

## MND Matters: Episode 12: Home Adaptations

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**Chris:** Alongside members of the MND community, we bring stories, information and expertise direct to your ears. Remember to subscribe to ensure that you don't miss an episode.

Hi. I'm Chris and I'm Director of External Affairs at the MND Association.

**Beck:** And I'm Beck and I'm one of the Area Support Coordinators at the MND Association, and I'm delighted to say that today's guests on this episode are going to be talking to you all about home adaptations for people living with MND. So, we've got Jane joining us who's a Specialist Occupational Therapist in the Dorset area and we've got Tom and Alice. Tom's living with MND and Alice is his partner.

**Chris:** You may hear a few beeps during this episode. Don't worry. It's not your laptop or phone playing up. It's just Tom periodically adjusting his chair to get comfortable. All three are here to share some insight on housing adaptations and, from their unique perspectives, will be able to tell us all about what good housing adaptations might look like and how they can be vital for people living with MND.

Jane, if I could start with you. Could you tell us a little bit about your role as a Specialist Occupational Therapist and, indeed, why housing adaptations are so important for people with MND.

**Jane:** Yes, of course, Chris. It's great to be here. As you say, I'm a Specialist Occupational Therapist and I work for Weldmar Hospice Care down in Dorset. Like many palliative care organisations, we're a charitable organisation part-funded by the NHS, and as part of the services that we provide, we provide the specialist service locally for people with motor neurone disease. And my role as an Occupational Therapist really is to help the person with motor neurone disease adapt to the changes in their abilities and to carry out daily tasks as the MND progresses. So that might be helping them with daily tasks that we all take for granted, such as getting washed, dressed, being able to move around the house safely, prepare meals, being able to socialise, go out to work, carry out hobbies, all those kind of things and really the aim is to help them develop and maintain as much independence in those activities as possible. So, it might be looking at the way that they're carrying out those activities, looking at different techniques, changing how that activity is carried out. It might be looking at specialist equipment to help that person be able to be independent or it might be looking at the help that they've got at home and, perhaps if they're given some help with part of that activity, they might be able to carry out the rest independently.

But, as you can imagine, when it comes to independence, it's the environment in which the person lives that can have the greatest impact upon their ability to function independently. So, if you can imagine, if your ability to walk is getting more and more difficult, if you live in a property that has lots of internal steps then your property is going to be working against you as opposed to for you. If perhaps you are having difficulty with your hand function, then a conventional toilet flush, conventional taps are going to start to be difficult use so, again, your environment is working against you as opposed to for you. So that's why housing adaptations are so, so important because it could mean the difference between being stuck in one room in the house

or being able to access most of the rooms in the house. It could mean every time that you need the toilet you're having to ask someone to help you or it could be the difference between actually being able to do that yourself, so it makes a huge impact on someone's quality of life and not only upon the person that has MND but also the people that they live with.

**Chris:** We often say that everybody's journey with MND is different and I can imagine when you first meet someone with MND that challenge is always different because the environment in which they live is going to be different and challenging each time I guess.

**Jane:** Exactly, yeah, totally agree. Obviously, what can be achieved in one property can't be achieved in another so, yeah, it really depends upon where the person is living, whether it's rented, whether it's their own property, there's so many factors involved.

**Chris:** Thank you.

**Beck:** Yeah, there's so much to consider and think about on top of everything else. So, Tom and Alice, I saw a few nods when Jane was talking about some of the things to consider there. Could you tell us a little bit about you moved into a bungalow didn't you when, Tom, you received your diagnosis. You took that decision to move from where you were currently living to somewhere that would be more accessible for you. Can you tell us about that?

**Tom:** Yes, that's right. We were living in a flat but it had an internal staircase so it simply wasn't practical and so we had arranged to move into this bungalow so Alice looked after everything and arranged financing and grants and everything so she could reply in more detail.

**Alice:** When we were in the flat, we got an estimate for a chairlift which would have been a short-term solution and it was £6,000 and we thought it would be better to spend that money on moving rather than on something that was only short-term because there wasn't enough room for a wheelchair really to move around upstairs. So, we moved here and we had a plan but, happily, because of lockdown we had to move in before we had the work done and, once we were here we changed our minds, or I changed my mind, about what to do and I'm really glad. So, living here before we did the work was really important in our decision making. Here, we only had a shower over a bath and at that time Tom was just about able to manage that sitting on a bench with my help, but we had a small extension to make a wheel-in shower which was a really, really good thing and then we had part of the corridor widened and two doors widened so that the wheelchair could turn in. We had ramps at the front and back door and a remote-control garage door.

We changed all the carpets to hard floor which was really sad but incredibly sensible in terms of going out to the park and coming back and me being dismayed to see tracks across the carpet. And, at that time, we also only had a mobile hoist which, to push the mobile hoist across the carpet was a bit of a nightmare, and obviously the Occupational Therapist there is saying 'of course it's a nightmare'. So, the Occupational Therapist organised a ceiling track hoist and we got rid of the carpet so all of that was a big improvement and we did spend out on a Japanese toilet and it was easier to do it because at that time we were having the bathroom extended so nothing was tiled and it was easy to fit the water and electricity. But, in fact, that hasn't been useful to Tom so it's not I think a long-term thing because you can't use it once you're in a wheelchair. Well, I don't know how we would use it now Tom's in a wheelchair.

**Tom:** I'm at that completely impractical level. We did learn how to use the mobile hoist at 2 o'clock one morning when I slowly fell to my feet and Alice had to wheel the thing in and we

were both on the floor looking up You Tube videos on how to use the thing and trying to operate the thing by looking it up. I think it took about an hour but it was quite a good lesson in cooperation.

**Alice:** To be fair to the Occupational Therapist, it wasn't apparent that we would need it. It had been delivered in advance of us needing it but, unfortunately, the need arose before we had the training so when the training was offered, we said 'we don't need that'.

**Chris:** Yeah. A decision you probably slightly regretted at 2 o'clock in the morning.

**Beck:** But thankful for hard wood floors! So, what would you say has made the biggest difference adaptation wise? Is there one stand out?

**Alice:** I think it's the whole combination. Jane was talking about being able to, say, go to the loo independently and I'd be really interested to know what you would recommend because we haven't achieved that. The fact that Tom can go around the house in his wheelchair without a problem, that I can hoist him without injuring my back and then the ramps because, before we had the ramps Tom wasn't in a wheelchair, he was using a mobility scooter so he would go to outside the door on the mobility scooter, he would stand while I lifted the mobility scooter over the threshold and then he had to climb over the threshold and sit back on the mobility scooter. So, for him to sit in the wheelchair and just waft along is wonderful.

**Chris:** Jane, I know we said everybody's journey is different. Does Tom and Alice's story resonate with you as a Specialist Occupational Therapist? You come across these sorts of challenges on a fairly regular basis?

**Jane:** Yeah, most definitely, most definitely. And I was really interested in hearing Alice talk about the decision making that was involved in terms of moving. As she rightly said, stairlifts are brilliant but they only meet medium-term needs so, when it becomes difficult to get on and off a chair, suddenly the stairlift isn't achieving what it needs to achieve for you. And, like you say, everyone's decision making will be different so it may depend on the form of MND that they have and its progression. Also, as we've already said, what is possible within the property that you're living in. It may be that some properties just simply don't have the space that is needed for an external adaptation or a through floor lift. And it also depends on how each person feels about those adaptations and what they're happy to accept, so the decision making will be based on so many things. So, I've had people that have been concerned about the legacy that the adaptations will leave for family, perhaps people that have got younger children, and so the decisions they make will be dependent upon how they feel about the adaptations themselves and what extent they're happy to go to. So, yeah, so much involved. So many factors.

**Alice:** I had a conversation with somebody that we met through an MND group and her husband, Tom has ELS which is the slow progressing form, this person had ALS and they were living in an ordinary house. And she said 'do you think I should get the double bed moved downstairs?' and I said 'well, take professional advice but my immediate reaction is no because we've progressed from a double bed to two single beds to a single bed and a hospital bed close together to a hospital bed with a space on each side and at no point would a double bed have been useful once Tom had started his deterioration'.

**Chris:** And I guess this is one of the challenges with MND as well is that trying to predict that progression in terms of changes and adaptations that you're going to make in the future and

trying to look ahead isn't it?. Not making those instant decisions which seem like a good decision at the time but actually turn out to be a burden when you move forward.

Jane, can I just ask you, I suppose it's a slightly difficult question to answer in a sense but what do you think good adaptations look like? You know, what are the sort of things that you've seen or done or worked with people on that have really helped them do you think?

**Jane:** Well, I was thinking about this Chris, and I think there's two things really there. I think one: a good adaptation meets the person's long-term needs, that's really important. That it considers what they're going to need right at the very end and, also, they need to be timely. We know that. Working with people with MND day in and day out, I'm so aware of the need for timely access to adaptations.

But, in terms of what a good adaptation might look like, I was wondering whether it might just be, we've talked about some things, but if I just talk through the kind of things that might be considered as part of an adaptation. So, obviously when I go and do my initial assessments, I'm looking at the environment in which somebody lives and I'm thinking about how it's going to meet those long-term needs. So, someone living with MND is likely, ultimately, to become a wheelchair user so it's about looking at that level access to the property, as Tom and Alice have had the ramps done. It might be, in addition to that, looking at changing what the path is made of - if it's a gravel path, that's going to be difficult to use a wheelchair on. We might be looking at widening the path, ramps as we said. Where ramps aren't possible, it might be that an external lift is needed to overcome the steps. Internally, the person's going to need level access really to all the main facilities within that space so if there are small internal steps it might be looking at how those can be ramped, how doors can be widened, looking at hallways – they might need to be widened with internal walls moved to accommodate the turning space for a wheelchair. It's not just the space going through the door, it's the turning space before you get through the door.

And then, as I've said, how are they going to access the bedroom, the bathroom. So, sometimes you're looking at a through floor lift but, as you can imagine, that takes a fair bit of space because it takes a bit of space in the downstairs room and a bit of space on the first floor. So, then you might be looking at the ground floor and how that can be adapted. Sometimes people don't need an extension. It might be that internal walls can be moved, or rooms can be kind of refashioned to become a bedroom but often an extension will be required so it's thinking about that, and it's also thinking about the space that you need within the rooms. As Tom and Alice mentioned, the need for a profiling bed, the need for a specialist wheelchair, perhaps a specialist seating, all these things, hoisting, it all takes space, so these rooms need to have enough space within them to accommodate all of that.

When it comes to washing and cleaning, the person, in order to be as independent as possible, is likely to need a wet room so that's a fully level floor so that it can be accessed in a wheelchair or a shower chair and also, within that, it's thinking about how the person can be as independent as possible within that room. So, as Alice has said, a wash/dry toilet can help for a certain amount of time. You might want to look at sensor taps so that it's easy just to wave and the water comes, so it's those kind of things within that that you're thinking about. And then if the person wants to be able to perhaps continue to play a part in preparing meals or preparing a drink, you might be looking at the kitchen and lowering the surface so that it's got wheelchair access. So, there's a lot to consider and, as Alice has rightly said, within all of that there's flooring, there's how do you access lighting and controlling the temperature independently, so environmental controls come into all of that. So, a lot to consider. Some people will be considering it all. Others won't need all of that. It just depends on their own personal situation.

**Chris:** Of course, yes.

**Beck:** The first thing that comes into my mind is it sounds very expensive and there is a lot to consider like you said there Jane. And it sounds like Tom and Alice you thought about this a lot with the things that you've mentioned there around some of the adaptations you made. So, how, if it's okay for us to ask that, how did you fund it and what was the thought process behind how it was funded?

**Alice:** The main part of the money came from our savings but some very expensive things, like the ceiling track hoist, were funded by, I don't know whether it's the NHS or Social Services, via the Occupational Therapist and the wheelchair is being financed by, provided by the hospital which is brilliant because they not only provide it but they adapt it as things change. We were very grateful for a grant from the MND Association, not only for the money but for the fact that you make it so easy to make the application. You've got your clear flowchart of what you might be able to have and then a form to fill in that's not difficult. So, we had £1,500 towards our house adaptations and then £500 towards us buying a wheelchair accessible vehicle and then I've had £500 for respite care. Yes, incredibly helpful and supportive and, not only that, but the person who locally administers it was helpful with his comments on what to do. The actual extension, because we had other work done it's hard to say exactly how much that cost, but it was around £6,000.

**Chris:** I'm so pleased that you were able to take advantage of the grants programme that we have because I think it's one of the most vital services that we provide as an Association so I'm really, really pleased that you were able to do that. It's nice to hear it's easy as well which is good news. That's always good to hear. Thank you.

Talking about funding actually, I just wanted to ask Jane about what support the local Council should provide in these circumstances and perhaps actually what other support might be out there for people.

**Jane:** Yeah. Well, what happens locally for us is, once I've carried out my full assessment as the Specialist Occupational Therapist, then I refer to my colleagues in Social Services who work for the Council, so the Social Services occupational therapists. And what they will do is visit the person's home with a technical officer, and the role of that visit really is to see what is possible within the environment that the person lives in and, following that visit, they will draw up a schedule of works and obtain quotes from contractors. And then, alongside of this, they have a preliminary test of resources which is a financial assessment so it looks at your income, your savings, your investments and properties other than the home that you live in and, depending upon your assessed resources, there may or may not be a contribution to pay towards the adaptations. For some, the calculated contribution might exceed the cost of the works in which case they will be asked to pay the full amount and for some, as a result, they decide to arrange their adaptations privately. If someone's on means-tested benefits such as Universal Credits, they don't need to have a test of resources because, of course, they've already had that as part of the means-testing around the benefits process and, also, as a result of that, they won't need to pay anything towards their adaptation.

So once those two things have happened, once you've had a visit from the occupational therapist with the technical instructor and the test of resources has been carried out, the occupational therapist can then apply on your behalf for a Disabled Facilities Grant and, depending on the outcome as I've said of the financial assessment, this will cover between 0%

and 100% of the cost. The schedule of works is then sent to the grants officer who then decides whether the works meet the eligibility criteria and once the decision is made then the works can get started. It's important to note that if you start to begin your own adaptations privately prior to the end of this process, then you won't be awarded a grant. So Disabled Facilities Grants can't be awarded in retrospect – that's really important for people to remember that. In terms of the maximum grant that's available, in England that's £30,000, Northern Ireland it's £25,000 and Wales it's £36,000 and, if a grant is agreed, it will only cover essential adaptations, so it's to meet the essential needs of a person. If people have their own thoughts about particular finishings to the adaptations, so I've had people that I've worked with before that have been concerned about what the wet room might look like when it's finished, so, if people do have an idea of particular tiles or a particular way they want it to look, of course, they could pay over and above that little bit extra to achieve that.

You asked about additional help. I can't praise the MND Association enough in terms of additional help. I find personally the professional website extremely helpful. There's a booklet particularly aimed at occupational therapists with regards to MND which is really helpful. There's also the detailed information leaflet for people with MND and their families entitled 'Disabled Facilities Grants and Home Accessibility' and that is extremely helpful. In addition to that, we've mentioned the MND Support Grants. I've accessed that on behalf of the people that I've worked with on numerous occasions. Through the grants, I've looked at stairlifts for medium-term needs because, of course, sometimes people will have a Disabled Facilities Grant application going through for a ground floor adaptation or a through floor lift to meet their long-term needs but, whilst that's going through, they've got the problem that their mobility's deteriorated and they're starting not to be able to access the toilet upstairs or the bedroom upstairs, in which case that's an occasion where it's really useful to have the MND Support Grants. Because the support grants won't cover what's going to be provided as part of statutory services, so it wouldn't cover what's being covered by the DFG, but anything that's not covered by that which would have an impact upon the person's quality of life we can apply for so that's been extremely helpful.

**Chris:** Thank you, that's really interesting.

**Beck:** Yeah, it's a funny thing isn't it, hindsight and knowing what you might need in the future but you also need to work out what you need right now and, Tom and Alice, you already mentioned that, in terms of sharing with local people with MND in your community and them asking you about beds. Well, you now know that actually it probably isn't practical to have a double bed because you're probably going to need to get around the sides but at the time you don't know what you need. So, sharing this information is so important so people can start to think about it now but what we also know is sometimes we don't have time.

**Chris:** One of the things we want Councils to do is to have a fast-track process for people with MND and also to remove the sort of financial assessments as well which can slow things down for the Disabled Facilities Grants if the Grant's under £5,000 so that's the sort of thing we're looking at. And I just wondered if you have found the process slow for your needs?

**Alice:** We didn't apply for a Grant because we were aware that we're lucky enough to have enough savings that we wouldn't be entitled. We won't have much left by the end. So, the only thing that's been really slow was a particular kind of postural support chair.

**Tom:** A static one. And that was being organised by the Council and it kept having to go to another Committee for approval but, at the same time, the Health Service was organising the

chair I'm sitting on which is a six wheel – it's wonderful. A power chair, and it does everything I think that posture chair would have done.

**Alice:** And, also, Tom can do it himself whereas the other one I have to work the controls which is just frustrating for him.

**Tom:** That I have to ask someone to push me from one room to the other, yes.

**Alice:** And there's an element of grumpiness by the pusher.

**Chris:** Thank you very much.

Jane, you've been involved with the Act to Adapt campaign. I just wondered do you want to talk a little bit about your involvement with the campaign?

**Jane:** Yeah, definitely. As you've mentioned, the Act to Adapt campaign followed the Act to Adapt reports in 2019 and that was written following surveys and engagement events I think with members and professionals, giving them the chance to talk about their experiences really across the country of that housing adaptations process. And, from the reports, it concluded with various recommendations of good practice that Councils might follow, and the campaign followed that with various recommendations and West Dorset here we were one of three pilot areas for the campaign and the idea really was to start looking at how our Council measures up to the recommendations. As you've said, recently the campaign is focussing on two, well eventually three, main areas. One is the fast-tracking process for people with MND. Just to explain that a little bit more, at the moment Councils have a statutory timescale of six months to come to a decision as to whether somebody is eligible for the grant. What fast-tracking says is what we would like Councils to say is the fact that someone has a diagnosis of MND, fast-tracks them to that eligibility so, if an application is made and they see that someone has motor neurone disease then, the very fact that they have that will qualify them for a Grant. And some Councils are doing this already but obviously there's more to be done. And the second one as you mention Chris was the removing financial assessments for DFG's under £5,000 for people with MND. So that might cover the medium to small adaptations and if you're saying there's no means testing, that's taking a level of the timescale out. The person's not going to have those financial assessments so in a way that's also fast-tracking.

And eventually I know, as part of the campaign, you're going to be looking at asking Councils to maintain a register of accessible homes for people to move into so that, as I mentioned before, sometimes people's properties just don't lend themselves to adaptation and moving house is the only option. Well, we would like Councils to be really on top of what is available locally for people. What we've been doing really here is I've been meeting with members of the MND Association. We've been talking about how we can look at how we measure up really to those recommendations from the report, so recently some of the members of that team met up with our Councillors locally just to see what could be done.

When it comes to the point of financial assessment, there's actually quite a lot of paperwork to gather and sometimes I was finding that the people I was working with, at the time the person came to assess their finances, they were struggling to get their hands on those pieces of paperwork so, if that can't be sorted within that visit, then it delays it until the assessor can come again. So, what we spoke about is if I can have a list of all the paperwork that's needed when I go and do that initial visit then people can start gathering what's needed. And, again, it's just looking at the pinch points in the process, where can we make things a little bit quicker, a little

bit smoother and sometimes there are quick wins in that. I was also asked to speak to Councillors at both the Labour and the Conservative Local Government Association Conferences last year which was a fantastic opportunity for the Motor Neurone Disease Association just to raise the profile of this campaign with Councillors and it was so great to be involved in that in the hope that Councillors would then take the message back to their respective Councils, so it's been great to be involved. Anything that I can do to kind of help the process be a little bit easier, well, I'm in.

**Chris:** Thank you. It's massively important to have your input. It really makes a huge difference. Thank you so much for all of that Jane.

**Beck:** Yeah, and if anyone's listening and wants to get involved in the Act to Adapt campaign, we've got lots of information on our website and we'll include the link as part of the podcast description for this episode. You can email us at [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org) and someone from the wonderful Campaigns team will get back in touch with you and just let you know how you can help us and be more like Jane and help us out.

I think we're probably coming to the end of this episode now but I just wanted to give the opportunity to Tom and Alice and Jane as well, if there's anything that you think we haven't covered that you think would be really good to share with anyone listening, or like any tips and tricks, or like the one big takeaway from this process when you were doing your adaptations, I think that would be really useful here.

**Alice:** When Tom was diagnosed, the Consultant said 'the question that you want to ask is the one we can't answer' which is how is this going to progress? And therefore, we have always felt that we can't make a plan because we don't know what we're planning for. You know, you can't say 'right I'm ready, I've got a plan' because you don't know what it is, and so my thought is to make the big changes which, for us, was getting rid of the stairs, and then everything else we've just done as we go along. And the really important thing, Jane was saying about leaving space to turn around, get rid of things. When you don't need them anymore, give them back or sell them if they're yours. Because otherwise, you know, at certain points when I wasn't sure if we'd finished with something or not, we'd end up with a traffic jam of zimmer frames and mobility scooters and the wheelchair that we weren't using, so, get rid.

**Jane:** Good advice. Good advice. I'd add to that, I think my piece or pieces of advice, seek an assessment from a qualified occupational therapist as soon as possible after diagnosis. I think that's really important – someone who can assess your individual needs – and your neurologist or your GP can help with that referral, so they can help you to access an occupational therapist. Secondly, I think my last piece of advice would be, I am so completely aware that when it comes to adaptations, we're asking people to consider something very difficult early on so, because of the timescale, because of the need for things to progress quickly so that you've got the adaptations in place for the time that you need them, really people need to start thinking about it often when they're just coming to terms with the diagnosis and it really isn't easy to be thinking about these things and we're forcing people to start to think about what the end stage of their MND might look like.

So, really, my advice to people would be to acknowledge that, that it's difficult. If they can, after the assessment, once they've got the information they need, to really just take some time out to really think about what they need and what they want but it also might be a question of how independent do I want to be? I guess what I'm trying to say is, if you've got a property that perhaps you can only adapt it so far in that you can have a bedroom and you can access a



living space but you can't have a wet room because it's not going to allow you to do that, then the question would be do I really want to stay here knowing that, possibly in the future, I may have to accept someone coming in to give me a strip wash and to help me in that way, or do I want to move house? And that can be a real, real difficult decision for people to make, like I say. If they've got family, young children living there, it all impacts on that decision. So, my advice would be take the time out, go out for a day or an afternoon, somewhere where you're relaxed and with the person that you want to talk this through with and give the time to it. It's not easy but if you manage to do that early on, then you will have the benefits later on down the line.

**Chris:** Thanks Jane. I think that's really, really good advice and thank you for that and thank you Tom and Alice as well for your advice and top tips. That's really, really helpful for people I think and just to add my top tips. To say, in terms of the MND Association, you know, we can provide support through our MND Connect line and also local support through our staff team and our volunteers and branches as well can provide support for people so that you're not alone in trying to make these decisions. And if you do have any issues with local Councils, then you know you have your local politicians, your MP's and councillors to get in touch with as well. We talked about the Act to Adapt campaign but, if individually you're going through these types of issues, then this is the time for your local politician to wield some power over the Council.

**Beck:** Thank you all so much for coming along and taking part in the podcast today and sharing your experiences. I know that this will be a great deal of help for people who are listening with MDN or affected by MND, and we hope that what you've said today has made it a little less daunting for others so thank you very much.

**Chris:** Absolutely. And indeed if you've been inspired listening to this podcast and you'd like to find out more about campaigning for the Act to Adapt campaign or the Welsh Homes for MND campaign in Wales, helping us to improve access to housing adaptations, you can get in touch with the Campaigns team as we've said who are also on Twitter @MNDCampaigns or via email at [campaigns@mndassociation.org](mailto:campaigns@mndassociation.org) or by searching for the MND Association's Act to Adapt campaign online.

So, thank you very much and thank you so much to Tom and Alice and Jane for sharing their thoughts and advice. It's been really, really interesting to chat to you. I've really enjoyed it I have to say, it's been great, thank you.

**Tom:** Thank you, you're very kind.

**Outro:** You've been listening to MND Matters, a podcast from the MND Association. Find more information at [MNDAssociation.org](http://MNDAssociation.org) and if you've been affected by any of the issues raised in this episode contact our helpline MND Connect on 0808 802 6262 or email [mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)