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PRACTICAL PACING & FATIGUE MANAGEMENT (Transcript)

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J. Parry Good afternoon, everybody. I'd just like to say how thrilled I am to be here. I'd like to start by saying thank you to Lara and all the EDS International team for inviting me over. It's a real privilege and an honor to be here. So that's me. I'm Jason Perry. I'm a clinical specialist physiotherapist, or physical therapist, in hypermobility. Well, actually, my full title is Clinical Specialist Physiotherapist Hypermobility/Extended Scope Practitioner—which is a bit of a mouthful and they didn't think it out, really. So I need a bit of gatefold business card for all of that, but I've had the privilege of working in all of the three main UK centers for hypermobility.

I currently work at University College Hospital London, where I do assessment and diagnostic clinics. I also work at St. John and St. Elizabeth Hospital, where I had the privilege of working with Professor Grahame, where I actually treat hypermobile patients. I spent 11 years working at Royal National Orthopaedic Hospital in Stanmore in London, where I helped set up a residential inpatient program for patients with hypermobility. Although I am not hypermobile myself, hypermobility is featured very heavily in my life. Although, to be fair, I did go a bit autonomic last night when I lost a big hand play in poker. That's another story.

I'd like to talk to you about practical pacing and fatigue management, which I think is a really important aspect of helping to manage this condition. Spoons- you're probably all familiar with "Spoon Theory." This was that analogy that was first introduced by Christine Miserandino in 2003 when she was describing how it felt to have Lupus to a friend of hers. She used this analogy whereby each spoon represents an amount of energy that she has within a day. She was clutching 12 spoons in her hand and basically said to her friend, "For every task or activity that I do, I have to use a spoon." Effectively, there's a finite amount of spoons and a finite amount of energy. So there's an energy cost to everything that she does. Basically, she was trying to make that point that you have to make decisions for everything that you do because it uses up a spoon.

Well, why is it that hEDS or HSD makes you so tired? There's a whole number of reasons, actually, and this is not by any means an exhaustive list; that should be exhaustion list, really, I suppose. But one of the reasons is pain. I'm sure you don't need me to tell you that pain is incredibly tiring. It's fatiguing. It's very, very tiring having pain all day long. That's one reason why people with hypermobility suffer from fatigue. Poor sleep, an absolute classic. People with hypermobility frequently report that they sleep badly for many, many reasons. They can sleep badly because of pain, because of anxiety, stress, all sorts of reasons, discomfort, poor pillows. All of that and Dr. Pocinki spoke a lot about sleep earlier.

Medication: so certain medications have side effects that can cause fatigue. This can be another reason why hypermobile patients often feel tired a lot of the time. Deconditioning: patients with hypermobility commonly are deconditioned and when you're deconditioned your body isn't robust enough to cope with the activities of daily tasks. There's an energy expenditure to everything that you do and that can be very, very fatiguing. Other reasons also include things like low mood, depression, vitamin D levels. Things like that. And, finally, poor patterns of behavior greatly contribute to fatigue and hypermobility.

I'm going to go on to describe this, and let's see if this sounds familiar to you. (Can I get this pointer working?) Right, so you wake up one day and you don't feel too bad and you think, "Okay. I feel relatively okay today. I think I'm going to get all those jobs and tasks done that I need to do." So off you go, pushing and pushing and pushing, doing everything that you've got to do. Doing more, and more, and more, more, and more, and more, until eventually, boom, you hit that point. You wake up one day and you don't feel too bad and you think, "I'm going to do all those jobs that I want to do. Get everything done while I feel okay." And so, off you go, doing all those jobs, pushing and pushing and pushing until you hit that point where, boom, that pain kicks in and then you've done too much and you have to stop and you have to rest.

And so you stop, and you rest, and you wait, and you relax. Eventually, everything settles and it calms down. Then you think, "Okay, now, I feel alright again, but I'm really behind with all the things that I want to do." And so off you go, trying to catch up with all the jobs and activities that you try to do. And so you keep going and you push, and push, and push until eventually, boom, you hit that point again. But you hit that pain point a little bit quicker than you did last time because your body's a little bit more sensitized than it was previously. It's a little bit more susceptible. So you have to stop and you have to rest and you have to wait. And you do. And you rest and you wait, and, eventually, after a few days everything calms down and settles, but it takes a little bit longer than it did last time because you're a bit more wound up and a bit more sensitized. But eventually, it settles.

And then what do you do? You think, "Okay, now I'm really behind with all the things that I want to do." So off you go, pushing, trying to do everything, all the jobs, all the activities, trying to catch up with all the things that you want to do. Boom, hit that point of pain again. But that comes a little bit quicker again this time because you're a bit more flared up and a bit more sensitized. And then you have to rest and you have to wait even longer. Does that sound familiar to anybody? Yeah. It's a very typical pattern of behavior, what we call an overactive/underactive cycle or boom/bust pattern of behavior.

What we know is that ultimately, over time, your levels of activity actually reduce. So you get less and less done. In this boom/bust or overactive/underactive cycle or pattern of behavior, the symptoms are in control or the pain is in control. So on a good day, you're really overactive. You're doing too much. You're pushing too hard. And on a bad day you're really underactive, so you're not doing anything. You're just resting and trying to recuperate from the flare-up that you've caused yourself. So your peaks of activity are reduced. Your periods of rest become longer and this actually contributes to the cycle of deconditioning. So, ultimately, over time you actually get less done and become more deconditioned, and it feeds into this vicious cycle of pain.

That might be helpful in the short term, but not in the long term. This is very poor control of pain and fatigue, but it's potentially one of the most common patterns of behavior that I actually see with my patients. Alternatively, some patients fall into this: what we call an under-activity cycle. This is where they're actually driven by fear, driven by their symptoms. They're scared of their symptoms. They start by doing a little bit of activity and then they think, "Oh. Better stop there. Don't really want to do too much, just in case. Don't want to flare myself up." So they do a little bit and then they stop and then they rest and then they relax and then don't do very much at all. And then they think, "Oh. I've got lots to do." So they start doing a little bit more- a few more jobs, a few more activities. And then they think, "Oh. That's enough. Just in case, you know? I don't really want to hurt myself." And so they're not achieving very much at all over time and they're really scared. They're driven by pain.

Once again, we can see that over time, they get less and less done. Again, they become more and more deconditioned as a result of their pain. So this is where pacing comes into its own. Pacing — the principle of pacing is all about stopping activities before pain or fatigue increases. Okay? So before — look, I'm underlining that several times here. It's in capital letters, okay? — stopping before pain or fatigue increases. It's all about breaking activities into smaller more manageable chunks, evening out your levels of activity, being more consistent. It's a consistent approach, doing a consistent amount every day, across the days, across the weeks. It's about frequently changing position. It's also about planning and prioritizing your tasks.

How do we do it? How do we put this into practice? Well, first of all, you need to work out what we call your baselines. What's a baseline? A baseline is an amount of activity that you can manage most of the time without increasing your symptoms. Okay? In order to work this out, usually, you require a timer to do this. I'll give you an example: if you want to work out a baseline for standing, if you know that standing

for 20 minutes will actually flare up your symptoms and increase your pain and make you more tired, then 20 minutes is too long to stand; 10 minutes would be a more appropriate baseline. In order to work that out, first of all, often you need a timer and you need to take yourself to that point where your pain increases, or where your symptoms increase. And then you make a note of that on your timer and then you either cut that in half or knock some time off of that. That would be your baseline.

But, depending on the task, time isn't always the measure. So you could use time to work out a standing baseline, time to work out a sitting baseline, but you could use distance, for example, to work out a walking baseline, or you could use number of repetitions to work out an exercise baseline, for example. Suffice to say, you can work out a baseline for pretty much most activities in life. Most things generally involve either standing, walking, sitting. Most of the things that you need to do are based around those. And a baseline, when you're working out a baseline, you should set this according to a bad day. This is no good thinking, "Oh. I don't feel too bad today. I'm going to work out what my standing baseline is." Because if you do that on a good day, then you wouldn't be able to achieve even that baseline on a bad day.

You need to kind of work out your baseline when you're having a relatively bad day; not a horrific day, though, where you can't, literally, do anything, but a relatively bad day. Because if you've worked out your baseline on a bad day, then that means that you should be able to do that amount consistently every day, whether it be a good day or bad day. With that knowledge in mind about baselines, we then need to put this into practice, and so we look at how to structure your day. I suggest, first of all, starting by completing a retrospective activity diary. This would be where you would fill out a chart for yourself, looking at a typical week where you've split it across Monday to Sunday, and across the days, you've chopped that into hourly chunks.

I'll give you an example: this is an example of a typical retrospective activity diary that somebody would've put together for themselves. As you can see, it's spread across the days, Monday to Sunday, and each hour is split up. And then this person has completed what they do during the day and during each hour across the week. Once they've done that, or once you've done that, then a good thing to try and do is incorporate what we call the traffic light system. This is where you apportion a traffic light color to the amount of energy that's required for each of the activities that you've put into your activity diary. You give a color red to those activities that are the most demanding ones, an amber color or yellow color to those activities that are moderate

in energy expenditure, and then green would be the lightest or relaxing tasks.

If we take our activity diary here, and then apply the traffic light colors to it, we get an example here. This gives us some really valuable information. If we look at this person's example here, what we can see is that they've pretty much front-loaded their week with lots and lots of reds. There's loads of red at the front of the week, and then towards the end of the week, it's chock full of green there. We can also see that there's big chunks of red all lumped together here. This isn't a particularly well-balanced week. This isn't a particularly efficient use of energy. Somebody who's week looks like this is going to pretty much exhaust themselves — well, usually either in the morning or by about this time in the day. Certainly, by the middle of the week, they're going to be shattered. Their pain levels will potentially increase, and their energy will just be completely gone, all depleted because they've done way too much earlier in the week.

With that knowledge and having filled it in your activity diary and colored it in with the traffic light system —that can help you then to plan your week better. Giving consideration to your baselines, you need to consider how to break up the long periods of red activity with some greens, and then to insert some red ones or some amber ones into where you've got long stretches of green activity. We know that certain jobs have to be done at certain times, so when you're structuring your day, then you can start by putting that activity into the day, to begin with, give it its color, and then put other activities around it with appropriate other colors. Also, you need to think about priorities.

Does that job or does that activity absolutely have to be done that day? Often we put an awful lot of pressure on ourselves to jobs or activities that really don't need doing. I mean, is it the end of the world if you don't make the bed that day? Is it the end of the world if you don't do the washing up? Who's actually got the gun to your head making you do that? Should I say gun to your head in The States? I don't know. If we look at the example: this is somebody who has then re-jigged their example week. What we can see is there's a much better balance of all the colors here. They've inserted some greens into the big blocks of red that were there before. They've split that front-loaded week up and spread the reds across the week so they're not all at the beginning of the week. There's greens and ambers all mixed in there. It's a much better balance of activities across the day and across the week, giving considerations to all the baselines as well, splitting up your tasks according to how long you can manage each one for.

By doing this, this means that your energy is going to be much better used across the day and across the week, and so you'll actually be more productive this way, rather than fitting into those boom/bust patterns of activity and just exhausting yourself or flaring yourself up. By doing that as well, that gives you that increased energy and reduced levels of pain, offering you that window of opportunity to then start to pace up and increase your baselines. Your baselines don't have to be your baselines forever. What they can do is they can start to grow. Once you've established a stabilized routine, you can start to think about how you can grow and increase and build on your baselines of activity. What you need to do is decide on a realistic buildup rate. If your standing baseline, for example, was 10 minutes, or if your sitting baseline, for example, was 40 minutes, and you've been sticking at that level for a little while, for a week or so and everything's going okay and you feel alright, then you can think about increasing, adding a little increment onto that.

It's recommended that you add on only about 10 to 20 percent. So you wouldn't double it because that would be too much. You add on a small increment, and then what you do is you give your body time to adapt to that new level before increasing again. It's a bit like a staircase. Increases should be routine, slow and steady. If we take the example here, you've got your baseline and you stick at that baseline for three, four, five days or so, six days, however long you feel appropriate. When you feel like everything is going okay and you're managing consistently across the days, then you think, "Okay, I can increase, add an increment onto my baseline." You don't have to increase every single baseline. You can choose one, for example. And then you add an increment on, and then you go up to that new level. You stay at that new level for a little bit: three, four, five days. If everything is going okay there, then you add another bit on, and then you stay at that new level. So you're progressively increasing in a way that's kinder to your body in a way that your body can cope with and can tolerate. And if you happen to increase, go up by an increment, and then you start at your new baseline level, and if you feel an increase in your adverse symptoms, pain or fatigue, then you can just simply bring it back down again to where you were, carry on a little bit longer at that level, and then try again after a few days.

Now, there are some really useful tools out there as well to help people with pacing. Timers, obviously are really important, because if you have a baseline of 10 minutes, 20 minutes, 30 minutes, whatever it might be for whatever activity, it's hard to guess that. Okay? If you don't use a timer then it's really easy just to go beyond your baseline and then you're going to undo all the good work because then your pain will kick in or your fatigue will kick in, and then you've just gone way too far. So, really, in order to pace appropriately, you need to use a timer to act as your prompt to stop that

activity. There's some software out there that people can download that can help you as well. For those of you that use computers, those of you that use PCs for Windows there's a piece of software called *Workrave*, and you can download this and then you can put in the settings and a little icon will pop up on screen saying, "Time to get up. Move around." And for those of you that use Macs, there's a piece of software called *Time Out* that operates in exactly the same way.

Sometimes people can use visual cues as a reminder for pacing. So if you were trying to pace good sitting posture, for example, then maybe every time an ad break came on tv, that could act as a reminder for you, or every time you receive a text message, that could act as a reminder for you to think, "Oh, how's my posture? Am I sitting in good in posture?" Or you could put Post-It notes on things. Friends, family, and colleagues – so getting them on board can really, really help with pacing as well. It's really useful if they can say to you, "Should you stop that activity now?" or "Do you think you've been doing that a bit too long?" or "How long are you meant to be doing that for?" So it's always helpful and useful if someone's there on board just to act as another reminder for you.

There are various bits of equipment out there that can help people with pacing as well. An example of this could be something called a *Flipstick*. This is like a little walking stick that you can carry around with you that's got a little seat on it. If you know that you're going out for a walk or you're going to be walking somewhere, and you know what your walking baseline is, and you're worried that there may not be a seat to sit down on, although you should've actually planned that in advance, but anyway – if there's no seat to sit down on then a Flipstick can be really useful because you just flip out the seat and then you have a little sit down. Make use of other equipment that's out there, things like food processors. Why stand there for ages chopping and cutting and doing all those kitchen tasks, food preparation tasks that could potentially take you right through your baseline, when you can use a bit of equipment to make life easier for yourself?

That's a screenshot of *Workrave*, by the way. So that's what it looks like. You just put your settings in there. And that's a Flipstick, for those of you that haven't seen it. It just folds up into a little portable pouch, and then just opens out, and then you can just flip out the seat and sit down. There's a pacing app out there that I discovered that's really useful as well. This is called the *ME/CFS Diary* app, and this is a really nice little app that helps you to calculate your baselines, and it produces lots of nice little graphs and reports as well. This can be a really useful tool for logging and monitoring

your pacing activity. I'm anticipating now, so I can already hear people just itching to say to me, "Yeah, yeah, yeah. I know, Jason, it's all well and good, but how can I pace? I'm too busy to pace." Or "I can't pace if I've got kids to look after. I can't pace when I'm at work. How can I do that?" And they're all valid concerns and I hold my hands up to that. Nobody said that pacing is easy, and isn't.

Pacing is difficult. It takes discipline. It takes self-control. It takes diligence. But it is possible, and it is practical. You just have to be creative with it. You have to plan. You have to prioritize. I promise you that pacing really, really can work for most people. I know that because I've used it with many patients of mine and I've seen the success that they can have with it and I promise you, if you pace and you apply it very, very diligently then it really, really can make significant differences to your levels of energy and fatigue. But, of course, as I put there, I'm not going to convince you all.

There are lots of difficulties with pacing. There are internal difficulties. People can get frustrated. They can get frustrated that they can't get the jobs done that they want to do because they have to stop, and that's a valid concern and expectations of themselves. Something I often hear is people saying, "Yes, but I should be able to do this. I should be able to do those jobs. I should be able to do those activities." Well, again, who said that you should be able to do those things? Who are you competing against? Who are you comparing yourself to? A lack of assertiveness sometimes can prove difficult with pacing. So people can often be a bit reticent to ask other people for help. They can be embarrassed or shy or just don't want to do it. Well, why? You know, at what cost? So that you're going to flare yourself up instead?

People often can get engrossed in activities. So, again, that's why timers are really important because you can sit down, and you can start doing a job and then you can go way beyond your baseline if you don't have that little reminder. And then there's external difficulties with pacing as well. Sometimes the environment isn't necessarily conducive to pacing. So you might have a sitting baseline of a certain amount, and you might be driving your car along the highway and you can't actually turn off. That's, again, a valid concern but, again, I would say you need to plan that journey in advance. Work: it can be difficult sometimes to pace at work. Often it can be difficult to pace at work but, again, it's good to have that conversation with your employer as well because if your employer can support you with regards to your pacing, then you're going to be more worthwhile and valuable to them because you're going to be there and you're going to be able to contribute to work, rather than having to go off sick where you're no use to your employer either.

Other people's expectations — so, again, people have difficulties with pacing because other people expect that you should be able to do more. I hear this a lot where other people say to me, "Oh, yes. But you look alright. You should be able to do that. You look okay to me." That's one of the difficulties, as you guys know, with an invisible illness. And the requirements of the task sometimes make it incredibly difficult to pace as well. Relaxation and sleep: so, again, if we're talking about energy and fatigue, people often say to me, "How can I pace up my activity when I'm so tired and I can sleep for 12 hours and I'm still exhausted at the end of it?" Again, Dr. Pocinki spoke a lot about sleep. He's a good guy to talk to. You need to kind of look at ways to try and help improve that. Good sleep hygiene principles are really important because sleep gives you, obviously it gives you more energy if you can get better sleep. So try to establish a regular bedtime, not using your iPad or your phone while you're in bed, turning the TV off a good hour or so before you go to bed. All of those good sleep hygiene principles can make a difference.

Using relaxation and mindfulness can be a really useful way of just being able to re-energize. You don't necessarily even have to sleep. These are well-proven techniques just to sort of re-energize you again. And also recognizing the different types of stressors that you may have that may be preventing you from getting good sleep and trying to address those. Remember, pacing actually does take a lot of self-discipline. It isn't easy. It is difficult, and you need to stop before the pain comes on, okay? So don't wait for the pain to be your prompt. Don't sit there at the computer and then think, "Oh, my back's killing me" or "My shoulders are killing me. I better stop now." Because then it's too late. You need to stop before the pain comes on. If you're pacing properly you should still feel like you could do more, but don't, okay? That's the classic mistake. If you're doing your activity and you're working to your baseline, then you need to stop at that point because you should still feel like you've got that capacity to do more.

Pacing doesn't take any longer to do jobs, it's just being smarter. It's being more sensible. So if it takes you 30 minutes, for example, to make a meal, if you split that meal into three 10-minute chunks, so doing some meal preparation, and then leaving it and then coming back to it later, doing some more preparation, leaving it and then coming back to it later, and then doing another 10 minutes to finish it off. Three 10-minute chunks still only takes you 30 minutes, so it doesn't take you any longer to do, you've just spread it across the day. You've just been smarter with it. By doing it that way, that means that you're actually able to do that and other things in your day as well, rather than standing there for 30 minutes all in one go and then that's the end of it. You can't do anything else for the rest of the day.

Pacing really does help to manage pain and fatigue more effectively. I promise you it works. Honestly, trust me. Take my word for it. So you still might only have a certain number of spoons in your day, but if you apply pacing and you are diligent with it, you may be able to turn those spoons into ladles. Thank you very much.

Transcription by Christina Cole