If only

Thom Dennis, D. Min., LCPC, CT

Ella can't sleep because every time she lies down and closes her eyes, she sees images of her mom lying in the hospital bed. Michael is angry about the care his wife received; he thinks the staff's neglect hastened her death. Betty feels she didn't do enough and regrets getting angry with her spouse. She can't remember if she told her husband that she loved him before he died. Bob thinks he killed his mother by giving her morphine.

Ella, Michael, Betty, and Bob are made up names but their stories are not. While they may not represent actual people, I hear stories like these every day when I talk with grieving family members.

Ella

Intrusive thoughts, images, & rumination

In my experience these types of troubling or intrusive thoughts are quite common during the first month or so following the death of a loved one. I know this may sound strange, but I have come to believe that these types of thoughts and images might actually be a part of the grieving process. As distressing as they are, it is almost as if the mind keeps pressing the rewind button, over and over again to help your heart accept the fact that the loved one is really gone.

In its most extreme form, these along with other symptoms, can contribute to *Post Traumatic Stress Disorder* (PTSD). However, whatever the case may be, if these types of thoughts and images are truly distressing or continue to persist, consider talking with a counselor who can help you develop strategies to address them.

Additionally, many people do their best to keep busy during the day in order to avoid the distressing feelings related to loss. Unfortunately, when they finally slow down at the end of the day, the thoughts they'd avoided all day long seem to seep back into their conscious mind. Getting enough sleep is especially important to good health. We know that a lack of sleep can impair judgment and concentration, increase depressive thoughts, and contribute to other health concerns. If you are troubled by a lack of sleep because of these kinds of thoughts, consider talking to your primary care physician about getting a prescription for a sleep aid or they may suggest trying an over-the-counter sleep aid, such as melatonin. Many people I talk to do not want to take medications because they are concerned about experiencing negative side effects or they are concerned about becoming

addicted. If that is true for you, consider doing an internet search for *sleep hygiene* or strategies to fall asleep. The good news is that most people eventually return to their normal sleep patterns without any need for other types of interventions.

Michael
Anger, questioning who is at fault, blame, responsibility, accountability, litigation
We are all aware of cases where a doctor or other hospital or hospice personnel failed in providing adequate care. In the most extreme cases of abuse and neglect, litigation may be necessary, not only because of what happened to your loved one, but to ensure that the same thing does not happen to someone else.[1] In other cases, it not so much a matter of malpractice, it is more like the loved one was treated disrespectfully, dismissively, or without the kindness and care one would expect from people in the medical profession. These situations are called, *empathic failures*, and unfortunately they do occur. I keep a quote pinned to my office wall to remind me that, **"No one cares how much you know, until they know how much you care."** Compassion must be at the heart of every encounter between clinicians and patients and their families. That anger you are experiencing may be pointing out that you need do something about it.

Contrary to popular belief, anger is not one of the "stages of the grief process." From my perspective it can be a legitimate, righteous response when someone you love is not treated appropriately. Of course what we do with that anger is also important. We are all responsible for regulating our own emotions and behavior. Anger is a primal emotion that evolved to empower action. Admittedly, for some people, anger is their primary go-to emotion. Ask yourself if you are one of those people. Ask your family members and the people who know you best if your level of anger is appropriate to the situation. Lots of people have lingering questions and concerns about their loved one's care and I encourage them to follow through. It can be hard to move forward with grief when you are stuck in anger. Access the medical records, contact the appropriate people, and ask them to help you understand what happened. At the very least an apology may in order, in more complex cases I would not be in a position to advise you what to do.

Additionally, I have to say that anger is a common grief response, but not in the way you may think. When confronted with the reality of personal powerlessness in the face of mortality some people will lash out at any or everything. It works like this, a person they love was taken from them and they figure someone, something, has to be at fault. That anger can be directed at God, or the world, the disease, the person who died or at yourself. Sometimes the anger is directed at the medical personnel. Before you act, I would encourage you to make an honest assessment and ask if your anger could at least in part be attributed to the idea that you are simply angry at the fact that they suffered and died and there was nothing anyone could do to stop it! While it may be true that if something was done differently the loved one's life could have possibly been extended, at least a little while longer, it is not always true that their living longer was in their best interest.

Betty
Guilt and regret
Betty feels she didn't do enough and regrets getting angry with her husband. She can't remember if she told her him that she loved him before he died. Guilt and regret, like anger, are common emotions after someone dies. My office frequently becomes a confessional where people admit to things they did or failed to do. While I cannot offer absolution, I can encourage them to seek out whatever means are available to them to find peace. Sometimes that involves

[1] Medical Error is the third leading cause of death in the U.S. as found in the *Journal American Medical Association*, July 26, 2000;284(4):483-5

talking with a clergyperson or simply praying for forgiveness. On occasion my office will also become a courtroom, where my client acts as their own prosecuting attorney, judge, and jury, handing down the harshest of sentences. As their defense attorney, I have to say that from my perspective, the offenses they describe are seldom as bad as they think they are and I have to remind them that an important mitigating factor was that they were operating under extreme pressure and stress. While under the stress of care-giving sometimes we all say or do things that under normal circumstances we never say or do.

Sadly, despite your best effort and the fact that typically, everybody says how much they admire the great care you took in caring for your loved one, they still died. Betty can't remember if she told her husband that she loved him before he died. I would want to ask Betty the following question: "How proximate to the time of death would it have to be to count?" What I mean is; I'm sure they both told each other a thousand times how much they loved the other. I am sure her husband knew. I would also want to remind Betty that 90% of our communication is non-verbal. Even if she didn't actually use those particular words, the fact that she was his caregiver, the fact that she held his hand and wiped his brow, (or bottom) and slept in a hospital chair countless nights were all acts of love. Sometimes words are inadequate to express the profound feelings we hold deep in our hearts. Trust me Betty, he knew.

Bob

Death and the modern world

In the space of just a century, advances in medical science and in public health have nearly doubled the average life expectancy in the developed world. For a male born in the United States in the early 1900's, life expectancy was 46.3 years, for a female it was 48.3 years. In contrast, for a male born in 2015 life expectancy is 76.3 years and for females it is 81.3 years. In 1900, by far, the leading causes of death were infectious diseases, today it is cancer and heart disease. The role modern medicine plays in delaying death has changed dramatically and new advances are made every day. That means that the role of the family who cares for a dying relative has also drastically changed. While death in a hospital ICU may limit the family's access to dying loved ones, death at home with hospice care is very different. In 1900 most people died at home and the process of dying was relatively quick. Family members were largely powerless to do anything about it. The best they could do was pray and try to make their loved one as comfortable as possible. Today, when asked, many people say they would prefer to die at home with loved ones near, rather than the unfamiliar environment of a hospital or nursing home. Those final wishes are often made possible because of hospice care. As a matter of fact, deaths in hospice account for approximately 46% of all deaths in the United States,[2] and that number will certainly continue to grow.

I share all of this because today dying and death at home is very different than it was a hundred years ago. Typically, dying lasts much longer today and involves complicated, not to mention costly, treatments and procedures. I imagine you still offered up prayers and did your best to make your loved one comfortable, but you also had to be constantly vigilant, to change soiled linens, and administer potentially dangerous medications like morphine. In hindsight, many family members report they had no idea of what they were getting themselves into by agreeing to support their dying loved ones at home. The stress and emotions surrounding care for the dying can be overwhelming, and many do these things without the help and support from homecare agencies or other family members.

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[2] National Hospice and Palliative Care Organization (NHPCO) 2012 statistics www.nhpco.org, Accessed June 9, 2015.

While I am not a nurse, I can say with a fair amount of certainty that, unless intentional, that dose of medication, that patch you applied, that pill you gave was not what killed your loved one. If you don't want to take my word for it, for goodness sakes, call and ask to talk to the nurse or doctor who oversaw your loved one's care. It is true that morphine has some unavoidable side effects; it makes you sleepy and causes constipation. But, and this is a very big but, it eased their pain and suffering. Second guessing is very common amongst the bereaved. For some family members, the question at hand is who's at fault, and what role did I play in their dying? In the final analysis, death is rarely the fault of a family caregiver, and like the story of Betty above, what you did or didn't do in that extremely stressful situation had very little negative effect on the final outcome. What I think this kind of thinking is pointing to is the desire for a different outcome. Hold on to the thousand kindnesses you provided and remind yourself that the ultimate cause of death was the disease.

While hospice staff visit regularly and teach family members how to carry out these roles, most people aren't trained as professional nurses or caregivers. Hospice staffs frequently reflects on what a privilege it is to be invited into your hearts and homes, and to witness the loving care you provide in what is certain to be one of life's most challenging experiences. Our patients are our teachers and you are our heroes.

If only

If only questions come in many shapes and sizes. They often point to something much more profound than what the surface of the question might suggest. As a hospice grief counselor, having sat with the bereaved individually and in groups over the past ten years or so, if there is anything I have learned about grief it is this; grief is much bigger than just the strong emotions a person feels after someone dies. It touches longstanding issues of love and relationship. At least initially it disrupts our concentration and our ability to process our thoughts. It will almost certainly affect us physically in some way. It will also trigger profound questions about life and death and our role in the greater scheme of things. And finally, grief invites us to think about the limits of being human and the human condition. I don't know if any of us find satisfaction in regards to all the questions loss and grief invites us to explore, but I would want to remind you that you are not alone. I would also add that it seems to me that although the questions arise early, I'm not sure we can get to the answers right away. As frustrating as that is, people have to first find some solid ground to stand on before the answers can be found. That means you have to deal with the myriad of practical matters that need to be done following the death of a loved one and to sift through the emotional turbulence left in their wake, before an answer can be perceived. The poet, Rainer Marie Rilke, offered this good advice to a young poet in 1903. I would like to think his advice is also for you and for me.

I would like to beg you dear Sir, as well as I can, to be patient toward all that is unresolved in your heart and try to love the questions themselves like locked rooms and like books that are written in a very foreign language. Don't now seek the answers, which cannot be given you, because you would not be able to live them. And the point is, to live everything. Live the questions now. Perhaps then, you will then gradually, without noticing it, live along some distant day into the answer.[3]

For more information about the *Grief River*® please contact: Thom Dennis, D. Min., LCPC, CT
P.O. Box 409427, Chicago, IL 60640
thomdennis@hotmail.com

[3] Letters to a young Poet, Translated and with a forward by Stephen Mitchell (1984) New York: First Vintage Books Edition.