



## The Invisible Grievors

Our story of grief continues with the invisible world of people who are coping with ongoing loss due to terminal or serious illness, chronic physical or mental limitations, and those coping with the threat of the ultimate loss—death.

You never know whether the person walking by you has a loved one at home lying in a bed of pain or if the woman sitting at the next table in the coffee shop has just come from visiting a dear one who no longer recognizes her. You may not know that the man buying tickets at the theme park is waiting for a child with braces who is being helped out of the car in the handicapped parking space.

While attention is typically drawn to people who have a loved one actively dying or who have recently lost someone—chronic, life-limiting conditions are given less attention by friends and neighbors after a while. For some, chronic can indicate “we have become accustomed to the situation at the house down the street, and don’t think about it much anymore.” For the family members providing continuing care for the chronically ill, there is no such thing as forgetting about it; they cannot “turn their eyes away.” They



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become part of a less visible world of grievors who must cope daily with both multiple, accumulating, and anticipated losses.

It is so important for us to be aware of the grief experienced by those individuals who are seriously ill, those living with permanent physical or intellectual challenges, and those with a lingering terminal illness – as well as the grief of their family members and friends. The climate of grief surrounding such families is often less understood and attended to than that of those who are bereaved. Consequently, these families typically receive less support than those who have already lost a loved one. The difference comes from the fact that the ill, disabled, and dying persons are still here—breathing, eating and requiring some level of care, attention, and love. Some are at home, yet many more are in hospitals, hospices, or nursing homes.



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### The Dying and The Family

Tending to the dying requires a different consciousness than tending to the memory of the no-longer living. What does “dying” mean? What do you say to a dying person or to the spouse, or child, or sibling, or parent, or best friend of a dying person? How do you offer comfort without crushing hope or raising it unrealistically? What do you ask? What can you do to help?

When I enter the room of a dying person I feel as if I am entering a sacred place. It may be dark or brightly lit; the television may be blaring or it may be very quiet; it may be hot, stuffy and have an unpleasant odor. It is not unusual for a seriously ill or dying person to confide in me about concerns that they feel they cannot discuss with their families. Often, they want to protect other family members from pain. I may not speak very much; I want to listen more than speak.

Being with a person who is at the very end of life can be an awesome experience. Family members need to be encouraged to use the final hours or moments to the fullest. I make every effort, within the scope of family and cultural traditions, to facilitate conversation and physical

contact, saying some words of goodbye or offering forgiveness in whatever way the family members are willing or able to do. This can also be a time for religious or spiritual practices. The final moments with a dying loved one can remain as a memory photo throughout a lifetime.

Sometimes family members will not know what to do in the final hours and minutes of their dying loved one's life. They may sit in the room, nearby or at a distance, looking at their loved one — or trying not to look. Some may congregate outside of the room— waiting. They say things like, “He isn't really here anymore,” or “She isn't really Mom anymore.” Still others may climb right into bed and embrace the dying man or woman. They may hold the person's hand, caress her face or wipe it with a damp cloth, or touch her arm, neck, or shoulders. They may talk to their dying loved one, saying, “I love you.” They may express gratitude and find a way to say “goodbye.” For many individuals, this final contact is a very important part of their grief process.

A young physician on weekend duty was called in to see an elderly woman who was dying on an inpatient medical unit. He was surprised to find only one visitor standing outside of the woman's room. When he inquired as to the whereabouts of the rest of the family he was informed that a number of others, including the woman's adult children and her grandchildren, had been sent home so grandma “could die in peace.” He immediately had the lone relative phone all of the family who had been sent away and had them all return. He invited them into the room, invited them to

circle the bed, make physical contact with the dying woman, and say their loving goodbyes to her. After the woman died, before they departed, they tearfully thanked the doctor for enabling this never-to-be-forgotten gift. This was their “memory photo.”

The young doctor is our son Ronald, —he was 12 years old when his brother Steven died.

### **Chronic Illness/Disability and the Family**

Some chronic, life-limiting illnesses or injuries that do not have a mortality risk may linger for many years but can create risk for other medical problems. These conditions include chronic bedsores, infections, depression, demoralization, and other emotional disorders. Other conditions which require long-term care where the individual may be significantly impaired either physically, mentally or both, and live for many years.

The existence of a life threatening illness in the family shifts the focus of attention and energy to the affected loved one and alters the psychosocial climate.

Family members will need to adapt to new ways to view their family unit and the way they relate to the outside world.

During the three years from the time of our son Steven's diagnosis of cancer until his death at age eight, we were a family living with a chronic, life-threatening illness. When the crushing news of his relapse came just before spring break, we decided, with his physician's approval, that the five of us would take a trip to Disney World. It was during this trip to Florida that we truly saw how different we were

from other families. Steven was weak and not able to do very much in the way of rides or waiting in line. My wife and I were uncomfortably aware of other people looking at us. We overheard some young children ask their parents, “Mommy, why is that boy in a wheelchair?” Even when people didn't say anything about Steven, we detected subtle reactions to the fact that our family was “different.”

In our minds, we stood out as very different from them. Later, we began to notice other family groups who were different— a mother in a wheelchair, a child in braces up on her father's shoulders, a teenager with a portable oxygen tank and nasal tube, and several families with Downs Syndrome children.

People often do not know what to do – to look away? nod hello and smile? I always appreciated it when strangers would talk directly to Steven and ask him if he was having a good time at the event or where we are from or what's his favorite thing so far?

You never know what is going on in the hearts of people – walking by, standing in a checkout line behind you or sitting at a nearby restaurant table. If they are friends or neighbors in families as described above – please reach out to them.

\*Excerpted from the author's book – Helping Grieving People –When Tears Are Not Enough: A Handbook For Care Providers. Permission to reprint is required.

We are all careproviders.



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