

Ep2: Sorting It Out

Dr Therese Burke

So to kick off Episode 2, we're going to commence our discussions by So we're going to look at some strategies to manage tricky times and we're going to start with talking about independence in So, a diagnosis of MS can sometimes impact on an individual's concept of independence. And it's a fine balance as much as you can when you can, but also letting others help if you want it or need I've heard over the years quite often that people just don't want to feel like a burden. It's a common theme. It comes up and finding the balance can be really difficult.

But you need to be honest about how you're feeling and that's the really. don't want to hurt anyone's feelings, but being able to sort of say, yes, I want your is it OK if you step back at the moment? Because I want to do this and I can I found just a little tip that it's usually easier if when you agree to ask for actually follow through with that and let the help happen because then people- Yes will know, OK, well, you know, she'll, she'll ask or he'll and I can help having those conversations early and setting the ground rules is a pivotal part of making sure that you can maximise and maintain your independence. And with that comes the next None of us have a crystal ball to know what your MS is going to do next or when and that can be a challenge for some people.

It can be an opportunity and we'll explore some of those a little bit I think something that is really important is actually acknowledging prepared for something that doesn't go quite the way we would hoped it would, but also never feeling like you need to change everything right now just in case. we can have very well educated guesses based on our experience about how things might go, but we still and we've all been very wrong about that at times, haven't we? Yeah. Mm.

But we still never know exactly what's going to happen in terms of where the relapse is going to be, what symptoms it might look like, what your response medications might be like. They're just things that we just at this stage don't know and can't know. I particularly like. And you've all heard me speak about this before, Kreiger, who's in New York, and he has this model of looking at uncertainty with his MS patients, which I really And I think it's very helpful and positive.

And it's looking at uncertainty in a different way. So we've traditionally looked at the concept of MS as a negative thing that we just can't tell you what's going to happen. But he said, what if we flip that and look at it as a because we don't know how this is going to go. Let's focus on that.

This might go really well and you might have a good response and we might be able to stop the relapses. might be able to prevent progression and more symptoms. And what if we really celebrated the gains that we make? So if you're coming in for an appointment and at particular time, there's no new MRI lesions, you're doing really well on medication.

That's a course for celebration. It's been a big win and celebrate that. So what if we looked at things in that positive light? And I really like what that brings to And knowing that capacity to flip it around, even just from our time in this disease, it has changed so much.

But even before we had the treatments, knowledge and the skills and the monitoring, we have now that misnomer that everyone in MS is going to end up in a not the case. Most people never ended up in a wheelchair even before we had the and the knowledge and the monitoring that we have now. So that understanding of things that we also used to caution people about, like exercise is now one of the most important things people can do to be in control of their side of

the MS as well. So those things just give us that next step of the future can be what I wanted it to be.

And on that note, we're going to talk about work and study next. So trying to find a new normal when everything around you is changing and you just want to hold on. For many people, work, career and study means their identity and adding it together with MS can be very and it can bring a lot to the surface. So Belinda, what do we know about work and we'll call it work, but there are obviously very many variations of

Belinda Bardsley

But there can be so many ways that MS and work can collide. And this can be around work hours and start and finish times and our enjoyment of work, how our work roles change, how to work effectively, balancing homework, families, social and MS So input from a psychologist can be really helpful in clarifying your feelings and your needs around work and exploring ways to make changes at work or, you know, study improve results. Being more conscious of taking work breaks, changing start and finish your needs and your energy levels. Also looking at getting some OT or physio assessments, some workplace assessments to help with make things more comfortable for your work.

looking a bit more at energy pacing to sort of manage fatigue levels can helpful here.

Dr Therese Burke

Yeah, because occupational therapists, are genius at like, oh, at that in particular, aren't well. Yeah, aren't they, with that workplace Yeah.

Tim O'Maley

look into, you know, how we find that balance in my time working in the community centre, you see a lot of people who take this opportunity to really evaluate where they're at and what they're doing, working out that work life balance. Belinda just touched on things as simple as adjusting your start and finish times, working a four day but a longer planning your breaks a little bit better with your boss or your study things like that means you can still get that sense of achievement. But it also can be a way that people just adjust where they want to little bit with that balance for how they're feeling with their symptoms, but also their relationship with their family, their friends, opportunities, but very

Sharon Barlow

And so I guess when you think about decisions that need to be made at this time, it's really important to take some of the pressure off, even if you are feeling pressure to answer questions and really weigh up the pros cons and not make decisions in a hurry, particularly points of crisis. So, you know, we touched on it episode around diagnosis, but also, if you were to be experiencing a relapse or progression or you're know, a big medication change, it's often better just to wait, see how the dust settles, return to baseline and then make a bit of a call around whatever it is you were contemplating and chat to the people around you, your feelings and your needs around what the potential time frame for a baseline might be.

We don't have a crystal ball and like we say, think it's very but usually, you can get a little bit of an idea around the trajectory and a range of what we're expecting. And that can decision-

making. workplace and study adjustments might be very short term, mightn't Yes. It might just be for a period of time that somebody needs to have those sort modifications made and then they can get back on their feet fully.

Absolutely. Yeah.

Dr Therese Burke

So talking about decisions, some of the biggest and most important ones that come up quite early are decisions about family planning, which we'll talk about next. So the importance of family planning can't be understated, particularly at the beginning, even the very early stages of particularly around selecting the disease, modifying drugs that to be using and future treatment. it might be for some people considering these types of things ready. They might be young, they might not be in a and such, but they're tricky issues.

But as with everything we've talked about so far, it's good to have it out open and have the conversations early, even if the answers aren't immediately there. And on a side note, menopause, we've got you covered in Episode 4, so we'll just move on with this concept of when the right time is to introduce it. There's never a wrong time, and it may feel like you're new to the diagnosis and a whole heap of decisions are way more important, but we want people to feel like this is going to be a part of something that put into their world when they are ready. We will always ask, is it on the agenda?

there a time frame for you to make you feel comfortable that we're going there, that opportunity will not be put on hold because of us?

Tim O'Maley

Sharon's going to talk a little bit more, but there's whole heap of information and research now that is telling us the importance of actually feeling like you have the right to have a and nobody should tell you otherwise.

Sharon Barlow

100%. I think we've all worked in the MS specialty long enough to see changes in how planning's been addressed in the clinic setting. And when I first started working in MS, I was told which were devastating about people being told not to have a baby because they had times and was talking to a mother of five children who said that she wanted 4, but she was advised that being pregnant is really good for your So she went the extra 1 and had 5! Family planning is a conversation that's an important part of MS care.

And it really starts right at that point, particularly around the MS treatment meetings. But if it doesn't come up, please bring it up. It's so valuable.

Belinda Bardsley

And research from key MS groups such as Jokubaitis, along with her colleagues at Monash University in Melbourne, tells us that pregnancy can actually bring some really positive to MS. So the top three things that Vilija would like you to know include that MS does not impact your ability to become pregnant, but it can sometimes affect what needs to happen to become pregnant. changed so she notes that sometimes pain or discomfort or dryness sometimes other

secondary things like mood or libido or relationship issues sometimes impact on those capacity to become But also keeping in mind that infertility effects about one in six Australian couples. So people with MS can be affected for those very routine kind of reasons as well, just like anybody else.

So if needed, fertility treatments are generally safe for women with but please talk to your neurologist about IVF treatments if you're heading that pathway. The second top tip is if you can aim to plan your pregnancy with that as healthcare they can just give you advice about the medication that you're taking and timing of that and its compatibility with pregnancy and help you plan out the best pathway forward. Most women feel great during pregnancy and their symptoms diminish completely And the third top tip is that there is a slightly increased potential for a relapse post in postpartum period. So we all keep an eye out for that as healthcare but this can depend a lot about the number of relapses you had in your keep, we keep an eye on people quite closely.

So we don't want you to stress too much about that. The best strategy is to make a bit of a plan with your MS care team your MS therapy after you've had the baby. And that'll be different for everyone depending what treatment you're going to So all really good positive news there.

Tim O'Maley

Sometimes men can feel a little bit left out with these as well. Yeah. sometimes that can be a little bit of a positive in that a lot of the medications and treatments we can give men really good reassurance that it's not going to affect their capacity help their partner fall pregnant. But at the same time, that's equally as important for the men as it is the women in terms of what they are comfortable being on conception process.

It also is really important that we acknowledge the symptoms and men can have problems with erections during that time and addressing those really early is a part of And of course, the other side of the male role is actually supporting their female partner living with MS in pregnancy and conception planning. How are they all comfortable with the information they've got about the medications, the treatments and the timing that fits with well.

Dr Therese Burke

Well, I want to move on now to parenting with So there's some special considerations that MS can bring variations of these. But there can be so unpredictability, not knowing when your symptoms are going to flare up. up. The extreme fatigue, which we're going to talk about in a in a little bit more depth, can impact people with MS and feeling different to other parents because of those symptoms, wishing you could do more for your children.

So lived experience research tells us that although parenting with MS has unique challenges, it can be highly rewarding and centering. But to do this well, you need to have all of those support systems in place we talked about in Episode 1. So Belinda, particularly of looking at uncertainty with benefits.

Belinda Bardsley

Oh, look, parenting brings such joy, doesn't it? it? And that's either with or without MS But it can also be a time of immense stress and reduced sleep strains and all sorts of challenges. and our enjoyment of know, parenting needs balancing with work, study, home life, medical care.

Of course, if you're dealing with MS and all the So Yeah. things I think symptoms can really impact on parenting. And probably the most common for all new parents, but especially parents with MS is fatigue. And so planning and implementing fatigue management strategies like accepting support, getting some help with the housework, including extended family and friends in balancing your work hours and trying to plan rest periods.

They're just as important Yeah. So we need to make sure that we make time for and just be really intentional, like build your parenting support network. I think this is good advice for all parents because as I say, it takes a So think about who your people are and be intentional about what you need, what you think you might for. I spoke a little bit about this before that, you know, it does little bit of planning when you're when you MS and you're on a medication.

So prenatal care does involve a bit of planning conception with a treatment management plan wherever possible and avoiding conception sometimes at key treatment times as well, depending on what medication you're on. And it takes a bit of the spontaneity out unfortunately out of the picture, but this is balanced by a plan to ensure the best possible outcomes for baby. And as we mentioned previously, there does seem to be some protection relapses during pregnancy, but your team will still want to keep a pretty eye on you and plan and commencements as necessary. Again, depending what treatment you're on.

you don't have to know all of the answers. will be a step by step process that you'll be guided through to help you make the right decision for you. Absolutely. There's some data available that shows that women who exclusively breastfed did reduce their risk of relapse.

However, we know that on its isn't necessarily a certainty. So we need to factor those things in. Overall, women are encouraged to breastfeed if they want to. And I think the mother's preference is a really this.

But also, even if you want to, it doesn't mean that of, you right. I think trying to take that pressure off yourself is really important. like you mentioned, knowing, having sort of a clear plan around when you want to restart or continue that treatment will help minimise the risk of having a postpartum relapse. And not everyone has one And I think we are much better now than we ever have been at working through and protecting mothers from having their postpartum relapse if they were to have one, based on the timing the treatment options.

Absolutely. And I think there's always uncertainty around breastfeeding, what goes into your body when you're breastfeeding from a medication getting that information from both your neurology team but also your obstetric team to sort of understand the individual risk benefit for both mother and that time frame, particularly that postpartum period can be quite possible outcomes for mom and

Tim O'Maley

Yeah. And especially if somebody was diagnosed after a pregnancy because still sometimes people's first experience is after a pregnancy. we also have to acknowledge that our treatments are much better these days than they were. What relapses people were having before they fell pregnant can give us some really good ammunition for you feeling confident in that postpartum period.

The top three things we should tell anyone at any stage is watch yourself and let us know when something's not quite right. out if you're struggling, we touched on the fatigue because this a

whole different type of fatigue that's going to impact your potential MS fatigue and just anticipating those things in terms of the happy to re engage with the neurology side of things and the treatment MS if that's restarting a medication.

Dr Therese Burke

So I guess to wrap it all up, it's about having that A- team in Episode 1, all on board and with you being confident comfortable enough to let people know when you're struggling and need the and getting it set up in because you often have a few months to do that now we're going to move on to talking about the those difficult emotions, which can really get in the way of living well with MS And they steal away joy. And to me, those words say it stealing away joy because that's what it does. there's various ways this may look - struggling with the saboteurs. That's when you get really into your head, feeling like I'm never free of feeling like you don't want to socialise, you just want to curl up on let the world go by refusing support when it might be good for you.

you. And there's many faces of fear that can present with It can be fear about symptoms, fear about the next relapse, fear about the disease modifying drugs that we're using and the side progression, disability. Fear of the wheelchair is a big one, but hopefully we've put that misnomer in its place because that just is not the reality that it used to be before we had treatments. So putting a words around your feelings and this load and psychological therapy can be a really important way to get through this difficult time.

People might want to talk to you about your MS, but you might not be ready on day. It might not be a good day for you versus you might want to rest from everything to do with MS And some people do take days, don't they? They've told me they'll take a rest day from having And sometimes you might feel like with your family and friends, that's all talk about, and that's what life has been reduced to. So we want to give you some tools now for tackling these sorts of tricky issues.

So particularly feeling a burden. Sharon, we mentioned this briefly in you

Sharon Barlow

unfortunately many people worry that their will make them become a burden to family and partners or even future partners that we haven't even met yet. Friends, work colleagues, you name it. So it's really important to talk about the feelings with your tribe. Just get it out there and make it clear that this is a worry because quite often the with the person who's worrying and less with the people who you are worried that you're impacting.

So psychology is a really important tool in this concept and actually able to work through that in a way that's But to, you know, try and improve your genuineness of your relationships and the quality that worrying about a future that may never happen. Will steal from you. I know that some people use strategies of just creating a time where they will worry about they might write it down, but then they allow enough that's been dealt with. I've I've acknowledged this worry.

I'm going to put that to the side now and try and be in the moment live in the present. So I think if you are feeling like you're not managing with this concept, it's important to just speak out, get that support, because it can really take away from an otherwise very rich and think

Belinda Bardsley

another thing that we really are much better at recognising and that is far more widely acknowledged now Mm-hmm. it's there's almost a loneliness epidemic out there, I think. Yeah. And we're far better, I think, at addressing it now than we used to be.

it's really helpful when people are able to, and although it's difficult, when people are able to express it and declare seek support and help for it, because it's, it's could be really crippling and that so sad when you come across it. We've said it in our clinic and some been brave enough to tell us that they're, they're If you can understand your personal support needs and have strategies to when you're feeling low or lonely, it's so important and so helpful. So having a trusted friend or confidante that you can reach or organising in advance for those days that are going to be particularly know, particularly, you know, birthdays or anniversaries or date of diagnosis, for example, might be particularly might just be for a Yeah be a really difficult.

For some. Allow yourself to seek pre-empt those times, seek some psychological support, peer group support. Those sorts of avenues are really helpful because you can feel lonely even if you're is absolutely lonely even if you're surrounded by people. You can be isolated And that's hard for people to talk about because it doesn't cognitively sense that they would feel Yeah.

lonely, which is, like you said, why psychology is so important in that. Yes, so true.

Tim O'Maley

And then there's the mood that can come with MS depression and anxiety are really common in our it is easy to sit in our chairs and kind of say, look, the stigma about this is getting better, but it's still there. And people can feel very held back about talking about this. But we know these are symptoms of They are far more common in people living with this disease. But some people, particularly younger women, have been palmed off with some of their early symptoms as being anxious and it's been something that's a trigger for them.

But again, as we've said over and over, and we will continue to say over, the support is there and these are real. They can be treated. And you drive those treatments and guidance and things like that. still the concept that you could actually be doing pretty well, your mum or your dad or your partner, they're the one that's actually struggling with how your MS is behaving.

you can guide them too and do partner those things are really important strategy that you can look into Yeah.

Dr Therese Burke

there was a concept that I discovered when I was doing my lived experience research that really touched me and it was reverse stigma. That was the term I gave what that mean, it totally threw me at the time. means is when someone's doing quite well with MS and they might not look disabled, they might be doing quite well and they've shared with other people. But then they don't look like they have MS and they feel a bit like an imposter.

So someone told me once that they went to a support group and people there were quite disabled, and they weren't. And somebody actually came up to them at the end and said, I don't think you should be here, you don't have MS And that was devastating for really put them in an awkward situation and they didn't go back to group after that. It's that imposter syndrome feeling. And we're going to see more of it Yeah now because our treatments are just so good

these days that people may have a lifetime of not looking like anything on the outside is wrong with them.

And so we may see that more and more, which sounds like a good problem to have doesn't you want it because of those issues, but it can cause some real psychological damage. So if you're in that situation, we'd recommend that you do get some psychological help or counselling. Also, it's perfectly OK to go to a support and most people are welcomed and do really well and find their tribe, but some people don't and it's perfectly OK to opt out of that. Mm.

If that's not for you may also need to go to several different ones. So if it doesn't work for Yeah work for you on the first time, as with anyone in life, you meet people all might just work and not work for you. But don't know, have another go and maybe share that with someone else who can sort of get you on the right path or into it's a peer support group, you might be able to have a word to one of the organisers to say, look, that group wasn't quite right for me or where else could just know that you're not alone if that's if that's how you've been feeling. And it's those invisible symptoms that aren't unique to It's not unique, but handling the symptoms are an important part of that fatigue management Mm plan in MS So these are the things that people can't see going on.

For instance, if you're having trouble walking or with your gait balance, that might be obvious to people. can, but Sharon, you're going to give me some Yeah some examples of where invisible symptoms are sort of hidden away from other people?

Sharon Barlow

Yeah, like you say, it's not unique to MS, but it is common in MS that people experience quite profound they can have sensory symptoms like pins and needles or numbness or hypersensitivity that, you know, it can be but isn't obvious to you know, the people looking in. You can have some neurogenic with their symptoms, and visual when you're looking at someone, people just assume that they see you and you can see them, but it's not always the case. And mental health issues, I think the stigma around that is because it's unseen. And so quite often, presenting their front forward, you know, everything's fine and you'll hear us say, how are Mm.

we want to know. We don't want the sugar coated. Oh yeah, it's We want to know about these hidden symptoms. And sometimes, symptoms as well, which can be amplified if you're quite stressed or anxious.

So these symptoms can be hidden. So the person with they're not saying or they can try and disguise them. but also if they are talked about, they can be ignored or forgotten by other people. And so that's a real isolating tricky times and I'd encourage you to be honest try and communicate that because we want you to have genuine connection and feeling like you are understood and your experience is understood because that really impacts on our quality of life.

Belinda Bardsley

There's almost two sides to the coin, isn't there with invisible symptoms. For some people, it's what I call a welcome cloak, particularly at work, if they haven't disclosed at work, it can be a real source of because their symptoms are visible to other people. So other people, they can keep their secret if that's what they choose to and that could be beneficial for them. But then for other people, it could be things like fatigue that you were talking about.

Sharon can be misconstrued as laziness or not wanting to help, which certainly isn't the case. And that can, that can be distressing. Absolutely. We've got some advice here from who's an MS Nurse at Saint Vincent's Hospital in Melbourne, and her advice about explaining invisible symptoms and their impact.

And she speaks about the importance of people with MS letting their loved ones know about it, their invisible symptoms and exactly what they feel and how they're affecting them. This knowledge, she says, you know, your family and friends are only to help you. You're probably doing a really good job at, you know, trying to symptoms to yourself. So they really can't be of much support if they don't about them.

particularly if they're, you know, somewhat embarrassing or sensitive kind of symptoms, it can be really hard for them to know how to help or experiencing them and going through them. And it might be also important to update them reasonably frequently if those symptoms are changing over time. They can fluctuate, you know, fairly frequently. So keeping updated is really important.

Equally important is to let your MS care team know how those symptoms are impacting on day life so that we can help you plan management strategies or refer you off for support and help.

Dr Therese Burke

Yeah. And it all feeds into all these decision overloads, it can be a real burden and a real demon to people on their journey. So many decisions, it can be overwhelming at And it's not just at the beginning of the journey. It's also as you go there might be a change to your status.

You might become more You might be developing some disability. There might be a change to drugs. You may have been on the same medication long time. And there's a change.

And all of these times of change can sort of play into those decisions. Tim. Yeah. And you know, the start of the journey, the middle it's a different time frame for but there is so many, what can say my really complex decisions to you know, give yourself time to digest everything you've got.

What's changed, what's new? What do I need to reconsider? Just pull it back, recharge, talk with people you care about and trust. Know from our perspective, there's no such thing as a wrong and nothing that we can't actually go back and change if it didn't work out because we've mentioned we don't have a crystal ball for you, but no such thing as wrong.

You know you better than anyone else ever will and nothing's forever. We can go and managing all of that information can be really tricky. We touched on that in episode 1. We're going to delve a little bit more into how feeling overwhelmed can impact on your know and can't Absolutely.

Just that feeling of being overwhelmed and constantly under the hammer and having to make decisions can actually affect the decisions that decision making.

Tim O'Maley

Yeah know they're from reading everything. And there will be people that walk out the door from the day they were told MS or this looks like MS, that will just read the planet and have everything. There will be others that really I just aren't ready and they'll go. I'm going to wait.

I'm going to get the ammunition. I'm going to discuss this with my trading team and leave it there. And there's no rights or wrongs to that. also can come across people who very really go, I think they've got it wrong.

And seeking a second opinion is absolutely your right. That is really important. But it's also knowing what to look for, read it's often better just to wait, see often see things where we go, I don't actually agree with that. but make sure what you are looking at is relevant to you, what's happening with you and your MS and the decisions that have been put front of you.

Sharon Barlow

I think touched on before, if you are going to be, you know, searching that to make sure it comes from like a reputable source. So you're getting good information. Because some of the information you extended family and friends weigh in and there's always like, oh, have you tried this? This is the best.

Like this is a or you're sent like emails or reels of messages around what you should be doing, which almost implies that what you're doing enough. True, yeah. so I think practising how you deal with that kind of information coming in is really helpful because having a plan ahead will prepare you to be able to acknowledge their attempts of trying to help because we know it comes from diagnosis, but also, realigning them with what you want to hear. some people have said, they just say, oh, that's I'll, I'll chat to my neurologist or MS Nurse about that when them in an awkward situation and they do.

My family members mentioned

Dr Therese Burke

We have some advice from Susan Agland who's an MS Nurse Practitioner in And she reminds her patients that receiving an MS diagnosis often brings overwhelming amount of information. And this can affect not only the person living with MS but also their support networks. So her advice is to look only at reputable providing reliable evidence based information as a helpful starting point. Yeah.

She says to think of those sites as a launching pad to help build understanding and confidence. And these include to say over and over, the support is there and these will be listed in the resources amongst other resources as well. So her key message is you don't need to know everything straight trust your instincts. You just need the right information and the support at the right time.

Keep in touch with your MS team for any questions or issues that arise. And before long you really will become your own expert. You'll know what your body is doing and what all the symptoms mean and you'll, you'll really be in charge of your own sort MS, I guess.

So that wraps us up for Episode 2, where we've hopefully tried to help you get sorted out on your road to living with MS. But join us for Episode 3 where we're going to really get our hands dirty and talking about the action plan of getting on with life with MS.