



# LOPEZ ISLAND HOSPICE & HOME SUPPORT

Winter 2014 Information and Resources

## Grieving When No One Has Died

By Elizabeth Landrum, PH.D.  
Board President, Volunteer Support Committee

*"Whether all is really lost or not depends entirely on  
whether or not I am lost."*

*Vaclav Havel*

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Hospice & Home Support  
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All services are free.

When Emma (not her real name), a 38-year old high school teacher, was diagnosed with breast cancer, she faced the news head-on, and then made her way through a chain of recommended treatments. It was five months after completion of surgery, radiation, and chemotherapy that she came to me for consultation in my psychotherapy office. She was optimistic about her prognosis; she had returned to work; she had received amazing support from friends and family; her marriage was thriving. Yet she felt "constantly down."

Because she hadn't suffered a loss of self-esteem, did not have significant negative thinking, and still had a great deal of hope, she did not appear to be depressed. "It feels like I'm grieving, but no one has died, and nothing's been lost," she said. In fact, when examining the obvious aspects of her life that she still treasured, nothing showed up missing or significantly changed.

But as we considered the possibility of grief, deeper questioning began to uncover subtle losses that came with the illness experience, many of them more existential than tangible. As she faced her own mortality, she had lost her imagined sense of safety and invulnerability; she had to put aside

some of her plans and dreams; she no longer trusted her body to be healthy, even though she led a very healthy lifestyle; and she had lost a sense of her former self, both internally and externally. Her students, colleagues, and the people with whom she was most intimate treated her differently now that she was seen as a "survivor" and "brave," though her confidence was shaky. She now had a life in which cancer played a major role. Emma began to feel relief from the simple act of naming what was lost. When she returned the following week, she brought a list of 23 losses, and then she began to grieve each one. Allowing herself to identify them, talk about them, and to feel them created her path to healing.

Emma's story is similar to what many people experience when faced with illness, whether acute or chronic, static or progressive, life-threatening or not. And with some particularly progressive illnesses, when patients or loved ones can see what lies ahead, a kind of "anticipatory grief" may be ever-present. Because loss and change are inevitable in life, grief cannot be avoided. Every major life transition (e.g. divorce, change of jobs, retirement, moving, childbirth, friends or children leaving you

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## Grieving When No One Has Died

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behind) involves grieving for what is lost. It is these life losses that are often misunderstood and overlooked when we talk of grief. We do ourselves a disservice when we think of death as the sole precursor to mourning.

As with any type of grief, we can find ourselves caught in the roller coaster of emotions such as sadness, guilt, anger, anxiety, and irritability. Living with grief's physical symptoms (insomnia, fatigue, loss of appetite, lowered immunity, "muddled mind") can make one feel caught in repeating waves. When grief isn't recognized, these experiences can be confusing and more difficult to work through. While they may have many of the aspects of grief we are familiar with, they are less understood by the bereaved and by others, less often supported by the culture or community, and less apt to find resolution or closure.

There are common patterns but no neat sequential stages, and no universal way of responding to grief. We now know that grief doesn't follow a linear path, but one that more resembles a spiral staircase. Healing happens gradually, with difficult periods becoming less intense and shorter as time goes on. It is when we try to damn the river of grief or ignore its presence that we prolong the natural process. And, like Emma, when we recognize what is happening, we can keep moving through it until the loss becomes something that lives beside us, rather than the front-and-center focus of our vision.



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[www.lihhs.org](http://www.lihhs.org)

## Grief and Caring for Someone With Dementia

Psychosocial research has for a long time focused on the stresses and burdens of caregiving when trying to understand the emotional toll paid by those who care for people with dementia. It is only very recently that the focus has shifted to grief as a helpful lens for seeing what happens to loved ones and caregivers in the process of being with a person with progressive brain disease. In the early stages of Alzheimer's there will be grief over the diagnosis and for losses associated with symptoms of the disease, as well as anticipatory grief. Each stage involves further losses as parts of the person seems to disappear; one must continually adapt to change. Grief can be the most intense at times of key changes (loss of the ability to drive, to be left alone, to recognize friends). The patient, too, will grieve, and even when he or she can't fully understand what's happening, these feelings may be expressed in behavior such as agitation or frustrated actions.

Losses and grieving occur in different ways at all stages of the dementia caregiving journey. A loved one might be grieving for a past that is gone, the present (as in loss of freedom, changes in routine), as well as for a future with plans and dreams that will not be fulfilled. A spouse might grieve the loss of a partnership or a confidante, the many losses that come with shifts in roles and responsibilities, and / or unique ways of sharing humor or finding joy. Yearning for the past and experiencing a sense of loneliness are common for caregivers, as are feelings of regret, resentment, helplessness, and guilt. It has been shown that caregivers grieve in certain styles, with differences mostly seen between genders and between people who care-give at home vs. in a facility. "Intuitive" grievers tend to experience waves of feeling, while "instrumental" grievers tend to be more action-oriented problem-solvers. In any case, coping with loss and grief can be more challenging and complex than the actual demands on the caregiver. When caregiving and grieving last for long periods, the physical, emotional, and energetic costs can be great. Compassionate understanding of what is happening in caregivers' grief (by the caregiver and by others) can lessen that toll.

## What to Do / What You Might Need

*Recommended ways of coping with loss are familiar to most of us now. It is always important to **take care of yourself**, particularly when you are needed to take care of someone else. Basics like good sleep, healthy eating, relaxation periods, and opportunities to do what you enjoy are critically important, yet often get sidelined. Remember that grief takes energy, too. Finding ways to “make deposits in your energy bank” can be essential to your health.*

***Face feelings** and recognize losses so that you can name them, reflect on them, and understand them to help you heal. The more complex and confusing the feelings, the easier they are to ignore. But acknowledging common paradoxes that come with dementia care (feeling married and not married, feeling like both parent and child, wanting the loved one to live and wanting the pain to end) can lead to a more compassionate understanding.*

*Identify people who are there for you in good times and in bad and make time for **connecting**, whether or not you choose to talk about your grief. Isolation is a toxic risk and yet very common in the dance of caregiving.*

*Examine your personal coping **strategies and strengths** in order to maximize them. You may find hope and signs of growth each time you make a positive adjustment to change.*

*Seek **information** to help you understand the disease, the losses associated with it, and your reactions to them. There are many resources available today, and Lopez Island Hospice & Home Support is ready to help you find them.*

*If possible, find time to **create**. Expressing emotions in tangible ways can provide an outlet and relief, as well as a sense of empowerment.*

*Find **balance** when you can. While you are coping with what must be let go, focus on what is not lost, on who your loved one still is, and what he or she can do. Look for ways to feel in control, even making small choices.*

***Group support** for non-professional caregivers is available on Lopez through LIHHS. We provide a place to confidentially discuss your concerns with others who understand.*

## New Programs in the Works

Thanks to requests from Lopez residents, Lopez Island Hospice & Home Support will be offering new educational programs and workshops.

Please let us know what opportunities and offerings you would like to see in the future.

Stay tuned for educational community forums on important topics, including:

- Being present with someone with dementia
- Making your wishes known:  
*Life and Death Planning*
- Palliative care at the end of life on Lopez Island
- After cancer, now what?

Watch for notices about possible new group support programs, including a closed, time-limited, professionally facilitated bereavement group designed around topics such as manifestations of grief, commemoration, family dynamics, and assessing values. Also, plans for offering a new cancer survivors' support group in the coming months are being discussed.



## Caregivers Support Group

Our Caregivers Support Group meets the first and third Thursday of each month at 1pm in the Lopez Island Hospice & Home Support office.

Most people benefit from sharing their feelings with someone who is supportive and listens non-judgmentally. Such sharing with a confidant often relieves tension, helps give a new perspective of the situation, increases mutual understanding, and builds support. Our Caregivers Support Group is designed to provide this opportunity for those who choose to attend.

Our group is focused on family caregivers, giving them a chance to share openly with others who understand, and to learn techniques for coping. It also provides an opportunity to share their knowledge and to help other members of the group.

## ***Jingle Bell Dinner an Enormous Success!***

Thanks to our sponsors, guests, auction donors and volunteers, the 2013 Jingle Bell Dinner was our most successful ever! With exciting auction items, wonderful music, and a fabulous dinner provided by The Bay, a good time was definitely had by all.

The generosity of our community made for an amazing evening. The event brought in more than \$28,000 to assist Lopez Island Hospice & Home Support in helping our neighbors in need.

Thanks once again for your support and dedication to Lopez Island Hospice & Home Support.

## ***New Board Members***

*We're pleased to announce three new Lopez Island Hospice & Home Support board members:*

Barbara Fleming - Barbara holds a bachelor of science in nursing from the University of Washington and a master's degree from the University of Santa Clara.

Felicity Green - Felicity was trained as an occupational therapist in South Africa, and has taught therapeutic yoga for nearly 50 years.

Anne Hietbrink - Experienced with dementia, developmental disability and psychiatric illness, Anne has a range of skills and interests that align with the mission of LIHHS.



*Grief Support Group meets the third Friday of the month at 10am at the Lopez Island Hospice & HomeSupport office, 178 Weeks Road, next to the market. Grief can come in many forms - all are welcome.*



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