

Special Issues in Memory Loss, Alzheimer's Disease and Dementia

Quick Start

Some Patients Do Not Want to Have Their Memory Evaluated

- Help patients understand that the goal is to improve their memory and allow them to continue doing the activities that they enjoy.
- Explain that there are a number of medications available that could help them.

Some Patients Do Not Want You to Talk to Their Family

- A few patients are able to manage the disease on their own, at least for a while.
- For the majority of patients, involvement of family or friends is a critical part of the patient's care, helping him or her to deal with and manage memory loss due to Alzheimer's disease or another dementia.

The Patient Who Does Not Want to Come to the Appointment

Difficulty in convincing patients to come to appointments to evaluate their memory can sometimes be one of the biggest obstacles faced by families. Patients do not want to come to the appointment for a variety of reasons. Some patients may not want to come to the appointment because they are fearful of the diagnosis of Alzheimer's disease, particularly if they watched their parent, spouse, or friend suffer with this disorder. Others may not want to come to the appointment because they are afraid they will be sent to a nursing home. And some may simply not want to come to the appointment because they do not recognize a problem and cannot be bothered with coming.

We admit that we have not been able to convince every patient to come to an appointment. We have, however, been successful with a couple of strategies. The most reliable of these is to explain to the patient (typically on the phone) that our goal is to improve their memory to allow them to continue doing the activities that they enjoy, and that there are a number of medications available to help their memory, and even to delay the onset of Alzheimer's disease. Sometimes it is not even what you say, but just spending a minute and making a connection with the patient helps to make the appointment less frightening.

A number of families will grab us in the hallway prior to the appointment and say something like, "Please measure her blood pressure... the only way I was able to get her to you was to pretend that this was for her routine blood pressure check." Although we do not condone deception as a way to bring a patient to an appointment (in part because it may lead to mistrust, in part because of the ethical implications), patients brought in this way typically do just fine. These patients discover that a memory evaluation is quite similar to other medical evaluations, not as frightening or threatening as they had feared.

The Patient Who Does Not Want You to Talk to Their Family

Sometimes it happens that patients come to the clinic and they do not want you to tell their family about their memory difficulties. Should we agree with respecting their desire for confidentiality, despite the difficulties and potential danger in which they may be placing themselves and others? Or should we insist that their family be involved? Our answer is that it depends upon the circumstances (see patient examples below). For the vast majority of patients, the involvement of family or friends is a critical part of the patient's care, helping him or her to deal with and manage memory loss whether due to Alzheimer's disease or due to another dementia. There are a few patients, however, who are able to manage the disease on their own, at least for a while.

Case Study

The First Patient

A patient came to our office about 10 years ago, driving himself the three hours to get to our clinic, with concerns about his memory. He had noticed mild changes in his memory, and was worried that he might be at the earliest stage of Alzheimer's disease. He had watched his father go through the disease, and so he knew the signs well. After evaluating him we made a diagnosis of mild cognitive impairment, and prescribed a course of medication. He did not want us to mention anything to his children or his wife, which we thought was acceptable at the time given how mild his memory difficulties were, how responsibly he was acting, and that he was taking a medication which had the potential to improve his memory to the level which it was at the previous year.

Several years passed in this manner. His memory became worse, and he was diagnosed with very mild Alzheimer's disease dementia. At each visit we discussed the importance of letting his family know about his difficulties, but he continued to decline our suggestion. He was able to persuade us, however, that he was taking all of his medications correctly, was driving safely, not getting lost, and not running into any serious difficulties. Finally a minor crisis occurred at home when he forgot to come home to take the dog out for a walk—a small thing, but very uncharacteristic for him—and he ended up explaining to his family about his disease and about not wanting to burden them with it. Our next visit with the patient included his wife and two anxious sons. We had a very productive meeting and learned many things we wished we had known about earlier, such as that he used many woodworking tools in the basement and was beginning to have minor injuries associated with not using the tools correctly. Overall, however, we were pleased that we were able to provide good treatment to the patient while at the same time respecting his wishes not to tell his family about his memory problems.

The Second Patient

Another patient came to our clinic several years ago. We knew that there were going to be some issues before she came in, because she had scheduled and then canceled the appointment four times before finally coming in to see us. It had also been clear to us ahead of time that she did not want her family involved, because when our secretary scheduled the visit and mentioned to the patient that she should bring someone close to her to the appointment, such as a family member or close friend, she adamantly refused to do so.

During the appointment she was incredibly anxious. We were sympathetic to her. It was perfectly clear that she was absolutely terrified that she might have Alzheimer's disease. Her mother had recently died of the disease, and we gathered that the experience of her mother's illness and death had been quite traumatizing to her. Her mother, however, first showed symptoms in her mid-80s and died at age 91. The patient herself was only 68 years old. Even before we finished interviewing her we could tell that her memory problems were significant, and we wondered whether she was really able to cover her difficulties as well as she stated.

We took an extra 10 minutes, and spoke with her about some of what we typically save for the first follow-up visit. We discussed that, if it turned out that she did have Alzheimer's disease, there are many treatments that could help her—more than were available when her mother was diagnosed. Additionally, we discussed a number of experimental treatments that were currently in clinical trials, treatments that had the possibility to significantly slow the progression of Alzheimer's disease.

We then asked about her family and, when we learned that they were supportive, we explained the importance of having her family with her. She hesitated, and we gently but firmly insisted that she involve her family and bring at least one family member with her to the follow-up appointment. We insisted because we were concerned that she needed the emotional support of family to effectively come to terms with her memory problems. Additionally, her memory was already poor enough such that she would be unable to hide it for long—assuming that it was not already apparent to those around her. Both her daughter and husband came with her to the next appointment, at which time we told her that she had mild Alzheimer's disease dementia. Although tears were shed, with their help she was able to accept the diagnosis, and she worked to have a positive attitude.

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