

# The Other Pandemic: What to Do About the Coming Alzheimer's Crisis

By [Reshma Kapadia](#) Updated February 7, 2021 / Original February 5, 2021



Illustration by Jess Suttner

When Covid-19 hit, Rosanne Corcoran went into lockdown mode, creating a cocoon around her family and dismissing the part-time paid caregiver who had helped her care for her mother, Rose, who has Alzheimer's. But for months, Rose has stayed up all night, leaving the 53-year-old Rosanne so sleep-deprived that her cardiologist recently counseled her to look past her fears about the virus and bring in help.

Rose was first diagnosed with mild cognitive impairment a decade ago. When, in 2015, doctors said she could no longer live independently, Corcoran put her Realtor license in escrow and brought Rose to live with her family outside of Philadelphia. The mother of two young adults snuck in a couple hours of normalcy to run errands, go to the chiropractor, or take a walk, with the help of a regular paid caregiver—until Covid-19 hit. Doing without the additional help has taken its toll. "My mother has declined, and I've declined. It's an awful choice to have to make, but I'm going to, because I want to survive this," says Corcoran, who just rehired a caregiver for weekend help, despite the pandemic.

Families grappling with Alzheimer's often face awful choices, but it has been taken to new heights over the past year. Roughly a third of the 450,000 Covid deaths in the U.S. have been at long-term care facilities like nursing homes, where about half of the residents are living with Alzheimer's or some other form of dementia. Even those who have been safe from the virus have suffered; 70% of caregivers surveyed by UsAgainstAlzheimer's this past fall reported a decline in their loved ones' memory or behaviors. Residents in long-term care facilities have been isolated from relatives and

friends who supplement their care, provide extra eyes that spot changes in health conditions, and tap into reservoirs of memories to keep them engaged, while unpaid caregivers like Rosanne have been cut off from support services.

The pandemic has cast a harsh light on the inadequacies of the U.S. caregiving system and the enormous emotional and economic burden on families—and ultimately the economy—bringing the fight against Alzheimer’s to an inflection point. It comes as the oldest baby boomers enter the age range where Alzheimer’s is often diagnosed, and against a backdrop where science could be on the cusp of sorely needed victories—including the possibility of the first new drug approval in 18 years, and progress in biomarkers to enable earlier detection.

[READ MORE](#)

### **From the Front Lines: A Doctor Talks About the Fight Against Alzheimer’s**

### **Biogen’s Alzheimer’s Drug Faces a Big Test**

### **What to Do if a Loved One Is Diagnosed With Alzheimer’s**

### **Futures Rise Ahead of Another Busy Earnings Week**

Alzheimer’s is a progressive brain disease that is the most common cause of dementia. Of the top 10 causes of death globally, it’s the only one that can’t be cured, slowed down, or prevented, at least not yet. The disease manifests in different ways, with some patients living 20 years after diagnosis, though it’s often closer to four to eight years. Although 80% of those with the

disease are 75 or over, Alzheimer’s typically emerges in midlife, 20 to 30 years before symptoms like memory loss or troubles with language appear.

With the world in the midst of an aging boom, the number of people living with Alzheimer’s or some form of dementia is expected to triple by 2050 to 152 million—a bit more than the population of Russia today. That is bringing recognition to the scale of the problem, with nonprofits, academics, businesses, and governments in January creating a global initiative, Davos Alzheimer’s Collaborative, aimed at speeding up the global response to the disease, in part by using the road map offered by the discovery of Covid-19 vaccines.

“Alzheimer’s is a disease of greater prevalence and greater lethality than Covid-19,” says George Vradenburg, who co-founded the advocacy and research group UsAgainstAlzheimer’s. “This is an ongoing pandemic. Its cost to America in terms of direct medical costs is significantly higher than cancer.”

Cost estimates vary, but a 2020 paper in American Journal of Managed Care put the total health-care cost of the disease at \$305 billion—and projected it would hit \$1 trillion by 2050. With few treatments available, most of the direct costs come from skilled nursing care, paid home health care, and hospice.

While some of this is covered by Medicaid for low-income Americans, most of it is not covered by Medicare, leaving families to foot the bill. The total lifetime cost of care for someone with dementia is estimated at \$357,000 in 2019 dollars, according to the Alzheimer’s Association. The bulk of those costs are borne by family caregivers, often in the form of unpaid caregiving—not to mention the psychological and emotional toll.



Illustration by Jess Suttner

# Alzheimer's is a disease of greater prevalence and greater lethality than Covid-19."

— George Vradenburg, co-founder, UsAgainstAlzheimer's

For Stephanie Monroe, the uncertainty, confusion, and fear around her parents' care during the past year have been the worst experiences of her life. Monroe, who retired from the federal government and now works on equity and access-related issues at UsAgainstAlzheimer's, has agonized over whether to find alternative housing for her parents. The Baltimore-area long-term care facility they live in had spotty communications about Covid-19 outbreaks and protocols, and there were signs that her father, who has Alzheimer's, was deteriorating as social activities like choir and mah-jongg were suspended. A move, though, would separate her parents from her aunt who lives in the community, as well as nearby church friends. "There's no good decision," Monroe says. "It's all about weighing the consequences, costs, and benefits—and feeling guilty about any decision you make."

The costs can ripple through generations, and not just due to lost wages or time out of the workforce for caregivers. Studies show that spousal caregivers who report strain face a 63% higher mortality risk in four years than noncaregivers who are the same age. Smaller studies also found that some caregivers have compromised immune systems and increased need for medications, and have seen their own health-care costs increase in the aggregate by an estimated \$9.7 billion. "The financial costs are underestimated. The emotional, psychological, and even physical costs are underestimated," says Amy Florian, CEO of Corgenius, which helps financial advisors navigate these issues with their clients. "It affects people in every respect."

Alzheimer's was recognized as the most common cause of dementia in 1976. In the 45 years since, progress in fighting the disease has been glacial, in part due to misperceptions about the disease that delayed funding and scientific research and created an inadequate care system in its early days.

"As a nation, we struggled to see the disease as a disease," says [Dr. Jason Karlawish](#), co-director of the Penn Memory Center. For decades, culturally, Alzheimer's symptoms—memory loss, confusion, or forgetting to pay bills—were brushed aside as just the natural course of aging, and problems that could be handled by family, almost always wives and daughters, Karlawish says.

With limited funding in the first 20 years, research was restricted primarily to how a brain with Alzheimer's changed, rather than to the multifaceted pathways that contribute to the disease, the factors that influence a person's risk, and devising cutting-edge clinical trials. Research talent was lost to diseases attracting more investment, says Dr. Maria Carrillo, chief science officer at the Alzheimer's Association. Even today, much of what is currently available is short-term palliative therapies that don't address the underlying biology of the disease.

“The complexity of the brain adds to the challenge. Because there isn't yet a solid understanding of why memory changes, the clinical trials for Alzheimer's take longer, often 18 to 24 months, because researchers need to see if the drugs move memory, rather than just look at underlying changes in the biology. Early trials were open to those who had a clinical Alzheimer's diagnosis. But now, trials include people with biomarkers like the amyloid plaques and tau tangles (both are forms of problematic protein deposits in the brain) that are now seen as hallmarks of Alzheimer's disease, and have been the target of many of the drugs in trial.

The past decade has brought change, partly due to the advocacy of organizations like the Alzheimer's Association and UsAgainstAlzheimer's. Funding for Alzheimer's and dementia research at the National Institutes of Health has increased to roughly \$3 billion, about half of what is spent on cancer, but far higher than the \$448 million allocated in 2011.

Drug development is also looking more promising; there are now more than 100 ongoing trials. More recent clinical trials for [Biogen's much-anticipated aducanumab](#) and [Eli Lilly's](#) antibody donanemab incorporated biomarker tests that earlier trials lacked. The near-term attention is on Biogen's monoclonal antibody aducanumab, which is awaiting a decision from the U.S. Food and Drug Administration, expected by June. It has been a bumpy road for the treatment, with an advisory panel of the FDA questioning the merits of aducanumab last fall.



Illustration by Jess Suttner

If approved, even with conditions, experts on aging say it will serve as a signal and bring in a rush of investment. A lack of approval could have the opposite impact in the near term, but researchers note several other treatments on the horizon, including drugs from Roche's Genentech and Japan's Eisai. Even more encouraging is the diversification of treatments deeper in the pipelines that go beyond amyloid and tau tangles—important because scientists think Alzheimer's will ultimately be treated much like heart disease, with a mix of therapies and interventions, or possibly a combination therapy.

There has also been progress around biomarkers and blood tests that could help with early detection—crucial since the disease can emerge decades before symptoms. “Ten years ago, we would have said it's science fiction: There's no way we can measure tiny proteins in the brain in blood,” Carrillo says. But C2N Diagnostics introduced a test last fall that has been tested on a small group, and Lilly and [Roche Holdings](#) also have tests, with trials possibly completed by summer and more information about whether they can be mass produced also forthcoming. “That would be game-changing,” Carrillo says.

With recent research suggesting that about [40% of dementia is modifiable](#), scientists are also testing how interventions around cognitive engagement, diet, sleep, and exercise could affect risk factors for Alzheimer's. That's another reason there's a push for doctors to make cognition tests part of their standard protocol: Currently, less than half of primary-care physicians in a survey by the Alzheimer's Association said it's part

of their standard practice. Technology could also facilitate earlier detection, with researchers looking to smartphones and artificial intelligence to pick up on subtle changes in keystrokes, typing speed, or writing patterns that could be early flags.

These scientific developments are reason for hope, but even biotech executives say that a cure is a ways away. As a result, care will continue to be at the center of Alzheimer's treatment, and fixing the U.S. caregiving system needs to be a top priority.

Unlike cancer or heart disease, much of the cost related to Alzheimer's disease comes from caregiving. Medicare doesn't cover most long-term care. Medicaid covers more, but requires near-impoverishment to qualify. The average annual Medicaid payment for those 65 and older with Alzheimer's is 23 times as high as for those without Alzheimer's—an annual average of \$8,779 versus \$374.

Caregiving typically is associated with helping older adults with feeding, bathing, grooming, or using a toilet, but those needs typically come in the last third of the disease. The first two-thirds are largely focused on helping Alzheimer's patients with daily life, including monitoring medicines and finances, transportation, and keeping them engaged and safe.

An army of family and friends—often women in their prime earning years—shoulder roughly two-thirds of the care for those with Alzheimer's. Many interrupt their careers, give up promotions, cut back on hours, or quit jobs. The average caregiver spends about five years on care for a dementia patient. That indirect cost can total roughly \$500,000 per person, based on models that account for lost wages, promotions, and benefits, as well as the obstacles most people face when trying to re-enter the workforce in their 50s or 60s, says Norma Coe, associate professor of medical ethics and health policy at the Perelman School of Medicine at the University of Pennsylvania.

The indirect costs are likely to be higher in the future, as a larger share of the next cohort of caregivers are primary breadwinners or single. The hit to their Social Security, for example, may be even greater than for some in the current cohort who may be able to claim spousal benefits on their higher-earning partner's record, says Coe. Rising female labor-force participation played a big role in the last economic recovery, especially as male labor participation has fallen. The absence of these women could further hamper economic growth.

Plus, fear of future long-term care needs for parents also weigh on their children's calculations about moving away and job choices, according to Coe. If parents have long-term care insurance to help cover such needs, adult children are more likely to move away and potentially take different jobs—suggesting that caregiving fears could also be restraining the type of mobility and productivity needed for a dynamic economy.

The financial costs can cascade through multiple generations as caregivers compromise their own finances and retirement security. At the local level, Medicaid budgets are crowding out investments in youth education. "We are seeing right before

our eyes the intergenerational impact,” Vradenburg says. Millennials make up a sixth of those caring for people with Alzheimer’s.

**“The financial costs are underestimated. The emotional, psychological, and even physical costs are underestimated.”**

— Amy Florian, CEO of Corgenius

The sheer number of baby boomers could outstrip available caregivers—including informal ones, since family sizes have been shrinking. With fewer daughters and sons able to care for aging parents, demand for long-term care facilities like memory care and assisted living will increase. Both are largely paid for out of pocket, raising questions of how families will digest those costs. The annual median cost of assisted living is about \$51,600, according to [Genworth’s Cost of Care survey](#). The median cost of assisted living facilities with memory care is even higher, at roughly \$57,000 a year.

With costs rising, demand for home and community-based services that can keep people independent longer and out of nursing homes will only intensify. Yet many of these services—such as adult day care—have been especially hard hit during the pandemic, with many forced to shutter because of lockdowns. Many of those that stayed open, meanwhile, have suffered a severe financial hit, says Kirsten Jacobs, director of Dementia and Wellness Education for LeadingAge, an association of nonprofit providers of aging services.

At some point, in the later phases of dementia, when people may get more agitated or their safety may be compromised, many Alzheimer’s patients will need round-the-clock care in a facility. Here, Florian worries about Covid’s lasting impact: “I fear that stigma is going to increase and persist after Covid because of what happened during the pandemic with people in facilities.”

Long-term care facilities could also come out financially scarred: Two-thirds of nursing-home providers in a recent survey from the American Health Care Association and National Center for Assisted Living said they won’t make it another year, given Covid-related costs. The pandemic has also thrown into question the business model of nursing homes relying on the short-term rehab stays that Medicare covers for those just out of the hospital to subsidize the long-term care these facilities provide for those on Medicaid, as fewer people have elected to get surgeries and the rehab business has dried up during the pandemic.

“This is our opportunity to really be thinking about how and where we can care for people at the lowest cost and get the best outcomes—lowering Medicare and Medicaid costs but also the cost to the family,” says Coe.

That will require investing in long-term care infrastructure. Near the top of the list is focusing on supportive services that ultimately can save money by keeping people at home longer, says Nora Super, senior director of the Milken Institute Center for the Future of Aging.

President Joe Biden’s agenda includes money for increased access to home and community-based services, funding for states to innovate more-creative and cost-effective ways of providing care, as well as tax credits for informal caregivers and increased tax benefits to buy long-term care insurance with retirement savings. Experts on aging want to see more investment in resources such as adult day facilities, training nurse practitioners to become dementia-care specialists, and creating dedicated teams that can help families navigate the web of specialists, clinical trials, and services.

Technology will also play a big role, and not just with telemedicine. Technology can provide a range of monitoring that allows for independence but alerts caregivers when needed. Sensors in rooms could mitigate physical danger, while software that can help monitor bill-paying or bank accounts could help, since impaired money-management skills are among the first visible symptoms.

Also high on the priority list: rethinking the value of caregivers. Many paid caregivers at long-term care facilities hold multiple jobs and have long commutes to work—both of which have made the entire system vulnerable during Covid. It has also contributed to incredibly high turnover and shortages in an overstretched industry. “The pandemic made it clear that how we pay caregivers isn’t adequate,” Super says. “We need to make sure we are paying them living wages and offering a career ladder to make this an industry they want to be part of. That’s going to take government intervention.”

Considering ways to compensate the army of informal caregivers that provide the bulk of care for Alzheimer’s patients also needs attention; proposals like paid eldercare leave and Social Security credits for caregiving could slow the intergenerational ripples created by the disease. Also on the table: ways to save for, and possibly insure against, the long-term care risk. For example, the bipartisan [Homecare for Seniors Act](#) introduced in the House in 2019 could be revived, potentially allowing home care to be considered a qualified expense that could be paid for by health savings accounts.

“There are models out there. It’s about the will to put them in place and recognize this is a big challenge that could really bankrupt our system,” says Super. “What gives me hope is that the pandemic has raised awareness of how the system is broken.”

**Write to** Reshma Kapadia at [reshma.kapadia@barrons.com](mailto:reshma.kapadia@barrons.com)

---

DAVOS

# The Covid-19 Vaccine Offers a Road Map for Tackling Dementia. Here's How.

By [Reshma Kapadia](#) Updated Jan. 25, 2021 12:37 pm ET / Original Jan. 25, 2021 6:00 am ET



Dreamstime

Though much of the world is still trying to get the coronavirus pandemic under control, the World Economic Forum on Monday launched a global initiative with governments, nonprofits, academics and the private sector aimed at accelerating the global response to another global public health crisis: Alzheimer's disease.

The initiative, called the Davos Alzheimer's Collaborative, will try to link discovery research, clinical trials and health system preparedness to tackle Alzheimer's disease, the most common form of dementia.

By 2050, dementia is likely to affect 150 million families globally—triple the number today—as much of the [world experiences an aging boom](#). It's the seventh leading cause of death globally, with an economic cost to the world of \$1.25 trillion that [falls heavily on families](#). Yet, there have been no new drugs on the market in 15 years for Alzheimer's.

"With that extent of suffering, what else can we call Alzheimer's but a global pandemic," said George Vradenburg, chairman and co-founder of advocacy and research-focused organization UsAgainstAlzheimer's at an online briefing about the initiative he helped put together. "There's new hope on the horizon, and it's time for the world to seize the opportunity to tackle this disease at the scope and scale at which it is attacking us."

The coalition follows the models provided by public-private health and health-care partnerships like the Global Alliance for Vaccines and Immunization (GAVI), and the Coalition for Epidemic Preparedness Innovation (CEPI). Both of the partnerships have worked with the World Health Organization to get two billion doses of the [Covid vaccine](#) for low- and middle-income countries.

The hope is the coalition can bring to Alzheimer's the attention GAVI and CEPI have brought to Covid and other infectious diseases. The new global initiative focuses on three main areas: building a global research platform with detailed data on a diverse population, efforts to create a global clinical trial network and a bid to invest and spark innovations that will help prepare health systems to detect, diagnosis and treat Alzheimer's. The initiative has a six-year, \$700 million budget, about [in line](#) with GAVI and CEPI.



While a cure for Alzheimer's may still be a long stretch away, a world where earlier diagnosis of the disease may not be as far away, said Biogen Chief Executive Michel Vounatsos at another online briefing on the Davos initiative on Monday.

Though considered a disease of old age, science has shown that Alzheimer's emerges in midlife, often 20 or more years before symptoms, making early detection crucial.

"We know that future disease modifying treatments will be more effective—and cost-effective—if diagnosis happens earlier," said Vounatsos. Biogen (ticker: BIIB) is awaiting a decision from the Food and Drug Administration for its aducanumab treatment; an approval would make it the first Alzheimer's drug to get approved in 15 years. Vounatsos said Biogen is also working with Apple (AAPL) on finding potential digital biomarkers that could help detection. The aim of disease modifying therapies and other interventions is to help patients stay independent longer by improving their activities of daily living, he added.

That optimism was echoed by Dr. Andrea Pfeifer, chief executive of Swiss biotech AC Immune (ACIU), during the online briefing. Pfeifer cited the 121 clinical trials and the learnings about biomarkers that allow selecting patients 10 to 20 years before symptoms occur for prevention studies and the possibility of using precision medicine, as is used in cancer, to change the paradigm for Alzheimer's treatment. Doing so, Pfeifer says, requires cooperation between industries and others to find the right biomarkers and to create possible combination therapies. "We are at the crossroads of the breakthrough we had in cancer 35 years ago," Pfeifer said.