

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. \sim Gail Sheehy

St. Luke's Hospice Bereavement Team:

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.

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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 your-self. 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. Counsel-ing 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 nor-mal 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

Grief Support for You

St. Luke's Hospice abides by CDC and Pennsylvania Department of Health guidelines for public gatherings during these challenging times. All support groups and workshops continue to be held virtually. Here are support options we currently offer:

Individual support: Our bereavement counselors provide support and information <u>through video</u> <u>and telephone counseling sessions</u>. Our contact information is on the front page of this newsletter.

Good Grief Workshops: These 90-minute workshops are offered virtually twice a month to provide you with a better understanding of what grief is, how it may affect you emotionally, physically, spiritually and psychologically, coping strategies and ways to reconcile the loss. For more information and to receive an invitation to join the meeting, call (484) 526-2499. You will be asked to download the Microsoft Teams app on your smart phone or computer. Workshop offerings include a daytime and an evening option each month:

Wednesday, August 10th 2022, 6-7:30PM Thursday, August 28th2022, 1PM-2:30PM

Video library: St. Luke's website includes a dozen short videos that provide information about the grieving and mourning process and ways to care for yourself after a loss. To view the videos, go to https://www.slhn.org/vna and click on the hospice heading. On the left side of the screen under the VNA heading, click on grief support. About half-way down this page, click onto the video library heading "Want to understand your grief?" Access the library by answering the question about your connection with St. Luke's Hospice (if any). Then view the videos from the comfort of your home.

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 them-selves

Additional Places to Find Support and Share Your Story

Below is a list of <u>free</u> bereavement services in the area. Because of the pandemic and the need for physical distancing, many resources may only be offered virtually. Please contact our bereavement department at 484-526-2499 if you need additional support.

Adult Support Information

Bradbury Sullivan LGBT Community Center offers bereavement support for LGBT people who have experienced loss. For more information, please visit their website at www.bradburysullivancenter.org or email at reilly@bradburysullivancenter.org.

The Compassionate Friends offers ongoing support for parents, grandparents and adult siblings grieving the loss of a child, grandchild or sibling. Visit www.thecompassionatefriends.org. Enter your zip code to locate the local chapter and contact person near you.

Doylestown Hospital Hospice offers a variety of support groups and programs that change seasonally. Visit their website at www.doylestownhealth.org/hospital/services/bereavement or call 215-345-2079.

Gentle Yoga for Grief, Stress and Life Transitions is currently being offered virtually by Wendy Littner Thompson, M.Ed., LPC, RYT. Visit www.givinggriefavoice.com or call 610-730-1992. Be sure to indicate if your loved one was a St. Luke's Hospice patient.

Grand View Hospital Hospice offers groups and services that change seasonally. For more information, call 215-453-4210.

Grief Share is a faith-based support group offered throughout the Lehigh Valley. Visit their website at www.griefshare.org and enter your zip code to find the contact person and program near you.

OASIS Community Center offers a variety of support groups to those grieving a loss due to substance related causes. Therapist-led meetings are held in-person and virtually for bereaved parents and young adults (siblings, partners, friends, etc.). Groups for bereaved youth ages 7-17 and bereaved caregivers raising bereaved children are offered in-person. For dates and times, visit www.oasisbethlehem.org, call 484-747-6825 or email at rhonda@oasisbethlehem.org to register.

GRASP (Grief Recovery After a Substance Passing) currently offers two virtual evening meetings per month, plus an afternoon meeting at the Oasis Center. Call 484-788-9440 or Call/Email at nancyhowe@ymail.com or 484-788-9440 or Tim Howe at howet60@yahoo.com or (646-401-4455.

Lehigh Valley Health Network offers many groups and services for adults and children between the ages of 6-17. For more information, call 610-402-7481. For information about program offerings in the Pocono area, call 272-762-3826 or email Bryson.Boes@lvhn.org.

Suicide Loss: The American Foundation for Suicide Prevention has excellent information on risk factors, statistics and education about suicide. Visit www.afsp.org and enter your zip code to find the chapter/contact person near you. All chapters are run by people who have experienced the suicide of a loved one.

Cancer Support Community of the Greater Lehigh Valley cancersupportglv.org

Find an individual therapist at: Psychologytoday.com

We encourage you to call the number on the back of your insurance card to find resources paid by your individual insurance plan.

Support Information in New Jersey

Karen Ann Quinlan Hospice offers support to those who are grieving the death of a loved one. For more information, call 973-948-2283 or visit www.karenannquinlanhospice.org/services/bereavement.