
The Grieving Parent **39**

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Timmy's room is my initiation into the visceral feelings that come when caring for a dying child and his family. I feel reverence for his courage, while the shadow of death leaves me subdued. At times I want to withdraw from the pain. Sometimes, I feel as if I am hovering, self-conscious about my "job" in this prolonged vigil. Timmy is "supposed" to have died in 48 hours but has lingered for 3 weeks. I am unprepared for just how sad I feel, scared that he will die on my shift, wondering how to feel competent. How to be aware of all these feelings, to tolerate them as much as possible, yet to function and to be helpful to parents.

Timmy's mother spoke at his funeral about her son's illness and how she adapted to a situation which initially seemed intolerable. When she first heard that her son had a tumor she was numb. Ominous words eventually become too familiar.

When Timmy had 8 months of remission she wanted to believe that everything was normal. But she lost this longed-for sense of security when he started having difficulty walking. She could not lose him and felt scared that she could no longer protect him from pain and death. As she sat in the hospital room for the last time, she wondered if she should tell him that he was dying. Timmy seemed to sense her loneliness and held her more closely.

The night before Timmy died, the nurses called me because he was cyanotic. I walked in reflexively, ready to examine the patient. I stopped in midstep. The father was curled up next

to Timmy and the mother was holding her son's hand. We all sat quietly, listening to our sadness, awaiting his death.

There is no escape from emotions around a dying child or grieving parents. After Erich Lindemann cared for hundreds of people who lost family members in a major fire, he outlined the grief reaction in his classic 1944 paper. Just as learning the pathophysiology of a disease process helps in treating the patient, Lindemann's¹ observations give a framework for understanding the parents' response. He cited as pathognomonic for grief: (1) somatic distress usually lasting about a half-hour such as tightness of the throat, lack of muscular tone, uncontrollable sighing, loss of appetite; (2) preoccupation with the image of the deceased, even carrying on an active conversation (this can be unsettling because people may feel that they are going crazy); (3) guilt as the survivor becomes convinced that she caused the tragedy (especially true of parents); (4) waves of hostility and free floating anger that raise anxiety about losing control or which become tightly harnessed in stiffness and distance; (5) difficulty functioning at routine chores, which seem to require inordinate amounts of energy; and (6) inability to initiate contact with friends and family, resulting in isolation.

Kübler-Ross² conceptualized the stages of death and dying which parallel the phases of parents' bereavement. She describes the initial shock and disbelief, the bargaining for more time or a different outcome, anger at the unfairness, and despair. Ideally at the final stage, the bereaved parents become more accepting and let go of some of the disappointment. It is problematic and dangerous to oversimplify this theory. Parents may shift abruptly or fluidly between these stages. People react individually, shaped by their previous experiences with death, losses, and disappointments. In addition, different circumstances alter parental reactions (accidental death, expected or chronic death, and finally loss of potential if the child lives).

As residents, we may be on the frontline for sudden deaths. For unexpected deaths parents are in a personal holocaust, something unpredictable, out of control, and horrible. Core expectations and operating principles are overturned. It is as

if they have put their foot on the brakes only to discover that the car accelerates. Nothing is believable or comprehensible. As a resident you sense that you are not really getting through to these parents, and you probably are not. Their child's death makes it impossible for them to hear anything else. They may ask the same questions repeatedly or seem preoccupied by something seemingly irrelevant. They are likely to grab for a positive turn of events when it is clear to you that there is only a bleak outcome. At times like this, don't expect parents to make decisions. It is helpful to get a social worker involved. Attention to concrete assistance (finding a telephone) will be helpful, when even heartfelt consolations may be out of place. Offer the family a chance to be alone with their child. Some parents need to know that the desire to see their child is part of providing closure. Others, particularly if the child is mutilated, may wish simply to talk with the caregivers. Let them tell you what they need.

Even if there is no reasonable connection between a child's death and parental care, parents will feel guilty and responsible. Parents cannot accept reassurance and will distort "facts" to punish themselves. A resident described this painful scene: Initially a baby had an apparently innocuous rash which rapidly progressed to disfiguring all the extremities and the face. When overwhelming meningococcal infection was diagnosed, the mother blamed herself for not having brought her child to the hospital sooner. When he finally died from the infection, the mother screamed apologies and threw herself on this totally disfigured baby.

Although often initially irrelevant, parents need honest reassurance that there is nothing that they could have done. It is helpful to arrange a follow-up telephone conversation a few days later and then several weeks later when they can ask questions and integrate information. Even if they have an established relationship with a pediatrician, the resident can provide information about events the pediatrician didn't witness. (Be sure to talk with the family's pediatrician first to get an update and to be sure that you provide consistent information.)

LOSSES SHORT OF DEATH

When parents speculate about their child's future they rarely consider that their child may have any abnormality that upsets their expectations. Initially parents may try to avoid the disappointment of an unfortunate diagnosis by bargaining for a different outcome or by changing physicians. Trying to convince the parents that many people have shared their plight can make the parents feel as though you are insensitive to their disappointment and loss. It may take some time for the parents to accept fully that a part of their dream is lost; they will need to grieve, and then build a new set of expectations. One disconsolate parent confided, "You know, I don't think that I'm ever going to accept the fact that my daughter has a lifelong and serious illness. On most days I have learned to come to terms with it, but I cannot accept it."

Ideally, parents eventually adapt and accept their child's condition and then focus on what needs to be done, what will help, and what can be appreciated. A mother described her child with cerebral palsy: "I used to look at Maggie and at first all I could see was that she was retarded, had contractures, and was blind. Over the years looking at Maggie it's as if she's in a time warp yet she seems to enjoy the most basic pleasures—our voices, food, laughter—which I never thought I could appreciate at the beginning. I still wonder if this infection or the next will get her, but I can allow myself to enjoy her more despite the worry."

Parents with a chronically ill child can seemingly distance themselves from their child's course. Even years after an initial diagnosis, parents may be so overwhelmed by the enormity of their loss that they cannot stay focused on the present-day condition of their child. Some parents are in such pain that they may prematurely separate and withdraw from their child. This is called anticipatory grief, mourning months or even years before the child faces death. And finally, after many false alarms, some parents may deny that their child is really dying. Speak with the attending physician and review how to respond to parental denial, stress, and any marital discord.

Parents may feel a special responsibility when their chronically ill child is dying, especially if they are actively involved

with the day-to-day management of their child's illness. One mother remembers that when her son died he was fluid-restricted and could have only one thimbleful of water. He was begging her for more water right before he died and she always reprimands herself that she didn't listen.

Sometimes, when the child has been suffering a long time (screaming with pain because of bone metastases), parents may be relieved that their ordeal is almost over. A resident's careless comments such as, "He looks good," may not only sound insincere but may also worry the parents that their child will stabilize at an intolerable level of pain. Parents value measures that make the child comfortable.

In unusual circumstances, it may be necessary to keep the child alive because of parents' need for additional time to accept the inevitability of their child's death. In the nursery, the staff was impatient with a family for keeping the newborn on a respirator and prolonging the staff's intense workload and discomfort after a diagnosis had been made of a fatal, progressive muscular dystrophy. The parents had wanted to wait 2 more days so that their child would not die on Mother's Day. At times like this our contribution may be only to ease a memory.

The pace and style of grieving can vary enormously and depends on what parents bring to dealing with their loss: how they coped with losses in the past, whether the child has a special meaning, and how much support they are getting. Each parent may respond differently. Mothers tend to be more immediately expressive and also have sustaining relationships in the hospital especially with primary nurses. Mothers often need to talk and actively remember the child on an hourly, then daily basis for months. Fathers may appear more reserved and feel a quiet frustration at being impotent to protect their child. Becoming more involved in outside work makes fathers seem even more detached. A resident in the neonatal intensive care unit (NICU) described parental differences well: the mother held the baby in her arms as he died. The father meanwhile was preoccupied with getting his camera from the car so he could have a picture forever. Another father, who was in the Navy, chose the unpopular night watch so that he could grieve in privacy.

As house staff we only see the acute phase of grief and only rarely follow its natural course in outpatient settings. Parental grieving is intense and prolonged, commonly lasting years. Approximately one fifth of parents, mostly mothers, will not maintain a steady return to daily functioning but instead become clinically depressed as the grief and guilt become a way of life more than a year after the death. Some pediatric services, commonly through primary nurses or social workers, will use protocols to follow by telephone a grieving family every 3 to 6 months for 2 or more years. If there is unresolved grief or signs of depression, clinical evaluation and psychiatric referral are indicated.

HOUSE OFFICER REACTIONS

A death can be experienced at a distance with no personal connection, or as a tragedy that breaks our heart. We make a choice of how to respond. There is no measured recipe for sharing in family despair. Parents usually don't remember what is said but rather how it is said. Sometimes if we have made a personal investment, we may feel like crying, or want to embrace the family. Fighting the sadness and walking away can be more damaging because it appears unfeeling and is experienced as a rejection. Identifying with the family, imagining what it would feel like to lose a child, we may withdraw from the pain to protect ourselves. This pain may seem intolerable, but it can be endured and is part of caring for the family.

It is important to be aware about what delivering bad news triggers in ourselves. For example, based on our inexperience, we may feel that we are in some way accountable or to blame for the death. A mother angrily asked if I realized what I was saying by telling her that further chemotherapy for her daughter was futile. The tragedy was that there was no treatment, not that I was saying it. But the sense of responsibility for the deed can make us withdraw, at a time when parents badly need our presence.

Generally our task is defined as taking care of the living, implicitly suggesting that someone dying is our failure. Thus we are susceptible to an overriding sense of inadequacy, as if

TABLE 39-1.

Practical Approaches to Discussing Distressing Medical Information With Parents

1. Shake hands and make eye contact.
2. Make sure your setting is in a quiet room with no disturbances, rather than a public hallway.
3. For the period of time you have, try to put yourself in a timeless place. By sitting at the edge of your seat, glancing at your watch, you communicate that you do not have time for the sadness.
4. Sometimes the "urge just to get it said" drives us to talk too quickly. We may hope to minimize our own pain by filling up the silence with chatter.
5. If you talk for more than 3 to 5 minutes at a tense time like this, you have probably talked too much.
6. Sitting with parents in silence can be in and of itself helpful.
7. Taking the time to listen allows the parents to speak.
8. Review with parents if they have had previous crises or losses, how they reacted, and what they found helpful. If past patterns were maladaptive, consider closer follow-up.
9. Avoid confrontation or repeated reassurance.
10. Respect the parents' defenses. If they are denying, don't push your own agenda.
11. If appropriate, ask to be included when a senior attending has to break bad news (usually in our more alert hours). Although we may feel like we are intruding, it is similar to any procedure that we want to learn: the more exposure we have to different approaches the better. It can be seen as a dress rehearsal helping us to tolerate the sadness. As the house officer, we sometimes have had the most contact with the parents and our presence can be a comfort.

our professional competence is called into question. An intern described a futile effort to resuscitate a baby for an hour. When it was clear that nothing else could be done, suddenly all the other doctors disappeared. He felt the isolation was an indictment. When he approached people later they seemed to brush it off, as if there was no need to talk. Finding other people to talk to not only breaks the code of silence surrounding death, but also allows you ease of the overwhelming feelings and reassurance that, like the family, you are not alone. Most

people face death several times in a lifetime. For doctors it may almost be a daily event. A staff meeting can help people acknowledge these feelings and regain stamina.

It is a profound experience to work with families that are suffering. We not only acquire knowledge but also broaden our sensitivity and understanding of ourselves. The underlying patience we bring to tragedy, the courage in confronting the unknown, is dictated by our own understanding of death. Most times, we are lulled into complacency, where our children, we ourselves, and our loved ones are protected by a guise of permanency. Auden's poem, "Musée des Beaux Arts," acknowledges our readiness to "walk just dully along" rather than explore suffering.

TABLE 39-2.

Common Practical Issues

1. Siblings visiting: Parents may wonder if their other children should be allowed to see the dead or dying sibling. If the parents are uncomfortable, find out what is troubling for them. First, determine if the child wants to visit. If the child is reluctant, this should be respected as it can be very frightening. The young child needs to be prepared for how the patient looks. Unless children say they don't want to see, it is reasonable to have one last view.
2. Autopsy requests: Usually to complete the death certificate it is required that someone request an autopsy. Ideally, the person who knows the parent best will request an autopsy. Unfortunately, residents are caught in the bind of making what appears to be an unfeeling request. The easiest way is to present it matter-of-factly as an option that may provide more understanding of the disease process or why the child died. If there has been a long-standing relationship with an attending, seek out the attending's consultation or involvement in the autopsy request.
3. Funeral: The house officer, if close with the family, may find much comfort and relief to see the strength of the family's community and to show that one's concern continues. The funeral may also be directly helpful to the resident in that it is a time for personal grieving and taking the time to process and begin to recover from the patient's death.

About suffering they were never wrong,
The Old Masters: how well they understood
Its human position; how it takes place
While someone else is eating or opening a window or just
walking dully along?

As doctors we are not detached observers but rather participants drawn into an intimate, privileged position. If we choose, we can be responsive and involved (Tables 39-1 and 39-2).

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SUGGESTED READINGS

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