In the early evening of Feb. 22, 1998, Larry and Marilyn Martone of Long Island, N.Y., received a phone call from Cook County Hospital telling them that their youngest child, Michelle, an undergraduate senior at the University of Chicago, had been hit by a car. She was on a ventilator and in critical condition with severe brain trauma. “Brain” and “ventilator” were the two words that Marilyn remembers as she, her husband and their sons headed out the door that night to fly to Chicago.

So begins the odyssey of the intrepid Martone family as they rescue Michelle from a health care system that just transfers her from one facility to another. At the heart of it is a gripping, deeply disturbing and painfully transparent narrative of Marilyn’s advocacy for her daughter’s well-being from 1998 until the present.

As they arrive in Chicago, they learn that Michelle is at level three on the Glasgow coma scale, the ranking just short of brain-dead. Within 48 hours, she needs surgery to reduce the brain swelling. On the “informed” consent form that Marilyn signs, next to “possible effects” is written “death” and next to “alternatives” is “none.” Marilyn comments, “No, I didn’t give informed consent, but we all pretended that I did. Signing consent forms was an illusory symbol that we had control over the situation, but we were all taking our cues from Michelle and only reacting to what needed to be done.”

The book exudes wisdom. Marilyn Martone, a professor of moral theology and bioethics at St. John’s University in Jamaica, N.Y., has published in more than a dozen different journals, including the Hastings Center Report, the Journal for the Society of Christian Ethics, Theological Studies, the Journal of Religion, Disability and Health, Origins, the Journal of Clinical Ethics and America. For her work on ethics and disability, she won a grant from the National Endowment for the Humanities and a fellowship at Weill-Cornell Medical College and the Hospital for Special Surgery.

The wisdom in these pages is not, however, the fruit of academic research alone; it is rather born from the reflective and sustained experience of a mother nursing and protecting her daughter with love, unwavering fidelity and hope.

For nearly eight weeks, Michelle remained unconscious at Cook County. Later she was transported to the Rehabilitation Institute of Chicago, where she needed to emerge from her coma within two weeks if she were to remain at the center. There Marilyn learned that acute care
and rapid recovery were the focus of professionals’ preference for brain trauma patients—rather than chronic care.

After four months in Chicago, an unconscious Michelle was shuttled to another facility, this one in Edison, N.J. Here Marilyn faced the question: will her daughter ever awaken? Again the staff decides that Michelle is not improving, and now the Martones are advised to consider withdrawing her artificial hydration and nutrition because one physician believes she is in a persistent vegetative state. (Too early for that prognosis, thinks Marilyn.)

With a sense that “as the medical magic ceased to work, Michelle was becoming less and less of a person in the eyes of medical professionals,” Marilyn watches as they transfer her to the facility’s “sub-acute division.” There, nearly eight months after the accident, Michelle begins to nod, respond and even speak. As she emerges from unconsciousness, she begins to experience excruciating pain.

She remains in Edison for one year, but her development is slow and the facility begins cutting back on her therapeutic sessions. Though she is conscious and aware of her family members and knows their love, her cognitive development and her memory are profoundly compromised. She moves to a facility on Long Island, and then, about two years after the accident, she returns home.

Throughout the account are some unbelievable stories: a roommate who beats her nurse with a metal bar and jumps from the hospital’s third floor window; an anesthesiologist who does not realize that Michelle has a tracheotomy; a fire on her floor in a Chicago hospital and a fire on her floor in the Edison facility. There is the lawsuit over the car accident, Marilyn’s surgeries (knee replacements, breast cancer and emergency gall bladder surgery), the occasional overwhelming depression, spiritual desolation and abiding sense of abandonment from the experience that long-term disabilities from brain injuries are simply not a health care priority.

*Over the Waterfall* is unlike anything else Martone has written or I have ever read. This is truly her own *Confessions*, filled with rich insights about the gift of a child and spiritual strength, about brain injury, brain development and health care advocacy. Above all, it is Marilyn’s description of Michelle going over the waterfall. There her daughter’s entire life, consciousness and even personality are shattered in her descent; and her family scrambles against the rushing water at the bottom of the waterfall to find the pieces to save her. They are there because they went over, too.

Twelve years later Michelle lives at home with her parents. For the young woman to whom most things came easily, today she works “very hard” with speech, motor and cognitive therapies and “is slowly forming her new identity.” When Marilyn Martone is not with her daughter at home, she is out raising consciousness about victims of brain trauma.

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