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What Parents Face with Their Child's Life-Threatening Illness: Comment on "How Much Emotion Is Enough?" and "Real Life Informs Consent"

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It has been 30 years since Charlie died. I think of him all the time. His deep, piercing eyes in the photo taken by our dear neighbor, Jill, look at me every day. The stocking cap that he wore in that portrait is on my closet shelf above the shirts I wear every day. Occasionally my wife, Cecy, and I say something to each other about Charlie, how old he would be, what he might be doing. In silence, he still lives with us.

This may seem unusual, but I remember that living with his illness was harder than recovering from his death. A child's potentially terminal illness, such as Charlie's leukemia, puts your life on hold. Your emotions and motivation are frozen. He was diagnosed at two and died a few days after his fifth birthday party. Everyday events, seeing him play in the yard, come with the realization that this beautiful child, this wonderful little person, may be taken from you. It becomes impossible to enjoy almost anything with him, because the more loving, talented, happy he is, the greater the dread that this wonderful boy may soon die.

When he died, we were freed from the unbearable stress and uncertainty of test results, possible exposures to other children and their illness, and constant adjustments in our lives out of fear and concern that we would do something wrong. You find yourself yearning for a resolution, one way or the other, as weak as that may seem. When he died, after a mercifully brief illness, simply put, we were relieved. We also experienced a sense of futility, loss after an enormous effort, but at least that was over. What was left was to rebuild our emotional lives, but that seemed easier than the daily roller coaster of hope, worry, adjustment, and dread.

And now, he's a sad memory, a long ago loss, a chapter in our lives that we will never get over and are not trying to block out. What we were given with Charlie was an insight into the important things of life, priorities, things that really matter. We grew from that experience, a good thing perhaps, but it was awful at the time.

Those who provide care to children with terminal illness may gain some insight into this situation from what we went through. Coping with an illness of this type, with the percentages, with the in and out of remission, is at times beyond what you think you can handle, and escape seems a very attractive option. Helping such parents begins with a recognition that they are suffering, and they are doing much of that suffering alone.

After the initial acute stages of Charlie's illness, changes with my job forced us to consider whether we wanted to be closer to our families. We lived in Washington, D.C. I am from Milwaukee and Cecy is from Green Bay. Mothers, fathers, sisters, brothers, and a multitude of relatives lived in those two cities. While our oncologist at Georgetown, Catherine, was so incredibly caring that we named our daughter after her, we agreed that if I could find a job closer to Wisconsin in a location with excellent cancer treatment, we would consider moving. I was told by a colleague that the University of Wisconsin was interviewing for an attorney for its Health Sciences Programs, the hospital, medical school, and such. I got that job, in Madison.

I knew that the clinical care at the university would be up to standard, but it was better than that. As at Georgetown, we bonded with one oncologist, Dorothy. This consistency, seeing her every visit, was extremely reassuring, especially to Cecy. They were friends. Dorothy came to our home, went ice skating with Cecy. We felt complete trust and caring. Maybe this approach would be impossible in most clinical settings, but within this mammoth medical center, we found excellent care for our son and deep concern for what we were going through.

The interesting part was that this move brought us close to family and out of the somewhat impersonal social rituals of Washington, what we had hoped for, but something unexpected happened. We found ourselves in a close-knit Midwestern neighborhood of well educated, mostly university affiliated neighbors who immediately introduced themselves and their children. Many of the moms were mostly at home, the kids played outside on the sidewalks, and since we had to ask about that dread disease chicken pox, they all came to know of Charlie's illness. The lesson is, tell parents not to hide this kind of an illness from anybody.

As wonderful as it was to have family close by, the daily support from our neighbors was a surprise and a Godsend. They were terrific, and we were blessed to have them nearby. Family visits were loaded with emotional baggage. They too were facing the possible loss of a dear child, a member of their family, and could project that impact onto themselves. Family members carry an emotional burden when visiting, new neighbors do not. It was frequently easier to spend time with a neighbor who knew than with your own brother. With family, the raw nerves were right on the edge. With neighbors, there was no agenda, no need to leave with a sense that you have helped Ed and Cecy deal with this tragedy, no need to try to make them feel better.

The neighbor experience is a reason why caregivers, acquaintances, and complete strangers who know the score are wonderful companions for parents with seriously ill children. They are not dealing with their own emotions, and thus have no emotional needs. In short, they can remain open to the stressed-out parents, compared with family who may be pretty stressed-out themselves. They have "emotional reserve."

This explains the well-recognized phenomenon that spouses frequently cannot help each other very much emotionally during the course of this kind of illness. The best that a spouse can hope to do to be helpful is consistency with the tasks and routines of daily living. Men and women form relationships to share experiences, bond emotionally, and travel through life with companionship. When a spouse is down, the partner is there to provide support. When a partner is worried, the spouse is there to help sort it out. When a partner is broken by a major setback, the spouse is there to help put that behind and move on with career, life, and goals. When both parents are dealing with the possible death of their child, they have no emotional reserve available to support their spouse. I don't know of any solution, except that caregivers may simply assure spouses that it's normal for a child's possibly terminal illness to create this distance.

One way for caregivers to help spouses is to try to find a way to speak with both of them. After his initial hospitalization, when both of us slept at Georgetown Hospital, Cecy took Charlie for most of his testing and treatments. I went to work. Since I have a background in healthcare and absolute confidence in Cecy, I

completely trusted and relied upon the information that she brought back from every visit. I did have some contact with the caregivers at Georgetown and in Madison, but that was infrequent.

But I can see that in other cases, allowing one parent to escape the burden of anticipating testing and treatments, and then actually being with their child during treatments such as spinal infusions, could lead to resentment. So try to make arrangements for both parents to come in, or to meet with the father, like me, who is at work and perhaps not facing the reality of what the disease is doing to his child or his wife.

Communicating with family other than the child's parents, even when a sister, for example, is playing an important role in the care of the child, has considerable risks. The sister may relay information to the mother in a more positive light than is warranted, and may exaggerate the positive, trying to boost the spirits of a sister. Thankfully, we had none of this. We had help, companionship, understanding, and prayers from our families, but no involvement or advice with the treatment decisions that we had to make and no predictions or suggestions regarding the outcome.

Another way that caregivers can help these parents is to avoid giving them options and choices that are complex, uncertain, and, especially, clinically unrealistic. If there are options, state them, but never do that without a recommendation. Many parents in this situation will research the course of the disease and available treatments. With the internet, caregivers can be confident that well-educated parents will have looked at everything from the *Ladies Home Journal* to the Mayo Clinic website to NLM's MedLine. Be willing to discuss this literature (be conversant with it for starters) and after looking over the field of options, share your conclusions. Tell parents what you think would be best for their child in terms of treating the illness, side-effects, likelihood of success, and possible complications. Don't burden parents with your indecision or lack of self-confidence.

Parents wish for a cure, but should not be encouraged to hope for the improbable. Becoming hopeful only to be disappointed adds to the emotional roller coaster. Caregivers lose credibility by painting too rosy a picture, and it's hard to recover from a parent saying: "We didn't expect this." Luckily, at Georgetown and Wisconsin, we were given straight answers, clear recommendations, and pretty much knew what we were facing. A clear prediction that the third loss of remission would mean that treatment had failed was better than not knowing what it meant.

We had very few decisions to make regarding Charlie's treatment. Back in the late 1970s the St. Jude protocols were the only approach anyone was taking. We were consistently presented with the rationale for changes in chemo, the need for radiation, and the changing odds for probable success. We knew and were prepared for the situation when Charlie came out of remission and went from a cold to complete respiratory failure in a matter of hours. Cecy and I had no great difficulty accepting the fact that heroic efforts to get him through that illness had only a slight chance of success and that, even if that happened, his chances for any real time of normal living were very poor. So we let him go, and have never regretted that decision. We were ready to make it because Dorothy had patiently told us what to expect.

Parents in this situation will blame themselves when the outcome is poor. Parents who have lost a child go back, relive what they did, looking for a cause, finding fault in their care for the child prior to and during illness. With leukemia, not noticing that a neighbor child playing with your son has a runny nose is an event that can be relived over and over. Reassuring parents that nothing they did led to contracting the disease, a loss of remission, or a final illness must be done over and over. This message does not sink in the first time.

Recovery from the death of a child is usually outside the purview of the healthcare provider. The close bond that forms during treatment with frequent visits, intense communication, and shared emotional experiences ends abruptly with the death of the patient. Parents are expected to seek support and grieve without the professionals. In most cases this is probably acceptable; certainly there is no payment for an oncologist's meeting with parents months after their child's treatment has ended. A brief phone call after several weeks and then after a few months could mean a lot to a parent who has been struggling. Grieving parents are sometimes reluctant to seek professional help. This call could be, in part, to determine whether that seems needed, and parents would understand the concern of someone who treated their child and may welcome that suggestion.

I hope that this personal recount of my experiences will provide some insight into the feelings and needs of parents as they try to cope with the possibly terminal illness of their child, and what a caregiver can do to make that burden easier to bear.

NOTES

This article is a commentary on A. Janvier, "How Much Emotion Is Enough?" in this issue of *JCE*; and F. Cohn, "Real Life Informs Consent," in this issue of *JCE*.