

# Hospice Aide On-the-Go™ In-service



## Anticipatory Grief

Volume 1 • Number 11

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As a person progresses through the dying process, a series of losses occur. Family members, caregivers, hospice employees, and others who are involved with the patient experience a sense of loss. Some of these feelings are anticipated; some are not. Grief, the normal response to a loss, is experienced when what is lost was of value to a person. When a loss is anticipated, people begin to grieve even before the loss occurs. Hospice aides develop relationships and attachments with patients and experience grief, even though it is not always recognized. Anticipatory loss and grief are stressful for the hospice aide.

Grief accompanies most forms of loss, and how one responds to an anticipated loss is unique to each person. Anticipatory grief may be expressed in the same ways as grief that happens after a death or other loss. Anticipatory grief often affects how a person thinks and feels. Frequently, cultural and social factors influence how a family works through the anticipated losses that accompany living with a terminal illness and related conditions.

As the patient and others deal with impending loss, people begin to prepare for the reality of it. Individuals experience anticipatory grief in different ways and with varying intensity. Some people experience little anticipatory grief—others, a lot. And even if a person has grieved a loss before it happens, that person may also experience grief following the loss.

Hospice aides are frequently with patients, their family members, and other caregivers as they cope with anticipated losses that happen during the end of life. Developing an appreciation of anticipatory grief and the ability to support people's anticipatory grief are important skills for an aide.

## WHAT IS GRIEF?

Grief is a reaction to loss—*any loss*—including anticipated losses, death of a loved one, divorce, loss of health, loss of a job, and so on.

Grief involves effort. Coping with loss and making adjustments in how we live to reflect the reality of the loss is the work of grieving. This effort is sometimes referred to as grief work.

## Anticipatory grief effects on feelings

Dealing with anticipatory grief frequently involves a range of feelings that are normal reactions to loss. Sometimes the intensity and duration of the emotions or swift mood changes can catch us by surprise. These effects of anticipatory grief are healthy and appropriate and help us in dealing with a coming loss. The anticipated loss of someone we care about is one of life's most stressful events and can cause a major emotional crisis.

These are some of the feelings that may accompany anticipatory grief:

- **Shock, denial, disbelief, and confusion.** These reactions are part of the emotional numbness a person may feel. Feelings may be expressed in a variety of ways such as, "No, that can't be!"
- **Sadness.** Feeling sad is common. Depression may occur.
- **Guilt.** Some blame themselves, wondering whether they could be doing more. Expressions of "If only we had ..." and "Maybe if I ..." are examples of guilt.



- **Anger.** Anger can take a variety of forms. Some people may say they are angry with God for putting them in the situation, and some people express anger toward others or themselves.
- **Anxiety.** Feelings of nervousness, worry, or lack of control may surface. Expressions of “How will I live without ... ” and “What will happen when ... ” may occur.
- **Yearning.** Part of anticipatory grieving may include thinking about what life was like before knowing that a loss could happen. Expressions of “I sure will miss ... ” are often heard.
- **Apathy or despair.** Some people may feel hopeless and think no one else understands their feelings or that everything is pointless. Life may lose its meaning.
- **Acceptance.** Adjustment eventually begins. People begin to prepare for the reality of the loss. Acceptance is often temporary; there may be further grief after the loss actually happens.

The effects of anticipatory grief on feelings will not occur in any particular order. Not every person will have the same effects. Intensity will also vary. It takes time to fully absorb the impact of an anticipated loss.

Hospice aides frequently witness the expression of feelings related to anticipated loss. Working closely with hospice patients, caregivers, and families requires dealing with the impact of anticipatory grief on feelings. It is important to allow people to express these feelings. Often we avoid, ignore, or deny that living with a terminal illness includes anticipation of losses. Staying non-judgmental and supportive are two skills the aide will find helpful. Keeping the hospice RN informed of concerns is important. Often other members of the hospice team, including the social worker, are involved in providing services specifically designed to assist with the feelings that accompany anticipatory grief.

## **Anticipatory grief effects on spirituality**

Anticipatory grief affects spiritual convictions. People may express anger at God or question their beliefs. They may think God is punishing them. For some, expressions of spiritual hope may be present—hope for God’s blessing in the form of a cure or a peaceful death, for example. People may feel prepared for what is to come, such as heaven or another afterlife, while also having spiritual pain related to the process of letting go of life as it is or as it was.

Part of a hospice aide’s role is to listen to expressions of anticipatory grief and witness its effects on a person’s spirituality. Communicating these issues to the hospice RN is important. The hospice chaplain or other community clergy may be helpful in providing spiritual counseling.

## **Anticipatory grief behavior effects**

Anticipatory grief affects how people act. Some become tearful, short-tempered, irritable, anxious, withdrawn, or unable to function normally. These behaviors may be temporary, lasting only for a brief time, may persist longer, or may reappear at random. Some behaviors, such as acting out grief, can be destructive to the person and to others, and it’s sometimes difficult to change this behavior.

The hospice aide’s ability to fulfill an assignment may be influenced by how the patient or caregiver is behaving. It’s important that an aide develop the skills to deal with different behaviors. Communicating with the hospice RN



about behaviors is part of the aide's role. Often the social worker will be involved in providing services to help the patient and others explore and modify their behaviors.

## **Anticipatory grief**

Anticipatory grief may include physical effects. Some lose their appetite; others experience stomach or head pain, feel exhausted, or have trouble sleeping. Other physical effects include feeling hungry and not becoming satisfied by eating, having a heavy feeling in the chest, or being jumpy. The intensity of these physical effects varies with each person and changes over time.

The role of a hospice aide often involves helping people as they deal with the physical effects of anticipatory grief. For example, an aide may be required to assist a hospice patient with care because the patient is "too fatigued" to do it him- or herself. This may be due to the terminal illness; it may also be due in part to anticipatory grief. The aide will be involved in reinforcing teaching that the RN or other hospice staff have done related to a patient's activities of daily living, use of standard precautions, or other aspects of the work.

## **Cultural and social factors**

As we go through life, we learn expectations for dealing with life's experiences. This includes expectations that our culture has for us when we are dealing with an anticipated loss. Understanding a patient and family's cultural expectations is helpful for the hospice aide. For example, some cultures expect that a person will "grin and bear it." Some cultures expect that emotions be expressed privately, whereas others express theirs openly. The individual in a family unit responsible for organizing and providing care often has cultural as well as social factors that influence anticipatory grief. A daughter may feel obligated to have her parent move into her home "when the time comes," causing an impact on her as she anticipates the loss of privacy, space, and time. Different people have social expectations related to upcoming losses. For example, this may be evident in how fellow employees begin to shift work tasks or in a friend's conversations and ability to be supportive.

One of the impacts of dealing with anticipated loss is that people may begin to adjust to living as though the loss has already occurred. For example, when a family in a neighborhood says they will be moving, neighbors may begin to treat the family as though they were already gone, forgetting to invite them to neighborhood parties and gatherings. Hospice patients may also experience this, finding that they are no longer part of planning and activities. A hospice patient's spouse may begin to notice that their couple friends act as though the patient is already dead. Feelings of abandonment may complicate the situation. Many hospice patients, caregivers, and family members walk the fine line of anticipating losses and the patient's death, while still wanting to find joy and meaning as they focus on living well during the end of life. Hospice employees bring sensitivity to this duality as they plan for and provide care, treatment, and services.

Listening to other people talk about grief can help aides understand their own reactions. Non-judgmental support is important, as is being aware of your own cultural and social expectations for people who are living with a terminal illness. Passing on your observations to the hospice RN will help others on your team, too.



## THE HOSPICE AIDE'S ROLE

Sharing information about anticipatory grief is only part of your role. Being a supportive, non-judgmental, effective listener is the most important tool you have as you provide hospice aide care for terminally ill patients and work with caregivers and family members. Listen to what is said and observe nonverbal communication. Paying close attention to what is being communicated helps grief-stricken people express, examine, and understand themselves. Crying with someone can be healthy and healing, if done at an appropriate time and place. Although each person hurts individually, we can grieve together with others and support each other.

The following tips will help you provide anticipatory grief support as part of your hospice aide services:

- **Share the sorrow.** Allow—even encourage—conversations about what patients and families anticipate for their future. Identifying the losses and sharing feelings and memories offers the opportunity to be a part of the sorrow.
- **Don't give false comfort.** It doesn't help to say, "I know how you feel," or "You'll get over it in time." Instead, offer a simple expression of sorrow and take time to listen.
- **Offer practical help.** Give needed help; adjust what you do as the patient or caregiver is less able to think or needs time to cry. Refer any need for added hospice support to the hospice RN.
- **Be patient.** Remember that the feelings, behaviors, and spiritual and physical effects of anticipatory grief are very real and often not controllable. Like any wound, it takes time for grief to heal.

Dealing with your own reaction to an upcoming loss is another important part of your role. Unresolved grief can cause emotional, physical, mental, and social stress for hospice employees. You are often very close to the patients and their caregivers, sensing the coming loss. You may be there as the patient and his or her caregivers begin to deal with the patient's decreasing ability to do the things he or she enjoys. You witness anticipatory grief when a patient talks about how he or she may not be able to walk to the kitchen soon, or see the birds from a favorite second-floor window. You help as the patient, caregivers, and family deal with anticipatory grief, and you are an important reminder that the patient is still alive.

Seeking the support of others as you deal with your ongoing anticipatory grief is important. Identify coping mechanisms and what brings you support. Some hospices offer opportunities for staff members to meet in groups or as individuals to help deal with the stress of providing care to the terminally ill, their caregivers, and family members. Journaling, meditation, religious practices, exercise, proper nutrition and hydration, nurturing relationships, and learning new hobbies or skills are some of the measures you can use to foster your well-being.



## OUTCOMES AND THE HOSPICE AIDE

Loss is an ongoing experience for the hospice patient, family members, caregivers, and the hospice staff. Losses can include loss of the ability to drive, go to work, or do other activities. Anticipating future losses is part of the hospice experience. The eventual death of the hospice patient is one of these anticipated losses. Although, on some level, we are aware that we will eventually die, that reality is more present when living with a terminal illness. Developing your skills in grief support measures will make you a more effective hospice aide. Being tuned into your anticipatory grief and that of other team members is an important part of your role. Taking measures to care for yourself as you deal with anticipatory grief is a necessary part of hospice work.

### CMS Expectations

A hospice must maintain a quality assessment and performance improvement (QA/PI) program that involves all services, including hospice aides. This program, among other things, will take actions to demonstrate improvement in hospice care and palliative outcomes.





## CASE STUDY

Ruth has lived in an assisted living facility since she fell at home and broke her hip several years ago. Ruth's congestive heart failure has been steadily progressing, and a few months ago her doctor referred her to hospice. Your hospice has been providing care for Ruth for 56 days. Ruth is weak and spends most of her time in her recliner. Hospice aides provide full bath and assistance two times per week and partial bath one time per week. The facility staff helps Ruth on the other days.

The facility staff refer to Ruth as "Granny." One of the facility staff, Clare, has talked with you several times about how she will miss Ruth because she is "exactly like my Granny, who died while I was away from home. I never did get to say good-bye to her."

Ruth has no remaining family nearby, but she has several friends in the facility. She and Anna are like sisters. Anna has talked with the hospice staff about her sadness at losing Ruth and, lately, Ruth has been a bit angry with Anna. For some reason, Ruth has been quite open in talking with you while you help her with her bath.

The hospice interdisciplinary team, as part of its comprehensive assessment process, has identified that some facility staff, especially Clare, are having anticipatory grief issues, as is Anna. The team is also concerned about Ruth's anticipatory grief. Your aide assignment includes providing anticipatory grief support, including compassionate listening, for Ruth, facility staff, and Anna.

Today, you learned from the facility staff that Ruth seems weaker after eating "almost nothing" for breakfast. Anna was crying in her room earlier because Ruth had kicked her out, saying, "You just don't get it—I'm dying." Even Clare was teary, saying, "This one will be hard for me." Before starting Ruth's care, you call the RN, and she says she will let the hospice chaplain know what is happening.

Ruth is in bed with her curtains closed. When you ask whether she would like to use a new lotion for her bath, she is slow to answer. She says, "My grandson sent me those from Germany. I miss him so. You just pick out one." Then she starts to tear up and says to you in a sharp tone, "Let's get on with this."

During the bath, you ask Ruth about her grandson, and she begins to reminisce. You listen intently, asking questions. When it is time for her to get dressed for the day, she smiles when she sees you holding one of her favorite sweaters. Before you leave, Ruth says, "You know, Anna just yaps and yaps like I'm going to live until my grandson can come home in two months. I don't think I'll make it. I'm never going to see him again." Ruth starts to cry. You pull up a chair, get the tissues, and wait. After she stops, she looks at you. You say to her, "It must be very hard." She sighs, pats your hand, and says, "Your listening is wonderful medicine. Thank you." You smile and say, "You're welcome. It truly is an honor to be with you." And, she, in her very matter-of-fact manner, says to you: "Can you open those curtains? I feel like I'm in a cave in here. Those night folks just seem to like to close them all the time when they check on me. One of these days, I'll need to tell them not to." You do as you are asked and say good-bye.

Prior to leaving the facility, you find Clare, who is talking with the hospice chaplain. You give a brief report on how Ruth tolerated the bath, and mention Ruth's comments about Anna and the curtains. Clare smiles and says, "We're so glad you are working with us. Ruth and Anna need your help. As for those curtains? Lately, we just can't please



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her.” The chaplain says, “Maybe it’s a way for her to have some control over her life. She knows she is able to do less and less. I know the social worker is planning to be here this week and will see Anna, as well as Ruth. And Clare, we are here for you, too.”

You finish your documentation. In your hospice note, you write a brief summary of your conversations and observations related to the anticipatory grieving of Clare, Anna, and Ruth. You also note your call to the RN and the conversation with the chaplain and Clare.

## THINK ABOUT IT

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1. What does Ruth anticipate she will be losing? What about Anna and Clare?
2. What did you observe that could be associated with the effects of anticipatory grief for Ruth, Anna, and Clare?
3. What other tips would you use to provide care to Ruth?
4. As a hospice aide, do you have a support system?