

Moving Forward:

The grief & ambiguous loss associated with caring for someone with dementia

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The Mourner's Bill of Rights

Though you should reach out to others as you do the work of mourning, you should not feel obligated to accept the unhelpful responses you may receive from some people. You are the one who is grieving, and as such, you have certain “rights” no one should try to take away from you.

The following list is intended both to empower you to heal and to decide how others can and cannot help. This is not to discourage you from reaching out to others for help, but rather to assist you in distinguishing useful responses from hurtful ones.

1. You have the right to experience your own unique grief. No one else will grieve in the exact same way you do. So, when you turn to others for help, don't allow them to tell you what you should or should not be feeling.
2. You have the right to talk about your grief. Talking about your grief will help you heal. Seek out others who will allow you to talk as much as you want about your grief. If at times you do not feel like talking, you also have the right to be silent.
3. You have the right to feel a multitude of emotions. Confusion, disorientation, fear, guilt, and relief are just a few of the emotions you might feel as part of your grief journey. Others may try to tell you that feeling angry, for example, is wrong. Don't take these judgmental responses to heart. Instead, find listeners who will accept your feelings without conditions.
4. You have the right to be tolerant of your physical and emotional limits. Your feelings of loss and sadness will probably leave you feeling fatigued. Respect what your body and mind are telling you. Get daily rest. Eat balanced meals. And don't allow others to push you into doing things you don't feel ready to do.
5. You have the right to experience “griefbursts”. Sometimes, out of nowhere, a powerful surge of grief may overcome you. This can be frightening, but it is normal and natural. Find someone who understands and will let you talk it out.
6. You have the right to make use of ritual. The funeral ritual does more than acknowledge the death of someone loved. It helps provide you with the support of caring people. More importantly, the funeral is a way for you to mourn. If others tell you the funeral or other healing rituals such as these are silly or unnecessary, don't listen.
7. You have the right to embrace your spirituality. If faith is a part of your life, express it in ways that seem appropriate to you. Allow yourself to be around people who understand and support your religious beliefs. If you feel angry at God, find someone to talk with who won't be critical of your feelings of hurt and abandonment.
8. You have the right to search for meaning. You may find yourself asking, “Why did he or she die? Why this way? Why now?” Some of your questions may have answers, but some may not. And watch out for the clichéd responses some people may give you. Comments like, “It was God's will” or “Think of what you have to be thankful for” are not helpful and you do not have to accept them.
9. You have the right to treasure your memories. Memories are one of the best legacies that exist after the death of someone loved. You will always remember. Instead of ignoring your memories, find others with whom you can share them.
10. You have the right to move toward your grief and heal. Reconciling your grief will not happen quickly. Remember, grief is a process, not an event. Be patient and tolerant with yourself and avoid people who are impatient and intolerant with you. Neither you nor those around you must forget that the death of someone loved changes your life forever.

Caregiver Bill of Rights

- I have the right to take care of myself. This is not an act of selfishness. It will give me the capability of taking better care of my relative.
- I have the right to seek help from others even though my relatives may object. I recognize the limits of my own endurance and strength.
- I have the right to maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things just for myself.
- I have the right to get angry, be depressed, and express other difficult feelings occasionally.
- I have the right to reject any attempts by my relative (either conscious or unconscious) to manipulate me through guilt and/or depression.
- I have the right to receive consideration, affection, forgiveness and acceptance from my loved one for what I do, for as long as I offer these qualities in return.
- I have the right to take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.
- I have the right to protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.
- I have the right to expect and demand that as new strides are made in finding our resources to aid physically and mentally impaired persons in our country, similar strides will be made towards aiding and supporting caregivers.

— Jo Horne, author of *Caregiving: Helping an Aging Loved One*

Case Study #1

Sue is a 75 y/o, female whose husband, Bill was diagnosed with vascular dementia about a year ago. Sue and Bill have been married for over 50 years and live in a single-family home. Sue is relatively healthy physically and has had an active life. She has always been very active in her church, volunteered at the grade school and kept a beautiful garden and immaculate house. Sue would often comment that she needed to stay busy to cope with the death of her infant daughter, Julie. After Julie's death, Sue had periods when she would need more sleep. Sue and Bill called it "leaving the world for a while". After a few days, Sue would come back to her life and attempt to regain normality.

Prior to meeting Bill, Sue had wanted to be a teacher but dropped out of college finding she couldn't focus. Distressed about the situation, Sue lost weight and found sleeping was the only time her mind quieted. At the time, Sue and her parents attributed her feelings to being homesick and young. Because she was not able to finish school, Sue always felt less than her husband, who had earned a master's degree.

On a recent visit, Sue's daughter, Anne, found several month's worth of unpaid bills and spoiled food. During a conversation with Anne, Sue shared she has stopped volunteering because she was no longer making a difference and had nothing to contribute. When Anne asked about Sue's recent weight loss, Sue said Bill's eating habits have changed and she doesn't like cooking for one. Sue also shared that she has a regular upset stomach. Anne also noted that Sue refused several social invitations using Bill as her excuse to stay home. Sue's family also has noticed some forgetfulness and change in her daily functioning during their more frequent visits since Bill's diagnosis. Sue has not shared she has been experiencing "sad times" most days. The family is strongly suggesting Bill and Sue move to an older adult community - ALF. Sue is anxious about going through things, packing and moving, not wanting to make more change.

Sue and her family don't know where to turn and how to move forward. What are your suggestions?

Group for 5 minutes to discuss the case and come back with some ideas about Sue.

Case Study #2

Ron is a 67 y/o, retired social worker. He lives with his wife of 43 years, Jackie, in their home in a small, rural community. They were high school sweethearts and went to college together. Jackie is a retired nurse. When they retired and moved 2 years ago to be closer to their children and grandchildren, Ron and Jackie had planned that this small farmette would be the forever place. Jackie was uncharacteristically unorganized and disturbed by the move. She unpacked things to unusual places, couldn't navigate the house even after several months and forgot to pay the new mortgage several times. Ron noticed that she was having trouble reading to her grandchildren. For a short time, Ron thought it was due to the significant life changes of retiring and moving from their home of 30 years. During a holiday visit, Ron's children expressed concerns. Ron scheduled an appointment pursuing a cognitive evaluation. Jackie was diagnosed with Alzheimer's disease last year.

Ron was devastated. Jackie denies a problem most days. Ron wonders how he will care for her and thinks about selling their property to make things easier. Jackie is otherwise physically healthy. The neurologist told Ron she could live for years as her cognitive abilities continue to worsen. Ron grapples with what to do next every day. He cries himself to sleep knowing things will never be the same nor look like what he and Jackie had planned for. He is constantly tired trying to stay one step ahead but has trouble sleeping. He has tried to learn to cook and sees laundry as an acquired skill. He tries to keep up with the checkbook, bills and grocery shopping the way Jackie did. Many times he feels he's failing. Ron has times of frustration and rage thinking that he should have known sooner. He often covers for Jackie in public and limits social engagements, rarely going out alone. Ron has stopped golfing and no longer attends his monthly retiree lunch with former colleagues. Ron sees his mission as caring for his wife the best he can. He constantly faces anxiety, regret and sadness about the things Jackie can no longer do. Ron has had to do numerous things for Jackie's safety including selling her car and preventing her from driving. Despite living within miles of their 2 children and feeling overwhelmed, Ron doesn't ask for help.

Ron and Jackie's children contact the ADRC for suggestions on how to help their parents. What are your suggestions?

Group for 5 minutes to discuss the case and come back with some ideas.