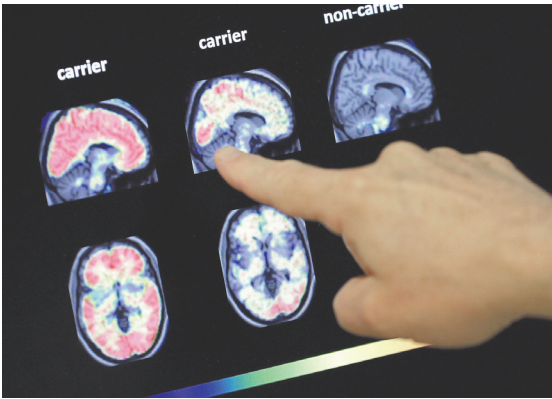


CNHI SPECIAL REPORT: DEMENTIA DEVELOPMENTS

CARING FOR FAMILY

In this photo from July, Indiana Rep. Greg Porter cares for his 94-year-old mother, S. Carmen Porter, who has Alzheimer’s Disease. The legislator from Indianapolis is one of the over 11 million Americans who provide unpaid care for a loved one suffering with dementia. In 2022, unpaid caregivers provided an estimated 18 billion hours of care valued at \$339.5 billion, according to the Alzheimer’s Association. (Photo: Richard Sitler, CNHI News Indiana)



DEMENTIA DEFINED

Dementia is not a single disease. It’s an overall term — like heart disease — that covers a wide range of specific medical conditions. Here’s a look at some of the forms of the disease and their symptoms.

Alzheimer’s disease: The most common cause of dementia, accounting for 60-80% of all cases. The most common early symptom is difficulty remembering newly learned information. Symptoms eventually grow severe enough to interfere with daily tasks. **How many affected:** An estimated 6.7 million Americans age 65 and older.

Creutzfeldt-Jakob Disease (CJD): The most common human form of a group of rare, fatal brain disorders known as prion diseases. The disease causes a type of dementia that gets worse unusually fast. **How many affected:** 1 million people annually worldwide.

Dementia with Lewy bodies (DLB): A type of progressive dementia that leads to a decline in thinking, reasoning and independent function. Its symptoms can include spontaneous changes in attention and alertness, recurrent visual hallucinations, REM sleep behavior disorder and tremors or rigidity. **How many affected:** An estimated 1 million Americans.

Huntington’s disease (HD): A progressive brain disorder caused by a defective gene. This disease causes changes in the central area of the brain, which alter movement, mood and thinking skills. **How many affected:** About 30,000 in the U.S.

Korsakoff syndrome: A chronic memory disorder caused by severe deficiency of thiamine (vitamin B-1). It is most commonly caused by alcohol misuse, but other conditions also can cause the syndrome. **How many affected:** No estimates available.

Mixed dementia: A condition in which brain changes of more than one cause of dementia occur simultaneously. It is most commonly a combination of Alzheimer’s and vascular dementia. **How many affected:** Data isn’t available.

Parkinson’s disease dementia: A decline in thinking and reasoning skills that develops in some people living with Parkinson’s at least a year after diagnosis. **How many affected:** About 500,000 Americans.

Vascular dementia: A decline in thinking skills caused by conditions that block or reduce blood flow to various regions of the brain, depriving them of oxygen and nutrients. Vascular thinking changes can range from mild to severe. **How many affected:** Roughly 15%-20% of all people suffering dementia in North America and Europe.

FACTS & FIGURES

- About 6.7 million Americans age 65 and older are living with Alzheimer’s dementia. 73% are 75 or older.
- Of the total U.S. population, about 1 in 9 people (10.8%) age 65 and older has Alzheimer’s dementia.
- By 2025, the number of people age 65 and older with Alzheimer’s dementia is projected to reach 7.2 million — a 7% increase from 2023.
- By 2060, the number of people age 65 and older with Alzheimer’s dementia is projected to reach 13.8 million, barring the development of medical breakthroughs to prevent, slow or cure the disease.
- Between 2000 and 2019, the number of deaths from Alzheimer’s disease more than doubled, increasing 145%, while deaths from the No. 1 cause of mortality (heart disease) decreased 7.3%.

TIMELINE

1906: Dr. Alois Alzheimer first describes “a peculiar disease” after conducting a brain autopsy that found dramatic shrinkage and abnormal deposits in and around nerve cells.

1910: Emil Kraepelin, a German psychiatrist who worked with Dr. Alzheimer, first names “Alzheimer’s Disease” in his book *Psychiatrie*.

1968: Researchers develop the first validated measurement scale for assessing cognitive and functional decline in older adults.

1976: Neurologist Robert Katzman identifies Alzheimer’s disease as the most common cause of dementia and a major public health challenge.

1984: The National Institutes of Health begins funding its network of Alzheimer’s Disease Centers at flagship medical institutions, establishing a nationwide infrastructure for research, diagnosis and treatment.

1993: The Food and Drug Administration approves tacrine (Cognex) as the first drug specifically targeting Alzheimer’s memory and thinking symptoms. Four additional drugs are approved over the next 10 years.

2017: Historic \$400 million increase for federal Alzheimer’s disease research funding signed into law, bringing annual funding to \$1.4 billion.

2021: Aducanumab receives accelerated approval as a treatment for Alzheimer’s disease by the U.S. Food and Drug Administration, becoming the first FDA-approved therapy to address the underlying biology of Alzheimer’s disease.

2023: The full approval of the drug Leqembi offers doctors, for the first time, prescription medicine that has been proven to slow the loss of memory and ability to do daily tasks associated with Alzheimer’s.

DID YOU KNOW?

Here’s a select list of famous people affected by dementia:



Charlton Heston



Evelyn Keyes



Sugar Ray Robinson



Tom Seaver



Ronald Reagan



Rita Hayworth



Pat Summitt



Jerry Sloan



Jack Hanna



Bill Buckner

Source: Brevard Alzheimer’s Foundation

RESOURCES

ALZNavigator: Will guide you to the resources and tools you need throughout each step of the disease.

The Knight Family Dementia Care Coordination (DCC) Initiative: Connects individuals and their families to free resources and helps to create a customized care plan.

Local Alzheimer’s Association offices: Face-to-face support groups and educational programs, many geared toward informing and empowering individuals in the early stage. Call 800-272-3900.

TURNING POINT

Newly approved drug slows cognitive decline

CARSON GERBER
CNHI NEWS SERVICE

A breakthrough. A game changer. The dawn of a new era.

The drug Leqembi won those accolades from some researchers in July when the Food and Drug Administration fully approved it as the first “disease-modifying” treatment for Alzheimer’s.

Its development traces back to 2021, when clinical trials demonstrated another drug called aducanumab slowed the progression of Alzheimer’s-inducing amino acids in the brain that lead to cognitive decline.

That research was conducted by the companies Eisai and Biogen and laid the groundwork for Leqembi, which they developed to treat dementia using a similar method.

Aducanumab has been under conditional approval by the FDA since 2021 as the manufacturers carry out more studies to confirm the drug actually does what is claimed. Leqembi received that conditional approval in January, but just seven months later became the first fully approved Alzheimer’s treatment in history.

Before now, dementia medications addressed only the symptoms of the disease, not the underlying conditions that cause it.

That includes often-prescribed drugs like donepezil, rivastigmine and galantamine, which have all been FDA approved for decades. The medications prevent a key brain-functioning enzyme from breaking down and temporarily alleviate or stabilize some symptoms of Alzheimer’s.

Other drugs such as brexpiprazole address non-cognitive issues, like agitation, that come with the disease. The pill suvorexant helps treat dementia-related insomnia.

Legembi is different, but it isn’t a cure. Clinical trials have demonstrated it modestly slows cognitive decline when taken in the early stages of the disease. The IV treatment is administered twice monthly.

Still, it marks a major turning point in fighting the underlying causes of Alzheimer’s, according to Rebecca Edelmayer, senior director of scientific engagement for the Alzheimer’s Association.

“We do think it’s a major breakthrough,” she said. “It’s really going to shift how we



actually treat Alzheimer’s disease moving forward.”

The drug comes with serious risks. It can cause brain bleeding and swelling. The FDA included a boxed warning in Leqembi’s label to raise awareness about specific side effects among at-risk populations.

The labeling will help ensure clinicians monitor patients’ safety closely, noted Maria Carrillo, chief science officer for the Alzheimer’s Association.

“However, the boxed warning should not keep clinicians and patients from having the conversation about the benefits and risks of approved treatment options,” she said.

Once the drug won full approval in July, Medicare immediately began covering the \$26,500-a-year treatment. That’s an about-face for the Centers for Medicare & Medicaid Services, which last year issued an unprecedented decision that all but denied coverage of drugs like Leqembi.

Now, the government is setting extra requirements for those receiving the medication through the federal insurance for those 65 and older, including enrollment in a federal registry to track the drug’s real-world safety and effectiveness.

Some Medicare patients could also be responsible for paying the standard 20% of the cost, or \$6,600 a year, though the amount will vary depending on their plans and other coverage details.

The caveats attached to the medication still don’t shadow the momentous achievement marked by the approval of the drug, according to Edelmayer.

“We know that these new treatments are unlikely to be the sole answer. ... But we do believe that it will be a very powerful component of how we effectively treat Alzheimer’s disease,” she said.

ALZHEIMER’S DRUGS

Aducanumab: Intravenous infusion therapy approved for early Alzheimer’s disease, including mild cognitive impairment (MCI) or mild dementia.

Lecanemab: Antibody intravenous infusion therapy approved for early Alzheimer’s, reduces cognitive and functional decline.

Cholinesterase inhibitors: Treats symptoms related to memory, thinking, language, judgment and other thought processes. Includes Donepezil, Rivastigmine and Galantamine.