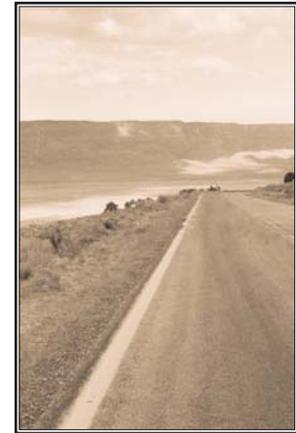


# The Long Road

An Article on Anticipatory Grief  
by Jennifer Allen



Who looks forward to their own or a loved one's death?

Anticipation is something I felt as a child when the state fair opened and later when I planned trips abroad; not a feeling I would have associated with a dying husband. When I first learned the term: "*anticipatory grief*," I thought it was a poor attempt of the English language to name a concept that death-denying cultures would rather leave un-named. I tripped over the word: *anticipatory*.

*Trepidation* — "*trepidatory grief*"— would be a closer fit for the kind of grief people with a life-threatening illnesses and their loved ones go through up until the point where bad days outnumber good ones. For me, it was only **when my husband, Tom, was suffering with little chance of cure, and I was overwhelmed with caregiving, did it seem possible to look forward to the death of my beloved.**

The definition of "*anticipate*" also includes: "*to foresee*." Despite all my hopes and the guilt for even thinking it, I did foresee Tom's eventual death. At least the thought crossed my mind as worry. That was enough to set the grief-up-front into motion. **It felt like an antsy-anxiety mixed a hearty dose of with low-grade dread of looming losses.** In my book, BONE KNOWING, I describe it as a pea under the mattress—sometimes hardly noticeable and sometimes gratefully uncomfortable—but always there.

And then there is: "*To act in advance to prevent, forestall*." Oh, the effort I put forth trying to prevent what I couldn't have known was inevitable! Bargaining with God was a staple. Guilt-tripping my husband into healthy changes and trying to make my love enough for him to live (as if he had a choice), were other game plans that eventually backfired on me. When all that remained was hope for Tom's survival, and he continued to decline, I felt absolutely helpless. My arsenal was depleted. **There was nothing to do but surrender and redefine hope to be much greater than whether he lived or died.** In the end, the effort "*to forestall*" seemed to cause everyone involved suffering. At the same time, it was an integral part of the journey.

Preparing oneself is also a part of "*acting in advance*." This could prompt end-of-life planning—something that is otherwise all too easy to put off and makes a tremendous difference when it's handled ahead of time. It could mean forming a support network, tending financial affairs, or talking to a trusted friend or therapist about the grief that arises, even though the loved-one is still living. For me, it was my work with hospice patients and their families that taught me about living with death on the horizon. Yet, it wasn't until Tom was very sick that we began preparing ourselves with plans and support. Like many of the families I worked with, I fell into the same dilemma of equating end-of-life plans with giving up hope. **One of the most difficult parts of anticipatory grief, I believe, is the challenge to hold both grief and hope, simultaneously. It's not a one-or-the-other deal.**

The bad news is that **all the grief done up front, doesn't necessarily mean you get to bypass the grief after the death.** The good news is that all the anticipating, which is not passively waiting for the big "G" (grief) after the big "D" (death), but actually **grieving the many losses along the way, can help with adjustment and integrating the loved one's death.** When it does happen, there's a well-worn path to the heart and grief isn't as likely to be the

blunt blow it might be in a sudden loss. Still, death—no matter how anticipated—takes away whatever is left of your loved one—for good. As the primary caregiver, the relief and sudden sense of freedom that came when Tom died outweighed his absence, initially. Then came the empty bed. Though I was done grieving the incremental losses that came with the territory of a sick spouse, a new grief arose. I longed for the partner—the vital man who would have comforted me and spooned my body in *our* bed; which had, all at once, become *my* bed. The smaller losses leading to this lonely void provided some sense of orientation to the grief that came after Tom's death—bereavement.

**Knowing the grand finale loss is coming down the pike is just part of anticipatory grief. Meanwhile, there are the losses that happen along the way.**

There is the loss of the lightness inherent to the oblivion of our mortality, the loss of a future dream, the loss of certainty, the loss of faith in what held our beliefs up until push came to shove, the loss of another income in the household, the loss of parenting together, the loss of a sex life, the loss of freedom to leave the house, the loss of independence, the loss of privacy, the loss of a mutual relationship, the loss of a good night's sleep and the loss of comfort. These losses are compounded by the sneaky nature of anticipatory grief. It creeps in just when things start to stabilize and fantasies of everything being okay start to blossom. People just far enough outside the intimate circle of the ill person's day-to-day, tend to run with hope more easily because they haven't been jaded by the ups and downs of the illness. **Those on the inner circle of care feel the angst of this invisible roller coaster and must keep it to themselves, lest they be perceived as compromising hope.**



This was especially true for me while my husband was actively pursuing treatment. I found myself hiding books on death and dying that I had checked out from the hospice resource center, for fear others may think I had given up on Tom. Only when it was unmistakable that he wouldn't be getting better and he discontinued treatment, did it feel socially acceptable to mourn the losses along the way. In my experience, the cultural discomfort with death in this country keeps those anticipating it as a possibility silent and isolated until the death actually occurs. Hospice is one of the few organizations that provides support throughout the process. Unfortunately, because of the cultural discomfort, these services are often avoided and associated with "giving up." **An important distinction between anticipatory grief and bereavement is cultural support and understanding.**

After Tom's death, I found my grief was not only allowed socially, it was expected. Grief was then a demonstration of love for Tom and not the lack of it, as it had been while he was sick. The whole thing was backwards and I felt like I was on the wrong page at the wrong time; hence, came my interest to promote a better understanding of anticipatory grief. It is a long road of grief to travel and a little paving may help.

Others have been paving the way of understanding anticipatory grief for some time. Kenneth Doka, Ph.D., is one of them. **He uses the term, disenfranchised grief for grief that isn't validated or supported.** When I first read this term, I thought it a better fit than anticipatory grief, but then I thought of a friend who experienced both types of grief simultaneously and a friend who experienced a community of support for his anticipatory grief during his wife's illness. The former was a friend who was divorced at the time that the father of her young children finally succumbed to ALS. Insensitive comments like: "Well, at least there won't be anymore custody battles," invalidated her compounded grief. She lost him twice without resolution of the relationship. Her anger only gave people an easy out to disqualify her from their sympathy.

The latter, was a friend who was involved in a men's group at the time of his wife's



diagnosis and continued to derive emotional support for him self there throughout her illness and death. He was lucky to have such a community and courageous to use it. Anticipatory grief doesn't have to be disenfranchised grief, but it's too often a form of it. Doka writes in *Living with Grief When Illness is Prolonged* (1997), "The antidote to disenfranchised grief lies in the simple acknowledgement that every circumstance of loss, including loss after prolonged illness, creates its own unique grief." **We all need validation of our losses, without the ranking and qualifying of them from others.**

"At least you had time to grieve and say goodbye, what if his death was sudden?" is a common phrase used with the best intention. Yes, I can vouch for the side benefits of having a window of opportunity for both the person dying and those close to him/her.

And there are complications along the, sometimes, very long road. Therese A. Rando, another contributor to the book: *Living with Grief When Illness is Prolonged* (1997) and to the study of anticipatory grief, lists the issues the anticipatory griever is up against: ". . . powerlessness, fear, uncertainty, confusion: violations of the assumptive world; ongoing losses; personal depletion from the stress arising from demands for major re-adaptations and

investments of self, time, and finances; long-term family disruption and disorganization; balancing of opposing needs, competing demands, discordant roles, clashing responsibilities, and antagonistic tasks; traumatizing physical, emotional, and social experiences during the illness; and major reactions of guilt, sorrow and depression, anger and hostility and anxiety." Whew! **It isn't a matter of comparing whether a sudden or anticipated death is worse to grieve; it's a matter of disintegrating any myths getting in the way of a healthy grief process.**

Rando (1997) also believes that **a person experiencing the constant threat of their own or a loved one's death, by way of a terminal illness, constitutes the clinical criteria for PTSD** (post traumatic stress syndrome).

Coming across this tidbit helped me to find a context for some of my craziness during that time (ie. hyper vigilance, restricted range of affect, feeling detached) and even after Tom died (recurrent dreams of him coming back, sense of a foreshortened future, etc.). The symptoms of avoidance (avoiding thoughts, feelings or conversations related to the trauma-death) helped me understand those around me who responded differently than I did. As a hospice social worker, it was more often the case than not, that people didn't want my support because it meant they would have to talk about it. Initially, I assumed that talking about it was the best thing. At least it was what I needed and it is what I was taught at school. I learned quickly that talking about everyday things could be a way of normalizing the experience. "Normal" could be relief to people who had been on the road of this grief too long. In the safety of our relationship, it seemed **our task was to make dying and grief integral to living.** After all, it was what they lived with every day — it was their "normal".

Elizabeth Kubler-Ross established the five phases of grief that someone who is dying goes through and these have been found to apply to the loved ones of that person before and after the death as well. The phases: **denial, bargaining, anger, despair and acceptance can occur out of sequence, stretch out over time, vacillate between each other rapidly and be revisited, just when you thought you were safely in acceptance.** Even when Tom's prognosis was "days" and I thought I had completely cleared the denial phase (Thank god! It felt like being the emperor with no clothes); I'd slip into daydreams of being at our children's graduations together.

**Those five phases can look different before the loved one dies than after.** I had done so much bargaining before Tom died, in hopes of preventing his death, that I had discarded such exchanges with God after his death. I became skeptical of praying for outcome and, instead, I became a fan of finding meaning in whatever "is." Acceptance came

in waves and had many layers. The acceptance I experienced when I learned of Tom's cancer, was probably closest to the one I felt at his deathbed, before and after all the practical aspects were considered. After his death, it took my insides a long while to catch up with what looked like acceptance on the outside, as I eagerly moved on with my life. Recurring dreams of Tom let me know that part of me was still comprehending the loss.

Though there are similarities to post-death grief and anticipatory grief, Rando notes that anticipatory grief “. . . is different (than post-death grief) in nature and impact, physiology and experiences of ambivalence, denial, hope, endpoints, and acceleration.” She observes that **just because one knows of a terminal illness, it doesn't mean they begin grieving the impending loss.** I noticed in my husband a denial on some level kept him from being paralyzed by fear or depression (for a time), while on other levels, the knowledge of impending death, gave him permission to live fully. I saw it with patients at the hospital as well. At times it looked like a purposeful denial to avoid a chain reaction of stress that might give the illness and upper hand, and at others, the patient or a family member, went on about their life without flinching, without even a glance in the direction of the future. Those patients and families usually declined hospice care and were often offended that it was even being offered. Based on my experience with Tom, I'd say they missed out on a once-in-a-lifetime opportunity. **Though, in the end, there really isn't a right way, there is only the way we do it and how we live with that.**

Finally, I found a definition of anticipatory grief that pulled a fuller meaning from the semantics. Rando (1997) says: “Anticipatory grief is a complex and multidimensional experience that can be defined as follows: . . . the phenomena encompassing the process of mourning, coping, interaction, planning, and psychological reorganization that are stimulated and begun in part in response to the awareness of the impending death of a loved one and the recognition of associated losses in the past, present, and future. It mandates a delicate balance among the conflicting demands of simultaneously holding onto, letting go of, and drawing closer to the dying loved one.” There it is again, the challenge of holding both hope and grief, **staying close and letting go—all at the same time. Paradox and contradiction run rampant in anticipatory grief.** Though there are so many losses, there are unforeseeable gains within them. Spelling out this paradox is like trying to grasp water and in doing so I run the risk of making the gains from them sound like silver-lining niceties. Besides, there is no guarantee that one will find the gems. Certain poetry moves one when its timing is right and the listener is open. At the time, I read and re-read how to make the experience of anticipatory grief meaningful, to no avail. The meaning popped into the strangest unexpected moments and could never have been planned or conjured up like a recipe. Ultimately, it was my heart cracking open out of grief, making itself big enough to hold both letting go and drawing closer — that was the gem. It came by the way of traveling the long road of anticipatory grief—no short cuts.



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