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Saying Goodbye

Coping With a Loved One's Terminal Illness



Nowadays, it's more common to lose a loved one to a lingering terminal illness than to a sudden death. Family and close friends, along with the person with the life-limiting illness, now have much longer to face up to the prospect of death and say their goodbyes. This in turn has changed the grieving process to one with unique stages that are increasingly borne by families, rather than just individuals.

The long goodbye

Today, having a loved one live with a terminal diagnosis for an extended period of time is fast replacing sudden and unexpected death as the norm. Consider, for example, that two

thirds of those who are diagnosed with cancer currently have a five-year survival rate.

The result of all of this is that death has become less and less a sudden and unexpected *event*. In its place has come a *process* that begins with a life-threatening diagnosis, proceeds through a period of treatment (or treatments), and ends eventually in death. This process means that both the terminally ill individual and the family are increasingly confronted with the need to “live with death” for a prolonged period of time.

Because the nature of death and dying has changed so dramatically, the way we grieve has also changed. The new grief differs from traditional grief in significant ways, not the least of which is that it includes the terminally ill person. In addition, what has increasingly become a protracted process as opposed to an event not only leaves individuals to mourn but typically draws in the entire family of the dying person for months or even for years. This process has the potential to alter lifestyles and force families to confront issues that once were dealt with only after the death of the loved one. It can easily evoke issues from the past that were never fully addressed or resolved.

Grief is a family matter

Grief today is a *family* matter as much as it is an individual one. What is needed is a new template—one that is relevant to families and their experience. That is what we present here. This model is intended to be a road map that you and your family can turn to as you navigate your way through the current realities of death and dying. And by the way, when we use the word *family*, we include not only blood relations but all those who have a significant connection to the person who carries the diagnosis.

The challenges that families must face when confronted with a terminal diagnosis of a loved one are complex. They include evolving new structures and dynamics as the person they love slowly slips away. It means learning how to cope with setbacks and deterioration as well as periods of seeming remission. It means dealing with the complexities of extended grief, which can wear individuals down and lead at times to ambivalence or the unpleasant feeling we get when we find ourselves wishing that the process would end. It means talking with a dying loved one about mortality and other issues that do not arise when death strikes suddenly and unexpectedly. It means learning to make space for extended grief in lifestyles that are typically busier than those of earlier generations.

Perhaps most important, the new grief involves confronting family issues that may have been dormant but unresolved for many years. These issues typically reemerge as families move past their initial reactions to a terminal diagnosis and are forced to interact and work

together through a process of extended grief. Finally, it means moving forward together as a stronger family after a loved one passes.

Without understanding and without guidance in each of these areas, family members who are forced by circumstances to cope with prolonged grief are vulnerable to serious psychological consequences, including depression, guilt, and debilitating anxiety. These circumstances can even lead to physical illness. Whole families are vulnerable to rupture as a result of a resurgence of unresolved issues that are unearthed as a result of a prolonged terminal illness in a loved one. Even loving couples may find their relationships in jeopardy as a consequence of unwanted lifestyle changes. What families need now—and will need in the future—is guidance for how to anticipate and deal with such issues.

We are proposing here a five-stage model for family grief. However, we want to caution readers not to expect that there will be hard-and-fast boundaries separating these stages. While virtually every family will experience each stage, you should not expect one stage to simply end and another to begin. On the contrary, anticipate finding yourself dealing with issues associated with more than one stage at any given time. In addition, the stages vary in length and intensity, depending, for example, on the length of the terminal illness and whether there are any significant periods of remission.

Stage 1: Crisis

The diagnosis of a terminal illness or a potentially terminal illness creates a *crisis* for the family. It disrupts the family's equilibrium, just as a rock thrown into the middle of a still pond disrupts its equilibrium. Factors that affect how you may react at this stage include:

- The history of as well as the current status of your relationship with the ill family member
- Whether the loved one is a spouse, a parent or a child.
- What your and the patient's past (and current) roles in the family are.

Anxiety is the most common initial reaction to the news that a family member is terminally ill. However, if your relationship with the terminal family member has been strained or alienated, you may also find yourself feeling guilty, resentful, or angry. If the terminally ill person is a child or young adult, anger at the seeming injustice of early death may be the dominant emotion shared by family members at this initial stage.

At this first stage of the new grief, all adult family members benefit from guidance issues such as what to expect in terms of their own emotional reactions, whom to seek support from, whom to share memories and emotions, with, and what to expect when they meet with the dying loved one and other family members.

Stage 2: Unity

The reality of impending death has the effect of pressing family members to put even longstanding complaints or grudges on hold as they pull together to move into this second stage of grieving. This may be no problem for family members who have no conflicted feelings or unresolved issues of their own with the loved one, such as favored children. On the other hand, if you feel that you were always a less favored child (or the family scapegoat), you should not be surprised if you experience a complex combination of emotions even as you strive to be a good team member.

In Stage 2, the needs of the dying become paramount. A major issue for all family members in Stage 2 is how they will define their roles with respect to one another and the terminally ill member. If they do not give some thought to this—a situation that is quite common—they may quickly find themselves having regressed into roles they played years earlier, as children and adolescents, but that they would not consciously choose now.

In this second stage of the grief process the family has much work to do, including:

- Choosing and working with a medical team
- Navigating the social services maze
- Pursuing and qualifying for entitlements
- Ensuring that critical legal work (wills, living wills, and so on) is completed

How the family organizes itself so as to complete these tasks can have powerful psychological and effects on each member, depending on how comfortable each feels with the role he or she is playing.

Stage 3: Upheaval

The family will eventually enter this third stage of grieving if the process of dying goes on for some time, which it typically does today. At this point, the unity that characterizes Stage 2 begins to wear thin as the lifestyles of all involved, whether they recognize it or not, gradually undergo some significant changes. Whereas thoughts and feelings about these

changes may have heretofore been put on the back burner, they can no longer be suppressed and begin to leak out. One such feeling is ambivalence, meaning mixed feelings that many people experience when the process of dying evolves into a protracted one in which the loved one's overall quality of life slowly deteriorates.

Emotions such as guilt, anger, and resentment are likely to emerge in Stage 3. At this stage the most important issue becomes being able to *communicate* honestly with other family members and with trusted loved ones. Suppressing thoughts and feelings about such upheavals can lead to strained relationships and eventually can cause the entire family to fall apart.

Stage 4: Resolution

As a family moves into the fourth stage of grief, the terminally ill loved one's health is typically marked by gradual deterioration, punctuated perhaps by periods of stabilization or temporary improvement, and the effects of the prolonged grief process can and should no longer be ignored.

As they enter Stage 4, family members often find themselves having more memories—both good and bad—of past experiences which usually reflect relationships with the patient, these important memories are different, typically telling the story of how family members have viewed their place and role in the family. Often they point to unresolved issues. Some of these memories may evoke feelings of joy or nostalgia; others, however, may evoke anger, jealousy, or envy. Others still cause feelings of pride or, alternatively, of shame and embarrassment.

Stage 4 represents an unprecedented opportunity, if families only choose to seize it. It is an opportunity to resolve longstanding issues, heal wounds, and redefine one's role in the family—indeed, to alter a family member's very identity. Every family, as they say, has its share of skeletons in the closet. It is in this fourth stage of the grief process that the skeletons can be brought out of the closet, exposed to the light of the day, and cast forever into oblivion.

In particular, Stage 4 is a time when the following can be addressed and resolved:

- Old rivalries and jealousies
- Long-held resentments

These two issues stand in the way of families being able to bond together as strongly as they

could and love one another unconditionally. Some family members, however, may react to this opportunity with anxiety instead of with enthusiasm. Rather than seizing the opportunity, they may try to avoid facing these issues. However, facing up to them offers the best opportunity for the family as a whole to move on together to a happier future. In this way the process of family grief can set the stage for growth and renewal for all involved.

Stage 5: Renewal

The final stage of grief actually begins with the funeral and the celebration of the life of the now-lost family member. This is a time of mixed emotions, to be sure, including both sadness and relief. If the family has successfully negotiated the previous four stages, however, this final stage also opens yet another door: to collective as well as personal renewal. It can be a celebration of life as much as it is a marking of a loss. It can be a time of creativity and planning, as the family decides, for example, how it will commemorate anniversaries and birthdays.

As much as Stage 5 is a time for remembrances, it is also a time for looking forward, to revitalized relationships and to new family traditions.

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