



How to Best Help Alzheimer's Caregivers? Teach Them Mindfulness

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For the 15 million in this country who are caring for a loved one with dementia*, this is what life is like -- according to the Alzheimer's Association 2012 Report:

- 61 percent of dementia caregivers suffer from high emotional stress.
- 33 percent report symptoms of depression.
- They experience caregiving strain regarding financial issues (56 percent), and family issues (53 percent).
- 43 percent experience high physical stress.
- 75 percent are concerned about maintaining their health.
- Dementia caregivers are more likely to have adverse physiological changes such as high levels of stress hormones, reduced immune function, increased hypertension, coronary heart disease.
- 37 percent rate stress as their greatest difficulty.
- In the last year of their loved one's life, 59 percent feel they are on duty 24 hours a day.
- 72 percent of caregivers express relief after their loved ones die.

The journey is not just intense, it is also long and stretches an average of four to eight years post-diagnosis. Learning how to reduce stress is a must for dementia caregivers. Not doing so jeopardizes their health and also the quality of care they provide for their loved ones.

This is where mindfulness practice comes in.

1. Mindfulness can reduce stress.

Mindfulness practice, the cultivation of intentional moment-to-moment awareness, without judgment, has been found to produce significant results in terms of stress reduction. Scientific studies of Jon Kabat-Zinn's Mindfulness-Based Stress Reduction (MBSR) program are showing the various ways that mindfulness positively affects our brain and improves our stress response:

- Mindfulness practice helps with dis-identifying from the content of our mind, thereby helping us loosen our attachment to stressful thoughts and emotions.

- Mindfulness practice helps develop attentional focus, i.e., we become more in charge of the way we use our mind and of what we choose to pay attention to.
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- Mindfulness practice helps decrease emotional reactivity; in other words, we can regulate our emotions better and not get so caught up in anger, fear, guilt, etc.
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- Mindfulness practice helps change the way we view ourselves toward a more positive stance.
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- Mindfulness practice helps reduce our tendency toward negative, self-focused rumination.

Mindfulness is good for our mind. It also does wonder for our body. Neuroscience shows mindfulness practice to have a positive effect on the immune system, and the treatment or prevention of stress-sensitive illnesses such as cancer, hypertension, heart disease, and diabetes. Such health benefits have not gone unnoticed, and mindfulness is now practiced in many mainstream institutions such as medicine, psychology, health care and hospitals, schools, corporations, the legal profession, prisons, and professional sports. MBSR alone is taught in 250 clinics in the U.S. , and many other similar mindfulness-based programs have spun out to address specific problems such as depression, addictions, relationship problems, eating disorders, elder care, etc.

Mindfulness practice is especially relevant to the predicament of dementia caregiving. It can give caregivers the inner resources to sustain themselves emotionally and physically over the long haul and is a tool they can always fall back on moment to moment, regardless of the intensity of the care relationship. Mindfulness can also help guard against the occurrence of depression.

Last, mindfulness can transform the way we experience our daily care tasks, from activities to be endured, to stress reduction practices that can enhance, rather than detract, from our well-being. One example is mindful walking. Practicing mindful walking with our loved one, we learn to pay attention to our steps and the way we are with ourselves, while at the same time matching our pace precisely to the other. By doing so we relax into the present moment, and we give our mind mini-breaks from our habitual, stressful thinking. The same goes with "sitting with," helping with meals, assisting with personal care, etc.

2. Mindfulness can improve the quality of care.

In regard to dementia care, mindfulness is not just a stress-reduction tool. It can also help with another critical aspect of dementia caregiving: the need to meet the person in the present moment, where they are most likely to reside and engage due to the dementia. Learning how to "be" in the present with the person is more important than any behavioral strategies as commonly taught. I love this quote from Nancy Pearce, in her book *Inside Alzheimer's*:

"I have discovered that it isn't so much about what I did or did not say or do that was key to pass on to professionals and family members -- it was more about the way in which I was being with the persons who have dementia that seemed important to communicate. [...] Each person with

dementia has taught me the importance of relaxing into being in the present moment. That moment may be perceived by her to be in a different place or time, but it is her very real and present moment."

The ability to be right there in the moment with the person also helps one adapt to the constantly changing and unpredictable nature of the person's experience. Mindfulness enables caregivers to be aware of the whole environment and all the factors with the power to either enhance or hinder the well-being of the person with dementia: sounds, light, visual, spatial, touch, smell, emotional, physical, etc. Maybe we are perfectly fine with the ambient temperature, but the other person who is sitting in a wheelchair, not moving and unable to talk, is feeling cold. We are left having to watch for subtle signs. A slight shiver in the shoulders could be easily missed if we are not paying attention. Such awareness can be used to remedy any potential problem before it causes too much distress in the person. This in turn will lessen the likelihood of the person having to resort to disruptive behaviors to communicate their unmet needs or distress from environmental triggers.

Mindfulness helps us stay in touch with our natural tendency to position the person as less capable than they are. Dr. Allen Power talks about the way that we all tend to position persons with Alzheimer's or other dementias as less capable than they are, thereby stripping them of their remaining abilities. If we don't stop and take the time to be fully present to ourselves and our thoughts, we are more likely to fall prey to positioning and engage in behaviors that will make our loved one more disabled than they really are. We may end up filling their cup of water for them when they could very well do it by themselves. We may speak for them, not waiting for them to say what is on their mind. We may behave as if they are not even there. So many ways, unconscious positioning can damage our loved one psychologically and further erode their already-compromised self-esteem

Practicing mindfulness, we can be aware of our thoughts and feelings as we approach our loved one, and we get a chance to correct silently in our mind, "There is a whole person there. I am going to hold back on my tendency to do things for him and give him a chance first." And we remember to honor the five universal emotional needs.

Last, mindfulness gives us the space to pause and not react immediately as we so often do to the demands of our loved one, heeding Viktor Frankl's advice:

"Between stimulus and response, there is a space. In that space is our power to choose our response. In our response lies growth and our freedom."

Caring for someone with dementia is made up of an infinite number of small moments where we can go either way, adding more stress or bringing more ease. The problem when we are not mindful is our words come out and our actions unfold too quickly for us to have a chance to choose the wisest, most beneficial route. Mindfulness practice slows us down and takes some of the edge off our reactive tendencies. Rather than giving into our irritation with our loved one's offer to help unload the dishwasher -- "She is so slow, she is doing it all wrong" -- we have a chance of being in charge of the situation and understanding the long-term benefit of letting her

satisfy her need to be useful. The more we practice, the more we learn to trust ourselves and appreciate the benefits from our non-reactivity.

Mindfulness is about slowing down enough to connect with ourselves and our loved one, moment to moment. As we do so, we can de-stress and at the same time give ourselves and our loved one the chance of experiencing greater well-being. We refuse to become another depressing statistic.

**Alzheimer's is the most common form of dementia.*

NOTE: Mindfulness-based dementia care as articulated here is a new approach to dementia care. It will be implemented at UCSF OSHER Center for Integrative Medicine in San Francisco later this year. For more information and updates, you may go to the Presence Care Project website: <http://presencecareproject.com>