Living with memory loss, working to fend off dementia

A mild cognitive impairment diagnosis is scary, but recognizing it early is essential to slowing its progression, experts sav

By Katherine Ellison March 3, 2024 at 7:00 a.m. EST



Jonel Dershem, left, poses for a photo with her son Bryce at their home in Voorhees, N.J., on Feb. 24. (Rachel

Jonel Dershem first noticed problems with her memory in 2016 after her breast cancer surgery. She was only 50 and at first blamed the lapses on chemotherapy, and then on her busy, stressful life.

So did her husband and friends — and doctor.

"I kept blowing it off," said Dershem, an obstetrician from Voorhees, N.J., whose challenges began with little things like leaving a faucet running and progressed to trouble finishing routine tasks. "I was our family's primary breadwinner. I didn't want there to be any serious problems."

In December 2022, nearly six years after her memory loss began, Dershem was diagnosed with mild cognitive impairment (MCI). Her delayed diagnosis wasn't unusual, but experts say that needs to change.

More than occasional forgetfulness, MCI causes problems that disrupt daily life but don't make it impossible to function, said Ronald Petersen, director of the Mayo Clinic Alzheimer's Disease Research Center and the Mayo Clinic Study of Aging. It is often but not always a precursor to dementia, he added.



Jonel Dershem, right, was diagnosed with mild cognitive impairment in 2022 after complaining about memory problems for seven years. She is shown with her son Bryce on Feb. 24. (Rachel Wisniewski/For the Washington Post)

"It's a subtle condition," said Petersen, who in 1999 led the first study <u>differentiating patients</u> with MCI from healthy subjects and those with dementia. If you miss a golf date once, no worries, he said, but if "that happened a couple of times last week and people in your family are starting to worry about you — well, that may be MCI."

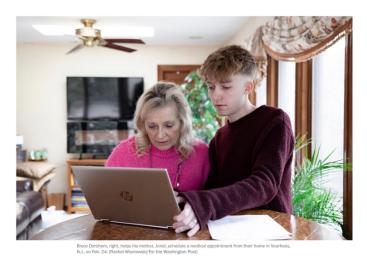
"With MCI, people can still drive, pay their bills and do their taxes — they just do so less efficiently," Petersen said.

A 2022 study in the journal <u>Alzheimer's & Dementia</u> projected that 14.4 million people in the United States would have MCI in 2025, and 19.3 million in 2050. An American Academy of Neurology subcommittee estimated that about <u>1 in 10 people ages 70 to 74</u> had MCI, and 1 in 4 ages 80 to 84 in 2018.

For Alzheimer's patients, a new era of treatment brings hope and risk

Denial about potentially worsening symptoms may be tempting, but it's dangerous, experts said. Dershem, who grew increasingly worried about her condition, said she raised the issue three times with her primary care doctor and saw two neurologists before she was diagnosed with MCI.

Both patients and physicians need to be aware of the symptoms of cognitive decline, said <u>Soeren Mattke</u>, director of the Brain Health Observatory at the University of Southern California's <u>Dornsife Center for Economic and Social Research</u>. "If you wait until someone's obviously symptomatic — like they can't find the door to the physician's office — you're going to be too late."



Bryce Dershem, right, helps his mother, Jonel, schedule a medical appointment from their home in Voorhees, N.J., on Feb. 24. (Rachel Wisniewski/For the Washington Post)

'Time is brain'

If you notice a significant decline in memory, reduced ability to absorb new information or understand social cues (like getting angry about a joke that wouldn't have been upsetting in the past), or an uptick in clumsiness in yourself or someone close to you, it may be time to talk to a doctor.

Research published last year <u>suggests approximately 92 percent</u> of people with MCI are undiagnosed. After analyzing data from 40 million Medicare recipients aged 65 and older, the authors of the study in the journal Alzheimer's Research & Therapy found that only about 600,000 of the expected 8 million affected by MCI had been identified.

"We expected it to be bad, but not this bad," said Mattke, the study's lead author. Detection rates are even lower for historically disadvantaged groups, such as Black and Hispanic Americans.

By the time of her diagnosis, Dershem had quit performing surgery. She retired from her medical practice in January 2023.

"The advantage of catching MCI early is that we can delay progression. Later on, less," said David Weisman, director of clinical research at Abington Neurological Associates in Abington, Pa., and Dershem's current doctor. "In neurology we learn the same lessons again and again: Time is brain."

Since February 2023, Weisman has been treating Dershem with lecanemab (brand name <u>Leqembi</u>), which federal regulators approved last year to treat MCI and early Alzheimer's disease. Lecanemab reduces the buildup of amyloid beta, a protein in the brain that is a hallmark of Alzheimer's. Clinical trials have shown it can modestly slow dementia's progress but can't stop the decline or make up for lost ground.

The new face of Alzheimer's: Early-stage patients who refuse to surrender

Diagnosis is also valuable because, in a minority of cases, something other than Alzheimer's disease — or a related incurable disorder such as <u>Lewy body dementia</u> — is causing MCI symptoms. But that doesn't mean it's not potentially serious, said Petersen. The potential culprits range from a brain tumor to medication side effects.

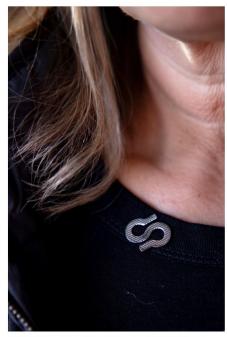
Many doctors are now buoyed by the emergence of amyloid-fighting medications such as lecanemab and donanemab, the latter of which has <u>yet to be approved</u> by the Food and Drug Administration. The caveat is that the drugs help only when the disease is caught early. Additionally, the medications can come with dangerous side effects. Leqembi carries a warning that it can cause brain swelling and bleeding.

Make memory a priority

Some deterioration in memory and processing speed is an inevitable part of getting older, although the <u>pace and degree vary</u> from person to person. Share this articleNo subscription required to readShare <u>Brain volume shrinks</u> on average by about 5 percent per decade after age 40, with the rate possibly accelerating after age 70. (Microbleeds in the brain due

to declining vascular health may also affect brain function.) If you find yourself having a little more trouble keeping up with conversations, losing the keys or temporarily forgetting the name of that guy you worked with for six years in the 1980s, that's just part of the journey.

But if you're noticing more worrisome cognitive gaps, talk to your doctor and make it clear that getting answers is a priority. "If you go in and say, 'I have the following 20 problems, and memory loss is number seven,' it's just not going to work," Weisman said. If you feel your doctor isn't taking your worries seriously, consider consulting a geriatric psychiatrist or neurologist, he added.







Anthony and Karen Sandone pose at their home in Doylestown, Pa., on Feb. 25. (Rachel Wisniewski/For the Washington Post)

Preparing for an evaluation

You can help your doctor and get a preview of your condition by taking an online test before your appointment and bringing in the results. The gold standard is the downloadable <u>Self-Administered Gerocognitive Exam (SAGE)</u>. (Beware of others that may be covers for ads.)

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— Bryce Dershem

Your doctor may conduct a more thorough test or a battery of neuropsychological assays before moving on to blood tests or an MRI to look for possible physical problems. If other causes are ruled out, a PET scan or spinal tap may be used to search for signs of Alzheimer's disease or Lewy body dementia, the second-most-common cause of dementia. New blood tests promise to make diagnosis easier in time.

Those experiencing serious cognitive decline often won't be the first to notice, Mattke pointed out. This makes it all the more important that you bring a personal "historian" to your appointment, said Weisman: A spouse or friend who may have a better idea than you do about the onset and pace of your decline.

Dershem's son, Bryce, now a junior in college, offered her that support, raising concerns about her memory loss during an appointment with the first neurologist she saw, when his mother was still wondering whether she might have ADHD or even Parkinson's disease.



Karen Sandone holds receipts for donations she has received for a Alzheimer's disease fundraiser she is heating. (Peach of Micropolal Vice the Weshington Beet)

"More and more I saw she needed help, like she'd be stuck in the middle of making a big dinner and get lost not knowing what the next step was," he recalled. His mother had also begun to have trouble typing up her notes from work, something she'd done routinely without effort for years.

If possible, bring someone with you to all medical appointments, a lesson Karen Sandone, in Doylestown, Pa., learned the hard way. She noticed that her husband, Anthony, a 55-year-old sales manager for a chemical company, was having memory issues in spring 2022. "He would forget what he was saying in the middle of a sentence," she recalled.

That April, Anthony Sandone saw a neurologist for a neuropsychological evaluation. About a month later he returned, alone, to hear how he did, his wife said.

"When he came back home, he said everything was fine," Karen Sandone recalled. "But he kept getting worse."

In October 2022, Karen Sandone looked over the evaluation herself — "and I was like, 'Oh my goodness, how could he say everything was okay?' I didn't realize that Anthony couldn't understand or remember what she was saying."

Anthony Sandone was diagnosed with early-onset Alzheimer's disease in October 2023. The couple has since joined the Alzheimer's Association in advocating for a cure.

If MCI is confirmed

Following an MCI diagnosis, it's especially important to take care of your brain, no matter how old you are, said Petersen. That includes carefully managing any other illnesses, such as diabetes, and adhering to National Institute of Aging guidelines on exercising regularly, getting sufficient sleep, limiting alcohol and stress, and maintaining an engaging social life. Diet is also important. Researchers have found that trading saturated and trans fats (in foods like beef ribs, sausage, butter, and commercially baked cookies and cakes) for unsaturated fats (think seafood, walnuts and olive oil) is associated with slower cognitive decline and decreased risk of onset of Alzheimer's disease.

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A 2019 pilot study found that a six-week classroom program of <u>memory</u> <u>training</u> may help slow decline. It's also a good idea to fortify your memory-support tools, such as calendars and notes and daily routines, and to put your keys, phone and glasses in the same place each day.

Eventually, a diagnosis of MCI that's on track to dementia should inspire some <u>hard thinking about the future</u>, including considering alternative arrangements for driving, designating a surrogate decision-maker for health care and financial affairs, and executing a will.



Karen and Anthony Sandone in their home on Feb. 25. Anthony Sandone was diagnosed with early-onse

It's not all bad news

Gloomy as all this sounds, there's also some positive news about aging brains. In recent years, <u>dementia rates around the world have been falling</u>, driven mainly by improvements in cardiovascular health. Researchers and policymakers are paying more attention to the problem, reducing the stigma and producing new treatments.

"My guess is that within five to 10 years from now, we will have better biomarkers for what's causing MCI and dementia — and combination therapies to treat them in each patient," said Petersen.

Dershem has already gotten some good news. During her first 11 months of treatment for MCI, she saw no further evidence of mental decline. The twicemonthly infusions may not be the only reason, Dershem and Weisman agreed.

"Being retired helps — there's a lot less stress," said Dershem, adding that she was also exercising more consistently, watching her diet and spending more time with her two children. "I'm just trying to do everything I can."

 $\underline{https://www.washingtonpost.com/wellness/2024/03/03/mild-cognitive-impairment-dementia-treatment/}$