

An Extended Coverage Insert contains more in-depth or wider ranging coverage of topics or opinions than can generally be accommodated in a regular ADC "Quarterly" feature.



question

My mother has Alzheimer's disease. Should I tell her?



answer

It depends.

On telling someone he or she has Alzheimer's disease

by Jason Karlawish

February 2006 saw members of Washington University in St. Louis' Alzheimer's disease Internet

Forum engaged in a brisk email exchange, the title of which was "Yet again: to tell or not to tell." The topic was disclosing — or not disclosing — a diagnosis of Alzheimer's disease to a person with the disease. The stories and views the members exchanged illustrate how diagnostic disclosure is among the

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ethically and clinically challenging issues in the care of person's with Alzheimer's.

On one side is the argument for disclosure. The patient deserves the truth and to deny him or her this information is to deny an adult's right to the truth. On the other side is the argument against disclosure. Not all truth is good to tell, especially to a person who may be harmed by it. In ethical terms, these competing arguments square off as a dilemma between respecting the principles of autonomy versus beneficence and nonmaleficence. In short, is it better to be honest but risk cruelty or kind but risk paternalism?

The arguments on each side are compelling. To resolve this dilemma, two issues need discussion. First is the practicalities of living with a chronic illness, and second, is the specific moral challenge that Alzheimer's disease presents to the family of one diagnosed with it.

Living with a chronic illness is different than living with an illness that, however severe and debilitating, is acute and self-limiting. A patient who suffers an acute illness such as pneumonia, fracture of a limb, or a kidney stone, usually has a story with a

typically dramatic, sforzando beginning, a suspenseful middle, and a definitive ending.

In contrast, the stories of patients with chronic illnesses all have one common ending: the death of the patient, either because of that illness, as in the case with a disease such as heart failure, or with the illness, as in the case of nonfatal diseases such as psoriasis. Living with a chronic illness is a story without an ending. Chronic illness becomes part of a patient's life. For a patient, and those who live with and care about him or her, the challenge is learning to live with the disease. One critical step in living with an illness is to understand and appreciate it.

ON KNOWING AN ILLNESS

What exactly does it mean to understand and appreciate an illness? These terms are taken from the language of capacity. Understanding is about knowing the facts. In the case of a person with a chronic illness, it means knowing what the illness is, what stage the patient is at, what to expect in the future and what can be done to maximize quality of life. In contrast, appreciation is about recognizing how those facts

apply to you. This ability is distinct from understanding because it refers to integrating knowledge into one's sense of self.

The distinction between understanding and appreciating a fact is perhaps best illustrated in the case of a person who suffers from a delusion. He or she might say to the doctor that while he understands that everyone says the voices he hears are not real, he knows that they are. So, while he understands the concept of delusions, he cannot appreciate that the voices he hears are just that: delusions.

Several years ago, I had care of a woman ravaged from years of diabetes. The toes of her right foot were black, blue and dead. Her white cells rising from a brewing sepsis. She could talk about gangrene, and knew what it was, but, in her mind, her toes were not dead. They were just dirty, and there was no way we were going to amputate her foot.

My colleagues and I tried to help her to appreciate the plain facts of her problem, but our efforts were fruitless. Finding her not capable of making the decision, and facing a life-threatening outcome, we turned to someone else, a close family



PHOTO: Alison Williams

Knowledge
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of the illness.
Appreciation
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member, to decide on the patient's behalf. We explained the patient's situation to her sister. She understood and appreciated the patient's problem and with her informed consent, we amputated her sister's dying foot.

KNOWING ALZHEIMER'S DISEASE

In the case of persons with Alzheimer's disease, several studies have examined patients' capacity to understand and appreciate information. A common finding is that many persons with mild stage Alzheimer's disease can understand information. They may not remember it, but when taught, they are often able to provide a relatively accurate restatement of the facts when asked to summarize what they have learned. This information ranges from descriptions of Alzheimer's disease clinical trials, treatments for Alzheimer's disease, and voting.

Appreciation is a more complex issue in persons with Alzheimer's disease for two reasons. First, it is referred to by at least three other terms. What bioethicists call "appreciation" psychologists call "insight." Neurologists, in contrast, refer only to its loss, labeling it

"anosognosia." Clinicians who see people with documented memory loss who complain of such memory loss call that complaint a "symptom." When we consider what each group means with these different terms, we see that, in fact, they are essentially talking about the same thing: awareness or lack of awareness of facts that other people think are true.

The second complexity is that appreciation is often mixed. A patient may appreciate one feature of his disease, but not another. In the case of appreciating Alzheimer's disease, there are at least three features: the diagnosis, the severity and prognosis. Studies examining appreciation show that patients may appreciate one of these features but not the other. That is, a patient may be aware of his or her diagnosis, but not the severity and prognosis. Or a patient could be aware of the severity and prognosis of his or her cognitive problems, but not the diagnosis.

Among persons with mild to moderate Alzheimer's disease who attend a memory disorders clinic, nearly half will admit they have problems with their memory. The other half says they do not. This symptom –

that of memory loss – becomes a sign when testing shows that the person does in fact have memory loss. A smaller proportion, about a third, recognizes that these signs of memory loss may become worse. That is, they appreciate that their memory loss is progressive. Finally, the same proportion says that they have Alzheimer's disease. But not all people who say they have memory problems and that they may become worse say they have Alzheimer's disease.

Comparing the cognitive symptoms that patients report to what their knowledgeable informants report shows a similar spectrum of awareness of problems. About one third of patients report a similar set of problems as their informant reports, such as remembering a list of grocery items, carrying on a conversation and following a book or a movie. Another third report only a portion of the symptoms their knowledgeable informant reports, and the final third report essentially no symptoms at all. In sum, patients' awareness of cognitive problems covers an extremely broad spectrum, from patients demonstrating high awareness of cognitive problems to having little or no awareness at all.

I once had a patient whose cognitive testing only showed a problem with his short-term memory. I explained that the tests suggested that the rest of his thinking skills were intact. He replied that he could not see how that could be the case and explained that his problems were not simply confined to a problem with short term memory, as he also had trouble concentrating on a book. Perhaps, he suggested, my tests were not accurate. In fact, he was right. More detailed testing showed problems with concentration and language. Such a patient shows exquisite insight into both the nature and the extent of his cognitive problems.

He is not alone. Research shows that some patients with Alzheimer's disease are highly aware of their problems. Ronald Reagan and Charlton Heston's very public and personal disclosures of their diagnoses demonstrate this. Yet other patients show awareness that is less comprehensive. For instance, some patients will say they have Alzheimer's disease but do not have memory problems. Others may say they have a memory problem that may worsen but do not have Alzheimer's disease. In sum, awareness in Alzheimer's disease has many different features. These may fit

together in an ordered picture that is clear and coherent, such as Reagan's announcement, but there may be aspects of a patient's life in which he or she is insightful juxtaposed along side aspects in which he or she is less self-aware. The picture is more an abstract expression than a classical form.

When thinking about how to work through the dilemma of diagnostic disclosure, these findings suggest that to argue either for or against diagnostic disclosure as the standard of care for the class of persons with very mild to moderate Alzheimer's disease oversimplifies the issue, and treats group uniformly when in fact patients differ in ethically relevant ways: some know there is something wrong, see that it has gotten worse and have even figured out or remembered they were told that they have Alzheimer's disease, while others do not. In order to determine how this applies to the practice, we need to consider a second issue.

THE DYAD OF ALZHEIMER'S DISEASE

Among modern diseases, Alzheimer's disease presents a unique moral challenge.

For every patient with the disease, there is someone else who, in a way, also suffers from it. This person may be called "the caregiver" or "the carer," though our research indicates that these terms are not uniformly applicable across cultures. Latinos, for instance, tend not to use this word.

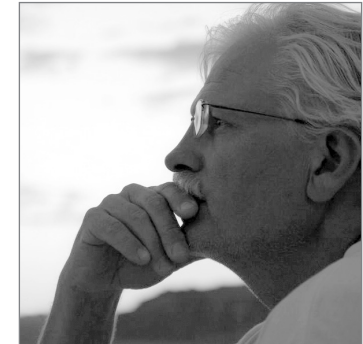
Regardless of title, those who care for someone with Alzheimer's disease have at least three roles. First, they serve as a knowledgeable informant with healthcare professionals. That is, they accompany the patient on physician visits in order to recount the events of the last few months and summarize any problems. They also assist the person with the managing his or her disabilities in performing activities of daily living such as shopping, refilling prescriptions and traveling about town. Finally, they may make decisions for the person in any number of aspects in that person's life. It is this third role that presents the most pressing moral challenges of living with Alzheimer's disease.

The decision to tell a person he or she has Alzheimer's disease is among the first of many decisions that illustrate the control a carer has over a patient. Other

decisions can range from the substantial to the prosaic. As a patient's capacity to make decisions declines, carers must decide any number of things, like whether the patient should go to the doctor, enroll in research or travel across country to a grandson's college graduation. In addition to these kinds of decisions, carers are also faced with the challenge of how far they will open the patient's window to the world. After the terrorist attacks on September 11th, carers told me how they struggled with whether to tell their relatives what had happened, and exactly how much their relatives should hear. One wife told me she simply hid the newspaper.

Carers have control, and they have it for good reason. A patient with cognitive problems left to manage the world alone is subject to a substantial number of harms as a result of the decisions he or she cannot make. The issue for carers is how to manage their control in a way that maximizes a patient's dignity and quality of life while respecting his or her choices.

When we consider a patient's capacity to understand and appreciate his or her situation, and we also take into account the role a caregiver



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plays in the patient's life, diagnostic disclosure is not so easily reduced to a black-and-white issue of telling the truth or lying. The issue of diagnostic disclosure is very much about a patient's unique situation. It depends on the capacity of the person to understand and appreciate the diagnosis, his or her expressed desire to know what's wrong, and the emotional and moral impacts that this knowledge may have. It should also account for the role of the carer and the power he or she holds over the patient.

PRACTICING TRUTH-TELLING

Ultimately, much of the decision for disclosure rests on three issues: the clinician's skill to assess a patient's understanding and appreciation of his situation, the patient's desire to know the cause of his or her problems, and the ability to convey these truths to the patient and their family. Some patients don't see that they have a problem, or if they do, they don't care to know why. Others become anxious when discussing their symptoms or upon hearing the word "Alzheimer's." Diagnostic disclosure makes little sense for these people.

Truth telling, like all acts of emotionally and morally significant communication, demands care and talent. It is all very well to deliver the truth but it must be done with hope and kindness. As a clinician, it can be especially difficult to balance truth, hope and kindness.

To achieve this balance, the clinician needs to learn the patient's desire to know what is wrong. I often find that once I get the words "Alzheimer's disease" out, I try and minimize how often I say it, choosing instead to focus on the symptom that bothers the patient, such as "memory problem." Colleagues tell me that they may bill for "memory loss" instead of "Alzheimer's disease" because the patient instruction form prints out the patient's diagnosis. They find it too blunt an announcement to have the words printed out above the instructions to the patient to increase his blood pressure medicine to two pills in the morning and schedule an appointment with the dermatologist. On the instruction sheet I give to patients and families the words "Alzheimer's disease" appear nowhere. Words are the powerful bullets of truth.

The truth does hurt. Persons who have insight into their cognitive problems tend to also

have more depressive symptoms than those who do not have insight into their problems. A clinician and family can manage this by recognizing the value of assessing a patient's mood and treating the symptoms of depression. Treatments range from anti-depressants to talking or offering support. The Alzheimer's Association recently established discussion and support groups for persons with mild to moderate Alzheimers disease to address just these kinds of problems.

I care for some several people who participate in these groups. I was seeing one of them in clinic. Part of my routine is asking the questions from the geriatric depression scale.

"I am going to ask you some questions about your mood over the last four weeks. These are all just 'yes' or 'no' answers." And then come 15 questions.

"Are you basically satisfied with your life?"

"Yes, but I wish I didn't have this Alzheimer's disease."

"Are you afraid something bad is going to happen to you?"

He hesitated.

"Well, with this Alzheimer's disease, I suppose so, but I just have to learn to live with that."

His spouse told me that, after attending a support group sessions, as they were walking home, he told her that if he reached the point where he needed to live in a nursing home, she should put him in one, and she should not feel guilty about that.

His answers to my questions and his wife's story of his candid comments to her illustrate a common finding from the psychology of learning a diagnosis. People typically learn to adjust to the situation. One patient late in the mild stage of Alzheimer's disease told an interviewer in one of our recent studies, "Right now my life is okay, you know, so I don't worry about it. I go bowling. I do all sorts of things and it's like it's a normal life. I know I have Alzheimer's disease but I live a normal life."

This sentiment is not unique to persons with Alzheimer's disease. Most patients with chronic illnesses adjust to their losses and typically rate their quality of life as better than how they rated it prior to having the illness when they were asked to imagine what life would be like



if they suffered the disease. In fact, patients uniformly rate their lives better than how those around them, such as spouses or children, rate them. The psychology of happiness shows that we rate anticipated losses worse than we do when we ultimately experience them, and, sadly, we overrate the anticipated pleasure of gains as well. In short, we overestimate both our expected pain and pleasure.

EXERCISING POWER OVER OTHERS

The Washington University email group exchange on the pro's and con's of diagnostic disclosure was a stimulating dialogue. Perhaps one of the most provocative posts was from a husband who defended his decision not to tell his wife her diagnosis and wrote a well-reasoned argument for this decision.

His email messages routinely include a link to a web page. I visited the link. The pages narrate in vivid and graphic detail his wife's life with Alzheimer's disease. They include her minimal state exam results, her problems with such basic activities of daily living as toileting and dressing and taking

her medications. He discusses decisions to start medicines and to enroll her in hospice. There are photos of her on vacation cruises.

The juxtaposition between this plainly public display of her disease on the world wide web, and the decision not to tell her of her own disease struck me with its irony. All of us hold truths about ourselves. Who we chose to tell those truths to and how we tell them are part of how we construct and reconstruct our identities and our selves. Imagine the transformation of both identity and self former New Jersey governor James McGreevey experienced when he publicly announced his resignation from office, and stated, "I am a gay American."

Reading this web content from the man who did not tell his wife her truth about her disease revealed yet another truth. In the life of each person with Alzheimers disease, we begin to hold their truths as ours. Whether and how we disclose this truth testifies to our power over another person and the responsibility we have to exercise it humanely. ■ ■ ■



The irony of one man's plainly public display of his wife's disease on a web site chronicling her activities, and his decision to withhold from her her own diagnosis revealed yet another truth.

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FOR FURTHER READING:

Papers on assessing the capacity of persons with Alzheimer's disease.

■ Karlawish J.H.T., James B.D., Casarett D.: Alzheimer's disease patients' and caregivers' capacity, competency and reasons to enroll in an early phase Alzheimer's disease clinical trial. *J Am Geriatr Soc* 2002; 50:2019-2024.

■ Karlawish J.H.T., Casarett D.J., James B.D., Xie S.X., Kim S.Y.K.: The ability of persons with Alzheimer's disease to make a decision about taking an AD treatment. *Neurology* 2005;64:1514-19.

■ Appelbaum P.S., Bonnie R.J., Karlawish, J.H. The capacity to vote of persons with Alzheimer's disease. *Am J Psych* 2005;162:2094-2100.