The Presence Care Project

5 Compassion Practices for Dementia Caregivers

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Compassion is good for others, and for us also. And nowhere is it more relevant than in dementia caregiving when we need to attend to a loved one's complex needs for years at end. Compassion is the ability to feel with the other person who is in pain, and to act upon that shared feeling so as to diminish the other person's suffering. This assumes we are able to notice and feel the pain that is felt by our loved one. Unfortunately, despite all our best intentions, we very often don't have enough knowledge to even start. For instance, the pain from dementia can be invisible and not show until hours later in the form of seemingly random outbursts, or worse resigned silence when attempts to communicate keep on failing. Compassion requires that we bring a deeper understanding of what the other might feel into our care interactions.

The good news is, informed compassion can be cultivated. Here are five practices that you can do on your own time:

1. Too much noise

Noise is a big stressor for the person with dementia. Next time you are in a noisy place, let's say a busy restaurant, put on your listening ears, and open the natural filters that usually shield you from the impact of such cacophony. When you do, linger for a few minutes, and take in the whole soundscape. You will find it very hard to sustain, and quite maddening. This is what a person with dementia may feel when exposed to too many auditory stimuli at once, including daily sounds such as that of the TV, phone rings, banging of utensils, etc... As part of the dementia process, the ability to filter and process sounds is impaired, leading to stressful sensory overload. That experience may lead the person to want to 'go home' although she may be in her home already.

2. Not in charge

With dementia, many of the freedoms we take for granted disappear, and over time, the person becomes stripped of the ability to make decisions about even the most basic things. To get the full impact of what that might feel like, I invite you to close your eyes and contemplate a scenario when life circumstances rob you overnight of your ability to take care of yourself, and you become dependent on others for your activities of daily living. You can no longer work, participate in house chores, drive, manage finances, or shower on your own. While you may still have some remaining abilities, you are at the mercy of others to get your needs met. How do you feel? What might you want most from those around you? You can take those insights into your care interactions. Such a practice may also give you renewed gratitude for all the gifts bestowed upon us who lead a normal life.

3. In a dream

Hallucinations may be a part of the dementia experience, particularly for certain types including Lewy Body Dementia, the dementia that was diagnosed in Robin Williams. I find it helpful to think about what happens during dreams. If you are able to remember your dreams, particularly the experience of being in a dream, and how real those may feel to you, you can then more easily extrapolate what it might be like to live in a different reality. Whether in dreams or during hallucinations, it is our brain that alters our sense of reality, and the experience feels no less real than during every day reality. This is why the first step in relating to a person who is hallucinating is to take them seriously. Inoffensive little children, scary demons, aliens each trigger their understandable reactions, to which we can relate. In the end, we want to evoke a sense of ease and safety.

4. Losing stuff

Now imagine you cannot find your most precious possession - for me that would be my laptop. You look all over the house, and still, no laptop. After a while, you become convinced, someone must have stolen it. How else could it have disappeared? You might become very upset. The possibility that you might have misplaced it does not even enter your mind. This is what happens to a person with Alzheimer's whose short-term memory is compromised. Of course, the most logical next step is to blame other persons living in the house. "You stole my wallet" is a common refrain. A mother may accuse her most dutiful son, the one who visits her every day. It is helpful to go beyond the apparent paranoia, down to the real reason behind the accusation. A solution can then arise from relating to the fear of having been robbed, in the form of a reassurance that the wallet is not lost, and that you will 'get on it'.

5. Sitting still

If your loved one is confined to a wheelchair, I highly recommend you take their place for a few hours, and see what it feels like. Although we may not realize it, we are constantly moving our body to stop the inevitable sensation of pain that arises anytime we stay still for too long. Meditators know this, who sit still for extended periods of time. Sitting in a chair, with advanced dementia, and without the ability to move the body and to communicate discomfort, can be hard to bear. Once we have felt the physical pain firsthand, we will be more likely to be attuned to our loved one's situation, looking for subtle signs of discomfort, small movements telling us to pay attention. We can then offer a pillow, or maybe help transfer the person to another chair or to a lying position.

There is no substitute for actual experiencing, or as close to it as we can get. Only then can we feel from the heart, the extent of what our loved one may be going through. This is much more powerful than just reading about it. With its built-in readiness, caring from the heart is a lot lighter on us and more likely to sustain us in the long run.