

Presented by:



Dr. Daniela Wittmann (PhD, LMSW) is a Clinical Assistant Professor in the Department of Urology in the University of Michigan Health System. She has 30 years of experience in individual, couple and family psychotherapy with patients with chronic illnesses including cancer and severe mental illness.

Dr. Wittmann: I want to start out by telling you what I'm going to talk about. I will start by talking about loss and grief in general and then I'm going to move to talk about losses in bladder cancer and how we cope with various kinds of losses. In that experience, what people have taught me about their coping and what is also known in the research about how people cope. We're going to move through all aspects of the bladder cancer experience.

To begin with, I'd like to emphasize that loss is really a very normal part of life that we all experience from the time that we are young to the very end of our life when we lose life ourselves, because even as young children, we observe family members die, we have pets that might die. Losses are involved in changes such as moves and job losses and so forth. This is not an unusual experience and everybody has reactions to it and learns to cope of the losses. Losses can be even a part of a good experience such as going to college or getting married because those changes, however happy they are, also involves separation from loved ones. Again, people have a lot of feelings about them and have to learn to cope with them.

Loss is a normal part of life

- Grandparents die
- Pets die
- Parents die
- Friend moves away

- Loss is a part of any change, even a good change
- Going to college
- Getting married



Loss is just a normal part of life, and grief is what is triggered by losses, grief, and mourning. Grief, just like losses are normal, so is grief a normal response to loss or to change. I have listed many feelings that are experienced by people when they experience loss. Some of them are very difficult feelings such as sadness or anger, guilt, hopelessness and helplessness and fear. Some can be also more positive feelings

Grief is a normal response to loss or change

Feelings associated with normal grief are

- ▣ Sadness
- ▣ Anger
- ▣ Guilt
- ▣ Hopelessness
- ▣ Helplessness
- ▣ Fear of the future
- ▣ Uncertainty about how to manage new circumstances
- ▣ Hope
- ▣ Comfort
- ▣ Sense of completion



such as hope or sometimes comfort or a sense of completion. Some of you will have learned about Kübler-Ross's stages of grief that are described as denial at the beginning and then bargaining and depression, and eventually, acceptance.

Researchers and people who have coped with loss have learned that there is no actual regular sequence to these feelings and to these experiences, that they go back and forth and follow each other in no particular order. There is a movement from intensity of feelings, which

is grief towards mourning, which is more going towards learning how to live with the losses that one experiences.

There are different types and forms of losses, and I'm going to speak briefly to each of them. The types are anticipatory grief, which we feel when we expect something to happen, a loss to happen. Normal grief that follows an actual loss and there are short, temporary upsurges of grief, which can happen through our lifetime even when a loss happened quite early because events and memories will trigger experiences of grief which don't necessarily last but should not be surprising.

The forms of grief are normal grief, straightforward grief, ambiguous grief, complicated grief, and those can all turn into chronic grief. Anticipatory grief, as I said, is a fear of something that's coming. There is a lot that is not known about what is coming, and so they may be exaggerated expectations, both positive and negative, over optimistic or over pessimistic. The feelings that are associated with anticipatory grief are the same as those that are involved in normal grief, except that anxiety is usually the most prominent feeling, which has to do with the fact that much is not known.

Types and forms of grief

Types

- ▣ Anticipatory grief – we know that loss is coming
- ▣ Normal grief – reacting to a loss that already happened
- ▣ Short, temporary upsurge of grief (STUG)

Forms

- ▣ Straight forward/normal
- ▣ Ambiguous
- ▣ Complicated
- ▣ Chronic

Rando, Research Press, 1993

Normal grief has those things that I've already described. As I said, it starts more intensely and then diminishes over time. It is very different from depression because depression is very much immobilizing while grief can be animating, energy-giving. Many times, people who are experiencing normal grief feel

inspired in the name of the loved one or the events that brought about the loss to do things that are creative. Start foundation, start BCAN, start various activities that benefit others.

The short and temporary upsurges of grief, as I said, are often experienced during anniversaries, birthdays. They can happen when someone else dies, maybe somebody who has got the same disease and dies. One's own grief can be stimulated. Very often when any minor of these are experienced, they can bring about the experience of reemergence of feelings about other losses that have been experienced. It's as if everything falls into the kitchen sink that is associated with loss once a loss is experienced.

As I said, we have thought of grief of having just stages. In fact, now we think of it more as something that we have to actively work through. There are tasks of mourning. The person, William Worden, who developed this model, wrote about children who lose their parents. He wrote about children's grief, but I think this is very applicable to any loss.

The Tasks of Grief and Mourning
(adapted)

- Accept the reality of the loss
- Experience the pain or emotional aspects of the loss
- Adjust to an environment in which the lost is missing – actively work towards restoring quality of life
- Preserve memories of life before cancer in a way that helps you focus on your strengths

Worden, Guildford Press, 1996

The first thing that we have to do is accept that a loss has occurred, so you have to accept its reality. Then comes the difficult experience of the feelings that are associated with coming to the realization that our loss is really real.

As we move towards mourning, we begin to adjust to the environment in which the loss has occurred and try to fill in the space in some ways without ever forgetting that the person or the loss that had occurred was there. One of the things that's important to

do is to preserve good memories or the strengths that we had before the loss occurred because even though a loss may change our lives unalterably in a certain way, we bring to it certain strength and certain ways that we cope that can be very beneficial.

For example, in working with children who had cancer, I learned that children are actually very curious. Those children who were diagnosed with cancer became extremely curious about their treatment regimen. Eventually, some of them, when they were older, became supervisors of the doctors, making sure that everything was done the right way. They employ their normal, natural curiosity to adapt to the new situation that they were in.

Now, let's talk about the forms of grief. Ambiguous grief is often experienced by people who don't quite know that a loss has or will actually occur. Often, the example that is given is families that have somebody in a war who get all this report that the person was missing in action. They don't know whether the person is captured, whether the person has died, whether the person is going to come

back. The outcome is unclear, and oftentimes, one can think of cancer diagnosis as that as well because the outcome is uncertain. This is a person who lives on two rails. One is the preparation for the loss and the other one is hope that the loss will not occur.

Complicated grief develops when there's a difficulty. Allowing one's self to experience the difficult feelings of sadness, depression, anger, hopelessness, and so on. Sometimes people get very frightened

Forms of grief that may become self-sustaining/self-perpetuating

- **Ambiguous**
 - No clear evidence to warrant grief
 - Uncertain outcome
- **Complicated**
 - Difficulty accepting loss
 - Finding ways of fighting the reality of loss through
 - Feelings of guilt
 - Avoiding the source of grief feelings
 - Anger at perceived guilty parties
- **Chronic**
 - Not being able to move on in life, maintaining grief as a way of staying connected with the loss/deceased

of those feelings and don't really want to feel them. We see that complicated grief can turn into a defensive way of coping with it by, for example, feelings of guilt like holding onto the idea that something might have been prevented when in fact, it couldn't have been.

In holding onto that guilt and belief, it's a way of not really going to the grief itself. Some people would avoid the source of the grief feeling. For example, if a family member gets killed at an intersection, they will never drive through that intersection.

Or sometimes people project it out and get angry with who they perceive as somehow being implicated in the loss that occurred.

Ambiguous and complicated grief both can turn into chronic grief, which then is long lasting and one can think of it as maintaining a relationship with the person that's lost or there could be a loss. While we never want to forget somebody who has died, for example, and want to memorize them and remember them at important times, chronic grief can interfere with a person moving on in their lives to stay connected with other people, to develop new relationships and so on, and that's how it is discovered that it is a maintenance of this ongoing sad feeling and preoccupation with the loss or with a loved one.

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