

A push for family input to detect dementia earlier

February 6 2012, By LAURAN NEERGAARD , AP Medical Writer

(AP) -- Alexis McKenzie's mother had mild dementia, but things sounded OK when she phoned home: Dad was with her, finishing his wife's sentences as they talked about puttering through the day and a drive to the store.

Then their phone service was cut off. "I mailed that check," McKenzie's father insisted. No, he'd mailed the phone company a bank deposit slip instead. McKenzie visited and discovered spoiling food. Dad the [caregiver](#) was in trouble, too.

[Dementia](#) can sneak up on families. Its sufferers are pretty adept at covering lapses early on, and spouses are sometimes there to compensate. Doctors too frequently are fooled as well. Now specialists are pushing for the first National Alzheimer's Plan to help overcome this barrier to early detection, urging what's called dementia-capable primary care, more screenings for [warning signs](#) and regular checks of caregivers' own physical and mental health.

For a doctor to ask someone with brewing dementia, "How are you?" isn't enough, says Dr. Laurel Coleman, a geriatric physician at Maine Medical Center who is part of a federal advisory council tackling the issue.

"So often I hear, 'The doctor only asks my mom how she is. She says fine and it's over,'" says Coleman. "That's not dementia-capable, or dementia-aware, primary care."

Family input should be mandatory, she told a recent council meeting. It's the only way to know if the person really is eating and taking her medicines as she claims, and not forgetting to turn off the stove.

The question is how to square that input with patient confidentiality, especially if the person never filed the legal forms clearing family members to intervene, as happened with McKenzie.

Plus, regularly seeking that input takes more time than the typical 15-minute visit and is poorly reimbursed, notes Coleman. But she says more primary-care physicians are starting to be trained in dementia's challenges.

More than 5 million Americans are estimated to have Alzheimer's or similar forms of dementia, although as many as half may not be formally diagnosed. With the rapidly aging population, the toll is projected to reach up to 16 million by 2050. The Obama administration is drafting a national strategy to try to slow that coming avalanche - with research aiming for some effective treatments by 2025 - plus find ways for struggling families to better cope today.

Step 1 is earlier detection. McKenzie directs an Alzheimer's assisted-living facility in Washington, so she knows about dementia. Still, it took some sleuthing to determine how much her 82-year-old parents, living a few hours away in Maryland, were deteriorating. She says her father refused any assistance in caring for her mother, and together the couple put up such a good front that even their regular physician hadn't realized their shared answers to standard check-up questions - How are you eating? Has anything changed? - simply weren't true.

"It's almost as if they're sharing a brain. That's how they get through a day," McKenzie says.

Sure, dementia patients' stories can be believable.

"It happens in doctors' offices all the time," says Beth Kallmyer, vice president of constituent services at the Alzheimer's Association. That's why it's crucial that family members are part of the screening process.

The diseased brain may not be able to pull up a recent memory, but longer-term memories remain, she explains. So an intricate description of, say, cooking last night's dinner may ring true because it was a real dinner, just not last night's.

And a long-married couple in a familiar routine and surroundings can appear far more normal than they really are - until something upsets that balancing act, like the caregiving spouse getting sick, adds Dr. Gary Kennedy, geriatric psychiatry chief at New York's Montefiore Medical Center.

How to get around the hidden-dementia conundrum?

-Medicare's new annual wellness visit pays for cognitive screening, simple tests that signal who should be referred for more extensive brain exams. "Even if primary-care physicians don't consider themselves experts at evaluating for Alzheimer's disease, or don't feel comfortable, they can screen," Kallmyer says.

-The government's Alzheimer's advisers want doctors to steer families toward advanced-care planning, including designating a health care power of attorney, as soon as dementia is diagnosed. Montefiore's Kennedy says early diagnosis gives patients a say in how they want to be cared for while they're still capable of making those decisions.

-A health care proxy won't be used until the person is quite sick. So Kallmyer advises also signing what's called a "release of information"

allowing the doctor to discuss the person's care with whoever is named right away.

Such steps are important, Kennedy says, because advancing dementia leaves people so unaware of their deficits that they can take family or doctor input "as an affront." He always asks new patients if he can fill in their loved ones, or invite them in from the waiting room, as a way of starting that conversation.

-Doctors can violate patient confidentiality if they believe the person's decisions or behavior has become a danger, Kennedy notes.

McKenzie says her father would never discuss naming a health care proxy and her parents were furious that she'd voiced concerns to their physician. She had to think up non-confrontational ways to get invited back into their doctor visits: "I'll drive you, and then why don't I take notes in case you have any questions later?"

It turned out that McKenzie's father had a non-cancerous brain tumor causing his own gradual dementia symptoms, which started becoming apparent with the phone mix-up, unrefrigerated food and eventually delusions. Finally, she had to go to court to get her parents the care they needed in an assisted living facility near their hometown.

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