



Comfort for the Grieving Heart

Provided by St. Luke's Hospice Bereavement Program

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People in grief need someone to walk with them without judging them.
~ Gail Sheehy

St. Luke's Hospice

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PLEASE NOTE: If you would like to be added or removed from our mailing list, or if you would prefer to receive an electronic copy, please contact Dawn at 484-526-2499.

One of the many pervasive myths about grief is that it occurs after the death of a loved one. Grief can also occur long before death and it almost always does when people are providing care to a loved one for years or even decades. This is particularly true if the person you are caring for has dementia or any other progressive disease. As soon as we become aware that death is likely to occur now or in the future, it's only natural that we begin to grieve.

This is called anticipatory grief. Dr. Therese Rando coined this term and it is the process of mourning, coping, interacting, planning and the psychosocial reorganization that occurs in response to an impending death. This grief is not only about coming to terms with a future death, it is also about grieving the many losses occurring as the illness or disease progresses. We grieve the loss of our loved one's independence, their physical abilities, cognition and identity. We grieve our future hopes and dreams.

Anticipatory grief includes many of the symptoms of normal grief such as sadness, anger, isolation, forgetfulness and fear. These emotions are often coupled with the exhaustion and burnout that comes from being a caregiver and a helpless bystander. Being aware of a looming death may produce an overwhelming sense of anxiety or dread. Knowing that death is on the horizon puts us in a state of hyper-alertness. We panic when the phone rings or when we hear the wail of a siren.

This takes a physical and mental toll on us so when death eventually occurs, we may feel sadness coupled with a sense of relief. These feelings are quite common for those who have experienced an anticipated death. Yet we feel guilty for feeling relief, thinking it somehow diminishes our love for the person. It doesn't, of course, but feeling relief confuses us. We need to consciously remind ourselves that relief does not change the deep love we had for the person; rather it is a natural reaction to an elongated trajectory of caregiving and illness.

Jean

The Grief Before Death

Accept that anticipatory grief is normal. You're entitled to feel this type of grief. It's a common phenomenon that has been documented for nearly a century.

Acknowledge your losses. People may say annoying things like "at least your mom is still alive." This minimizes the grief you're experiencing. Allow yourself to acknowledge that, although the person hasn't died, you are still grieving.

Connect with others. Anticipatory grief is common among long time caregivers but when all of your time is consumed with caregiving, you may feel totally alone. Seek out caregiver support groups in your area or online to connect with others who understand the challenges you're facing.

Anticipatory grief doesn't mean you're giving up. There comes a time when we must accept that recovery is no longer a possibility. With this acceptance may come guilt. Focus on what you *are* doing – still supporting, caring, loving and creating meaningful time together with your loved one. Shift your energy from hope for recovery to hope for meaningful and comfortable time together.

Communicate. Everyone in the family experiences and copes with anticipatory grief differently. Keeping the lines of communication open helps to understand how each person is experiencing many losses. As you plan for the remaining time to be meaningful and comfortable, include all associated family members and friends in these discussions.

Take care of yourself. You simply can't take care of others if you don't take care of yourself. This advice is easier said than done, but it's essential. Investing 15 to 30 minutes in an activity that gives you pleasure each day will give you more energy for your caregiving role.

Take advantage of your support system. Caregiving and the anticipatory grief that accompanies it can be a long road. Assess your support systems so you know which people you can count on for help (and those you want to avoid!). If there aren't enough people in your support network, enlist help from neighbors, friends and church members. Make a list of what you need and who may be able to help you.

Say yes to counseling. Many people still think that counseling is only for people with serious mental health issues. Not true. Counseling is helpful for anyone who needs a place to explore and understand complicated emotions. Counseling is a wise decision because family and friends may not always be able to serve in the role of the compassionate listener. That's because they may be grieving, too.

Relief is a very typical response. When someone dies after an elongated illness, you may feel a sense of relief. This is completely normal, but it may also create feelings of guilt. Feeling relief after an anticipated death does not mean you loved the person any less. Instead, it is a normal reaction after a stressful and overwhelming time in your life.

Don't assume. Because your loss was anticipated, do not assume this will either speed up or slow down your grief response after death occurs. Grief is a very personal and individual response and every person experiences grief differently.



Coping with Anticipatory Grief

Suppose you are standing on a crowded street corner and someone quickly approaches, fists and arms swinging. Because it's a crowded corner, there's no room to maneuver so you ready yourself for an assault. You steel yourself and assume a fighting stance, legs spread apart and fists raised to defend yourself. When the assailant strikes, you are ready for it and despite the pain of the blow, you're somewhat prepared to defend yourself. This is similar to an anticipated death. We see it coming.

In contrast, imagine you are standing on a street corner minding your own business when all of a sudden someone comes up from behind and hits you. The blow comes from out of the blue and you are knocked to the ground. Before you can respond, you have to figure out: What just happened? What am I doing on the ground? Where is this pain coming from? What do I do now? This is what happens when we experience sudden death.

In both instances, the pain of the blow is the same and you end up on the ground. However, when you see the blow coming you have some time to prepare and know why you have landed on the ground. You can direct your energies toward coping with the attack. But in sudden death, this preparation and comprehension is missing. As a result, the ability to cope with the situation — to decide what to do in response to the blow — is compromised. You are stunned and shocked. You are at a relative disadvantage to the person who had seen the blow coming and was able to prepare to defend themselves.

Open/Drop-In Grief Groups

Our Open/Drop-In Grief Groups allow you the chance to receive and provide support in a collaborative environment. Groups are facilitated by a grief counselor and participants suggest topics for discussion. Come and meet others to discuss similar challenges and experiences following the death of a loved one. No registration needed. We offer three groups and each one meets for 90 minutes:

Easton: First Monday of every month from 4-5:30 pm at St. Luke's Anderson Hospital Campus, 1872 St. Luke's Blvd, Easton, 18045. We meet in the Medical Office building next to the hospital in the lower level conference room A. Due to the Labor Day weekend, September's group will meet on Monday, September 16th.

Quakertown: Second Monday of every month from 6-7:30 pm at St. Luke's Quakertown Hospital Campus, 1021 Park Avenue, Quakertown, 18951 in the cafeteria conference room (lower level of the hospital).

Brodheadsville: Third Tuesday of the month from 1:30-3 pm in the second floor community room at the Brodheadsville ShopRite, 107 Kinsley Drive, Brodheadsville, 18322. The community room is near the entrance to the store. Follow signs and take the stairs or the elevator to the second floor. Please note that the September meeting will be on September 24, which is the fourth Tuesday of the month.

Additional Places to Find Support and to Share Your Story

This is a list of free bereavement services in the area. Please call the bereavement office at 484-526-2499 if you are in need of something more or for referrals to other services.

Adult Support Information

Bradbury Sullivan LGBT Community Center at 522 W. Maple Street, Allentown 18101 offers a professionally led monthly bereavement support group for LGBT people who have experienced loss. The group meets on the 4th Tuesday of each month from 5:30-7:00 pm. Please register with Ariel@bradburysullivancenter.org.

The Compassionate Friends offers ongoing support groups for parents, grandparents and adult siblings grieving the loss of a child, grandchild or sibling. Visit their website at www.thecompassionatefriends.org or contact these local chapters: Allentown chapter (call Dawn De Long at 610-837-7924), Easton chapter (call John Sabo at 610-866-5468), Carbon County chapter (484-719-6753) and Quakertown chapter (484-408-7314).

Doylestown Hospital Hospice offers a variety of support groups and programs that change seasonally. Visit www.dhospice.com or call 215-345-2079.

Gentle Yoga for Grief, Stress and Life Transitions is offered by Wendy Littner Thompson, M.Ed., LPC, RYT. Please contact her at 610-730-1992 or visit her website at www.givinggriefavoic.com to learn more. Let her know if your loved one was a St. Luke's Hospice patient.

Grief Share is a faith-based grief support group program offered at many locations in the Lehigh Valley. There is a Grief Share program on Sundays from 2:30-4:30 p.m. at the Mt. Eaton Church in Saylorsburg, 18353. Call (570) 992-7050 for additional information. For other Grief Share locations throughout the area, visit their web site — www.griefshare.org — and enter your zip code to find the location of a group near you.

Grand View Hospital Hospice offers many groups and services that change seasonally. Please call 215-453-4210 for more information.

GRASP is for families whom have experienced death due to substance abuse. The daytime support group meets at the First Presbyterian Church in Allentown, room 118 on the first Monday of the month at 12 noon. Please register with Jenny Kemps at 610-422-8490 or email jenkemps@ptd.net. The evening support group meets on the third Monday of the month from 7-8:30 pm. Please register with Nancy Howe at 484-788-9440 or email nancyhowe@ymail.com.

HALOS – CLC (Hope After a Loved One's Suicide – Child Loss Chapter) is for parents, grandparents and adult siblings who have experienced loss of a child or sibling to suicide. The group meets on the 4th Thursday of the month from 6:30– 8:30 pm at Hughes Library in Stroudsburg, PA. Call to register with Alice Keyes at 570-236-1168 or email at alicekeys00@gmail.com.

Lehigh Valley Health Network offers many groups and services that change seasonally. Please call 610-402-7481 for more information.

Lehigh Valley Home Care & Hospice Pocono's bereavement support group meets on the first and third Wednesdays of the month from 12 noon-1 p.m. Anyone who has experienced the death of a loved one is invited to attend. The support group meets at 502 VNA Road, Route 447, East Stroudsburg, PA 18301. Please call Tammy Hiestand at 272-762-3826 to learn more.

Suicide: The American Foundation for Suicide Prevention has excellent information on risk factors, statistics, education and local services. Visit their web site at www.afsp.org and enter your zip code to find the chapter nearest you. All chapters are run by people who have experienced the suicide of a loved one.

Virtual Grief Support is offered by Dr. Don Eisenhauer. Don has a background in counseling and pastoral ministry and runs monthly tele-grief groups and chat room support. Participants either dial in via phone or log in via computer to share with other grievers. For more information about the dates and times of these opportunities, contact Don at onlinegriefcommunity@gmail.com.

Support Information for Children

Lehigh Valley Health Network offers “Stepping Stones for Children” for ages 6 through 17. This is a combination of education, activities and support to help facilitate healthy grieving with others who are the same age. Please call 610-402-7481 to register. The group meets at 2024 Lehigh Street, Allentown, PA 18103.

Support Information in New Jersey

Karen Ann Quinlan Hospice 800-882-1117 www.karenannquinlanhospice.org/services/bereavement