



Letter From a Loved One Living With Dementia

By: Hilary Mincenberg, activities coordinator at RoseCrest Assisted Living at St. John Community

Like many others who have had a loved one living with dementia, I often fantasized about what my mother, who lived with that diagnosis from 1995 to 2002, might have told me if she had been able. My hope is that anyone who has a loved one living with dementia will write their own letter from their loved one to themselves, to encourage others to share this difficult, but significant, experience.

Dear Daughter/Son/Husband/Wife,

I am sending this letter from my heart to yours. Your visit today has compelled me. You sounded so cheery when you greeted me, but you looked exhausted. Talking and talking as you gathered up my laundry and tidied my bathroom, you barely took a breath.

With so much bustling, I was distracted and couldn't follow what you were saying. A few times you asked me a question, and I caught the inflection in your voice, but I had no idea what you were asking me. You paused, waited for my answer. Silence. You tried again to engage me in conversation. Again, I did not respond. You asked me if I wanted to stay in my room and visit or take a walk with you. I could not decide. Finally, in exasperation, you shouted, "Well, what DO you want? God, if only you could just TELL me!"

Immediately, you came over, hugged me, and apologized. It was unnecessary. I sensed the strain you were feeling. Since you were small, I've always answered your questions as honestly as I could. Why should that change now? True, you've grown up and dementia has made it impossible for me to put my response into words, but I will try to speak to you through my mind, from my heart. Since you've asked, would you please...

Be open to anything I do. I feel it when you expect something from me. I can't tell what the expectation is, of course, but I can sense your tension. Then I get tense, too.

Talk to me about what's important to you. Tell me about your life. Share anything and everything with me, as you have always done.

Don't quiz me—about anything, but particularly about your identity or how you're related to me. I know who you are. I know you on a deeper, more primal level than you can ever imagine, more than be described by any label such as "daughter" or "son." You are not forgotten. How could you be? You are a part of myself.



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Please be brave enough to be silent with me sometimes. I know you're afraid I'll never speak again, but never mind all that. Hold my hand, be still with me. Are words really necessary between us? Don't be afraid to just look in my eyes. Instead of searching for what is 'missing,' please see what is still there. My soul, that part of me that is unchangeable, the authentic Me is closer to the surface than ever. Because of this, I can enjoy just being with you, experiencing your presence and your love.

Protect my dignity. Even if I am behaving in a childlike manner, please, remember that I am NOT a child. YOU are MY child. Don't ask me to believe an oatmeal container is a drum or that a toilet paper roll is a horn, not when I've been a lifetime lover of music. Respect what you know to be true about me. Bring me a pair of maracas and a real drum if I want them.

The same request for dignity applies to clothing. If I wish to wear a sombrero for Taco Day, by all means, help me to do so. In the name of all that defines maturity and respect, however, please do NOT allow anyone to put a balloon hat on my head unless I expressly ask for it!

Encourage me to be creative, to try different things. Maybe I was too shy or too self-conscious to dance and sing in my earlier life, but I may have changed. Let's enjoy my new freedom together.

Give me an opportunity to contribute in some way, whether its by helping with housekeeping or visiting nursing homes. I need to be purposeful. It shaped my life in the past, and it is just as important to me today.

Be my advocate. Speak up for me if the culture I love is not being made available to me. Yes, I may not remember the name or the piece or recognize the composer, but music reaches me in ways that cannot be described. I can still enjoy all of the arts that I have always loved, even if I express it in a different way. Please know that my eyes being closed does not necessarily mean that I have dozed off. I might be letting the music just wash over me and fill me up with memories.

Join me in exploring this strange new world in which I now live. Whether it takes me into the past or to places I've never been, let me navigate but please, come with me. I would be so happy for your company.

I've saved the most important request for last. ***Everything that you are doing for me, please do for your own dear self.*** Treasure yourself, just as you have been treasuring and caring for me.



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These are my requests, since you've asked.

Let's not waste any time grieving over how different things are today from the way they used to be. It may not look the same, but we can still enjoy each other's company. That does not have to change.

Please know, to the core of your being, that I love you, just as I know, down to the core of mine, that you love me.

This too, will never change.