CHAPTER 7

IN CASE: CONTINGENCY AND PARTICULARITY IN BIOETHICS

DISCURSIVE METHOD AND CLINICAL MIDRASH
BRIEF NOTES ON A LESSON FROM MY TEACHER
BARUCH BRODY

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I. OPENING AND SAYING: IN BIOETHICS

When you work at the major regional pediatric medical center, you can watch the evening news and see the case coming. It is summer, and the first drowning case is on, in a blur of ambulance lights flashing on the walls of a small suburban apartment house, and a very small body on the stretcher. The reporter interviews a stunned young mother who tells the camera that she wants to beg other parents to simply move away from places with pools. “You just cannot make it safe,” she tells us. “I am talking now to save your child,” she says.

There were fences, closed doors, a careful grandmother. But nothing keeps us perfectly safe. I turn from the screen to my oldest son, the grown-up. “I am going to see that one,” I say. “God, I hope she lives,” he says. “Look how little she is.” The TV is on to the next drama, framing the world as a series of hungers, losses, desires, with commercial breaks for solutions that you can buy. I am thinking—or I hope—that she is swiftly dead”.

A month later, when the call comes for a consult, I remember the name from the TV story, and it is the very worst of options. The little girl is not quite dead and not quite alive, but comatose, unstable (an individual that Baruch Brody has named a “not dead, but no longer a person”), her case deepening into a tragic finality. Her father now wants to ask the doctors about when they should stop the life support, the tubes that are feeding her. And, the doctors want to ask the ethics committee.

We meet in the hospital cafeteria conference room. It is too hot in here, there are no windows, and the walls are thin enough that you can hear the laughter and calls of other kids in the hall outside, alive, alive as we listen to the story. We are quiet, waiting for the last committee members, the parents politely sitting, and the

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laughter of other people’s children rises outside in bursts, and they keep their polite faces. When we hear them laugh, I see the attending look at me, and shudder.

Not everyone can come, it was short notice and, it being summer, the season of swimming pools, after all, people are away. Sister Mary Margaret is here, and Lilly Jolson, and Catherine Key representing the community of parents, one with her very severely disabled child, the other with her story of her child’s fitful cancer recovery: they come to our committee meeting, wearing their stories like letters on their skin. There are two doctors, Roger, the serious assistant head of the NICU, and Len, the hematologist; the committee social worker, Bettina, is here, and the risk manager, Lawrence, and the new lawyer, Pam, edgy, and fiddling with her pen as she walks in the door.

The child’s health care team speaks first: of the hopelessness of the case, of the full 10 minutes before the child was found, the full 43 minutes before her heart beat again, the abnormality of the evoked potentials, the EEG, the CT scans. It is early in the course of things, only 30 days. But still. The rehabilitation team sees little hope. The baby girl is as limp as a rag doll, and this is not a good sign.

The parents speak. Father first. “I have spent the night in thought and prayer,” he says. “And I know that it’s time my baby girl is with my Lord. I think that she is there now, and that we need to let her body go there too. But I know that this has got to be a shared decision, and I know that my wife is not there yet with this decision. So we came here to talk about it.” He is a large, white, young guy, with a sweet, soft, round face, and a round belly, with big hands. He reaches for his wife and takes her hands in his. She looks enough like him to be his sister: blond, round-faced, round bodied. They are both tagged with the little cheery paper name tags from security (“Hi! My Name is….”). They have both written their first names carefully, like good students in fourth grade.

“We don’t want to be having to make this decision,” she says. “We don’t want to be here at all. But we are, and we just need to figure out what is the best thing. For Emily.” I remember her brown eyes from TV.

Here is the problem. The parents, even now, just want to be sure that Emily will not wake up. “Give us anything you know,” says the father, opening his big hands to us.

But we cannot be sure, not in the way they mean. We cannot know anything, really. We know, I tell him, that most of the time, babies this sick, with brains this damaged, either die, or live just like this, curled on the bed, wake and sleep, wake and sleep, with no more sweet smile, or favorite toy, or knowing that it is morning. While we can do lots of miraculous stuff with the extraordinary machines, we cannot do miracles. Emily has been without oxygen to the cells of her brain far longer than the four minutes that it takes for the neurons to begin to die. This is called anoxic brain damage, and it causes widespread and global neuronal death. The brain cells become necrotic, liquefying, then calcify and the brain structures are destroyed; the fine architecture that holds thoughts, nursery rhythms and dreams in place disappears. We can see this on the brain scans already and the neurologist shows the family a scan of a brain in the final stages of this process. “This is where