

# For Down syndrome adults, death and dementia often come together

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(HealthDay)—Seven in 10 people with Down syndrome show evidence of dementia when they die, new research from Britain reveals.

"The link between Down syndrome and Alzheimer's disease has been known for some years now," explained study author Rosalyn Hithersay, a doctoral candidate in the department of forensic and neurodevelopmental science at King's College London.

The link may boil down to a specific protein that both conditions share, she explained.

Down syndrome often comes with intellectual and developmental disabilities, and [patients](#) are at risk for a number of health issues. "Down syndrome is a genetic condition caused by having an extra copy of chromosome 21," Hithersay explained. "On this chromosome, there is a gene—the [amyloid precursor protein](#), or APP gene—which controls the production of a protein called amyloid."

Sticky clumps of that very same protein accumulating in the brain is a well-known characteristic of Alzheimer's, Hithersay added. "All adults with Down syndrome will have lots of these plaques in their brain," she said, even if not all go on to develop early signs of dementia.

That said, many will. In fact, the study team found that 70 percent of the Down syndrome patients who died during the 5.5-year study period had dementia.

And "we found that people who had two or more other health conditions developed dementia earlier," Hithersay added. "So it is vital that common health conditions are given appropriate attention and treatment in these older adults."

Fifty years ago, [life expectancy](#) was typically just 10 years among Down syndrome patients, the researchers said. Often, deaths occurred within the first year, as a consequence of congenital heart defects.

But better care has extended [average life expectancy](#) to nearly 64, with respiratory illness the main cause of death.

But longer life expectancy has yielded a new problem: early onset dementia.

"People with Down syndrome are at increased risk of developing Alzheimer's disease dementia at a younger age, approximately 20 years earlier in life, as compared to the general population," noted Hithersay.

Investigators peg the average age of dementia onset at 55, with upwards of nearly 90 percent of patients receiving a dementia diagnosis by the time they hit 65.

But to what degree premature death among Down syndrome patients is directly linked to early onset dementia has remained an open question.

To explore the issue, investigators tracked 211 British Down syndrome patients. All were 36 years old and up, and nearly a third were diagnosed with dementia prior to the study's launch, at an average age of almost 52.

By the study's conclusion, 27 patients had died. Of these, 19 had dementia. Investigators determined that those with dementia were five times more likely to die early than those without dementia.

Among those who died seemingly dementia-free, epilepsy appeared to be the only "significant factor" implicated. The [team](#) theorized that some of them may in fact have struggled with undiagnosed dementia.

The findings were published online Nov. 19 in the journal *JAMA Neurology*.

Dr. Michael Rafii is medical director of the Alzheimer's Therapeutic Research Institute at the Keck School of Medicine of University of Southern California in San Diego. He wrote an editorial that accompanied the study.

"The findings from this study highlight the urgent need for research into treatments to prevent or delay" Alzheimer's in Down syndrome patients, Rafii said.

"With advances in [medical care](#) and improvements in the overall health of individuals with [Down syndrome], life expectancy has increased dramatically," Rafii noted. "However, along with this longer life span comes the prospect of an increased risk for of developing dementia due to Alzheimer's disease."

But, "although most people with Down syndrome will experience brain changes associated with Alzheimer's disease as they age, not everyone will develop [dementia](#), and it is not inevitable for all," Rafii stressed. "This is an important phenomenon and needs much further study."

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Michael Rafii, M.D., Ph.D., medical director, Alzheimer's Therapeutic Research Institute, and associate professor, neurology, Keck School of Medicine, University of Southern California, San Diego; Nov. 19, 2018, *JAMA Neurology*, online. [jamanetwork.com/journals/jaman.../jamaneurol.2018.3616](http://jamanetwork.com/journals/jaman.../jamaneurol.2018.3616)

The U.S. National Institute of Child Health and Human Development has more on [Down syndrome](#).

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