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Q & A with Jill Gafner Livingston

Contributed by the Area Agency on Aging 1-B

Jill Gafner Livingston, BSBM, CDP, CADDT, has something powerful to share with caregivers.

Having been her husband’s sole caregiver when they were in their 30s raising two young boys, she has a perspective borne of lots of hard knocks.

Bob, a radio personality in Houston, fell ill with lung cancer and then a brain tumor. The radiation treatments he underwent were blamed when he developed early-onset dementia. He was 35.

For the next two decades, Jill, now 61, was the primary caregiver for Bob and their children. The challenges with family, doctors, and work left her exhausted, depressed, broke and isolated.

In 2005, in the midst of the turmoil, Jill began to speak publicly about staying sane as a caregiver. A year later, she wrote a book because nobody, it seemed, was talking about supporting caregivers. Bob passed away in 2012, 21 years after his diagnosis. He beat the odds by 20 years and 11 ½ months.

Jill, a St. Clair Shores resident, will offer practical advice and inspiration at a **free** 2 ½-hour seminar in Novi on March 20 that is sponsored by the Area Agency on Aging 1-B (AAA 1-B). She’ll offer the same seminar at other metro Detroit locations in (click on link below).

AAA 1-B caught up with Jill to talk about her work.

Q. What will you cover in “Caregiving Survival, Plus Caregiving for a Loved One with Dementia?”

A. There are two primary focuses: Caring for myself as a caregiver and caring for my loved one who has dementia. The seminar will offer tips to survive this extremely stressful time.

Most caregivers die before their patients because of stress, and stress is more intense when you’re caring for someone with dementia. The amount of guilt the majority of caregivers have, it locks them in. You’re held hostage in this painful circle of life.

We talk about the right to be social, to go to the doctor, etc., the risks of caregiving, recognizing burnout, things to do with a loved one to help with communication and routines, the benefits of a care plan and addressing repetitive behaviors.

When they leave, caregivers have tools to allow them to take care of themselves and their loved one or patient or whomever.

Q. Is caring for someone with Alzheimer’s or other dementias uniquely challenging?

A. Yes! Statistics show that severe depression is more common for caregivers that are caring for someone with dementia.

Q. What do caregivers tell you is their biggest challenge?

A. The guilt.

Q. Can you tell us two or three strategies for surviving caregiving?

A. Acknowledge yourself: it’s the ‘I matter; I have the right to go to the doctor, to enjoy life.’ We stop acknowledging ourselves because everything becomes the patient. You will be a better caregiver if you’re in good shape.

Q. Why did you write “Personal Positioning for the Caregiver?”

A. It was acknowledging the need for caregiver support. When Bob got sick, ‘caregiver’ wasn’t even a word. If I used the word, people would be confused; they thought I meant ‘caretaker.’ It was hard to find support when even the word itself wasn’t regularly used. You didn’t have a network or support systems. Even the Internet was somewhat new.

When I published it and realized how many people were asking for it, I thought it was something I should make bigger. Fifteen years later, Caregiving Survival is still the number one class in Michigan. There were 15 million caregivers back then. There are 65 million today. The message doesn’t get old.

*“Caregiving Survival Plus Caring for a Loved One with Dementia” will be held from 9 -11:30 a.m. Friday, March 20, at the Novi Civic Center, 45175 Ten Mile. There is no charge, but registration is requested by calling 833-262-2200 or emailing* [*wellnessprograms@aaa1b.org*](mailto:wellnessprograms@aaa1b.org)*.*

Area Agency on Aging 1-B will sponsor other Caregiving Survival seminars by Gafner Livingston in March, along with our Powerful Tools for Caregivers workshops. For a full schedule, <https://aaa1b.org/caregiver-resources/classes-for-family-caregivers/>.