

# Cerebral Palsy with Richard Luke, Scope and Karen Watson, CP Adult Advice UK

**Speaker Key:**

**CB** Chantal Boyle

**RL** Richard Luke

**KW** Karen Watson

00:00:20

**CB**

Welcome to the Sunflower Conversations. I'm Chantal, your host, and I have the pleasure of being joined by Richard Luke, from the charity Scope, and Karen from the charity CP Adult Advice UK. CP stands for cerebral palsy, and that is what we're going to be discussing today.

We are really, really fortunate to have both of them online to discuss the topics and the questions that have been put forward by the Sunflower community, so we will dive straight in. Karen is sunning herself in Spain at the moment, and Richard is freezing in Coventry. So we've got extreme weather conditions at either end, here. And I'm actually a little bit hot in South London, so there we go.

So, thank you both for joining us today. Both Karen and Richard live with cerebral palsy, so they're talking from lived experience but also within the profession of what they do. We're going to dispel some myths about CP. I'll be probably switching between CP and cerebral palsy throughout the conversations. So, welcome to you both. How are you?

00:01:38

**RL**

Thank you. I'm very well, thanks. Good to be here.

**KW**

Yes, thanks for inviting us here today.

**CB**

Right, so let's start with the first question, which is the most obvious. Richard, can you explain what is cerebral palsy, and why does it occur?

**RL**

Okay, so the NHS definition for cerebral palsy is it's a name given to a group of lifelong conditions that affect movement and coordination and balance. It's caused by a problem with the brain that develops before, during or soon after birth.

Now, the causes are likely to be multiple and complex, but some of the most common causes are exposure by the expectant mother to certain infections, viruses or chemicals, premature birth, around less than 32 weeks, low birth weight, less than 1,500 grams or 3.3 lbs, multiple births, so being a twin or a triplet, damage to the brain in the young child in its early years, and birth trauma. And birth trauma is described as anything that happens during the birth process that is unplanned for, so asphyxiation by the umbilical cord, or general foetal distress during the baby's journey down the birth canal.

**CB**

So any one of those things is not an unusual or uncommon thing that can happen during birth, is it, the trauma to the baby and the delivery, so what are the statistics? NICE report that globally the prevalence of cerebral palsy varies between 1.6 to 3.4 per 1,000 live births. How does that equate to the UK?

00:03:39

**RL**

In the UK, the generally accepted figure for people with cerebral palsy in the general population is 1 in 400, or 2 to 2.5 per 1,000 live births. So translating, that's approximately 1,800 children that are diagnosed with CP, cerebral palsy, each year in the UK population of 65 million at the time these figures were collated.

The adult population who lives with cerebral palsy in the UK is around 135,000 to 136,000, which is a figure comparable to similar neurological conditions such as Parkinson's and MS.

**CB**

Right, but you guys are here because you really want to shine a light on cerebral palsy, because I think when we spoke before, outside of this recording, it's that there really isn't as much awareness about cerebral palsy, and Parkinson's etc has a lot more awareness about it.

**RL**

It does. It does. My opinion on that is that non-disabled people can acquire Parkinson's and MS, and non-disabled people cannot acquire cerebral palsy. So they're very similar neurological conditions, but the way that somebody would acquire it is very different, and therefore, because cerebral palsy's treated as a

childhood condition, it gets less coverage than its more famous counterparts in the non-disabled community.

**KW**

That's exactly as I see it.

00:05:30

**CB**

I guess we'll come on to this, but one of the questions, and we see it a lot with children who have autism, or are diagnosed with autism, that there is some support, but then once they become an adult, the support seems to drop off. Is that the case of what you find with cerebral palsy? It's treated as a childhood condition, what happens when the child then turns into an adult? And what age does that switch-over of care change?

**KW**

Yes, absolutely. It is seen as a childhood condition, not a lifelong condition, and that is a huge problem to us. The support group that I run, it's a peer-to-peer support group, and we run over Facebook. We see a lot of adults joining us who are coming to us around 30, 35, because they're finding at that age that they then need support. They've gone from 16, 17, I'd say 16 or 17 is the drop-off point, but some are lucky, some go on into their 20s. But then it does end. There's just nowhere to refer them to.

**CB**

That must be so frightening.

**KW**

Unfortunately, it's not. And that might sound like a strange thing to say, but personally, as a teenager, when I was 16 and my consultant said, right, that's it, we don't need to see you anymore, everything's done, goodbye, go and get on with your life, I was delighted. I thought that was great.

And I'm thinking, if this is it, I can cope with this, I can get on with it. Ditched the splints, ditched the crutches, I didn't need them anymore. And then, in my 30s, when things started to go wrong, that's when you realise, hang on a minute, I've missed out on a whole chunk of things that I perhaps should have been doing.

00:07:25

**CB**

Yes, care and provision. And actually if you'd had that, do you feel that the symptoms and your health would not have been as severely impacted?

**KW**

I think so. There's no guarantee of that, but I do think so, yes.

**RL**

Yes, I have to agree with Karen, because I remember it like yesterday, where my consultant said, we don't need to see you anymore, and I was like, thank god, no more physio, no more stretching, no more smelly mats, no more being told what to do.

And off I went. Because we were told, and our parents were told, cerebral palsy does not get any worse. And we thought, great. And just like Karen, I thought, well, if this is the level I stay at, I'm going to have a sweet life, I can cope with this brilliantly.

And while they're right, the brain injury that causes cerebral palsy doesn't get worse, I hate the phrase but doesn't get worse, the effects of living with a physical disability on the body change over time. So I think if I'd have had ongoing input from a medical professional, a physiotherapy professional, I would probably still be in a wheelchair but not as quick as I was.

**KW**

Yes. I think I would have rebelled, to be honest. I think I would have said, at that age, I don't want this anymore, it's my decision and I don't want it. But looking back... And I think that's a message, and important message to get to teenagers, today's teenagers, just think of your future. Because I really wish that I'd taken it more seriously when I was younger. I don't want to scare anybody, I'm just being realistic.

00:09:22

**RL**

And it doesn't have to be something formal, like going to see a physio. Just keep swimming. Keep swimming.

**KW**

Yes, or cycling, if you can ride a bike. I used to ride a tricycle. I couldn't balance a bicycle but [overtalking].

**RL**

Yes, it could be something fun, but just remember for every hour you're on Xbox, do an hour on a bike.

**CB**

I think that is a key nugget, there, definitely. Exercise and movement doesn't have

to be really arduous, does it? It can be something that's enjoyable and pleasant, you can still play over [?] Xbox, and you will reap the benefits, physically and mentally, from that.

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So, let's talk about the range of associated symptoms are, what the misconceptions are about cerebral palsy. So, I guess if we can start off with what the symptoms are, presumably your symptoms are different to Karen's symptoms?

00:10:37

**KW**

I was just going to say, I think everybody's symptoms are different. We are all different. We've got a community of almost 2,000 members now on Facebook, and we're all different. But basically, the stiffness, spasticity, weakness, a combination of both, which can be quite confusing.

Because I've only recently learnt that muscles that I thought were stiff are actually weak. So the movement that I'm trying to do, I'm thinking I'm fighting against stiff muscle, it's actually weakness.

**RL**

We're all very, very different, but we're all given these labels that we sort of fit under, medically. So you have different types of cerebral palsy, so you have spastic, which is tight muscles, which is the type that Karen and I have, you have ataxic, which is a mixture between stiffness and blockiness of muscles, which makes coordination of movement extremely difficult, and you have athetoid or dyskinetic. That, again, is all about the movement control, and that can sometimes affect the facial movements, swallowing and verbal communication too.

But alongside that, you've got a range of associated symptoms, because cerebral palsy is a neurological condition, and we know how complex the brain is. For example, if you knock one bit out, it's going to have a follow-on effect on another part of the brain.

00:12:14

So with that in mind, 86% of people with spastic CP, tight muscles, will have epilepsy. 1% or 2% of people with CP have a hearing impairment. 10% of people with CP have a visual impairment. 25% of people with CP have some kind of learning difficulty, which means 75% don't, it's important that we remember that. But we'll get onto that later on.

Mobility, a third of us in the CP community aren't able to walk. And there are

other issues that are really hard for medical people to identify. And sometimes, and Karen will attest to this, people with CP themselves won't realise they're living with these additional issues. So visual perception, distinguishing between and comparing shapes. Visual, motor and spatial awareness, so combining movements with vision, such as hand-eye coordination, and short-term memory and memory retrieval. A lot of people don't realise and they just struggle on. And so...

**KW**

Yes, because it's normal for us.

**RL**

Yes. I see that such a lot. Really, really capable, educated, successful in the world of employment people with cerebral palsy contact me and say, I think I'm getting worse, I think this is happening, I'm struggling and having to write things down more. And I say, okay, yes, one, you could be stressed and tired, two, we're all getting older. My best friend is a Post-it note. Or three, you've probably never noticed it but you've had it all your life.

**CB** Yes.

00:14:14

**RL**

And what I do, I work with them to tease out what it could be, small, little life changes. And if they get more sleep and are more relaxed and they start meditating or mindfulness, and that helps, brilliant. If it doesn't, then we can explore the other route. Is it something that you've had all of your life but have never realised it because you've never been in a pressured environment where memory retrieval has been so key to what you were doing?

**CB**

Yes, so it's really working with people on an individualised basis.

**RL**

Yes.

**CB**

I guess that kind of brings us on to the misconceptions, because you've covered a lot there, and the different types. And excuse me if I don't say this correctly. Just to recap, you've got spastic CP, which is tight muscles. You've got ataxic, as you say, atathetoid.

**RL**

Athetoid.

**CB**

Athetoid.

**RL**

Athetoid.

**CB**

Athetoid. And then dyskinetic.

**RL**

Yes. That's the modern word for athetoid. I do that because some people watching the podcast might think, well, I was told I'd got this. They change the terminology a lot. So now, instead of saying, you're complex or mild, they'll tell you what number you are on a scale. When I deal with new parents and they contact me, they'll say, my little boy or my little girl is a three. And I thought, what the hell does that mean? And they're raising their own children.

00:16:06

It's a thing called the gross motor function classification system. What that does, tells you the level of mobility and body control a person has. I'm a level 3, for example. It's supposed to be used to help plan future support, which is pretty good because it gives the person and the parent, or the partner, an idea of where they're at.

It's not an exact science, Chantal, as you can imagine. You can't really pigeonhole people and say, well, you're a two. So obviously, one is very mobile. I should have explained it. So, for example, you can walk up and down stairs holding an object so that's very mobile. Five is not very mobile. You need a lot of support. You need a lot of additional equipment, maybe a power chair, maybe an Eyegaze. Maybe you're non-speaking or non-verbal. The three's between. But people can fluctuate between them. You know?

**CB**

Yes.

**KW**

Even on a daily basis.

**RL**

Yes.

00:17:27

**KW**

Some days I'm a lot better than others.

**CB**

What do you find are the misconceptions about CP?

**KW**

One thing that really, really gets me, and it has done since childhood, because I went to a school for children with physical disabilities. That type of education doesn't really exist anymore. It wasn't special educational needs. It was just for physical disabilities. Some of the children at my school was non-verbal. I've gone back to the 60s now. Showing my age now.

At that school I had a friend who was non-verbal, but even as a child, I recognised that she knew what was going on. She didn't have learning difficulties. The teachers, unfortunately, didn't recognise that at the time. I see this even more now with people who join my group. But luckily, now we have the Eyegaze that Richard just mentioned so they do have a method of communication. Through that they can communicate to us just the same as we are, really. It takes them a little bit longer.

It's just a misconception that, because they can't speak, they've got no understanding and that really does annoy me because it's very often isn't true.

**CB**

I think Richard mentioned before that only 25% of people with CP have a learning disability so that plays into what you're saying in that the comprehension, understanding and intellect. Would you agree, Richard, then, that that is a misconception that people assume that if you have cerebral palsy, the intellect is...

00:19:15

**RL**

And of the 75% that don't have a learning challenge, the majority of them are of above average IQ so I will have to agree with Karen as well, made a point there. I think it's not just opposing things. I think a lot of the disabled community face a lot of these assumptions that obviously you've got learning difficulties or the person you're with is your carer or your PA.

**KW**

Yes, I get that as well.



**RL**

I get loads as well, especially when I'm out with my wife. I think Karen's point's a good one, though. That one, for me, really sticks out. People assume that you don't know what's going on, when nothing could be further from the truth.

**CB**

How does it make you feel when these wrong assumptions are made about your partners and when you're in public by strangers?

**KW**

Well, I see the funny side of it, to be honest. My husband's very good at ignoring people that are talking to him when they should really be talking to me. He'll just stand there like he's not there because they're not speaking to him either about... One example was, I ordered a cooked chicken at the deli counter in Tesco's and the lady got the chicken, put it in the bag, and handed it to Chris. He just stood there looking at her and she said, here's your chicken. And he said, I didn't ask for a chicken. My wife did. He's very good at that.

It can be annoying. I think you've got some even better examples than that, haven't you, Rich?

00:21:02

**RL**

I've got a few. Is it a family podcast? When I was younger, it really used to get under my skin, I'm not going to lie. I think one of the best things about getting older is you don't really care as much because you think, well, you can think what you want but my wife and I. I know if someone said that to her when we were out and about, she just absolutely lay one on me, a big French kiss in front of them and just really [unclear]. They don't understand with that sort of thing. No reason to, it wasn't appropriate to do that.

We've had it all the time where, I've paid for something and they give the change, when we used to use money, they give the change to my wife or recently, they give the change to my daughter.

**CB**

It's just so insulting, isn't it?

**RL**

It is because my daughter won't give me the change back. She'll [inaudible].

**CB**

I'm coming out with you, dad.

**RL**

Yes. She calls it the dad tax.

**CB**

Sensible girl. You could correct me if I'm wrong but I believe that's part of the reason Mike Adams created Purple because he would go out with his wife and shop assistants or whoever would be talking to her instead of him. It was one of the things that really rankled and he, I am your customer. I am the person who is spending money here so please give me the respect of actually talking to me.

00:22:53

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We've got a lot of questions and I am conscious that we're halfway through this already. What I'm going to do is I really want to make sure that we the questions from the Sunflower Community. Just before we go on to that, I just want to ask you what you think about the Sunflower and if you feel it's a valuable tool to support people, who have CP feel more confident in public spaces? Richard, if you want to answer that, that'd be great.

**RL**

Yes. I think it is very valuable because, as I've explained, cerebral palsy is a very broad condition. You will have people that are, if we go back to the gross motor function classification system, who are a grade 1, so very, very mobile. It might not look like they've got any physical condition or impairment at all. Having the Sunflower allows them to feel confident that their needs will be easily identified because everybody recognises the Sunflower lanyard.

I think, for people with very mild, in inverted commas, CP, it is really, really useful but Karen's got a better example than that, that I had never thought of so I'm going to hand over to Karen.

**KW**

I'm not sure which one you're talking about here but when I met you guys at Naidex, I was aware of the Sunflower but I didn't think it applied to me because, obviously, my disability isn't hidden. I'm in a power chair. But after talking to Paul [?], I think it was, the TEO [?] webmaster, I realised that when I'm in a vehicle, my disability is hidden. So, we now have Sunflower on the back of the motor home and also on the back of the car.

00:24:56

Last night I was giving this some thought for today and I was thinking back to when I was younger. I was a teenager on a bus with my mum and the bus was really crowded. Somebody came to me and said, you should stand up and let this

elderly lady have your seat. I was about 14, 15 at the time. Very, very embarrassed. Very, very conscious of my disability, although it was mild at the time. I could walk, but aided. I couldn't walk very far and I was a bit wobbly. But I didn't have any aid.

My mum said to me, you stay there. I said, no, I'm going to stand up because now there's going to be a scene. So, I stood up on the bus, and I was holding on for dear life as the bus was driving round the corners and the elderly lady sat down. The lady that sat down, she was all apologetic. The person who asked me to stand up was apologetic but, as a stubborn teenager, I was determined, I'm going to stand up now, because I can.

I think if the lanyard had been available back then, that would have been [unclear]. I could have sat there without worrying. [Overtalking] people are thinking, why have I not stood up for this lady?

**CB**

One could imagine that being on a bus is actually quite a dangerous scenario for somebody who has mobility issues. They jerk around. No offence to bus drivers, but quite often you have the brakes being put on sharply. You've got the hustle and bustle of people getting on and getting off. It is not a relaxing journey and sitting down is definitely the safest option.

00:26:39

**KW**

Yes.

**RL**

Absolutely right.

**CB**

That's the misconception, again isn't it, that young people can't have a disability?

**KW**

Yes.

**RL**

Yes. Can I just add in a bit about attitudes towards cerebral palsy? I get less stares now because I've let my grey beard grow out so I look like the age group that would be in a wheelchair.

**KW**

Yes. I think that as you get older, the wheelchair is more accepted.

**RL**

Yes, absolutely. That's really good point that Chantal raised that. I think, when you look the part, people don't tend to look.

**CB**

Yes, which is why the sunflower plays a vital role, I guess.

**RL** It's really important to the whole disabled community. It's such a valuable tool that we've got.

**CB**

I am going to move on to the questions from the Sunflower Community. Some of the questions I had already incorporated in the ones that we've covered but here are some more. Question one, what age can children be diagnosed and what is the process?

00:27:56

**RL**

Usually, it's from about 18 months all the way up to three years old but it can happen a lot later, depending if there are co-existing issues within the child so a diagnosis of cerebral palsy is more of a process. It relies a lot on health visitors and midwives and observations and, of course, the parents noticing. The child is probably not in those standard milestones that we would expect.

For a new parent, if it's your first child, it's quite worrying so that's why it's really, really important to have a good team around you, a good GP, a good health visitor, a good midwife. A lot of times though, we see cerebral palsy getting diagnosed a lot later because it is quite mild in some cases. I know Karen's had this. We've had adults come, about 50, mid-50s particularly, to me. They've just received the diagnosis.

Now, I don't know whether it's because their CP is so mild, it got missed or whether there was a little bit of stigma and taboo within the family.

**CB**

What age did you find they're coming to you?

**RL**

Around mid-50s.

**CB**

Wow, that is late.

**RL**

Yes. They usually come to me and say, I've been told, or, I was clumsy all my life, and they were dropping things. They were falling over a lot. They couldn't run like their friends at school and their mum and dad said, oh, don't worry, you're just clumsy. All the teachers were horrible and called him, clumsy. And then they go to the doctor, and the doctor would say, well, Mrs or Mr So-and-so, you do know you've got cerebral palsy, don't you?

00:29:55

Back then, even when I was born in 77, disability was huge taboo. You didn't share with your neighbours, this is Richard. By the way, he's got cerebral palsy. You just didn't do it. I think that's reason why. It's a process. You can use MRI scans, which they do use now, but it is not a magic ticket. It needs a team of professionals around them that know what they're doing because it can't always see the area of brain that has been damaged.

It's very dangerous that we're putting so much faith in these tools, which are brilliant, but they need to be used as a toolbox. A tool in a toolbox.

**KW**

Yes. I couldn't have an MRI scan for my diagnosis. Obviously, I was born in 1962. There was no MRIs then. But I had to have a brain MRI in 2009 for another condition. They came back to me and said, you did say that you've got cerebral palsy and I said, yeah. It's not showing on the scan. So my CP didn't show up on an MRI.

**RL**

They can't always see the area of damage that the person sustained. Then I have a lot of people coming back to me who have been on this huge, long diagnosis journey with paediatricians, GPs, and health visitors, and physios that said, your little one has got cerebral palsy.

They get booked in for an MRI, have the MRI. The MRI operator comes back and says, no, there's no damage to the brain. And then, oh my God, what's wrong with my baby? And then the GP looks at it, says, no, they haven't got cerebral palsy, when they have. The MRI just didn't pick it up.

00:31:59

**CB**

Well, the next question, actually, is, my son has all the symptoms of CP. Only mild but they're finding it hard to get a diagnosis. Have you got any advice for them?

**RL**

Yes. Get a referral to a good paediatric neurologist. I know it's exhausting and I can imagine what situation they're in. And it's tiring and emotionally draining but you've got to fight your corner. You've got to demand second opinions because what they need to do, it's not hard to identify. It's a process of ruling stuff out. Sometimes FND, functional neurological disorder, can look a lot like cerebral palsy but it's different. You [overtalking] at the same time by going in too deep into that.

You've really got to fight your corner so get a good paediatric neurologist. And you need a period of observation so if the child is at school, any reports from their teachers or SEND support workers about dexterity, about ability to write, ability to pay attention, anything. When I say, a team of observation, I mean it. You need everyone that's involved in that child to be able to state what they're seeing and what they're noticing on a daily basis. You've got to fight your corner. Get a good neurologist to really, really see it through.

00:33:36

**CB**

That's really good advice. I heard another parent talking about that with something else. But, again, the diary from the day at school was different to the diary from the evening when they came home and so getting that 360 was really important to get the whole picture of that individual. So, that's really great advice. The next question is, can you get diagnosed with CP as an adult? Thinking about somebody who's not on their records from whenever, from before, what would the process be?

**RL**

Again, go to your doctor, list everything you're experiencing, and ask for a referral to a neurologist, who will then send you for an MRI. Now, it might pick something up but I think, generally, if you're an adult and you're experiencing that, get your GP to have a deep dive into your medical records. Because more often than not, your diagnosis is already there. And whether your loved ones have chosen to share that with you or not, that could be the reason why you don't know that you've got cerebral palsy.

**CB**

That's really interesting. That's going back to the shame and stigma associated with disability, isn't it?

**RL**

Unfortunately so.

**CB**

Then, this question here, which is really great. We touched on it earlier. Is there

something you wish that society knew about cerebral palsy to help stop stigmas?

**KW**

I would just say that society, and the NHS, and the government all need to recognise this as a lifelong condition because that is a major, major problem for the adults. Richard covers CP from birth but the people I'm involved in, I'm only involved in the adult community, obviously. It's a major problem to the adult community. It's almost like we shouldn't have CP as an adult because it's just not accepted that it's a lifelong condition. It sounds bizarre, but that is just how it feels.

00:35:45

**CB**

What comments do you get, then? Like, how come you're still ill? How come you still got CP?

**KW**

Yes. We've had that recently. We've had doctors say that to people recently. How come you've still got CP? Another lady, recently, was in hospital and was asked, well, how did you manage to get that then? You don't get CP. This needs a medical professional. Richard and I, we speak to student nurses and hopefully soon we'll be speaking to medical students to try and educate them. That's how bad things are, really. It's just not recognised.

**CB**

Is that because it's covered in, if you're going to be doing paediatrics? That's children's-focussed, isn't it, medical?

**RL**

Yes.

**CB**

Is that because it's not covered in general practitioners' training?

**KW**

It is. It's only touched on. Tiny. It's only touched on small, isn't it, unless they go into orthopaedics, or neurology, or whatever. I met a doctor recently at Nottingham University and I was having a chat with her. We both come to the conclusion. Basically, we've had so many doors shut in our faces. We go to physiotherapy and we get discharged because there's nothing they can do.

00:37:07

We get referred to consultants and the consultant says, well, now you've got CP. You're doing quite well, really, for an adult with CP. There's nothing I can do to help you. We get so many doors shut in our faces, that we don't bother going looking for help. And we're hearing this more and more now. I've given up asking for referrals because it gets me nowhere anyway. And what can they do? They might give me six weeks' physio sessions and that's no good to me so I don't bother asking anymore.

I don't want to go into orthotics because they never fit. They never work. The splints are not comfortable. And so, consequently, doctors are not seeing adults with CP very often because we don't go. You see what I mean? [Overtalking].

**CB**

The whole CP community is being marginalised out of existence. It's not a problem that needs to be dealt with.

**KW**

Yes, because it can't be dealt with, but in reality, it can. We know that it can. We're also involved in research. Richard and I get involved in as many research projects as we can to try and make a difference in the future.

**RL**

We do.

**KW**

From the research that we've been doing, quite a lot with Nottingham University, but we are finding that things can be done. We can be helped. But we're having the problem now [inaudible]. We're having a problem now convincing the adult community, themselves, that they can be helped.

**CB**

Oh really?

00:38:39

**KW**

Yes.

**RL**

A lot have given up. Just to add a little bit to Karen's point, depression and anxiety is 41% higher in the cerebral palsy population compared to the general population. And a lot of that, I think, is because you feel like you're going mad because you go to the doctors and you say, this is happening and that's happening, and they don't help you or can't help you or won't help you. So, you



then go home and don't try again. You just get lower, and lower, and lower, and lower, thinking, people think you're making it up when you're clearly not.

The main issue for me is the NHS as well. Officially defining cerebral palsy as a childhood condition means that, at 16, there's nothing so we need to get that changed and we're working on it to get it changed to child onset condition. That one word is so, so important.

**KW**

Yes. So, really, in answer to your question, it's more the NHS than society. Do you agree with that, Richard?

**RL**

Yes, because where did you go when you need help to keep yourself healthy and fit so you can work, go to uni, have relationships, hang out with your friends? If that fails you...

00:40:16

I need to add this in very quickly as well. The socio-economic disparity in the CP community is huge as well. If you're working class, or from a working class. Or lower socio-economic background or family, your experience of living with cerebral palsy is like night and day compared to somebody that's got the money to get the best equipment, the best therapy, the best doctors. It's like night and day. So, there's that disadvantage as well because the majority of us are good old working-class lads and lasses.

**CB**

To know that there are things that can be done is quite heartbreaking. You're making inroads, are you?

**RL**

Absolutely. Slowly

**CB**

Is there anything that the community can do to help support what you're doing, to get the endeavours achieved any greater or are there any petitions or things that people can join to support?

**RL**

I would say join groups like Karen's group, if you're an adult. If you're a parent or family with a younger person with CP, i.e., under 18, join up with me on Scope. We all work together anyway. But join these groups. We need your voice. We need your e-mails. We need your passion. We need your anger. We need to all

direct it in the one space because I'm a bit of a big gob but I need all the help I can get.

**CB**

Well, the voices of many is greater than the voice of one.

**KW**

Exactly. Together, we can make a difference.

**RL**

We can.

00:42:16

**CB**

Yes. That's great. I've got a couple of other questions. I know that we've had quite a long conversation, which, to be honest, it's gone really quickly. I wanted to ask, what is the education and employment situation like for people who have CP?

**RL**

I guess this one's for me. The main issues that I see through my work supporting families of children with cerebral palsy is issues with SEND's provision. And getting the schools and local educational authorities to adhere to what is in the educational health care plans of the child. This becomes more acute when the child then transitions into secondary school. That is where the system quite often just completely disintegrates and the families are left there trying to fight for what is their legal right.

They don't just make up these educational health care plans out of thin air and think it's a good idea. So, that's one of the major issues at the moment. At university and further education, it's slightly better because, obviously, the person living with CP is slightly older and is able to advocate for their own needs as well.

There's great disability student associations at unis and UCAS is very helpful during the initial application process as well. The form will be filtered and if you've put that you live with cerebral palsy or physical disability, you'll then be fed into the disability team of the institution where you wish to study. So that works slightly better. But that is the major issue in education, is getting these local educational authorities and schools to adhere to the educational health care plans of the child.

00:44:23

In terms of employment, there isn't much CP-specific data so I can speak in

general terms around disabled people in the workforce. The employment rate of disabled people is 53%, compared to 82% of non-disabled people. Disabled people are twice as likely to be unemployed and three times as likely to be economically inactive. We call this the disability employment gap at Scope. And that is 29%, and it measures the difference between the employment rate of disabled people, compared to non-disabled people.

So, there's a lot of work we still need to do, as a society, to utilise the talented people we have in our disabled community, including the cerebral palsy community, because it's such a waste. We've got these brilliant people that can't get a foothold and help make a difference in our society.

**CB**

Yes, it makes absolutely no sense, does it? It makes no sense when you think about it rationally and sensibly. And so much more could be achieved, and, yes, socially, economically, it would be good for the country. It's obviously going to be good for the individual, and just being excluded like that, well, it's a crime. I just wanted to go back to the EHCP. It's a legal document, is it? They should be following these plans, the educational institutions where they are, whether it's a school, college or university?

**RL**

They should, yes. And what often happens is, the local education authority or the school will try and dilute what is in there. They will try and say, oh, well, we don't need that, we don't need that.

00:46:43

And the problem, from a cerebral palsy perspective, one aspect of it that's really important is, the child could have physiotherapy built into that educational healthcare plan. So, instead of, maybe, one lesson a day, a physio would come in and do stretches and activities and physical activities. Some schools are great with that, and particularly in primary school, they'll incorporate that into a fun lesson where everyone does a little bit of boogying or a bit of stretching. But a lot of schools, they think it's more work for them.

Well, of course, they're not doing their therapy. But I do understand that councils are under financial pressures, but this is a child's life and a child's future, and if we can't make that important, then what are we doing?

**CB**

Exactly. Nobody is more important than another, and all children should be nurtured and cared for. That's just how it should be. I have my final question. what support is available from Scope for individuals with CP?

**RL**

Okay, so the support I offer via Scope is the Cerebral Palsy Network, and that is an information-sharing area on the Scope website and the Scope online community. I also take direct referrals from our helpline to help people get in touch with referrals they might need, dating and relationships or access to equipment.

00:48:30

I also put them in touch with Karen's group because, I think, working together and collaboration is the way forward. Scope also has employment services that can help people that want to start looking into the world of work, or they need support staying in the world of work, or they want to go back to the world of work. So, we are a helpline for benefits. We are a disability energy service. We do the whole range, really, and if anybody wants any support or any help, please, drop me an email, and I will do what I can.

**CB**

Fantastic. We will put all of the details in the show notes. Karen, did you just want to give an overview of what people can expect from the Facebook group that you run?

**KW**

We run a Facebook group. It's a peer-to-peer support, so the members just support one another from their own lived experience, which is absolutely vast. Their knowledge astounds me some days. So, yes, we've got that. We also have subgroups. So, we've got a ladies' group. They can talk ladies' problems. The men's, the men, they're not very good at it...

**RL**

We're not.

**KW**

But we do have that availability. We also have a group for parents, not parents of children with CP, but parents who have CP themselves. It's only a very small group, but it's a really valuable group. So, they can help each other. Will this work for me? And I did that, and that's how I carried the baby, and what have you. So, yes, that's, basically, what we do. We have a weekly Zoom session, where people can come and just have a general... And the ladies' and the men's also have a once-a-month Zoom.

00:50:25

**RL**

You forgot the football group. We, basically, take the Mickey out of each other. That's all it is for really.

**KW**

Yes, it's just a bit of friendly banter from other people who possibly love the game and can't get to the matches, or can get to the matches, and then they can share their experience with others. Do you want to say something about the Leeds Hub?

**RL**

So, what we're doing, Scope is expanding the Cerebral Palsy Network service, and we're recently opening the Leeds Community Hub. So, that's a premises in Leeds that is going to be a dedicated space for disabled people and people with cerebral palsy. And I'm going to have a brand new colleague, who will be the cerebral palsy information specialist covering Leeds and the North. So, we're trying to expand our service out across England and then into Wales if it's a success.

Kind of, a prototype service right now, but I think it will be a success. We're going to expand it as far as we can.

**KW**

I think it'll be great that people can actually go in, person-to-person, because since COVID, that's something that's definitely coming out. We've got people with CP in their 40s and 50s who've never, ever met another person with CP.

**CB**

Really? Right, okay.

**KW**

Yes, so it's important. I've never experienced that because, like I said, I went to a special school, so I've got lots of friends with CP. So, that's something a bit alien to me, but people need to actually meet, face to face, with other people with their condition.

00:52:04

**CB**

For sure, definitely. Well, that's great. So, we'll put the links into the show notes. Thank you so much, both of you, for your time. Karen, continue enjoying your holiday in Spain.

**KW**

Thank you.

**CB**

And Richard, put another scarf on or something. Keep warm.

**RL**

Will do.

**CB**

If you are concerned about any of the subjects discussed in the podcast, please, follow up and seek support from your healthcare practitioner. If you enjoyed this podcast, please, share it, leave a rating and review to help raise awareness of non-visible disabilities and the Hidden Disabilities Sunflower. You can also follow and subscribe to the Sunflower Conversations Podcast.

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