

*THE BLOG*

08/08/2011 08:16 am ET Updated Oct 08, 2011

# Terminal Illness and Family Upheaval

By Joseph Nowinski, Ph.D.

Modern medicine is rapidly transforming the nature of death. **Increasingly, sudden or quick death as the norm is being replaced with a lengthy process that only begins with a terminal diagnosis that marks the beginning of a long, winding and grueling crisis. This process is what we call the new grief.** Unlike sudden death this new grief is a crisis that includes the patient as well as his or her family and loved ones. And much like Ebenezer Scrooge in Charles Dickens's "A Christmas Carol," during the long night that is terminal illness families may find themselves confronted by many unpleasant ghosts before dawn arrives. However, just as Dickens's story has a happy ending, so can the process of family grief.

## **Upheaval: A Normal Part of the New Grief**

**When they first learn that a family member is facing a terminal diagnosis most families will typically come together and rally their resources in order to aid the ill family member. We call this the “unity” stage of the new grief.**

At this point other priorities are often pushed aside and old grievances are put on hold as the family comes together. One or more family members may emerge as primary caregivers, while others may take on other responsibilities that were once carried by the patient. In “Saying Goodbye: How Families Can Find Renewal through Loss” we offer families specific guidelines about things that need to be addressed even at this early stage in the process. That advice is based on the many interviews we conducted with families who found themselves in the throes of this new grief, as well as with those who’d gone through it and could now look back and reflect.

**Even as the family pulls together in this unity stage there will usually be some initial signs that reflect the underlying upheaval that prolonged terminal illness creates.** Just living with the uncertainty that is associated with a terminal diagnosis is stressful, not only for the patient but for the entire family. Beyond that there are the actual lifestyle changes it creates. Loved ones may initially have willingly altered their own lives and shifted priorities to pitch in and accommodate the needs of

the ill family member. However, that is only the beginning of a process that can extend for years. Over time, stresses and tensions will almost inevitably emerge, for the following reasons:

- Lifestyles can get seriously skewed and out of balance as a consequence of added responsibilities. Established routines become disrupted and new ones may have to be added. Priorities may have to be realigned and the time devoted to them reapportioned. The impact of these changes may not be very noticeable (or bothersome) at first, but eventually it can't be ignored.

- Former family roles are often re-created and issues that may have been buried long ago begin to rear their heads again. For example, people find themselves falling back into old family roles, such as mediator or problem solver, that they wouldn't choose now or had thought they'd shed long ago.

Here is how one woman — the only child of divorced parents — described the impact her father's prolonged battle with cancer has had on her life:

“Managing the rest of my life has been so hard. “Numbing exhaustion” is a constant state for me — emotionally and physically. I feel like I can't even process and grieve because I need to keep going and doing the next thing and there is always some sort of crisis. I work full time as a paralegal and can hardly focus on work, plus I am constantly on the phone with doctors and taking my dad to appointments. I've been

married for just two years and this situation has put so much strain on my relationship with my husband in so many ways. Yoga is the only thing that I have that makes me feel better and I never have time to go. **I always feel stretched thin and like I'm not doing well enough at anything.** I know my dad would not want his illness to be so stressful for me and of course I feel incredibly guilty for ever feeling like I want this to be over, for him to die so I can have my life back. At the same time, this has changed me profoundly in so many ways

The above is a perfect example of what we mean by upheaval. Sooner or later the family confronting the new grief will drift into this stage.

### **What to Expect**

First and foremost, **expect the situation to be fluid. Also, expect everyone to experience fluctuating moods as well as periodic changes of attitude — for example, from a willing and eager helper to a resentful and reluctant helper.** Tensions can become particularly volatile during periods of remission, when it seems as if everything is back to normal and at least some family members want a respite from any added responsibilities they have taken on.

Family dynamics will dictate how the family — as individuals and as a unit — copes with the situation. “Family dynamics” means the way a family functions, including the unwritten rules it lives by and the roles

that different family members play. Some family members, for example, are accustomed to playing the role of mediator or peacemaker; others are organizers. **The strains in the family system that are caused by terminal illness first show up in the form of emotions that family members may feel uncomfortable acknowledging. Anger, resentment, and jealousy are the most common ones. Family members may feel guilty about having such feelings in a time of crisis and may try to suppress them. But such feelings are normal and to be expected. You can try to suppress such feelings, but in the end you can't help feeling as you do. Try as you may, these feelings will occasionally erupt. As dismaying as this may be, it is actually a potentially healthy thing for the family as a whole because it gives everyone an opportunity to face reality — the stresses on the family — and to create new family dynamics that meet changing circumstances.**

**It is not unusual for the stress created by chronic or terminal illness to manifest in impatience — with the person who is ill, with fellow caregivers, and with professionals. At this point everyone's attentiveness is stretched and their reserves of energy are depleted; therefore, everyone is vulnerable to losing patience.**

### **What to Do**

First and foremost: ***Accept and embrace the reality***

***of upheaval, instead of running from it or resisting it. There is use denying that the new grief places a great deal of stress on families. As time passes, it can affect every aspect of family life. It can be very uncomfortable. Yet it is that very discomfort which can set the stage for family renewal.***

There is a saying that goes something like this: *Every crisis creates opportunities*. And so it is with terminal illness. As disruptive as the terminal illness of a loved one can be, it also presents the family with an opportunity. Embracing upheaval affords us the chance to tie up loose ends and resolve issues that may have remained buried for many years.

For more information on upheaval and the new grief visit [www.newgrief.com](http://www.newgrief.com)

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