

Relentless Goodbye – Grief and Love in the Shadow of Dementia

by Ginnie Horst Burkholder¹

Book Review by David Tillman, Grief and Loss class, United Theological Seminary, October 2013

Describe the main characters and the loss and grief issues:

The story is written by Ginnie Horst Burkholder. She is married to Nelson Burkholder. Her story starts when she and others begin to notice changes in Nelson's behavior. Her story continues over the next twenty years. In her book, she then highlights the events and her thoughts for each month, starting in January of 2006 through December 2011. Her story highlights their journey with living with Nelson's dementia.

Nelson Burkholder was born on a farm in 1945. He was a physically active and fun loving. Ginnie Horst Burkholder was born in December 1944 and had also grown up on a farm. They were married in October 1974. They "spent the first six years of [their] marriage in Chicago doing voluntary service and then working [their] way through college at the University of Illinois Chicago Circle campus. After graduation Nelson was offered a teaching job in Canton, Ohio, close to [Ginnie's] family. [They] quickly adopted First Mennonite Church as [their] second family."²

Their son, Eric, was born in 1973 and in 1995 began attending college in Goshen, Indiana. Amy, their daughter, was born in 1979. In 1986, their family bought a one hundred year old home situated on two acres outside of Canton. "Nelson enjoyed renovations and [Ginnie] loved working in the garden" (16). Their two children, Eric and Amy, lived in other states at least during the six years from 2006 to 2011, which is the timeframe for most of the book.

¹ Ginnie Horst Burkholder, *Relentless Goodbye- Grief and Love in the Shadow of Dementia*, (Harrisonburg, VA: Herald Press, 2012).

² *Ibid.*, 15-16.

In 1991 it was becoming noticeable to Ginnie that Nelson needed more help than seem warranted. Throughout the 1990's Nelson had sleep disturbances which were becoming more frequent. Over the next few years they saw different doctors, got different diagnoses and medicines that did not solve the problem. It was becoming an ambiguous loss. They could not pin down the problem or how to make sense of what was happening to Nelson. In the fall of 1995, Nelson quit his teaching job due to his medical issues.

In December of 1996, after a visit to Northwestern Medical Facility Foundation in Chicago, they were “finally given an accurate diagnosis of Lewy body dementia [LBD].”³ “Lewy body has dementia symptoms that resemble Alzheimer’s as well as kinetic symptoms that resemble Parkinson’s. One of the symptoms somewhat unique to LBD is fluctuating cognition-an aspect of the disease that keeps caregivers on an emotional rollercoaster...other typical symptoms...are hallucinations, transient and unexplained unresponsiveness, delusions, illusions, visual impairment, sleep disturbances such as are seen in REM behavior disorder, and autonomic dysfunction.”⁴

Identify theories and theologies of grief:

As Ginnie tells their story of the effects of Nelson’s Lewy body dementia, one can read examples of many of Kenneth Mitchell and Herbert Anderson’s different types of loss, material, relationship, intrapsychic, functional, roll, systematic and other losses.⁵ Also one can read about Ginnie’s and other’s “ambiguous loss” that Pauline Boss writes about.⁶

Mitchell and Anderson states that, “Relational loss is the ending of opportunities to relate oneself with, talk to, share experiences with, make love to, touch, settle issues with, fight with and

³ Ibid., 18.

⁴ Ibid., 20.

⁵ Kenneth R. Mitchell and Herbert Anderson, *All Our Losses, All Our Grievs – Resources for Pastoral Care*, (Louisville: Westminster John Knox Press, 1983).

⁶ Pauline Boss, *Ambiguous Loss – Learning to Live with Unresolved Grief*, (Cambridge: Harvard University Press, 1999).

otherwise be in the emotional and/or physical presence of a particular human being.”⁷ Over the twenty years the book encompasses, and especially in the last six years, the effect of Nelson’s Lewy body dementia has been for Ginnie, a significant “relationship loss.” Ginnie says, “How do you begin to talk about the experience of letting go of a spouse one day at a time for years on end? Where are the words to describe the sense of having a husband, but not have a marriage? What do you say about the depression that inevitably color days or weeks at a time? What do you leave out because you want to protect them from your pain? What do you leave out because you don’t want to feel the pain?”⁸ She goes on to tell of her just wanting the reassurance that she is going to keep the faith, her tiredness, and bouncing between hope and despair.

Another loss that Ginnie is experiencing is intrapsychic loss. Mitchell and Anderson tell us this “is the experience of losing an emotionally important image of oneself, losing the possibilities of ‘what might have been,’ abandonment of plans for a particular future, the dying of a dream.”⁹ Ginnie says, “What is it? I am not sure. I know what commitment is. We have that. But love? It seems like this impossible dream that teases me, and I forever believe it is possible. But just when you think maybe I have it, it seems to evaporate because love is supposed to be a two-way giving, a two-way sharing, a two-way managing, a two-way effort, and it all feels so one-way; I do not yet know how to love when so many supposed-to-bes have gone away with no hope of returning, and I am left holding all the responsibility with absolutely no room for letting Nelson cover my back, but always and forever, I need to cover his.”¹⁰ Ginnie’s intrapsychic losses force her to redefine over and over again who she is and where is love in all of her broken dreams and grieving.

⁷ Kenneth R. Mitchell and Herbert Anderson, *All Our Losses, All Our Grievs – Resources for Pastoral Care*, 26.

⁸ Ginnie Horst Burkholder, *Relentless Goodbye- Grief and Love in the Shadow of Dementia*, 218.

⁹ Kenneth R. Mitchell and Herbert Anderson, *All Our Losses, All Our Grievs – Resources for Pastoral Care*, 40.

¹⁰ Ginnie Horst Burkholder, *Relentless Goodbye- Grief and Love in the Shadow of Dementia*, 44.

Ginnie writes about being at that point that she thinks she “has it,” or has figured it out, and then it seems to evaporate because love is supposed to look a different way in her mind. This evaporating love and understanding is like Luke’s Emmaus story. As Jesus was with the two he had meet on the road to Emmaus, “he took bread, blessed and broke it, and gave it to them. Then their eyes were opened, and they recognized him; and he vanished from their sight.”¹¹ In that moment that our eyes are opened to see God’s more clearly, we may find that in the next moment our clarity evaporates. We may once again be left in the question “Where is God in all of this?” Throughout the book, Ginnie is trying to make sense of what is happening to Nelson and her, only to find around every new corner God’s short, but fleeting, clarity.

Nelson’s Lewy body dementia was a functional loss.¹² LSB affected his physical and mental capabilities. As Ginnie states, “A huge added challenge with LBD is the fluctuating cognition. He may be back today with higher functioning cognition. He may be back today with higher functioning than yesterday, reminding you once again of how much has been lost and of happier times.”¹³ As a caregiver, Ginnie would grieve Nelson’s functional losses over and over. He would get better, offering hope and renewed connection, only sometime later revert back. Ginnie was his main caregiver for years, having to help Nelson get thorough each day with his declining functional physical, mental and emotional capabilities. Her caregiving to Nelson and others has taken a physical, mental, spiritual and emotional toll on Ginnie as well.

Ginnie and Nelson are also experiencing a “roll loss...the loss of a specific role or of one’s accustomed place in a social network.”¹⁴ Ginnie says, “Lewy body disease slices life into two:

¹¹ Luke 24: 30-31, NRSV

¹² Kenneth R. Mitchell and Herbert Anderson, *All Our Losses, All Our Grievs – Resources for Pastoral Care*, 41.

¹³ Ginnie Horst Burkholder, *Relentless Goodbye- Grief and Love in the Shadow of Dementia*, 66.

¹⁴ Kenneth R. Mitchell and Herbert Anderson, *All Our Losses, All Our Grievs – Resources for Pastoral Care*, 42.

before LBD and after. Equal partnership evolves into caregiver and care receiver. Roles change into the managed and manager.”¹⁵

They are experiencing a systematic loss: when one counts on a personal relationship system which unexpectedly changes.¹⁶ Ginnie says, “I have watched Nelson go from an intelligent, self-sufficient, entertaining, and engaging person to a dependent, unresponsive, illusive shadow of who he was.”¹⁷

They are also experiencing one kind of “ambiguous loss,” that Pauline Boss describes as “physically present but psychologically absent.”¹⁸ Ginnie writes about her difficult “emotional work of living with a husband who is both with me and lost to me.”¹⁹ Her loss is confusing and hard to make sense of, which is the nature of an ambiguous loss.

In that last year that Ginnie is writing about, she tells the reader about the challenges of finding and moving Nelson into a workable healthcare facility. His health needs had become more than she could provide. Later that year, Nelson is moved to another facility due to his declining abilities. At the end of the book, Ginnie is still daily visiting Nelson. Her story is still unfolding as she loves, visits, advocates and cares for Nelson each day.

Your assessment of the books strengths and weaknesses:

Ginnie is a gifted writer. Written as month by month highlights, over a six year period, gave me a greater understanding to their magnitude of loss and grief over all those years. Their journey covered all the types of loss we have discussed. Ginnie was speaking from her heart and from years of grieving. It was their love and commitment to each other that showed up in her writing about

¹⁵ Ginnie Horst Burkholder, *Relentless Goodbye- Grief and Love in the Shadow of Dementia*, 127.

¹⁶ Kenneth R. Mitchell and Herbert Anderson, *All Our Losses, All Our Grievs – Resources for Pastoral Care*, 44-45.

¹⁷ Ginnie Horst Burkholder, *Relentless Goodbye- Grief and Love in the Shadow of Dementia*, 167.

¹⁸ Pauline Boss, *Ambiguous Loss – Learning to Live with Unresolved Grief*, 9.

¹⁹ Ginnie Horst Burkholder, *Relentless Goodbye- Grief and Love in the Shadow of Dementia*, 31.

every monthly step of their journey together. Ginnie shared some moments where Nelson was able to show her love and affection, a touch or words. This has helped her to stay connected.

As I was reading the book, I realized how much Ginnie took on the majority of the role of carrying for Nelson, until that last year. I read about her sister and husbands visits every other weekend to support her in Nelson's care. She only mentions a few times about their son and daughters visits back home. I would like to have read more about how she felt about her children, family and friends support over these years. It would have been helpful to read more about how their church community did, or did not, support them throughout these years. I would also, like to see an appendix that outlined the symptoms and other information on Lewy body dementia.

I would have found it helpful to hear more about her journey as it related to Kubler-Ross's five stage of dying. Early in the book she talked about their denial. She wrote very little about her and Nelson's anger, bargaining and depression. She did write about how she had come to a place of acceptance of Nelson's LBD and her role as caregiver. I think her acceptance came from being exhausted after many years of caregiving and having no other choice than to accept what is.

I would recommend this book to others who are dealing with dementia or other long term illnesses.