

# Coverage of Bruce Willis' frontotemporal degeneration shows media misconstrues the disease

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A new paper in *Innovation in Aging* shows that a great deal of media coverage of the actor Bruce Willis' condition, frontotemporal

degeneration, was inaccurate, revealing the public's limited knowledge of the disease.

In 2022, Willis' family released a statement saying that he had been diagnosed with aphasia, an acquired language impairment, and would retire from acting. Ten months later, the family issued another statement indicating doctors had diagnosed Willis with a more specific condition, frontotemporal degeneration. This resulted in an explosion of media coverage, as prominent news outlets produced stories describing frontotemporal degeneration to a public largely unfamiliar with the disease. The quality of these stories varied widely, and in many cases journalists misrepresented basic descriptions and facts about the relationship between aphasia and frontotemporal degeneration.

Confusingly, aphasia is a cognitive syndrome referring to the presence of language impairments, rather than a neuropathological diagnosis that relates to the underlying source. Aphasias can be caused by different things, the most common are [neurodegenerative diseases](#) and brain lesions due to strokes or tumors.

Rather than describing how frontotemporal degeneration was discovered to be the underlying source of Willis' aphasia, many reports described his aphasia as "progressing into" frontotemporal degeneration, implying they are two different disorders. The official statement from the actor's family described the relationship between aphasia and frontotemporal degeneration accurately: frontotemporal degeneration was a more specific diagnosis of the cause of the aphasia suffered by Willis. When paraphrased by news anchors on multiple television shows that evening, however, the relationship was re-worded in a misleading way.

As Norah O'Donnell put it on CBS evening news: "His family says that has progressed into frontotemporal dementia, which impacts personality, behavior, and language." Similarly, Entertainment Tonight reported that

the family "... revealed that his brain disease has progressed to frontotemporal dementia." This is inaccurate. His aphasia did not *turn into* frontotemporal degeneration. His aphasia was a symptom of frontotemporal degeneration and after ten months his doctors had figured out the underlying condition. The relationship is roughly analogous to that between high cholesterol and something like chronic kidney disease. A patient with high cholesterol may have chronic kidney disease, but the high cholesterol doesn't progress to [chronic kidney disease](#).

Why did journalists make this mistake? The paper speculates that aphasia developing into something else made for a better narrative: an esoteric and complicated story about diagnostic clarification is not nearly as interesting as a story of as one about a movie star suffering further hardship.

The paper also notes that the term "[frontotemporal dementia](#)" may also have led to confusion. "Dementia" invokes many unpleasant connotations in the public imagination, which may have shaped the [news coverage](#). In fact, the [nonprofit organization](#) that provides information and support to those affected by Willis' condition, the Association for Frontotemporal Degeneration, removed the word "dementia" in its name back in 2011, preferring the work "degeneration" instead.

"Last year, Bruce Willis' family released a statement saying he had to retire from acting due to impairments in language, known as [aphasia](#)," said the paper's lead author, Robert Hurley. "Earlier this year, Mr. Willis' family released another statement saying that he had received a more specific diagnosis of frontotemporal degeneration. These disclosures resulted in an explosion of media coverage, drawing valuable attention to frontotemporal degeneration, while also exposing the media and general public's unfamiliarity with the disease."

"Given the confusion surrounding frontotemporal [degeneration](#), the courageous disclosure by the Willis family is a model for educating the public about this still hidden disease," said Steven M. Albert, the editor-in-chief of *Innovation in Aging*, which published the paper.

The paper, "The Media Coverage of Bruce Willis Reveals Unfamiliarity with Frontotemporal Degeneration," is available at <https://academic.oup.com/innovateage/advance-article/doi/10.1093/geroni/igad125/7330314>.

**More information:** Robert S Hurley et al, The Media Coverage of Bruce Willis Reveals Unfamiliarity with Frontotemporal Degeneration, *Innovation in Aging* (2023). [DOI: 10.1093/geroni/igad125](https://doi.org/10.1093/geroni/igad125)

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