

PHOTOGRAPHY *by* JULIAN KINGMA

HAIR AND MAKE-UP BY JULIA GREEN AND JAMIE MINNEY. STYLING BY MILANA DE MINA. NEALE WEARS COUNTRY ROAD SHIRT. JAN WEARS WITCHERY DRESS.

NEALE DANIHER

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Play on

Neale Daniher made his name as an AFL player and coach, but since his diagnosis with motor neurone disease six years ago, he has created a legacy. Still leading the fight to find a cure, Neale shares some hard-won wisdom with **Susan Horsburgh**.

If you ask Neale Daniher about the bald, brutal reality of living with motor neurone disease (MND), you won't hear him complain. Apparently he never does, and he's not inclined to start now. When pressed, though, he describes it as a daily battle.

"You never totally accept it," says the 58-year-old. "The voice is never far away, saying, 'You're f**ked, mate'. One minute you might be able to lift a fork, the next you can't. You get a little cold and can't cough, and you feel like you're drowning."

At this point, Neale can't cradle his grandkids in his arms, can't brush his teeth or sometimes even catch his breath. But this is what he *can* do: he can jiggle his legs to rock his newborn granddaughter to sleep on his lap; he can share a cracking bottle of red and some laughs with his wife and four kids; and he can raise millions of dollars to fight the incurable disease he has dubbed "The Beast".

For Neale, it's the second list that counts – and every day he chooses to dwell on the positive. "I didn't choose MND," he says. "My only choice is my attitude and how I deal with it."

Neale has decided to dedicate the time he has left to finding a cure, and has won admirers all over the country with his courageous, tireless commitment. One of the AFL's four famous Daniher brothers, Neale played for Essendon in the 1980s, and later coached Melbourne to a grand final – lending his voice to MND research has proved a game-changer for the cause.

Charity begins at home

Since he co-founded FightMND in 2014, its fundraising tally has topped $40 million – fed by campaigns like the Big Freeze, which sends celebrities into icy water at the MCG every Queen's Birthday weekend. This year the sale of beanies alone raised $3.2 million.

When he took up the fight five years ago, Neale never expected to save himself – what he wanted was a purpose to help him transcend his situation.

"The disease was going to kill me, but surely we could find a way to change the outlook for the next generation," he explains. "There is always opportunity to be found, even when you're dying." Life doesn't promise to be fair, he says, but everyone has the power – even in their darkest days – to make their life matter.

Facing death, Neale has inevitably reflected on life. A self-described "thinker", he has always been on a spiritual quest, but last year, when he learned his son Luke was expecting a baby, he decided to distil his beliefs into a book for the grandchildren he might never meet. Part memoir and part manifesto, *When All is Said & Done* tells Neale's story, interspersed with life lessons he has picked up along the way – musings on love and leadership, friendship and forgiveness.

Today, in his comfortable home in Melbourne's leafy eastern suburbs, Neale's freshly printed hardback sits on the coffee table as the Danihers buzz about the living room. Recent holiday snaps of the four kids together – including Luke, who now lives in Perth – are stuck on the fridge, and their Labrador, Murphy, is sprawled out in the spring sun.

Neale sits on the sofa, his hands limp in his lap. His speech is slurred and he occasionally struggles to take a breath. Yet, he says, he's luckier than most →

MND sufferers: "Only about 10 per cent live longer than five or six years after diagnosis," he points out, "and I'll be one of them."

He has witnessed Luke's wedding, walked both daughters down the aisle, and met his first two grandchildren, none of which he thought he'd do. And now he has produced a book to guide them when he's no longer here to do it himself. It tackles nothing less than the meaning of life. Each chapter is labelled with a self-styled truism, such as "Grow through what you go through", "Don't let the bastards win both ways" and "When you're dying, everyone thinks you're a great bloke". Neale calls it "dunny-door wisdom", and he has been collecting it all his life – ever since he was growing up, the third of 11 kids, on a farm in Ungarie in NSW's Central West.

"Being anxious doesn't do much."

It was "the quintessential Aussie country upbringing" – one that valued hard work, honesty and humility. Chores and Sunday Mass were non-negotiable, and his parents, Jim and Edna, just got on with it, despite the inevitable hardships of farming life. Passionate about football, Jim helped set up the Ungarie junior footy club to give his four sons something to keep them out of trouble.

Neale won a scholarship to St Patrick's College in Goulburn and, hoping he might be steered toward the priesthood, Edna sent him off to boarding school just before his 12th birthday. It was an oppressive Christian Brothers environment, with curfews and strappings, but Neale excelled at sport and learned to be self-sufficient.

The first in his family to go beyond Year 10, Neale switched for his senior years to Kilmore's Assumption College, a breeding ground for Aussie rules footballers. After graduating, he joined Essendon Football Club in 1979 alongside big brother Terry, and enrolled in science at Melbourne University, eventually transferring to computer science at RMIT University. He'd go to training after uni lectures, and went on to work as a computer programmer while playing in the VFL.

Back then, he was so conscientious and quiet he was given the nickname "Rowdy". Young and hungry, he was named VFL Recruit of the Year, but his playing career was cruelled by three knee reconstructions in four years – shattering at the time, but a wake-up call for Neale in hindsight.

"My whole identity was wrapped up in being number six for Essendon, and to a degree I had allowed myself to accept that my worth as a person was in part measured by my worth as a footballer," he writes in his book. "I might otherwise have run the risk of ending up as one-dimensional as my footy card."

In 1997 he became the coach of Melbourne Football Club, taking the Demons from the bottom of the ladder to the grand final in 2000, but by mid-season 2007 – after a string of poor performances – commentators were baying for blood. Neale resigned.

His departure left him angry and disappointed – "I felt a bit like the garbage that had been turfed out the back door" – but he knew acceptance and forgiveness were the way forward. Again, it came down to attitude, the one variable he could control.

Despite the ups and downs of his football career, his happy family life has remained a constant. When Neale met Jan, a keen netballer, at a country 21st, she was drawn to his humour and honesty, and they married in 1985. Jan was the warm, sociable one, while Neale was more judgemental and impatient, too often perceived as "a rude bastard".

In fact, his only regret seems to be that he was too much of a "hard-arse" in his early years – too critical and uncompromising. "The book," he says, "is probably old Neale talking to young Neale, saying, 'Loosen up a bit, mate. Don't be so earnest.'"

Neale did manage, however, to leave the pressures of his coaching job at work and to find time for his family. The youngest, 26-year-old Ben, grew up idolising his father and has fond memories of his dad coaching his under-15 footy team to the grand final. "We were the only team he coached to a flag," he says, laughing.

Neale has always been the Daniher kids' go-to for life advice. "He says what he thinks and, I hate to tell him, but he's usually right," explains Ben, a recruiter. "Since his diagnosis, our conversations have gone much deeper, because you don't know if you'll be able to have them later, so we've sort of cashed in."

Neale's belief system faced its biggest test at the age of 52. By then he was living in Perth, the general manager of football operations for the West Coast Eagles, and the first sign of his condition was a weak right hand – Neale started fumbling with his car keys and a mate ribbed him about his limp handshake. Within weeks, his sisters were discussing the slur in his speech. Finally, in May 2013, after months of tests, a Perth neurologist told him all indicators pointed to MND. A second opinion in Melbourne only confirmed it.

His oldest child, Lauren, a nurse, had been looking after MND patients for two years in a respiratory ward. "I remember thinking, 'I wouldn't wish this disease upon my worst enemy,'" says the 33-year-old. When her seemingly invincible dad told her he had MND, Lauren knew only too well what he was in for, but her siblings had no idea. All Bec knew was that Stephen Hawking had it.

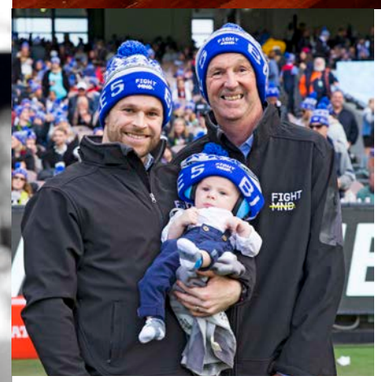


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Clockwise from left: The Daniher boys got game as youngsters; Neale and Jan at their 1985 wedding; Bec, Jan, Neale, Ben, Lauren and baby Rosie; with older son Luke and grandson Cooper; Neale's glory days as an Essendon player in 1990.

Difficult news

Post-diagnosis, the first port of call these days is the internet, and the news from Dr Google was grim. MND affects the nerve cells, causing weakness in the muscles and eventually paralysis, while the mind usually stays sharp, meaning the sufferer becomes a helpless witness to their own demise. Patients progressively lose the ability to walk, talk, swallow and ultimately breathe. The average life expectancy is 27 months from diagnosis. There is no cure.

Jan remembers reading the bleak statistics. "We were both devastated, but no, he wasn't depressed," she recalls. "I was. I was just numb for quite a while. But he turned his thinking around so quickly."

Neale says he cycled through all the normal emotions, including despair, but soon realised he couldn't wish away reality. "Being anxious and depressed doesn't do much good for you, your partner or your kids," he says, lifting one hand with the other to rub his eye. "So you've got to find another way."

He has kept it light from the start, insisting there's "no time for crap red wine anymore" and joking that he can't do the dishes because he's got MND. When he sent a group text telling his friends of the diagnosis, he signed off with the footy phrase, "Play on. Neale." →



"Find the courage to take responsibility for your own life."

He wasn't interested in ticking off a bucket list; he wanted what was left of his life to count. FightMND has given him, and the whole family, a focus. "It's his way of fighting the disease," says Lauren, "and our way of trying to help him." For the road trip Daniher's Drive in October, for example, Lauren organised a fundraising night and Ben was MC. For the first Big Freeze in 2015, the family was up until 3am some nights, packing up beanies in the living room.

Formerly an accountant, 29-year-old Bec has become the foundation's campaign director, working closely with her dad. "He's not getting paid a cent," she says, "but he's working twice as hard as everyone else to make sure that FightMND will last longer than he will."

Family support

No one escapes adversity in life, but Neale has taught his kids by example how to cope. "He showed us the way," says Ben, "and we're all better for it."

The family has always been tight, but Neale's diagnosis has brought them closer, and made the weddings and new babies even more special. The most precious times, they all agree, are usually around a table, wineglasses in hand. Says 31-year-old Luke, a health manager who welcomed his first child, Cooper, in February: "The best memories are when we're all together, when Dad's the resident DJ and we're just sharing stories as a family."

Mum Jan, they say, is the unsung hero, caring for Neale and supporting them all. "It's getting harder, but because he's so positive, it rubs off on everyone," she says. "There are a lot of people with terrible things happening to them, and if you dwell on it, life's going to be a lot worse. We've been able to work hard at something that will hopefully make a difference."

That's not to say, however, that she hasn't struggled. "At one stage I was really down – grumpy and just not great to be around – and Loz [Lauren] told me to pull my socks up," she says. "It made me stop and reassess."

A high-school relief teacher, 57-year-old Jan goes to work during the week and carers come in. Neale is becoming more reliant on others, she says, but he mostly keeps his frustrations to himself. "He just keeps going – working hard with the foundation, with the book, whatever he puts his mind to next," she says. Often he can be found in the study, reading his personal development books.

Now, Neale has added his own wisdom to the bookshelves. His memoir ends with a letter to his grandchildren, most of whom he probably won't meet. He tells them how their "Poppa" would love to be around to watch them grow up: "And I will miss having little conspiracies: eating meat pies and chips down at the beach after school, even though your parents told me not to let you have junk food, leaning in and whispering, 'Don't tell your mother.'"

Mostly, he urges them to embrace life and be brave. "Life can be tough, you will have your hurdles and setbacks," he writes. "I don't want you to feel overwhelmed or to become a victim. I want you to learn a bit of grit, a bit of resilience … [to] find the courage to take responsibility for your own life."

Chances are, Neale Daniher won't slay The Beast in his lifetime, but he has created an army that he hopes one day will. And he plans to remain defiant to the end, to muster all the courage and optimism he can. "I personally [cannot] conquer The Beast," he writes, "but I would rather get knocked out in the 15th round than not even enter the ring." **AWW**





Clockwise from top: Neale at home; with nephew (and Essendon player) Joe and fellow former coach Kevin Sheedy; Neale leads the AHG Walk to the 'G in 2017.

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