

A Grandmother's Grief and Lingering Questions: A Response to a Visual Case Study

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In 2003, Annette O'Brien's grandson, Liam, died after a struggle with lissencephaly at age 2 and 4 months. The arts often provide unexpected and profound revelations—ways of helping family members make meaningful connections between their own experience of loss and what the artist portrays. I recently asked Liam's grandmother to respond to Deidre Scherer's "Child." (In a Visual Case Study, a work of art, whether an image, photograph,

even a quotation, acts as a trigger or prod—and as a means to deeper understanding.)

Liam's grandmother used her Visual Case Study to raise a question that continues to haunt her: Did we serve Liam's best interests by prolonging his life—and possibly his suffering—another 6 months with a feeding tube?

In Scherer's "Child" (Figure 1), I notice that the mother closes her eyes. She is upright in her chair so sleep cannot creep up on her. How could she live with herself if she fell asleep, only to awake and find him gone? She and the child are swaddled together in the all-too-familiar quilt she made to celebrate his birth. Now she uses it as a shroud. His sunken eyes are wide open; she sees his boney prominences; she hears the whir of the feeding pump. Just who is she trying to sustain?

The child shown here is suffering. He no longer wants this artificial feeding that has gradually become a painful experience for him. The child hopes his eyes will meet his mother's eyes so that she can see what he is trying to tell her. He just wants to lie down beside her and close his eyes. Can't she see what his eyes are saying?

How old is this child? How long has he been ill? Was he once a healthy child, or has he been sick since birth? Not that this really matters. The death of a child is always unexpected. We somehow shelter ourselves from thinking the unthinkable—or from thinking that today is the day. We keep busy—that's the American way. We protect ourselves from any unpleasantness such as death. We are the fix-it generation. But not all things can be fixed, and try as we may to sustain life through artificial feeding, we cannot postpone indefinitely the certainty of an impending death.

My eyes become fixated on the child's plastic feeding tube, carefully woven through his clothing. I find it so difficult to look at this dying child tethered to a feeding pump. Painful memories of our own experiences

flood through my consciousness. The child here is dying...food is for life. But what life does he have left? And does this sad, grieving mother really believe that after one more ounce, one more feeding, all will be well? She is not comfortable, nor is her child. Why do we make dying so prolonged and difficult, especially for our children?

I ask myself, "How and why did the feeding tube get in this child's life?" As a former nurse, I see the child pictured here is frail; his sunken eyes suggest to me dehydration; his protruding bones suggest he is undernourished—or perhaps ravaged with disease. Why then do we continue to fill his little body with food? Is it symbolic, productive, or is it simply a myth that continuing nutrition will prevent pain and death? Is the decision not to feed through artificial means tantamount to euthanasia? Was the mother given the option to forego life-sustaining interventions like a feeding tube? Did anyone consider that not to feed him may be in the best interests of this dying child? This Visual Case Study speaks volumes to someone who has been there.

Remembering Liam

My grandson was born following a full-term, uneventful pregnancy and normal delivery. His first 4 months were filled with joy and anticipation, as he reached milestones in development. Then—without warning—he began to have infantile spasms. He was diagnosed with lissencephaly, a rare genetic condition marked by profound developmental consequences. His prognosis was grave—a life expectancy of 2–3 years. We cried for what seems to be months, but we

quickly went about the task at hand, to love and enjoy him for whatever time we had. My son-in-law collected volumes of information on Liam's diagnosis. He contacted the world's leading expert in the field and began a dialogue with him. We wanted to know all there was to know about Liam's diagnosis. We also considered ourselves realists; we were as prepared as anyone could be to accept our baby's fate.

Confronting the new reality

As experienced nurses, both my daughter and I were accustomed to "difficult conversations" with families. These types of discussions are never easy; there is really never a good time. Our time came within the first few months after he was diagnosed. Here we were, sitting as a family, talking about things no parent or family should ever have to discuss. As his condition progressed, we knew we would encounter feeding problems. At some point he would simply not open his mouth to accept food, would not be able to get the appropriate brain signal to swallow; and the absorption of nutrients would be compromised. The deterioration of his neurological system would ultimately lead to bowel-evacuation problems. Enemas, suppositories, and manual disimpaction would become a necessary part of his daily routine.

Artificial feeding

I looked at my daughter as she held her beautiful, healthy-looking son. I could see the pain in her eyes through her tears. Next to her sat my son-in-law with tears running down his face. We struggled to talk about

decisions we knew we would have to make. The most controversial, critical issue was artificial feeding. What would we do when “normal feeding” was no longer possible? What possible benefit would there be to artificial feeding? What would we do if he became obstructed? In our initial discussions, my daughter and her husband had strong feelings against artificial feeding and any other life-prolonging interventions. Liam’s comfort and quality of life were the paramount concerns.

For the next year we struggled to maintain adequate nutrition and hydration for our baby. At times we would spend the better part of an entire day just trying to feed him adequate amounts of food. This activity was followed by an aggressive bowel regime. As predicted, he stopped taking oral feedings, and his seizure activity worsened at approximately 2 years of age. The neurologist had explained that his inability to accept oral feedings along with increased, uncontrolled seizure activity would herald his final months. We began to think the unthinkable: This was the beginning of the end.

We made an appointment with his neurologist. She examined him, noted that he was not gaining weight, and, to our disbelief, she raised the issue of inserting a feeding tube. My daughter, then pregnant with her second son, tried to remind her of our earlier discussion about foregoing a feeding tube; she then stated, “I don’t have a problem with your decision, *but* there are others who would call it child abuse!” I will never forget the impact of those words—*child abuse, child abuse*. How could anyone look at our baby and even think such things?

She suggested we see the gastroenterologist. We expected that he certainly would support our decision in light of the major problems we were experiencing with his bowels. Quite the contrary, he insisted on placement of a gastrotomy tube. “You have no option,” he reiterated the neurologist’s refrain, “You can’t let him starve to death; it’s a horrible death.”

How could the medical community of which I was a 44-year veteran be so



Figure 1. Detail from “Child.” Fabric and threads. Reproduced with permission of Deidre Scherer, 2001.

uncaring? What had we done to deserve such inhumane treatment? Wasn’t it bad enough that we were going to lose him?”

Liam’s legacy

For the last 6 months of his life, we watched our baby suffer as he struggled to absorb the artificial feeding. His little body began to look like the child shown in Figure 1. I would look into his eyes, looking for direction, guidance, and meaning to his life. I remember with a sad heart the minutes, hours, and days I had the privilege of having my very own angel here with me. I mourn his passing. His beautiful yet short life has changed the dynamics of our family now and forever. He brought us such joy and such sadness.

He’s just a child sent from above to teach us faith, and hope, and love.
He’s just a child, Liam is his name.
He touched our souls, we’re not the same.*

Doing this Visual Study Case has been a cathartic experience for me. I hope that sharing my innermost feelings about our Liam will benefit

other families. We need to rethink our approach to dying children. We need to look into their eyes and see what they are saying. There is meaning to their brief lives. We only need to listen.

The families are in such pain; guilt can be overwhelming; decision-making can be insurmountably difficult—with the ever-present force of desperation. They cling to hope, a hope that can never be realized. It is incumbent upon professional caretakers to be sensitive, compassionate, and, most important, supportive of the decisions these families make. There is no greater love for a child than parents letting their child go. Who are we to question their decisions?

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**Poem sent by a close family friend. Author unknown.*