

Three Important Actions for Alzheimer's Caregivers

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Many caregivers for people with Alzheimer's disease (AD) and other dementias do not learn quickly enough about three important actions that they should take as soon as possible after their loved one receives a dementia diagnosis. Were healthcare professionals to suggest these three actions, caregivers' lives would be a lot less stressful as they try to provide their loved ones with the best care possible. What follows is a summary of these suggestions, which are derived from my personal experience caring for my spouse.

Caregivers Should Seek Out and Join a Caregiver Support Group

The first and most important action that all caregivers should take is to seek out and join a caregiver support group, preferably one that meets on a weekly basis and that is designed solely for others in similar caregiver roles. All AD caregiver support groups can be helpful; however, if a caregiver joins a "targeted" caregiver group, such as a group whose members are all spouses of people with AD or a group whose members are all children caring for parents with AD, the caregiver can receive more helpful suggestions and information about caregiving from others in similar positions.

Even more importantly, in a targeted group, caregivers can receive the emotional support that is so desperately needed from others who are in similar situations—others who "get it" and can fully appreciate what everyone in the group is experiencing. Caregivers in support groups soon learn that the course of this disease varies widely, and a common expression one hears is, "If you know one person with Alzheimer's, you know one person with Alzheimer's." However, there are more similarities than differences, and certainly the caregiver's relationship with the person with AD, whether as a spouse, child, other relative, or friend, will greatly affect the caregiving process.

I have participated in a wonderful weekly support group, designed solely for spouse caregivers and sponsored by the Long Island Alzheimer's Foundation (LIAF). In addition, I also participate in the online support group www.thealzheimerspouse.com, which is designed exclusively for AD spouse caregivers. Unfortunately, no healthcare professionals ever advised me of the existence of such caregiver support groups. I had to learn about such groups on my own, and that is something that must change.

Caregivers Should Meet With an Attorney With Eldercare Expertise

The second important action for all caregivers is to meet with an attorney who specializes in eldercare issues. The attorney will offer guidance to ensure all end-of-life documents are in order (eg, wills, trusts, living wills, healthcare proxies, durable power of attorney) and, if not, the attorney can prepare such documents. Caregivers should also discuss a long-term healthcare policy if their loved one with AD does not currently have such insurance. Although such a policy may be too costly to initiate at this point or the person with AD may no longer even qualify, the eldercare attorney should discuss such options with the caregiver as part of a comprehensive review. Once again, no healthcare professional ever advised me to do this, but we talked about the need to do so in my spouse support group.

Caregivers Should Meet With a Certified Financial Advisor

The third important action that all caregivers should take is to meet with a certified financial advisor to discuss preserving, protecting, and growing current income, investments, and other assets. This is also another opportunity for caregivers to discuss long-term healthcare policies that may impact other financial decisions. As loved ones with AD decline, caregivers will slowly but surely discover their need for respite. Hiring part-time home health aides, companions, and enrolling loved ones in day care programs will be considered. As the AD worsens, caregivers will wrestle with the need to hire full-time home health aides or private nurses, or consider placing their loved one in assisted-living residences, nursing homes, or hospice facilities. All of these decisions have financial implications, and a financial advisor can help the caregiver plan more wisely for the future. Again, no healthcare professional ever advised me to seek out a financial advisor, but we talked about this need in my spouse support group.

Take-Home Message

Caregivers cannot prevent the inevitable outcome once their loved ones receive a dementia diagnosis. However, healthcare professionals can empower caregivers by suggesting the aforementioned three actions: join a good support group, meet with an eldercare attorney, and meet with a financial advisor. Healthcare professionals who take the time to do this will enable caregivers to better protect and provide for themselves and their loved ones emotionally, legally, and financially.

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