



BETH GOODY

## When Is the Best Time to Tell Friends And Colleagues You Have Alzheimer's?

**As more people are diagnosed early, they face hard decisions about when and how to reveal the news**

BY MARC AGRONIN

### 'I HAVE ALZHEIMER'S.'

Those are the three words that many of my patients most dread saying, even to their closest family. They struggle with whom to tell, when to tell, and what to tell.

There was a time not long ago when this wasn't an issue; by the time a person was diagnosed with Alzheimer's, it was pretty obvious that something was wrong. But now, thanks to advances in our ability to detect the disease early, more patients are being forced to confront those questions.

As the director of a memory disorders clinic, I work with such patients all the time, and see how difficult the decisions can be. One patient, an orthodontist who had to take an unexpected retirement even though his cognitive changes were barely detectable, was embarrassed and reluctant to say anything. But he and his wife decided it was time to divulge the truth. He reached out to each one of his colleagues and friends and made that simple revelation: "I have Alzheimer's." To his surprise and



relief, everyone was supportive and empathetic. Some friends even confessed their own cognitive lapses and sought his advice on what to do.

Sadly, though, not everyone is so lucky. Given the stigma and misunderstandings about the disease, some people infantilize these patients in person or ostracize them in social circles. Coworkers or bosses sometimes question their ability to do their jobs, or perhaps even fire them.

One of my patients has two well-meaning daughters but they get frustrated with her memory lapses and sometimes scold her for them. "I hate defending myself," my patient tells me, "but I have to have my voice heard and remind them that I'm still here."

Still, while the reveal can be agonizing, if done carefully, the payoff can help normalize and support an otherwise difficult path.

### When it's time to tell

There is no hard and fast rule about when to tell people. It depends. But the one guiding light should be that it serves a purpose.

For my orthodontist patient and his wife, they believed the disclosure would dispel growing suspicions among family and friends. Even though the earliest symptoms of Alzheimer's disease are often subtle, they may be more noticeable in social and work settings when a person is behaving or performing differently from before. As the disease unfolds, these mild changes are amplified by commonly associated problems such as anxiety, depression or apathy. Disclosing to others the reasons behind these changes can enable them to better understand and rally behind the affected person.

Beyond that, here are some other considerations when disclosing:

- There must be a clear and certain diagnosis based on a comprehensive and expert evaluation. Revealing a false or uncertain diagnosis only complicates the disclosure.
- The person disclosing the diagnosis must be able to explain it correctly. Telling someone you have Alzheimer's disease without knowing exactly what that means may unnecessarily confuse them. A vague explanation may lead people to google the diagnosis and read about all sorts of extraneous, irrelevant and hyperbolic details that may never apply to the affected person.
- Focus on simple explanations and describe the current state without speculating on the future.
- The timing and audience for a disclosure should depend on whether it helps the affected person feel understood, normalized and supported. When these factors are off, it can sometimes backfire.

As the disease progresses and symptoms become more obvious, the circle of people in the know will likely enlarge, providing a precious opportunity to accurately educate them and seek their support.

### How to tell

The basic strategy of how to tell others about an Alzheimer's diagnosis is to craft the message to their level of understanding and involvement. A close family or friend, for instance, will benefit from a direct reveal of the diagnosis along with a basic explanation of how it was determined. Since people will be motivated to help, it's also good to be specific about what's needed, such as planning regular and enjoyable social activities and excursions, help with transportation and breaks for the caregiver.

If a diagnosis is made in midlife, there may be school-age children or adolescents who need to be told. Again, the guiding rule should be to speak to their level of understanding, provide reassurance and normalize life for them. It also depends on the specific child: While the diagnosis may frighten a more-dependent child, it may be taken in stride by a more-independent teen.

Sharing a diagnosis with a coworker, supervisor or employer carries the risk that they will scrutinize the person's job performance and worry about productivity, safety and liability. One of my patients who is an attorney was asked to retire immediately after informing his firm, not because of concerns about his still-excellent performance, but due to fears of how clients and opposing parties might question it if word got out.

### Advice for the receiver

There are a few golden rules for someone who is the recipient of a reveal.



First, listen and don't make it about yourself or other people you know with cognitive changes. Everyone is different and you need to simply let someone describe his or her own journey.

Second, don't offer your own theories or therapies; leave it to the experts.

Third, spend time with such people as you normally would and don't ostracize or abandon them. You can't catch it from being around them.

Fourth, focus on people's strengths and abilities and don't remind them of what they forgot or can't do as well.

Fifth, ask about family and care partners, who are going to need your support as well. Don't be shy: Ask affected individuals and care partners what is needed, and jump in. It can be a lonely road without the presence of others.

After three decades of service in the Alzheimer's storm, I know how tough it is to navigate a diagnostic disclosure, whether from doctor to patient or from patient to friends and family. But I have one firm belief, which is that the way we provide care and support has the potential to change each person's course for the better. It isn't always easy, and we sometimes have to fight our own instincts, but doing it right can make all the difference.

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