- Conquer the Logistical "Discharge Cliff"
- Protect the Child’s Mind-Space and the Sibling Dynamic
- Bridge the Transition to Adulthood (The 18-Year-Old Cliff)

child life ON CALL®

HOPE for HIE
awareness • education • support

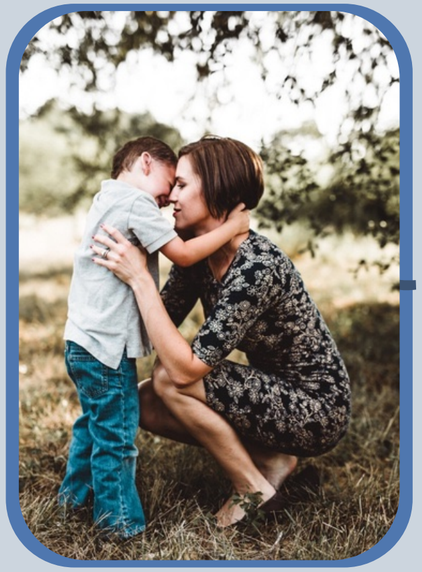
CCLS for 16 Years

support spot
with AngelEye Health

INSIDE the Children's Hospital

A safe place for families to share their stories and experiences

300+ Stories Later...

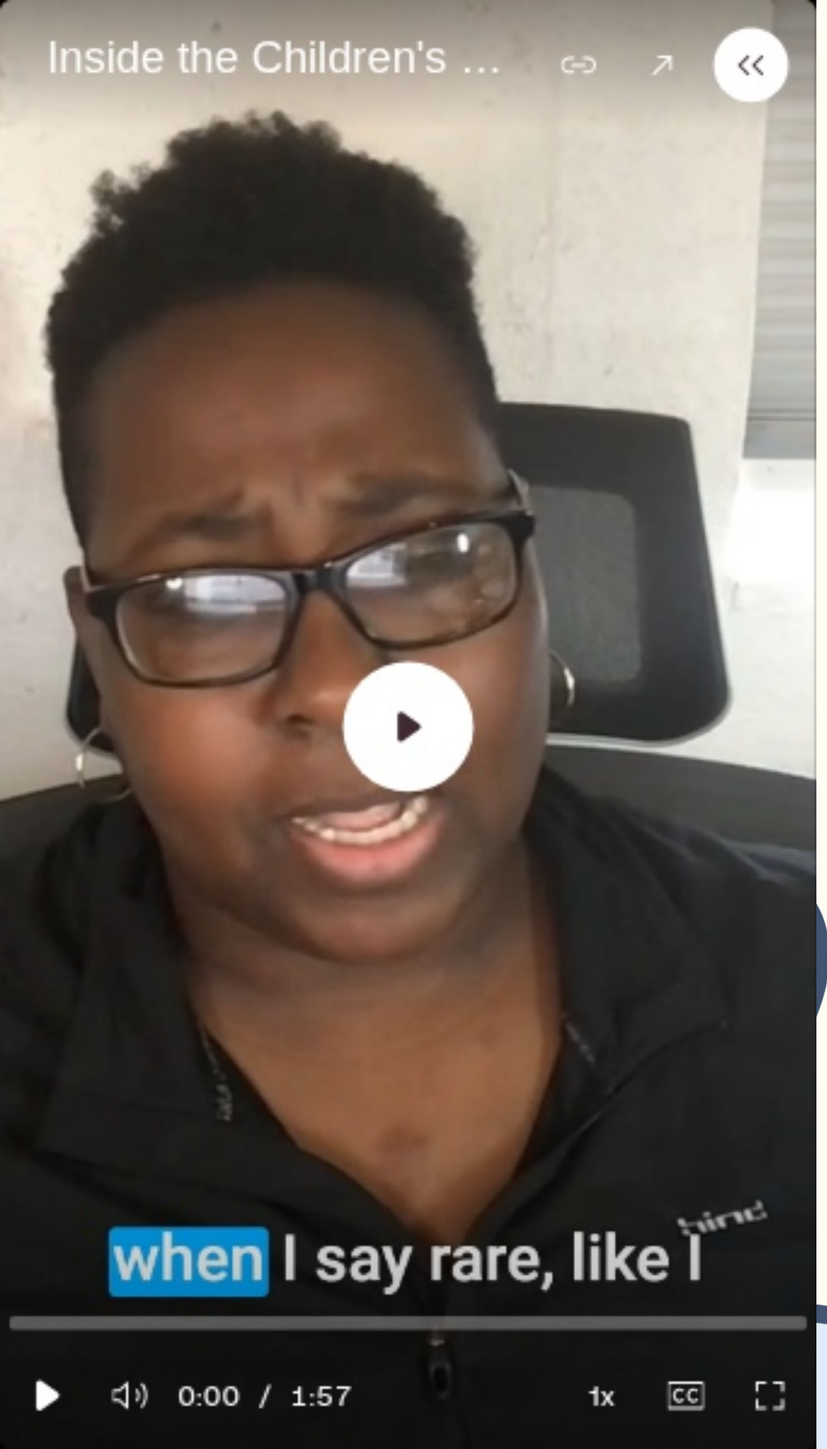


“Can you connect me with another parent who’s been through this?”

Families don’t just need information, they need connection, reassurance, & to know they are not alone.

“This is the first time I felt safe to share my story.”

Inside the Children’s Hospital exists to ensure that no parent ever has to navigate pediatric healthcare feeling isolated by creating a safe, trusted space where families can share their stories and find one another.



Phase 0: Dropped in the Jungle

The sudden drop:
A critical life-threatening diagnosis

The overwhelming load:
Medical world, bills, other children, all in state of shock

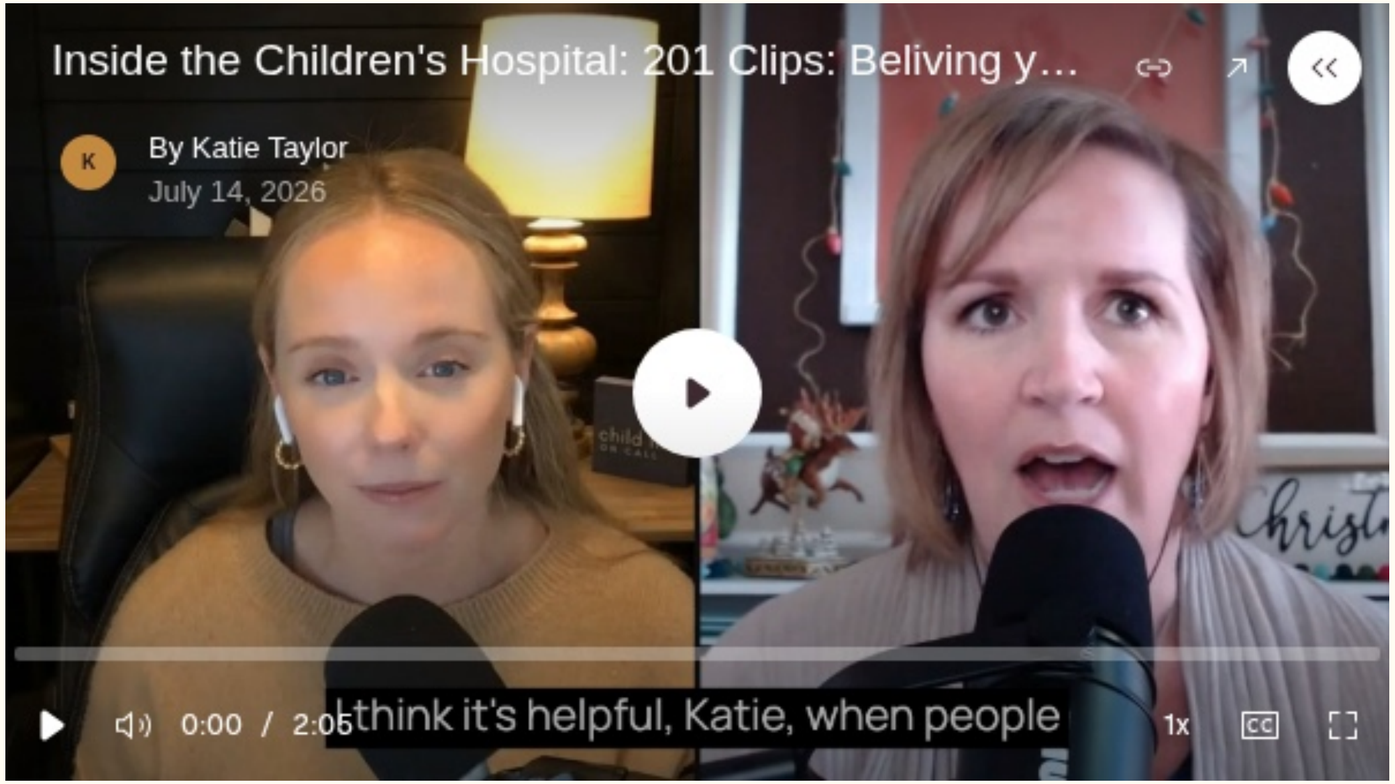
Others have traveled here, too, and have left a pat for you

The Advocacy Tip:

Look for the path other parents have created before you

inpatient stay

Phase 1: The Expert on your Child



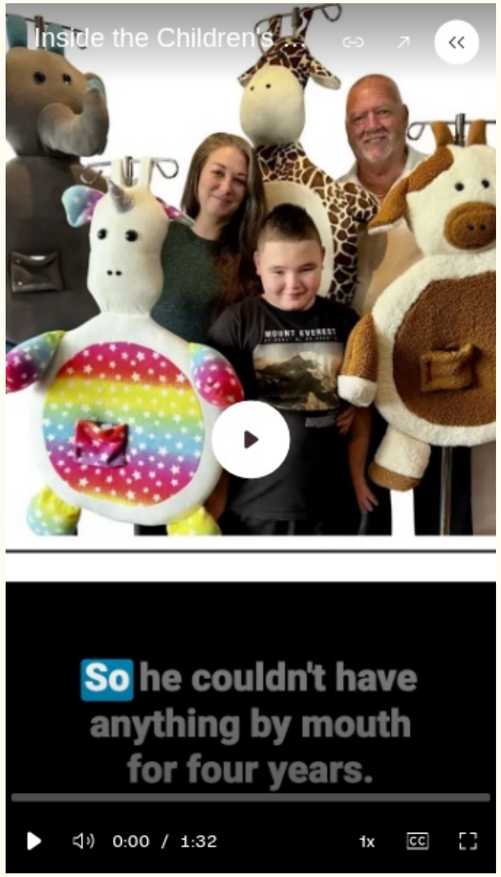
- **The Expert in Your Child:** Stop wondering if you are "lucky" to be in the room and asked questions, try to recognize that the medical **room is lucky to have you in it.**
- **Become the Bedside Historian:** Section your daily notebook into segmented parts: date, time, clinical plan of care, and medications.
- **Command the Conversation:** Make it a priority to attend daily medical rounds. If you cannot be there, have your bedside nurse document specific questions to present to rounding doctors.

The Advocacy Tip:

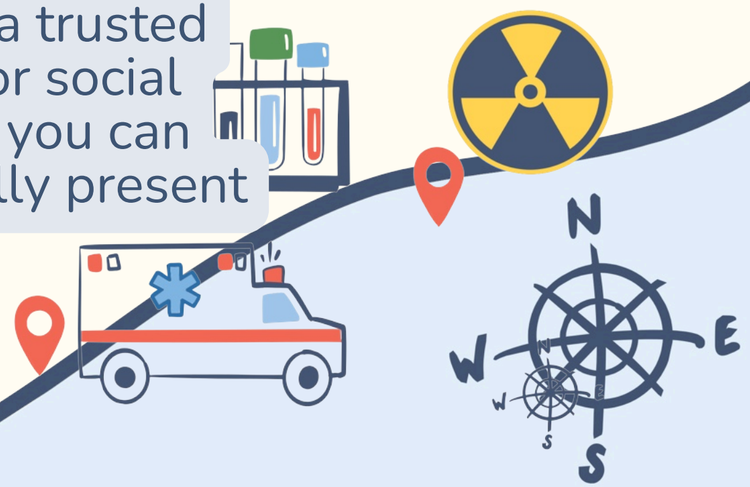
Be the parent in rounds who is just as informed as the provider; if you can’t be there, ask your nurse to stand in for you

Phase 1: The Family Care Conference

inpatient stay



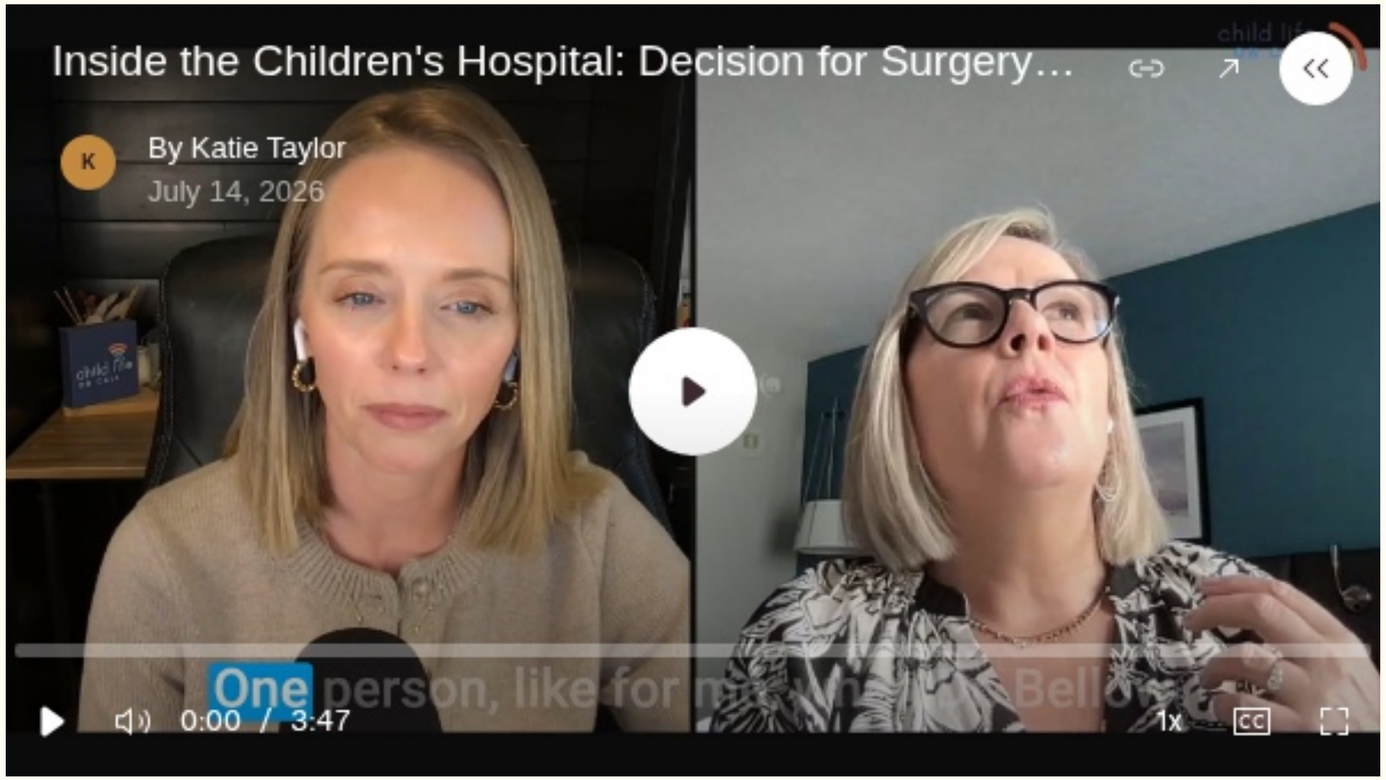
- **Gather the Puzzle Pieces:** When multiple specialties (neurology, GI, nutrition, surgery) overlap, ask the care team for a Family Care Conference.
- **Laying It All Out:** These meetings get everyone on the same page, aligning goals and accelerating a safe discharge.
- **The Notes Hack:** Bring a trusted friend, family member, or social worker to take notes so you can remain 100% emotionally present with the team.



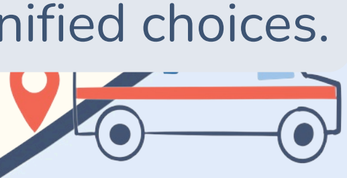
The Advocacy Tip:

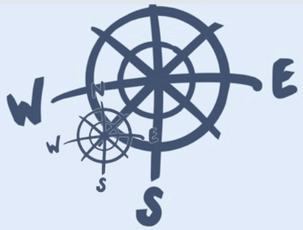
Ask for a family care conference, and ask a family friend or allied health professional to join and take notes

Phase 2: The Surgical Decision



- Opening the Toolbox: A surgical workup is not a commitment to surgery—it is a detailed fact-finding mission that often improves outcomes regardless of your ultimate choice.
- The Drug-Resistant Threshold: Knowing the clinical guidelines (failing two targeted anti-seizure medications) helps parents confidently advocate for a surgical consult.
- Bridging Caregiver Styles: Respect the differing decision-making styles of partners (the "deep-dive researcher" vs. the "least necessary information" style) to make unified choices.





The Advocacy Tip:

Understand that you and your partner will come to conclusions in different ways. Request that each of you have your questions heard by the team.

Phase 2: Opportunities to Advocate During Surgery

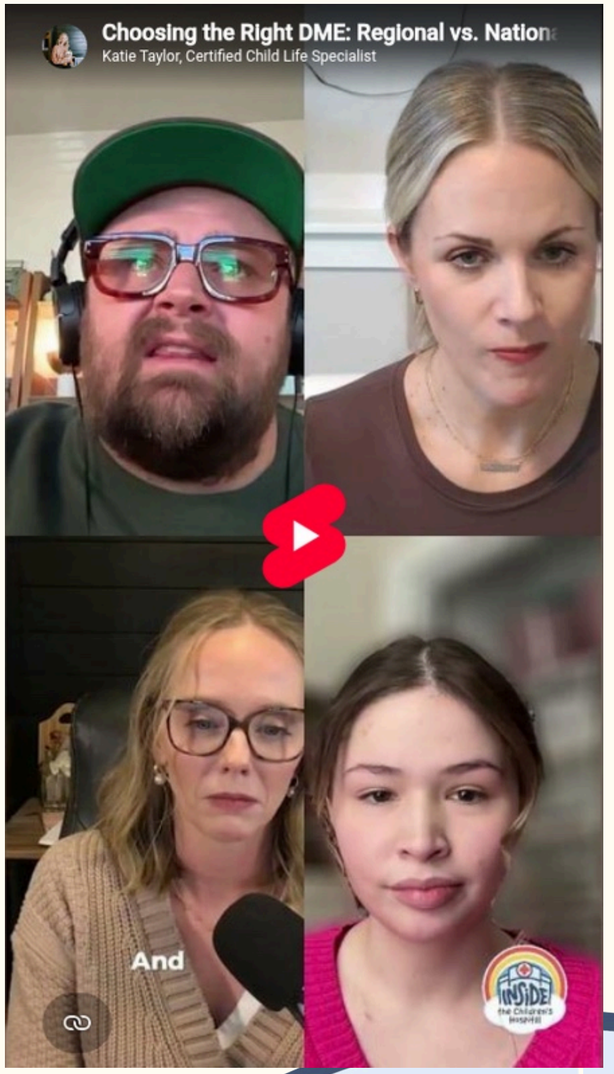
- Pre-op
  - Parental presence for as long as possible (including the anethesia induction)
  - IV medication to reduce fear/anxiety
  - Have every member of the team write their name on a sheet of paper
  - Prepare for what child will see on their body when they wake up
  - Ask how pain will be assessed first 12 hours after surgery
- During Surgery
  - Any outstanding labs drawn while under anesthesia
  - Predictable check-ins from staff about phases of survery
- PACU/Recovery
  - Parents brought back as soon as is safey

The Advocacy Tip:

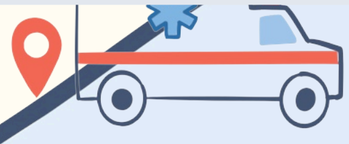
You have more control over the surgery process that you think. Refer to the list on the previous slide to share your choices with the care team.

Discharge

Phase 3: Navigating the "Discharge Cliff"



- The At-Home Clinic: Coming home often feels like "a hospital threw up all over your house".
- Regional over National: Prioritize smaller, regional DME (Durable Medical Equipment) companies over massive national ones to ensure you get a real, flexible human on the phone.
- Unlock Insurance Advocates: Ask your insurance company or the hospital billing office for a dedicated Patient Advocate to help match CPT codes and prevent stressful denials



The Advocacy Tip:

The “list” you get from the hospital is not the end-all, be-all. Talk with your community about what has worked, or ask your social worker to get connected to another family in your area.

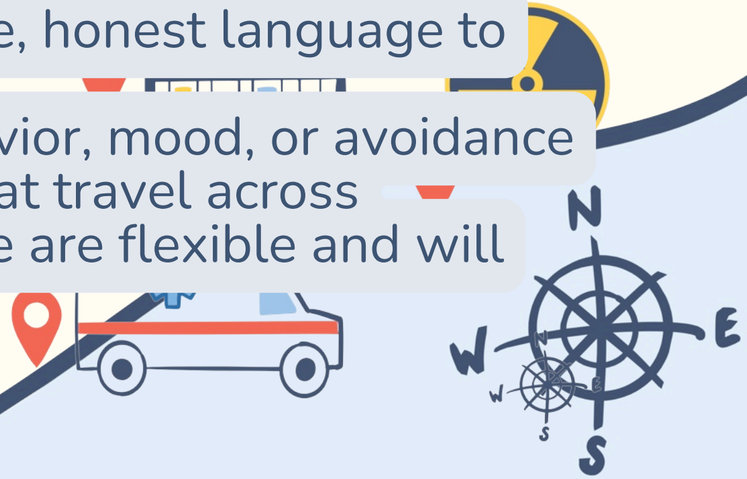
Phase 4: The Emotional Well-Being

What do you know about _____?

Your job is to _____.

What worked last time?

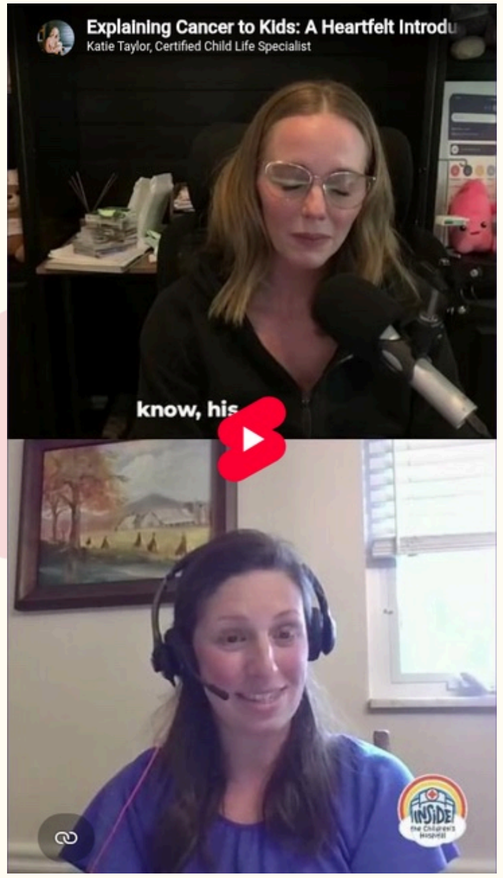
- **In the hospital**
  - Prepare children honestly for what they will see, feel, and experience - regardless of their developmental level
  - Offer meaningful choices whenever possible
  - Prioritize comfort, play, routine, and connection
  - Help children express fear, anger, sadness, and questions
  - Reduce unnecessary restraint, surprises, and loss of control (and people if need be)
- **Outside the hospital**
  - Make room for school, friendships, hobbies, and ordinary childhood moments
  - Give children (and siblings) simple, honest language to explain their diagnosis
  - Watch for changes in sleep, behavior, mood, or avoidance
  - Create consistent coping plans that travel across appointments and settings - these are flexible and will change



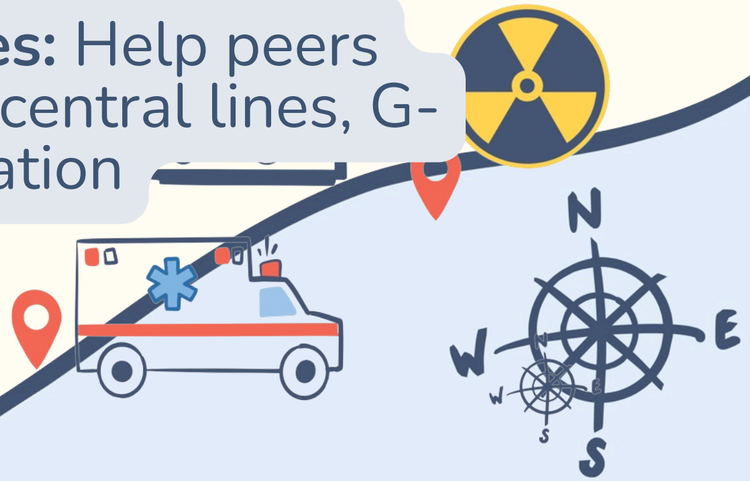
The Advocacy Tip:

Preparing your child for what to expect, will also prepare you for how they will react. When you're prepared, you'll have more bandwidth to advocate. Ask for child life!

Phase 4: Sibling Support & Peer Inclusion



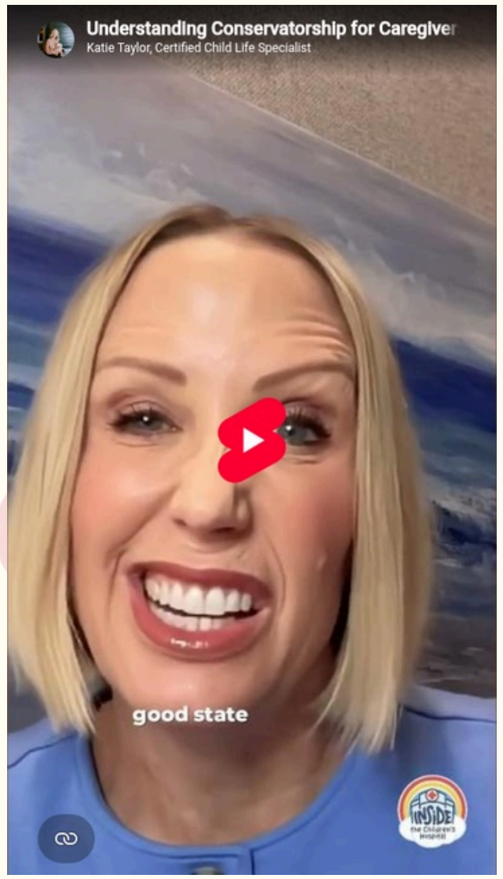
- **Remove the "Buffer":** Trying to shield older siblings by hiding the hard truth often backfires. Involve them in age-appropriate care routines to build empathy and resilience.
- **Educate the Classroom:** Bring the medical world to school by reading inclusive, developmental books to the sibling's or child's class.
- **Demystifying Visible Differences:** Help peers understand medical equipment (central lines, G-tubes) through hands-on exploration



The Advocacy Tip:

Inform the siblings' community and "trusted adults" about what is happening. Recruit help from school counselors and others to offer connecting during high stakes moments.

Phase 5: Adolesecent and Beyond: Shifting the Reins of Advocacy



- **Breaking the "Good Patient" Trap:** Teach children that they are morally allowed to demand respect and have a say in their care.
- **Shift from Driver to Supporter:** Gradually step back during adolescent appointments, sitting in the corner and letting your teenager explain symptoms directly to the doctor.
- **Bracing for the 18-Year-Old Cliff:** Turning 18 is "almost like getting a diagnosis all over again". Begin preparing for the legal, financial, and clinical transitions (conservatorship) at least six months prior.

The Advocacy Tip:

Prepare for 18 before 18 hits. Rely on other “savvy” or “veteran” parents who have walked the path before you.

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Inside the Children's Hospital
with new episodes every
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