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Alzheimer's takes toll on caregivers, too

OUR HEALTH: Respite can help fight Compassion Fatigue.

Sunday is World Alzheimer's Day – established to raise awareness about the disease that impacts as many as 5.2 million people and is the sixth leading cause of death in the United States.

By 2050, the estimated impact of Alzheimer's will be 11.3 million to 16 million Americans, unless a cure is found.

But it's not the Alzheimer's victims I want to talk about. It's the victims of the victims – the caregivers who increasingly are dealing with what is called Compassion Fatigue, a gradual lessening of compassion and an increased sense of tension.

Dr. Terry Eagan is medical director of Moonview Sanctuary in Santa Monica, a non-residential treatment center with special programs geared toward someone caring for persons with chronic illness and end-of-life issues.

Q. Alzheimer's has to be a difficult disease to deal with as a caregiver and even a care provider.

A. Absolutely. From family members with loved ones to friends and neighbors who try to help to nurses who work with the patients. Even case managers and social workers and the physicians themselves find it difficult because, despite our best efforts, the outcomes are pretty poor.

Q. I can't imagine being a family caregiver.

A. It can be demoralizing. We want our efforts to be corrective and Alzheimer's care is palliative and sometimes not fulfilling.

Q. But other diseases are equally time consuming and often have poor prognosis. Certain types of cancer, for instance.

A. Yes, there can be Compassion Fatigue if care giving is a very long and drawn out process and the person is in a lot of pain, regresses psychologically, is angry and bitter, and difficult to work with.

Alzheimer's is a confused state, however. Patients are uncomfortable and crying out and can't tell us what they need. It's a guessing game to try to figure out how to soothe them. And they just get worse over time.

Q. What can you tell these caregivers to make their burden easier?

A. We tell them they must get respite. They have got to get away and have a break for themselves.

There are day treatment programs in most communities for seniors of all levels. Oftentimes they are confused and need to be in a skilled residential environment. But they need supporting and encouragement to do as much as they can for themselves.

Q. It's easy to talk about getting respite care, but not much is provided or available.

A. Sometimes a physician writes an order and Medicare will pay for a home technician to come, usually to distribute medication. The system does not pay for the family to get away.

There are organizations the family members can go to for support. Groups such as the Alzheimer's Association (949-955-9000 or www.alzoc.org) can help.

Q. I know what you mean about getting respite. I found I needed respite when I cared for my husband, although he did not have anything like Alzheimer's. As a result, I encouraged the non-profit I founded, WomanSage (www.womansage.org), to consider that respite care. Through the generosity of a donor, we are able to take 22 caregivers on a four-night cruise to Mexico in January. We also pay for respite for their loved one.

A. That's fantastic! An incredible service. I have never heard of anything like that.

At Moonview Sanctuary, we offer Eastern and Western modalities of treatment. We have about 40 different modalities, including acupuncture. We take a case and coordinate a team.

Sometimes families need psychological support and assistance. We help the family work together and with outside specialists, such as financial planners and attorneys.

No family, no caregiver, should be overlooked. Every one of them faces potential Compassion Fatigue.