

Alzheimer's disease in Down syndrome: effective treatments depends on research

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Additional funding and support is required to build and expand the infrastructure to conduct prevention trials of treatment that could transform the prospects of older individuals with Down syndrome, and potentially help other people at risk of Alzheimer's disease as well.

People with Down syndrome have been increasing their life expectancy compared to their peers 50 years ago, and 40% of individuals with Down syndrome in Europe are currently aged 40 years and older. There is an estimated ~500,000 (6.4/10,000) individuals with Down syndrome living in Europe. Down syndrome individuals experience the highest burden for Alzheimer's disease of all the population groups in Europe today, affecting their quality of life and life expectancy, and the quality of life of their carers.

Older individuals have an ultra-high risk for dementia due to Alzheimer's disease; recent estimates suggest a lifetime risk of ~90%. The average age of dementia diagnosis in Down syndrome individuals is 55 years, much earlier than for the general population. In many individuals, cognitive decline such as memory problems may already be observed after age 40 years and Alzheimer's diagnoses increase from 9% to 23% between the ages of 35 and 49 years, to 55% in those between 50 and 59 years. 75% of persons who live beyond the age of 60 years may be affected. Furthermore, Alzheimer's disease is now the main cause of death in adults with Down syndrome.

Because of the predictable and high rate of Alzheimer's disease, clinical trials of preventive treatment can potentially be conducted very efficiently in Down syndrome individuals.

Numbers of people that need to be included in such trials will be much smaller and therefore more affordable than in the general population. Researchers in Europe have developed the clinical tools to track the development of memory problems in people with Down syndrome, and we have also been the first to identify blood and imaging biomarkers that is associated with onset of dementia. We have established a clinical trials consortium (Horizon 21 consortium, funded by the LeJeune Foundation) in readiness for new treatment options for Alzheimer's in Down syndrome.

Alzheimer's disease has become the most pressing health concern in aging populations, and there are currently no effective treatments available to reduce cognitive decline due to the disease. There are new treatments being developed or tested; these typically target the underlying disease processes, including amyloid or tau protein deposits. So far, results of early trials have been disappointing. It is now believed that disease-modifying treatments (that is, treatments that can stop or delay the development of Alzheimer's disease) may only be effective during the early phases of disease, before people have significant symptoms. However, conducting trials of treatment that could prevent onset of disease at such an early stage is not possible in the general population, because it is not possible to predict who are most at risk. But we can do such trials in people with Down syndrome if the potential treatment(s) have an appropriate safety profile.

Additional information:

1. <https://alz-journals.onlinelibrary.wiley.com/doi/full/10.1016/j.trci.2018.10.006>
2. [https://www.thelancet.com/journals/laneur/article/PIIS1474-4422\(18\)30285-0/fulltext](https://www.thelancet.com/journals/laneur/article/PIIS1474-4422(18)30285-0/fulltext)
3. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5683343/>
4. <https://www.t21rs.org/>