

Dementia Caregivers: How to Build Meaningful Relationships in Spite of Memory Loss

By

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Being the caregiver for someone you love who is gradually losing mental capacities is about as tough as it gets in human life outside of wars, disasters and profound poverty. Parents who were once your source of nurturing and knowledge; who worked hard to take care of their family; who had interests in politics, religion, sports, movies, celebrities and more; who had fun with their friends; who may have been among the best in their field. Parents who lose their mastery and become unable to manage their own affairs or to care for themselves in the most basic ways -- parents who become dependent on you to take care of these things for them -- can be, and often are, a source of great sadness.

Spouses and lovers who were your soul mates, your partners in life, the people with whom you shared your most important, moving, pleasurable and challenging moments - - spouses who gradually lose their capacity to be with you as companions and confidantes can also be a source of great sadness.

On top of this, the time, energy and resources that it takes to be the primary caregiver for these people who are so important to you, can sap your own strength. You can feel that it is more than you can stand.

What can help?^{1, 2}

Changing your expectations of the person with declining cognitive capacities can make a big difference, helping you to be less frustrated and irritated by his or her inability to do what they once could and especially to be with you in the way they once were.

Focusing less on the past and on a wished-for future can make it possible to connect emotionally in a new way and to get the most out of the moments you have together. Our relationships are often oriented toward a collective future: retiring together, traveling together, getting old together. It can be daunting to maintain a relationship that does not have the kind of future we always assumed it would. But it is not impossible to have

¹ Sanders, S and Swails, P. "A Quest for Meaning: Hospice Social Workers and patients with End-Stage Dementia" in *Social Work* Vol 56, Number 2, April 2011.

<http://oberon.naswpressonline.org/vl=5971918/cl=20/nw=1/rpsv/cw/nasw/00378046/v56n2/s4/p129>

² Zeisel, John. *I'm Still Here: A New Philosophy of Alzheimer's Care*. Avery. 2010.

relationships in the moment that are emotionally satisfying even if we are terribly sad about what they, and we together, have lost.

Understanding that the person we love is still there, despite their inability to access memories without help, can also make a difference. Reminiscing together -- even if it is mostly one-sided -- can be a gratifying experience, especially when the person's eyes light up with recognition. Talking about and engaging in old interests, listening to favorite music, going to a baseball game or even getting the feel of it on TV, watching old movies, taking a walk in the old neighborhood -- all these can be sources of satisfaction in the moment. Even if the explicit memory of these experiences slips away because of the complex ways in which dementia affects the brain, the emotional connections remain.

Discovering the possibility of being together in silence can be deeply moving and meaningful as well. When we put aside our dashed dreams long enough to be open to the rich emotions alive in that silence, just being together can release an unspoken emotional exchange.

But what about the really difficult times? Dad has wandered away again. Is he safe? Mom says she doesn't recognize you and yells for the police when you visit. Your wife curses you for cheating on her. Your husband demands sex with the home health aide. Your friend seems lost in himself and does not respond to your presence at all. What can you do?

There is no magic wand guaranteed to make bad times go away. Even if by changing our own behavior we reduce their anxiety and agitation, sometimes the people we care about remain disengaged. Some people's disappointments and angers run so deep that moments of peaceful, loving exchange seem impossible. Some of us who are caregivers can't stand another minute.

But these terrible times do not beset all people all the time, not by a long shot. It may seem impossible for the person you care about to get meaningful satisfaction out of a life so different from the life she or he lived before cognitive decline. It may seem impossible to have a meaningful and satisfying relationship with a parent, a spouse, a partner or a friend with whom you can no longer have in-depth conversations. It may seem that they cannot possibly find life worth living.

But a great many can. People with significant cognitive limits can get satisfaction out of life, and it is possible for us to have meaningful relationships with them -- if we learn to shift what we want and expect from them, see the person who is still inside, and develop the capacity to live in the emotional moment.

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