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Preparing for the loss of a dementia sufferer

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By *Micha Shalev*

From many years in this business I found out way too often that adult children caring for a parent diagnosed with dementia and/or Alzheimer's disease are ill prepare for the death of their loved one.



It is a very difficult topic to address even as an administrator of a rest home facility.

"We prepare more for a vacation than we do for loss and death," said [Shelley Whizin](#), a certified death midwife who spoke last year on the topic at a Motion Picture & Television Fund women's conference in Los Angeles.

[Laurel Lewis](#), a nurse and end-of-life expert also on the program, believes "loss can be complicated. It's not just physical separation, but also emotional and spiritual. Usually there's a financial component. You are vulnerable, confused, scared and forced to make big life decisions in an altered state."

On the other hand, Lewis notes, "If you tie things up before the loss, you can live your life more fully and the grieving process may be shorter than if you were in denial."

When we know someone is going to die there it is sometimes accompanied by [anticipatory](#) grief. Like the sadness you experience after a death, you may feel depression, anger, guilt, fear, sadness and denial. The "good" part about it is that there's time to do and say the things you want. You can plan, and you should.

Here are some ways to prepare:

1. Conserve your energy. Rather than be barraged by phone calls and emails from friends and family seeking an update, communicate just one time. It could be a conference call, or a website like [CaringBridge](#). Another site, [Lotsa Helping Hands](#), lets caregivers post the help they need and others sign up for duties. You might also want to create a family website and divvy up jobs. One sibling can make sure all documents are in order and have a master list of passwords, while another can research funeral arrangements.
2. Take cues from the one who is ill. Some people want to talk about what they're going through, or what happens after.
3. Seize the opportunity. You want to feel that you have done everything you can for your loved one and for yourself. Do you need to say thank you, I forgive you, I'm sorry, or I love you?
4. Be good to yourself. Caregivers are always told this, but if you are able to sleep, eat well, exercise, and/or find a place to vent, you will be in better shape to cope. Support groups, meditation, yoga and short breaks

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that may include a pedicure or coffee with a friend are good ways to think about you.

5. Don't wait for the funeral. You can say all these wonderful things about the person after he or she is gone. But what about telling that person before he or she dies? You can make a video of the people in the person's life talking about how they feel about him or her. Then share it with that person.

Three days before Whizin's best friend died, she arranged to have eight of the woman's dearest friends fly in from around the country to gather around her "and talk about how much they love her while she could hear them, not at a service when she won't be around," said Whizin. "We were all so grateful to have this opportunity. It eased the pain. We wanted her to know that she had made a huge impact on our lives."

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