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Managing the Stress

Of Life with Congenital Hyperinsulinism

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HI and Me

HI Creates a Different Type of Stress

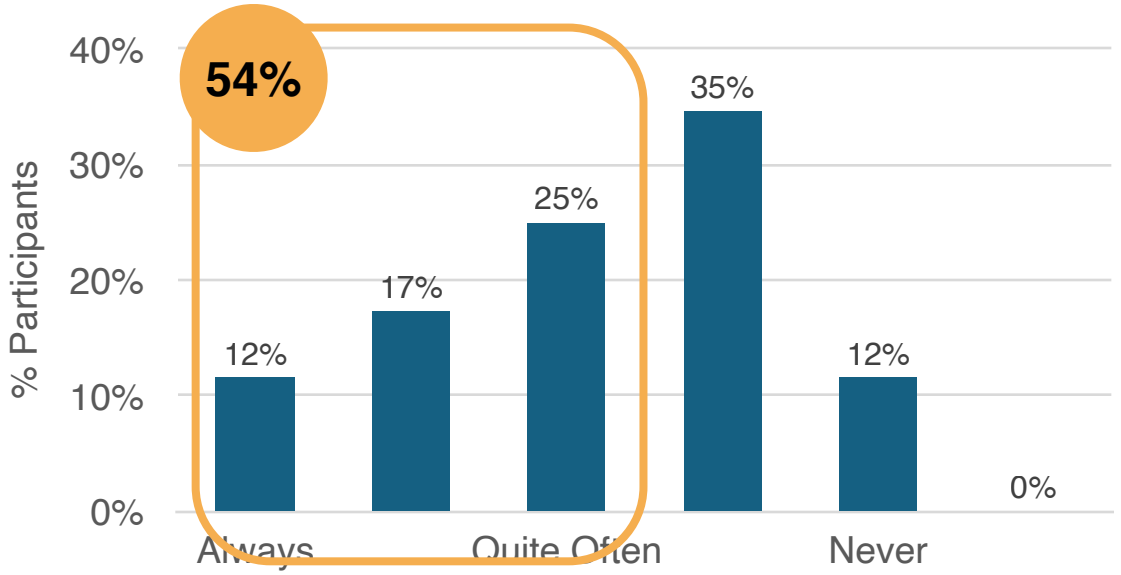
The threat is real — and the work is repetitive, unpredictable, and often invisible.

- LOW — Hypoglycemia can be sudden
- 24/7 — Monitoring and prevention do not follow business hours
- FOOD — Food can become treatment, not just a meal
- Trust — Someone else must sometimes become the “expert”
- ??? — Illness, growth, sleep, activity and treatment changes add uncertainty

International HI Guidelines (2024); Banerjee et al., Orphanet J Rare Dis (2022); HIGR.

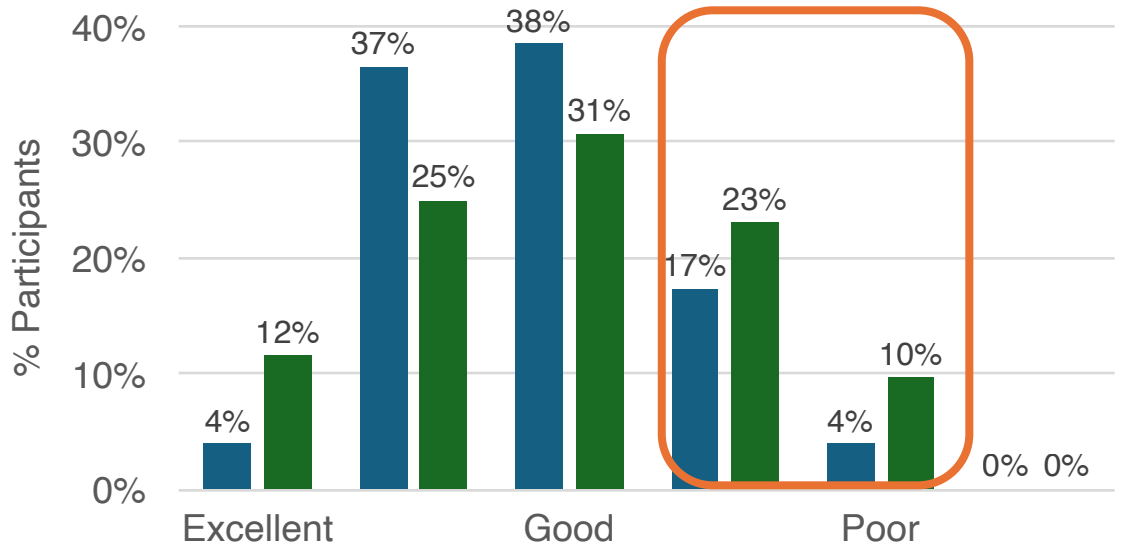
Participant Perspectives

Do you feel that your life is ruled by your HI? (n = 52)



How would you rate your:

- **Physical health? (n = 52)**
- **Mental health? (n = 52)**



Over half (54%) of participants with HI feel that their life is ruled by their HI

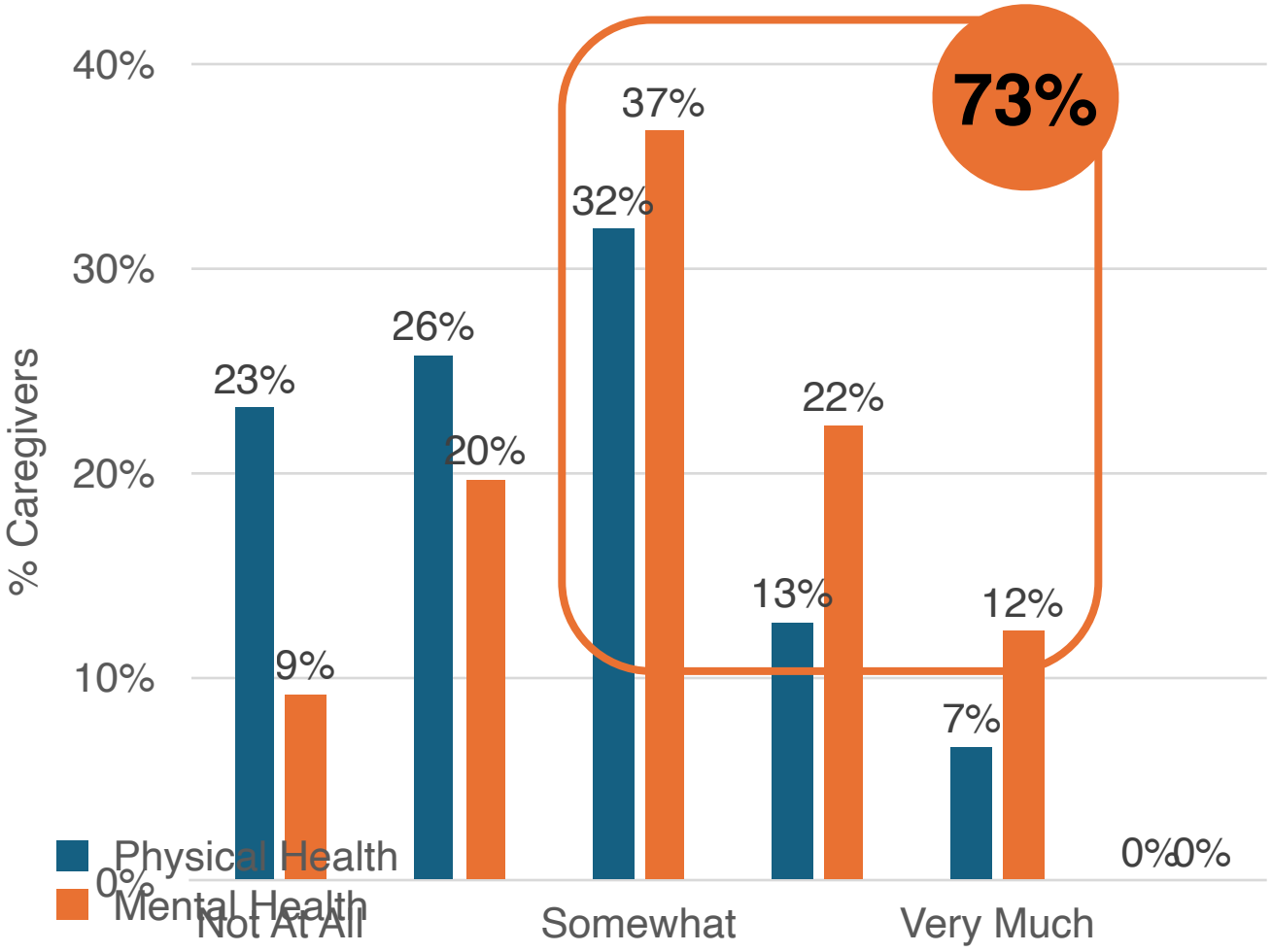
- **1 in 4** participants rated their **physical** health as fair or poor
- **1 in 3** participants rated their **mental** health as fair or poor

"Participant" = person with HI

Participant QOL is assigned to all participants > 14 years old

Parent Mental Health

Do you (as the caregiver of the participant with HI) feel your **physical / mental health** has suffered from caring for the participant with HI? (n = 229)



Many parents report that their mental health has suffered

"This journey has also taken a personal toll, straining my marriage to the point of divorce and leaving me as the sole caregiver and provider. The isolation can be heavy at times, and balancing my child's emotional challenges while staying motivated isn't always easy. But every day, I do my best to keep moving forward."
- Parent of an 8-year old child with HI

Invisible Mental Load

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KEEP MY LOVED-ONE SAFE

- When did they last eat?
- Does school really understand?
- Is the CGM right?
- Why are they still asleep? Why are they awake?
- Do I have enough medicine?
- Where is the glucagon?
- Can they go to the sleepover?
- Am I there for my other kids?
- What if this stops working?
- When is the next treatment?
- What if they get sick?

Let's Pack for a Weekend Trip

Non-HI Child

3 Shirts
1 Sweatshirt
2 Shorts
1 Jean/Long Pants
3 Underwear
2 Socks
1 Swimsuit
Gym Shoes
Sandals
Toothbrush/Toothpaste
Hairbrush
Suntan Lotion

HI Child

- 3 Shirts
- 1 Sweatshirt
- 2 Shorts
- 1 Jean/Long Pants
- 3 Underwear
- 2 Socks
- 1 Swimsuit
- Gym Shoes
- Sandals
- Toothbrush/Toothpaste
- Hairbrush
- Suntan Lotion
- Medicine
- Medicine Cups/Syringes
- Ice Pack/Cooler for Any Refrigerated Medicine
- Dextrose (If Needed)
- Pump (If on Dextrose) and Tricks to Hang the Pump Away from Home
- Test Kit with Glucometer
- Device for Dexcom
- Spare Dexcom Sensor
- Glucagon
- Rescue Snacks
- Food for When Your Child Does Not Eat at the Restaurant

Vigilance versus Hypervigilance

The goal is not “stop worrying.” The goal is to make vigilance sustainable.

PRODUCTIVE VIGILANCE

- Follows the medical plan
- Responds to actual data or symptoms
- Uses predetermined thresholds
  - What is our target?
  - What do I treat? How do I treat?
- Allows attention to return to life
- Can be shared with trained others

EXHAUSTING HYPERVIGILANCE

- Checks beyond the agreed plan “just in case”
- Treats uncertainty itself as **danger**
- Makes delegation feel impossible
- Keeps the body on alert after danger passes
- Shrinks normal activities to avoid fear

The "What If?" Loop

Anxiety tries to solve uncertainty by thinking harder. Unfortunately, uncertainty has no finish line.

1 — Trigger

CGM arrow, illness, overnight alarm

2 — Prediction

“What if this becomes a severe low?”

3 — Action

Check • Recheck • Stay Awake • Cancel Plans • Treat • Treat Again... Just in Case

4 — Relief

“Okay…for now.”

5 — Learning

My brain learns:
Uncertainty = Emergency

What Can I Do Differently??

Interrupt the loop at Step 3:
“What does our plan say to do right now?”

The Response Approach

Anxiety Reacts. Logic Responds.

1

Trigger

CGM arrow, illness, overnight alarm

2

Prediction

“What if this becomes a severe low?”

3

Respond

What does our plan say to do right now?

4

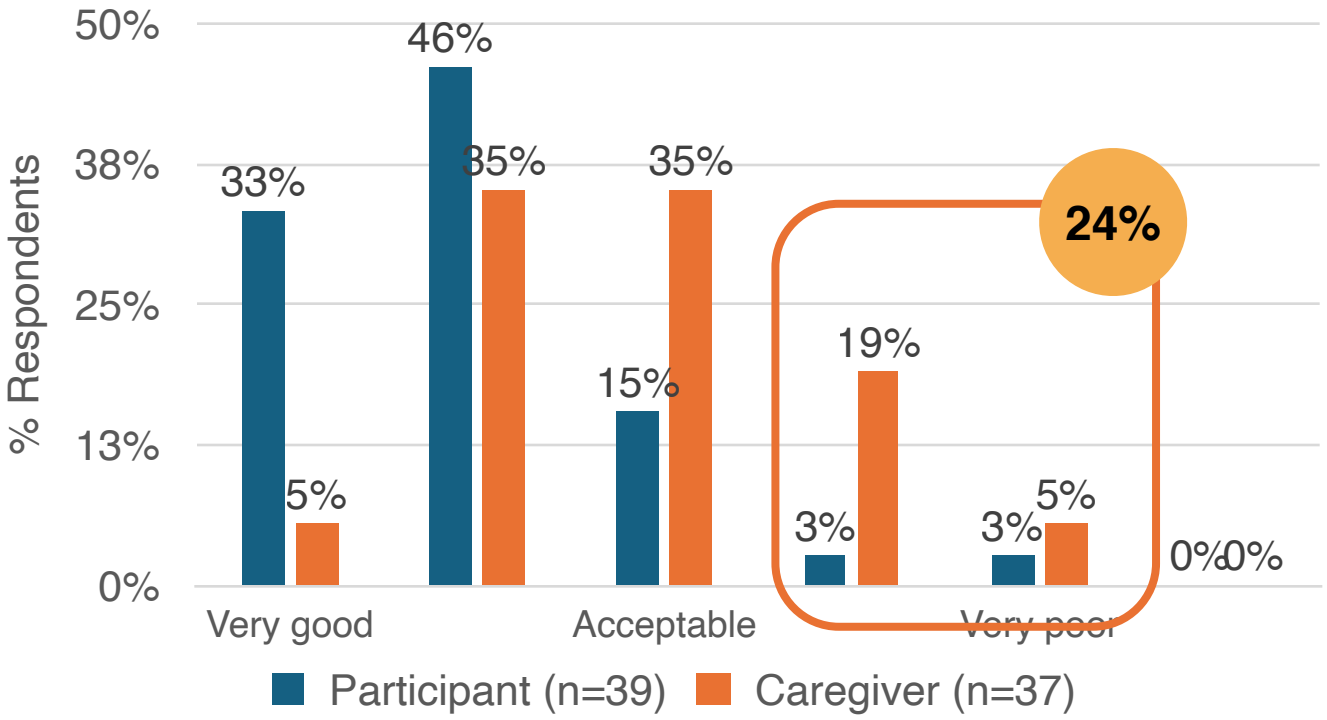
Learning

My brain learns:
I Can Do This

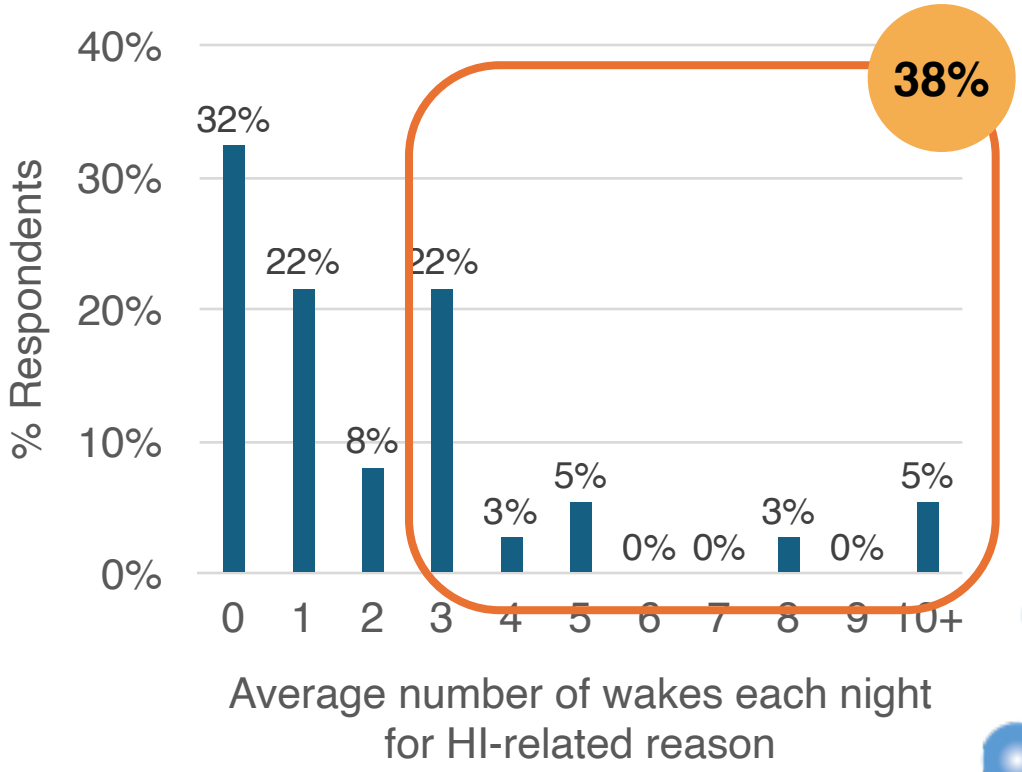
Instead of acting on fear, we start acting on protocol

Sleep Quality

On average over the past 6 months, how would you rate the quality of the **participant's / caregiver's** sleep?



On average over the past 6 months, how many times do you wake up in the night for HI-related reasons? (n = 37)

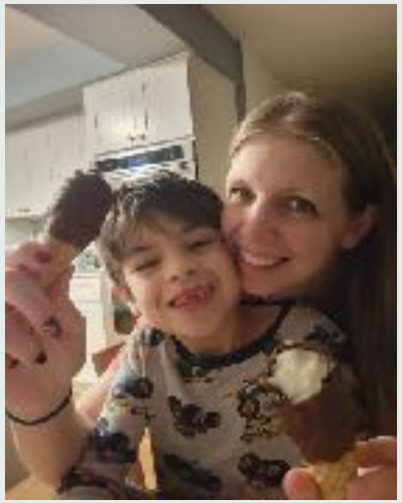


Things That Go Beep in the Night

Sleep loss makes coping harder — and HI can make sleep feel unsafe.

2:13 AM

I hear the alarm.
Is it real?
Do I confirm?
Do I treat?
Can I go back to sleep?



Reduce middle-of-the-night decisions

Use written thresholds and “if/then” steps.

Plan the handoff

When possible, rotate who is “on duty.”

Recover on purpose

After bad nights, lower nonessential demands as much as possible.

CHI parent study: sleep disturbance associated with greater burden and poorer parent quality of life (Meissner et al., 2022).; HIGR

Food Becomes Medically-Significant

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"Just eat" can become one of the most emotionally-loaded phrases in the house.

For the parent

- Will they eat enough?
- What if they refuse?
- Do I push?
- Is this behavior—or physiology?

For the child

- Am I hungry—or being treated?
- Why do adults watch me eat?
- Can I stop when I'm full?
- Why is my food different?
- I don't want to have a snack when my classmates are not eating.

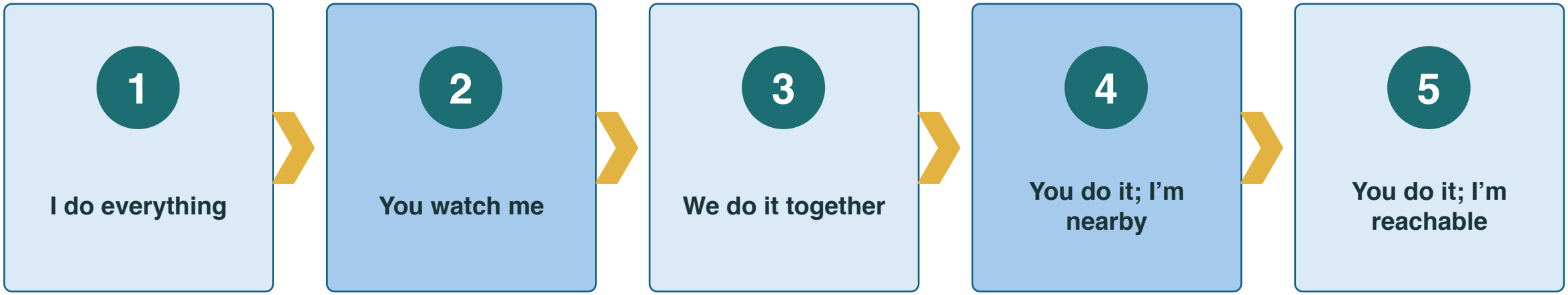
For the family

- Meals become timed tasks
- Siblings notice unequal rules
- Restaurants/travel require planning
- Pleasure can get crowded out

Banerjee et al. (2022) describes frequent feeds, feeding difficulties, invasive delivery methods and feeding-related anxiety as contributors to CHI burden: HIGR

It Takes a Village...
But Trust Can Be Hard!

School, grandparents, babysitters, sports, sleepovers: safety eventually has to become shareable.



Trust is built through competence + repetition, not reassurance alone.

A "Good Enough" Safety Plan

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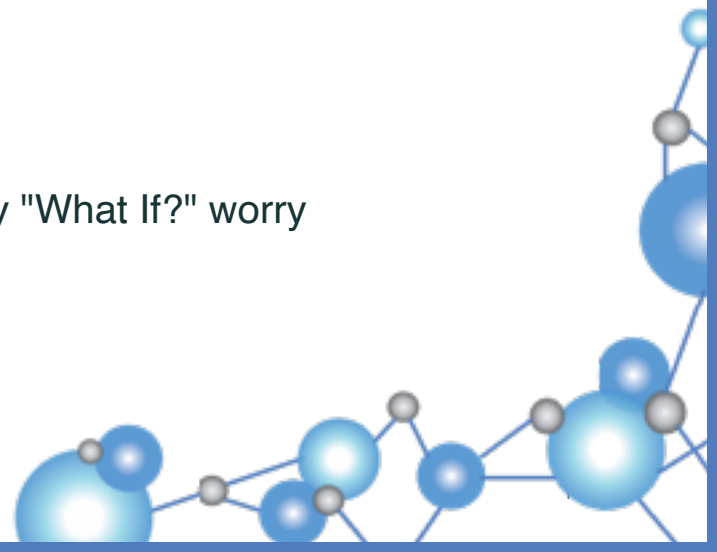
WRITE IT	Simple if/then plans for lows, illness, feeds, equipment failure
DUPLICATE	Supplies in predictable places; backups for high-risk failures
SHARE IT	At least one additional, competent caregiver when possible
REHEARSE	Practice rescue steps when there is no emergency
REVIEW	Update plans after developmental or treatment changes — not after every "What If?" worry



Protect Your Identity

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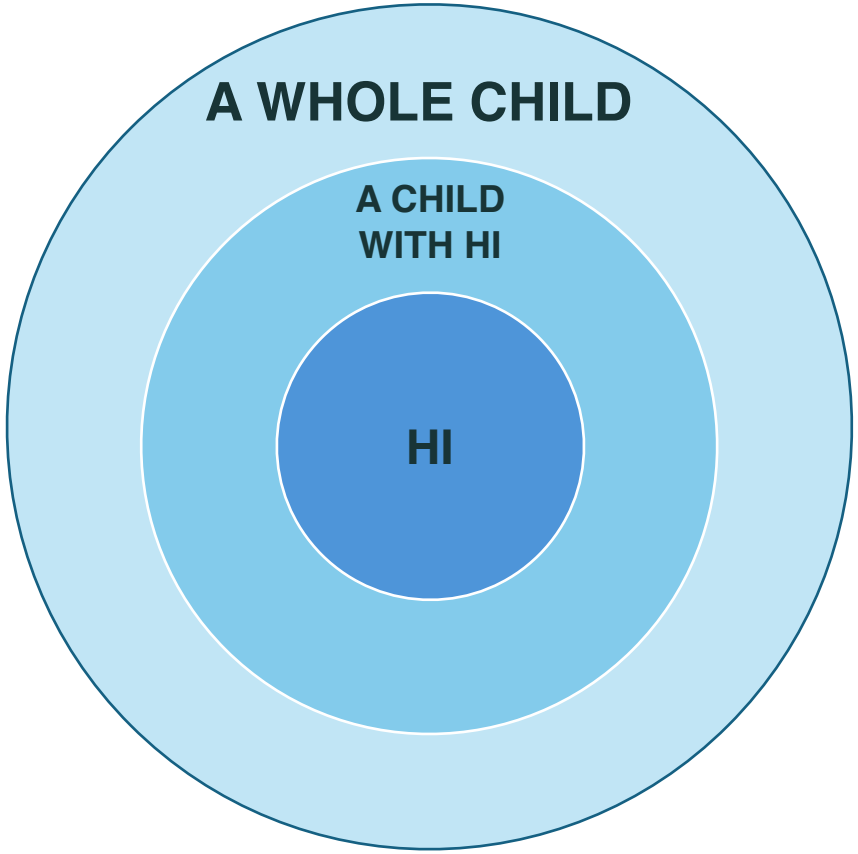
Make room for:

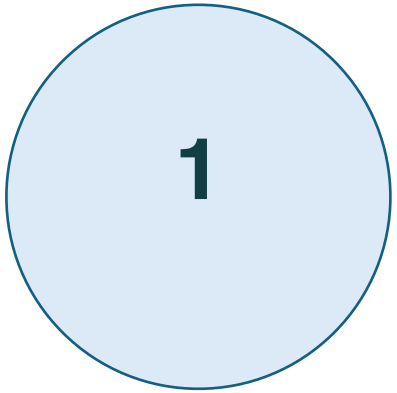
- Preferences
- Friendships
- Competence
- Privacy
- Consensus
- Mistakes
- Age-Appropriate Independence
  - Sharing/Transferring Responsibility



This applies to siblings, partners, work, joy, and ordinary family chaos.

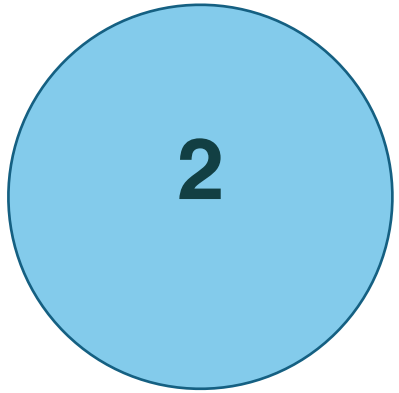
Reset Your Nervous System

This does not fix glucose. It helps your brain come back online so you can **follow the plan.**



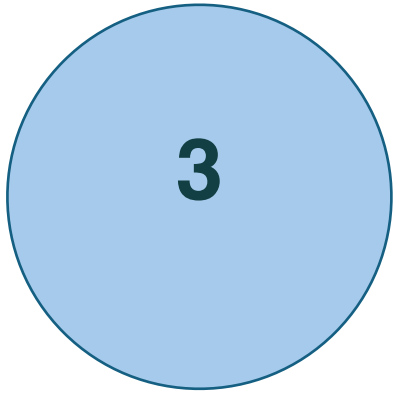
ORIENT

Name what is actually happening now.



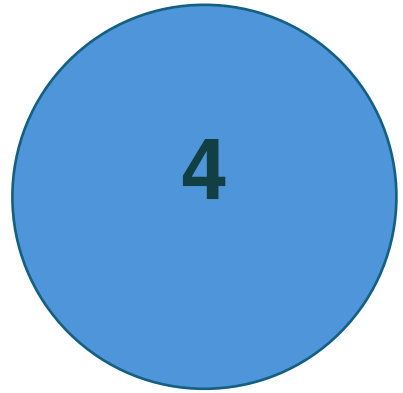
EXHALE

Longer out-breath × 3–5. No perfect technique needed.



PLAN

Ask: “What is the next indicated step?”



ACT

Do that step — not every possible future step.

When Stress is Too Big

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Consider extra support when…

- You have a solid plan, but your fear keeps growing
- Sleep is impaired even when monitoring does not require wakefulness
- You avoid necessary separations or normal activities
- Intrusive memories or panic follow medical events
- Irritability, hopelessness, numbness, or relationship strain persist

Support can include…

- A therapist familiar with chronic illness or medical trauma
- CBT/ACT approaches for uncertainty and anxiety
- Trauma-focused treatment when indicated
- Parent/caregiver support groups
- Couples/family work when illness has reorganized roles

Clinicians can help by…

- Screening caregivers periodically
- Asking about sleep and functioning—not only glucose
- Providing clear written plans
- Normalizing psychosocial referrals
- Treating caregiver capacity as part of the care ecosystem

Take Away Tips for Managing the Stress of HI

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1	**Name the load**	The invisible work counts.
2	**Use your plan, adapt your plan to significant changes**	Let protocols—not fear—decide the next step.
3	**Share your brain, so you can share your responsibility**	Support works best when others are genuinely trained.
4	**Protect life beyond HI**	Safety matters. So do childhood, relationships, sleep and joy.

It's OK not to feel OK. You can still do this.