Ep1: Navigating the Early Days

Dr Therese Burke

Welcome to our round table discussion aimed at placing you firmly Back on Track. I'm Therese and I'd like to Welcome my colleagues Tim and Belinda and Sharon. Thank you for joining me. So between us, we've got about 140 years of nursing experience and about 100 of those in neurology, immunology and MS in particular. So we worked out recently that between us we've probably seen over 4000 people with MS in our practices and in our clinics because we all work in really big city centres. Chances are some of you may have already met one of us.

Today we're going to be offering you some suggestions and exploring some themes around managing the issues in MS that may impact on your life and your quality of life. So today we're going start at the very beginning with diagnosis, and in particular, we're going to talk about the diagnosis. So there's a really broad spectrum to this process. The road to diagnosis. For some people it can be incredibly fast and there's lots of inherent problems within that because sometimes things just move so quickly and you don't have time to catch up.

But for other people it can be a really slow process just by the very nature of some of the symptoms of MS They can be very vague. They're intermittent, they come and go, they can be easily missed, and the road to diagnosis can be incredibly long. But most people are somewhere in between that. So it's unique for everyone and lived experience research tells us that the impact of this time in the lead up to diagnosis and diagnosis itself can be with you for many years to come. So we want to explore some of the issues around that and give you strategies to manage that. For starters, tests, tests, tests.

So we all know that it can feel like a barrage of tests and there's no clear answer because it's important to remember that there's no one single test to diagnose MS. And often the process involves looking at things that may look like MS and excluding them. We need to get this right at the beginning, and there's a few reasons for that. One, we want to get early treatment in as quickly as we can. The treatments are very expensive. They're in the tens of thousands of dollars in Australia. We're very lucky because many of those treatments are by the government through the PBS.

But also these treatments are not without side effects, so we don't want to get it wrong in the beginning, which is why the process can be so arduous. So, Tim, talk us through some of these tests and how we can manage it.

Tim O'Maley

Anyone who's listening to this, you will have been through a whole heap of tests, blood tests. You will feel like somebody's tried to drain you dry. Most of the tests that we actually do really are to exclude other things. I think it is tough when you're going through this journey to go, I'm doing all these tests to kind of exclude something else to get to the point of MS A lot of the blood tests we do can even be part of the planning for your treatment down the track, but we'll come back to that a little bit more. So blood test, blood test, blood test, blood test.

Sometimes you'll get an evoked potential where people are trying to measure the speed of your optic nerve and how that's working. If you've had any visual symptoms, sometimes you'll be sent for a nerve conduction study test, which can be a little bit uncomfortable. But again, it's it's trying to put a really good picture together of everything you've been through. But MS is still an incredibly clinical diagnosis. Your neurologist will ask you the same question ten different ways, trying to tease out the things that you've experienced, put up with the symptoms that have come and gone.

That seemed really vague, particularly if they started when you were young and active and thought my legs a bit sore, maybe I've overdone it or, you know, pins and needles that happened after an injury that persisted a little bit longer than the injury. They're the kinds of things they're trying to pull back and get from you as they try to clarify that picture about what you've been through and are we getting this diagnostic process right for you. punctures we will chat a little bit more. They kind of went out of vogue with MS for a little while, but they are certainly coming back in and they're a very, very important part of the criteria.

Not everybody will have one, but they can be a little bit scary. We will talk about that a little bit further on. The most important thing we want to kind of get back to is, you know, what happened with that wonky eye? How long did it last, that burning little foot that you kind of ignored for a while because you were 20, but now it's come back and, and, and we're getting that checked out. What do all of these mean and how do we put that picture together for you, Belinda? That brings us onto MRIs as part of that picture.

Belinda Bardsley

Yeah, MRI is obviously a really critical part of diagnosis. And so it's, critical as both the primary diagnostic criteria, but also will be really important in, in your ongoing management of, of your condition for future sort of disease monitoring. So the, the MRI is looking for MS lesions in the central nervous system. And so that includes the brain, optic nerves and the spinal cord. it's important to note that it's not an X ray. So it doesn't involve any radiation. It's looking at a mixture of magnetic fields and radio waves in order to sort of identify lesions in those areas of the central nervous system.

And sometimes you might be given a contrast agent. So that'll, that'll be some dye in into the, to see whether we can identify any fresh areas of inflammation in the central nervous system. And those will appear a little bit different. So they'll look a bit juicier. And that, that will give us an idea of what, what is potentially new and what might be older. And these will be, quite regularly to in order to sort of see how you're responding to treatment and whether you've had any new appearance of any, any new everybody tolerates an MRI particularly well. And I know that I had to have one once to sort of see what was going on for migraine.

I was really nervous because I am claustrophobic. But radiographers are very, very used to dealing with that. And, and the team in MRI departments are very familiar with managing people who are sensitive to MRI. They're very loud and hammering noises that can be quite confronting for people. So just make sure that you inform the the MRI department if that's how you're feeling, if you've got concerns, and they can really help you manage them really nicely. They often put some music in some earphones and you can try and just lie there pretending you're lying on a beach with some hammering noise in the background.

Yeah, take a support person with you, try and go at a time of day that's, you know, a calm one for you. And sometimes you can have a bit of sedation if it's quite problematic for you. But it is a very important tool for managing and monitoring your MS. So it will be something that you'll you'll need to undergo pretty regularly, which is why it's a good idea to manage that well and get

Dr Therese Burke

Yeah.

Belinda Bardsley

a plan from the

Dr Therese Burke

Yeah. Because this is going to be your mainstay absolutely for the rest of your life. Very important. Yeah.

Sharon Barlow

So with regards to symptoms, if you've come to the attention of the neurology team, it's it's because there's some symptom that's declared itself. And these symptoms will be different for everybody, but most people are really worried about what's happening to them. Why is it happening and when is it going to go away and feel better? In my experience, most people feel really distressed and overwhelmed at this time and it's a difficult time to sort of absorb new information, learn unfamiliar words that you've you've never heard before.

And also just dealing with a different like how your body's feeling it and the function of your body in in response to you know, what's happening with your diagnosis. So I want to stress, reach out to the team, make it a dynamic process, ask questions, seek clarification. There is no such thing as a silly question. Be really honest about what you're thinking, even if you feel sort of a bit embarrassed or uncomfortable by that. And if you're lucky enough, you this might be the time that you actually meet an MS Nurse and really that kind of honest relationship builds the foundation for your relationship, as you go through this journey.

So I guess as Belinda mentioned, you know, we know that some of these tests can be really uncomfortable just from a, you know, worry perspective. Having symptoms can also make it a bit tricky. You know, if you're lying still in the MRI machine, but physically or you know, if you're concerned and that's impacting on your ability to concentrate, just talk it through. Because sometimes that process is enough to, or often it's enough to just get through and tick that off and hopefully get a, a step closer to the diagnosis, which leads us to the way we diagnose, Tim.

Tim O'Maley

really important that anyone that's given a diagnosis wants to be really sure that we actually know what we're talking about. There is an internationally agreed criteria. It's called the McDonald criteria. We're now up to the 2024 revision of that criteria. Some of the smartest minds in the world get together every few years. Look at everything we've learned. Look at everything we've got to give you the most speedy, but more importantly, accurate diagnosis as quickly as possible.

That's important because we want to give you the opportunity to start to look at how do you want to treat this, whether that's with the medications we can now offer, but also the things that we know are incredibly safe for you as a lifestyle management. To start tackling with this disease. So, fast is good, but it can also feel a little bit rushed and a lot of information, again, as you'll hear from all four of us through the course of these chapters, stop us, ask us. Make sure you're comfortable with the information and why people are suggesting certain things or giving you particular labels and diagnosis and things like that.

on it really quickly. You know, there's a couple of different forms of MS if you look around, relapsing or meeting and primary progressive and secondary progressive might be a little bit out of sort here, but I think a lot of us are getting away from those labels. We just want to manage your MS treatment that's appropriate for you right here and right now. But that's often a question that will come up. What type of MS have I got? And we will do our best to explain why we're looking at certain treatments, looking at certain pathways and planning particular you

Dr Therese Burke

And Tim, that brings us to a universal fear is the lumbar puncture. And it's a very, very reasonable thing to fear.

Tim O'Maley

Look, the lumbar puncture, like I mentioned earlier, we've, we are starting to probably see them requested a little bit more than they were maybe 5 or 10 years ago. But they are an important part of the criteria. The procedure itself, it, it isn't pleasant, but asking questions, knowing what to expect, bringing somebody with you for that particular test, again, it could be the piece of the puzzle that gets you the answer, the diagnosis and the next phase of where we go to and what we can do with the treatment. Again, it's another strange thing to say. We throw it in there.

It's not an MS specific, but it can rule out other things for us as well. It's a day procedure. Most people are in and out in an hour and a half, two hours, and it can really just be that final dotting the I and crossing the T's and you've got the information you need. you

Dr Therese Burke

I think most people say, I didn't really enjoy that, but I'm glad I did it because now it progresses people to the next steps and they feel more confident with that diagnostic process. They're not going to be asked for a lumbar puncture unless it's going to be helpful. The neurologists are, are lovely people. They're not usually we're not doing it for fun. Which brings me to some research work that I uncovered when I was doing lived experience research and it was a phenomenon called Surplus Suffering and I mention it here because it comes across a lot in this lead up to diagnosis and around the time of diagnosis.

And what Surplus Suffering means is extra burden placed on people on top of their diagnosis of MS. So they already have the physical, emotional and mental health implications of being diagnosed with MS. And then extra is put on top of them by other people. And it can be healthcare professionals that can be their family, their friends, people at work, people at school. It was first coined by a sociologist called Canada. She's now Professor of Sociology, and she noted it in some other disorders and other disease states like cancer and children and things like that.

And so when I first heard about it, it gave me a label to give this thing I kept hearing about. And I'm sure all of you have heard about it from multiple patients over time about how they felt brushed off, dismissed, particularly in the early days, like I mentioned before, because of that vagueness of symptoms and how intermittent they are. And so how do you manage it? And I think these days we've probably heard it referred to as medical Have you all heard that recently? It's it's come up a lot in the press and it's the same sort of feeling. So how do you manage that? Well, firstly, a tool you can use is just to talk to someone else about it.

So talk to your current healthcare professional about what might have happened to you in that lead up to diagnosis. You might have had a really awful time with the lumbar puncture or in the MRI machine, or you might have seen somebody who brushed you off and said, look, I don't think there's anything really wrong with you and you're not feeling great about that. So getting some professional help early is really key. And if you're somewhat down the line and this conversation is making you think that's what happened to me and I don't feel really good about this, please seek, seek some help.

There's no timeline to when you get psychological help in your journey. So even if it's not right at the beginning for you and it happened to you, it's important to get some help. So we'd recommend that. So that brings us to the time of diagnosis. This day is really important in the lives of most people with MS and it has different feelings for everybody. Research has also shown us that people remember this day in vivid detail, even down to the colour tie that the neurologist was wearing. And we hear people telling this down the line in stories after the diagnosis. So there's a lot of different ways to impart the diagnosis.

There can be a very slow build up as we've already heard about, or it can come completely out of the blue. And the way that the diagnosis is imparted to you may suit you or it may not. So there might be some issues there. So we're going to explore this a little bit and offer some advice. So Tim, the day of diagnosis

is really when reality hits

Tim O'Maley

and look, there is, there is no one size fits all with this. Some people will be expecting the news, somebody will had a good journey with, you know, this is why we're doing it and this is what we think it is. For others, it can be a complete shock. For some people, it can be a total relief. And whether you're diagnosed as somebody who's actually in hospital with a relapse that's needed to be admitted and treated versus work up through the outpatient process, it can be very, very different than everybody is actually going through. You don't have MS until the neurologist confirms that diagnosis internationally.

It is something that must be delivered by a neurologist. So that is a part of your relationship building. This is the person you were going to remember. And hopefully you've got somebody like us in that environment with you that will check in with you. We don't expect people to take a lot on. And in fact, sometimes smart people like us will ask the doctors to step back a little bit, let you digest and then come in with the information that you're looking for at that time.

It's also really important that a lot of people have had experience with MS, whether it's somebody else in the family, seen stories on the television and things like that, which is wonderful because it really is getting the the message of this this condition out there. But also some of those experiences can be somewhat confronting. Again, I'm really old. I've been doing this for a long time. One of the magnificent programs MS societies in MS Australia did was the readathon to raise money and awareness, but they were offering putting people that were relatively disabled in front of young children.

So that's sort of how a lot of people experience their first, with this label. So it can be any range of emotion and every single one of them is the right thing to have at that time. And managing information at that time can be really tricky. Belinda

Belinda Bardsley

Oh, absolutely. I think I often hear from people later that they didn't take in anything beyond that diagnosis and those two, initials of M and S And so I feel that repeated information given in small chunks is often really helpful at that time of diagnosis. And I think that's a really important role of the MS Nurse. Again, if people are fortunate enough to have access to one, some people will leave that appointment and want to go home and sort of Google everything. And I really caution against that unless they're looking at really reputable sites. And we will provide information about that later on.

And I also caution because often you'll find extremes of information out there on websites, if it's not that those reputable sites, people tend to report extreme information, either highs or lows and not the middle ground and the reputable ground, websites. And it's also a difficult time because of people have just been given a diagnosis and, and they're expected often to feed back to their loved ones or support people, something that they don't yet know about themselves. So I think having good, support team around them to give them the information that they need or having, good information around them at that time.

So also taking a breath to just process what's going on. I think it's invaluable at this time. And also maybe staying off the computer is is not a bad idea as well. So I do encourage people to just be really selective with the information that they take on board at that time of diagnosis.

Sharon Barlow

Yeah, just building on what you said, I think, having those different touch points as the MS Nurse, you're fortunate enough to be able to come back. So the diagnosis has been given. And as you said, they've remembered M I've got MS. So when they go back until their family members or whatever, I've got MS What does that mean? I don't know what's gonna happen next. I don't know. And so in my experience, I usually just try and, and make a time when I can come back and make sure that their support people are with them because, as many ears as you have creates an extra opportunity to sort of remember some of that information.

But also we all come with different questions. And so, you know, the people you bring, they know you, they know, you know, some of the things you might be worried about. And because you head is so full, they can, follow through with some of those questions and then after when The health professional goes, you've got that interaction with your loved one to be able to embed that information. Like what did she say? Oh, Oh, yeah, she said that. So they're going call me, you know, to find out the next steps. And, you know, if they haven't, this is the number I've got a call. So it it just helps cement that information.

And probably the other thing is just most people know how they learn information better. And it's really hard to, the time of diagnosis say, well, actually I'm a visual learner, so can you please provide me information? But if you are one of those people who, can articulate that, then please, please do because then we can support your learning preference. sometimes good health practitioners will actually say, do you prefer just to hear things? Would you like some written information? I usually just give everyone written information too. So they've got that touch point as a way of moving forward.

But it's a privileged position to be with someone at the point of diagnosis. And you're right Therese, people. They come back and say, I remember when, you know, you told me you were there with the diagnosis and how much you helped me, you know, process that information. And

I hope everyone has that experience. But yeah, ask questions and and take that time because it is a really important moment.

Dr Therese Burke

Yeah, so, and the day of diagnosis. So you've received the diagnosis or we've had the diagnosis confirmed, but that's just the start. It's not the finish of anything. It's the start of a lot of decisions, particularly in these early times that can seem really overwhelming at times. And so now we're going to move on to disclosure and how you tell people what's happening in your life and, some ways of managing that. So disclosing your diagnosis and telling other people is a really big deal and it deserves really careful, thoughtful planning.

So some patients have told me it feels a bit like giving a gift, sharing this information with other people and a really important part of themselves. So over the years we've all seen many ways that people can do this and who manages what and when. And we've brought in Sally Shaw, who's a psychologist in Melbourne who in MS, to also give us some help with this too. So Sharon, what have you seen?

Sharon Barlow

Well, I guess we're all saying some people just don't tell a single soul that they've been diagnosed with MS Other people will just tell everyone and anyone who will listen. Most people are somewhere, you know, in the middle. Importantly, what you choose to do is completely up to you, to be aware that there are pros and cons to all of the choices here and taking time to actually process the information you have before you decide how you want to disclose that is key.

I usually just suggest start small and then evaluate as you go kind of leads us in a little bit to, you know, who and how you choose to disclose and who to through your journey to get the diagnosis. There's a really good chance you've had close family or friends there with you. They're going to be aware of it, but still not necessarily understanding how you're

Tim O'Maley

feeling about that. Therese really quickly mentioned Sally Shaw. So I'm going to beg your forgiveness because I want to give this sort of tips and tricks a little bit of credit. We'll be reading a little bit from a script here, so do be patient with me. I think one of the most important things Sally says is making sure you have a reason why you were telling the people you telling. What you need from that explanation doesn't matter whether it's for you or for them. Be really open with the information you give them. Don't kind of fluff around with it. Say I've got MS, I've known for a while, but this is good. It is not a crisis.

Do you have any questions? And asking people to feed that back that way. Again, knowing that you might be asking people that, not necessarily sitting in that really close friend family circle because you might need to lean on them if something's not quite right. Can somebody you trust pick up your kids from school or from work and things like letting people know that your MS is going to be different to other people's experiences with MS. And if they've seen it before, it can be really, really different to where you're at right here and right now. It can be variable. It can be scary.

Some people are going to come up with some wonderful ideas and text you and ring you every time something pops up on 60 Minutes or the news. It's important to be thankful and take it all on. Another thing Sally highly recommends is, is get your little key messages and practice them. Know how you want to deliver that information, how it's relevant to you, but also letting them know why you're entrusting them with that information. Some people's responses can be really, really amazing. Some people can be really worried, terrified for you.

So with that kind of point, it's also really important that you've got a little bit of a exit strategy from that conversation, a way to change the topic back into something that would be more of a normal encounter with that family, that friend, those workplaces and things like that. I think one of her most important little tips when you are picking on who you might choose to tell, you can't expect them to keep it a secret, they're going to have a different circle. And it's important. You can't expect somebody else to hold that, even if you trust them implicitly.

So just knowing where that information might go and what that could feed back to you in that form form, it's it's not an easy thing picking choosing how this again will be you. And there are resources around through MS Australia and various other services that can help you with that process too.

Dr Therese Burke

I think Tim, one thing there too is once you have told someone a couple of things. One, you can't be responsible for their reaction to you. That's that's happening to them as well. And so you can't take on the responsibility of of that. And also that people, when you tell them about your MS, they might need someone else to talk to, which is why you were saying it's important to realise that the secret might might get out because they might need to then talk to someone about how that's impacting them, depending, you know, of course, on that that relationship.

So you might tell your best friend and their best friend's going to tell their husband or their wife wife or their partner. Things are going to go. If it's school children and things like that, that's going to go through that little friend network with those people as well. And we will come back, we'll talk a little bit more about kids and things like that later on. It's also important, Tim, as Sally has mentioned, that if you're telling someone about your diagnosis, that you also let them know who else you've told.

Tim O'Maley

Absolutely.

Dr Therese Burke

Because you might be withholding the diagnosis from children until that you can, you know, get a better handle on that. So it's important for them not to be telling their own children about it and who you have told. And that can then flow onto other things in a wider circle. Belinda

Belinda Bardsley

it can be sometimes easier for people to just let the word spread. Really. Like Tim said, you know, people can't always keep a secret. But actually sometimes that's a helpful thing. if this disclosure just happens organically, people can just get on with their lives and let the word spread organically. So that can be quite helpful for them to just be able to focus on their lives and getting used to the diagnosis themselves.

Sharon Barlow

Yeah, yeah, absolutely. I, I often get asked what should I tell in terms of their employer And I, I won't go into too much, but I do caution people just to take some time because it at the time of diagnosis, it's not always helpful to talk to your employer about what's happening. And mostly it's just because they're going have questions and you don't even know the answers to their questions yet. just reinforcing to take the time to work out what you want say to who, but but also use the people around you to make that decision.

I guess, you know, your neurologist can help or you can chat to a psychologist or your MS Nurse or any other health professional to try and work out what's right for you. Like MS isn't the same for everyone. The way that we do this isn't the same for everyone. And we just need to, you know, take the time and do it well or as well as we can.

Dr Therese Burke

So important. So then that brings us on to how do you break the news? How do you tell people - there's no textbook for this, is there? Because it's going to be different for every situation, every family, every workplace. So we're going to work through a few ways to do that now. But also remembering with the breadth of cultures that we have in Australia that English as a second language can also create a lot of obstacles, can't it? Because people are then having to tell parents and grandparents and there might not be equivalent words in in their native tongue to be able to do that. And, and messages can get relayed in the wrong way.

So you might also need to rely on family members to help you with that. But we, we're going to look specifically at telling children and adolescents first. Tim.

Tim O'Maley

Yeah. And this can be a really tough thing for parents, the maturity of your child, the way that they like to learn and how you can share that, looking for resources that are appropriate for them. There's some brilliant resources out there which you can be linked into. MediKidz is one that we use quite a bit and it's a very comic book style delivery and it really does fit quite a range of children's ages within the same thing.

One of the stuff that comes up with that is, you know, sort of helping explain why mom or dad could do this yesterday, they do it today Is, is something that kids do actually struggle with a little bit and just being really sort of upfront with how things are feeling. Our kids are probably a lot smarter than we ever give them credit for from any parent's point of view. So they will pick up on those kinds of things. And the really pleasing thing is a lot of the time they will surprise us by how much they care, pick up their game. In my really crusty old bad days, I said, you don't have children anymore. You have slaves.

Get them to do things for you. But actually, even bringing the kids to an appointment when you think they're ready to be involved at that level is, again, a very, very personal thing. But it can be really helpful in making them feel a part of this with you.

Dr Therese Burke

Yeah. And adolescents would sometimes need a completely different approach to younger children and say, so those resources can help in that. And we'll have them at the end. So Belinda telling telling parents,

Belinda Bardsley

telling parents. Well, flipping that around entirely, you know, we know that often people are diagnosed their 20s and 30s. So often it's about telling how to tell their parents about their diagnosis. And as a mum, obviously really very distressed when anything goes wrong with your children. So it can be quite difficult to to deliver that diagnosis with sensitivity and tact. And as Tim described as well, the earlier descriptions of MS were somewhat confronting. And so getting an understanding of what their parents' perception of MS might be is really important.

And then you can demystify sort of some of those misconceptions and explain that really things are are really much more positive these days.

Sharon Barlow

Yeah. I think telling people who love you and care about you about MS diagnosis is a really sort of emotionally charged conversation. And I've had people say they don't, want to worry anyone, so they don't want to tell them. But on the flip side, they feel uncomfortable with, the genuineness of their relationship not sharing that information as well. So I think it's good to practice that. You can practice that with, your MS Nurse or partner or trusted friend. But in my experience, I found it easier if if it's sort of like a story that has a beginning, a middle and an end. So you know how I was experiencing this symptom, whatever it might be.

I went to the doctor and they did an MRI and some other tests and they found out that I've got MS That's the middle bit. And then the end of the story is, well, you know, this is really good now because I know what it is and there's so much that I can do. I'm learning more about it, but I'll keep you in the, And so, some people might come back with lots of questions about that and some of them will have none, you know, your people. And you can probably anticipate what that's going to be. But also it's OK to say you don't know. No one knows everything.

Dr Therese Burke

Yeah. And look, we've very commonly had if people are comfortable to bring either, you know, family members or support people into clinics with them. I've offered to speak to children or to parents and explain the diagnosis to them. And that's worked really, really well. So I'm very happy to do that. And it can be a very positive experience for everyone involved because it can be really confronting when you don't really understand yourself, can't it? And then And then you have to then go home and explain it to people who love that can be, one of the top worries, can't it?

For people of when they're leaving the clinic, we think sometimes they're thinking about which medication and all of that, but no, they're really thinking about how they're going to have those conversations. So

So Tim, which brings us work and study

Tim O'Maley

and study and we, kind of have to acknowledge that most people are getting this diagnosis when they're starting careers, starting in the workforce, completing their studies, things like that. I really briefly mentioned, when we're talking about how you disclose to people with family and circle, they're not going to keep a secret. Work is different. You do have a right to respect some confidentiality when you disclose. There is a actually a really, really good body of work from MS Australia over many years that does say the people who disclose to the workplace early will be much, much better supported in that workplace.

But it is still an environment where that trust needs to be there. Who you choose to tell - your immediate manager or go way above them or colleagues that you were working side by side that might just see a few little things and be your partner in getting things done for you so that you get more comfortable that this is still going to be where I want to be and how I want to do it.

Sharon Barlow

I think when like people who are studying, there's definitely seeking additional help is really beneficial. Even like if you're at uni and you, your MS isn't impacting you at all, you don't really think you're going to need it. Just having that done in the background means that if you do, you can have some scribes for exams, you can have a little bit of extra time to hand up an assignment or do any or sit your exam. And you can even stand up and change your posture and and get more comfortable as well.

If you have symptoms which are intrusive and with regards to sport to think about, do you tell your teammates or your coach because they can really support you, for example, with your cooling strategies and how you might be able to manage some of that during training and games? So yeah, disclosure isn't just about telling your nearest and dearest. It can spread right, right over to all domains of your life.

Dr Therese Burke

So now we've walked you through the disclosure part. After the diagnosis, we're going to move on to something now that's more supportive. So we're going to be talking about finding your A-Team and your support. So depending on your age and wellness and what's happened to you in the past, this might be your very first foray into the specialist or hospital land. So it's a whole new language, a whole new world. So we want to set you up for success and what that might look like for you so that you can find your feet. And part of that is getting the right people around you. So learning from what's gone on before.

So what's worked for you in previous times of adversity. And it doesn't have to be in terms of illness, it can be in terms of relationships, financial adversity, emotions, things that have happened at school or work, and you've built up resilience. So thinking about what works for you well in your life. So part of that can be a very effective tool called Being Your Own CEO. Belinda

Belinda Bardsley

yes, what do we know? we'll quote Sally Shaw again here, as Tim mentioned earlier, a psychologist based in Melbourne and she has this lovely model that she calls being the CEO of your own company, the chief executive officer. And so she talks about a concept where you can appoint your own board of directors. And that can be all the very wise people that you want to have in your life to help you, you know, to support and advise and manage your life and your care.

So not only necessarily the healthcare professionals that are involved in helping and support you with your MS, but closest friends, you support people, your family, key people that will really help to get you back on track and help you manage your life. And it's a really beautiful model that's described very eloquently by Sally and I probably wouldn't do it justice. So we're going to have a link to to her concept of being your own CEO in our resources.

Tim O'Maley

So, Tim, there's quite a few allied health professionals that that you can have on this a team and and this board of directors. You can start to feel like you've been inviting all these people into your world that you never wanted to meet. But it's about putting people in place that you can call on them when you need them. A lot of them may be not experts in MS, but a lot of this is going to be building that relationship of trust that we're doing the right things that you need. Physiotherapist, test your strength, help you with your walking, help you with your gait coordination, balance.

Exercise therapists, Exercise Physiologists give you that confidence with exercising and programmes that are right for you. Occupational therapists if you need them. Speech pathologists, you may need any one of these people in your world at some time. Psychologists, I think every one of us here will say reach out earlier than you think do. That can just be, you know, I'm actually in a good spot and that's helping, but that may not be there in a year or two years later. And knowing that neuropsychologists are another thing and they are very different.

They will test memory, concentration, problem solving, things that can actually give you the confidence that you can continue working, you can continue study, you can manage your own company as your CEO. a little bit rare. They can be a little bit confronting those tests, putting those in place when they actually suit you and when you need them on the psychology, you might be doing great, your partner might not. So it's not always just about you. You can say, look, I'm actually doing a lot better with this than you are. have you thought about talking to somebody and taking a little bit remote?

So those are important parts of managing that company for you as well and for parents and children as well. Absolutely, that can be an important part.

Dr Therese Burke

So Sharon, what about community support?

Sharon Barlow

Well staying connected to community is important for everyone and so thinking about how you can do this can be really valuable. Some people just want to connect specifically with people who have MS and they look at being part of an MS support group that meet in person or a virtual group on social media or peer support programmes at MS Australia. But others find connection at the gym or in exercise groups or sporting teams, learning a new skill, doing something creative communities. So find what works for you. But we do know that having that connection is a really important part of managing your overall health, which will impact on your MS

Dr Therese Burke

And you can opt in and out of that, can't you? It might suit you at one particular time and then other times it might not. It might be the mix of people, it might be how you're feeling yourself or what's happening with you. But you can opt in and out of that. So another important part of setting up success and using your A-Team to its maximum potential is being well prepared for your clinic appointments and visits. So Belinda, I know that you've got some advice for how that can go.

Belinda Bardsley

we're not able to see patients as often as we would like I'm sure as often as some of our people diagnosed with MS would like. So it's really good to think about the clinic visit that you have coming up and think about what's really important to you to have discussed in that consultation. So think about it in advance. Bring any notes and questions or burning sort of issues in with you to that visit. Have have a bit of a think about that in advance.

If if you have any urgent paperwork forms that need to be completed or letters that you need to have written for particular matters or issues, make sure you bring them in or send them in into us in advance so that we can be prepared for those at that visit. I think that's probably the best advice I can give, but make sure that you come prepared so that we can ensure that we address all those issues at that time.

Sharon Barlow

I think Imogen Milner, who's an MS Nurse in Wellington, New Zealand, reminds us to don't just think about like you do all that prep that you you've explained, which is so important, but you might not get everything. So review that do you have a good understanding about what's happening and what the next steps are? And if you don't, then reconnecting with your healthcare professional to sort that. So everyone's trajectory is in the same.

Tim O'Maley

It's reflecting on what's happened in that appointment And did you get the information or did you understand all that information.

And again, if you are in a service that has an MS Nurse, you have the opportunity to ring back while it's still fresh and go, look, I wasn't 100% clear on that. Or could you explain what they meant by this? So just again, knowing who's in your A-Team, can you reflect back on that and, and highlighting what went really well and what you would like to do a little bit better next time?

Dr Therese Burke

So thanks for joining us for the first episode. This brings us to the end of Back on Track Episode We're going to talk about the nuances of day to day living with MS in the next episode, and we'll see you then.