Purpose in life may decline after a dementia diagnosis. Experts share what to do | CNN

Feeling a sense of purpose drops after dementia, new study shows

By Madeline Holcombe, CNN

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A person’s sense of purpose declines leading up to and following a diagnosis of dementia or cognitive decline, according to a new study.

“Purpose in life is the feeling that one’s life is goal-oriented and has direction. It is an important component of well-being,” said Dr. Angelina Sutin, lead author of the study published Wednesday in the journal JAMA Network Open.

Researchers now know a sense of purpose is an important factor of good health across adulthood, added Sutin, professor of behavioral sciences and social medicine at the Florida State University College of Medicine in Tallahassee.

“Previous studies have found that individuals with more purpose are less likely to develop Alzheimer’s disease and other dementias,” she said in an email. “Here we look at the relation between purpose and cognitive impairment in the other...
While there were some signs of decline in feelings of purpose in the years leading up to cognitive impairment, the decrease was more rapid after it was identified, Sutin said.

The results weren’t surprising, given what scientists know about declines in mental health after a diagnosis, said Dr. Sam Fazio, senior director of quality care and psychosocial research at the Alzheimer’s Association.

The impairment was identified from cognitive tasks, not a diagnosis from a health care professional. But the results are reliable because they utilize assessments over more than a decade and the trends were replicated in both groups, Sutin said.

“Purpose may be an intervention target following cognitive impairment to maintain well-being and to reduce or slow emergence of behavioral symptoms associated with low purpose,” the study said.

The sweet spot for support

How much feeling of purpose each individual lost varied by person — some declined rapidly and others not at all, Sutin said. Future research needs to explore these patterns to identify who is most at risk, she added.

But it is critically important for everyone to maintain a sense of purpose later in life, Sutin said.

“The opposite of purpose in life — apathy — is a significant problem in dementia. Individuals with dementia lose their drive to engage in life,” she said. “It is critically important for individuals to maintain their purpose in life to prevent or at least delay this apathy, which can reduce quality of life.”

Caregivers — whether they are professionals or loved ones — are important in helping someone with cognitive impairment maintain engagement, Fazio said. That is especially true as dementia progresses and makes it harder for someone to initiate some activities themselves.

The key, he said is to find ways to help involve the person with cognitive impairment and bring them into activities, but not take over so much that they don’t have a sense of independence and engagement.

“Too much (assistance) is going to make me shut down and I might not be involved,” Fazio recalled people telling him.

“Too little is not going to make me be as successful as I can be, or as independent as I can be.”
Caring for the individual, not just the disease

The best support focuses on the individual and doesn’t reduce them to just their disease, said Fazio, noting that the Alzheimer’s Association has resources for caregiving and living well with dementia.

Good caregiving involves taking the time to learn about the person and helps them reconnect with that identity, Fazio added. That could mean talking about their former career or baking their famous cookies alongside them.

“When Dad is no longer talking about his job, how can we initiate that conversation to get him talking about his job?” Fazio said. “Get to know who somebody has been their whole life, so that (you) can use that information and weave it into every interaction throughout the day.”

Through a group of advisers in the early stages of cognitive impairment, he learned that it is not support from other patients they were craving, but more connection with the people they already had in their lives.

“What some people told us that was really eye opening for me is just like, ‘You know what, I don’t necessarily want to make new friends right now. But how can you help my friends understand that I’m still the same person so that they still want to be around me?’” Fazio added.