

BRUCE WILLIS FAMILY ANNOUNCEMENT – 2/16/2023



KEY TALKING POINTS

About the Announcement

- On February 16, 2023, the Bruce Willis family announced that Bruce Willis has received a diagnosis of frontotemporal dementia (FTD). The announcement, along with resources and an AFTD statement in response, are available on [our website](#).
- AFTD applauds the family for publicly coming forward with their FTD story. They are bringing newfound awareness to FTD, likely making it easier for families to get an accurate diagnosis and quicker access to targeted support more easily during this time.
- The family has asked that Bruce's and their privacy be respected during this time. AFTD does not have specific information about Mr. Willis's symptoms, and it isn't our place to offer perspective on those.
- When talking about this news, please don't speculate about specific behavioral symptoms that Bruce Willis may be experiencing. Please keep any discussion of FTD symptoms either generalized or specific to your experience.
- Instead of speculating about details of his condition, we would ask that the press focus on bringing new awareness to a terminal form of young-onset dementia that impacts tens of thousands of Americans and many more around the world... and on its vital responsibility to inform the public about ongoing efforts to address this disease.
- The stigma around every form of brain disease is a barrier that prevents timely diagnosis and access to available support for many individuals and their families. In breaking that stigma, every FTD story counts.
- If you have personal connection to FTD we encourage you to share as much information as you are comfortable sharing publicly about your FTD journey.
- Recommended hashtag for solidarity: **#SupportBruceWillisFTD**
- Recommended hashtag for FTD awareness: **#EveryFTDStoryCounts**
- Recommended hashtag for research/hope: **#EndFTD**



About FTD

- FTD (frontotemporal dementia or frontotemporal degeneration) is the most common dementia for people under 60.
- Onset can happen as early as someone's twenties, with the majority of cases occurring between 45 and 64.
- FTD is not the same as Alzheimer's. It affects different parts of the brain and generally causes changes to a person's behavior, personality, language, and/or movement. Memory usually remains intact, at least at first.
- FTD actually represents a group of brain disorders – including behavioral variant FTD, primary progressive aphasia, FTD with ALS, progressive supranuclear palsy, and corticobasal degeneration.
- FTD affects an estimated 50,000 – 60,000 people in the U.S., but experts believe that number is low, due to how difficult it is to diagnose.
- Because doctors typically don't expect dementia in younger people, FTD is often misdiagnosed as depression or a similar condition. Additionally, many healthcare professionals simply don't yet know about FTD. As a result of these challenges, diagnosing FTD takes 3.6 years on average.
- There is currently no cure for FTD, and there are no approved disease-modifying treatments.
- Today, FTD is always fatal – a reality we are working every day to change. While the length of progression ranges from two years to two decades, the average life expectancy following diagnosis is 7 to 13 years.
- Researchers are advancing our understanding of FTD every day. Multiple potential treatments are currently in clinical trials, providing hope that approved therapies are on the horizon.

About AFTD

- AFTD (The Association for Frontotemporal Degeneration, online at theaftd.org) is the country's leading nonprofit focused solely on FTD. We fund research, answer questions via our HelpLine, provide medically accurate information, train FTD support group leaders, and educate healthcare professionals and the general public about this disease.
- Founded by volunteers, our work is made possible by thousands of individual donors across the country. We are a community-driven organization, and we're here to help.