MND Matters: Episode 37: Eating and drinking

Domonique Dickens
Welcome to MND Matters, brought to you by the MND Association and sponsored by Toyota and Toyota Financial Services. I'm Domonique, and today we're exploring a topic that touches the heart of daily life, eating and drinking while living with motor neurone disease. For many of us, sharing a meal or enjoying a favourite drink is second nature, but for people living with MND, these simple pleasures can become complex and emotionally challenging. Today, we're opening up that conversation, looking at both the practical and emotional sides of eating and drinking with MND, and joining me, we have three incredible guests, Lorraine, who was diagnosed with MND in 2024 will share her personal experiences of how she made the decision to have a feeding tube fitted and how she's adapted to these changes. Emma, a clinical lead dietitian who provides diet and nutrition support to people with MND. And Jonathan, a broadcaster cook and MND Association ambassador. So grab a cuppa, settle in, and let's get started. First of all, I just want to say a really big thank you to you all for joining me today to talk about, you know, the impact of eating and drinking when living with MND. And to start with, for any of our listeners who perhaps don't quite understand how motor neurone disease can affect eating, drinking and swallowing, Emma, I was hoping you could explain some of the basics on how MND can impact those things?

Emma Woods
Yeah, sure. I mean, the symptoms of MND can present such a challenge to being able to eat and drink. Well, within motor neurone disease, obviously, it's the motor neurones that are responsible for transmitting the communication between our brain and spinal cord to the muscles that we use to move and when they're affected, that does have an impact on our ability to eat and drink. So for example, if your arms or legs were weaker, you know the ability to physically go and buy food or prepare food in your kitchen, standing for a length of time to do that, or chopping food, preparing food, you know, using oven utensils, those sort of things can become more challenging, and even the physical act of getting your food to your mouth can be difficult and a challenge when there is weakness there. Also, you know, the muscles in your throat can be affected, which then affects your speech and your swallowing. So your ability to chew can be more effortful, and you may, you know, cough with certain food textures, because it's it's more difficult for your for your muscles, your your swallowing muscles, to control, control that and swallow that food safely. Even things like moving the food around your mouth, because your tongue can be affected, can be tricky controlling your own saliva, so can often feel like there's a lot more saliva in your mouth, when actually that isn't the case it's just that your ability to control that and swallow that as you normally would has changed, and that can make it a challenge to enjoy what you're

eating, and the ability to have a lip seal as well, so actually, keeping the food and the drink in your mouth can be a challenge, and we need to think about things like posture as well. Being able to sit for long enough in a good posture to allow you to have a meal or support your head during a meal can be, can be, sometimes a challenge for people and even things like, you know, breathing can be a challenge for people with motor neurone disease, and coordinating breathing with eating can be difficult. And if you're not breathing as well, because your your breathing muscles are a bit weaker. You can build up carbon dioxide in your system, which can make you feel nauseous and can give you a reduced appetite. So there's lots of things that not everyone will experience them all, but some people will experience quite a few of those. And it's a multitude of factors that then all have that, that impact, and if we think about the psychological aspects of being having this diagnosis as well, that can impact on your appetite, and we know eating and drinking, like you've mentioned, is a huge part of a person's quality of life. So being able to support patients and their families, you know, through these changes that affect eating and drinking is so important, so that we can still obviously help them to eat as easily as possible, and try and maintain that pleasure and that enjoyment that we get out of it. Because, like you say, eating isn't just about nourishing us physically. It has very psychological and social implications. We put a lot of value on eating and drinking. You know, it's something that we do, like you say, second nature, but it forms a lot of our daily life and a lot of our social gatherings. It's about friendship. It's about care. You know, it symbolises a lot of celebrations that we have, you know, so it's important that we look at the whole picture.

Domonique Dickens
Yeah, yeah, absolutely no. I couldn't agree more. And it's, it is that social side of it? It's that, you know, it's something that a lot of people find joy and comfort in as well, isn't it? Lorraine, was there anything there that Emma mentioned that resonates with you or that you're already experiencing?

Lorraine Redmond
Yes, so I currently my tongue, it doesn't move in the way that it usually did. So when I have food in my mouth, my tongue doesn't move it around my mouth in the same way, and sometimes it pushes it out of my mouth, and I'm having to try and keep it in, but the muscles are not allowing me to so sometimes have to use my hand. And then in doing all of that, the saliva, you're also managing the food, and the saliva control as well. So you find that the food is coming out, but there's also a little bit of drooling as well. In terms of swallowing, there's certain foods that I choke on, and is that a bit watery, um, things that I might be spicy, I choke on my own saliva. I choke on water, albeit that, if it's really ice, cold water, I don't choke, which is a bit strange. I choke on sweet drinks. So I tend to stick to water. Um, swallowing has over the months becoming more challenging, but I'm still able to eat. With water, because I want to keep my body hydrated, I have had a feeding tube fitted, and that was fitted last year, October, and I tend to put water through that, so approximately one to one and a half litres a day, and then I try to have hot drinks and cold water throughout the day in addition to keep me hydrated. Um, but my my swallowing, sometimes it feels like I'm not gonna be able to swallow and I force it, but sometimes by forcing the food down, you choke, or you feel like you're gonna be sick.

Domonique Dickens
Yeah So you've, you've actually had to kind of adapt the way that you interact with eating, with drinking, with swallowing, as your MND is changing and progressing every day.

Lorraine Redmond
Absolutely.

Domonique Dickens
You mentioned that you've had a feeding tube fitted, and a lot of people listening to this will either be preparing for a feeding tube fitting, or they would have just had it done themselves, or they'll be considering whether it's the right choice for them. How did you come to that decision to have the tube fitted?

Lorraine Redmond
So I was I was told about the feeding tube and the possibility that with MND, I wouldn't be able to swallow or eat food as it progresses due to the nature of the illness affecting the muscles. So that was put to me is, you know, it is my option to have it. I was shown and a picture of the types of tube, what it does, how the operation works, and so forth. And I then asked, what would happen if I didn't have it and I couldn't eat? Basically that would be, I, I was, there's a possibility that I could starve to death, because once you when you have MND, it affects your muscles in your mouth, your your throat and your chest. And what, what was said to me is that sometimes when it progresses to that stage, it's too late to do the OP, because your muscles are so weak, it can be a risk to you to do the operation. So the preference is to do it as early as possible before you get to a stage where you can't have it. So, but it's still an option. You don't have to have it. But for me, the option was really there wasn't that option. It was for me, if I if I had lost the ability to eat, then I'd be speeding up my own demise. So I chose to have the feeding tube fitted last year, October.

Domonique Dickens
Yeah, yeah, of course. And you know, it's a decision a lot of people are presented with and they do have that support and guidance a lot of the time. And you know, the Association is always here to provide, you know, guidance on that decision. Jonathan, I saw you kind of nodding along there while Lorraine was talking. Was there anything in particular that kind of struck a chord with you there?

Jonathan Phang
Yeah, well, it all does, to be honest. Because, you know, I've sort of been through the motor neuron disease journey twice so far in life, and with a dear friend of mine called Jane, and then my sister. And so when it came to my sister having to make that decision, I fully supported her having the feeding tube as quickly as possible as well. Because I think the you know, one has to be hydrated. One has to have as much nutrition as possible. It will keep things going for as long as possible and make your life a little bit easier in between. And you know, and it is, the other stuff that resonated with me as well, is that you weren't there were so many sort of unusual aspects of it. Everything's unusual with it, but it's rather like we grew up with very spicy food. My sister adored spicy food, but everything changed. You know, her whole palate changed again with cold water, she was fine, with warmer drinks she wasn't. So, you know, it's just but things do progress and change all the time as well. So when we were getting used to one way of life, and it would sort of suddenly change as well. So it's just you just don't know how this will affect you, and how it will change your appetite and your taste buds and all of those things, really, and you have to just keep an eye on it and expect it to change frequently and and then it's, it's trial and

error. You know, my sister could tolerate rice for quite a long time. She adored rice, and she could actually swallow that a lot easier than, say, a pasta or, you know, so stuff that was just constantly changing and constantly a surprise. But, I mean, we came from a very culturally rich background. My father was Chinese, but from the Caribbean. My mother was mixed race, from the Caribbean, and so we had a very kind of eclectic mix of food. And I think food is something that is a real expression. And in our family, my parents being immigrants and having a very different experience of life to their offspring. Sometimes it was their only way of expressing themselves. And I think that my sister and I expressed ourselves via food as well during her illness. And so it was very important to me that she had familiar flavours and things that reminded her of home, reminded her of her family. Sometimes, if it was just a teaspoon, you know, teaspoon of sweet and sour sauce or something. It just meant something to her.

Domonique Dickens
Yeah, no, absolutely. So with that, Emma - Jonathan's obviously mentioned there about creating meals that were, you know, tied into family memory. They, you know, bring comfort, bring joy. Is that something that you often see that kind of emotional connection to food in your work and as a clinician, how do you support that when someone with MND comes to you with that problem?

Emma Woods
Yeah, absolutely, like we say, we associate a lot of positive things with eating and drinking and a lot of care and love. People want to show that to their loved ones, and they do that a lot through food. And and some of the conversations that we do have around when we talking about the option of feeding tubes, there's sometimes that misconception that people think that once they're accepting a feeding tube, that they're not able to eat and drink, but actually they still are able to eat and drink for as you know, the quantities of food that they wish and the types of food that they wish. But obviously we may need to alter that texture so that it's a little bit less stressful for them to eat that if they are struggling to chew and swallow that. But it's more that then that tube then just takes that that pressure away, because meal times can become a little bit pressured and a bit distressing, and that can then, you know reduce somebody's appetite. They may not feel like they want to eat and drink, but you know, having that tube is a bit of a backup plan and an insurance policy to obviously give you a top of hydration, like Lorraine, or top up of food, if you know that you're going to feel particularly fatigued at the end of the day, so you probably have a bit of a top of at that point, of some nutrition, and what we've started to do as well, really, in relation to tube feeding, although we obviously promote food fortification and support patients with recipe ideas and meal ideas, and we always talk about when you're removing, perhaps, texture from a food. You know, people with motor neuron disease have still got all of their other senses, they can still see, they can still taste, they can still smell. So it's so important that we get those elements right, so that the food still looks appetising, and patients want to or people want to eat it, and they still want to be involved in family meal times and certain celebrations, and even if somebody does have a PEG tube, like you say, it might be, they can have a small mouthful of food, but it's becoming a bit more popular, or a bit more you know, we're getting more guidance around it and policies around it that we can offer having blended diet through a PEG tube. So although you might not be able to eat it orally, you could still have the same things that your family are having at home, but through your peg tube as well. But I think, you know, it's getting that. It's marrying that balance between, yes, we want to keep you as nourished as possible, because we know in the literature and the research that is a big

signal that if we can maintain somebody's weight, help them gain weight, or if they have a higher BMI, that has almost a protective effect, and can, you know, influence almost the trajectory of the disease by helping to slow down the disease progression and increase survival? So we really, you know, do want to support people to make the right decision that's for them, and making them aware of kind of the research that's out there at the moment, what the benefits might be, but we look at the clinical benefits as well as the quality of life benefits, because I think that's really important. And having a PEG tube might not be what everybody wants to do. And they would rather, you know, they would rather just have as much food and as fluid as they can orally. That is possible that we would support them with that so looking at modified texture, looking at thickening, looking at positioning, working with our MDT colleagues, like our occupational therapists now physiotherapists to help protect someone's airway as best that we can, and obviously help their positioning so that they can be as independent as they can with eating and drinking for as long as they can. Looking at nutritional supplements that are prescribable, trying to give because, you know, rules change then within eating and drinking, if the person who has the MND was the household cook and shopper, you know, people's roles really change, and it might not have been their partner's role, and they're then learning, you know those cooking skills, but the person with MND that might have been their their passion, and it's trying to still keep them involved with that. So they might be involved then still in meal planning, in in ideas for if there's a family gathering, things that are going to be on, on the buffet, being able to still online shop, almost being a head chef, in that they can give the instructions and obviously pass on their recipes that they enjoy and those sort of things, I think it's still trying to, you know, create some positivity around eating and just because it is becoming more difficult, this still can eat well, and there can still be pleasure in eating. We just need to think outside the box sometimes try new things and obviously continue to adapt as things change. Like Jonathan said, it's not always the same, and it's just a matter of seeing what what they're faced at that time, and coming up with the best solution that that helps really.

Domonique Dickens
Yeah, it's, and I think as well, you've touched on it really well, there it's, it's about still being involved and still participating in those meal times, in those social activities, like you said, and you know, as your MND progresses, the way that you, you know, interact with food, and the way that you can, you know, keep food down, keep feed in your mouth, like Lorraine was saying earlier about how her MND has changed as it's progressed. You know, it's really important that you're still part of those moments, whether it's giving the shopping list or it's, you know, saying a particular dish that you'd like to try that night. And Lorraine, you mentioned earlier about some of the, you know, the changes that you've experienced with your MND, what kind of, you know, adaptations have you made around meal times? Is it, you know, you're taking smaller bites? Is it that you're you're laying back on the chilli and your food, perhaps?

Lorraine Redmond
I have changed some things. So for example, I might substitute rice with potato um, because rice depending on how it's cooked. It gets stuck in my throat, and so even, like one hour later, I can feel like a rice grain. They're still in my throat, and they won't move. Oh, I'm still have some spicy food, because I like it. I've think what I've learned is that I know it's rude to talk while they're eating, but we all do it, and I found that if I'm talking when I'm eating, I'm definitely gonna choke, especially on spicy food. So

I'm really I still socialise, I still go out for meals with family and friends, but I'm really conscious about not speaking, because when you're with friends and family and you're eating and you choke, they panic. They don't know what to do so, and that can make your choking worse. So I just try and prevent it by doing things slightly different, ordering things on the menu that won't make me choke, or, if it is spicy, not talking and eating, waiting until I've swallowed everything my throat is clear and and then I might talk before taking the next mouthful, all of which you're, whoever you're eating with, they won't notice that you're even going through all of those stages just to eat a meal. But I'm really conscious of those types of changes that I've had to make, and even like I'm vegetarian. So I had a McDonald's, for example, they do plant based burgers, and sometimes I might, I don't have it often, but if I do the the burger, I've noticed is, is it's got a different consistency to me, obviously, but it looks the same. But also it's grainy. Once you've swallowed it, I find those grains in my throat and so, um, I don't really have it, because I know it's gonna take hours for these grains to be to move from my throat, and in the meantime, while those grains sit there, I'm still having to I'm trying to drink water to get rid of it. I'm also having to navigate my saliva and every so it's like a whole different, yeah, it's a whole different lifestyle. It's like having to learn how to eat, like from a baby stage, almost.

Domonique Dickens
Yeah, it's those changes, isn't it? And you gave some really helpful tips there that I think you know, anyone that's listening to this, that's going through what you're going through, or supporting someone who's going through this will really take away. You know that, you know, and you're right. We are all guilty of having a little chat while you've got some food in your mouth still, because you don't want to forget what you're saying. And it's the conversations riveting. So I think there's some really helpful things that you've shared there. And you know, as an Association, we are dedicated to supporting people to maintain that quality of life, that social aspect of life, staying connected with people that they love. And, you know, things that they enjoy, like food. And we do have an eating and drinking guide, and it's it's packed with practical advice, nutritional tips, recipes all designed to help people with MND continue enjoying foods in ways that kind of work for them and around their MND. And I know, Jonathan, that you have contributed a recipe to that guide. Can I ask you to share what inspired that dish and what does that mean to you personally?

Jonathan Phang
Oh, it's just, you know, it was just flavours that my sister liked very much. And I also think, you know, I think Emma was mentioning earlier about, you know, food needing to look appetising, and it's a really vibrant looking dish, and it's colourful and it and she loved the way it looked, and she liked the taste of it, and also, at the earlier stages of her MND, it's a prawn dish, and she was able to swallow that quite easily. So it's just, you know, packed with flavours of home. And that's was, that's what I tried to cook her all the time, just something that would just, sort of, you know, to give us something to remember our parents by and just be a little bit sentimental, and something that, you know, flavours that we shared when we grew up, and it just meant something. And as far as you know, I used to take her everywhere, so throughout her illness, you know, yes, there are hurdles. And you know, when you first see an MND patient look they're choking. It is really scary, and you don't know what to do, and you don't know whether to sort of make them drink, which is sometimes going to make it worse, or whatever. And so, you know it's it's challenging for everybody in in the situation, but you have to just make sure that people have a good a time as possible, and spend time with loved ones and friends and family and

experience life whilst they can. And then, you know, that's why I think the feeding pegs are really important, actually, because, and then, you know, learn what works when you're out. So it's about listening to people, communicating, understanding it, and making sure that no one's at risk when you're anywhere social, but I think the worst thing you can do is just, you know, be scared of the whole situation. And so Jane, my other friend, was took a long time to get a feeding peg because she was really resistant, and then sort of wished that she'd done it much sooner, because it gave her a bit more freedom, essentially. But I think for me, I was really creative with recipes I could take on board her new limitations. Food temperature was something that really changed as well. So the temperature of food something that I felt was quite just warm and not hot, as in temperature my sister found very hot so, you know, so I was constantly learning, and we were learning from each other, and then just tried to be creative and adapt to the situation.

Domonique Dickens
That's like, it sounds as well like, you know, as difficult as that, that journey is together, it did actually bring you very close as well.

Jonathan Phang
Oh, yes. I mean, I think that it's totally did in a very unexpected way, in a very rewarding way. And I think, you know, there were just absolute moments of togetherness and sort of love between us, and sort of, you know, sharing something that you know, on one level was incredibly special and something that memories I will cherish, actually, because it did give us a closeness which I didn't expect to have with her. She was my, you know, six years older than me.I have a brother. She always thought, you know, the brothers against the sister and all of that kind of stuff. And it just turned out very, very differently. And, you know, there were moments that, as I say, were just incredibly special and really bonding. And, you know, I've always used food to sort of to bond with people and to express and communicate, and it continued with that, and I was determined for that to happen. I didn't want her not to have that joy that we'd always experienced growing up, and something that was so vital to our family, you know, we our family basically, it was all about, what are we eating next? And that still continued through her MND.

Domonique Dickens
Oh, I love that. And you know, be both Lorraine and Jonathan, you've shared some really kind of meaningful and tangible ways to still be involved in those meal times and kind of still be able to connect with food and find joy in food. Emma, is there any other small but kind of meaningful adaptations you've seen people make, or maybe you haven't heard today, that can help people stay involved in meal times, even if they're not eating in that traditional sense?

Emma Woods
Yeah. I mean, just to jump and go back with what Lorraine had said there, obviously highlighting that, you know, all of these things are going through your head, Lorraine, while you're eating your meal that other people might not be aware of. But for that person, for them, sometimes they can feel the anxiety of that really, you know, they have a fear of then going out into public places and eating, but actually being able to voice those and talk about what their concerns are and come up with with strategies. And once they do it, they do feel a lot more comfortable. So like you say, you know you you're choosing

purposely not to speak when you're eating, certain you know you having that mouthful of food, but little things like, you know, choosing your meal beforehand and pre ordering that in. So if you have difficulties cutting up your food and you don't want that to be cut up the table, that could be pre cooked, cut up in the kitchen and brought out to you so that there's no nobody around you would think that that was any different. You know, things like, if eating takes a long time, and you talked about temperatures there, Jonathan, sometimes it takes a long time for people to eat foods and what it did before, and meals often then go a bit cold, or they take longer to eat than other people in their party, and they don't want other people to be waiting for them. So just choosing a starter size portion, like a, you know, going for a starter off a menu, and thinking about before you go out, making sure you're having a bit of a rest, you know, not having a long conversation prior to being out. Or, you know, resting your swallowing and speech muscles before going out, so that you can then make the most of that time when you are are out, just some little tips that might help. Even asking for your meal to come in a pasta bowl so you've actually got the side of the bowl to actually then help get your food onto your utensils, rather than a plate can be a small tip that might help. Often, people are worried about, you know, I don't eat as tidily as I used to, and it might be a little bit messy. So wearing darker clothing or clothing that's got patterns on it, then makes it less obvious if you do happen to spill anything, they can sometimes be little tips to share, trying to think of other things, obviously, in the restaurant as well, it's choosing a position that is a bit, perhaps a bit more private, so it's not on show. So perhaps you're not the one facing out to the restaurant, but facing the other way, maybe out of the window or more of a corner position. And it could be that maybe friends or family check out the venue before you get there, because it might not only be about eating, but about accessing the tables in there, and can you get to the toilet okay. And all of those things bring an element of anxiety for people who, you know, have enjoyed going out in the past and still do want to, but they've got a lot of these things going around in the head about, you know, will it be possible? And all of these things might make it more awkward, but actually, some of these little things can really make a big difference and help people still be involved in going out with meals, with family and friends, and still doing the social things that they used to and even with peg tubes, depending on how confident you feel, we do have some of my patients that go out and they will use their peg when they're out In a restaurant to give them a little bit of food while they're there, whether that be something that's prescribable or a blended food, then some people will still do that as well. So they're still then involved in that social experience. It all just depends on the confidence of the person and obviously trying to give them the support around that. It's kind of starting maybe something small, and they might build up to, you know, so if it's a small cafe down the road, they then might build to, to, you know, another restaurant, as you know, it all depends. It's all individual, really.

Domonique Dickens
Yeah, yeah. So it's all in the individual's experience and, and also it's, you know, it's take it as as as you can, right? You know, don't rush these things. Build your confidence, if that's what you need to do. And you know, just take each day at a time, which is what a lot of people have living with MND, kind of live by it, you know, one day at a time. So Lorraine, in terms of that, you know, we've had a lot of practical tips and advice about how you manage your eating and drinking and swallowing. How can friends and family support you with your eating and drinking and swallow, whether it's out and about or whether it's at home?

Lorraine Redmond

So at home I still try and cook, but it's getting harder. It's much harder than it was before. So the support I need at home, I'd say, is with chopping things and helping me to cut things like onions and peel the skin off. And you know, they're simple little things, just recognising that my hands are not working in the same way, and my legs are not working in the same way. And although I'm still standing and walking, it's not the same and I get tired quicker. So I think my the majority of my help is needed with chopping things when I'm out, because people offer you food or sweets and, you know, fruit and things like that. And I was in the meeting the other day, and someone offered me some grapes. And I said, no, thank you. And then later on, they often be grapes again, no, thank you. And they was like, Lorraine don't you like grapes. I do like all fruit, but I can't eat anymore. It makes me choke. I can't the juice that come that grapes and fruit like oranges and red melon, which I really love, I can't navigate all that juice on my saliva and swallow. And I find sometimes I even even to just eat food that is easier for me. My tongue moves in such a different way that I'm often biting it now. So my tongue gets sore, then eating juicy fruits is is hard and I love fruit, but I can't eat. It I can't eat sweets again. All that juice that comes from a sweet, plus my saliva and that constant swallowing, and if I swallow, um, that sweet juice from a sweet, and choke is more severe. So it's just having that understanding about how those things that accumulate lots of fluid that plus the fluid that you naturally have in your mouth, can actually cause you to choke or it just your palate can't handle it anymore.

Domonique Dickens
It's that recognition, isn't it? And that kind of understanding and that kind of, you know, unspoken support in some respect and in terms of Jonathan, your experience, obviously with your friend Jane, and obviously with your sister as well. Is there any advice that you would give to someone who is supporting a loved one with MND, but they still want to share those kind of meaningful food moments together?

Jonathan Phang
Yes. I mean, I think the thing is, I I think people are embarrassed to ask for help, and I think that all of us naturally want to offer help. And sometimes, you know, people are ignorant about situations, until an illness actually affects you personally. You don't generally know what the right things to do are. So you know, and you actually really need the person to tell you. So my advice is for somebody with MND, just you know, you find out what works best for you. Tell your friends what help you need. So Lorraine, you know, get your friends around for a party. Sit there. Let them do the chopping for you. Tell them to batch cook for you, for stuff that you like, those things that you can that you find less challenging to eat. Let them be involved, because I'm sure they want to be, and I'm sure they want to help you. And you know, until they you know all the stuff about the saliva and the juice and all of that resonates. I remember all of that with my sister, with the dribbling, was a big surprise to everybody at the time, and people don't know right from wrong, so you just have to express yourself and tell them what works for you and what doesn't, and let them be involved, let them do what they can for you, and then it will be a lot more harmonious, and you'll have a much better time, I reckon.

Domonique Dickens
That's wonderful advice. Honestly, really lovely. And then Emma, from your kind of clinical dietitian nutritionist perspective as well, are there any additional practical or kind of emotional tips that you can

give to someone who is supporting a loved one through MND and those changes that come around with its progression towards eating, drinking and, of course, swallowing.

Emma Woods
Think it's like Jonathan said, it's having them open discussions, isn't it, about what works and what doesn't work. And we, we obviously are here to support in any of those conversations, and anything that we can do to help, I do remember we once facilitated it was kind of a sort of a carers group, where we did have a chef come in, and we talked around preparing different textured foods to give them a lot of practical tips and a bit more confidence on how to do that, where to get help, where you needed it. Because it's not that you always have to make everything from scratch, like you say, you can batch cook. But also, there is food delivery companies where they make modified textured foods, just to make that a little bit easier on occasions where it might you might need a bit more convenience. And we, we support, kind of through our hospices as well, we were offering kind of like a first contact group, where we had the opportunity to speak with patients who had MND and their families, but also separately, so they had the opportunity to perhaps raise concerns that they maybe had and maybe didn't want to say in front of their relative. And it's, I think it's, you know, just acknowledging that we appreciate that it is difficult and it is changing, and there's lots of other things that are changing around them, not just their ability to eat and drink in the nutrition side of things, there's lots of other things that that go on as well, and it's having a holistic view of all of that, and being able to identify what is the priority. But we do try and support as much as we can, with regards to, you know, you know, trying to give them some reassurance that they're doing the right thing, and trying to, you know, alleviate pressures, like we say, because sometimes it can be pressured on both sides. I think if you've got a relative that is struggling with eating and drinking, there is a sense of guilt from the other party if they're eating and drinking food. That the other person can't so I think there is a lot of emotions and sensitivities that you, you know that you you're working your way through, and it's kind of giving them permission to be saying it's okay to be feeling like this, that it's quite a natural process. And, you know, helping them work through that, really, and hopefully them bringing them both together.

Domonique Dickens
Yeah, it's really helpful, really helpful. Thank you so much. Where there's so much fantastic support and guidance that you've all shared today some wonderful practical tips, and I've really enjoyed speaking to you all, and I'm sure that you know, lots of our listeners will really resonate and connect with a lot of what has been shared today. So I want to say a really big thank you for your time.