

Dementia in the Workplace

How long should someone with dementia keep working? BY GINA SHAW

In August 2011, University of Tennessee (UT) women's basketball coach Pat Summitt announced that she had been diagnosed, three months earlier, with early-onset dementia. She also stated that she would continue to coach her Lady Vols through the 2011-2012 season.

Summitt's announcement has spurred an important national conversation about how long people diagnosed with Alzheimer's disease or other forms of dementia can or should continue working. It's a complicated decision, and one that thousands of Americans are faced with every year.

STRUGGLING AT WORK

The new computer system in her office shouldn't have been a problem for Diane Carver.

For more than 20 years, she had worked as an office manager for a flooring company near her home in Altamonte Springs, FL. During most of that time, Carver trained every new employee that walked in the door on all the company's products and taught them how to use the computers. But then the company changed computer systems, and Carver found herself struggling to learn the new technology.

"I've never had issues with learning new computers, but all of a sudden, I'm having problems grasping what to do, and I'm thinking, 'How can this be? I train people! How can I train them if I can't get it myself?'" recalls Carver, now 60.

It wasn't the only problem. A big part of her job was making calculations and giving price quotes over the phone. Carver found that this task, once easy, was growing increasingly difficult. "It got to the point where I was bringing things home and studying to try and sharpen up," she says. "But I never thought it could be dementia. My brother, who'd had Down syndrome and meant everything to the family, had passed away, and I'd lost my

mother a few years before that. So I figured I was depressed, plus I was going through menopause."

In December 2008, after months of mightily resisting suggestions from her husband, Larry, that dementia might be involved, Carver finally agreed to go to a neuropsychologist at nearby Florida Hospital Neuroscience Institute. After a series of tests, the diagnosis was clear: Alzheimer's disease.

At first, Carver continued to work. "I had worked there for so long, I had trained everyone there, and they all helped me out," she says. She even paid one staffer to spend time with her after hours, helping her get acquainted with that troublesome new computer system.

But a month or so later, her doctor told her that she should stop driving. And then one day at work, she found herself on the phone with an irate customer. "I had given him five different quotes, and he kept saying, 'That price is wrong.' I'd try to refigure and give him another number. Finally he said, 'Lady, how stupid are you? You have no business working there!' and he hung up. I came home crying."

Two days later, Larry and Diane went into the office together and explained her diagnosis. She asked to be placed on disability and resigned from her position.

THE IMPACT OF EARLY DIAGNOSIS

Usually, by the time someone's condition has actually progressed to the point of a diagnosis with dementia, it can be challenging to continue working, says Anthony LoGalbo, Ph.D., the neuropsychologist at Florida Hospital Neuroscience Institute who assessed

As doctors are able to diagnose people at earlier and earlier stages of dementia, the question of whether to keep working has become more common.





THE GAME PLAN
University of Tennessee head coach Pat Summitt, right, talks with Meighan Simmons during a game in November 2011.

Carver. “I will often encourage them to stop at that point, because it’s better to leave work before a big problem happens rather than wait until you make a serious mistake.”

But some people in the early stages of dementia, like Summitt, continue to work. And new sets of diagnostic criteria now allow physicians to diagnose Alzheimer’s disease before the condition has actually progressed to the level of dementia.

“When people have started to show some cognitive changes—a condition known as mild cognitive impairment or MCI—we can make a diagnosis of Alzheimer’s disease with substantial confidence before they meet the criteria for dementia, using new technologies involving imaging and spinal taps,” says Jeffrey Cummings, M.D., member of the American Academy of Neurology and director of the Cleveland Clinic Lou Ruvo Center for Brain Health, which has sites in Las Vegas, NV, and Cleveland, OH. “As we become more able to diagnose people who have these beginning symptoms, the question of whether to continue working will become more common. It will become a much more common challenge for families, patients, employers, and physicians than ever before.”

MAKING THE DECISION

How should someone diagnosed with dementia or MCI approach the decision about whether or not to continue

working? Several factors should be considered, says Gary Kennedy, M.D., director of the Division of Geriatric Psychiatry at Montefiore Medical Center in New York, NY.

Safety is first. If others’ lives depend on the person’s job performance, then he or she should consider retiring as soon as impairments are noticeable. For example, for a surgeon, a nurse, an airline pilot, or a school bus driver, errors can cost lives.

Rick Phelps, now 57, was an emergency medicine technician (EMT) in the same town in Ohio for more than two decades when he began having trouble finding the addresses during emergency calls. He tried talking to his boss about it, but the man just laughed and said, “Hey, we’re all getting older—I keep losing my car keys too.” Phelps was shocked when his supervisor said that he could continue working even after his dementia diagnosis because there hadn’t been any problems yet.

“I’ve seen individuals in jobs like these, and I’ve advised them to stop working before anyone notices a problem,” says Dr. Kennedy. “Once someone else notices, then you’ve endangered others.”

One day, Phelps and his partner had a very rough call: A four-year-old boy had had a seizure; the child was blue and not breathing when they arrived. They were able to start an

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airway and revive him, but the child died at the hospital. Phelps knew he had made no errors on the call and that the death was not his fault, but he feared it was just a matter of time. Several days later, he quit. “I never forgot a procedure or did anything wrong to a patient, but I knew it would have ended up that way,” he says.

Beyond safety, other serious risks should be considered. Aerospace engineer Robert (Bob) Patterson, from Manhattan Beach, CA, didn’t have people’s lives in his hands, but he held final authority for sending multimillion-dollar satellites into space. “It was a job of incredible responsibility,” says his wife, Karen. “While that was a difficult job under any circumstances, as time went by it had become more of a burden than a joy.”

In 2005, Patterson was recruited for a prestigious new position in Colorado and passed a panel of interviews with flying colors—despite the fact that he knew he couldn’t even remember the names of the people he’d spoken with. The company hadn’t noticed a problem. But Patterson knew, and he turned down their offer. He retired a year later, at 59. “These things have to work. You’ve gotta get it right. I love aerospace and satellites, but it was just too hard. I felt I would be shortchanging them,” he says.

Another factor is the degree of innovation versus repetition. “Dementia is always couched as a memory disorder, but in reality it’s a learning disorder. Old memories, old habits, old patterns remain until the dementia becomes far advanced. But you cease to be able to learn new information,” says Dr. Kennedy.

So if the job is very repetitive—stocking shelves in a warehouse in the exact same way, for example—a person with dementia may be able to stay at work much longer than someone whose position requires them to constantly respond to a changing flow of information, like a stockbroker.

“In its early stages, dementia also has little impact upon personal characteristics like an outgoing personality, charismatic leadership skills, and an intuitive sense of how to work with people,” says Dr. Kennedy. “That’s not likely to change until later on in the disease process.” So someone like Pat Summitt should be able to motivate and inspire her players, as well as work with them through familiar drills and practices—but will

probably need assistant coaches to make snap judgments about strategy in the middle of a fast-moving game.

Finally, the level of pressure needs to be taken into consideration. High-stress, high-pressure jobs—like Rick Phelps’ EMT position or Bob Patterson’s aerospace engineer work—are particularly wearing for someone with dementia. But a gardener or a teacher’s aide in a preschool (who is always backed up by another teacher) might be able to continue working longer.

TIPS FOR STAYING ON THE JOB

For those who choose to continue working, certain strategies can be used to help minimize the effect of dementia on job performance. One of the most important strategies, says Dr. LoGalbo, is structure.

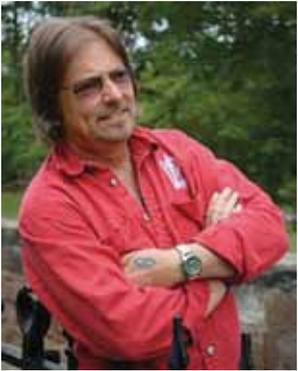
“People with dementia should use calendars, day planners, and checklists to remind them of exactly what they need to do and when they need to do it,” he says. In addition, they should try to keep their days as structured and predictable as possible. For example, if a daily meeting must be held, a person with dementia should try to schedule the meeting at the same time and in the same office each day.

That’s the kind of thing Summitt has done with what she calls her “dementia game plan.” Each morning, she reviews a daily schedule to prepare for what is on her agenda that day. (See box, “Pat Summitt’s Dementia Game Plan.”)

“She is all about her game plan,” says Debby Jennings, associate athletic director for media relations at UT. “We are learning along the way and modifying and reshaping our strategies just like our coaching staff does in the middle of a game.”

A person with dementia will also need to rely on trusted coworkers for help, as Carver did and Summitt is doing now. “Let’s say someone with dementia is a waitress,” says Dr. Kennedy. “She has retained good interpersonal skills, and her dementia isn’t so advanced that it’s changing her personality. The chef who plates the food and gives it to the waitress can remind her which table it’s for, and someone else can check the figures on the bill.”

The Americans with Disabilities Act does provide limited protection to people with Alzheimer’s disease and other dementias in the workplace. It requires that companies with at least 15 or more



THIS IS SERIOUS
EMT Rick Phelps began having trouble finding the addresses during emergency calls. He tried talking to his boss about it, but the man just laughed and said, “Hey, we’re all getting older—I keep losing my car keys too.”



Pat Summitt's Daily Dementia Game Plan

- ▶ A good breakfast
- ▶ An exercise routine—she has worked out every day for over 40 years
- ▶ An hour or more in the morning working on memory exercises, puzzles, and word games, on her iPad (her son Tyler, a 21-year-old junior on the UT men's basketball team, constantly finds new ones for her)
- ▶ Lunch
- ▶ Meetings with her coaching staff
- ▶ Review of team performance on video
- ▶ Practice
- ▶ Unwind time
- ▶ Dinner
- ▶ More memory exercises on the iPad
- ▶ A good night's sleep

employees make “reasonable” accommodations for job applicants and employees with physical or mental disabilities. So, for example, someone with dementia might ask his boss to switch him to a less demanding or stressful position, or reduce his hours so that he is still working but has more time to rest.

WHEN IT'S TIME

Ultimately, though, the time will come—as it did for Phelps, Carver, and Patterson—when a person with dementia can no longer work. “Even though continuing to work may be beneficial in some ways, providing the person with a social outlet and meaningful things to do, it can also become quite frustrating or embarrassing to be in that environment and not do as well as he or she once did,” says Dr. LoGalbo. “I ask patients, ‘Would you rather stop working now through your own choice, or wait until someone realizes you’re having trouble and you get fired?’” Getting fired, he says, may mean a loss of benefits or difficulty going on work-sponsored disability.

STILL IN THE GAME
Summitt instructs her team during a game against Pepperdine in November 2011. Summitt's team won 89-57.

Fortunately, when the time does come to leave work, it has become much easier for people with younger-onset Alzheimer's—diagnosed before age 65, like Summitt, Phelps, Carver, and Patterson—to obtain Social Security disability. In March 2010, the Social Security Administration added young-onset Alzheimer's disease to its “Compassionate Allowance” list, which fast-tracks the approval process so that benefits can start within days rather than months or years.

“We applied and were fully funded six weeks later,” says Karen Patterson. “That was the quickest thing I could have ever imagined. Knowing that that's available might ease some of the pressure to keep working for some people.”

A SENSE OF PURPOSE

Of course, work isn't just about money. For many people, it's also about finding something meaningful to do with their day. When dementia forces a person to give that up, it can be isolating and depressing. Experts recommend that people with dementia find something else to do with their time that provides a sense of purpose, such as volunteer work, an exercise group, or regularly scheduled activities with friends such as knitting or scrapbooking. Carver frequently goes out to dinner with old coworkers to catch up on gossip. She also enjoys working in her yard.

“I wasn't going to sit on the couch covered up with an afghan watching Dr. Phil,” says Phelps. “Maybe I can't learn anything new with this disease, but I've started a Facebook group called Memory People that provides a community for people with dementia, and I'm working on a book with a co-author and doing videos. Those are things in my long-term memory. And if I have a bad day—I don't even know what happened to me yesterday, for example—I don't have to work that day.”

Bob Patterson had hoped to mentor young engineers at his old company, but taking on a volunteer position at an aerospace company was impossible since any kind of work in such a firm requires an active security clearance. So he now volunteers with the local Alzheimer's Association chapter and regularly goes on rounds with his doctor, Dr. Cummings, helping to teach young physicians about Alzheimer's disease.

“Bob's ability right now to talk about the disease gives him a special way of teaching people. He always says to me afterward, ‘I feel like a teacher again. I really enjoy this,’” says Dr. Cummings. “Our work is one of our greatest sources of self-worth, and giving that up can lead to an erosion in self-worth. So there is every reason for people to continue to be engaged for as long as they possibly can, even when paid work is no longer an option.”