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Recommended Citation

Christy, Alison, "Difficult Conversations." (2019). *Articles, Abstracts, and Reports*. 2536.
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Difficult Conversations

Child Neurology Open
Volume 6: 1-2
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DOI: 10.1177/2329048X19886723
journals.sagepub.com/home/cno



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Received September 30, 2019. Accepted for publication October 09, 2019.

The neonatologist paged me during my outpatient neurology clinic and told me about a newborn who was still on the way to the hospital. It was a full-term baby, from a perfect pregnancy and a healthy mother. The mother spiked a fever during labor, the baby's heart rate dropped and her doctors did an emergency C-section—so far, a straightforward story, nothing unusual. But a minute after birth, the baby's heart rate suddenly dropped and stayed down.

Despite stimulation, despite positive pressure ventilation, despite everything her doctors tried, her heart rate stayed low. For 40 minutes, pediatricians worked to resuscitate her with chest compressions and injections of epinephrine.

Forty minutes is a long time.

"I wanted to warn you," the neonatologist said, "because I think we're going to have some difficult conversations."

I sat on a chair next to Harriet's mother's bed. She looked beautiful, like new mothers do, with thick hair and glowing skin, and a soft, rounded belly. But she was missing the look of exhausted joy. She looked sad, worried, and confused.

Birth is hard. It is hard for women and it is hard on babies. All babies experience oxygen deprivation around their births. Most babies recover, even when labor takes a long time. They cry and turn pink. They come out with molded heads and bruised faces and then they bounce back. They are designed for this.

But on the rare occasion, babies have too little oxygen for too long, and it damages the brain. We call this hypoxic-ischemic encephalopathy, or HIE.

One way to help babies overcome this kind of injury is by cooling their bodies. We feed them through intravenous lines placed in their belly buttons or arms. We put electrodes on their heads to monitor for seizures. We wait to see if they will recover.

Some of these babies have seizures. Some of these babies are floppy, with legs that frog out at the hips, and some are stiff and jittery. Prediction can be challenging: some recover beautifully and others have lifelong brain damage.

Harriet lay on a cooling blanket, intubated, perfectly still. We usually sedate babies when they are cooled because cooling

is uncomfortable, and babies wiggle. Harriet was not on any medication, but she didn't wiggle. She didn't move at all. I lifted her eyelids easily. She didn't squint or struggle. Her eyes faced directly forward, locked in place. Her pupils were wide black holes that did not shrink to light.

Nothing. This baby had no response to any stimulation.

Our jobs as pediatric neurologists are full of difficult conversations. We tell parents their children have seizures, migraines, or tics and often we can't tell them why. We don't know whether any particular child will stop having problems and come off medication or need multiple medications for a lifetime. The words we use—*epilepsy*, *cerebral palsy*, *Tourette syndrome*—come laden with history, culture, media images, misconceptions, and shame. There are few easy conversations about something that may be wrong with the brain of a child.

It is hardest to talk about the future. We never know what will happen. All we have is the knowledge from the patients we have seen, and what we've learned from other neurologists. Families need us to guide them with prognostication and recommendations in the face of the very uncertainty that confounds us as well.

Harriet's parents had many questions, that all came down, in the end, to one question: what is going to happen to Harriet?

Harriet's ultrasound showed that her brain was swollen from injury. Her electroencephalogram (EEG) didn't show seizures, but there was much less electrical activity than we would expect from a brain that had not been injured.

The most important way we look at Harriet's brain, I said, is to look at Harriet. What is most concerning to me is that she isn't doing anything. She isn't moving. She isn't reacting. She isn't making any attempts to breathe. She isn't getting better with time.

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I told the family that based on all of our tests—and more importantly based on how Harriet appeared—even if her brain recovered and remodeled and rewired, I did not think she would ever walk or talk. More likely, her deficits would be much more severe: she might never interact with her environment.

I said that even in the most severe cases, some people choose to take their babies home on a ventilator, with a feeding tube. Many of these families love their children with all their hearts and believe that their children enjoy a good quality of life.

But can miracles happen?, they asked.

Miracles do happen, I said, but they don't happen very often.

Sometimes, when a child is sick, when a baby is neurologically devastated, it's easy to maintain distance:

This wouldn't happen to me, because I didn't do meth while I was pregnant. This wouldn't happen to me because I'm physically healthy. This wouldn't happen because I read the baby books, because I had the ultrasounds, because I did all the things I was supposed to do while pregnant.

Even if I never say the words, even if I don't explicitly think them, they stay in the back of my head, reassuring me. *This didn't happen to me, this didn't happen to my 2 beautiful healthy children, because I was in control.*

I know without a doubt that I could have been Harriet's mother. Anyone could have been Harriet's mother. Anything can happen when a baby is born. I know that, but for protection I distance myself: *this wouldn't happen to me, because, because, because . . .*

I met with the family again the next day. I asked if they had any questions.

Difficult conversations—I had been warned.

"Is there any hope?" they asked. "Is there any way we can repair the brain?"

The sad truth is that once the brain is damaged, we don't know how to repair it. This is true with strokes, injury, and concussions. All we can do is watch and hope the brain repairs itself.

We talked about withdrawing life support. Harriet had almost died when she was born, but because her caring medical providers worked ceaselessly for 40 minutes, she didn't. Despite the best of intentions, they forced this decision on her parents, who couldn't simply mourn the death of their baby. Her parents had to make a choice, and live with that choice for the rest of their lives.

The other doctors and I didn't tell the family what we discussed behind closed doors—that if we waited too long, Harriet might start to breathe on her own. A little less swelling, a little recovery in the deepest structures of the brain, and she could breathe. The respiratory centers in the brain are the last to be

injured, so if she breathed it wouldn't mean that the rest of her brain wasn't horribly, irreversibly damaged.

Difficult conversations.

At our third meeting, Harriet's parents said they wanted to let her go. Her whole care team was there, including her nurse, her neonatologist, and me. We told her parents that this was a reasonable decision. A caring and selfless decision. A horrible decision to have to make, but in the end, a loving decision.

Harriet's parents would then go home to a furnished nursery and unused baby clothes. Breasts leaking unneeded milk. A lifetime of strangers asking "Do you have kids?" A lifetime of Mother's Day displays in the stores. A lifetime of listening to people complain about their perfect, healthy, flawed children. A lifetime of people who say "My child had the same thing and they are fine" or "I know someone who made a different choice and their baby did great."

When we talked about the future, Harriet's mother said she would never do this again. Even if she changes her mind, gets pregnant again, and has a perfect healthy baby—it will not be the same. There are people who get to believe that a positive pregnancy test and a faultless pregnancy mean that you bring home a baby. There are people who don't.

I stopped by the next day to see if the family had any more questions. I wanted them to go forward without guilt, without ever questioning whether they had made the right decision. One last difficult conversation.

Her mother was sitting in a rocker, a pillow on her lap, baby Harriet cuddled against her on the pillow. I could finally see Harriet's dark hair, now that the EEG cap was off. She still had a breathing tube but all the IVs were gone. We talked about how beautiful she was. A tiny, perfect baby.

"We do have a question for you," her father said. "Since you're a neurologist."

I waited for it, hoping to answer their final questions, to reassure them that this was the right choice.

"Why does it feel so good to hold an infant?" he asked.

I paused.

"It just feels so right," her mother explained. "The perfect weight in your arms."

That feeling. That perfect weight. I know.

There was nothing to say.

Author's Note

Names and identifiers have been changed to protect patient confidentiality.

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