Academy of PHYSICAL MEDICINE

Transcript

Juvenile Hypermobility and CRPS

With Dr. Nathan Hasson

APM: We have with us this evening Dr. Nathan Hasson.

NH: Good evening.

APM: Nathan, lovely to have you here. Thank you for coming to join us. Nathan has been a medical practitioner for many years. He was practicing in Cape Town 30 years ago before coming to the UK. He lectures to all sorts of people across the UK. He has regular contact with multi-disciplinary practices including our own Steven Sandler in the osteopathic world but enough of that. Nathan, I know you said you wanted to introduce yourself. Can you tell us how you got to where you are now?

NH: I think it's nice to know my background and to start off with, originally actually from Zimbabwe and then trained in Cape Town and then was coming here about 30 years ago just to let my wife do her master's degree and started working here and loved it here. And also, got to meet people that were really the people who wrote the books and in medicine, that's what is important. So ended up getting a job about 30 years ago at the Hammersmith Hospital and that job entailed looking after children with muscle diseases, neuromuscular disorders and —

APM: Is that what you specialized in Cape Town as well or —

NH: No. There, I was just doing pediatrics and just did my medical degree and then pediatrics and then I started working at the Hammersmith Hospital with Professor Victor Dubowitz and learned a skill then, which I still use every day now in my practice which was how to assess muscle strength in children. So we would have children between the age of 4 and 18. You can't do muscle strength under the age of four, appropriately, using manual muscle testing. So from the age of 4 up to 18-year-olds, I learned how to examine muscle strength in children. So I worked for quite a while at the Hammersmith Hospital, looked after boys with muscular dystrophy and children with neuromuscular disorders and then moved on to Northwick Park Hospital to extend my practice into the world of rheumatology and I think it was Professor Dubowitz and Professor Woo who thought that this would be a good mix of specialism, mixing neuromuscular with rheumatology because then you would get a true sort of musculoskeletal person and I think I was the first of that group of musculoskeletal pediatricians, not just knowing about neuromuscular disorders but knowing about rheumatological disorders and there was quite a lot of overlap. We looked after children with dermatomyositis that initially, actually, neuromuscular people looked after then rheumatologists looked after. So there is quite a lot of overlap but really, I learned the skill of examining joints. So I learned how to examine muscles in children and then I learned how to examine joints in children and those two skills have really turned out to be very useful over the years. Because of my rheumatology background and experience, I obviously look after children with juvenile arthritis but that's extremely rare. But what we find as much more common today is related to musculoskeletal problems in childhood which transpired to be related to the fact that children today are physically really weak and if you're weak…and particularly, one group of children I look after, the children who are hypermobile which we'll talk about later, if you're hypermobile and you're weak, it's not the hypermobility causing you the problems. It's the weakness. And so with the skills I had, I was then able to help look after children who had problems, musculoskeletal problems related to being flexible and having muscle weakness.

APM: We've discussed this on occasions in the past and it's sort of intuitive to say, "Oh, it's the modern age. It's the technological age. Children spend all their time indoors on PlayStations and so on. Therefore, they must be weaker than they were before." Is there evidence to back this up or —

NH: Yeah, there is…I mean not just my evidence from examining children and at Great Ormond Street Hospital, we've done several papers now explaining about that link with modern weakness but even if you look at things…like the Australians did a study, I think it was 45 years ago, where they took 10-year-olds, got them to run a mile and timed them, waited until those 10-year-olds had their own 10-year-olds. I think the aim of the study was to prove that as human beings, we'd get faster and quicker and better and fitter and stronger and healthier. What was interesting about the current day 10-year-olds of those original 10-year-olds is for the one mile which is four and three quarter laps, the current day 10-year-olds, on average, are one and a half minutes slower.

APM: Minutes.

NH: That's more than a lap, more than a lap slower than their parents. So we know children today are physically, definitely, weaker than they used to be and that's not just in this country. I've visited clinics in Israel, in Canada, in Australia, in South Africa and I know this is now becoming a worldwide phenomenon that children, through lack of physical exercise, are becoming physically weaker and it's something that the physiotherapists that I've always worked with like Great Ormond Street has found over the years is this weakness. It is a medical fact. We know it. Children are weaker, children are slower. There's lots of other things that are interestingly tied into it like vitamin D levels being low, obesity. Really, they talk about all this sugar issue and stuff, you know. When we were kids, we drank Coca-Cola. We ate crisps. We ate 3,300 calories a day.

This is, again, a medical fact. We ate 3,300 calories a day. Children today eat 2,500 calories a day. We had 1% obesity levels. It's now 30% and that 30% is due to inactivity. It doesn't matter what you eat. If you do enough exercise to burn off those calories that you're taking in, you are not going to be overweight. So it's a —

APM: We could probably have a separate discussion about obesity, couldn't we?

NH: Hours. Hours of it.

APM: Given what's the news at the moment as well.

NH: Hours of it.

APM: Do you still work at Great Ormond Street?

NH: No. So I then worked part time at Great Ormond Street and then for about five years which was up until about 6 or 7 years ago, I worked full time at Great Ormond Street and ran the hypermobility service there. So in fact, we had split up rheumatology into inflammatory which is arthritis and dermatomyositis and lupus and the inflammatory conditions and what we call non-inflammatory musculoskeletal syndromes. And so that's where we started to look after patients with hypermobility related problems, with things like complex regional pain syndrome and all the musculoskeletal things we see today which actually overtook the inflammatory part of what I did but about 5 or 6 years ago, I stopped working at Great Ormond Street. Mainly work privately now and just for a few NHS trusts, I do their rheumatology.

APM: Now, I understand that you prefer the term reflex sympathetic dystrophy rather than complex regional pain syndrome. Is that just because of your old school or is —

NH: No. It's because sometimes I like things to say what they are, you know, and in medicine, often, you know, you hear things like Osgood-Schlatter. It's a very common condition, tibial apophysitis, traction apophysitis. People used to talk about Osgood-Schlatter and I don't like people's names being applied to things because they don't really tell you what it is. You know, if you said it's a traction apophysitis of your tibial or these days, we see Sever's of the heels much more commonly, hardly ever see Osgood-Schlatter, you know, it's much better to explain what it is and complex regional pain syndrome doesn't really explain, "OK, it's a complex. It's a regional pain but it can't be quite a generalized pain and pain syndrome is pain syndrome," but I prefer reflex sympathetic dystrophy because that's how I explain reflex sympathetic dystrophy to parents which is CRPS. That it's a reflex that happened. It's not something that was planned. Nobody wants to develop it. Nobody wants to have it. It's a reflex that your body allows to happen. So it's a reflex condition. Sympathetic's important because that's what's behind the problem. It's the sympathetic nervous system that mediates the pain and that explains why standard pain killers, even morphine, fentanyl, pregabalin, gabapentin, things that people take don't work because it's not a normal pain. It's a pain mediated by your sympathetic nervous system and that's why I like the word "sympathetic" in there and then if you don't use a limb, the thing we know from children with arthritis and all these conditions, even if you've had a fracture, you get dystrophy. You get wasting of that area. So it really explains, in three words, exactly what's going on and it makes it much better to explain to parents what it is. Complex regional pain syndrome doesn't really explain it. It's —

APM: I've always felt that complex regional pain syndrome sounds like a bit of an IBS diagnosis. It's sort of a catch all term. As you say, it doesn't explain —

NH: But that's very interesting you say that because in South Africa, we never use the term "irritable bowel syndrome". We use the term "spastic colon". Now, spastic colon…the word "spastic" isn't used these days. It's not politically correct but actually, it describes the condition that happens, but if you're an anxious, worrying person, a nervous person, that nerves can go into your colon and make your colon cramp and spasm and cause what's called a spastic colon. You're actually describing exactly what's happening which is tummy aches that kids get. Even four-year-olds now, with spastic colons and sometimes I even call it to parents…I call it spastic colon because I much prefer that, because irritable bowel syndrome, well, it's not really describing what's going on. What's going on is you have a spasm of your colon and it's something that we've very hot on teaching in Cape Town when I was there. We learned how to examine the tummy of people with spastic colon and the fact that this…when you pushed up in the right upper quadrant, left upper quadrant, that didn't hurt but when they breathe in, as they breathe in, suddenly they have this severe pain. Why? Because the colon is up here. It gets pushed down by your diaphragm, hits your fingers and then that spasm in the colon, as it hits your fingers, causes pain. And so yeah, that's a very descriptive word but spastic colon is much better than irritable bowel syndrome because with IBS, also, people start to associate, "Oh, well, this causes my IBS to worse and that causes my IBS to get worse." If it's mediated by anxiety and, you know, your sympathetic nervous system is causing your colon to spasm, telling yourself that milk causes this to happen will make even false milk make it happen. So I don't like the IBS. I prefer spastic colon and I guess that's the same as RSD and CRPS.

APM: Now you corrected me earlier on when I got my terminology wrong. Could you just, for the benefit of the audience, elucidate on the difference between benign joint hypermobility syndrome and juvenile hypermobility —

NH: Hypermobility syndrome, OK. So one of my predecessors, the person who actually taught Professor Woo who was my professor, who taught me my rheumatology was Barbara Ansell and Barbara Ansell was the mother of pediatric rheumatology in this country and she recognized…in 1967, she wrote a paper with Bywaters, another colleague, all about the fact that sometimes people develop musculoskeletal aches and pains not related to arthritis or some other rheumatic condition but she recognized that sometimes people who are flexible develop aches and pains and they called it the joint hypermobility syndrome. In that paper, interestingly, they said that it was in people who are otherwise normal but flexibility is a normal variant in society. In some societies like in Brazil, in Chile, 40% of people are hypermobile and Caucasians, depending on which background, 20%, 30% of people are hypermobile. So how can hypermobility cause pain? And I think that was one difference that…they were coming from the rheumatology point of view, they recognized that these people were double jointed, were flexible, were supple but they didn't really know, "Well, how come…if 30% of the population are flexible, how come 30% of the population don't have aches and pains?" And what they hadn't known is that the association is not so much the flexibility but being physically weak and being flexible then causes the issue. So they called it joint hypermobility syndrome and it was sort of further refined down to…in children, benign joint hypermobility syndrome because it is benign in children. In fact, it's what people used to call growing pains. We now know…as rheumatologists come to one of our conferences, pick up one of our textbooks, look in our journals, there's never an article on growing pains because we know growing pains don't exist. What's thought to be the original growing pains is actually joint hypermobility syndrome, particularly in children and when they grow, it's not the growing that causes the pain. It's the relative lack of muscle strength for the new person, compared to the old person that causes the aches and pains. So they called it joint hypermobility syndrome. In children, we call it benign joint hypermobility syndrome because it is benign in children. Children don't suffer damage from being flexible and not being strong. Children can repair. Children can improve. Children can do extremely well but if you're an adult who's flexible and you stop exercising and your discs start to go or your hips starts to grind down, that is going to not be benign because that may need hip replacement. I'm seeing parents of kids that I'm seeing who are 40 years old now having hip replacements, knee replacements, that have discs that have bulged and causing sciatica. So in adults, they're called joint hypermobility syndrome and in children, we call it benign joint hypermobility syndrome but we don't really call it juvenile hypermobility syndrome. So that's not a word that as rheumatologists, we use. We tend to use benign joint hypermobility syndrome.

APM: Well, as you know, we can put some flesh quite literally on your description of this because unusually, for our proceedings here, we've actually got a sufferer from benign joint hypermobility syndrome in the studio this evening. He's the son of a good friend of mine and I'd like to welcome him into the studio now. Robert Newitt, lovely to have you here.

NH: Hello there. Hello.

APM: Thank you for taking the trouble —

BOB: No problem.

APM: And Jake, very kind of you too to come in —

JAKE: It's all right.

APM: So that you can discuss your problem in front of our live audience. I'm going to start with you, Jake, if I may because you're the star of this show in the sense that you actually have had…have got this problem. How does it feel to you?

JAKE: It's incredible because you can't do nothing about it but it's really painful. Like it started in my arm but then it went to my legs then my other arm then my neck then my back and then —

APM: All at the same time or any one of those at a time?

JAKE: All at the same time and I'll like feel them in my fingers. My wrists will start to hurt. My hands feel like on fire. So it's like it's not just pain. It's really like…feels like almost like flaming knives being sticked (sic) into your arm.

APM: And you're 12 now, aren't you? So when did this start with you?

JAKE: I was about 10. Well, no, sorry, 11 and I had a car crash and I had whiplash and we believe that's how it began. And then a few months later, I started to have pain in my arm. That's a bit weird but then like I got over that and then before I know it, I was playing football at school one day and I went for a tackle. I fell over and my leg started to hurt. That goes and two days after, at school, my arm starts hurting. So then that leads to over to Kettering (General Hosiptal). Well, and then sleeping at Kettering and —

APM: So let me interrupt you for a second now. I mean so you were a bit sore.

JAKE: Yeah and it hurt —

APM: Just a bit sore. It wasn't desparate.

JAKE: No and it's like yes, it hurts little bit but at least not my legs, at least not my back. So yeah, we get back. We didn't know still what it is and then Christmas happened and it was all…well, not perfect but it's all right and one day, I just…I was walking and it…one day, I just…my right leg, I couldn't stand up. I had to hop all the way to the car and hop back to my house. And then —

APM: So this was more than just a mild pain then. This was —

JAKE: Yeah, it's like…I was a bit shocked about it and then a few months later, I'll get it on my back. And so I can't lay on my back now. Then I got it in my right arm. So I can't use both arms. At least I can use my left leg but no I couldn't, couldn't use it. So I was in a wheelchair and then —

APM: So this has now progressed from your mild pain, following a couple of incidence, to you being in a wheelchair. Nathan, if I can turn to you, is this a normal pattern? We've got two possible traumas here, the car accident and then the tackle that you described in a football match.

NH: Sometimes we know that what happens with reflex sympathetic dystrophy or complex regional pain syndrome is something triggers it off and really, that's why I like to call it a reflex because then your body starts to develop this as a reflex, a way of trying to protect you and then something quite simple, like maybe just a little twisted knee or a bumped elbow because I think, you know, your elbow was quite a problem, can lead to this massive cascade of pain but your body is really trying to protect you to the degree that even touched with cotton wool…even somebody walking too fast past you actually induces pain. It's very hard for people to understand it. The medical word for it is allodynia, pain that is being caused by something that can't cause you pain, you know. Somebody walking past you can't be damaging you and hurting you, yet it feels incredibly painful. And so it sets off this reflex that can then move around and the point is yes, it can move around. So I've seen children with reflex sympathetic dystrophy affecting one ankle then it's another ankle then they're in a wheelchair and then the arms from pushing the wheelchair around gets strained and then they develop it in their arms. So it can move around like this and cause what happened to Jake, yeah.

APM: Bob, I noticed you were trying to jump in earlier on. What I'd like to get from you is how did this…how were you affected by this? Because it would be a holistic problem.

BOB: It was just incredible. I mean it first started off, you know, he had a bad neck, we popped to a GP. Did he sleep on it odd? We knew he had the car accident. There's nothing particular after the car accident, nothing. So then this, you know…so we've done that and then all of a sudden he has an elbow problem. The elbow problem's a couple of weeks. It was there. Again, going to hospitals, having x-rays. Nothing wrong with it. This continues. The elbow's OK for —

APM: So how is this affecting you though? Because, you know, it was going on —

BOB: Well, months and months and back and forward to hospitals, being told, you know, "There's nothing wrong with you. We've had the scan on your knee. We've had the scan on elbows. We've had all these scans." We've been administered morphine at hospitals, you know. That's the —

APM: So morphine should kill the pain, surely.

NH: So if you have standard pain, so if you have a bad accident, crushed your leg, break an ankle or something, get a bad burn and you give a child a dose of morphine, literally they'll start, within a short while, laughing, actually giggling even though they're burnt or cut or broken or whatever. And so that's because that pain is going through the normal pain channels, going through the…from the pain fibers which the pain and cold, travel in the same fibers, up to the spinal cord and then that pain goes to your pain sensor but the point is that the morphine then blocks off that pain but in complex regional pain syndrome, reflex sympathetic dystrophy, the pain is really mediated by the sympathetic nervous system and we know that because in the past, people used to block the sympathetic nerves with guanethidine and do guanethidine blocks and those would help for an instance or a short while and then the pain would return. So we know that morphine blocks the normal pain channels and what's interesting about that is, also, the area that has the RSD, when you touch the area that's sore, what they'd tell you is that it feels numb. They can't actually feel it but surely, if it's the most painful thing on earthy, surely you can feel it and they tell you no. The pain is intense but they can't feel it.

APM: But this is a fake pain, isn't it? You were telling me earlier on.

NH: Well, yeah because it's —

APM: Doctors can prove this is fake pain.

NH: So in the old days when people had this, somebody would come in, hopping on their leg, saying their leg hurts and stuff and the doctor would get the person or child to sit on the bed and then what they would do is they would distract the person and say, "Oh, look at that out the window," and they would kick the leg that the person was complaining about and they'd get no reaction. Then they'd take a piece of cotton wool and touch the leg and the person would scream and shout in agony. And so they say, "Well, look, they're obviously making it up because you saw me. I bumped the leg, didn't jump and such." What doctors hadn't realized is that the person wasn't making up those pains. This is a real pain. What the doctors had done is distract the person and in fact, distraction works better than morphine. If you are distracted, for some reason, your sympathetic nervous system is switched off for an instant and then you don't feel the pain. And also, in a way, it's also like tickling. I know it sounds like pain and ticking are pretty separate things but how I explain it to parents is the tickle theory. If you tickle yourself, it's not funny but if somebody does exactly the same thing to you, you get this weird sensation and ticklishness and stuff and you can't tickle yourself. So people with RSD, when they touch the area, it isn't as bad as when you touch the area even if they touch it harder than you. You can touch it with cotton wool. They can touch it properly and they'll tell you it doesn't hurt and that's because it's all mediated by the sympathetic nervous system and morphine doesn't block the sympathetic nervous system. So what's always…that I see is that patients that come to us with RSD are often on fentanyl patches or morphine. They're on codeine. They've been on pregabalin, gabapentin with no help at all and it's not because they've made up the pain. It's because those pain killers treat a specific pain that is not the pain of RSD. So that's the point with pain killers and morphine not helping.

APM: Bob, back to you, what you haven't said and what…I should let people into a secret here, shouldn't I? That Bob is actually my hairdresser. All right, Bob, so you're either going to get lots of business after this or you're getting no business, whatsoever but you are responsible for my coiffure. What you've told me, when I listened to you talking about Jake is that he's been screaming. You have not known what to do. You had to give up work because someone had to look after Jake.

BOB: Absolutely.

APM: So there's a lot of stress going on in this household.

This transcript will shortly be replaced by a concise text summary.

BOB: Seven weeks straight, I didn't work for because at that point, before we saw Nathan, we were pushing him around in wheelchairs. I mean at that point before, it's like anything, the knowledge. That was what was given to me from Nathan, the knowledge and some hope that we can turn this around.

APM: But why did you see…we will come on to that, I promise. What I'm just thinking here is that Jake's in pain. He doesn't know why. Bob is desperate because his son's in pain and he doesn't know why and he can't find out why and surely, all of this is a vicious circle because it's —

BOB: Absolutely.

APM: It's just the opposite of distraction, isn't it?

NH: It's just compound pain because we know one of the background issues…you see, so with complex regional pain syndrome, RSD, I've never seen it in a child who's not flexible, firstly and one of the things about being a flexible person is you also tend to be a person who tends to be a worrier. It's a natural thing that…and there's many papers on the —

APM: Are you a worrier, Jake?

JAKE: Huh?

APM: Are you a worrier?

JAKE: Yeah.

NH: Do you worry? They all worry and you can tell because they always have sweaty palms. So if you feel his palms, you'll see. And they get tummy aches and stuff but it's that worry that —

APM: I thought that was normal for young people —

NH: No, it's only in people who have an overdrive of the sympathetic nervous system who gets sweaty palms. So one of the things is that anxiety makes pain worse. Often, when I'm examining children…and when you examine children today, the left trapezius muscle in all children is now very painful. When you see children sitting, firstly, children these days sit like these because they don't have any core stamina and when you sit them up like this, what you notice, and many osteopaths see that the left shoulder is higher than the right shoulder and that's due to trapezius muscle spasm and when you actually palpate the trapezius muscle, it's very painful but if you teach the patient to relax, if you tell them, "Look, like we did, you know, breathe in through your nose, out through your mouth. Let your shoulders drop. Say to yourself, 'relax'. Don't listen to the pain," because also, one of the things I teach them is useful pain, you know. If you fall down and break your arm, actually useful, you go and get an x-ray, you get a cast, you're better, or useless pain. CRPS, RSD is the worst pain on earth yet it's not serving you any benefits. It's like I said to parents, you've had a headache before. That day you had a headache, did you have a brain tumor? Did you have a stroke? Well, why did you have a headache? A bit of muscle spasm, whatever it was. The next day, you were fine, "Was that an important headache?" It was a real headache. Even people who get migraine, that's a severe pain, a severe headache yet the next day, if you said to them, "What was the point of that pain?" there's no point. So sometimes in our bodies, we have pain that is severe, real severe pain but there's no point to it and what we do is try and get them to relax with the pain and not listen to it. So he was in a wheelchair when he came in. His parents probably thought I was the most awful person on earth because I made him get out of the wheelchair and sit on the bed, OK? And he did it. He did it, you know. He got through the worst pain on earth and he did it.

APM: What was that like, Jake?

JAKE: I hated it. It was the worst day but it's the best day because I was in the worst pain, I was stressed, I was tired, I wanted to know what it was but then…it was like really painful but it got through it and look at me now. I walked here from Rushden.

APM: And you've been walking around London having a good day. Tell everybody at school because you're taking the day off. Well, can I take you back to something you said a minute ago?

BOB: Yeah.

APM: You went for a long time through GPs and so on without getting any assistance.

BOB: Of course.

APM: So maybe it's a question for you, Nathan but what's the state of a normal general practice when it comes to this sort of condition?

BOB: Looking on the Internet, while I was there, Googling it, you know, I would say I'm more knowledgeable now than a GP is.

BOB: And I am, you know. What I know now and the psychological side of things, the physio, the strength in the body, everything is almost like a vicious circle but the right way around. If you chip at it, chip at it, chip at it, you'll get on the good circle. Things can spin around. It's not one magic thing. It's chipping away —

APM: I really feel really sorry for GPs because the poor buggers are supposed to know everything.

BOB: Absolutely.

APM: You know, they can't —

NH: But there are areas and yeah, I say the same. I say, you know, "If your child has a heart murmur, don't come and see me. Go and see a pediatric cardiologist because I could tell you your child's got a murmur. I'm not going to give you a diagnosis." And each of us have our own skills. I'm in that lucky position where I work with neuromuscular people, I work with rheumatology and I know about this because I've seen it and I've worked with it but if you've never seen it, you've never heard of it, you don't know about it and anyway, then on the Internet, you start finding things like it's all made up and, you know, teenage girls get it more often, so therefore, it's obviously just attention seeking matter. It's not. It's an absolutely real thing but people don't know that and then they don't understand why pain killers…like if they give them a dose of morphine, surely they must be better. Put them on codeine, surely must be better but that's treating the wrong pain. You haven't touched the sympathetic nervous system and people don't know about that and, you know, there's a lack of knowledge of but we all lack knowledge in many fields.

APM: You're a normal parent in this respect with an unexpected, unexplained problem. What did you do and how long was it before you saw Nathan?

BOB: It was six months, yeah or something.

APM: So six months of screaming pain from your son which must be really stressing. What was the process? You went to the GP, I'm sure.

BOB: GP time and time again and then obviously, when I have what some people call as the burst, like I would say, when it's phenomenal screaming pain, I would fly to A and E. We were not knowing, as a parent, what to do.

APM: What did they do?

BOB: Nothing. They would adminsister4 pain killers and sometimes the burst in themselves calm down and then we would go home and kind of wait until this happens again in three hours, tomorrow.

APM: So would you not say that…if you've gone to your GP and you've been administered codeine, did you say?

BOB: Codeine is the one —

APM: Well, you've been to A and E and they probably —

BOB: Three or four times.

APM: And it hasn't fixed the pain. Shouldn't somebody have twigged that this is obviously not responding to pain killers, therefore, it must be a different kind of —

This transcript will shortly be replaced by a concise text summary.

NH: So unfortunately, often, people then just think it’s made up, that it’s just some psychological thing that this child just…you know, hysterical and reacting and stuff and that’s traditionally have always —

APM: Is that because they don’t know about the syndrome—

NH: Yeah, they don’t know.

APM: --or because they’ve heard about it but just don’t believe it?

NH: No, they just don’t know about it because once you understand it, once you know about it, once you’ve seen people with it and you understand the basic physiology and what’s going on then it’s obvious, you know. It’s —

APM: So the chances are that if we, as physical therapists, are going to see this, it will be somebody who’s been to the GP, they’ve been to A and E and they’ve got this problem. They think, “Well, then cranky, I can’t think of anything else, you know. Last resort, we’re going to try the osteopath, the chiropractor, the physio, sports therapist.” We would expect to see someone who’s in pain, not necessarily at that time but has been, hasn’t responded to analgesics. What would be your diagnostic process or is that enough in itself? How did you examine Jake?

NH: So one of the things is I always look for the hypermobility, for the flexibility. So when you’re looking at joints and stuff, you could see how flexible, you know…90 degrees. He’s double jointed. That’s what we’re talking about is double jointedness. So I always look for that because I know that it’s…I’ve never ever seen it —

APM: There’s a nine-point scale, isn’t it?

NH: There’s the Beighton criteria. Beighton was one of my lectures in Cape Town and he was professor of genetics there and there is the nine-point Beighton criteria. The problem with the Beighton criteria is 6 out of 9 are in upper limbs. So it’s elbow hyperextension, fingers bending back 90 degrees, thumb touching your forearm and not everybody can do that.

APM: Can you do that, Jake?

NH: So six —

JAKE: I can do a little bit but my friend at school can do it.

NH: So 6 out of the 9 are upper limbs but often, patients are coming to see me…children often are complaining of lower limb pain. So really, want to assess the lower limbs and the Beighton in the lower limbs, it’s just whether your knees hyperextend and our children’s knees don’t hyperextend anymore. Children today…in fact, if you go into a classroom of five-year-olds now and ask five-year-olds to touch their toes…I can touch my toes. Five-year-olds struggle to touch their toes because of tight hamstrings. So tight hamstrings has now become a norm in society and why is it normal in society now to see tight hamstrings even in five-year-olds is the fact that our children's muscle strength today, when you examine manual muscle testing, when you examine muscle strength, of the 22 muscles we routinely test, only five are now normal. The right biceps is normal, the hamstrings and the quads and so the hamstrings —

APM: This is in a right-handed person.

NH: This is on…well, that's another thing we could talk about is whether left-handedness exists. Well, what I've noticed…we're going sideways but what I've noticed in the last five years, we did an audit of all my left-handed patients, they're all right-handed, just writing with their left hand. Most of them will tell you they cut with their right hand. They play tennis with their right hand. Even their parents. And so again, the…I see a biased population group because I've seen kids that are generally only hypermobile. I've never seen children who are not flexible which is a message in itself. So what's interesting is all of these hypermobile kids who are writing with their left hand are actually right-handed and —

BOB: I think Jake's similar. He's left-handed but took an age and he can do things with his right hand that I can't with my left.

NH: Yeah.

APM: One of the basic criteria, is it not, is to be able to place your palms flat —

NH: So what I was saying is that…and that's an important one. So firstly, their knees don't hyperextend by 10 degrees because their hamstrings are tight now, because our children's quads today are weaker than their biceps. When I first examined him, his quads was weaker than his biceps and that is now a norm in society. So if you've got a very strong hamstring, very weak quad, you get a tight hamstring then you can't even touch your toes. Most children today can't get within six inches of their toes.

APM: Is this though just the children that you see?

NH: Even the hypermobile children. That's the general population. So if you go to a classroom of five-year-olds and ask five-year-olds to touch their toes now, it's something like 1 in 20 cannot touch their toes because they've got tight hamstrings, because their hamstrings are strong and their quads are weak. So that Beighton criteria, being able to put your palm flat on the floor is now lost because our children have changed so much and then hyperextension of the knee is lost. So really, you're now only looking at upper limbs with the Beighton score and really, the problem is often lower limbs. So we look at…I use the Bulbena criteria. It's a chap from Barcelona who came up with further criteria, looking at the hip movements, looking at flat footedness which is very important, the patellar instability, easy bruising. So they've added to the Beighton criteria and a lot of it is now lower limb which is really important.

APM: And can we get access to those criteria online —

NH: Research Bulbena criteria hypermobility. There's the list of all his 10 criteria and how to examine for them and it's more extensive than the Beighton. So personally, I don't use the Beighton but anyway, the kids are hypermobile you know if their fingers bend.

APM: Let me take you back to something you said. How on earth do you tell whether a quadriceps is stronger or weaker than a biceps?

NH: So when you do manual muscle testing, you examine shoulder abductors, shoulder flexors, elbow flexors, wrist extensors. So there are 10 muscles in the upper limbs, five on each side, we examine and our children today only have normal right biceps. That's it. Every other muscle group…and I'm talking 18-year-old first-team basketball players, do this and I can overcome the shoulder abductors with one finger but I can't overcome their mothers and a mother should be weaker than their 18-year-old son especially if he's playing first-team basketball. But anyway, when it comes to the legs, we get them laying down on the bed, to lift their leg up and I see if I can actually physically push the leg down and all it takes is one finger to beat their quads. They can hold their leg up like this and I will beat their quads, pushing here with one finger but I can't pull their biceps with all my might, with my whole body pulling. I can't beat this which means right then and there, their quads is weaker than their biceps and lots of parents know this. Parents come in with kids of…12-year-old kids and tell me they can't ride a bicycle because to push a pedal around, you have to have this muscle here and they can't do it. So lots of kids now can't ride bicycles and stuff. So we know in the general population…you know, in the background, parents already know that their children are weak but that's how you examine it. So it's manual muscle testing and the 12 muscles we examine in the legs, the hips flexors, the hip extensors, the hip abductors, the hamstrings, the calves, tibialis anterior. So out of the 12 leg muscles, our children usually only have normal hamstrings and calves left and that's it and right biceps. So out of 22 muscles we test, the score is now five. I mean I saw an England football player, a 17-year-old boy who plays striker England Under 18 recently and he came to me groin strain, pulled hamstring, back problem, shoulder problems. Anyway, out of 22 muscles in his body, seven were normal. I could beat his quads with one finger but I couldn't beat his biceps and he is a striker, kicking with this muscle and that's why he had a groin strain.

APM: So when you examined Jake, you had a very unwilling but determined patient who —

NH: They don't have a choice.

APM: He walked from his wheelchair. I know he got a lot of encouragement from you, to the treatment table and you went through all this muscle testing. What did you find? How many —

NH: I found him to be hypermobile. He was very weak but understandably because it was very hard for him to do anything. He had elbow pain and he had leg pain and backache. So it's very hard for him to do it but I made him to do it because one thing they have to learn straight away is that you're going to have to do it. There isn't a choice here, you know. People who say, "Oh, well, if that's sore, I better not touch it. If that's sore, I better not touch it," and stuff, you will never get over your RSD. I've seen people in wheelchairs…when I was working at Middlesex University College Hospital, there was a girl who was playing basketball for the England Paralympics team and she had RSD and she was now permanently in a wheelchair. So you could end up being permanently in a wheelchair if you don't push them because yes, it's sore but it's not damaging sore. It's not harmful sore. I make the parents rub the area and it's agony. The kids are screaming and it's agony but they're not harming their child. They're getting those nerves to understand that this is normal, that a piece of cotton wool can't harm you and you have to do it. If you baulk to it and if you sit back and if you say, "Well, shame, if that's sore, we don't it and if that's sore, we don't do it," they'll never get better. Kids come to us at Great Ormond Street. They used to come, hadn't walked for two years, in wheelchairs. So you have to do it and that's what I make the kids do. As often as it kills me inside. I mean I'm a really soft person and inside me, the trauma I go through is as much as the trauma they go through on the day and I sit there just…I get home shattered after seeing a person with reflex sympathetic dystrophy because I know how tough it is and I know what they're going through and I know it's real but there isn't a choice. If you do not push them, they will never get better and that was our Great Ormond Street motto, you have got to push them. They can't sit and say, "Well, it's a bit sore. OK, take it easy."

APM: So what did you recommend for Jake after? He's seen you once —

NH: So he saw me and then I recommended that he needed to see the multidisciplinary team that was going to help him and in my experience, the best team that I knew of at that time, having visited different units around the country, was the team at Great Ormond Street. So even though I'd stopped working there, I knew Sue Maylard and the psychologists and the physiotherapists and the OTs and the people working at Great Ormond Street were in the best position to help him because they don't baulk to this. They know that if you sit back and because a person screams, you stop touching them or you stop desensitizing the area, you will never ever get better.

APM: Is that where you've been?

BOB: Well, what we did is we went to see Sue initially but that was…I was on a private booking. So there was X amount of months and because they weren't in my catchment area, I had to build a case for my local GP. In the meantime, we were on the list for Oxford at Nuffield. So Nuffield came in a lot quicker. So we had 2 or 3 appointments at Nuffield but the knowledge I learnt, I was the general at home. So realistically, we have had half a dozen appointments at Oxford over these last few months but I've been through it and he cries and he screamed and as you said, you have to put cotton wool in your ears, go around and tell your neighbors that this is happening and for…once I knew, as a parent, that I was not physically hurting my child…which before the information, if your child's screaming to…you're never going to make him lift his arm.

NH: He couldn't undress himself.

BOB: He couldn't undress himself but once I had the knowledge, again, going back to the knowledge, that I am not physically hurting my child then as hard as it was, we pushed through, day after day after day after day with some setbacks here and there.

JAKE: Physio.

BOB: Physio, physio, physio and I think the psychological side where again, you chip away at it, I feel more confident. That goes on to my child. He can see that. He can see there's a driving force and we pushed and pushed and pushed and literally, a few months out, he's kicking footballs about.

APM: Exactly. You felt the difference, haven't you? How has it felt when your dad has been telling you to do these things or doing these things to you?

JAKE: The first few months, I was a bit like, "Are you putting me through hell or something?" Because when I got…when I had to do it, at first, I was like, "I can't do it." Daddy said, "Yes, you can. You have to," because if I didn't do it then at the minute, I've been kicking footballs about. So I wouldn't be able to do that. So I'm like, "OK, I'll do this but…" I couldn't do one but dad will say, "Well, you have to do it because do you want to be back in that wheelchair?" I said, "No." So he said, "You have to do it," and…because I was spoon fed initially. He said, "When you eat your dinner, you have to do it." I —

APM: How has it affected your schooling?

JAKE: It's been…they had been really good to me. They've understood it, how it is and they said, "If anything happened at school, come to the…like to the treatment room and see what we can do." I'm in this room where it's really quiet and basically —

APM: That's what you need, isn't it? You want to be somewhere with distractions —

NH: Distractions help. That's why we make them get back to school —

JAKE: I'll go out 1:10 but then I have to do my physio which now, it feels like nothing. It's weird because a few months ago, I was screaming in pain just doing them and now, I can do them.

JAKE: Yeah, like that.

APM: How often a day do you have to do these exercises?

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JAKE: I had to do them two times a day. Sometimes I'll do them one but I do loads of…I do all these. I'll do them. Yeah, I do lots because it's all for different areas, like these ones for the legs and I'll do ones for my back and then ones for my arms. I mean it's stressful but if it's going to help me in my life, now that's what I want to do because I don't want to be like this forever. It's calmed down now which I'm happy but I can't let it come back to that because if I do, I just would…I can't do anything because…well, I have to because I can't let it come back to that. So I'm fighting.

APM: If we had an audience in here, you'd get a round of applause because I'm not sure many people are brave enough to do this because it sounds actually bloody terrifying.

NH: It does

APM: Bob, you've been to pain management groups, haven't you? Is that part of your recommendation, Nathan, that people go to groups —

NH: Yeah. You need to always be careful with groups, you know. Groups need to understand the way to really help you, you know. So there's some groups…like if patients have certain things…so, you know, I always say to patients…I have a Down syndrome always become a member of the Down Syndrome Association because they'll give you all the best help and connections and stuff whereas if somebody has ME, if you become a member of an ME group, research has shown you generally do worse than if you don't. So I think groups are important but it has to be from the right direction. The groups have to know how to help you, give you the correct advice.

APM: What have you found in the groups you've been to? I think you've told me that, actually, Jake is a champion for this because he'll stand up in front of any group, as he's doing now, and tell people what they need to —

BOB: What I thought was fantastic when we did go to Oxford, there was a lot of children there ranging 17 to probably 5 I think the youngest was.

JAKE: The youngest.

BOB: Lots of crutches and wheelchairs and things and what was lovely was Jake was almost…he gave hope to this group, you know. We've got a lot of kids there. We're allowed to go around, explain our situation and then you could have a lad that could say, "We have been as bad as being wheelchair bound and if you do the right things…" He had parents coming up to him afterwards, after he spoke, saying, "You've given people in this room hope today," and my biggest thing from there was when they were asking questions…I mean Jake had his hand up every 30 seconds. He knew everything he needed to know. It was the level of people that didn't know I found shocking.

APM: Which is an important message for us, isn't it? Because, you know, we do come across people with conditions like this in our physical therapy practice,

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possibly before we refer them to experts like yourself and, you know, we have to emphasize to them that, you know, there's a lot of knowledge out there and that…particularly with children. I mean he parents' role is all important in this, isn't it?

BOB: It's huge.

APM: And as you said, it's a terrifying role because you, at first, thought you're hurting your child.

BOB: Ultimately, the child has to do it themselves. No one can do this for them but they are children and they will lie in bed if their arms…there was a young lad there, 16 and he'd had it since he was nine years old. He's standing there, similar, twitching, moving his shoulders round, I could tell and speaking to his dad but he laid in bed every day. He didn't do his exercise. He didn't do the things he should and we had a good chat with him and the dad and I was saying, "The next time I see you 'Leon', we're going to be…there's going to be a huge difference if you do what you're…if you do what you need to do, it can be dramatic." I'm talking in months, the change.

APM: So your recommendation for any parent or any child with this syndrome, is it the same? Is it the same exercises? What are they?

NH: Yeah, it's exactly the same. So the most important, first thing, is desensitization. They need to understand that the area that's painful, whatever it is…knees, ankles, whatever it is, is safe to be touched and what we find is…so we give them a sort of program to start doing and the program is desensitization and what we always suggest is first, that the child themselves, time on the watch, rubs the area for five minutes and rubs it and rubs it and they have to do it. They don't have…and actually, when they do it, it's not as bad because of that sympathetic nervous thing. You can't tickle yourself. It actually doesn't really let you hurt yourself that much but then the parents have to do it for five minutes or the sisters or aunts or whoever's around, has to do it for five minutes and then they have to move for five minutes and we give them —

APM: All the areas that are painful.

NH: Well, it's usually, more or less…quite often, it's only just one area. They'll have gone over on their ankle and now they've got RSD of the ankle or their wrist. I've seen, you know, kids with two knees. I've seen people with half the body. I've seen a girl with RSD of her tummy and stuff but they have to touch it. You have to desensitize. You sometimes have these little toys. I don't know if you used —

BOB: We've used Buzzy, yeah.

NH: Buzzy for short. It was something invented in America to distract children when you have a blood test. It's like a vibrating tool. You put it on and then when you do the blood test, they don't really feel it but actually, that works out to be a very useful desensitizing agent because when you first put it on, the people think it's just crazy. It's the worst pain they've ever felt but actually, gradually, they'll think, "Oh, actually, you're not so bad." When you take it off and touch their skin, they'll say, "Yeah, it's not sore." It actually desensitizes the nerves and I guess in adults, it's similar to TENS. TENS is used a lot in adults. Children don't like being electrocuted. So this is just a buzzing and that's quite useful in children. I mean I've seen a boy in a wheelchair and he came in and we put one Buzzy on each knee. He got up and he walked. He'd been stuck in a wheelchair and literally, there and then, just got up and walked because his knees were distracted. The pain was distracted, better than any pain killer or anything. So distraction's important.

APM: What we do with TENS, we tend to…there's two types. There's low frequency, high frequency. The high frequency is pain gating, isn't it? So it should cease to have an effect after you take the Buzzy toy off but it doesn't.

NH: But it doesn't. Once you take the toy off, those nerves are actually desensitized for a short while but it also…it just means that they can just keep using the area or keep rubbing it and stuff and then moving it and movement's extremely important because the last thing you want to do with RSD is move. You'll see people who've got it on their wrist and they'll be right-handed and they'll be doing everything. They'll come in and they're scratching and they will not move the right wrist. Even though they're right-handed, they will not move it and movement is extremely important and we get that moving it, moving their fingers, moving their elbows —

APM: So five minutes of self-rubbing, five minutes of —

NH: Parents rubbing, desensitizing then five minutes of movement. You have to do it.

APM: You had to do it, legs, arms, back. You had to do all those areas.

NH: The whole body.

JAKE: Well, but it's —

BOB: The physio. The physio has been huge.

JAKE: Mostly, what's even worse , they say move it around, but if you keep your…if you have like an arm problem, if you keep it like that, so that it doesn't get worse, going to get worse because then you do everything with the one hand and then that one starts to hurt. So what do you do then? That just makes it worse. So doing the physio makes it actually better. Even though it feels painful, it's making it better because not holding it, it…I used to have mine in the pocket. I used to have to go to school and have a hoodie on and had to have it in the pocket because —

BOB: We didn't know what it was, didn't we?

JAKE: No, we didn't.

NH: You can say that now.

JAKE: It's not a broken arm though. So if it is a broken arm —

NH: You could.

APM: I have been asked by…one of the viewers has asked. They're asking you specifically, Jake, how did you put up with the pain and keep going with the exercise? Because most people would give up..

JAKE: You can't, as Dr. Hasson says, you can't because if you do, you're stuck in a wheelchair and you're the…keep on just sitting there, not doing anything with your life, just watching the TV, not doing anything and it's not going to be fun. You're just in pain, you're just sitting there. You can't do anything about it. So if you do your physio, you're actually going to do something with your life. Let's say still has this pain but you're not doing anything with your life, you're probably not doing nothing with your life. You're going to sit down, do nothing but if you keep on doing physio, you could do something great. You could be a millionaire. You could be an exercise person. You could be in footballer. You could be a person who does rugby. You could be anybody that you want to be if you do the physio and you have this pain.

APM: That's great. It's great to hear. I just want to move on though because you talked about the first part of this which is stimulating the area, desensitizing of the area.

NH: Ah yeah.

APM: What happened…what…?

NH: And then movement but what's underlying it all is the fact that our children today are physically weak. And so as he's been…Jake's been saying is the physiotherapy is extremely important to rebuild strength and stamina. You need to hold your body together. If you're a flexible person, you need to have strength and stamina. And so it's rebuilding that strength and stamina but also understanding that anxiety is your biggest enemy. If you are anxious and if you worry about pain…and I think most people that we see with chronic pain syndrome and stuff, what's really underlying it, you know, with fibromyalgia and things which we now realize is just all a spectrum of people with hypermobility and CRPS is anxiety is your biggest enemy. And if you're worried and you think, "Oh, if I do that, I'm going to be in pain," "Oh, I shouldn't do that," and, "Oh, I can't do that," and stuff, you're going to suffer and you're going to get worse, as you say.

APM: So in terms of the exercises, we keep talking about physiotherapy. I don't want to offend any of our non-physiotherapists in the audience, of course, particularly my fellow osteopaths, what specific…are you saying muscle specific exercises —

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NH: What you need to do…yeah. So muscle specific exercises. So they're given a program of exercises that start off with just five repetitions. So you want to build up quads, five…which is doing five exercises where you're lifting your leg up and down and then gradually move…after a week, going to 10 and then 15 and 20, 25, 30, seems to be the magic number and then when you get to 30 and you're good at doing 30 repetitions every day of your exercise, whatever, then putting a half pound weight around the ankle and then a 1-pound weight, 2-pound weight and gradually building up with just a very low amount of resistance. Exercise has to be against resistance and we do specific muscles. People —

APM: Hydrotherapy, is that good?

NH: No. Hydrotherapy is probably the opposite of what you need because with hydrotherapy, your muscles will relax, won't build up strength and stamina. So no, we don't…hydrotherapy is very good if you've got arthritis and your knee is stiff and you want to straighten up the leg. Fine, hydro will help you straighten up but hydro's not going to help you if you've got weakness in muscles. You need to do dry land exercises like Jake's been doing with weights, against resistance and you rebuild, strengthen stamina. So we rebuild children now. We make them back to full strength. Full strength, not always being enough to hold you together if you're a flexible person because as you'll know, parents come in with totally full strength with slipped discs and frozen shoulders. Well, they have full…of normal strength, measurable normal strength and they've ended up in trouble. So we know normal strength isn't actually quite enough for flexible people to cope with the modern world. They have to be better than normal strength and our children today aren't even normal strength. So they're really in a difficult position. So yeah, building up strength and stamina of specific muscles and then doing stuff like swimming and cycling, you know, aerobic type exercises and stuff, pilates —

APM: Because I was going to say the initial part of that sort of flies in the face of conventional thinking about training for activity which is they must be functional but you are doing muscle specific exercises in this —

NH: No, you have to rebuild our children's muscles. Our children now end up, at the age of four when you examine their muscle strength, the 5 out of 22 normal muscles in their body and they're very, very different. You know, I know children 28 years ago weren't like that because that's what I did every day was examine those children. So you've got to do very specific exercises to rebuild our children but you've also got to make it fun. So they've got to do some swimming and stuff like that but, you know, I see people who are achieving top sporting things in this country who are physically, totally weak, you know. The world silver-medal pentathlete suffering from exhaustion and, you know…don't want to mention names, you know, but people who are really, really achieving the top and when I examine them, physically really quite weak.

JAKE: And dad helps me sometimes with physio and when we do, we'll look at each other. I can do three more than he can do.

NH: There you go.

JAKE: So I'll do that and —

NH: Always. We always get him doing it with somebody else. It's much easier. If you're the only kid in the family who's having to sit there and do exercises, everybody else watching TV and…do it with somebody —

JAKE: Actually, I just…I'm doing this and then he'll be like, "Can we do like one more?" I'll be, "No, 2, 3 more."

BOB: Create a monster.

NH: That's good.

APM: In a good way. What's the prognosis for this? Is this going to resolve completely?

NH: So if he builds up strength and stamina, if you understand it, you don't let it come back. As he quite correctly said, you don't want this ever happening again to your body but unfortunately, people who don't understand it, people who have it and it'll maybe go away eventually and then they'll get it somewhere else…it will keep moving around and you do see people who come in who have had several bouts of CRPS or reflex sympathetic dystrophy but once you've been through what he's been through, you know, and it was actually all over then you don't let it happen again and you stay ahead of it and you realize that sometimes, we have unimportant pain. That's very, very severe pain but it's not pain that you have to listen to and that's the tough thing. If you can get your psyche route not listening to unimportant pain…which maybe it's easier for kids. I'm a pediatric rheumatologist. So I don't know. Maybe looking after adults with this, they just don't have the energy of these guys that they can actually see past this and will do it because maybe a lot of adults wouldn't manage to do it. I don't know. I don't look after adults with this.

APM: Well, Jake, I'm not reading out everything that's coming through to me at the moment because we still have time and actually, a lot of them are the same. The words coming through on these cards are that you are incredible.

JAKE: Thank you.

APM: You're welcome. That you could've gone through this with what appears to be a great degree of fortitude and cheerfulness. Astonishes me. I'm —

NH: He wasn't so cheerful when I first met him.

APM: No but at the same time, I'm full of admiration for a parent who's persevered and found the right route for his child and got a solution to this and the child—

NH: It’s not easy.

APM: --is a champion of the condition, if you can be such a thing, because you’re spreading the word to other people with it and I’m conscious we’ve kept you here for a long time but I’m really grateful because I…actually, before we go, is there any…what can they do…I don’t know. Are there dietary matters?

NH: No.

APM: Because somebody…recently, somebody said that vitamin C have a big role to play in CRPS.

NH: So what we know is that vitamins don’t have anything to do with this.

APM: Really?

NH: If it was a vitamin thing…I mean, you know, we’re not lacking vitamin C. We don’t have scurvy. We do lack vitamin D these days and that certainly doesn’t have anything to do with this. So there isn’t any dietary thing for this. You’ve got to understand the mechanism of what’s going on and you’ve got to understand that the only way around it is desensitization, move it and don’t listen to it and you’ve got to really be psychologically really high to be able to do that, to be able to overcome that intense pain that you’ve feeling and stuff and not listen to it. You know, it’s overcoming a reflex. Overcoming reflexes is not easy.

APM: We were talking about vitamin D earlier on, weren’t you, Bob?

BOB: Yeah because when we actually had the test, they did say he was low in vitamin D. So he does have to take a supplement twice a week.

NH: But what’s really interesting is all children in this country are now low in vitamin D. That’s a stat. I mean today, I saw 3 or 4 vitamin D levels, all of them really, really low and that’s not so much causing him a problem now as what will maybe be a problem in the future with our children having poor bone stock in the future and ending up getting fractures in their 20’s like, you know, grannies in their 80’s get —

BOB: So it is right for him to take this.

NH: So it’s very, very important that he takes vitamin D. It’s not going to help him now, what he has now and his problems at the moment…well, lack of problems now which is a good thing but certainly, it’s going to give him a bone stock that by the age of 20, he is going to have good, tough bones. He’s going to do lots of exercise. He’s going to have his vitamin D and he is going to have tough bones and when he falls over when he’s 30 or 40, he’s not just going to break his hip as if he’s an 80-year-old.

APM: So it’s a separate problem —

NH: So it's a totally separate thing but all of these things are, in a way, related because vitamin D is low because our children don't go out anymore because their iPads and their computers and their TV don't work so well outdoors. And so children aren't getting out and that's part of this whole problem of our children today, being weak. Their weakness comes from inactivity in fact ukactive, a few months ago, with Lord Sebastian Coe branded this generation "generation inactive". The top of all the sport world and medical profession have branded this generation inactive and all the things we see today —

APM: Well, I said I was going to let you go a couple minutes ago. I just thought I'd get a last few comments there.

NH: Sorry.

BOB: Thank you.

APM: Jake, you're a real star—

JAKE: Thank you.

APM: --and I wish you well with this. You're clearly going to progress very well because you've got an attitude which I've rarely seen. You know, I've been through Royal Marines training and you've got the guts to do that. You really have. It's been a great pleasure having you on board. Bob, thank you for taking the time to come down and —

BOB: Absolute pleasure. Great to see you again, Nathan. Thank you.

JAKE: Just one sec-.

NH: You did it.

APM: We're going to go on to talk about adult manifestations of this condition or hypermobility generally and I'm aware that there are two people watching this evening who have an interest in that. They are patients. They're not practitioners themselves. I just want to reemphasize to them that they are very welcome to send in their own queries, send in their own questions and ask Nathan, you know, for his advice here and now. So it's free advice from one of the best consultants you could get —

NH: While remembering I'm a pediatric rheumatologist.

APM: We were all children once. So yeah, you were saying that, you know, it's benign in children. So what are the consequences in adults?

NH: So benign in children because children don't suffer the damage that happens in adults with hypermobility. So what we know about children is that they don't slip discs. They don't end up with wear and tearing away of their joints and ending up with osteoarthritis and needing joint replacements in their 30's and

40’s. So in children, it’s a benign condition. Yes, they have aches and pains. They have tiredness. They have difficulty with certain things. They could develop reflex sympathetic dystrophy but really, it is a benign condition in children because there is no long term harm or damage and as long as you change things around whilst they’re still children, you can actually completely change their future. You can stop them getting what adults then get and, you know…

APM: Well, there are adults who have no previous experience with it. They’ve not had any manifestations of this —

NH: And that’s very interesting to think about it. They’re hypermobile. So why didn’t they have aches and pains and problems as children? Because they had decent strength when they were a child. What happens when they get to university? What happens when they start having children? They stop doing the amount of exercise. So what’s always interesting is people will say, “Oh, well, I was a gymnast when I was young and now, I’ve got backache.” You don’t have the backache today because you were a gymnast when you were a child. You were a gymnast when you were a child because you were hypermobile and flexible and you could do gymnastics. That didn’t damage you and harm you. That’s why it’s benign in that age group. Even if you’ve got a bit of backache and stuff as a child, it’s just muscular. It’s just tightness of muscles and some cramps and things like that. So what happens when you’re an adult is you stop doing what you used to do. That’s when you fall apart. Not because you did but because you stopped doing it and as an adult, if you start to fall apart, if you start to have babies, particularly in women, you know, discs L4-L5, L5-S1 start to go, neck discs start to go, shoulders start to freeze, if you stop doing exercise then you are going to end up having problems related to your flexibility and wear and tear and then that becomes true damage. You have then got damage and you have got discs that have prolapsed but as many people who have flexibility and disc problems will tell you as soon as they start doing pilates, as soon as they start doing swimming, as soon as they start rebuilding their strength and stamina, they find their pain goes away. As soon as they stop doing their exercise and stuff, pain returns. So you can manage it through exercise and getting fit and strong as an adult.

APM: So would you then recommend pilates over yoga, for example?

NH: Yeah. So yoga’s very static, OK? And people who are hypermobile do yoga. So I was in a country where everybody is hypermobile. Yoga comes from there and massage comes from there. I can’t remember and what’s interesting is that people who are flexible find it easy to do yoga. Yoga, not really being that helpful because it’s static. Now, there’s I think hot yoga or something where maybe it’s a bit more active. I don’t know what hot yoga is but pilates would certainly be much better than yoga because yoga, in a way, if you’re flexible, it’s easy to do it, you know. You’re cheating. Because you’re flexible, you can automatically get into those positions whereas if you’re doing pilates, you’re actually then physically building up strength and stamina and core muscles in your muscles and that will then protect your joints and improve pain in adults and that’s it. Parents tell me that.

APM: One of our questions is from, one of viewers actually asked, whether there are specific exercises that you would tell people to avoid with this condition.

NH: No. So what you have to do is you have to be careful, you know. People say to me, “Oh, you know, you’re hypermobile. Don’t do gymnastics.” Really, every gymnast on earth is hypermobile, OK? Every ballet dancer is hypermobile. Every good sportsman, every good tennis player is hypermobile. So people sometimes get the wrong side of the coin and say, “Oh, if you do that you’ll run into trouble,” and, you know, “Avoid this and avoid that.” No, I never ever…particularly in children, never ever tell them to avoid anything, you know. My son’s hypermobile, plays American football, played first-team rugby in the scrum —

APM: Well, interestingly, that was one of the questions, would you avoid contact sports —

NH: No, not at all. My son plays American football at university. Just won the cup for, you know, the British universities’ team and is a tackler and is totally…when I lecture on hypermobility, all the slides are my son in hypermobile positions but he’s an athlete. He’s a lifeguard. He’s a sportsman. He plays American football, played first-team rugby in the scrum. No, you don’t avoid anything because —

APM: Has he suffered from RSD?

NH: No, he hasn’t suffered from any consequences of being flexible because he’s strong, OK? Now, my other son maybe has suffered from some problems because maybe he didn’t do as much exercise as the other one and end up with ACL torn, with cartilage problems, has had several operations on his knee because maybe he wasn’t as sporty as the other one. So yes, you know, you can, with flexibility, run into trouble if you stop doing the amount of exercise you need to be doing and that becomes the problem in modern living. Which parents have the time every evening to spend 2 or 3 hours doing exercise? They don’t, so therefore, their bodies weaken. They get tired, so therefore they can’t do stuff and they end up in vicious cycles of tiredness, aches and pains and, you know…it’s interesting. I was recently at a conference and there was an adult who runs a fibromyalgia clinic and when he was talking about adults with fibromyalgia, it sounded exactly the same as the kids I see with chronic fatigue and kids with flexibility and aches and pains and pressure points and stuff. You see all of that in kids and you begin to realize that we’re actually looking after the same spectrum of people, you know. There are things like fibromyalgia, chronic fatigue, chronic pains, all part of the same thing, that if you’re a flexible person and you’re not strong enough, you end up in a vicious cycle of aches and pains, of tiredness and then as an adult with damage and it’s hard to come back from damage. So we do…I do understand that. I know that.

APM: What’s the prevalence of joint hypermobility in children?

NH: So it's the same. There's no difference in adults to children because if you're born flexible, you're flexible, you know. All the top tennis players, Djokovic, everybody, they're all hypermobile. It depends on the population group. So we know, having spoken to rheumatologists from Brazil and Chile, that in South American countries, it's…around 40% of people are hypermobile. So that's why you can't see hypermobility as a disease because it's not. It's a normal variation in the population. Being flexible is a normal variation in the population and the proof of that is…people say to me, "Oh, you know, hypermobility," and stuff and when I turn around to them and say, "OK, so for…" They talk about this condition, Ehlers-Danlos type three, Ehlers-Danlos hypermobility type which is —

APM: You sound a bit skeptical.

NH: Well, because it's all hypermobility and also, if that condition existed, you know, what is the genetic defect? If they call it a defect, what is the defect? Because I don't see it as a defect. I see being hypermobile as an enhancement of a normal person. That you can become a Wimbledon champion. You can become the best swimmer on earth. You can become the best sportsman on earth if you're flexible. So I see it as an enhanced state if you're strong. So the hypermobility, per se, is not a diagnosis. That isn't the issue. The issue is if you become weak and you're flexible, now you're going to be in trouble. And there is no gene for it because it's not a defect. It's a normal variant. Forty percent of Brazilian people are hypermobile. You can't say 40% of a population are defective. It's not a defect. That's why they're so good at football. Most good football players are flexible. So, you know —

APM: But what you are saying is that if you are hypermobile and you allow yourself to become weak, this is almost a certainty.

NH: Then you are going to be in trouble and we're beginning to see it now in children, you know. Things that you only used to see in adults…like women after their second pregnancy would get prolapsed discs and get sciatica and problems like that, that's never been seen in kids. Recently, I've seen a 10-year-old boy, already, prolapsed the disc and a 16-year-old girl with two discs, L4-L5, L5-S1 prolapse with sciatica. Things that have never ever been seen before, we are now seeing in young people because they are so deconditioned, so weak that is now…they're now ending up with problems that adults used to get.

APM: What's the mechanism for that then? I mean the discs themselves…

NH: They grind down. So what I would always explain is if people are hypermobile, what we always see is that the finger joints bend back 90 degrees. What I show them is that when you put the wrist back, these fingers don't bend back quite often in the kid who is hypermobile because this muscle is controlling these joints but on this hand, you can get the fingers right back 90 degrees. And what I show them when I put those fingers back is I start to move these fingers around and I tell them, "Imagine this is your vertebrae and your discs are here and when you are hypermobile and you have no control, look what’s happening,” and I move their fingers round and round and you begin to see that these areas here are being ground down and ground down and ground down and ground down. And I show them this and I say, “But look, in this person who’s hypermobile, this hand’s strong. These areas don’t grind down. That’s your discs. You know why your discs went? Because you are hypermobile and you were not strong and you grind down your discs, you grind down your joints,” and that’s what happened. You do get wear and tear in adults. So the secret is don’t get weak or if you are weak and you have back problems, do pilates, do exercises and get physically strong to hold yourself together. That’s the most important thing.

APM: One of the things that strikes me as really important about the conversation we’re having now is the preemptive aspect of this because we’ll see patients whether they’re adults, parents or whether they are children and it’s very easy to say to parents as well, you know, “It’s very important for children to do exercise,” but there’s some really strong evidence from what you’re saying…proper evidence, not just your extensive clinical experience but lots of evidence to say, “Look, you’ve got to get that child out doing some exercise. Keep him strong,” because being outside, they’ll get some vitamin D, hopefully, as well but also, they might prevent any problems, particularly if they hypermobile or especially if they are hypermobile. And that’s a really useful message to take away from this because —

NH: You change their lives. Children come in with tiredness, poor concentration, aches and pains, waking up at night with cramps and stuff and come back and parents tell you, you know, things like, “Not just their aches and pains are gone, they’re not tired anymore.” It’s so funny. Recently, a seven-year-old boy came in and he’d done all his physio, was physically fit and strong and he said to me, “Doctor, I think there’s something wrong with the sugar in my blood.” And I said, “Well,” you know…wow, that’s amazing. He’s diagnosing diabetes and I said, “Well, why do you say that?” He says, “Well, doctor, at the end of the day…I think I probably have a sugar rush the whole day because I have loads of energy in the evening and when I say to my friends, ‘Come out and play,’ they’ll tell me they feel tired and want to go home and watch TV and they can’t come out to play but I can play. So what’s wrong with me? Why do I seem to have a sugar rush all day?” And I explained to him sugar rushes don’t exist. Your insulin keeps your sugar under decent level and diabetics have high sugar…believe me, the last thing they feel like doing is rushing and what you are feeling is what we all thought when we were kids. We had unlimited energy. We did three hours of sport every afternoon. We cycled down. We had a swim. We got on your bikes and we went —

APM: Well, you did it when you were in Southern Africa.

NH: In South Africa, maybe but you didn’t have TV, you didn’t have anything else and none of us were ever tired. We were never ever tired. It’s the biggest cause of tiredness in kids today is the fact —

APM: I’ve had some skeptics around because when you say that, you sound like, you know…we are of a similar age. You sound like kids these days, they’re just not like we were but this is all based on evidence, isn't it?

NH: It's 100% based on, like I told, the Australian study. Like all our Great Ormond Street, we're looking at muscle strength in children, fatigue in children, vitamin D levels comes from one thing and even obesity, you know. Obesity, everybody talks about sugar and sugar's…it got nothing to do with sugar. When we were kids, we drank Coca-Cola. We ate huge crisp chips every day. We had the most junk possible. In fact, it's a medical fact that as children in the '70s, we ate 3,300 calories a day. This is a fact. Today's children eat 2,500 calories. They are eating 800 calories a day less than we ate. We had 1% overweight levels. It's now 30%. So how can you eat 800 calories a day less than the previous generation and have 30 times the level of overweight? And the one thing is inactivity. So we know today that our children are the most inactive generation and, you know, ukactive with Sebastian Coe …I'm not talking, you know…they are the top of the top. If they branded this generation inactive, it's a medical fact and children have to exercise.

APM: But we live in a society of extremes, don't we? We have some fantastic athletes and, you know, the last Olympics, we did extremely well, better than we've ever done before but at the other end of the spectrum, we've got the people —

NH: Don't know how we'll do in Brazil. It'll be interesting and the four years after that, it will be very interesting to see because knowing what I know about the top athletes in this country, and I look after children who are top achievers in this country, when I see how physically weak and how much trouble they're running into…and we know things that, you know, children are getting slower and bigger and less fit and so we'll see in the future. Up to now, we've been okay.

APM: There's a question here which I think you can probably answer very easily because you did mention it earlier on. How can you tell the difference between hypermobility and Ehlers-Danlos 1, 2 or 3?

NH: So basically, it's all the same thing, OK? But somebody decided to put a name on to it. Now, Ehlers-Danlos type 1 and 2 has now become the classical type of Ehlers-Danlos and all it means is you're a flexible person who has very flexible skin. So one of my sons who's hypermobile can pull his skin from there and get to there and my other son who's as flexible, as hypermobile can't do that. So one of my sons has it in his skin, the other doesn't. So do I call one of my sons Ehlers-Danlos classical type, the other one Ehlers-Danlos just type 3? No. They're just all flexible kids. Sometimes the flexibility's in the skin. All of them have flexibility in the joints because that's what being flexible is. So really, Ehlers-Danlos is not a term I use at all. I really don't use…certainly not 1, 2 and 3, in any way. What are you going to do? You can't treat it and stuff. There's nothing you need to do to prevent it or…

APM: So your treatment would be the same —

NH: But Ehlers-Danlos type 4, there is a known gene and blood vessels do burst but it’s very rare. Out of maybe 10,000 children I’ve seen with hypermobility over the last 20, 30 years…because even at the Hammersmith, we used to see kids who arrive, you know…does this child have a neuromuscular disorder? And it was just a very flexible kid who just needed some muscle building and off they went with totally normal muscles. Just flexibility. So in my whole career, I’ve seen three people with Ehlers-Danlos type 4. Now, that is a true genetic problem. It’s a hereditary problem and their blood vessels do go. There’s no treatment anyway. I mean I probably wouldn’t even want to know if I had it because, you know, it is unfortunately fatal and stuff but that is extremely, extremely, extremely rare. Everybody else is just a flexible person and if they know that if they’re fit and strong and they stay strong and they’re not tired and they do their exercise, they’ll be fine.

APM: So if you had that type 1, type 2, type 3, your treatment regime would be exactly the same. It doesn’t matter what —

NH: Because it’s not a disease. They’re just flexible people, some who have skin flexibility and some who don’t.

APM: Can people turn themselves into hypermobile people?

NH: No. So I tried my whole career. I was a very, very fast sprinter when I was at school and we did three hours of sport every afternoon. In Zimbabwe, where I came from, there’s no afternoon school like Finland and places. There’s no afternoon school. So in the afternoon, you do sport and I was a very, very fast sprinter but I couldn’t do hurdles and why? Because all the hurdles would sit there with that leg out, this leg up here, on the floor practicing their hurdle technique and I tried for 6, 7 years to get to that position. With all my training and everything, I never achieved it because I didn’t have 90 degrees of rotation at my hip like the hypermobile —

APM: Interesting. There are people who build careers on saying that you can teach yourself to do the splits either forward or lateral —

NH: Couldn’t do it but people like Andros Townsend, the football player, he can do the splits because most good football players are hypermobile. You take to what sport you want to do because of your underlying hypermobility but the people who are hypermobile are not because they made themselves hypermobile. They were born hypermobile and then took to their —

APM: So there’s no hope for the rest of us who want to —

NH: So I was stuck, could never do hurdles. I was the fastest sprinter in the school and couldn’t get into the hurdles because I could never get that leg there, couldn’t do gymnastics, was a terrible football player, terrible swimmer, couldn’t do backstroke and all of it because I was not hypermobile. So you can’t make yourself flexible.

APM: Do you see malalignment problems connected to hypermobility? And if so, are there occasions when you might recommend strapping to correct those, strapping or taping?

NH: I mean are you talking in terms of scoliosis or…?

APM: Scoliosis and you already mentioned —

NH: So you do see that. Yeah, I mean you do see that you're a bit more prone to developing a scoliosis if you're flexible and if your core muscles aren't strong and the thing about strapping and stuff is it does seem to…and there's Kinesio taping, but that does seem to stimulate the underlying muscles to work better but obviously, them doing the physio and exercises to make those muscles strong is the way around there.

APM: Do you think Kinesio tape or RockTape I ought to spare using a branded name K-Tape…do you think that that provides the distraction that you were talking about earlier on that might help alleviate RSD?

NH: No, I don't think it would distract you enough because once RSD develops, that's a, you know, nerve mediated thing but I think it'll help you to keep in a better position. So maybe your knee won't twist or your ankle won't go over and you won't get the initial trigger that might settle for RSD.

APM: What made me ask you is because a long time, the philosophy about, say, Tubigriip was not that it did anything to support a joint because it doesn't but it provided a stimulus to the brain which made you think about that sort of thing —

NH: But it also becomes a crutch. These guys arrive with Tubigrip around their arm and you try and take it off, you know, but you try and touch it with cotton wool and they won't let you touch it with cotton wool but put a piece of Tubigrip over and they love it but it becomes a crutch. They come in with the wrist splints like this and those are just crutches and the first thing we do is we take them away and we say, "You got to move it." Being in a splint like that is the last thing you need, to be kept in if you've got RSD —

APM: And yet, they would've been put in that split by a practitioner.

NH: By a practitioner who thinks, "Oh, if you got a sore wrist, let's pop you in a splint," rather than build up the muscles and help you through your own muscles. They'll pop you into a splint.

APM: One of the questions we've had asked here…I'm sorry if I keep hopping around. I'm trying to all the questions.

NH: Fine.

APM: Is there a link between hypermobility and reflux?

NH: Yes, reflux, gastroesophageal reflux. So when you're flexible, what I always explain to parents, there seem to be sort of roughly three areas that are affected by…in people that are hypermobile. One is obviously the joints because that's hypermobility. The second is the skin and that's why people bruise very easily, people scar very easily and sometimes can do tricks like that and wrap skin around. So it can be in the skin and bruising easily is the…and in fact, in the Bulbena criteria, ecchymosis, bruising is one of the criteria, easy bruising and all the parents say, "Yeah, gosh, he's always bruising very easily," and I reassure the parents. I say, "Don't do blood tests and stuff. They bruise because their skin is flexible and they bruise easily —"

APM: Well, that poses…sorry, I'm interrupting you but that specifically poses another problem because if you go to a conventional practitioner, your child is continually bruised, there's a chance they're then going to refer to social service because they'll think there's something strange going on.

NH: And parents do come in and say, "Gosh, you know, we've been through social services because my child is covered in bruises," and they've realized that…but particularly, bruising from the knee down or lower back bruising, those are what we call acceptable, normal bruising. Yeah, if you've got a lot of bruising in unusual places, you might begin to think about that but easy bruising is a feature, but also, the gastrointestinal tract is affected and in two ways, one, the lower esophageal sphincter is very lax…so a lot of the babies have gastroesophageal reflux and then as adults, they can have a heartburn and indigestion. So reflux is a thing we see and also constipation. Their colon can expand to hold huge stools. I mean parents of two-year-olds bring pictures in of what these stools look like and you can't imagine a two-year-old could pass a stool like that because their colon expands and they do suffer from constipation at that end. The other area we see sometimes affected is that people who are hypermobile have low blood pressure which is very healthy to have low blood pressure. No strokes, less heart problems but one of the things they do get is dizziness. So if you don't have a good muscle pump in your quads and you stand up and you don't pump blood up, your blood pressure drops and then you get like a moment of dizziness or a head rush. So dizziness happens and then more recently, there's a condition that's diagnosed by some people called POTS, postural orthostatic tachycardia syndrome and actually, that's just a normal physiological response that's exaggerated in hypermobile people. So if you're a weak hypermobile person and you've got low blood pressure and you stand up and your blood pressure drops, your heartbeat has to speed up and you might get palpitations and you might feel dizzy. And so that became POTS but actually, it's really an exaggerated physiological response. You make those people strong. You tell them to put salt in their diet, drink lots of water, get strong muscles, their symptoms do improve.

APM: That's hypotension. Is that due to increased elasticity of the vasculature?

NH: Of the blood vessels, yeah.

APM: So in —

NH: That's for breathing

This transcript will shortly be replaced by a concise text summary.

APM: I was going to go on from that and say in particular, in the lower legs, does that lead to problems? Because of course, if you can't return blood effectively then…

NH: You don't see any more DVTs and stuff.

APM: No DVTs, no thrombosis.

NH: Not that we've seen. No.

APM: Now, this is quite a lengthy question. So I'm going to read this one out. The member of our audience says, "I have a patient who has one hypermobile spinal segment, who is very fit, active and physically strong when he started hurting at 19." I appreciate that he's not in front of you but, "Is there anything you could suggest or recommend…or do you have any thoughts?" This is a question, not a challenge persay.

NH: So what we find is as strong as people are…I mean you think somebody is playing, you know, football for England Under 18, first-term obviously must be strong. You'd think a world silver medal pentathlete must be strong, the British Under 14 800-meter champion must be strong. When you actually physically examine them then you realize how, you know, deconditioned and how strong people are these days and people aren't as strong as they think and if you do proper manual muscle testing, if you've learned how to do proper manual muscle testing, you really begin to realize how just weak…18-year-olds, 19-year-olds basketball players do this and I can overcome their wrist extensors and I can't overcome their mum's left hand but I can overcome their right hand. You begin to realize that as strong as you think people are and because they're playing for a team and…they're actually really physically not strong anymore and building up muscle strength and stamina, core muscle strength and stamina is important and especially with something like that, you know, building up core muscles is what it's all about.

APM: It's interesting though that…you said earlier on that you got an England footballer whose quads are weak because you would've thought—

NH: Kicking muscle-.

APM: --they would be built up just through the exercise.

NH: Kicking muscle but they've never had been strong. What we know from studies now is that the muscles you have by the age of six, you have forever. So if I test left forearm, your left forearm would be of normal strength and it has always been of normal strength, not just being in the Marines as you were,l it's always been like that. If I examined you at six, I would not have been able to overcome your left forearm. If you, by the age of six, have been playing with iPads and watching TV and doing stuff that children do today and not being allowed to go to the park and not being allowed to ride a bike in the streets and stuff then by the age of six, you don't have normal muscles. You have five normal muscles, your right biceps, your hamstrings and your quads and those five muscles, you'll have forever. You can lie in bed for three months. Get out of bed and you'll still have those five muscles but the muscles you've not had, unless you actually do specific exercises to build those muscles, you don't build them through sport because sport is at a different level now, OK? And coaches tell you that, you know. Coaches are getting so frustrated with kids in gymnastic teams and swimmers and stuff because they're just not getting anywhere because what they haven't realized is they're not dealing with the same population that used to be and that's the problem. So building up specific muscle groups in addition to all the other stuff is important.

APM: I'm going to ask though…this isn't a challenge either. I'm intrigued. Could you perform that test on me? Test my —

NH: So in terms of the manual muscle testing…so the one is shoulder abductor. So if you lift your arms up like that. So an 18-year-old boy now doing that, I can take one finger and I can overcome their shoulder abductors like that but their mum does what you've just done and I can lean my whole weight on the mum's arms and she holds me up laughing, like, "What? That's not difficult."

APM: That could've been really embarrassing, couldn't it?

NH: But their 18-year-old son can't do what you just did. And then there's shoulder flexors, elbow flexors. So their right arm when they do this, in a four-year-old…there was a little four-year-old I saw today. I could not, with all my strength, overcome her right biceps but her left arm, I just did this. They're the same size.

APM: And do you grade this? Do you say —

NH: Yes. So it's done on the Oxford scale of five, OK? And five is normal strength. Four is strength against some resistance but it can be overcome. Three is antigravity muscles. So our children today, their inner range quads, the vastus medialis muscle in our children today is now generally weaker than gravity. If you ask a child to keep their leg up and tense up the thing and keep up like that…and I do that. I help their leg up and then I let their leg go. Their leg drops like that and they have a quadriceps leg. Even football players and 18-year-olds can't hold their leg like this but their mums can do it and they can't do it and that's because inner range quads is very weak. And then they end up with patellofemoral, you know…what we call chondromalacia patella. It's common now, 1 in 3 teenagers or even younger kids now have that and it's because of muscle weakness. So that means they don't have antigravity. They don't have grade three muscle strength in that muscle there. And yeah, so we grade it on the Oxford scale and that's what I was taught to do 28 years ago.

APM: And things haven't moved on since then in any way?

NH: Well —

APM: You’re probably…you must be at the forefront of this knowledge because —

NH: I mean very few people have been in that position where they’re examining joints and examining muscles but people now know about this, you know. People who work in the neuromuscular world know. It’s very hard, these days, to tell the difference between somebody, say, with muscular dystrophy or not. The boy I recently…I saw a boy with Becker muscular dystrophy and the way I told that he was weak compared to everybody else is when he bent…lay on his tummy and when he bent his knee, I could overcome his quads with one finger but I can’t overcome a four-year-old’s quads with all my strength now because their quads are still normal whereas this boy, at the age of 13 —

APM: Quads or hamstrings?

NH: Sorry, hamstrings. I overcame his hamstring with one finger and straight away did a CK. It was 10,000 and he turned out, from a biopsy, to have Becker muscular dystrophy. So it’s becoming that the only way you can really tell the difference between a normal and a person who has a disease is now through 1 or 2 muscles whereas before, it was easy, you know. A boy with Becker muscular dystrophy had 10 out of 22 normal muscles and everybody else had 22.

APM: I’ve just had a question which says what exercises then should we be recommending if sports isn’t enough? You’ve talked about quadriceps exercise.

NH: So what we do is we give them a general programme of exercise. A lot of schools, like his schools, take it on board and have started to build up children’s strength and start running —

APM: Do schools know about this stuff?

NH: Some schools do. We’ve been into schools and we explained it but also, where there’s been a child with that sort of problems, he goes into school and says, “Look, I only have five normal muscles in my body. All the sporting stuff we do,” which isn’t very much these days…and so the school’s introduced things like doing an exercise program like pilates, like physio sort of exercises and you have to build up specific muscles. If you just try and do it through sport, people aren’t pushed anymore. I always tell them, you know, when we did cross country, you know, you’d be running along and if the sports master caught you, take his whistle out of his mouth and you’d get it, you know. To get encouragement to —

APM: The good old days.

NH: The good old days, encouragement to run faster. Now they’re not even doing cross country, let alone being encouraged to try harder and push and push and push. So yeah, we’re at that level. People are —

APM: So actually, the multigym or the exercise equipment gym is a good place to be.

This transcript will shortly be replaced by a concise text summary.

NH: Very good.

APM: Because you can get target specific exercise. We're looking at muscles which aren't normally strong. Our hamstrings and calves, we can —

NH: Hamstrings and calves are strong in our kids.

APM: So quads —

NH: And right biceps and that's it. Ever other muscle group…yeah —

APM: Simply get them just to do their left biceps in the gym and —

NH: Yeah and hip extensors, you know, kids will lift their left leg up and I can overcome their leg with my little finger —

APM: And there are machines that they can use to train those muscles. So there's lots of —

NH: So for adults, it's definitely…gym is the way forward, yeah.

APM: And I have to say it's an eye-opener for you because I'd always said to people, don't go to the bloody gym. Just get out on the —

NH: It's important. If you're not of normal strength then you're in trouble, you know. Gym is important and, you know, people say to me, "Well, you know, how hypermobile is my kid? What are the degrees of hypermobility?" and what I explain to them is one thing. The people Cirque de Soleil are the most flexible people on earth and they are…none of them are complaining and have disc problems and leg problems and stuff. Why? Because they're also the strongest people on earth. So a lot of parents say to me, "Oh, you know, how hypermobile is my child?" It's not how hypermobile. It's how strong your child is is important because they can be the most flexible person on earth. If you're strong, you don't have trouble. It's an important message.

APM: I've been sitting on this question for a while. It said, "Do you recommend any medication or any other remedies? Are there any…". You might need vitamin D for other reasons but —

NH: No, vitamin D, they need for bone stock but other than that, no diet, you know, and if you do enough exercise, you can get kids' weight under control by burning as many calories as they eat. If a kid knows that, you know, a two-bar Kit Kat is 97 calories and that's 10 minutes on an exercise bike and then make a decision. "Do I want to spend 10 minutes on a bike or maybe I just won't eat that?" And, you know, for the future, that's important —

APM: Or make them cycle to the bloody shop to buy it.

NH: Cycle to buy it and cycle back, now you can eat it.

This transcript will shortly be replaced by a concise text summary.

APM: We talked about taping and strapping earlier on. Someone here has asked whether you recommend pelvic stability belt at all to prevent further joint strain.

NH: No.

APM: Even in acute cases of pain or…?

NH: I mean, you know, in acute cases…but you've got to be very careful because they become a crutch and the most important thing is to rebuild strength and stamina and if you can rebuild…if you do pelvic floor exercises and back exercises and pliates, starting very slowly, very, very slowly, you know, in a very, very gradual way then you can get on top of things. If you try and jump the deep end, you're going to drown but start slowly and build up but be very careful about outside things, you know. Not a big believer.

APM: Last one.

NH: Sure.

APM: We talked a lot about you testing muscles and so on. This question is…and again, I think it's just for reinforcement to what you said earlier on. If someone comes in with pain in a specific place, are you just testing the muscles in that area or are you going to go through the whole range of your 22 muscles —

NH: The whole range because kids come in and tell me they have leg pains, knee pains, ankle pains. They have Sever's, they have chondromalacia patella. I examine everything because they'll sit there with their shoulder higher than this with headaches. That's why I send people to osteopaths to get rid of this spasm and get rid of these spasms, get rid of their headaches. I examine everything. You know, I always say to a child, "When you write, does your hand get sore?" He'll say, "Yeah, my hand's sore. I can only write half a page and my hand hurts," but that never happened to us. We could write for three hours with no hand pain. Why? Because we actually had strength and that was a study done in Scotland 30 years ago. They did it with dynamometers, with handheld dynamometers. They gave us the levels of grip strength in children. We knew that a kid of 10 had 60 Newton or whatever it was of grip strength. They repeated the study two years ago. Our children's grip strength is now 1/3 of what was normal. When a 10-year-old squeezes your finger, remember, back to when they were one, it was harder when they were one than they now have at 10 because this and this does not build strength. So you have to build strength.

APM: So this is my final question which is my own personal one on the basis of…well, I have to say, it's been a really eye-opening, illuminating discussion because it's been…it wasn't what I was expecting at all and having our two guests here earlier on was a real treat as well. Do we need to refer people to you if we suspect this? Because you've told us, "Test the muscles." You've told us to make them do exercise and make them do their desensitization exercise. Is that enough? At what stage do we refer to an expert like yourself?

NH: Because what else could it be? You know, when you have allodynia, when you touch them with cotton wool and they're screaming in pain, that is all part of CRPS, of reflex sympathetic dystrophy. I have never ever seen anything- and people tell me, "We've been for nerve conduction studies and we've been for MRI scans." Really? Allodynia where you've got pain, where you can blow on a hand and it causes agony is only in this condition and then you know what it is and you know what to do. You couldn't have missed anything else because in all the years I've seen this, I've never ever heard or seen or, you know…not diagnosed with some neurological thing, you know.

APM: Perhaps the reassuring thing is…and it's a horrible reassurance is…the horrible reassurance is that they aren't going to like this. They're not going to enjoy this.

NH: No, of course not.

APM: But you have to push through it and —

NH: As he said, if you don't do it, you're going to be in that wheelchair forever And I've seen that.

APM: Doctor Hasson, this has been a real treat. Thank you very much.

NH: Pleasure, absolute pleasure.

APM: I'm glad we could fit around your diary and get you in this evening—

NH: Thank you for changing your day.

APM: --because this has been a real eye-opening talk and I'm sure there would be many more questions but we are going to cut it short —