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As dying changes, so does grieving

"Saying Goodbye: How Families Can Find Renewal Through Loss" co-authored by Barbara Okun, explores "contemporary grief" *Photo: Mary Knox Merrill*

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"Saying Goodbye: How Families Can Find Renewal Through Loss" co-authored by Barbara Okun, a Northeastern University professor of **applied psychology**, explores "contemporary grief" — the new reality of prolonged death, with earlier warning due to regular exams and advanced diagnostic tests, and potent treatments that target terminal diseases and extend life. Looking back at Elizabeth Kubler-Ross's landmark 1969 book, "On Death and Dying," which laid out a five-step model for grieving, Okun discusses the new stages of grief.

How have the stages of grieving been altered?

The major difference is that, with modern medicine prolonging the lives of people with a potentially fatal illness, death becomes a drawn-out process rather than an event.

The stages of this prolonged grieving include: crisis, when the patient and family are awaiting tests to confirm diagnoses and dealing with the shock, fear and anxiety about lack of control that accompanies this news; unity, a time of everyone pulling together to establish a medical team and legal and social services teams, and the rules and roles of family behavior are in the process of reorganization. Past resentments and alliances are put aside to focus on the tasks that need to be attended to; upheaval, a period like a roller coaster where there are remissions, recurrences and treatment side effects, and family members feel ambivalence, shame and guilt for their feelings about burdens, obligations, responsibilities. Tempers begin to fray and previous family dynamics may surface; resolution, the time when the end is near and people — often including the patient — plan for how they want things to be at the end; and renewal, after death, when people first feel relief that it is over, guilt for those feelings and then the grieving that, while never ending, recedes over time as people reorganize their lives and move on.

How are the dying affected now that they are included in the grieving process?

The dying may direct how they want to live whatever time they have left, doing things they have put off, repairing relationships, revising priorities, participating in treatment choices, estate planning, deciding who their health care proxy will be, preparing the family for life without them and also helping others to do what he or she typically handled.

In the resolution stage, the dying often decide where and how they want to die: In hospice? At home? In a hospital? And whom do they want by their side? Many prepare their own funeral service, selecting ushers, music and the officiator, writing letters and saying goodbye the way they want to.

Does prolonged dying give families time to say goodbye and find comfort, or does it mean prolonged sadness?

People have the time to review their lives together, to have fun and enjoy each other, to prepare one another. This is a process of balancing hope for the best with preparation for the worst, for learning to live with uncertainty and tie up loose ends. There is sadness and anger but there is also pleasure about being able to make choices, enjoy relationships and say and do what you wish to others. How families negotiate this process

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is significant — we recommend open communication, having difficult conversations, sharing the caretaking, delegating and assigning tasks, agreeing to disagree and caring empathically for each other.

As people grieve during prolonged illness, are there separate stages for grief once a family member has passed?

Once a family member has passed, there is enormous sadness, but not the shock and denial that Kubler-Ross suggested. She was a pioneer, but dying was much more sudden and quick in her era. People typically go through weeks and months of being task-focused and there are individual differences in how people grieve. Grief is life-long. It changes with time and becomes a part of you. The lost one is always a part of you.

How might families find comfort in contemporary grief?

I think they can find comfort in the new relationships with each other that they have developed during the process of dying, in the fact that they have shared and worked together to ensure that the lost one got to choose how to spend his or her last years and that everyone had a chance to say goodbye in their own way.

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