Coping with Ambiguous: The Enduring Grief

Much has been written about degenerative diseases that disrupt brain function such as Alzheimer’s, Parkinson’s and multiple sclerosis. Counsellors may not be as familiar with traumatic brain injuries (TBI). It could emanate from a severe jolt to the head as a result of an accident or sports injury (concussion), or exposure to an explosive device such as what our military is experiencing during times of war.

Severe Concussions

The term concussion stems from the Latin cutere (“to shake violently”) or concussus (“action of striking together”). Concussions are considered not only the most common form of TBI, but the mildest. There may be symptoms of momentary dizziness, blurred vision, a ringing in the ears, nausea, vomiting and even a temporary memory loss. After a rest of a few minutes, hours, days or even a week or two, a full recovery is expected.

However, there are different degrees of concussions. Some can lead to continuing symptoms and consequences with ominous long-term effects. (Tell that to members of the National Football League). Severe concussions may lead to serious TBIs with symptoms including:

- Physical. Vision and hearing difficulties, convulsions, continuing dizziness, amnesia, nausea, problems with balance and coordination, loss of consciousness for long periods of time, sleep and eating patterns radically altered, hyperactivity, even violent behaviour.

- Emotional and Cognitive. Loss of self-esteem, restlessness, an impairment or slowed reaction times, irritability, feeling like “in a fog,” excessive anger, lack of interest in what was once meaningful and pleasurable, disorientation, intense mood swings, lethargy.

These types of TBIs create an ambiguous grief with a physical presence but a psychological absence.

Is the name Ben Utecht familiar to you? Some may know that he had a distinguished six-year career in the National Football League. He, like most football players, was no stranger to concussions. After his first reported concussion, he soon returned to practice and continued to play with severe consequences.

When helmets collided, his neck was severely contorted, his vision was impaired and he had difficulty communicating, persistent headaches and long-term memory loss. Even though he was both a groomsman and a singer at a friend’s wedding, there was no recall of the event.

It was only after the fifth collision did he agree to visit Robert Cantu, MD, at the Boston University School of Medicine. Utecht later said, “Dr. Cantu opened my eyes to all those aspects of brain health that I had never known. And I’m thinking, man... if only I had this information six years ago.”

When not identified, such concussions could lead to cognitive impairment accompanied by feelings of helplessness and hopelessness. Football players Junior Seau (Chargers), Andre Waters (Eagles), Ray Easterling (Falcons) and Terry Long (Steelers) all had documented brain damage from head trauma resulting in suicide. What is both astonishing and alarming is that much was already known years before of the perils of crashing helmets.
When a Loved One has a TBI

What happens when a loved one is “lost” to us as a result of a TBI – whether from a sports injury, accident, fall or war wound? No, it is not an actual death. There are no services. No burial. No rituals to support the survivors and help them cope with their loss. Yet, their loved ones are no longer the people they used to cherish. With ambiguous loss, the sadness may appear impossible to move beyond. Forced to bear witness to their loved one’s continual decline, family and friends may become stuck in their endless grief.

There is the story of the husband who was involved in a serious car crash. People marvelled that he had survived the ordeal. Friends told his wife, “Don’t you know how lucky you are that he is still living?"

Their words brought scant consolation – just the opposite. Her husband was no longer the sweet and understanding person she knew. Because of his profound emotional impairment, he had become irrational, demanding, even hostile. She said, “They call him my husband but he is a man I really don’t know.”

Dr. Jeffrey Kreutzer, director of Virginia’s Traumatic Brain Injury Model Systems (TBIMS), has been studying the impact of TBI on relationships for the past quarter of a century. He calls this the “stranger syndrome.” Loved ones become transformed – turning creative minds into couch potatoes. And as a result, partners are instantly turned into caregivers, putting a severe strain on their life’s relationships. In her article “You’ve Survived a TBI – But Will Your Marriage?” that appeared in December/January issue of Neurology Now, author Gina Shaw attests to the importance of couples asking for help to cope with their difficult ordeal.

How to Help

Explain to clients that ambiguous loss is different from other types of painful trials (i.e. death or divorce). With TBI, loved ones may be “present” but their minds are impaired. Both the victims and their loved ones mourn their loss and grieve their future.

Encourage, no – urge the injured to seek immediate help. Don’t be surprised if there is reluctance even defiance. Public knowledge could mean the loss of a job. Or a sense of the injured party’s instability and “weakness.” This is especially true for males. The popular term “macho” is a Spanish word, meaning “aggressively masculine.” Men have been taught as children to be strong, brave and silent despite severe distress. In high school, football players often prepare by running into other players to gauge their toughness. No wonder they are reluctant to report any painful injuries.

Advise families to find a specialist knowledgeable in this area and to obtain the best information of the physical and cognitive effects of that particular wound. Questions might include: What is the present status? What changes may be anticipated in the future? Are there other approaches for more rapid improvements? Know that brain recovery is more rapid in the young than the aged.

Help both the injured and their loved ones to understand that the anger, hyperactivity, memory loss and depression of the individual with the TBI are not intentional. These are behaviours they cannot control – symptoms of their illness. They have become victims of their own degenerating brains.

Caregivers, too, suffer with their grief and struggle with bereavement issues. The body of their loved one may be present but the mind may not be functioning properly. These caregivers become exhausted, suffer with guilt, while feeling trapped in their new restrictive styles (some call it a “prison”). Their experience of isolation intensifies; anxiety and loneliness become overwhelming. Withdrawal may seem like the easiest road to travel.

How to now cope with their ambiguous losses?

I love the Czech proverb, “Do not protect yourself by a fence, but rather by your friends.” Emphasize how caring people may be vital in assisting them through their tribulations. They should choose friends who will listen to them and not tell them how they should feel; not overwhelm them with their presence. Instead, allow spaces in their togetherness and when required, offer compassionate non-judgmental support; and accept their need to express anger, guilt and anxiety.

People need people. Friends need friends. We all need each other. Caregiving is a high-stress activity. If they collapse under the tension, they cannot effectively care for their loved ones. Many people find practical (respite care) and emotional assistance from the Brain Injury Association of America (http://www.biausa.org/) or the Family Caregiver Alliance (https://caregiver.org/caring-adults-cognitive-and-memory-impairment).

Inform caregivers about the importance of support groups and help them find such groups in their locale. At support groups, they will meet those travelling similar agonizing paths. Their terrifying feelings are not unique. They are not crazy. They better understand the range of feelings caregivers may experience from sadness to guilt to anger. Together, they share fresh constructive approaches. In helping others, they will help themselves.

No, their lives may never be the same. Yet, life still can have promise and meaning. As counsellors, we help them to develop a more stable tolerance to their ambiguous loss. There is hope.

Perhaps, this is the best articulated by the old psalmist (126.5) in his “Song of Ascents.” This passage has brought consolation, solace and encouragement, throughout the centuries.

“They that sow in tears may again reap with songs of joy.”

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 copng with bereavement have sold more than a million copies. For further information, visit www.beacon.org/grollman.
All you need is love,” famously sang the Beatles. I couldn’t agree more. We come into the world yearning to give and receive love. Authentic love is God’s greatest gift to us as human beings. Love is the one human experience that invites us to feel beautifully connected and forces us to acknowledge that meaning and purpose are anchored not in isolation and aloneness, but in union and togetherness.

What higher purpose is there in life but to give and receive love? Love is the essence of a life of abundance and joy. No matter what life brings our way, love is our highest goal, our most passionate quest. Yes, we have a tremendous need for love – love that captures our hearts and nourishes our spirits. In fact, our capacity to give and receive love is what ultimately defines us. Nothing we have “accomplished” in our lifetimes matters as much as the way we have loved one another.

“Every time we make the decision to love someone, we open ourselves to great suffering, because those we most love cause us not only great joy but also great pain. The greatest pain comes from leaving … the pain of the leaving can tear us apart.

“Still, if we want to avoid the suffering of leaving, we will never experience the joy of loving. And love is stronger than fear, life stronger than death, hope stronger than despair. We have to trust that the risk of loving is always worth taking.”

~ Henri Nouwen

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The experience of grief is only felt when someone of great value, purpose and meaning has been a part of your life. To mourn your loss is required if you are to befriend the love you have been granted. To honour your grief is not self-destructive or harmful; it is life-sustaining and life-giving, and it ultimately leads you back to love again. In this way, love is both the cause and the antidote.

Yet love inevitably leads to grief. You see, love and grief are two sides of the same precious coin. One does not – and cannot – exist without the other. They are the yin and yang of our lives. People sometimes say that grief is the price we pay for the joy of having loved. This also means, of course, that grief is not a universal experience. While I wish it were, sadly it is not. Grief is predicated on our capacity to give and receive love. Some people choose not to love and so never grieve. If we allow ourselves the grace that comes with love, however, we must allow ourselves the grace that is required to mourn.

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Yes, it is a given that there is no love without loss. Likewise, there is no integration of loss without the experience of mourning. To deny the significance of mourning would be to believe that there is something wrong about loving. Just as our greatest gift from God is our capacity to give and receive love, it is a great gift that we can openly mourn our life losses.

It is important that you understand that grief and mourning are not the same thing, however. Grief is the constellation of thoughts and feelings we have when someone we love dies. We can think of it as the container. It holds our thoughts, feelings and images of our experience when someone we love dies. In other words, grief is the internal meaning given to the experience of loss. Mourning is when we take the grief we have on the inside and express it outside of ourselves.

Making the choice to not just grieve but authentically mourn provides us the courage to live through the pain of loss and be transformed by it. How ironic that to ultimately go on to live well and love well we must allow ourselves to mourn well. Somewhere the collision between the heart, which searches for permanency and connection, and the brain, which acknowledges separation and loss, there is a need for all of us to authentically mourn. You have loved from the outside in, and now you must learn to mourn from the inside out.

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 Loving from the Outside In, Mourning from the Inside Out, from which this article is excerpted. Visit www.centerforloss.com to learn more about the natural and necessary process of grief and mourning and to order Dr. Wolfelt's books.