

## YOUR LEGACY A FUTURE FREE OF MND

Together we can beat the Beast





Average life expectancy of a person living with MND is **27 months.** 





Your lifetime risk of being diagnosed with MND is 1 in 300.



## A MESSAGE FROM OUR CEO

Dear Valued Supporter,

Motor neurone disease (MND) is what we call the Beast. Today, two Australians will be diagnosed with MND and two more will die. At any one time more than 2,000 people are living with MND. There is no cure. While some can live a longer life, for many its progression is swift, with the average life expectancy 27 months from diagnosis. Diagnosis itself can take months which is precious time.

#### This is why we fight.

FightMND is striving for a world free from MND. We do this so that one day, no individual or family suffers from the devastating impact of the Beast. We can only do this through the help of amazing supporters like you.

We understand planning your estate is a time to reflect on what matters most. After providing for your family and loved ones, will you consider a lasting legacy with a gift in your Will to FightMND?

Including FightMND in your Will helps fund our relentless pursuit of effective treatments, and ultimately a cure, long into the future. Big or small, your gift will power researchers, fund clinical trials and provide much needed support to those battling MND every day.



Since 2014, FightMND has worked to make targeted investments in cutting-edge research projects focusing on both fast tracking new treatments and driving discoveries towards a cure. This is only possible thanks to the support of people like you.

For the last 10 years our investment has helped build a solid research foundation. But there is still a long way to go. We have a global impact and take a leading role in co-ordinating the great minds of the world towards our goal. Our fight isn't over and we're not backing down.

By considering a gift in your Will, you're showing that same unbreakable determination. You're declaring that MND's days are numbered. Together, we're an unstoppable force against the Beast.

Thank you for considering this powerful way to leave your legacy.

Kind regards

Matt Tilley

Matt Tilley CEO FightMND

## NEALE DANIHER'S LEGACY: FIGHTING THE BEAST

#### Neale Daniher AO needs no introduction.

An AFL champion, captain and coach, Neale has inspired players and fans for decades. Throughout his career, Neale's determination and grit have seen him hailed as one of the game's greatest players and leaders.

It is these traits that have characterised Neale's battle with motor neurone disease (MND).

Diagnosed in 2013, Neale has been determined to make a difference ever since. He has made it his legacy to fight tirelessly for those diagnosed with MND and those who will be diagnosed in the future.



FightMND co-founders
Neale Daniher, Pat
Cunningham (whose
wife Angie died from
MND in 2016) and
Dr Ian Davis, who
died from MND
in 2018.



The beginning!
Packing Big Freeze
Beanies around the
family kitchen table
with Lauren, Jan and
Bec Daniher.

Neale knows research is the best weapon against the Beast and the only way to increase our chance of a scientific breakthrough is through funding vital research.

This is why he co-founded FightMND in 2014 with Pat Cunningham and the late Dr Ian Davis.

From humble beginnings around the Daniher kitchen table, today FightMND is one of the world's largest independent funders of MND research.

Your generosity enables MND research in Australia to be competitive and world-leading in driving a pathway to better treatment and a cure for MND. While we have come a long way, there is still a long way to go—and we need your help.

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Neale's philosophy is Play On. Grab the Opportunity. Fight Back.

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MND is a Beast and we are in the critical phase of the fight. We need our supporters to step up and take the lead in the fight so our kids and grandkids will know a world without MND.

Thank you for considering a gift in your Will to FightMND.

Neale Danil

**Neale Daniher** 



## **MICHELLE'S LEGACY**

Michelle's beautiful son Robbie was just 34 years old when he was diagnosed with MND.

He died in 2019, just two years later.

Michelle has included FightMND in her Will as she is determined to help others living with this devastating disease.

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We made a promise that we would try and help find a cure and care for those that have to live with MND like our son Robbie.



### WHAT IS MND?

Motor neurone disease, or MND, is a devastating progressive, terminal neurological disease. It is the name given to a group of diseases in which the nerve cells, or neurones, controlling our muscles fail to work normally and die.

With no nerves to activate them, the muscles gradually weaken and waste. Over time, MND takes away a person's ability to walk, talk, feed themselves and, ultimately, breathe.

Many individuals first see the effects of MND in a hand or arm. They might have difficulty with simple tasks like writing or buttoning a shirt. Or, they might notice they trip or stumble more often.

While the muscles weaken as disease progresses, often a person's cognitive abilities remain intact. This leaves those living with MND motionless, unable to communicate, trapped, and aware of the progressive loss of their function and ability.

There is no truly effective treatment. There is no known cure.

This is why we fight.

### YOUR IMPACT

Before FightMND was established in 2014, Australians living with MND had no access to clinical trials, drugs or therapies. **This is because there was no clinical trial infrastructure in Australia**.

What a difference a decade makes.

Thanks to supporters like you:

- Over 600 Australians have had access to clinical trials through FightMND-funded projects.
- We have funded 15 clinical trials across 10 sites in Australia and supported
   30 drugs in the drug development pipeline.
- Five potential treatments developing through clinical trials.
- Two further **potential therapies** set to commence clinical trials for MND.
- We have invested \$85.5 million in MND research for a cure, helping
   Australia to become a world leader in pushing towards better treatments and a
   cure for MND.
- We have invested **\$12 million in care support and research**, including assistive equipment to improve the lives of Australians living with MND.



There is real optimism that MND will be a treatable disease instead of a terminal one. This is only possible through careful, rigorous research. This takes time and investment.

By including FightMND in your Will, we can continue to invest in world-leading MND cure research and care initiatives.

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I have decided to leave a portion of my estate to FightMND.

I became aware of this insidious disease when Neale Daniher was diagnosed. I was inspired by his strength, and this motivated me to assist in finding a cure. I am proud to be a part of the FightMND community, fighting to beat the Beast for good.



## TYPES OF GIFTS YOU CAN INCLUDE IN YOUR WILL

Thank you for considering a gift in your Will to FightMND. It is a wonderful act of generosity and a way to make a significant impact beyond your lifetime.

Many of our supporters that have left a gift in their Will to FightMND say they want to leave the world in a better place. **Imagine your legacy being the gift of more time with loved ones. The gift of movement. The gift of speech.**The gift of MND being known as a treatable illness.

By including FightMND in your Will, you're enlisting in the fight for generations to come. You're giving hope to thousands of people and their families living with MND.

There are different ways you can leave a gift in your Will.



#### A residual gift

After making provisions for your family and loved ones, you can choose to leave all, or part, of the remainder of your estate to FightMND.

Many people prefer to give a residuary gift because it keeps in line with inflation, so their wishes are honoured and their gift does not lose value over time.



#### A specified amount

You can leave a specific sum of money.



## Whole or percentage of your estate

You can choose to leave your entire estate or any part of your estate to FightMND.



#### A specific item

You can leave specific items of value, such as shares or real estate.



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I'm excited to see our science research now moving closer towards finding ways that we can apply new knowledge to helping people with MND.



#### **Dr Adam Walker**

The University of Queensland Dr Walker was awarded a FightMND Fellowship in 2022

## Suggested Will wording to leave a gift in Will (bequest) to FightMND

After considering your family and loved ones, you may wish to leave a gift in your Will to FightMND and help lead the fight against the Beast that is MND.

(1131113)	
of (address)	
Postcode	
give and bequeath to FightMND, ABN 62 740 350 704 (or its legal successor),	
	(the residual of my estate) or
	(percentage of my estate) or
	(the sum of \$) or
	(specific item/s, asset)

for its General Purposes and direct that the receipt by the company's CEO, Treasurer, or other authorised officer of FightMND will be an absolute discharge to my executors/trustees.

Please note: This is suggested wording. We recommend seeking professional advice to formalise your Will.



## A GIFT OF HOPE

In 1987, Judith lost her beloved father Keith to MND. Keith, a World War II veteran, was diagnosed after experiencing muscle twitches and falls. MND ravaged his body, robbing him of his mobility and independence.

"I remember visiting him in hospital the last time... seeing him struggle to breathe was extremely upsetting."

Back then, little was known about MND. Today, thanks to our FightMND supporters, we're making significant strides in research and support.

Keith was 64 years old when he died. He didn't make the three years doctors had predicted.

Inspired by her father's fight, Judith has left a gift in her Will to FightMND. Her legacy will help our relentless pursuit of effective treatments and a cure.

TOGETHER, WE CAN CREATE A FUTURE FREE FROM MND, HONOURING THOSE WE'VE LOST AND SUPPORTING THOSE STILL LIVING AND DIAGNOSED WITH MND.

WILL YOU STAND WITH US, LIKE JUDITH, AND LEAVE A LEGACY OF HOPE?





Judith with her dog Taxi. Judith has left a gift in her Will to FightMND.



## FREQUENTLY ASKED QUESTIONS

#### How do I include FightMND in my Will?

There are many ways you can create or update your Will to include FightMND.

This can include:



Decide to include a gift in your Will and speak to your family and loved ones.



Decide on the type of gifts you want to leave in your Will.



Get legal advice in the development of your Will. You may wish to use our recommended Will wording. You can also use an online Will platform such as Safewill.



Please let us know your intentions so we can thank you for joining the fight against MND.

#### I already have a Will. Do I need to update?

Your Will records your wishes at a point in time. If there has been a significant change in your circumstances, or your Will no longer reflects your wishes, it may be necessary to make a new Will. You should consult your solicitor about whether a new Will or a codicil (a short amendment to your Will), is appropriate for the updates you wish to make.

#### How will my gift be used to make an impact?

We work carefully to invest your generous gift into the most promising projects across the globe. Your legacy will help us to fund world-class research, collaborate with the best and brightest, build the MND workforce capacity, facilitate knowledge-sharing and invest in research infrastructure. This is critical to beating the Beast and improving the lives of people living with MND.

#### If I leave a gift in my Will do I need to let you know?

You don't have to let FightMND know if you leave a gift in your Will. However, we would love to hear from you so we can thank you and discuss how your legacy will be used in accordance with your wishes.

#### Do I need to tell FightMND about my gift?

We will always respect your wishes, and you can remain anonymous if you prefer. However if you let us know you have left a gift in your Will to FightMND, there are opportunities available to you. This includes grant naming rights, event attendance, private tours and/or appearance in the FightMND annual report and honour rolls.

#### What is the difference between a bequest and a gift in Will?

A bequest is another term for a gift in Will. The two terms are often used interchangeably in Australia.



### **OUR PROMISE TO YOU**

## We respect that your family and loved ones come first.

We are grateful for any size gift you may leave FightMND.

## We welcome you to the FightMND family.

You can choose the level of communication you have with us. We would love to include you in events, recognise your gift publicly, or just keep you updated if you prefer. We also understand if you wish to remain anonymous.

## We will respect and handle all gifts with compassion and gratitude.

We appreciate all gifts left to FightMND in your Will. If you choose to leave a gift in your Will in the name of a loved one, please let us know.

## We will respect your privacy.

We will ensure that any information you give us about your personal circumstances remains confidential.

## We will honour your legacy.

We would be delighted to discuss any specific requests in your Will.

## We will strive for impact.

FightMND will use your gift carefully and in a cost-effective manner to ensure the greatest impact.

## **JOAN'S LEGACY**

Dr Joan Wilkinson AM dedicated her life to healthcare and medical advancement. Born in 1927, she pursued a diverse nursing career, from working in hospitals across Victoria to lecturing in nursing education. Her passion for learning led her to earn multiple degrees, including a PhD in Human Resource Management.

Throughout her life, Joan supported numerous charities. Her generosity extended beyond her lifetime through the gifts she left to causes she was passionate about.

Joan remained committed to making a difference until the end of her remarkable life, and FightMND is grateful to have been bequeathed a gift from her estate. This gift reflects her lifelong dedication to advancing medical knowledge and care.

By supporting FightMND's mission to find effective treatments and ultimately a cure for MND, Joan's legacy continues to contribute to the fight against this devastating condition, embodying her spirit of continuous learning, innovation and care for others.

Joan passed away in 2022 and left a gift in her Will to FightMND.



# THANK YOU

# FOR CONSIDERING A GIFT IN YOUR WILL TO FIGHTMND.

A promise of a future gift is deeply appreciated. Your kindness ensures FightMND can continue investing in world-leading MND cure research and care initiatives.

If you decide to include FightMND in your Will, it would be a privilege to hear your story, learn about the intentions behind your gift and to thank you personally for your generosity.



Please contact our gift in Wills team on **1800 344 486** or **wills@fightmnd.org.au** for a confidential discussion.

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ABN 62 740 350 704

FightMND, also known as Cure for MND Foundation, is endorsed as a Deductible Gift Recipient (DGR). It is covered by Item 1 of the table in section 30-15 of the *Income Tax Assessment Act 1997*.