

Frontline

This newsletter is dedicated to professional caregivers. It is our hope that this newsletter will help you give comfort and strength to those you serve.

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Dying in Pieces: The Caregiver's Grief



By Dr. Earl A. Grollman

Someone asked a physician, "What is the most difficult diagnosis to make?" Her comment, "It used to be that dreaded word 'cancer.' Now it is 'memory loss.'"

Modern science has helped us to live long, healthier lives. However as medical technology has assisted us to live beyond previous lifespans, the odds increase that we are more prone to dementia.

The word dementia comes from the French dement, "a condition of madness or insanity." The modern usage now implies cognitive damage affecting learning, planning, remembering and retrieving. Alzheimer's disease is the most common form of dementia.

Studies indicate that 10 per cent of the population age 65 and over will suffer from Alzheimer's. The incidence increases with age. Twenty per cent of those 85 and older will become the sad inheritors. At present, there is no cure. No race, gender or socio-economic group is exempt.

Alzheimer's is relentless. Individuals are deprived of memories, language skills and the ability to reason, concentrate and know where they are in time and space. As a patient lamented during a moment of clarity, "I no longer have a sense of time and where I belong in the world. I am adrift."

But not only is there the anguish of the Alzheimer's patient. The words of Shakespeare's Hamlet are enlightening with the description of accumulating heartbreak. After the death of Polonius and Orpheus together with Hamlet's apparent madness, are the famous words, "When sorrows come, they come not in single spies. But in battalions!" (IV.V ff)

With Alzheimer's, there is exhaustion, confusion and turbulence for the caregiver – the sorrows that come "in battalions."

Caregivers may be surprised to learn that they are going through a grieving period. They may be confused: "How can I be grieving? My loved one is still alive!" But grief doesn't occur only after the death of a loved one. Grief is a natural reaction to any kind of painful loss including a disease that takes away a loved one's mind. Alzheimer's disease is a "series of grief experiences."

Caregivers grieve as they are forced to redefine and re-evaluate their lives – relationships, careers and future. There may be the accountability of arranging health-care assistance, checking medications, bathing and cooking. There may be financial responsibility. There may be need for alternative arrangements for both family as well as the patient. The list is endless.

Caregiver's syndrome explains how they may be the last to seek help even though they may be the neediest. As a result of stress, exhaustion and self-neglect, they themselves are at risk for physical and emotional illness.

Grieving for an Alzheimer's patient is not a disorder or a sign of weakness. It is an emotional, physical and spiritual necessity – the price paid for loving and caring. No matter how strong and resilient the caregivers, they may experience the following emotions:

Denial

"There must be some mistake; there is no definitive proof; life will go on as usual." Denial is a coping tool, a part of grief. When life appears unbearable, denial intervenes.

By buffering this catastrophic blow, caregivers are granted time to absorb the reality and face the future.

There may be good and bad days as the disease progresses. When the loved one seems better that day, hope and denial spring forth. When bad days return, reality returns. Caregivers must have the courage to confront this sorrowful illness. There is no cure. And as the disease progresses, the patient's condition steadily declines.

Physical Illness

"I have a sickening sensation in the pit of my stomach." "I have trouble sleeping." "I have no appetite." Caregivers may worry that they too are starting to experience the symptoms of Alzheimer's disease.

These physical problems are real. The caregivers are not hypochondriacs. Aching hearts take a physical toll on the rest of their bodies. They should consult a physician and mention the loved one's illness.

Anger

With the loved one's embarrassing behaviours, the groundless suspicions and a sense of helplessness, grieving may turn to overpowering hostility. Anger is a part of mourning. It is important that caregivers acknowledge, express and try to resolve their emotions. Holding back feelings may lead to clinical depression.

Caregivers have no control over the words and confusing actions of their loved ones. Both patient and caregiver are victims of this cruel disease.

Guilt

"If only I had known that she would have been stricken with this terrible illness." "If only we had taken the vacation that I promised her." "If only I could be more patient, more understanding." "If only he would die so I could have my life back."

"If only." There are always some nasty words that can't be forgotten; some fight that can never be erased. Even the most dedicated caregivers are plagued with "If only . . ." and "I never did enough." Guilt is a normal grief reaction, replete with "if onlys."

Caregivers must accept their fallibilities. All of us fail. No one is blameless. Problems are not solved with "if onlys." As Judith Viorst says in *Necessary Losses*, "We saw them as less than perfect and we loved them less than perfect."

Complicated Grief

"I don't care how I look anymore." "I don't care about anything anymore." "I would like to go to sleep and never wake up."

Indications of complicated grief include continuing:

- Feelings of helplessness and hopelessness.
- Decreased energy, fatigue.

- Extended feelings of guilt.
- Severe insomnia, oversleeping, weight gain, weight loss.
- Inappropriate social behaviours, risk taking.
- Excessive use of drugs or alcohol.
- Flashbacks, recurrent nightmares.
- Loss of interest in pleasures that were once enjoyed.
- Suicidal thoughts or actions.

If caregivers become "stuck in their grief," sinking into apathy and despair, they should consider professional help.

A proper diagnosis and treatment are required. Psychotherapy and a variety of antidepressant medications have proved invaluable. Together with emotional support, understanding, patience and encouragement, they will be more equipped to work through their suffering.

Finding Relief

Alzheimer's disease brings a series of losses – emotionally, physically, behaviourally, spiritually. Each caregiver must find the most effective coping mechanisms. Suggestions include:

- Giving Alzheimer's disease a description – GRIEF.
- Acknowledging grief is the first step in its resolution.
- Expressing, not repressing or suppressing, emotions will help to avoid deeper psychological problems.
- Seeking out understanding from caring friends and support groups designed for those experiencing the same heartaches – effective grief work is not done alone.
- Learning to care for themselves – an overwhelmed caregiver cannot be an effective caregiver.
- Finding information about Alzheimer's and its possible progression.
- Seeking solace in spiritual resources.

Caregivers may gain fresh insights from their grief. Jonathan Kozol, in his book *The Theft of Memory*, describes his father, an eminent psychiatrist who died at age 102 of an Alzheimer's-related death. In public, the father was widely acclaimed. At home, he was uncaring and uninvolved. During the long illness, Kozol would recall fond memories, like the times he and his father went fishing together. These rare moments made a past distant relationship more palatable in the present. In sickness, father and son were finally able to make peace.

About the Author

Dr. Earl A. Grollman, a pioneer in crisis management, is an acclaimed writer and lecturer. In 2013, the Association for Death Education and Counseling presented him with its Lifetime Achievement Award, only the fourth time in three decades. This award honours "his national and international impact on the improvement of death education, caring for the dying person and grief counselling." His books on coping with bereavement have sold more than a million copies.

For further information, visit www.beacon.org/grollman.

Dispelling Myths About Grief



By Alan D. Wolfelt, Ph.D.

Many caregivers have a real desire to learn more about aiding those who are grieving. Without a doubt we have witnessed an upsurge in interest in bereavement caregiving. However, many well-intentioned yet misinformed people are still victims of some widely held myths regarding grief.

The purpose of this article is to identify, describe and dispel some of the myths about grief. Providing quality care to the bereaved requires that we as a society work to dispel these myths outlined below. People who have internalized these myths become incapable of helping griever's move toward healing.

These myths are not intended to be all-inclusive or mutually exclusive. Observation suggests that many people who believe in any one of these will also believe in many, if not all, of the others. Our joint task is not to condemn these people but supportively encourage them to broaden their understanding of the complex experiences of grief and mourning.

Describing and dispelling the myths

Myth #1:

Grief and mourning are the same experience.

The majority of people tend to use the words grief and mourning synonymously. However, there is an important distinction between them. We have learned that people move toward healing not by just grieving, but through mourning.

If we want to help the bereaved, we can work to understand the semantic distinctions of these commonly used terms. Simply stated, grief is the thoughts and feelings that are experienced within oneself upon the death of someone loved. In other words, grief is the internal meaning given to the experience of bereavement.

Mourning is taking the internal experience of grief and expressing it outside of oneself. The specific ways in which people express mourning are influenced by customs of their culture. Another way of defining mourning is to state that it is “grief gone public” or “sharing one’s grief outside of oneself.”

In reality, many people in our culture grieve but they do not mourn. As opposed to being encouraged to express their grief outwardly they are often greeted with a message along the lines of “carry on,” “keep your chin up” and “keep busy.” So, they end up grieving within themselves in isolation, instead of mourning outside of themselves in the presence of loving companions.

Myth #2:

There is a predictable and orderly stage-like progression to the experience of mourning.

Stage-like thinking about both dying and mourning has been appealing to many people. Somehow the “stages of grief” have helped people try to make sense out of an experience that isn’t as orderly and predictable as we would like it to be. Attempts have been made to replace fear and lack of understanding with the security that everyone grieves by going through the same stages. If only it were so simple!

The concept of “stages” was popularized in 1969 with the publication of Elisabeth Kubler-Ross’ landmark text *On Death and Dying*. Kubler-Ross never intended for people to literally interpret her five “stages of dying.” However, many people have done just that and the consequences have often been disastrous.

One such consequence is when people around the grieving person adopt a rigid system of beliefs about grief that does not allow for the natural unfolding of the mourner’s personal experience. We have come to understand that each person’s grief is uniquely his

Being surrounded by people who believe in these myths invariably results in a heightened sense of isolation and aloneness in the grieving person. The inability to be supported in the “work of mourning” destroys much of the capacity to enjoy life, living and loving.

or her own. As helpers we only get ourselves in trouble when we try to prescribe what someone's grief experience should be.

This author prefers a helping attitude that conveys the following: “Teach me about your grief and I will be with you. As you teach me I will follow the lead you provide me and attempt to be a stabilizing and empathetic presence.”

Myth #3:

It is best to move away from grief instead of toward it.

The unfortunate reality is that many griever's do not give themselves permission or receive permission from others to mourn and express their many thoughts and feelings. We continue to live in a society that often encourages people to prematurely move away from their grief instead of toward it. Consequently, many people grieve in isolation or attempt to escape from their grief.

The result of these kinds of messages is to encourage the repression of the griever's thoughts and feelings. Refusing to allow tears, suffering in silence and being strong are thought to be admirable behaviours. Many people in grief have internalized society's message that mourning should be done quietly, quickly and efficiently.

Returning to the routine of work shortly after the death of someone loved, the bereaved person relates “I'm fine” in essence saying “I'm not mourning.” Friends, family and co-workers often encourage this stance and refrain from talking about the death. The bereaved person, having an apparent absence of mourning (having moved away from their grief instead of toward it), tends to be more socially accepted by those around him or her.

However, this type of collaborative pretence surrounding grief does not meet the emotional needs of the bereaved person. Instead, the survivor is likely to feel further isolated in the experience of grief, with the eventual onset of the “going crazy

syndrome.” Attempting to mask or move away from the grief results in internal anxiety and confusion. With little, if any, social recognition related to the pain of the grief, the person often begins to think their thoughts and feelings are abnormal. As a matter of fact, the most frequent initial comment of grieving persons at our Center for Loss and Life Transition in Colorado is the statement, “I think I'm going crazy.”

If we want to help bereaved people we must remember that it is through the process of moving toward pain that we move toward eventual healing.

Final thoughts

Again, be aware that the above myths are not intended to be all-inclusive. This author suggests the reader develop a list of any additional “grief myths” observed in our society.

Being surrounded by people who believe in these myths invariably results in a heightened sense of isolation and aloneness in the grieving person. The inability to be supported in the “work of mourning” destroys much of the capacity to enjoy life, living and loving.

Only when we as a society are able to dispel these myths will grieving people experience the healing they deserve!

About the Author

Dr. Alan Wolfelt is a respected author and educator on the topic of healing in grief. He serves as director of the Center for Loss and Life Transition and is on the faculty at the University of Colorado Medical School's Department of Family Medicine. Dr. Wolfelt has written many compassionate, bestselling books designed to help people mourn well so they can continue to love and live well, including *Understanding Your Grief*, *The Mourner's Book of Faith*, and *Loving from the Outside In, Mourning from the Inside Out*. Visit www.centerforloss.com to learn more about the natural and necessary process of grief and mourning and to order Dr. Wolfelt's books.



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