

The Art and Challenge of Learning to be a Care Partner

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One of my professional heroes is Brene Brown. She is a researcher, storyteller, and best-selling author. She has written a great deal about vulnerability, connection, and resilience - topics I believe relate well with learning how to be a care partner for someone living with dementia. Brown has been quoted as saying that “vulnerability is basically uncertainty, risk, and emotional exposure.” Sounds a lot like the journey of caregiving in a nutshell to me!

An important finding in Brown’s research is that: “A deep sense of love and belonging is an irreducible need of all people. We are biologically, cognitively, physically and spiritually wired to love, and to be loved, and to belong. When those needs are not met, we don’t function as we were meant to. We break. We fall apart... We get sick.” Although Brown was not specifically addressing dementia in her book, I think her words apply beautifully to both the person living with dementia, as well as to the care partner who is frequently trying to provide care with limited skills, knowledge, and support in the process. Love and belonging are important ingredients to both parties, but not always easy to consistently access for either.

Pauline Boss is another writer that I truly admire. She originally coined the term “ambiguous loss” which applies directly to the world of dementia. Ambiguous loss is when the person living with dementia is still physically present in your life, but is psychologically absent and emotionally unavailable because of their disease/dementia. In her book, *Loving Someone Who has Dementia*, Boss advises: “To embrace ambiguity, we need to work at learning how to hold two opposing views at the same time—my parent/spouse /friend is here, and not here.” Boss urges us to achieve a “psychological shift or transformation” for when our relationships are significantly changed by dementia, with the goal of accepting the ambiguity involved in that evolution. This is a difficult concept for many caregivers to grapple with, but a necessary one for thriving in the long haul of caregiving.

I once read that “strength doesn’t come from what you can do. It comes from overcoming the things you once thought you couldn’t.” Caregivers know the meaning of these words intimately. They live them every day through trial and error, through the good times and bad, through success and failure. This serves as a reminder that there are lessons in caregiving and adversity which can strengthen us if we are willing to change our perceptions of what is possible along the way. That is the true art involved in care partnering. The challenge is up to each one of us to embrace it.