



Loss and Grief in the Next Room:

Families coping with chronic illness, disability or terminal illness

by J. Shep Jeffreys, Ed.D., F.T.

Our story of grief continues with the invisible world of people who are coping with ongoing loss due to serious illness, chronic physical 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 or that the family in the pew behind you is praying for a loved one who is in a coma and not expected to live much longer.

While attention is drawn to people who have a loved one actively dying or who have recently lost someone, chronic, life-limiting conditions become less attended to by friends and neighbors after a while. For some, *chronic* means “we have become accustomed to seeing the wheel-chair-bound mother in the house down the street and don’t think about her much anymore”; or what life might be like for the man we see taking walks with a



portable oxygen pack and nasal tube. For the family members providing continuing care for the terminally ill, chronically ill and/or permanently disabled, there is no such thing as forgetting about it; they cannot turn their eyes away and forget. They become part of a less visible world of grievers who must cope daily with both multiple, accumulating, and anticipated losses.

The Many Faces Of Grief.

As we have mentioned earlier, the human grief response is not reserved for death, divorce or separation only. In addition to the grief of the person who is ill or disabled and requires special care, family members who provide this care and support are also dealing with grief. The climate of grief surrounding such families is often

less understood by neighbors than the grief of those who are bereaved. As a result, these families may be less supported 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, love and attention. Some are at home, yet many more are in hospitals, hospices or nursing homes. One study found that about 70% of people who die are in a hospital or a nursing home at the time of death. Over 40 million family caregivers care for the remaining 30%, who die at home. More than 1,700,000 people die annually from illnesses and many of these deaths represent months or even years of care by family members.

Wherever the terminally ill or chronically ill/disabled person is in residence, the continuing grief of family members will be affected by medical reports, mood and symptoms of the cared for person, limitations on life activities and the statements and reactions of other family members, neighbors and community. You may be thinking right now of someone in your family or in some part of your community. A man with paralysis due to stroke, a teenager who has cerebral palsy,

a woman whose cancer has metastasized and is now under hospice care, a bald-headed child being treated for leukemia, a returning member of our armed forces who is an amputee or has suffered other physical and emotional damages.

Effects On The Families.

Families caring for a member with a life-limiting or a terminal condition will typically find themselves drained of physical and emotional energy, find their life activities severely restricted and their finances depleted. Individuals who cannot take care of their personal basic needs – sitting up, dressing, bathing, toileting, feeding and transferring from one location to another – require strong and continuing physical assistance. Finances to purchase needed homecare services may not be available and families will have to manage this all by themselves. Other than long-term insurance, there is no coverage for extended home care. However, where hospice service is appropriate, there usually is significant relief for the family.

Such families need support from their extended family, friends, neighbors, religious groups and other parts of their community. This can be in the form of “check-in” phone calls and/or visits, providing some meals, food shopping, house cleaning, laundry, transporting to medical appointments, making phone calls, just visiting and discussing the news of the community, praying together or reading stories, playing board games and doing other errands needed. These families may be truly shut off from the outside world and you can bring some freshness to

their lives. Please don't say, “Call me if you need me.” Rather say, “I will call you tomorrow;” and please be sure that you do.

Dying Persons And Their Families.

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? In our next article we will focus on the needs of the dying and their families.

Peace,



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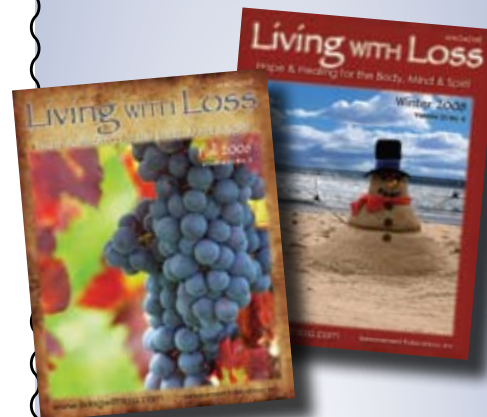


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