Turning an Alzheimer’s diagnosis into something positive

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A new study shows that family members are paying for the care costs of their loved ones with dementia. In fact...

Every now and then, people lose a tragedy and turn it into a gift that helps others. This is such a story. It’s about Alzheimer’s disease.

According to the Alzheimer’s Association, Alzheimer’s disease is now the sixth-leading cause of death in the United States. More than 5 million Americans are living with Alzheimer’s, and as many as 16 million could have the disease by 2050. The cost of caring for those with Alzheimer’s and other dementias is estimated at $230 billion in 2017, and could balloon to a staggering $1 trillion by mid-century.

In Iowa, there are 64,000 people, age 65 and older, living with Alzheimer’s disease. That number is expected to jump to 70,000 by the year 2025.

One Iowa couple directly affected by the disease elected to take this diagnosis and do something that would positively impact people with dementia and their caregivers for generations to come.

When Jo Hoyt Freeman, a former English teacher at Warner Harding, Junior High School in Des Moines, was diagnosed with Alzheimer’s dementia in 2001, she and her husband, Claude, decided to write about it. Their motivation was to document her day-to-day experiences so that others could better understand the very personal impact of Alzheimer’s. That knowledge would help all those in support roles - doctors, nurses, direct care workers and family members - be better informed and better able to identify ways to improve how those with Alzheimer’s were cared for and treated.

Mrs. Freeman once said, “If you have a memory loss … maybe you can listen to my story, and it would make a difference.” Since her passing, Mr. Freeman has continued her legacy through his publication of “Jo’s Story,” which is captivating and the creation of Jo’s Joy of Freeman Dementia Educators and Outreach fund at the University of Iowa’s College of Nursing. The Center is expanding access to person-centered care for individuals and families dealing with dementia. In addition, support is being provided to the Iowa Caregivers educators and education programs for direct care workers such as certified nursing assistants, home care and hospice aides.

At both the University of Iowa College of Nursing and at the Iowa Caregivers, the support from Jo and Claude as helping nurses, direct care workers and family members work together to improve care for people with dementia. The idea is both simple and impactful — to promote more communication and build better relationships between family members and the paid providers of care. By doing so, the understanding of the person with Alzheimer’s can be improved. That knowledge can be used to design programs and activities in which the individual finds meaning and joy.

These programs are being provided free of charge. It’s our hope that they will be available online in the spring of 2019 to allow many more to take advantage of these.

Both of our organizations applaud the commitment of the Freeman’s to helping paid and volunteer caregivers provide better care and support. We know that hard the roads, and we know the value of stories in addressing these needs.

One person’s story can help create a better Iowa. Jo and Claude have made a real difference in the work we do, and have helped us better support the people we serve on the front lines making life better for the tens of thousands in Iowa impacted by this horrible disease called Alzheimer’s.

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