

LIVING WITH HOPE: HOW FERMANAGH MAN HAS LEARNED

EXCLUSIVE
BY ROISIN
GORMAN



DEMENTIA champion Davie McElhinney says Hollywood superstar Bruce Willis can build a new life with the condition.

Davie, who has the same form of dementia as the actor, says there's no doubt Willis has been robbed of opportunities.

The Die Hard star retired from the big screen last year after developing language issues, and his family told the world recently he'd been diagnosed with frontotemporal lobe dementia (FTD).

But campaigner Davie, from Fermanagh, says their openness will help Willis, as well as the people who are quietly coping with the bombshell diagnosis.

"It's shocking in the career he's had and it's shocking now in this stage of life. It's robbed him of everything," says the dad of two.

"There's still a person there, but breaking the stigma and education is the big thing."

The 67-year-old star announced last March he was giving up acting after struggling with aphasia, a language disorder which affects how people communicate, and can leave them struggling to find everyday words.

RELIEF

Wife Emma Heming and his ex, Demi Moore, revealed in a family statement last month that he'd been diagnosed with FTD and described the family's relief at having a diagnosis.

"We know in our hearts that - if he could today - he would want to respond by bringing global attention and a connectedness with those who are also dealing with this debilitating disease and how it impacts so many individuals and their families," said the statement.

Emma, who has two daughters with Bruce, has since asked the paparazzi not to yell at the star in the street in case it causes him distress and has reached out to other dementia carers for advice.

Davie, who turns 60 next week, was just 54 and working full time as a chef when he got his diagnosis. He says support is key for people with dementia and Willis' family are doing the right thing.

He has the behavioural variant of the condition, which affects the ability to plan, solve problems and focus on a task, while the actor has primary progressive aphasia, which as well as communication will impact his ability to recognise familiar faces and objects.

"In my case the family realised it, but I was in denial," says Davie.

His memory issues came to a head when he couldn't find his car in a supermarket

SCREEN ICON: Hollywood star Willis

MY MESSAGE TO BRUCE WILLIS: THERE IS A LIFE AFTER DEMENTIA

car park and was referred to the memory clinic.

"It took me the guts of a year to come to terms with it personally. Just that it had happened to me and I didn't see much of a future. Pure denial was holding me back at that time. I really thought I had weeks to live," he says.

STRUGGLING

"Thankfully my family have been very open to it and know the pace I go at sometimes and just go along with it. My son and daughter look out for me, and my wife Alison.

"Try and support the person and if they're struggling just try and nudge them. Don't contradict or question them or don't put people over things. If I can't

remember something, they leave it at that.

"Just go with the person and get as full an understanding as you can of the condition and what it entails."

He turned a corner after reaching out to Dementia NI, and now sits on its board. Davie has also become a regular at the Men's Shed in Lisnaskea in Fermanagh and says while he's lost his love for TV and reading newspapers, he's found a new passion in model building, puzzles, swimming and music.

The campaigner says brain fog and frustration can be an issue for people like himself and Willis but getting the right help and being open about the condition is life-changing.

"At Dementia NI it's all peer

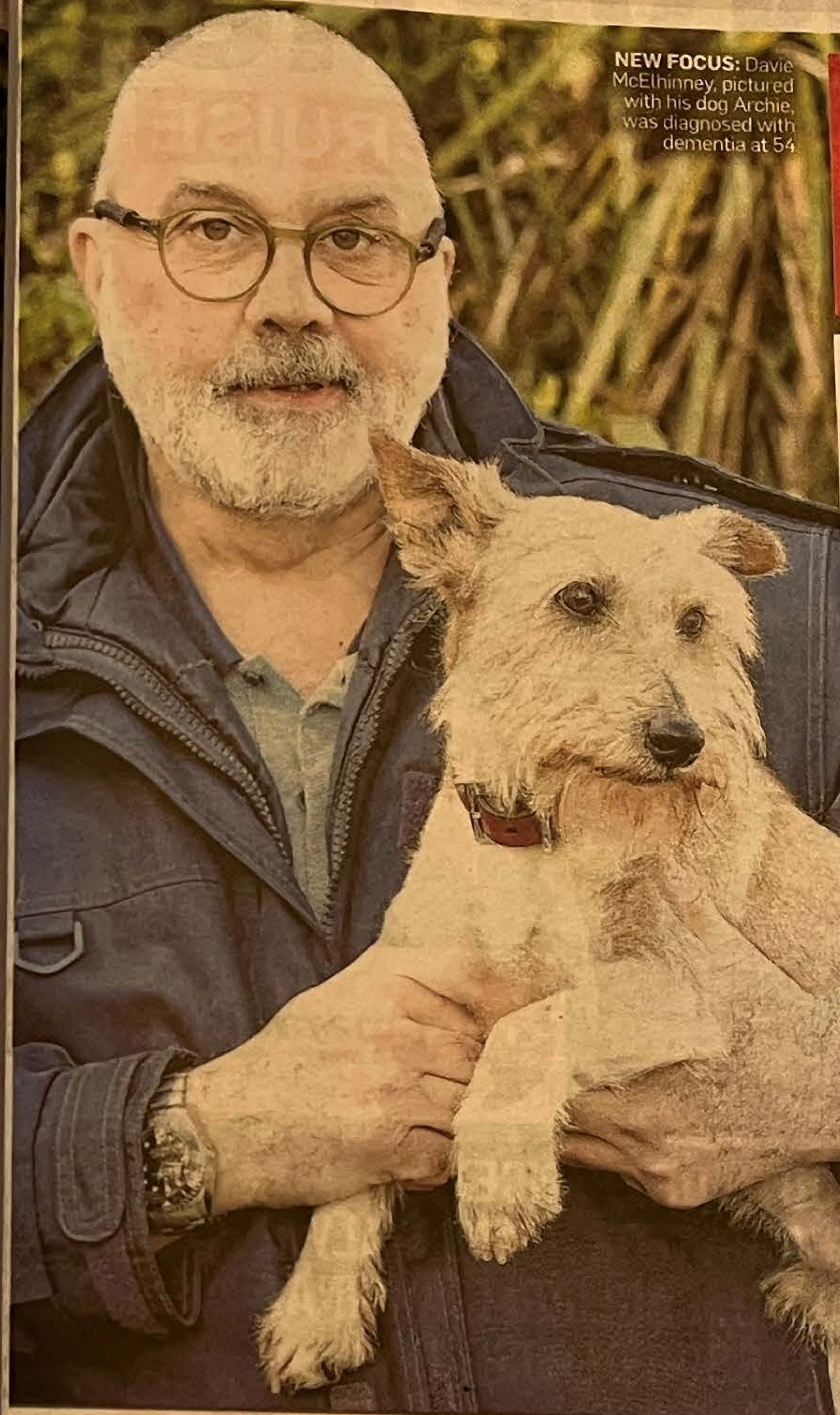
support. We support one another very well. It doesn't take away from the diagnosis, but it helps with that shock. Just to hear someone else talk about it is a big thing. We strive every day to break the stigma and educate. It's nothing to be feared. The person just gets on with their life the best they can."

SURPRISED

FTD is usually diagnosed in people younger than the actor. It occurs when disease affects the frontal and temporal lobes and breaks down connections between them and other parts of the brain.

People meeting Davie for the first time are often surprised to learn he has dementia. There is no cure for the condition but he's on a drug therapy which helps to

TO DEAL WITH HIS OWN DEVASTATING DIAGNOSIS



NEW FOCUS: Davie McElhinney, pictured with his dog Archie, was diagnosed with dementia at 54

'I try every day and I look ahead a day or two, but I don't have big plans for the future. As every day comes, I deal with it'



KEEPING BUSY: Davie McElhinney is a keen model-maker in his spare time and likes to work in his garden (left). The Fermanagh man has the same type of dementia that Bruce Willis (pictured above with wife Emma Hemming), whose family have been very public about his condition in a bid to raise awareness

slow down some of his symptoms.

He struggles with coins and notes and gets annoyed at being unable to finish a task, and the condition has also affected his hearing.

"I set out to do something and then it just goes blank and I can't remember what I was going to do," says Davie.

"I try not to let it impact on my life at all. There are still small things going on with speech and memory, but I work hard at it. I probably notice more things than other people would notice.

"I try not to dwell on it. I don't live in the past, that can't be changed. I try every day and I look forward a day or two, but I don't have big plans for the future. As every day comes, I deal with it.

"I sometimes worry that people

think if I'm doing well it makes them feel bad if they're not just doing so well themselves. I'm always conscious of that."

IMPACT

He says the biggest impact of the movie star's diagnosis is that it will shine a light on a condition which is usually associated with the elderly.

"It does highlight it when a very recognisable person is diagnosed. It helps to reduce the stigma. It's sad for the person involved. The only thing is there are thousands of people dealing with this daily.

"It takes a star to have dementia for people to realise it's there. Don't get me wrong, it's terrible for anyone, but there are thousands every day getting on with their lives," says Davie.

star...and shares his insights into the cruel disease