A gift in your Will could give hope of a world free from MND

David and Paula at Northampton Guildhall, where they married after David’s MND diagnosis.
What if our generation could beat MND?

Our vision is a world free from MND – and that’s a goal I believe we will reach. With all the will in the world, we won’t beat MND today. But a gift in your Will could make that future breakthrough possible – the one that could mean future generations see a world free from MND.

Since the MND Association was founded in 1979, we’ve made great progress in MND research, care and campaigning – thanks in large part to dedicated supporters remembering our work in their Wills.

The journey towards new treatments and a cure is one we need to make as quickly as possible. We will continue to build momentum and pursue the most promising avenues of research so that we can improve care for people living with MND. We will drive forward treatments that bring us closer to a world where MND is a thing of the past.

That’s why I hope you’ll take some time today to consider including the MND Association in your Will. Thank you.

Sally Light, CEO

5,000 people in the UK are living with MND at any one time. There is currently no cure.

80% of people with MND will have communication difficulties. Many will lose the ability to speak with their loved ones.

1/3 of people living with MND lose their life within one year of diagnosis and more than half within two years.

6 people receive an MND diagnosis every single day.

Gifts in Wills form 33% of our income. We rely on your gifts to support people with MND and continue our search for a treatment.
“I can’t beat MND – but it’s not going to beat me either.”

David was 63 when he was diagnosed with MND in October 2015. He and his wife Paula have faced the diagnosis head on, while raising funds for the MND Association.

“The help that I’ve had from everybody at the MND Association has been amazing, so many people there have become good friends to me. Their care services have been incredible: from helping us pay for alterations to our home, helping me communicate through an iPad and just being there to listen and support us when we need advice. We’d be lost without them.

“Paula and I both fundraise, she’s already run three marathons, and we talk to people about MND too – we want to spread the word and try and find a cure for this disease. We want there to be hope – and we know that gifts in people’s Wills are the key to that.

“This is a tough journey and we’re grateful not to be on it alone,” adds Paula, “We’re thankful to everyone who remembers the MND Association in their Will because we know what their support could one day mean to a family like ours.”

With a gift in your Will, you could help make sure that one day nobody has their life cut short by MND.

“I’ve had so much help from the MND Association, if our story can convince just one person to leave a gift in their Will, I’ll really feel like I’ve given something back.”

David Solomon
With research there is hope...

Jessika Bridi studying fruit flies, which make it possible to observe genetic changes linked to MND.
The MND association funded their first research project in 1980. When I joined in 1996, we were spending just £150,000 a year on research. But since then, the number of projects we’ve funding has skyrocketed. We currently spend an average of £3 million – and MND has gone from being a disease nobody has heard of, through to being at the forefront of neurological disease research.

The pace is building up. There are things happening now, like genome sequencing, that ten years ago would have been considered science fiction. It gives me real hope for the future.

“We’ve been funding research for four decades. We know more than ever. We must sustain the momentum.”

“I firmly believe we will find a treatment in my lifetime.”

Gifts in Wills have made our achievements possible – and our future research depends on them.

1991 We awarded our first MND research grant to a project at The Charing Cross hospital.

1993 A major advance – the discovery of the SOD1 gene that we now know causes 10% of inherited MND cases.

1998 By 1998, we were funding more than 20 studies into MND than ever before, spending around £1 million per year on research.

2000 We joined forces with the Department of Health to fund a trial in Non-Invasive Ventilation (NIV) to help people living with MND to breathe.

2004 We approve the first DNA samples to be sent for analysis to the International Project MinE initiative — the largest genetic research project in the world, aiming to analyse the DNA of at least 15,000 people living with MND.

2006 Mistakes in the C9ORF72 gene were found to cause up to 40% of all inherited cases of MND. Prof Huw Morris, pictured, was in the team that made the discovery.

2008 The MND DNA Bank opens to the worldwide research community as an important resource for identifying causes of MND.

2010 We hold the first ever International MND Symposium, bringing MND researchers together from around the world to share their findings. The symposium has since grown into the world’s leading regular gathering of MND experts.

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2016 Our biggest-ever research project, AMBRoSIA begins its search for MND biomarkers in 1,500 participants to help us better understand the various types of MND and how each type affects people living with it.

2011 NICE (the National Institute for Health and Care Excellence) issues guidance for the use of NIV in MND. That formed the foundation for the eventual NICE guideline on treating MND.

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Professor Al-Chalabi has been a driving force behind our increasing knowledge of MND over the past 25 years. “When I first started, if you had asked me if we would ever effectively treat MND, I would have said ‘No’. I feel very differently now,” he explains. “People often ask me ‘Are we really making progress?’ The answer is ‘Yes’.”

Looking to the future, Prof Al-Chalabi expects research to help us understand how different types of MND relate to the underlying causes – a step towards effective treatment. But funding is vital.

“Research needs two things – people and money,” says Prof Al-Chalabi. “UK science has excellent people with the ideas, skills, and drive to push research forward. However, research is very expensive. Gifts in Wills are a powerful way to make sure that MND research can continue until we find an effective treatment.”

Professor Ammar AI-Chalabi is Director of our MND Care and Research Centre at King’s College Hospital.
Achieving our vision together

Our vision is of a world free from MND.

Our legacy promise to you

∙ If you remember MND Association in your Will we promise to spend your money wisely so it achieves the greatest possible impact for people living with MND.

∙ We understand that your family and loved ones come first.

∙ We won’t put you under any pressure – it’s a decision you will want to make in your own time.

∙ You don’t have to tell us your decision – we completely respect your right to privacy (although we’d love to have the opportunity to say thank you).

∙ We will share news of the vital work gifts like yours make possible. You could transform the lives of people with MND, their families and carers by providing support, or by funding research which brings us closer to a cure.

∙ You can change your mind about a gift in your Will at any time and any gift you leave will be handled sensitively and respectfully.

We will always be here for you. If there is anything you want to know about your legacy, please get in touch with Emma Fellows on 01604 611898, or complete the form overleaf.

What kind of gift can I leave in my Will?

Once you have provided for your loved ones in your Will, there are three main types of gift you can choose to leave to the MND Association.

A residuary gift
This is a percentage share of what remains after all other gifts and expenses have been paid. One of the advantages of a residuary legacy is that it rises in value with inflation, meaning your gift could help us fund much more research years down the line.

A pecuniary gift
This is a gift of a set amount that allows you to specify exactly how much you would like to leave in future. These gifts do not increase with inflation.

A specific gift
This is a gift of any form such as a house, car, property or jewellery.

How do I make a gift in my Will?

We highly recommend you consult a solicitor when making or amending your Will. They can make sure that your wishes are recorded correctly, preventing future complications for your loved ones.

Your solicitor will require the name, address and charity number detailed below, so please keep this information safe.

The Motor Neurone Disease Association
David Niven House
10-15 Notre Dame Mews
Northampton NN1 2BG
Registered Charity No. 294354

Want to know more about the work we do and the impact you can help make? Visit our website: mndassociation.org

Our mission

We improve care and support for people with MND, their families and carers.

We fund and promote research that leads to new understanding and treatments, and brings us closer to a cure for MND.

We campaign and raise awareness so the needs of people with MND and everyone who cares for them are recognised and addressed by wider society.

Our questions answered

Helping create a world free from MND with a gift in your Will is simpler than you might think. Here we answer a couple of key questions.

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"When it comes to my Will, the MND Association was always going to feature."

Wendy hopes her gift will mean we can beat MND.

I became a passionate MND Association supporter after what we went through with my uncle. He was the life-and-soul of our family, the glue that held us together. Just six months after his diagnosis, he was gone.

Without the MND Association, the short time we had would have been unbearable for us – and especially for my uncle. They helped us get the equipment we needed to make his final days as comfortable as possible. While I’m alive, I’ll carry on giving to support the practical side of MND Association’s work because I know what a difference the little things like a wheelchair, ramps or a stair-lift can make.

Of course a cure for MND is top of my wish list. But I know that won’t be tomorrow. It might take years, even decades. That’s why, when it comes to my Will, the MND Association were always going to feature. I’d like to think my legacy gift will one day help create a world free from MND.

What if there was real hope of surviving MND? A gift in your Will could mean one day there is.

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“So much has changed with MND in the past few decades. Imagine what a gift in your Will could help us do.”

Dr Brian Dickie
Director of Research Development, MND Association

Your next step matters most
If you plan to include the MND Association in your Will, or you have already, you don’t need to tell us but by letting us know, you could help us plan ahead. We would also love the opportunity to thank you and keep you up to date on our progress.

If you have any further questions, or there’s anything you would like us to know, please use the space below.

Your personal details
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Address ___________________________________________________________
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Email __________________________ Phone _______________________

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Please help us create a world free from MND for future generations, with a gift in your Will.

Thank you.

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