

Grief and Loss with Alzheimer's disease and Dementia

Caregivers as well as patients experience multiple losses throughout the disease processes of Alzheimer's disease and dementia. Sometimes, these losses can continue for years, finally resulting in loss of the physical person. This piece addresses such loss.

"I don't understand it," Marla said, "I lost him years ago to Alzheimer's disease. There even came a point when he no longer remembered me. Why do I hurt so much now?"

It was easy to understand Marla's feelings. The man she had been married to for over 50 years had developed Alzheimer's disease six years prior to his death. She had been with him for those six years, watching his slow descent. Marla described Ed as a shell of his previous self toward the end: he barely communicated. Once open and engaging, he became guarded and scared. He no longer recognized her or their children. "Beyond his appearance, there was nothing left of the man I married," she recalled after his death.

Marla grieved all of those losses along the way. She cried bitterly the first time he asked who she was. She grieved when they went to a department store and Ed wondered if any of the photographs displayed in the picture frames were their children. She felt emotional pain every moment of his decline.

She also grieved all the ways her life had changed. She mourned the loss of companionship and intimacy. She missed the walks they took together. Marla could no longer enjoy those wonderful times when she would watch her husband play with their grandchildren.

Now she grieved Ed's death. That surprised her. She had thought that when he finally died, she would feel a burden lifted. She thought it would be a relief from the constant demands of care.

She was surprised at how complex her responses were. She did feel some of that relief. Yet, there were other reactions as well. She felt guilty, remembering all the times she had lost patience with Ed, upset and angry over lapses of memory that he could not control. She also felt a sense of gratitude for all the sharing, all the better memories that bound them throughout their long years of marriage. She experienced anger, asking why this good man had to die this way. There was resentment about the comments she received from neighbors and even friends after his death. So many people told her she was better off, which was not what she felt or wanted to hear.

There was the loneliness, and the spare time. That surprised her. She missed Ed's company and she seemed lost with the time. "I did so much for Ed when he was alive. That is all I did. I never seemed to have enough time. Now, the hours seem to drag endlessly."

All these responses confused Marla. Yet, all are normal and expected in long chronic illnesses.

Grief is intense and complex. It is not unusual to grieve the losses along the way, each change or deterioration. At each stage of loss, even the death, there is more loss to experience. These losses should be acknowledged. Grief is a journey. Throughout that journey, bereaved individuals need good listeners support, and respect.

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