

Fiona MacDonald, 66,
was diagnosed with
motor neurone disease
in 2021 and is facing her
future with tenacity
and courage.





The road to a cure

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In the face of a life-changing diagnosis, Fiona MacDonald has “taken the bull by the horns”, turning her efforts towards raising vital funds in the quest for answers about motor neurone disease.

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FORMER TV STAR FIONA MacDONALD KNOWS TIME is running out. Diagnosed with motor neurone disease (MND) in November 2021, she is determined to make the most of every moment she has left. And she’s not sitting still. Last year, Fiona, 66, and her younger sister Kylie Thynne embarked on a ‘big lap’ around Australia, driving more than 15,000km over 40 days to raise awareness of the disease and funds for vital research.

“It was a tremendously empowering trip. I could drive hundreds of kilometres and feel the independence of living my life on my own terms,” Fiona says of her fundraising venture, It’s a Big Lap For MND.

“It’s very difficult to accept that your life is changing; that you won’t be talking anymore, you soon may not be walking, and your hands might fail before you succumb altogether. That’s the hideous nature of motor neurone disease – it slowly robs you of your power.

“It’s a Big Lap was a way of seizing the day and being on the road while I could still manage. The fact that we raised over \$100,000 was the cream on the cake.”

Travelling from town to town, Kylie recalls how they took thousands of photos, laughed, enjoyed their favourite songs, saw spectacular sunsets and starry night skies, and witnessed a rare rain shower on the Nullarbor. The journey was captured by the ABC's *Australian Story* and, since returning, former *It's a Knockout* star Fiona has boosted her fundraising target to \$250,000.

Money raised will support the work of the Macquarie University Motor Neuron Disease Research Centre in Sydney – Australia's largest facility solely focused on uncovering the causes of MND and developing therapies to cure the condition. Leading the team of multidisciplinary experts is Professor Dominic Rowe, a clinical neurologist and researcher, as well as Fiona's neurologist.

People with MND face significant challenges as their condition deteriorates. For Fiona, the disease she and her doctor refer to as "a shit sandwich" has taken her voice and impacted her mobility.

Kylie describes her sister as having "taken the bull by the horns and tackling it head on", but she admits some days can be tough.

"Not every day is a good day for Fiona. She can no longer verbally communicate with us, she is losing her strength in her legs and is becoming more dependent on her walking aids. With all of these roadblocks, Fiona is continuing to raise



Fiona, with sons Harry and Rafe, on her return from the Big Lap trip. Right: with co-driver, sister Kylie.

awareness and vital funds for Macquarie University and Professor Rowe with the end goal to find a cure."

THE KILLER CONDITION

According to the charity MND Australia, 'MND' describes a group of diseases that affect nerve cells called motor neurones (the condition is also referred to as amyotrophic lateral sclerosis, or ALS, overseas). They normally carry messages from the brain to the muscles via the spinal cord, allowing people to make voluntary movements such as walking, swallowing, talking and breathing.

With the disease, the nerves become damaged and start to die, so muscles gradually get weaker and waste away.

"This is a disease that robs you of your ability to speak, to swallow, to walk, to use your hands, to breathe and ultimately, it kills you. You don't die from MND, it kills you," says Professor Rowe.

The most effective way to care for patients with MND is with an expert team of health professionals that look after a person's multiple requirements, he says. This can include physio, occupational therapy, speech and language therapy, nutrition and respiratory support.

"We know multidisciplinary care nearly doubles people's survival. So having patients looked after by people who know what they're doing, who can anticipate problems before they arise, is the crux."

There is a medication available in Australia that can help slow disease progression in some patients, but global efforts to find better treatment options are ongoing.

FINDING ANSWERS

There are also moves around the world to uncover what causes the disease. According to MND Australia, theories being explored include exposure to environmental toxins and chemicals, infection by viral agents, immune mediated damage, premature ageing of motor neurones, loss of growth factors required to maintain motor neurone survival, ageing and genetic

KEY FACTS FROM MND AUSTRALIA

MND may be diagnosed at any age, but most commonly shows up when people are in their 50s and 60s.

Around 10% of patients have an inherited form of the disease, but the cause for the remaining 90% of cases is still unknown.

Around 800 Australians are diagnosed with MND annually, and two die from the condition each day.

There is no known cure or effective treatment, and the average survival time after diagnosis is two-and-a-half years (although it can vary based on individual experiences).

Early symptoms can be mild and include stumbling due to weakness, difficulty holding objects and slurred speech.



susceptibility. Some scientists have specifically flagged the need for further investigation into the link between cases of MND and exposure to a toxin found in blue-green algal blooms.

Of particular interest to Professor Rowe are several MND clusters in NSW areas, including the Riverina, Tamworth and Lake Illawarra. What's common across these sites, he explains, is contaminated water. And it's a theory that's also emerging overseas, as geolocation data on cases is analysed.

In response to community concerns in NSW, Premier Chris Minns announced \$2 million in funding, which he says will go a long way in helping to better understand the incidence of MND.

Professor Rowe and Fiona would also like to see MND become a notifiable disease, where government authorities must be informed about each case. "Researchers and doctors need more powerful data – they need to know

"That's the hideous nature of motor neurone disease – it slowly robs you of your power."

FIONA MacDONALD

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where MND is happening to inform the why," explains Fiona. "If hotspots can be identified, it will help researchers to delve into potential environmental causes behind the high growth in MND in Australia."

QUEST FOR A CURE

Professor Rowe has hope for the future of MND. "It's possibly preventable. I refuse to believe that it is incurable. It's underfunded and underestimated. With adequate resourcing, you can get a lot accomplished," he says.

"We do have long survivors with

this disease. We need to understand the biology of these long survivors versus short survivors, because maybe the answer to the biological process is staring us right in the face.

"If we could slow the disease by 50% then we could quadruple people's survival from an average of 27 months to 10 years. Now, that's still not good enough, but if it gets a 55-year-old to 65, albeit with a lot of challenges, then that would be a good thing."

This is why fundraising efforts, such as Fiona and Kylie's Big Lap, are vital and inspiring. "The resilience and tenacity that the vast majority of people have is truly breathtaking. That's what Fiona has in spades," Professor Rowe says. "If she isn't proud of herself, then she really should be." ●

To make a donation to It's a Big Lap For MND, visit gofundraise.com.au, click on 'top fundraisers' and search 'Fiona MacDonald'.