



RECALIBRATING

Navigating the Journey

*A Workbook for Parents and Caregivers Facing a Life
Altering Diagnosis*

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THE HEART OF THE MATTER

None of us imagined this version of our lives. When we first stepped into the role of parent, we prepared for sleepless nights and first steps, not for the heavy silence that follows a doctor's words. Whether that moment arrived while your baby was still nestled in your arms or after years of watching them grow, a diagnosis is a fundamental shift in gravity; it can steal the breath right out of your lungs.

"To empower patients, caregivers, and professionals navigating the complexities of rare and life-threatening illness by providing safe, dignity-centered, and evidence-based tools... we value the precious time of those in our community."

This workbook is a tool for your kit—a way to help you process the "recalibration" of your own heart while laying out a practical plan for the conversations ahead. As always, take the parts that resonate with your family's needs and leave the rest behind.

SECTION 1: IT STARTS WITH YOU

Understanding yourself is the first step. It is hard as a parent to think about ourselves, but your care matters. You are modeling healthy behaviors for your child. You are deserving of time and intentional care, not just because your child matters, but because **you** matter too.

What do you bring to this conversation?

Think about a time you handled a hard situation well. What did you do? What does this say about your strengths?

"I AM" Statements

Define yourself outside of the diagnosis. (e.g., "I am creative," "I am a problem-solver.")

SECTION 1: MAPPING YOUR NEEDS

Needs are fluid and can change. Listing them helps ground you. Think about support, solitude, information, or presence.

The Strengths & Needs Map

Use this space to visualize how your strengths can meet your current needs.

The diagram is enclosed in a dashed-line border. At the center is a circle with the text "OURFAMILY". Surrounding this central circle are four rectangular boxes, each with a title and five horizontal lines for writing:

- STRENGTHS** (top-left box)
- NEEDS** (top-right box)
- SUPPORT ALLIES** (bottom-left box)
- GOALS** (bottom-right box)

SECTION 2: UNDERSTANDING YOUR CHILD

Children are smart; they pick up on cues. It is okay to be sad or afraid—it gives them permission to own their own feelings. What we want is to avoid a situation where they feel they must care for us.

How aware is your child currently?

What questions have they asked? What fears have they shown?

The "Comfort Zone"

When and where is your child most comfortable talking? (e.g., during a walk, in the car, at bedtime?)

SECTION 3: BEGINNING WITH THE END IN MIND

Take a moment to define what success looks like for this upcoming conversation.

Desired Outcomes

What do you want for your child, yourself, and your family in this moment?

The "Need to Know" List

What is critical for them to know **now**? What can wait for the future?

Establishing Boundaries

What rules will keep them safe? (e.g., "No internet searching without a parent present.")

SECTION 4: EMPOWERING YOUR CHILD

When they are ready, offer them autonomy. These questions help them regain a sense of control.

- Who** do they want to tell about their diagnosis/procedure?
- How** do they want to share that information?
- What language** is important or comfortable for them to use?

"Remain rooted in love; there is no better anchor."