

**Empowering people with Alzheimer's disease and their caregivers – there is still  
much work to be done**

Allan Vann

*Dementia* 2013 12: 155

DOI: 10.1177/1471301212454356

The online version of this article can be found at:  
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>> Version of Record - Apr 8, 2013

What is This?



## Empowering people with Alzheimer's disease and their caregivers – there is still much work to be done

Dementia  
12(2) 155–156  
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DOI: 10.1177/1471301212454356  
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**Allan Vann**

Commack, New York, USA

After extensive testing, my wife was diagnosed with early onset Alzheimer's disease (AD) at the age of 63. For the previous two years, my wife had been asking me the same questions over and over with no memory of having asked me that same question. She was getting lost while driving, experiencing both aphasia and agnosia, and was no longer able to follow cooking recipes. When the doctor said my wife's diagnosis was probable Alzheimer's, it was a sad confirmation of what I had been expecting. However, to my wife, who was in complete denial, it was a tremendous shock.

When we left the doctor's office early that evening, we were given no written materials to take with us about what to expect in the near or long term. There was no information about websites we could consult or books we could read in order to learn more about AD. There was no mention or discussion of support groups. I had to research all of that on my own. I have since learned from members of my real and online support groups that our experience was all too common. Nearly all of my AD spousal support group members indicated that their doctors also provided no helpful information upon diagnosis, nor did their doctors point them or the diagnosed person to AD support groups.

Such a lack of communication from doctors is inexcusable, especially in this day and age when there is so much information readily available. Doctors should provide written handouts for people with AD and caregivers upon diagnosis so they can be more aware of this disease and have informed conversations with their doctors. I can understand if doctors may want to wait a few weeks after issuing an AD diagnosis before providing such information. Caregivers and the person may know very little about AD when they hear this diagnosis, and they may react with surprise, denial, fear, helplessness, sadness, anger, and a variety of other emotions. Even if they are aware of declining memory, cognitive, or executive functioning skills, the last thing that they may be expecting is a diagnosis of Alzheimer's. Perhaps a period of several weeks before issuing and discussing that handout, to allow the person and caregiver time to fully process an AD diagnosis, may be warranted. But they need to be fully informed about what lies ahead for them, if not immediately then very soon after the diagnosis is given.

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**Corresponding author:**

Allan Vann, Commack, New York, USA

Email: [acvann@optonline.net](mailto:acvann@optonline.net)

The handout should provide information about AD symptoms, stages of the disease, and medications to inform and empower the person and caregiver by providing knowledge. It should also refer both of them to helpful support groups, internet sites, and books for additional information. It is in the first few weeks and months after initial diagnosis when the person and caregiver have the most questions, fears, and anxieties that often can be somewhat mitigated with access to more information. This is also the time period when the person and caregiver have the most need to join a support group to help them deal with what is currently happening, as well as to prepare themselves for the future. The goal should be to avoid a commonly heard remark in spousal support groups: "I wish someone had told me about that when my spouse was still in the earliest stages so I could have prepared myself better."

If there are no local support groups available, doctors should speak with leaders of their local branches of the Alzheimer's Association and the Alzheimer's Foundation to ask them to start such groups. Doctors should recognize that support groups can be a major component of the treatment protocol after an AD diagnosis. Support groups can be invaluable in helping caregivers learn how to cope better as their spouse or parent declines further. Although no two people with AD may decline in the exact same way, all caregivers are rowing in the same lake. Meeting regularly with other people who "get it" can be incredibly empowering and emotionally supportive at the same time.

Having such ready access to more information upon or shortly after diagnosis can be extremely helpful and reassuring. A doctor would never let a person just diagnosed with a heart condition leave the office without information about necessary life style changes and future expectations. All it would take is a simple handout to empower the person with AD and that person's caregiver.

**Allan Vann** is a retired public school principal, who is now a full-time caregiver for his wife. His wife was diagnosed with early onset Alzheimer's Disease three years ago at the age of 63. Based upon his experience as a caregiver, Allan Vann is writing articles to suggest how doctors can improve the process used to diagnose this disease, and how doctors can more effectively deal with Alzheimer's patients and their caregivers after such a diagnosis.