

Prolonged illness and grieving

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ABSTRACT

A new book examines how patterns of grieving are changing as people and families endure terminal illnesses for longer periods of time.

FULL TEXT

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When terminal illness lasts a long time, so does saying goodbye.

The death of someone you love is never easy to experience, whether it comes suddenly or after a long illness. And the way we grieve depends on the circumstances. Over the years, experts have proposed many models of grief to help people understand what they're going through. Elisabeth Kübler-Ross introduced the idea of "five stages of grief" (denial, anger, bargaining, depression, and acceptance) in 1969 in her landmark book, *On Death and Dying*. In those days, sudden and unexpected death was more common than it is now. Thanks to advances in diagnosis and treatment, people are living longer with life-threatening illnesses, such as cancers and heart disease. One book argues that this changing reality has changed the grieving process as well.

In *Saying Goodbye: How Families Can Find Renewal Through Loss*, Barbara Okun, a psychologist and clinical instructor at Harvard Medical School, and psychologist Joseph Nowinski propose a new five-stage model -- crisis, unity, upheaval, resolution, and renewal -- for what they call the "new grief." (See "Stages of the new grief.") In the book, which is co-published by Harvard Health Publications (publisher of *Harvard Women's Health Watch*), Okun and Nowinski also suggest how families can better negotiate the challenges of protracted and likely terminal illnesses. We spoke with Okun about some of the issues involved. Here are some excerpts from that interview.

Stages of the new grief In *Saying Goodbye: How Families Can Find Renewal Through Loss*, Barbara Okun and Joseph Nowinski identify a pattern of grief commonly encountered by families who face the loss of a loved one to protracted illness. It includes the following stages: **Crisis.** Family life is disrupted by the diagnosis. People are upset, saddened, and anxious. Other, unexpected feelings -- resentment, anger, or guilt -- may also emerge but often go unexpressed in the interest of rallying around the patient. **Unity.** The patient's needs are paramount. Okun says, "This is when everyone is on the same page: what can we do to help?" Activities include managing medical treatment, lining up social and support services, gathering insurance and other information, and attending to legal matters such as wills. **Upheaval.** The patient may be in remission or doing relatively well. But for others, unity and patience may have worn thin as protracted illness buffets their lives, relationships, and routines. At this stage, it's important -- though often difficult -- for family members to communicate honestly about the upheaval they're experiencing. **Resolution.** As the patient's health deteriorates, everyone comes to accept that the end is near. Decisions about hospice and other end-of-life matters have been made. Now is the chance for resolving old issues, healing wounds, and addressing resentments and jealousies -- factors that can undermine family members' ability to come together and support one another. **Renewal.** This final stage begins with the funeral and continues for a long time, as individuals adjust to the loss and to their changed roles.

What's different about the new grief from the Kübler-Ross model?

When Kübler-Ross was doing her work, people got a diagnosis and it was a matter of weeks, maybe months at

most, before they died. Now, we're talking years. The fact that families and loved ones have time to prepare influences the way they go through the stages of the grieving process.

How does the prolonged nature of terminal illness affect grieving?

I think what it does is to make people more conscious of time, of being together, and being sure they do what they want to do. It also gives people time to think about not just the patient but also the family. How do we want to be? How do we have those difficult conversations that we've never had before? How do we find out what the patient really wants? How do we help him or her cope with this illness with dignity? And how do we balance everybody's needs? So it gives you time not just to prepare for loss but also to prepare for living -- for living with uncertainty, and for living beyond loss.

A cancer diagnosis may mean "terminal illness," but these days, many cancer survivors don't think of themselves as having a terminal illness.

And many times today they don't. But the point is, once you get a diagnosis like that, it does affect your sense of mortality and vulnerability. In my patients, friends, and relatives who have breast cancer -- even stage 1 -- the diagnosis has made them think about, How do I want to live the rest of my life? What do I want to do differently? What do I want to have happen with my family for which this could be a point of departure? That's what we're really talking about. Not, When are you going to die? Because none of us really knows. I would say to those people the same thing I say to new parents: have you made legal arrangements, in case, God forbid, something happens to you? I would say that to anybody. This is something we should all be doing, and not wait. Just to be prepared, to plan. A metaphor might be if you had to make an unexpected trip to a foreign country. How would you plan? You'd have to get certain visas, you'd have to get certain shots.

In the first stage, crisis, you recommend that families designate a point person.

I think each family needs to have somebody who's going to be in contact with doctors, because physicians don't want six different people calling them up every day. Sometimes it's the person who lives closest to the ill person, sometimes it's the spouse or an adult child, perhaps a physician or lawyer. Often it's a female, because females have been so socialized to be primary caretakers. We also strongly recommend that somebody, preferably the point person, go to all the medical appointments with the patient, to take notes, to be a second pair of eyes and ears. This person can also help keep other family members informed. Sometimes family rivalries develop, so it's a good idea for adult family members to agree when they designate this point person and set up channels of communication.

You say that one of the common feelings during this prolonged grieving process is ambivalence. When is that most likely to happen?

It probably starts during the upheaval stage. Because in the first two stages -- crisis and unity -- you're very task-oriented. There's so much to be done, so many arrangements to make. In the upheaval stage, it's like being on a roller coaster. You can't really plan. It just feels like everything is out of control and you don't know what to do. You feel ambivalent: When is this going to be over? How can I stand this? I'm going to lose my job if I don't go back to work! Who's going to take her to chemo next week? Who can I rely on? And, What about me? People feel guilty for feeling that way, which causes more anxiety. If only they could realize that all those feelings are normal.

So what do you do at this stage?

You need to get yourself some respite. Go for walks, get massages, go to the movies, listen to music. Whatever works for you. You need to get some balance.

What are some of the things people who've lost loved ones after prolonged illness have told you they wished they'd done or known beforehand?

They wish they'd gotten some counseling. They wish they'd delegated more. They wish they'd gotten help with talking to their children. They wish they had shared more with other people and asked for help more. A lot of people said they wish they had found support groups and taken advantage of them. There are a lot of online support groups, even if you're stuck at home, for both patients and family members. A lot of people said they wished they'd had family therapy, because [the prolonged process] brought back a lot of tensions and unfinished business in the family, and it might have been helpful for having those difficult conversations and finding out what people needed.

Conversations can be hard to get off the ground. Some people don't want to talk about death.

Some don't. But a woman called me this summer and said, "I don't even know what my husband wants, where he wants to be buried, whether he wants to be cremated. He refuses to talk about it." So I suggested to her that she say to him, "You know, I've been thinking since you've been sick, I want you to know what I would want, just in case. I need to know that you know what I would want." And that opened up a conversation. There are different ways to start these difficult conversations. Two men told me that they never had a chance to reminisce about their lives and their marriages and their families with their dying wives because their wives would never acknowledge they were dying, even at the end. That's why one of the things I suggest is that you take the opportunity to go over family photographs or to make new albums together and to talk and do a lot of reminiscing with the kids and the family. It's a unifying experience. And it gets you talking.

Selected resource For more information and to join a conversation about Saying Goodbye: How Families Can Find Renewal Through Loss, go to <http://newgrief.com>.

What's the biggest challenge of prolonged grief?

The biggest challenge is living with uncertainty. Not knowing what's going to happen. Most of the time while you're going through this as the next of kin -- as a spouse or daughter or son -- you don't really have time to think about what your life will be like afterward. You're so preoccupied with functions that you don't get to think about it, unless you and [the patient] talk about it. One of the downsides -- and this is particularly true for women who've never worked or haven't worked for a long time -- is that after the death, they lose their job. Caring for the person was their whole meaning and purpose in life for several years. Now what? Not only are they without a partner, say, or a child, or a parent, but now they have all this time and energy, and they are totally at a loss. For them, I think it's very difficult to get through the renewal stage, to begin to build a life.

Do you have any advice for women in that situation?

One of my suggestions would be to find some way to do some volunteer work and continue your caretaking. Find some way to have meaning in your life. And to give it time.

DETAILS

Subject:	Grief; Womens health; Families &family life
Publication title:	Harvard Health Publications. Harvard Women's Health Watch; Boston
Publication year:	2011
Publication date:	Mar 2011
Publisher:	Harvard Health Publications
Place of publication:	Boston
Country of publication:	United States, Boston
Publication subject:	Medical Sciences--Obstetrics And Gynecology, Women's Interests
ISSN:	1070910X
e-ISSN:	15575608

Source type:	Magazine
Language of publication:	English
Document type:	Journal Article
ProQuest document ID:	1370744262
Document URL:	https://www.proquest.com/magazines/prolonged-illness-grieving/docview/1370744262/se-2?accountid=11774
Copyright:	Copyright Harvard Health Publications Mar 2011
Last updated:	2016-02-08
Database:	ProQuest Central

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