Academy of PHYSICAL MEDICINE

Transcript

360R- How Best to Exercise with Fatigue Symptoms with Kam Saggu

Jake Cooke

Hello and welcome to this evening CPT broadcast. You've probably spotted them not actually Steven. That's because he's asked me to stand in for him this evening apparently feels that you might need a break from the system and who better than a chiropractor to take his place. I'm Jake cook. As I said, I'm a chiropractor, but I'm not a complete stranger to AP. I was actually Stephens guest in December when we talked about neurological testing. Today I'm going to be taking talking to someone who is also a repeat offender here at the Academy cam. So Gu cam has a rehab specialist with a degree in Exercise Science and many years experience working in the NHS. In this evening, we'll be discussing how you can help your patients suffering from fatigue getting back into exercise, whatever the course may be. Cam Good evening.

Kamaljit Saggu

Welcome. lovely to be here.

Jake Cooke

So, this is a topic that's really close to my heart, I have a lot of patients who struggle with fatigue. So yes,

Kamaljit Saggu

same here, same here. I hate fatigue is a common symptom. Now I'm coming across many conditions I'm working with and it's a lot of them could be because it's a direct symptom of their condition, or it could be sort of a byproduct of the condition they've got unpretty comes in. So the common conditions that I find a lot of this in is a lot of neurological conditions, as you probably know, so Ms. Parkinson's, something called functional neurological disorder. Frederick ataxia is one of them as well. So those are the neurological ones. And then you flip it onto the side of EDS. Ehlers

Danlos Syndrome, you've got fibromyalgia, you've got me. So they have got direct symptoms of fatigue, based on the conditions they've got, I find with the neurological conditions, it tends to be more along the lines of the mental power it takes to actually move with the condition they've got. So just to go over a little bit Ms. The high overview of MS is my understanding is autoimmune disease, the message the signal from the brain to where it needs to go with the myelin sheath, it can get lost, it can get lost, it could get jumbled, it can go the wrong way around. And sometimes it takes a few moments, if not a few minutes to get the movement to come with Parkinson's, or its dopamine, lack of dopamine in the brain. And that then stops that signal getting to where it needs to go, or it delays it quite significantly. And then from functional neurological disorder that I think is quite a new, I'm finding it's not very well known in the medical world, it may be, but I'm coming across it more and more where it is just a signal is not getting to where it needs to go full stop. And it could lead to sort of non epileptic fits, it can lead to some forms of paralysis, it can lead to speech problems as well. So I've come across all these people in terms of exercising and fatigue is a common symptom between all of them. And on top of that. Frederick ataxia is also another condition that's neurological and that's protects him that missing like dopamine is missing in Parkinson's, it's missing in missing in this particular condition. So the lack of control in the movement is there. ataxia is just that tremor, that sometimes rigidity, sometimes it can be the movement is just taking a lot longer to get their weakness kicks in if they don't exercise properly. So the efficiency of the movement drops considerably. And if they're not exercising to try and maintain that efficiency, fatigue can kick in quite considerably.

Jake Cooke

So when you're talking about fatigue, and we're talking about different categories of fatigue that being talked about, so content fatigue, so I see a lot of patients with chronic post traumatic brain injury, yes, yes. So they'll often fatigue is often one of the last sticking points, you know, they'll say, movements got better balance got better coordination is better. Maybe they can start using a computer again, and they can start holding conversations like this or going to the supermarket. Yes. And yet fatigue is one of the last ones that

Kamaljit Saggu

to get it goes. And I can understand that. The understanding I've got a fatigue is if we've got a glass of energy, that is how much we've got. And that's how much we've got to play with for the whole day. So, for example, in fibromyalgia, I'm not sure if you've heard, they tend to use the spoons as a way of measuring their energy. And it's quite common that some of my clients will say to me, I've run out of spoons today, I've run it and I think it's just coming down to managing what you can do in that day. And if you know you've got something big coming up, like you've got an event coming up, you've got an outing where you're going to have to converse with somebody, make sure you factor in afterwards that you have that downtime and recovery. Fatigue is a difficult one because if you overdo it, it could knock you out for several days, but you also need to push it just enough to see if you can improve.

Jake Cooke

I've not heard that before. So what's the spoons? spoons,

Kamaljit Saggu

this is in the fibromyalgia world. They use spoons as a way of measuring energy. So if you've got five spoons of energy for throughout the day, say going for a walk. That's one spoon getting washed and dressed and eating something and logging onto a computer. That's another spoon done. So like the clocks have changed this weekend. One of my clients just say that change has taken up Too many spoons are interested. So it's an interesting concept. I don't know why they've picked spoons, I'd love to know that. But today, I've always gone with a glass of energy. And this is how much you've got. But the spoons is seems to be in the fibromyalgia world, and they relate to it. And that's how they start conversing. And when I first heard that phrase, I just went, What on earth is a spoon? So I don't know where it's coming from, or how experienced you save energy before, I know, but they relate to it. And then all of a sudden, they'll say, I've only got three spoons of energy left. And it makes sense to them. So they know how much more they can do in that day. So So yes, fibromyalgia uses spoons, I tend to still refer to a glass of energy, and how much you can use that in terms of exercise. So when it comes to conditions like fibromyalgia, eds, me, I would encourage them to use that scenario, whether it's spoons or glass, use that quite a fair bit, to know and understand their body enough to know how far they can push it. And exercise is one aspect of it, I will always encourage washing, dressing, eating all those fundamental things you need to do first, get that out of the way, use as much energy as you want, and then do the exercise. Because if you do it before, and then you've got no energy to get food for yourself or get yourself Washington dress. It defeats the whole object of doing exercise in the first place. Yeah,

Jake Cooke

absolutely. You're here to take a question. Yes, absolutely. So Sarah says, What kind of work do you do with people with fnd? Have you had much success?

Kamaljit Saggu

I have. I've worked with them in terms of a low impact exercise class, this particular lady that's coming to mind is online. And it was working in a great deal of knowing what her symptoms are that day where her pain is that day, what his worth T levels that day. And then it's adapting to either chair based stuff, standing stuff, reining in the technique, or reducing the amount of reps, it was just trying to make the exercise functional for what they've got going on that particular day. And sometimes it wasn't physical, sometimes it was, a lot of it was the anxiety that kicked in the mental stress that kicked in, and it was, in a way using exercise to bring them down on that level as well, and getting them back to a level they can manage. And

Jake Cooke

so I see a few fnd patients, and they can be bizarre currently. So yes, and it can be almost anything. So it could be a sensory basically motor based, it could be digestive issues, it Visual Basic, you know, just somebody has tunnel vision in one eye.

Kamaljit Saggu

Often when they turn up to my classes, you quite don't know what to expect. The consistency and what their symptoms are showing is not always there. But you just have to go with it, run with it and see. And what I always ask is for them to at least turn up every single time turn up on the sort of session that we've got together, we'll do something we'll do some sort of movement, whether it's regressed right the way back, or I push them a little bit further on a good day. So I try my best in order to keep them functionally moving the best I can I think

Jake Cooke

optimism is a big part of it, isn't it? Positivity that you're like you're saying, You're not trying to push them too far and show them how you're not trying to reinforce what they can't do. But you're also not trying to baby them and you're trying to meet them somewhere in the middle and say, Okay, this is these are the bits that do work and and can we try and integrate it across,

Kamaljit Saggu

I will always highlight what they have succeeded in, in that session, as opposed to what they've it's an interesting topic that you've hit on. Because I am finding that all these people, they've got these conditions, some of them embrace what they've got, and understand their progressive conditions or they're with them long term. Others will take it to the point where I don't want to, you know, it doesn't define me. I don't you know, fibromyalgia is not me, I'd rather not think about that. I've got that condition, almost to the point where they bury their head in the sand. And I'm like, Well, no, you still do need to acknowledge you've got something but you don't have to make it your whole life. So it's bringing that positivity back in actually, based on my experience, you can do X, Y and Zed. From what I've seen. Let's go with that. Let's build on that rather than what you can't do.

Jake Cooke

Absolutely. I've definitely noticed with fibromyalgia patients there is a not not everyone for sure. But there is definitely something in there that they sometimes over identify with the condition. So everything is now impossible because I have fibromyalgia and a topic trying to get into the headspace

Kamaljit Saggu

of yes country I had. I have this conversation quite repeatedly. They will medical staff. And then the clients themselves are both under this perception that whatever pain they may be in whatever fatigue whatever symptoms they're getting, could be based on it's all Fibromyalgia but it isn't it isn't From my understanding, generic pain relief does not hit fibromyalgia pain. But some will just not take any pain relief to see actually, is it a muscular problem? Is it something else have they pulled something that they shouldn't have pulled? So this is where I often then signpost to chiropractors or osteopath and say, well actually, have you actually had it looked at to see is it a muscular problem as opposed to a fibro problem? And can it actually be fixed? And often it is, but for a long time, they

will just keep thinking it's Fibro pain. So therefore, absolutely, not a lot they can do. Well, there is there is a lot they can do. You're absolutely

Jake Cooke

right. And that's why I've tried to do that kind of examinations we will out as they say, like said, is it just a local muscular pain? Or is this more your widespread pain central sensitization is really key. Peters come and say that spoon seem to smaller energy, or perhaps buckets should be.

Kamaljit Saggu

I agree with you. I agree with you. I really don't know where that analogy has come from. And it feels like it is too small buckets, I think will be probably more accurate. I do agree.

Jake Cooke

So we've got quite a few questions. I'll put them to me. So one of them is from Leo, asking about what's the conventional I NHS wisdom on dealing with chronic fatigue or me?

Kamaljit Saggu

Oh, okay. As it stands from it is graded exercises. But what those graded exercises look like, I think varies to each team that might see you. The way I would teach it is know what their baseline is, and build on it. But then I'm a little bit more autonomous in how I teach. The NHS I think does have a very sort of strict guideline as to which exercises they do, how often they do it, how they grade it, how they build it up. The problem I find with the way the NHS runs it, and this is from feedback from my client is it's a bit careful, I would say it's a little bit patronising in the sense, they'll make it feel like it's all in your head, you it's not as bad as you're making it out to be. And it's really got their backups and to the point where they won't complete the programme with the NHS and they come out of it. So this has come from a few of my clients who've experienced it from the NHS aspect first find found it's they're not being heard, they've, they've stuck them all under one umbrella. And it's not one size fits all. So I feel like it's a one size fits all, in terms of education and the exercise itself. And for some it may work, but the people that come to me find it needs to be a little bit more geared up to them, as opposed to what the policies are saying. Yeah, that makes sense. individualistic.

Jake Cooke

Yeah. Yeah. That's very interesting point isn't because I definitely know this patient led patient support groups, yes. For trying to support each other where they didn't feel like maybe had been heard or they're quite

Kamaljit Saggu

powerful. They are they are, I think it varies which area in what trust you're under, it does vary. So it may be that the ones I've come across, it wasn't a very developed area in terms of having those support groups. But I do agree the support groups are very powerful, because you're with people who understand. I mean, we got to remember, these are hidden illnesses. These are working people. A lot of people they're working with don't understand, well, that they will say, Well, what if you if you're in pain, just take a painkiller. Or if you're tired, just go and have a good night's rest, you'll be fine. They don't understand how these symptoms work. So being in a support group, I can it is very powerful.

Jake Cooke

It's interesting, because I think the one of the stereotypes with fibromyalgia, probably from a doctor side of thing is that they can be a bit because they're in pain all the time. And they have fatigue and stomach issues and brain fog and all these other cognitive issues. They are a pain, frankly, that yes, this kind of like you're being a hassle, because you complain about so many different aspects. Yeah. And so then they stopped talking to people about it. Yeah. But I think if you if you meet someone who has proper fibromyalgia, and you see how pain sensitive they are, it's ridiculous. You can do like the lightest touch and they respond like you're really pinching them.

Kamaljit Saggu

They're really sensitive, aren't they?

Jake Cooke

So we've got a couple of good questions here on when you're talking about getting patients to turn up. Sarah's asking, do you get them to just kind of do get how'd you commit? Do you get him to write something down? Do you just

Kamaljit Saggu

have a conversation with them? I have a conversation with them a frank conversation at the beginning of their journey with me. And, and what I'll do is it's not just one class, I'll offer various options throughout the week. So if they purchase one class a week, they can depending on how their symptoms are, they can flip between whichever class it is and all I ask from them, and it does make a difference because they're paying for my service is that they there's a need and a want and a bit of motivation to attend as well. But I will have that crank conversation is I need commitment from you. In order for this to work. I need you to actually turn up regularly Not once a month and then wonder why it's not working. And they're on board with that, because they're paying for my service. They know what they're getting themselves in for. And I'll offer a trial class, if they want to try it and see how they are. I'll gauge how they are a few days afterwards as well. But generally speaking, because I keep it light hearted, fun, the conversations flowing, it's not all about the focus is not all about the exercise. It's the social, psychosocial interaction, it makes them, it goes back to that support aspect you were talking about, they can come into my class, it's a safe place, and someone

will say, So and so has happened today, and the rest of the class will understand exactly what they're talking about. So

Jake Cooke

when you're talking about different classes, you have different sized groups, I

Kamaljit Saggu

try and minimise and keep them as small as I can between eight to 10. Because you do need to adapt for every person, whether it's online, I think online for fatigue based syndromes really helps because you're taking the travel out of it, you're taking the whole having to get dressed and get in a car getting there. And sometimes that's enough to wipe them out. So you take all of that out. And they can turn up in their pyjamas two minutes before the class starts, then they have the energy for

Jake Cooke

the class. And then how often

Kamaljit Saggu

some people choose once a week, and that's enough, some people choose twice a week, some people will take what I'm doing, and I'll give them advice to do five minutes every day. When we're not training together, it very much depends on them, and how much they want to push themselves and

Jake Cooke

and with once or twice a week is that enough to be able to like meaningfully change the fatigue or is that just helping,

Kamaljit Saggu

it helps them manage it. It's my feedback from what they what I see and what they observe or maybe what other clients in the in the group observe. It allows them to manage it better understand their body a lot better know when they can attend. And they will give it their all they know when it's not going to happen today. I've overdone it, I can't come today and have. But that happens is getting less and less, the more they come that happens less than less. And they always end up feeling a lot better afterwards. So I think once or twice a week in terms of keeping them on top of their fitness journey, keeping their motivation going and keeping their goal in mind on what they want to achieve is enough to keep them going. And they do little bits on their own as well.

Jake Cooke

Put a couple more questions in so some of them quite big questions. So Sam, is it says that file manager can be a bit of a blanket diagnosis, in his opinion, like in the past? So we say your lumbago just you know, just a board. You have back pain? Yes. So if the body is not functioning as it ideally should, there must be an underlying cause or functional cause. And then Dawn kind of comes in with that as well says Do we understand the physiological cause of fatigue? So that's slightly different question. So if you say Fibromyalgia first,

Kamaljit Saggu

it does a very good question. And I have questioned this myself as well. Obviously, I'm not a doctor. But when I'm training my clients, I do wonder if it is just that blanket, you've got Fibromyalgia because they don't know what it is. The more I trained them, the more I actually think you know what, I think you've got something else. I think often I think it's EDS. I think they've got a version of EDs, but it's common to the fibromyalgia umbrella. Or I feel there's something else going on, in addition to fibromyalgia, it's not the you know, all of it. In terms of I have heard this that it's that if they can't work out what's wrong with them, then it ends up being the fibromyalgia is blank and

Jake Cooke

considered a wastebasket diagnosis, right?

Kamaljit Saggu

Yes, yes. I struggle with that a little bit because I think well, what's going on? So when I work with other fellow osteopath, chiropractors, and we have this discussion, we do often wonder, is there some sort of trauma that's gone on earlier on in life? Often there is, is this other comorbidities going on? Are they very overweight? How much movement are they doing? Are they in global pain because of fibromyalgia or there's something else going on? So often, I think for my role, it's ending up signposting to get a little bit further investigation done either by yourselves, or going back to the GP and actually working out. Is it actually Fibromyalgia stating that I am now doing exercise? I'm following the protocol of what you're expecting me to do with this diagnosis. This is still happening. Can you investigate further? I do find it's a blanket. And it's the I have come across therapists that will say we don't know what to do with them anymore. And this is where I can come in and say, well, actually, they just need to know how to manage their condition a bit better.

Jake Cooke

I think you're absolutely right. I think that past traumas, particularly in women, we know the numbers of women who've been had sexual trauma, sexual traumas or physical traumas or neglect or whatever age, you know, that's a massive predictor, not just for back pain, but the fibromyalgia. And I agree with that.

Kamaljit Saggu

So I agree with that. Yeah,

Jake Cooke

we definitely see, you know, central changes in the, in the brain, spinal cord. So that that's why it's so hard because in it, because you're not just seeing as that sympathetic tone goes up and parasympathetic drops, because you're in this constant fight or flight, yes, of course, you're gonna change your gut, because the person, the vagal, output is going to be reduced, you're not gonna just be so well. And if you're not sleeping, well, of course, you're not going to think well, because you're not sleeping. So no cognitive activity goes down. So

Kamaljit Saggu

you're not sleeping, you've hit it on the head, that if you're not sleeping well, and the brain fog is there, automatically, the fatigue will get worse, it is a bit of a default that you have fatigue, because of that global pain in the first place. But because you can't rest and actually recover, it is a vicious cycle going around around, I do. I do wonder how much viruses trigger off as well, whether I, I've had a few of my clients already got the diagnosis, we've been training for some time, then they get COVID, or they get some sort of virus. And that lingers, the effect of fatigue lasts a lot longer.

Jake Cooke

So that ties into what Dawn was asking. So she's doing sound, the physiological cause of fatigue is it mitochondrial dysfunction that can be that can be certain to certain systems in the body, eg neurological dysfunction, and MS or muscular mitochondrial dysfunction and fibromyalgia. So Jeff fourth come through a part of the story that or

Kamaljit Saggu

I've touched on it, but not in a great deal. But I do understand where she's coming from. Is it at a cellular level? And is there something you need to do from a cellular level? That's a little bit out of my understanding. But I do find from a cellular level, yeah, I think it can be, I think from from a Fibromyalgia point of view, yes, it

Jake Cooke

definitely ties in with, with fatigue, and why it's considered a function, that polarity parts story. So we saw with COVID, one of the really horrible things, we told them that shutdown mitochondrial function, so basically, your mitochondria became part of the immune system and just lower their energy levels. And then then you switch back on. So you have all these long, COVID patients who are then basically all the other symptoms have gone. But they're still complaining of bad fatigue, dizziness, brain fog, stuff like that. So

Kamaljit Saggu

it does last a long time. I've had someone who had it last summer, and she's still not quite back to where she was before. So it may switch back on. It may not. I think it depends on what their baseline was before, as well.

Jake Cooke

So as Simon said, he was diagnosed with transient chronic fatigue syndrome, after his mother in law died, and very sad to hear that. In the end, it was a physical manifestation of grief. Yeah, what's the grief was dealt with? There was no more chronic fatigue syndrome. He's not trying to go to this point.

Kamaljit Saggu

So that's a good, that's a valid point. Is it more about mental health support? Is it talking therapies that you need more than the physical? So I think the physical side, the exercise, and all of that, yes, it will help medication, whatever. But is there something we're missing in terms of getting more talking therapies? To try and deal with the core problem? Which is what we've touched on with the fibromyalgia? Is it actually Fibromyalgia presenting it? But are we actually getting to the cause of it as to what's triggered it off in the first place? And have they dealt with that issue. And

Jake Cooke

so that should just be part of it. Sorry, depression must be

Kamaljit Saggu

anxiety, depression, panic attacks, I've seen all of that. To the point where I've seen one, one of the worst sort of more extreme cases of fibro that I've seen is the panic attacks kicked in to such an extent, her body goes rigid and freezes. And then she can't it looks like she can't move. And at that point, she is on the verge of having a full blown panic attack if we don't try and calm her down manager. And I know we're not supposed to promote smoking and vaping. But at that point, her vape is what allows her from stopping from going from panic attack, to staying on the side where she can bring it back down again. So mental health is a big one on one.

Jake Cooke

So there's such a huge topic, so many people have questions relevant for themselves. So Kassar saying she's been diagnosed with Fibro has had a lot of trauma 18 and also neurodiverse, which is also a vicious cycle, but even when skinny still have problems with Fibro So, yeah, that that history of trauma is just a huge part of isn't it that you're priming their nervous system to look out for danger and enter into that sympathetic state? What about Wait, is that related to fatigue and into fibromyalgia?

Kamaljit Saggu

I don't think it helps. I did. Generally speaking, they are the ones I I train anyway, the ladies I train tend to be on the overweight side. And then again, you've got a question, are they overweight, because it's not as simple as they're just overeating or they're not moving, I think there's more underlying causes that trigger off. So the weight will not help, I find that some of them that have needed some sort of surgical intervention due to the pain that they're in, can't have it done because of the weight limit. And then this passing it to one of the nice artists will be willing to do it surgery. So it does start to limit them. But it's all that comes into, I think the weight comes into that whole vicious cycle again, that at the end of the day, there is something that is triggering it off. And I think it is some level of trauma. And until that's dealt with, the rest of it sometimes just doesn't shift.

Jake Cooke

So when you experience cameras, is it that patients have pain fatigue, let's say we're talking about five miles, you're purely they have pain, fatigue, cognitive issues, therefore, they don't want to exercise because it's not comfortable, and then they put on weight, or is it they're already leading an unhealthy lifestyle.

Kamaljit Saggu

And then I think they're already on that trajectory in the first place, before the diagnosis happens. And then once the diagnosis happens, well, it's then very hard to come out of that cycle. So a lot of my role is actually taking them from not doing anything at all, which is what we'll do with the demonstrations of exercises today is taking them from not doing because it is the fear factor kicks in the fear factor kicks in, how much will I actually be able to do and then take them with that positivity, that positive feedback, seeing what they can do encouraging them, showing them that they can do a bit more. And then if more movement happens, the more muscle mass improves, the more efficient they're gonna get with their movements. And it could make make or break from, you know, I could walk with my husband or my wife. Whereas normally I'd have to sit while they walk, I might just be able to walk with them, it makes it that makes a little bit of difference to their quality of life. So yes,

Jake Cooke

it's a little bit off topic, but we see that with migraine patients that people with chronic migraine health is like high frequency migraines, so that could be like 10, migraines, 40 migraines, a lot, you know, basically every other day, yeah, having a headache. There's a relationship with weight there as well. So unfortunately, if you're in the overweight category, you're more likely to progress and have frequent headaches. But also if you're on the underweight category. So with castlerea if you you know struggling with weights, but also if you're kind of swinging from, from underweight to overweight, both those categories aren't great. And then if we look at the population, two thirds of the population overweight, yes. And then you're not saying that last third is, is healthy weight, because in that we've got the underweight category as well. So actually, the percentage of the population that are to their ideal weight is probably quite low,

Kamaljit Saggu

not very often you come across that I do find, I try not to focus in on the weight, I think, for me, it's focusing on the movement and getting them moving successfully first. And if they can break that cycle of moving a bit more successfully managing their fatigue and their pain a little bit better. The weight is something that will come naturally afterwards, rather than focusing on the weight first, the chances are they've just done very little movement at all.

Jake Cooke

I think what we think we should do is I know you've got a whole load of cool practical stuff, too. So should we move into that in a minute? Yes. So Simon, put in a nice comment, but basically highlighting the fact that EDS equal Danlos Syndrome and chronic fatigue syndrome to have two separate conditions. And that again, the wellness EDS is pretty pretty poor in society. So yes, those patients quite long time to get diagnosed. It

Kamaljit Saggu

does take a long time. Often they've been suffering with it for quite a number of years. I would even say as long as some early teens maybe earlier than that. And one of the ladies I worked with didn't get diagnosed until just before she turned 40. And that in itself is a whole host of issues as well, because you don't know what it is do half the time. Absolutely. I'm just gonna

Jake Cooke

rush through these just so we can get your practical. So PIP came back to mitochondria dysfunction is asking if if it does play a part are supplements like Coenzyme Q 10 helpful Are you do you know much about them? So

Kamaljit Saggu

not a huge deal? No, no, that's a little bit out of my remit. Yeah,

Jake Cooke

I know a little bit about it. So. So yes, we want to Coco, Coco 10. To save me the tongue twister. It's just an essential part of that mitochondrial production. Yeah, so, Cokie 10. Magnesium riboflavin will be the classic ones. They're also the cocktail we tend to use in migraines as well. Yes. So migraine, you have this mitochondrial dysfunction. Yeah. And James asks, What's the prevailing sleep apnea among fatigue patients

Kamaljit Saggu

Okay, that's a good question. It does. It has I've got clients with sleep apnea. And quite a bit, actually, some of them are on CPAP machines. Because it is that extreme. Some people just can't, wants their brain goes into overdrive, and their body has gone into overdrive and they've got into

that situation where the fatigue and pain has gone past a certain level, then yes, the sleep apnea kicks in. And and then it's that vicious cycle again, so that I think there's a strong correlation between between both of those definitely is

Jake Cooke

interesting with men and women that they present differently with sleep apnea. So men, the diagnosis is normally made on witnessed snoring and witnessed apnea that the wife basically or the partner says, he stopped snoring stops breathing for 30 seconds. But in women, it's different. So the sleeping husband doesn't notice that she's not breathing that. So instead, women have to rely on the fact that they wake up. Their mood has changed. Yes. And they have morning headaches. Yes. And they're fatigued. Yes. So whereas men have an easy ride, they just basically snore a lot, annoy their partner. Yeah. I can't rely on the fact that yeah, they noticed their mood isn't as good. See them? I have this morning headache. So any patient who wakes up and says, I don't wake up feeling refreshed? I've got a headache is likely to have to wrap up there.

Kamaljit Saggu

It's happening more than we think I think. And we'll

Jake Cooke

go to the practical now. But Anna asked, How was fnd diagnosed?

Kamaljit Saggu

is the big question. I don't think there's enough known about it to start off with, I recently spoke to an occupational therapist, who's also a friend of mine, and her daughter's been recently diagnosed. But it was not through the NHS, I think because of her sort of medical understanding. She went private. I don't quite know what she actually did in order to get that diagnosis if I'm honest. But I do find it's not easily recognised as a condition. And I do wonder if it's falling under the fibromyalgia, if it's not that it's not that it's not that then maybe this is what it is because it presents very, sometimes very similarly to MS is sometimes presents very similarly to Parkinson's, even post stroke. They're kind of similar symptoms. It's all neurological. But is is fnd. The new Fibromyalgia as in we don't, it's not Ms. It's not talking to this, not this. So maybe it's because

Jake Cooke

you're this kind of you're identifying that we really do have sensory motor changes. But then all your physical exam, you do nerve conduction studies, you're doing MRI, CAT Scans, CT scans are what's normal. Yeah, but you're right. So it's basically you have to get to the point where the the diagnosing doctor can accept that what they're going through is real. But there's no real explanation. Yeah, there's

Kamaljit Saggu

no lesions when it comes to Ms. There's no lack of dopamine when it comes to Parkinson's, but they're definitely showing similar signs of how I mean, the act. The ataxia is their stiffness, the rigidity, the hypermobility, it depends on each each person, they're all presenting with it.

Jake Cooke

Do you want to go and show us some? Yes. Yes, fantastic. Sorry. So if you want to learn more about fnd, if you go on to something like PubMed, you can just search for the diagnostic criteria. And there's some official criteria for them now.

Great, where are we starting with

Kamaljit Saggu

wonderful. So when it comes to teaching exercise with people with all sorts of fatigue symptoms, I try and make it functional. So what we said about the levels of energy they've got, rather than taking a chunk of energy, putting them in a gym and saying go and do certain gym movement, it's going to take too much of their energy up. So what I tend to do is make it functional with their day to day activities, but increase it to the point where they can incorporate it into their daily activities, but also build and hopefully improve the first one. A lot of it is how they stand up. So I'm going to try and sort of work my way through if they had EDS, and they've got hypermobility, how do we move with them? If they've got MS? How do we improve that movement? It's the whole idea is to improve the posture, the transfers and how well they transfer, their coordination, balance and gait. So those are those sort of five things I will focus in on and work round it in terms of building exercises on board based on what their baseline actually is. So for some people, they've come to me and they have not exercised for me you can count never probably and a lot of them sometimes will be sitting for a long period of time. The back will be up against like with itself where your back is up against the chair. They could be working at a desk where their back is fully supported so their core is not in gauging at all, in terms of their sitting tolerance. And if they're sitting tolerance isn't there, then it gets a little bit harder in terms of building up for standing tolerance and then further fall in terms of walking tolerance. So I will see how far they can actually sit from a posture point of view. And actually, so if you don't mind my lovely, trying to come forwards a little bit, so it's actually you're not leaning against the back of the chair. That's perfect. And you're engaging your tummy muscles, the posture in terms of your shoulder blades are down your neck. And fellow fellow osteopath told me this, putting a soft peach under your chin, imagine you've got a soft peach under your chin, but you're not going to you're holding it in place, but you're not going to squeeze it. Does that make sense? So it's putting yourself in the right posture, engaging your tummy muscles, and actually seeing how long you can hold that position before. Often muscular fatigue can kick in, at this point, if they've not been holding it for, well, if they've not held their own muscles up for a long time. So how long would someone I will time this?

Jake Cooke

So she has EDS. Yeah, it can literally be in minutes before they trapped

Kamaljit Saggu

but Oh, not even minutes, it could be a lot less than that. So what I find with EDS is their proprioception of where their joints are sitting is often not there. There are normally very hypermobile. So where where you're sitting, and when me and you would say the shoulders are set in a certain place for them. They don't know what their norm is where where the shoulders actually serve. So they could already be hyper flexed already. So this is where sometimes taping can come in to put the shoulder back in place. And this is where chiropractors and osteopaths do come in to try and put their, their their joints back to where they should be. So I'm mindful of that. So sometimes it could be just up to a few seconds, there could be up to a minute, could be a couple of minutes, but it's recognising that actually, my body is now tired, and then I'll get them to sit back. But the main one I want to talk about is the various exercises we do from a sit to stand perspective. So we have to stand up quite a lot throughout the day. But do we use it as exercise and that's what I wanted to go through. That if you don't mind popping your hand, there wonderful. If has any, you must have heard of a tricep dip, where you've got your hand and you lift up and down. This is essentially what we're doing here. In terms of using your hands. All I'm going to ask you to do is try and just lift your bottom, off the chair and lower back down again, using your arms, that hands by your side, lift your bottom up. Oh, look at you, right, most people won't be able to do that. That's impressive. Most people that I train will just about get the bottom, they may not even get it off the chair, it's just enough to engage those muscles and lift and get that bottom somewhat off the chair. Often I find that when they sit comfortably, this is a lovely chair. But if you think about a sofa that sinks in at the back, it's putting them in the wrong per posture. And just that lift and practising that lift will allow them to try and manoeuvre in the chair. So you could lift and come forward a little bit you can lift and shuffle left or right. Depends if they're wheelchair bound. It depends if they've got walkers or they're walking on their own steam. So that's one is just lifting, engaging, coming back down again. The next one, if you don't mind, if you just come forward,

Jake Cooke

how many? How many reps reduce, right? So I mean, that

Kamaljit Saggu

depends on each person, I would test it with them. Five tends to be a right sort of a starting point. Sometimes it's not even 510 seems to be the max I will do and then I'll get them to repeat it again,

Jake Cooke

I'm just holding that hold for a second or so. Ideally

Kamaljit Saggu

about five seconds, if they can. If nothing else, if it comes to itself, MS and Parkinson's initiating the movement sometimes is enough just to get the signals going. And sometimes the movement doesn't happen after the first or second reps, but third and fourth one it will start to kick in. So the next one is when your bottoms forward. Actually, you're in the correct position there. Do you want to take your legs out? Yeah, most people when they're sad, their legs are out in front of them. You're going to struggle to stand up efficiently that way. So it's popping your legs back to where you're tucking them under as much as possible. Feet flat on the ground. You've shuffled forward, so you're as close to the edge as possible. Wonderful, nose over toes. And now you're going to propel yourself up into a standing position. Good beautifully done nice and tall, tuck your hips in. This was a very good example of how it should be done. When people have got fatigue, when they've got neurological conditions, it gets to the point where they'll get halfway. And that's enough. And then they'll sit back down against the can you sit back down again? So when I'd like you to stand up, half stand up, if that's all right hands, stand up halfway through pause. That might be enough, I would call this your you're using your quad muscles, can you feel that there, you can feel that all engaging, can you feel that all in your arm, and you're probably working the core as well. So all of a sudden, you've got your arms working there, you've got your Tommy who's working there, and you've also got your legs working there, just by trying to do half a stand. So when you stand up fully, and then I asked you to stand up 10 times, that suddenly becomes quite a difficult but full body exercise. When it comes to EDS and fibromyalgia, particularly EDS with hypermobility, you've got to make sure the posture is in the right place, it has got to be in the right place. And with hypermobility, they can probably do the movement endlessly and take their arm back where it's not normal. But we don't want that we want it where it should be sitting, and try and get them to stay in that position. Does that make sense?

Jake Cooke

Because I spent a lot of time looking at sit to stand as a predictor. You know, it's a predictor of falls and longevity and pain and stuff like this. But I'm really thought about it as a as an exercise over test in my head,

Kamaljit Saggu

I use it as a as an exercise. And often it will start with the sitting tolerance, then the lift, then the half lift, and then into a full stand. So if I can ask you to stand up for me, wonderful. So if they can get to this stage, and they're standing up there nice and tall, they feel okay. Sit back down again. Now, yes, please sit back down again. But this is where now I'm going to ask them to bring the controlling, not flopped down that often, there is a massive Oh, I can sit down, let go and they flop. And that's what I don't want. This is where I want the control to come in. Arms, gently lower themselves down again. Now what I will encourage if they're a little bit more advanced than this, then they can do a bit more up to 10 repetitions, it also gets to the stage where you might not need the arms. So I needed the arms to demonstrate now because majority people need the arms to pull themselves up, eventually the transition will happen that the legs will get stronger, and it will actually be the legs that pulling them up as opposed to the arms. So you could have your arms across your chest with the same legs tucked back in nose over toes, you don't mind popping your hands across your chest and then trying to stand up that way. That's a more advanced movement. But it's now engaging a lot more muscles at the same time. And then you can lower yourself down again

Jake Cooke

up aim for like three to five reps.

Kamaljit Saggu

Yes. And if they've been training with me for some time today, reps, five to 10 reps, five to 10 reps could be more could be less depending on what energy they bring in with

Jake Cooke

just three sets. So

Kamaljit Saggu

I tend to do as much repetition as they can manage on that particular exercise code, go to a different one, and then maybe come back to it and see if they can do a little bit more. So the repetition part is important. The technique is important in terms of building leg strength, if they're seated, it literally is sticking your leg out, pointing the toe, what would the leg straight out, lift up, point the toe towards you. And YuLing it your quads will start to engage, you'll feel that in the calf. That is a nice way to start building up those quads if they're already not on their feet, much as it is in terms of based on this movement altogether. If you've got your feet in front, and then you slide it back, if you don't mind having your toe on the floor, heel off the ground, and you start to slide it back, lift it up, slide it back to that now work in the back of the leg. In terms of loosening it up, what I find is the hamstrings shorten, I'm sure we all know this it starts to shorten will not really use the glutes very much the cause a little bit weak. And it all goes out of proportion. Often actually, the quads tend to be a little bit overactive. If I'm honest, I find that the hamstrings get tight, weaker, glutes are weak, but the quads seem to be overactive. And then when they stand up, everything's out of proportion. So it's the question of engaging the glutes when they stand up, making sure the legs tucked in as far back as possible, maybe do that exercise in itself, do the leg raises in itself, and then combine them and put them together. It's

Jake Cooke

interesting, because some of these movements are very simple. And when you're able bodied, and fit and healthy, are very simple. And they should be yes, if you've got something like Parkinson's or MS, or anything along that line, you

Kamaljit Saggu

just trying to get their leg back is not easy. But it is important when standing is a problem in terms of how long you can stand for balance comes in, your confidence comes in risk of falls comes in, doing it seated, at least keep that mobility going, what some of my clients do is they'll put paper bag, or they'll put a plastic bag under their foot. So it allows that like to happen, but with Ms. And with

Parkinson's, you do get that it doesn't want to move until you keep initiating that movement over and over again until it does move.

Jake Cooke

Yeah, cuz you're trying to turn a fight that either spasticity, whatever, the hyper, you know, we're in the extension or time or we've all we've lost all ability. And they just don't kind of activate those muscles in the first place. No, no, it's interesting how these moves can be so slow you like you said they can you say Go Go Go and then slowly, their brain somehow inhibits the time slowly it comes, you have

Kamaljit Saggu

to give them time. So could you feel those movements as you want to Yeah, you can see them what so they are simple. Often they're simple functional movements, but done well, with the correct posture is what's going to make them start to build up gradually, and then that graded sort of way. So that half lift almost becomes half a squat. When you're standing up and sitting down, you got your arms across your chest, you could actually could I get you to demonstrate arms across your chest standing up. And then before, I'd like you to lower yourself down, but before your bottom hits the chair, come straight back up again. So down, and then straight back up again, and all of a sudden you're doing a squat. But you've got the chair behind you in case, your legs can't hold you. It's the safety aspect of it. But all of a sudden, we're doing squats. And if I ask them to stand in the middle of the room and do a squat, they may not feel as safe. But this has got the chair behind it. And from a simple stick to stand movement where now tricep dips are happening, squats are happening. You're having squat and holes, and all of a sudden it's becoming into movements that you would classify as generic exercise movement. But it's in a functional way that they can do you know, what is the commercial break? Let me try and do stick to stand five minutes. While there's a break, or, you know, while the kettle is boiling, I'll do so so many movements. So it's bringing it into their functional life.

Jake Cooke

And I assume that balance is often often compromised. So yes, Alice has a confidence games too. So it's

Kamaljit Saggu

deconditioned already that's gonna be compromised. And the condition itself will cause balance issues. Now, if I can ask you to stand up my lovely. Sometimes feet shoulder width apart. And just standing just like the sitting and just standing. And how long they can stand for successfully in the correct posture with the hips tucked in is enough of a balance exercise, I can really take it as simple as that sometimes, in order to build that up. If I can get you onto the mat, my lovely at the front of the mat. They can do this with a chair with their Walker. Or if there's a kitchen top, they can do it along their kitchen top. And the idea is to put one foot in front of the other. Just be careful maybe come on to the mat. And just hold there holder. Just try and stand up nice and tall. Now this is a big

movement I'm asking people to do this one really does scare people. So this is where having a chair having something nearby and can you feel yourself wobbling just just just by doing that. So I would encourage you to stand up nice and tall, find a focal point in front of you and try and hold it as steady as you can. So now we're moving on simple balance movements. And I will encourage this on all of my clients to try and build that up. This one is a timing one. So again, if the kettles boiling and you're in your kitchen, you can be holding on to the kitchen sink, watching the clock and seeing how long you can hold it for and the more you do it a little and often, the better it will get. If you want to progress on from that one, it becomes a walk. So imagine you've got a tight rope in front of you and you're going to do one foot in front of the other and walk How does that feel? But wobbly. It is more blazoned that this will challenge your so people with fatigue syndromes, eds, fnd, all of that, they might find this a little bit easier. People with neurological conditions may struggle to get that one foot in front of the other. So this is where the static one will come in all the simple standing.

Jake Cooke

I love balance exercises as part of rehab. Yes, it's such a good way to fire the extensor tone, you know, get you up, right, that vestibular system is firing your extensor muscles, which vice gravity is such a great, great way I

Kamaljit Saggu

also find is if they're only doing a static movement, and they're not doing the walk one foot in front of the other one side is significantly better than the other, you got

Jake Cooke

to do dynamic. And you'll often see a lot of patients will hang off the lake setback. So they're not really engaging muscles, they're just trying to like hang off joints, rather than really engaged in musculature. So that posture is talking about about really trying to encourage that good posture is essential for it.

Kamaljit Saggu

Can I get you to stand here, my lovely next, the other things I will do for posture is so imagine you've got a chair in front of you, I'll ask you to go up onto your toes come back down. So you've already seen your feet go sideways. So it's not so easy, just going up onto your toes. And and this is where it might challenge where I asked you to rock back onto your heels onto your mat set well done. And then back onto your dose at this at this point. So go onto your toes and onto your heels, and keep rocking backwards and forwards. This is I would encourage with a chair or a frame or some sort of support, because the odds of doing this completely free standing with these conditions is a little less. And I

Jake Cooke

actually get Parkinson's patients to do this as well, or is this a SS? Yes, yes,

Kamaljit Saggu

it takes a little bit of convincing. But it's sometimes when that trust has been built between myself and them, they were willing to give it a go on there. And they do try Yeah. And sometimes I know we're showing a very good movement or lifting. But sometimes it's not as good as that it literally is initiating the movement, somewhat of a left, come back down again, I think confidence is a big one on this one. If they're anxious, or they're worried, it will throw them quite a bit as opposed to not being able to do the movement.

Jake Cooke

And with some patients, it's almost just saying to them, try even if you can't get them, just try to visualise what that would feel like and and,

Kamaljit Saggu

and you know, when they do succeed, it's that positivity, it's that oh my god, I didn't realise I could do it. They didn't, they didn't realise they could do it. And all of a sudden, they've done more than they anticipated they could do so then it drives them to do a little bit more a little bit more. So the lady I teach was Frederick ataxia, her coordination can be all over the place, but it's honing in that control. So this movement in itself is a big ask for her. And to be trying to hold it in place, or even this one, what I find is, people with ataxia, find they they lock their knees, because it's a safety aspect. And I've seen it in MS as well, they will lock their knees, and to relax them and release them is quite a feat. So I'm asking them to relax and then just to go up on their toes, and might combine it with a squat, they'll come down, come up, and then go up onto their toes. mental power it takes to do that particular movement is quite intense, as well. But it also starts to encourage the knees to stop rocking, which is also important as well, I find that when they're like this, well you can imagine their posture as their bottom is sticking out there. And and they're leaning forwards, and things are not moving the way they should be. And there's compensation going on left, right and centre. So it's putting them into the right posture up and then back down again. For someone who's got those kinds of conditions like Frederick ataxia, Parkinson's, this is quite a big movement I'm asking them to do and they do succeed, they give it a go, doesn't happen first time round, we come back to it. Second time round, they've done a little bit more third time round. They're now familiar with the movement, and they're now more confident give it a go.

Jake Cooke

Because they're free drinks, we get a lot of that kind of tranquillise accident where they can't just maintain you know, something that does feel so simple for us. No, they get these horrible movements. So the narrower their base of support gets, the worse that movement becomes.

Kamaljit Saggu

And that's worth challenging. I do find that's worth challenging and and the more I throw challenges, the more they think actually no I can do this. Obviously it's in a safe environment. This I tend to do more in a one to one than a class base because I can control the environment a bit better and they can control it a bit better as well but I do find when I push her she succeeds, but when I initially met her hands are up in the air, she doesn't quite know if she'll be able to walk without her walking aid, let alone do balance exercises. It is it's all over the place, the hands are all over the place, legs are all over the place. But with regular practice, the control is coming in, the arms are coming down, the breath is starting to regulate the panic has stopped. And then they can work their way through that heel, toe, heel toe gate. So it does work. If you're persistent with it,

Jake Cooke

practice makes perfect. Practice makes better as makes better makes better.

Kamaljit Saggu

So I've gone from someone who's really having panic attacks to try and do even a couple of steps on their own without their walking aid, to now walking the length of a room and coming back with more confidence with more ease, or

Jake Cooke

Friedrichs is a horrible on a sec, because you've got a tax here, and it's coding, apathy, as well as peripheral nerve damage. So it's a really horrible fatigue must be a huge part of it. Because if your heart's not working well, your muscles aren't working well. And you can't control them properly. Like, where do you start? Where do you start. So you start with these simple, basic movements.

Kamaljit Saggu

And they get bigger and bigger and bigger and bigger as they get more control, more strength dots to build. I also find with coordination. I find boxing, believe it or not, I try and make them assessment sessions fun, relevant, they've got to have a purpose as to what I'm doing. But I find boxing is a good way for coordination as well. So I'm teaching a young girl at the moment who's got MS. A lot of ataxia hands. Tremors are quite significant. So if I asked her to do certain shoulder movements, her hands would collide. And they will she would hurt herself. But boxing with those gloves on. So if I'm stood in front of you, and I've got mitts there, and I'm asking you to hit here, then I'm asking you to hit here, then I'm asking you to hit here. Not only is that coordination, but it's also bringing in that control a little bit in terms of the tremors, they feel so bit of strength work to start making them stronger. All of a sudden, as you get stronger and stronger. So we'll do more basic movements, bring in weights for those kinds of movements. But then once the strength is build up in the arms in the shoulder and the chest, upper back area, then you bring in the coordination and all of a sudden, that's great. They're hitting where I want them to hit rather than bypassing where I want them to hit. So it's becoming more targeted and more controlled. So that's how I would work with coordination of fine. Bringing in boxing gloves, just makes it fun. They're having a good time. And before they know it, I've asked them to coordinate. So if you're if I'm stood here, I could ask you to

punch here my lovely. Oh, no, you don't have to punch very hard, then I could be over here, then I could be down here. Down here. We go over here. This is looking easy. But imagine if you've got a fair bit of ataxia and a lot of tremors. This is not as easy, of course.

Jake Cooke

So some of the ataxia, you're gonna see these nice movements are gonna see this with a texture, it's crossing the midline. So they're gonna have these kind of movements, you're gonna have these undershoots, where overshoots, so Demetria, where they're gonna stop too short or punch through your hands. And that's when you need to get your rings off, because

Kamaljit Saggu

but no, all they circle around their hand. And then they get quite disappointed when that happens. So I've got to say, actually, you know what well done, you're actually getting closer and closer to hitting the target. Keep going, keep going and then learn below the target stop getting hit More often than not, let

Jake Cooke

me see if I was there real life. So putting the key in the front door. Yes, you know, we laugh about it when a drunk housemate comes back. And you can hear their key scratching around the door. But but if you imagine how frustrating it and intention tremor with cerebellar disorders, the closer he gets to the target, the worse the tremor gets. So you start here and you feel pretty good. But by time you're trying to get like in the door, you're all over the place. Boxing is a great one. So if you actually start to get lucky and just get into your house, the simplest of things, or

Kamaljit Saggu

picking up something off the floor. Hence why a guy quite low down, can they get down there to pick something up off the floor, some of the movements where I'll be standing at the side of them, and I'm getting them to punch left and right makes a difference where they can pick that cup of water up at the side of them and bring it to them. Can they actually eat without missing there.

Jake Cooke

I remember working with a poor kid, he had a virus and unfortunately kind of hit the cerebellum. And he had the best sense of humour, and he had a glass of water. And as he went to take a drink someone made him laugh and he threw the entire pint of water over himself lucky could laugh it off a bit. How frustrating is that? It's almost you laugh and that throws your muscle coordination off so much. She literally pints. Pour a pint of water over yourself whereas most of us you can be in a row Start with friends and laugh and not have any issue with that tool.

Kamaljit Saggu

And when I, when it comes to MS, I've got the one of the ladies I'm training, I have to be careful not to make her laugh when she is standing up. So we've gone from lying down exercises to seated tolerance to build in similar movements to what we've just done today. And then she's getting to the stage where she's standing. If I make her laugh, that throws her off completely, and she needs to sit down. So it's that borderline of encouraging her to try and stay standing, hold it for as long as she can. But at the same time, not make her lap. So she'll sit down. It's it's a fine line, because it's daunting to stand up if this is not what you do on a regular basis. So you're right. For all of us, it's just straight and straight out. But for them, it takes a lot of and I think this is where fatigue kicks in for these conditions. When I speak to my clients, I do find that nothing can be spontaneous, everything needs to be done with planning, even if me turning up, it needs to be with planning, they need to be on their chair long before I arrive. So they're settled and they've had a bit of rest, if they need to go out to get their eyes checked, is how do I get into the car? How do I get out the car? Does my wheelchair have clean access? Or will my walker get in and all that so when all of that puts into play, that mental stress of having to organise it all also contributes to the fatigue. So it's probably finding solutions to try and help route work around that. So

Jake Cooke

a lot of us will see hypermobility. So have you got any other gems for us in terms of doesn't have to be as extreme as EDS, because a lot of us will see patients who just have,

Kamaljit Saggu

I would encourage them in terms of postures if one example if I can get you to tuck your elbows in my lovely have one hand on top of the other. So with hypermobility, all I'm going to ask you to do is open, take it as far as you can, and then come back in again. So with hypermobility, they can carry on going and going and going. So I would encourage them to stop roughly where the joint should stop. Does that make sense? And it's just encouraging them to stay within where it should be. So even if I'm asking you to take your arms above your head with hypermobility, you have to be careful if the joint is sitting where it should be sitting, or if it's already out. And me and G will just go up and down. But for them, it might be pushing it too far. So actually, with hypermobility, it's minimising the movement, and just going a little bit high, coming back down again. So the focus is still on building that shoulder strength, but minimising the movement. So they've got control, as opposed to pushing it to where they probably could take it, which is way beyond what me and you could probably do. But that's where the injury start to happen. So I actually where it's a running joke between my clients, but baby flying the movements, doing the movements, but bringing them in a lot smaller, until they know that and listening to their body. One of my clients says she has internal conferences. So it's normally the wrong muscles that's getting activated when I asked them to do a shoulder press or you open and close or even standing. So it's actually getting the right muscles to engage, which takes a little bit of time and a lot of practice for the right ones to actually kick in, and then do that. So it's a correction of right muscles, getting the posture in place, getting the technique right and making it a lot smaller. So

Jake Cooke

as you have to give them little sensory cues and tips to try and get them to engage the right muscles and like movements.

Kamaljit Saggu

Yes. And as time goes on, they pick it up themselves, they then start to understand their bodies a lot more. But when I'm watching them and initially observing them, I'll say right, I'd also go by pain, I would also go by, you know, visual cues from them sensory cues from them, also how it feels as well. And that's where I'd go from.

Jake Cooke

And you do much with isometrics.

Kamaljit Saggu

Already, yes, yes, I can depending on the condition, what the exercises, sometimes isometric exercises is the way forward in order them to activate and build the strength without having to move much

Jake Cooke

because I've often gone starting like prone and supine or side laying and doing kind of isometrics first, but But absolutely there is a disadvantage that is obviously that their heart rates low the blood pressure is controlled, and energy output is controlled. The disadvantage is it's not that realistic in real life. So doing a bunch of floor work is great but if it doesn't, chance doesn't transfer into like say getting out of a chair and

Kamaljit Saggu

the movements are one I would encourage always doing is the glutes, I find do tend to get a lot weaker. They play a massive part in balance. and transfers. So just simply, if I know you're not gonna be able to see this, you probably won't be able to see this, but squeezing your bottom muscles, lifting your pelvic floor and engaging those tummy muscles, puts it all in the right place, and then a big deep breath in, blow it out and then relax it all. I find that works the deep core, and it's the hold. And can they hold it for one breath? Can they hold it for two breaths? Can I hold it for three breaths and isometric exercises like that where they hold starts to build up. And also, if I slow the movement down, whichever movement it is, and get them to hold at the end of it, we're onto a winner, then that's when it starts to make a difference. Great.

Jake Cooke

So what about later on when they're hopefully a little bit stronger? How would that how would you progress from doing these kind of simple exercises into into something that's more.

Kamaljit Saggu

So I will always revert back to these exercises, if they're on a not so good day. But on a good day. This is where I'll bring in weights, they can be half a kilo weights, they can be resistant bands, they could be a kilo weights, they could be a little bit more depending on how comfortable they feel. As long as they do not compromise their posture positioning and their technique, then we're good. I'll even start bringing in bigger movements. Simple like kettlebell swings where the thrusting their hips forward, but not with a massive kettlebell, just to be with a dumbbell or their hands. And then just thrusting forward, you'd bring in the more generic movements like squats, lunges, curtsy squats, shoulder presses, rowing, all those kinds of movements, but with a bit more control, and then adding on weight. So it's still functional. But now it's getting into more larger grip muscles. And you're

Jake Cooke

monitoring heart rates and stuff like that or not not so fast about it.

Kamaljit Saggu

It's difficult to monitor if they're online, at home. If I'm seeing them face to face, I will observe them in terms of are they starting to get dizzy? Is the pain kicking in certain movements, I know probably will trigger off dizziness. So it's monitoring those symptoms, as opposed to actually measuring heart rate. So it is still trying to make it a fun fitness.

Jake Cooke

And have you found that people using all these watches, like the cuff or the names have gone away like Apple Watch. And is there a better version of it? People with fatigue using those a lot now?

Kamaljit Saggu

Yes, I do. I do find that they are using them. I query how accurate they are. But they are monitoring their sleep on them how many steps they've done, you know generally how much energy they've expended in that day. I find it helps them gauge it themselves in their own mind how much they've managed. And if the following day things are hurting more than normal, they can revert back and have a look and say what did I actually do? Look, I did 2000 steps more than I normally would do? Spent

Jake Cooke

by experience when I should have found three? Yeah.

Kamaljit Saggu

So it's a good way of indicating for them to manage their own energy levels. And I think these exercises that I teach starts to get them to think about how much energy they're actually expending and how they can refine the movement. So it's less energy spent, how they can incorporate it into their day to day stuff. So some of them could do it just before they get out of bed. Some would do similar things like this at the edge of their bed, or they're sat on a chair, first thing in the morning, get washed and dressed around and we're away

Jake Cooke

as any other ones you want to go through or should we head back over to the I

Kamaljit Saggu

think that's all right, I've got coming to mind at the moment. Right.

Jake Cooke

Okay. Thanks, Chris. Okay, great. Let's go. Oh, okay. So we have a few questions. Right? can watch have an evidence base for these exercise protocols? Or was it something you've kind of developed yourself? Or is there a research base

Kamaljit Saggu

that we can with trial and error with feedback from my clients, I've got the understanding, I've got a general idea of what to teach. But then it very much depends on their feedback. And I find that it's the strongest because everyone's individual, if I've got five people, I've got fibromyalgia and one class, they will all present differently. So it's getting to know them, and what their limits are. So I tend to go by feedback, and what they can manage and how they've coped afterwards.

Jake Cooke

So Robin, also really interesting question which is have you we've been doing these in like a hydro pool be

Kamaljit Saggu

beneficial. I'd love to. I would love to I think this huge benefits in that. It's the availability of it, and the practicalities of it because a lot of my clients, you can it's whether they can get to the edge of a pool and then successfully get into a pool. It's the logistics of it all but I would love for that to happen more and more under the NHS, they'll only give it to you for a certain amount of time. And then the waiting list increases. And it's they're pretty much left on their own to do it on their own back,

Jake Cooke

I have a patient who pays for it herself. But she swears by it, she's,

Kamaljit Saggu

I would agree, I think it's a powerful, powerful. But the problem is, I just don't know how well it's known amongst my clients. It's not something I can offer yet, but it's something I would like to offer. Because I think the benefits of doing all of this in water is phenomenal, I think it'll help a great deal.

Jake Cooke

So would walk along a wall for support. That's good exercise. And something that really builds confidence, which I think is huge part of pain and balances is this kind of underlying confidence issue,

Kamaljit Saggu

I find that if they've had a fall or a near fall, and even sometimes they haven't had a fall at all, but the confidence really does come back, it plummets, it goes through the boots. So half of the battle that I'm actually doing, when I'm teaching them is yes, it's focusing on the movements, but it's actually building their confidence up to say, actually, look, you've just walked along the wall, one foot in front of the other, or whichever way you want to look at it, and then they know they can do it. And the confidence makes a huge difference,

Jake Cooke

because you'll definitely notice this with some some people, but when you distract them, they'll do a movement perfectly normally. But when you're doing it under an assessment conditions, they perform poorly. Yes,

Kamaljit Saggu

I know this is a little bit I don't know if this is controversial or not. But when I teach, I will make my classes or my one to ones fun. I'm laughing, I'm joking with them, I'm telling them stories. And by the end of the session, I'll then recap and say, look, you've just done this, this, this, this and this, and oh my god, because of that particular reason, if I'm just sat there watching them intently, we'll put them off. But if I'm laughing and joking and making it look like it's a very relaxed environment, they're gonna do more, today, they want to do more.

Jake Cooke

So two people have commented that some of these exercise could be beyond the capabilities of some patients, which is true, but obviously that then you're dealing with quite compromised patients in the first place.

Kamaljit Saggu

Then you drain it right the way back here, and you'd bring in more as isometric exercises, initiating the movement, as opposed to actually doing the movement and seeing how much. So for example, I know I asked this, lifting the leg up and coming back down again, some people, they're not going to get their foot off the ground. And so but you can see the muscles twitching, that they're trying to initiate the movement, they're trying to push through and get their muscles to work. And with a little bit of perseverance, they might just move that foot a little bit. So yes, some are a lot more advanced in their conditions, and you really have to rein the movements back in this next question

Jake Cooke

is from Carrie. And it's actually a little bit hard one to ask is asking what kind of what time period people tend to improve? I appreciate it, it's a hard question, because it depends on the condition. But if we were to say, if you had a general period of time in your head, that use if I'm a new patient, and I say, how long is it gonna take? Yeah, do you give them a general idea? It's for six weeks, eight to 12 weeks, six months, a year? What would you I

Kamaljit Saggu

will depends on on their motivation. It depends on their commitment. And it also depends on how well they cope with the first couple of sessions I do with them, I sometimes can't give them a natural will in four weeks, you'll be able to do this in six weeks, you'll be able to do this, I kind of take that pressure off them because some of them will take that goal and they will I should have been able to do this by six weeks, why can't I do it? I let them go with the flow, but still push them. But then I will remind them well, it's post six weeks, look at what you can manage. Now look at what you can manage, though I it depends on the personality, some will need that goal. And they're quite happy to go with that goal. And that is their motivation. But I have to be careful not to give them a timescale like that. Because if they don't reach it in that timescale, it can disheartened them quite a bit.

Jake Cooke

I spent some time with Ms. Nurses. And they were telling me that there's a seems to be a kind of personality type in Ms. You get people who are high achievers, so they were you know, a woman was a full time lawyer working crazy hours and running marathons at the weekend. And she has three kids, and was really proud of that fact, she's doing all these things and then develop ms go through all the hell. But then when they're trying to do the rehab, they're trying to hit it with the same approach to the word, but obviously, fatigue and things you can't you can't just say look, I know it's gonna be six weeks, because that's how it used to be. It's now yeah, we've got to take that fatigue into into account.

Kamaljit Saggu

Absolutely. And I find those are the types of personalities that it takes me having to really talk to them and say that is what you it's really hard actually because the what they were before the

diagnosis to what they are they really can't get their head around. founders in, this is my new baseline. And this is half the battle is getting them to understand where they are now it is okay where they are now and what can we do realistically with what they've got now, as opposed to what they could do before. I've had a lot of countless the high achievers have often said to me, I really don't know when you when they say comments like, Oh, I could have done this before. Or if you've come to me five years ago, I could have done this, this, this and this. I'm like, Yeah, but you're not there. Now. We're here with what we've got now.

Jake Cooke

And the frustration associated with the reset the standard, and they're just frustrated with that process, because they used to be able to do a sits down with

Kamaljit Saggu

what I find is people that are surrounding them could be families, it can be friends, it can be work colleagues, who can't understand why they can't just stand up and there will make flippant comments like, well, you just have to stand up, why can't you do it? It can't and then that frustrates them even more. So you have to be careful when it comes to goals like that tend to let it go a little bit more natural. In terms of fluidity rather than letting them say in six weeks, you should be here, because it doesn't want to happen.

Jake Cooke

So Helen had a good question, which is stress and lack of sleep are not gonna help with outcomes and weight. Can that be tackled through mindfulness or breathing techniques?

Kamaljit Saggu

Absolutely. Whatever works, um, breathing techniques could be one mindfulness. Some people choose Reiki, some people choose reflexology. Some people choose acupuncture. I think all these alternative therapies, if it helps them bring that stress level down, and manage their condition. I'm all for it.

Jake Cooke

You know, you know, if you're having a lack of sleep, you're gonna eat more calories the next day, so you put weight on? Or if you do try and not you try and calorie manage. But you have bad sleep, you tend to lose muscle mass. Oh, yes. And put on fat. Yeah. So although your, your weight may be going down, you're not feeling any better, and you're not looking any better. So that process is just a painful one of each day, I don't eat what I want to eat. And I still feel

Kamaljit Saggu

that vicious cycle, isn't it? So I try and tackle one thing at a time. For me, it's always the exercise side of things. If if they need to tackle the sleep, then there's various ways of finding it on my send them back to the GP and see, what can you do to tackle that sleep? You know, magnesium seems to be the hot word at the moment in terms of taking magnesium to help the muscles relax and actually sleep. I don't know, it works. For some people. It doesn't work. For some people, it's upsets the Tommy for some people, some will swear by it. It's finding a way then once you've tackled asleep, then maybe you can tackle the overeating. And if you try and do it all in one go, it gets overwhelming. And then they can't manage it. And then they don't do anything at all. I

Jake Cooke

hate studying sleep. Every time I study sleep, I suffer from insomnia. Yeah, I know. I understand that. Like, every time I learn about it, then that guaranteed next few weeks, I'm like speech really important. And

Kamaljit Saggu

then I can't unwind. Wow. And then what I find is, this is one thing I will touch on with EDS. I have found one of my ladies has found that she's neurodiverse possibly got ADHD, hyper focused in a very high, high profile, high demanding job. And she feels like she has to perform all the time. And when that hyperfocus kicks in, and when the stress level kicks in, she's managing a team of people, the sleep does not come. And how do you get an I think sometimes I have to spend the best part time just letting them get it off their chest. So they can almost work it out by themselves how they have to bring themselves down. Otherwise, they're not going to sleep, it's just gonna go around around around in their head. They're hyper focusing on a problem that is not going to solve two o'clock in the morning. But because they're not sleeping, they're waking up not refreshed, and it's that vicious cycle. And yes, so tackling the stress, I think would be a big one.

Jake Cooke

Jamie asked if it's worth checking base levels like I'm very nearly I'd be 12 for

Kamaljit Saggu

Absolutely, absolutely. I wouldn't even touch on. If it's ladies of a certain age, pre menopause, menopause and seeing if there's hormonal fluctuations going on, are they hitting because menopause, on its own will start to increase fatigue levels, your muscle mass, bone mass, everything will go down. There's massive changes going on. You sticking out chronic health condition at the same time. With a little bit of balance problems. There's a lot going on at one time. So it's definitely worth getting those underlying things checked.

Jake Cooke

perimenopause is a really good point because you see that a lot with neurodiverse people as well that they, especially women, they can mask far more than the men or boys or girls often Lawmaster

symptoms far more than boys and they may get they may cope. So they struggle with certain aspects but they kind of do okay. And then when they hit that menopause stage, suddenly everything falls apart and they're like Who am I what happened? I used to be able to do all this stuff and I can't do anything. Yeah,

Kamaljit Saggu

I've done a lot of research on this. A lot of I'm one of my very good friends is a women's health GP as well. So I've learned a lot from her in that sense. And there's a lot at play here pre menopause, and resistance training, strength training, exercise, in cardio, all those kinds of things, whatever level you can manage, before you hit that phase, this is why it's not just exercise in the sense it's helping managing people their conditions. Currently, it's their future, if they're heading towards there, they're going to be in a better place when those time when that time of their life happens. And then probably will not experience such a rapid drop, it might be a little bit of a drop, but it's very important that they do exercise not just for their current management of their condition, but further down the line when situations like menopause happen.

Jake Cooke

So Pete asked a really good question earlier on. So it was a comment that there's 13 genetically different types of EDS. Do all the EDS variants respond to the same intervention? So if you

Kamaljit Saggu

know, so I could have someone with EDS who is hypermobile has got Potts, little bit of sugar level dropping during exercises as well. And then you've got the extreme opposite where they're rigid, they are unable to move, you'll be lucky if you get minimum movements out of them. So there are absolute extremes, some can do full contortion movements, where I've asked them to take their head back, and their head just keeps going and going and going. So it's bringing that range of movement back in. So you're right, there is a lot of versions of EDS. And I've been in a room full of people with EDS, and every single one of them presents differently. And every single one of them has slightly different symptoms. So this is why keep the classes small. Because then you can say to this person, right, you see you do seated, and this is how I want you to do that move, but you do the movement this way. But they do they're there they're past,

Jake Cooke

the underlying approach would still be the same. Yes. If

Kamaljit Saggu

I'm asking them to do a shoulder movement, I will still ask all of them to do a shoulder movement, but it will be adapted to what they can manage with or without weights, how far they can take it? Do we make them make the small movement a lot smaller? And if I'm asking them to do leg

movements, do they do it see to do they do it standing? It does vary on what they can manage. Great

Jake Cooke

question from Marian was do you have to work with focal dystonia at all? And if so do you do the same approach with this?

Kamaljit Saggu

No, I haven't come across it. I wouldn't turn them away. But they're not currently in my client list at the moment. So it will depend what they come with. Yes, if they're in a class situation, I will try and do the approach I'm doing now. And if it doesn't work, I'd adapt it. But if it's a one to one level, then it is focused on what they can manage. So

Jake Cooke

focal dystonia, dystonia in general is an interesting one, because it's a little bit like fnd. And in terms of is perhaps a processing error. So we think that the, if I want to keep my head here, and I have my brain has to work out what stresses are placed in my head, and then what muscles do I attach it to keep me stable. And yet in dystonia? We think there's probably a processing error where the brain perceives here I'm not stable. And so it activates muscles in a way that things stabilise my neck. Yes. But unfortunately, it pulls me off to one side. Yeah, but that could also happen when I'm writing with a pen. So I go to write and I get like Writer's cramp. And then it goes up like this. Yeah. So in theory, anything where you're helping someone control that stability, movement, balance coordination.

Kamaljit Saggu

I know it sounds sometimes a bit too simple, but it is bringing it back to where it the head should be sitting, for example that you've used where the head and I will use visual cues if they've got mirrors in front of them. I'll get them to look at the mirror in front of them so they've actually can see where their head is, as opposed to where the proprioception of that knee actually is. I find feet and ankles on another one of those where they could be flat footed their foots not quite landing where it should do their gait is not where it should be, even if they're standing flat footed their foots inverted inwards so one of my ladies will wear shoes, I will encourage her to wear the right shoes with orthopaedic whatever orthopaedic shoes off they've got installed in or whatever they need to do to make sure their foots in the right place. So when they do do a squat or a sit to stand, their knees are actually where they should be as opposed to where they would be if they weren't wearing those specialised footwear.

Jake Cooke

One final question is kind of how do you fit your How does your overall treatment approach fits in with other healthcare professionals? So do you tend to work on your own? Do you work with others?

Kamaljit Saggu

Good question. I have an ecosystem of chiropractors an osteopath. I do have a couple of neuro physios I work with, and a GP. And so it's I signpost when I think it's relevant. And we work very there's cross referrals between. So I complement their services and they complement my services. So sometimes they've been to the Osteopath or chiropractor first, and they'll say they need regular exercise and they send them to me, or they come to me and I say, actually, I think you need treatment first. And often, particularly all of the clients I've mentioned today, all the conditions I mentioned today, they will have another clinician involved. We worked together. And it worked really well. Yeah, I

Jake Cooke

can be a great I work with him almost exclusively with chronic pain, chronic dizziness. And I think you shouldn't be the only person treating them you need a team. There is a team better for you, but it's always

Kamaljit Saggu

there's always a team and the ones that have a team with them. So they could have made they could have a neuro physio. This is my MS. Lady, she's got a regular reflexologist even the hairdresser. I know it sounds really but the hairdresser is what brings that stress level down. And it's part of our routine to get ahead and feel nice. It's a team of people that are keeping her functioning well. So I totally agree with that. Great.

Jake Cooke

So that's it for this evening. Thank you very much.