

MND Matters: Episode 18: Gifts in Wills

Intro: You're listening to MND Matters, a podcast from the MND Association.

Helen: Welcome to MND Matters brought to you by the MND Association and sponsored by Toyota GB and Toyota Financial Services. Alongside members of the MND community, we bring you stories, information and expertise direct to your ears. Remember to subscribe and ensure you don't miss an episode. Hi, I'm Helen and I'm a regional fundraiser at the MND Association. In this episode titled, *Your signature is more powerful than you think*, we're delighted to be joined by five guests to explore the difference gifts in Wills makes to funding vital MND research, as well as care and support we can offer people living with and affected by MND. Our guests today are here to share real life examples of the difference gifts in Wills have made to support people affected by MND, so say hello to Debbie Hyslop Professor Majid Hafezparast, Dr. Greig Joilin, Libby Moody and Hetty Smith. Debbie is a Legacy Marketing Officer here at the MND Association and supports our in memory and free Will services. Majid is a professor of Molecular neuroscience at the University of Sussex, who is a grantee for two projects which are fully funded by a legacy. Those projects are being researched by Greig who is a research fellow in neuroscience at University of Sussex, and Libby, who was a PhD student in neuroscience also at the University of Sussex. We are also joined by Hetty who is the chair of South Hertfordshire branch, which received a £5000 legacy last autumn. The branches use the funds to provide support to their local MND community. Thank you so much for joining us all today to share your experiences. So let's start with Debbie so that we can better understand what gifts in Wills are.

Debbie: Hi Helen, thanks for asking me along. Gifts in Wills also known as legacies are a way for someone to leave a gift to a charity in their Will. This can be a percentage of your overall estate called a residuary gift, or a fixed cash amount, a specific item perhaps such as a piece of jewelry, or a piece of artwork. And this is known as a pecuniary gift. -

Helen: So people can leave anything. But what's really important is the difference that those gifts make. Can you give us an idea of really the impact that somebody can have in leaving a gift.

Debbie: Of course, gifts in Wills to the MND Association are hugely significant to us in our work. We rely heavily on the generosity of people making this amazing choice and gifts in Wills left to us mean we can continue to provide support, care and services to those living with MND, their carers and families, and also campaign for the rights of those living with MND and fund vital research to achieve our vision which is a world free from MND, and gifts in Wills account for a third of our income. So without generous supporters remembering people with MND in their will, a third of our work simply just would not be possible, Helen.

Helen: That sounds incredible. Thank you so much, Debbie and what we're really lucky that we can share with you and share with our listeners some real stories about how gifts in Wills have made that difference. But can you also give us an idea of how every penny makes that difference for people living with MND?

Debbie: A gift no matter how small will make a huge difference. For example, £10 provides an information pack for a newly diagnosed person with MND. £100 funds laboratory equipment for two days vital research into finding the causes of MND. £250 so provide a grant to help a young person or carer affected by MND, have a day out or take part in something special. £1000 pounds will pay for detailed analysis of the DNA of someone with MND to help us better understand the causes of the disease. £4000 could fund a person with MND to participate in a clinical trial for a year.

Helen: Incredible, those costs really do highlight how it doesn't matter how little or small that gift is. It can truly make and start making a difference as soon as that that gift in Will is made. But there may be many myths around leaving a gift or a legacy in your Will. Do you mind just starting by dispelling some of those myths for our listeners?

Debbie: Yes, of course. Helen. I think it is so true. And I think people feel you can only leave a huge amount to charity. So they feel difficult about it and then don't leave anything at all. But this just isn't the case, a gift to us, no matter how much someone leaves will make a huge difference to the support we can provide. A gift doesn't cost anything to someone now. So for people with financial commitments or future care costs to consider, it's a great way to ensure that when the time comes, money is invested into a cause that they care about. Financially legacies left to charities are free from inheritance tax. So that's good to know. Any amount really does make a difference.

Helen: There's some really useful information that you're sharing with us Debbie. But I want to know, is it difficult to make a Will?

Debbie: Well think people think, Helen it is. And really, it's not that hard. So I would say to listeners, please don't be put off considering thinking about making your Will. At the MND Association, we offer two free Wills services to supporters. And it's easy to make a start.

Helen: Thank you so much, Debbie, that has been really enlightening and useful in dispelling those myths and helping us better understand why people should and when they can make a gift in their Will.

Debbie: Yes, if anyone has any queries, please don't hesitate to contact us in the legacies team. We'd be more than happy to answer any queries or questions that you have. And as I say, please do refer to the show notes. And and please do consider it it's so important, not only to help those causes you care about but also, you know, to make sure it's peace of mind that you know your loved ones are provided for, and that your wishes will be as you want them when the time comes. So thank you so much for asking me.

Helen: So now we've heard from Debbie about what a gift in Wills is. I'm really pleased that we're joined by Majid, Greig, and Libby who are directly benefiting from a legator, somebody who has left a gift in their Will, towards their research. So Majid, can I start by asking you to kind of explain the research that is being undertaken because of this incredible gift in Wills?

Majid: Thank you, Helen. Yes, of course. Basically, there are several fundamental questions that scientists in MND research are trying to answer. These questions are, how does a MND start? How does it progress? And how can we diagnose it as early as possible? And ultimately, how can we stop and prevent it? So in my team, we are working on these questions by trying to better understand how defects in the axonal transport which is defects within the motor neurons transport system, which we have shown that is one of the earliest events in MND can make the motor neurons more vulnerable to degeneration, and how can we reverse that? Another area of research is on understanding how the immune cells of the central nervous system, when activated, can contribute to the demise of the motor neurons and to the progression of MND. And again, how can we reverse that. And finally, we are particularly keen to find molecular biomarkers in the blood that we can use as a diagnostic tool, as well as helping to predict and the prognosis of a MND and ultimately, to be able to use these biomarkers for developing new drugs for treating MND, people with MND. And gifts in Wills have been vital for this very important lines of research. And indeed in Greig and Libby are here and their projects have been supported by gifts in Wills. And they're here to tell us more about it.

Helen: Amazing. Thank you, Greig and Libby for being here. Greig, can we start with you and just can you give us an overview of what the aim of your research is that you're doing?

Greig: Yeah, sure. So my work is looking for biomarkers for motor neurone disease. So what we're basically looking for is for the presence of something or something changing, kind of as a result of disease. So I guess, yeah, the one kind of biomarker that we're all pretty well aware of these days is the presence of the COVID 19 virus that you can pick up with something like a lateral flow test. So that's an example of a biomarker. So what we're really interested in looking at, is trying to find something very similar for motor neurone disease that we can check your blood and look to see whether there's something there that's not normally there already does a change. And what we're hoping we can do as a result of that is help speed up the diagnostic process. Not only would it mean that the diagnostic process is a lot faster. But we can also have a lot more information when it comes to designing clinical trials and enrolling people with MND into clinical trials, which may mean that we actually get a lot better success. The work I'm doing is vitally important to help us to get those new treatments and without gifts in Wills, yeah this work wouldn't be possible. So, yeah, all this work has been made possible by this very simple generosity of people.

Helen: Amazing. It sounds like incredibly important research. Research, from my experience of working in the MND community, is where we get a lot of our hope from that one day, we're going to get those answers that you're looking for. Libby, can can we come to you? And can you explain a bit about your research and your aims?

Libby: Yeah, absolutely. So I am currently in my second year of a fully funded legacy PhD. And I'm actually going, looking more into what is going wrong. So Majid mentioned earlier about the immune cells of the brain and spinal cord. And I am looking particularly at the microglia. Now, these cells are constantly looking out for signs of danger. This could be for example, damage to neurons, or a sign of infection. And these microglia respond to that by releasing signals to try and clear up and eradicate this danger that they've encountered. But we know in motor neuron disease that these microglia are more activated than perhaps they should be. And as a consequence, they are potentially contributing to

damage of motor neurons. And so my work is really looking at one way in which they might be doing this and contributing to motor neuron degeneration. And that is through the release of a very small fragments of RNA, which are called micro RNA. So we are comparing the release of micro RNA between healthy controls and motor neuron disease models, and working out what effect these micro RNA have on motor neuron degeneration. If we can identify some micro RNA that are problematic, we can look into how we can either prevent those micro RNA being released by the microglia, or how we can reverse the effects of what they're causing in the motor neurons. And yeah, just to emphasize my work is fully funded by a legacy. So it's completely enabled this entire research project to go ahead.

Helen: Again, it just amazes me hearing researchers talk about MND, and about their own projects. Majid, how far do you think researchers have have come in understanding MND and kind of moving us towards getting a treatment and or a cure?

Majid: Well, in the last 10 years or so, actually, since the the Human Genome Sequencing Project has come to completion or near completion, there have been tremendous advances in MND research. One reason has been because we have found genes that are involved in MND. Although MND is not a genetic disease, typically, finding these genes and the functions and the pathways that are been involved in has really pushed the boundaries a lot so that we know detailed molecular mechanisms that are involved in MND and the degeneration of motor neurons. We know they helped me know a lot a lot about MND now and molecular mechanisms, but you know, there is a still a lot to go for. And to find out how we can stop these defects. How can we reverse them? So yeah, there have been a lot of progress but there is a lot more to do.

Greig: I think I would just add that one of one of the other things that has happened probably over the last 10 years is that technology has come a long way in terms of research. And it's made everything a lot cheaper. So, back when I did my PhD about a decade ago, yeah, just to do the kind of work that I'm doing, it would cost probably about £5000 to do. And now we can do that for about £1000. So yeah, it means that we're able to do things a lot easier, a lot faster. That that's also made quite a lot of difference to what we can do research over the last 10 years as well.

Helen: It certainly sounds as if all of your research as well as is massively interconnected, in a sense that's dependent on each other's work and focus to kind of come together to find those answers.

Greig: A lot of our research is very collaborative. So my work is really reliant on clinicians across the UK, collecting blood from people with MND. And so yeah MND research across the world is very collaborative. So my project has a lot of collaboration with a lot of clinicians across the UK, and across Europe. Libby's project is also very collaborative, as well, she's, she's got collaborations across just not within Sussex but she's started up a potential new collaboration with people at the University of Oxford and, you know, this collaboration kind of network that we're we have across the UK, really helps to enable a lot of this research that couldn't be done just by single centre.

Helen: Amazing. A wonder if you could tell us a bit about if this if the legacy funding hadn't come through and funded this research, how would you go about fund funding research? How difficult is it to find alternative means of being able to fund your work?

Majid: It's, it would be really difficult, I mean, we wouldn't be really able to have this continuity that we have now to follow it up, Greig's work, for instance, it discovered a few more biomarkers that he can tell you more about. This legacy, this gifts in Wills support, enable us to continue that and now he's working on the prognosis of biomarkers that could help us with the prognosis of the MND. So, without that gift, then we probably wouldn't be able to do that. I mean, to continue that and having progressed progressing the initial findings, is that correct? Correct what you think?

Greig: Yeah, I definitely. And I think the other thing is that, you know, with COVID, and with Brexit, funding has got very difficult in research, because we've lost a major, major funding stream from the EU, there's less money available for research funding, from Charity bodies, from the Research Councils, you combine that with the increased sum in living, that's also having an effect on our ability to buy things. Yeah, without research funding without money provided for gifts in Wills and other sources, yeah, we just wouldn't be able to do what we're doing. And so for me, I wouldn't have been able to continue with my biomarker work.

Libby: I think also, just to add to what Greig said, there. So obviously, my PhD is completely funded by gift in Will and that has given us the opportunity to recruit more researchers into the MND fields. So without that funding, I potentially wouldn't currently be pursuing a research career in MND, and learning all those techniques and skills and just gaining all the understanding that I now need to take forward a career in MND research. So I think, you know, without it, I mean, who knows where I will be, for example, like, so it's just really giving opportunities for recruiting more researchers into the field, which is massively important.

Majid: Retaining expertise is really, really important. If we didn't have that gift, then would be difficult to keep Greig and, and having Greig has been fundamental, bringing in a PhD student like, Libby = who can benefit from expertise, Greg's expertise,

Helen: Amazing. I mean, I'm sure everyone listening to the podcast is going to be incredibly grateful to the people who left that generous gift in their Will that has enabled the MND research field to keep Libby and for her to be able to learn everything that she's going to learn, for Greig to be finding those biomarkers and moving us forward. And Majid, thank you for all of your hard work all three of you. And your perseverance and commitment to helping the MND community find the answers that we so desperately deserve. But we're also joined by Hetty who is the chair of the South Herts branch of the MND Association. And you received as a branch, a really generous gift to help people living with MND. Can you tell us about what difference that that gift in Will has made for you in your branch?

Hetty: That's made a huge difference, especially as it was received just after COVID, when the main aim of the branch is to raise funds to support people living in in our area. And in South Herts, we have 60 plus people living with MND. And that £5000, as I say came when fundraising was so difficult. And it's made it's made a huge difference. And it's allowed us to carry on, on a very timely basis, being able to turn around these requests for help. Just to show you the amount of requests for help that we get. I mean, in 2020, we gave nearly £15,000 out for requests. In 2021, which was right bang in the middle of COVID, that was nearly £30,000. And this year, so far, nearly £18,000. And our fundraising doesn't

match that. We get lots of donations from people who do, who want to know, legacies, small, small legacies much smaller than the one that we got the £5000. And it's it's huge. It's hugely valuable. I mean, as you all know, I mean, MND patients, they can't wait for social services to intervene and provide equipment because they need it. By the time that happens, they would need something else. So to be able to meet these requests and make life as comfortable as we possibly can for these people is hugely important to us. And that £5000 made a huge difference.

Helen: Thank you so much Hetty, because listeners might normally know, from a branch and group - you're all volunteers.

Hetty:

Yeah, so we're all volunteers. And our main aim is raising funds to be able to support these people, but also very important to us is raising awareness. So but that's raising awareness is really important to us as well.

Helen: Phenomenal. So you're there, and your whole committee at South Herts and all of the other branches and groups across the country are there to support people affected by MND and offer those those grants and financial assistance. And that's what this legacy has gone to help provide. Can you give us some examples then of what sort of equipment or activities that the people living with MND might request from the branch?

Hetty: We get probably get about 10 to 12 requests for riser recliner chairs, so that people can independently transfer themselves out of a chair to standing positions. We have one gentleman who we've been funding for two years for Pilates and massage sessions because he's still working. His progression is quite slow, but he finds it a huge benefit to him to be able to keep as mobile as he as he possibly can. We provided quite a large amount of money last year to a gentleman who wanted to be able to access his own garden, but with being in a wheelchair couldn't do that anymore. So we've paid for works to be done to his home. Its whole very varied, wealth of activities and equipment that we that we're able to help. Personally, I find it very gratifying that when somebody requests help through national office, that's just a quick email for me around our committee members to make sure that at least two or three people are happy with that. And then within a week or two, that funding is sent through and virtually immediately that person can have that piece of equipment that they that they need, which is yeah, which is absolutely great. And there's just making sure that people are aware that we're here as a branch to support them in any way we can. I've been chair of the branch now for nearly three years. And we've never said no.

Greig: What I want to do was to thank Hetty because yeah, it's people like her who are helping to raise the awareness of the Association which helps. The gift that was given to us wasn't someone directly linked to MND, but they had awareness brought to them of the Association and the work they do, because of the work that were done by people like Hetty who run the branches. So yeah, I just wanted to say thank you to Hetty for you know, giving all the time and effort and energy that she does to do what she does, because it is really important for people like us who are doing the research, you know, I mean, I can't do what I'm doing without people like Hetty so I just want to say thank you.

Majid: The great thing about the MND Association is the close link between people like Hetty who are putting so much effort on voluntarily helping raising awareness and funds for research as well as looking after people with MND and their families. So there's a very close relationship between us and the volunteers within the MND Association. So yeah, I mean, this is a very, very, an amazing community of researchers, carers, volunteers, families, members, and also in people with MND. This is a very, very tight knit between them.

Helen: Yeah, that is, is wonderful. This podcast is all around like the importance of gifts in Wills. And I did give you all a warning that one of the questions I was going to ask at the podcast, was to sum up the importance of gifts in Wills in only one word, so that is hard. Is anybody prepared to give us their first words of the importance of gifts in Wills?

Hetty: From a branch point of view, with fundraising being so different having been so difficult, I would say it's **vital**. It allows us to carry on doing what we're doing. We had that one very generous legacy, we've had lots of smaller ones as well. And cumulatively that it's, it's vital, along with all the other fundraising, it's really important.

Majid: My one word would be **continuity**. That's so important to be able to continue the research and build on what what we have achieved and keep the momentum going.

Libby: And so I would say it's an **opportunity**. So most importantly is an opportunity for the person generously leaving the gift in their will to make a mark and know that they are contributing to helping someone maybe facilitate being more comfortable with their living with MND so it's an opportunity to provide care. From a personal perspective, it's an opportunity to beginner research in motor neuron disease and being funded myself by legacy. And it's an opportunity from a research point of view, to explore more avenues and try because we're going to be exploring new avenues, we might be able to find a cure somewhere within those. So with that money, it's really an opportunity on lots of different levels.

Greig: And I think my word would be probably **hope**, because, you know, I think the person who is giving this gift to the MND Association, they have a hope that their gift that they are giving to the MND Association is going to make a difference.

Helen: So when we say 'Your signature is more powerful than you think', your signature is, hope, is continuity. It's opportunity, and it's vital. So Debbie, if people have been inspired to write or review their Will, how can the MND Association support them in doing so?

Debbie: Well, in the first instance, all details can be found in the show notes linked to this podcast where you can find links to the gifts in Wills and free Will services web pages, further information as well is available on our website. And if you want to go ahead, it's quick and easy to organise. And it's peace of mind that everything is organised as you want it to be. We're also running several virtual legacy events this Autumn, including one in September on making your Will if you want to find out more or register an event, please do have a look. And we hope that you will consider it.

Helen: And I know once people have listened to this podcast and listen to the the real life examples that have been shared, they are likely to want to help make that difference. So if anyone has any queries, they can also contact you direct can't they, on the legacies team contact number, which is 01604 611799. Well, thank you so much to all of you for for coming along and telling us all about your work and more importantly the difference that the generous people who have left that gift in their will have made.

33:02

Thank you. Lovely to meet you. Thank you.

33:04

Thanks so much, Helen. Thank you. Thank you.

33:09

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