

Help Coping with the Diagnosis of Dementia:

by William Zeckhausen

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After I received the diagnosis of Alzheimer's I had many questions that went unanswered by my care givers. Statistically 50% of American adults will develop dementia after 75, most likely Alzheimers. I want to share with those who have it, or will have it, what was missing for me, for at least a year, after I received the diagnosis, and what would have made a major difference in my coping with this condition. Too many primary care physicians, who give the diagnosis, have too little, if any, training in discussing it with their patients. Even specialists often don't suggest what to do about it. There are two drugs, that may be offered. Like all drugs, they may or may not be effective and they may have side effects. They can slow the progression of cognitive and memory decline for several months, but no more than that. They do not stop the progression of the disease.

Hundreds of clinical trials hold promise and hope for a possible cure within the next decade. Good news, but too late for many of us.

To receive a dementia diagnosis is Traumatic, Depressing, Stressful, and not surprisingly, launches a painful struggle with suicidal thoughts, sometimes carried out.

There are two things that I feel should automatically be given along with the diagnosis, to offer valuable support.

1. The [Alzheimer's Association](http://www.alz.org) (www.alz.org) is a wonderful resource, easily reached online for patients, family members, or physicians. They will send a free packet with all kinds of useful information. They provide free phone assistance 24/7 with competent, compassionate, trained persons. I only learned about this resource a year after my diagnosis.

2. The book, [Alzheimers From The Inside Out](#), was written by Richard Taylor, a psychologist who developed Alzheimer's himself. He has testified before Congress, and presented at medical schools here and in Britain. After a year of feeling lost, when I read that book, I felt "found".

Taylor describes his inner experience with the disease, that echoed and normalized my own experience.... What a gift it has been! I learned of his book through the Alzheimer's Association, a year after my diagnosis. All of us will know patients, have relatives, and friends with Alzheimers. To recommend this book to them would be a profound gift.

3. The natural response to the diagnosis of AD is to hide it from others; but sooner or later this becomes impossible. It is such a relief to be open about rather than try to hide it. The Alzheimer's Association emphasizes the value of being open.

I hope this information is irrelevant for most of you. But if it has value for anyone, I'm glad to have shared it.