

## ME/CFS and Long Covid with Russell Fleming, ME Association

### **Speaker 1:**

Welcome to the Sunflower Conversations where we explore the Hidden disabilities Sunflower and its role in supporting people with hidden disabilities.

### **Chantal Boyle:**

Hi, I'm Chantal. And joining me on the Sunflower Conversations today is Russell Fleming from the ME Association to talk about ME and chronic fatigue syndromes. Russell has lived-experience, as well as being an employee at the ME Association. So, hi, Russell. Thanks for joining me today. How are you?

### **Russell Fleming:**

Thanks for having me. I'm very well, thank you.

### **Chantal Boyle:**

So, let's just start off, can you tell us the main symptoms of ME and CFS, and how debilitating is it?

### **Russell Fleming:**

So, myalgic encephalopathy, or myalgic encephalomyelitis, there's two main names for it, is also known as chronic fatigue syndrome, and chronic fatigue syndrome doesn't really do it justice because it focuses on chronic fatigue when there are a lot of other symptoms present. And patients tend not to like CFS for those reasons. It's rather like if you call dementia, chronic forgetfulness syndrome, it doesn't really do it justice.

At the end of 2021, the National Institute for Health and Care Excellence, or NICE, published a clinical guideline on ME/CFS. We fully support the recommendations in the guideline, and it provides a framework to the NHS and to Social Care Services on how they should diagnose and look after people with the condition.

So, the four main symptoms for suspecting ME are, debilitating fatigue that is worsened by activity, post exertional malaise after activity in which the worsening of symptoms is often delayed by hours or days, unrefreshing sleep or sleep disturbance or both, cognitive difficulties, which are sometimes described as brain fog.

There's also other symptoms that can affect a person's ability to function normally, and it can affect people very severely. So, people with very severe ME tend to be bedbound all day, they don't have the energy to get out of bed, they're dependent on care 24 hours a

day, they will need help with personal hygiene and eating, they can be very sensitive to external stimulations, so noise, light, in particular. Some people may not even be able to swallow, and they may need to be tube-fed-

**Chantal Boyle:**

That sounds debilitating.

**Russell Fleming:**

It is. And people in that condition can literally waste away in front of their friends and families' eyes. Severe ME, people may be able to carry out minimum tasks only such as facial washing or cleaning of teeth. They're likely to have severe cognitive problems, and they may depend on a wheelchair to get around. They're often unable to leave the house, or if they do, then they suffer a prolonged after-effect. They may also spend a lot of time in bed, and again, are extremely sensitive to light and sound.

Then, you have people who are moderately affected. So, we've gone from being unable to do pretty much anything for yourself if you're very severely affected, through to severely affected, now we're at moderately affected. People with moderate ME will have, again, reduced mobility, very restricted in anything they can do. So, the normal daily activities that healthy people would be able to manage, moderate people would not.

However, they may well have peaks and troughs in their abilities throughout the day or throughout the week. They're still likely to have stopped work or be unable to attend school or college or university, and they will often need to rest in the afternoons. Again, sleep at night is generally poor and quite often disturbed.

Then, you have people who are mildly affected by ME, and it's a bit unfortunate that we categorize them as having mild ME because it implies that it doesn't affect them to the same extent as other people in the other categories, but it still has a big impact on their lives. And you may find people with mild ME are able to work or to go to school, college, register for school, college or university. But a lot of the time it will be part on a part time basis.

Then, when they come back from work, they'll be crashing out in their home lives, and they'll probably use the weekends to crash out as well just to try and regain some of that lost energy so that they can go back to work in subsequent weeks. Then, it still impacts their leisure and social activities.

So, you quite often find that they focus their limited energy in a particular direction, and then everything else around it stops or is reduced. So, that's more or less an overview of where we are with symptoms.

**Chantal Boyle:**

Well, that's the thing, life is about balance. So, if you're having to save all of your energy for your employment or education, then there's no balance, is there? There isn't room for the

leisure activities that bring joy and are good for your nourishment, for your mental health. So, it's a post-viral infection. We're not born with it or is it something that's dormant in us?

**Russell Fleming:**

So, for the majority of people, they can trace the onset of their ME to an infection of some sort, and it can be any infection from the most common is a viral infection, Epstein-Barr virus, which is glandular fever to most people, or mononucleosis, and you tend to get that as a teenager. And that accounts for the largest onset, the biggest trigger.

Unlike everybody else, a certain percentage of people just don't get back the health that they had before they got the virus. So, that's what we mean by post-viral fatigue syndromes, and that then develops into a diagnosis of ME/CFS at around the three-month mark. If people haven't gotten better, then they get diagnosed with ME/CFS, ideally.

And unfortunately there's no specific treatments, there's no cure. It's a question of learning to live with the condition, which can mean having to make quite drastic changes to your life, to your lifestyle. But for other people, they can't figure out what might have triggered it. So, there's still some uncertainty, while it seems to be infectious for most people, and we've seen it in a big array of different infectious triggers.

So, there's some susceptibility in people, perhaps. Perhaps it's a genetic thing. We don't know. It seems likely that that genes play a role. We also see, within families, that more than one family member can get ME, so-

**Chantal Boyle:**

I was about to ask you that.

**Russell Fleming:**

Yeah. So, you can get a mum has ME, and then children who develop ME. Again, we don't know if they're born with this susceptibility, but it doesn't seem that both the mum and the children get it at the same time. We've also seen, in families, in fact, one of our trustees at the charity, Nikki, her two children both got ME.

**Chantal Boyle:**

Really?

**Russell Fleming:**

Yeah. And you're seeing it, as well, with Long COVID, which we can come on to talk about a bit.

**Chantal Boyle:**

Yeah, that's what I was going to ask you. So, I've read that there are now more people with Long COVID than ME.

**Russell Fleming:**

Yeah. So, the trouble with ME/CFS is that it's never been properly supported by the government or the NHS, and we really don't know how many people have ME. The research that has been done in this area, some of it's been reasonably good, but it's not comprehensive enough. So, we think that there's at least 250,000 people with ME, or with the symptoms of ME, in the UK. But that's a drop in the ocean, isn't it, When you're talking about 2 million people with Long COVID.

**Chantal Boyle:**

Yes, yes. And the symptoms are basically the same?

**Russell Fleming:**

Very similar. I'm looking at the Office for National Statistics' latest report on Long COVID, which was February, and they were saying that about 1.8 million people had Long COVID after a COVID infection 12 weeks ago. So, that seems a reasonable figure to use. But 1.8 million compared to 250,000 for ME, you can understand why all the resource and effort has gone into better understanding Long COVID.

But what we're now finding, and I was at a big Long COVID conference last week, we're now finding that Long COVID researchers and clinicians are being more engaged with the ME community to try and learn from us, because the management of Long COVID is very similar, if not the same, as it is for ME. So, it's all about activity management and pacing, learning to live with the condition.

And research as well, they have been looking at the ME research to see if they can find similarities and differences with Long COVID. And I think, as we said before before we started recording, I think more clinicians and researchers are coming round to thinking of Long COVID as a post-infectious fatigue syndrome, which is what ME has always been classified as, a neurological illness, a disease that primarily affects the nervous system. But we've got to see where the research takes us.

Interesting, you mentioned similar symptoms. So, with Long COVID, debilitating fatigue was the most common reported symptom according to the ONS report. 71% of those who reported Long COVID found that debilitating fatigue was their number one issue, and this was followed by difficulty concentrating, which is the cognitive problems that I referred to earlier as being one of the diagnostic symptoms of ME.

Then, it was shortness of breath and muscle ache. So, muscle ache, again, the same as with ME, shortness of breath, well, we know that COVID-19 particularly attacks the lungs. So, we know shortness of breath is a consequence of having lung damage. So, that's quite unique to COVID-19 when you compare it to ME and to other viral triggers.

Other viruses also have unique aspects. So, I don't think it excludes Long COVID from being thought of as a post-viral fatigue syndrome. I just think that Long COVID has more similarities with ME than it does differences.

**Chantal Boyle:**

With COVID being a very new and recent pandemic virus, it's still, obviously, in circulation, it's going to take some time before researchers and scientists are already to remove the separation and banner it under ME. Presumably, there's so much more research to be done into that virus. As each infection happens, the virus mutates a little bit. So, do you not see that the funding pop encompassing ME for a little while yet?

**Russell Fleming:**

Yeah. Another interesting thing to come out of recent research about Long COVID is that half of the people with Long COVID do fit the criteria for ME/CFS. So, if we're talking 2 million people with Long COVID, then we could potentially be looking at a million people getting a diagnosis of me at some point. So, there's still this confusing area.

I know personally that some GPs are now seeing people who they've diagnosed with Long COVID who haven't got better after two years, and they are now re-diagnosing them with ME. So, I think there's a bit of confusion now, and I think the NHS need to lend some clarity to the diagnostic procedures.

**Chantal Boyle:**

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You said that there isn't a cure. And when you become ill, that's all you want to hear, isn't it?

**Russell Fleming:**

It is... Yeah.

**Chantal Boyle:**

What are the clinical pathways for patients?

**Russell Fleming:**

So. The good news, I suppose, if you're lucky to have one, is that, whether you've got a diagnosis of ME or you've got a diagnosis for Long COVID, you should have access to an ME/CFS specialist service or a Long COVID clinic. And these are both staffed by specialists who will be able to confirm your diagnosis, and then help you learn how best to manage your condition. And they should be providing personalised advice based on your needs.

And the NHS England have pumped millions into creating a network of Long COVID clinics, and they did the same about 20 odd years ago to develop a network of ME/CFS specialist services. So, the NICE guideline breaks down exactly what the referral route should be, and it also says who should be involved in your care at these specialist services, which are

usually based at hospitals. You visit them as an outpatient, you'll have a number of sessions with them where they transfer their knowledge to you to help you manage your condition.

Now, the new NICE guideline on ME/CFS, it's all about maintaining and continuing your healthcare, because what we were finding prior to the guideline was that people would get a referral to the specialist service, they'd be there for six weeks worth of sessions, say, if they could manage it, of course, and then they'd be discharged, and then they wouldn't have any other care again.

**Chantal Boyle:**

Oh, boy.

**Russell Fleming:**

And there was no follow-up, there was no continuity of care. But with the new NICE guideline on ME/CFS, it's very much about this tailored support, creating a care and support plan that is then shared with your GP and with Social Care Services if you need them, to ensure that you remain part of the NHS, essentially, so that you should have this continuity of care and you shouldn't be just left to fight it alone.

We've got a brilliant NICE guideline on ME/CFS. There's a lot of stuff in there. I recommend that anybody with ME really tries their best to read it or get somebody to read it on their behalf. But the NHS is in such a state at the moment that we're having great difficulty getting the recommendations implemented.

So, I think, as a charity, we're going to be working with the NHS and Social Care Services to get all the recommendations implemented across the whole of the UK for at least the next five to 10 years because it's a huge task. And the NHS, it's in a bit of a state at the moment, to say the least.

**Chantal Boyle:**

They need all of the support they can get to affect the changes. You've spoken about the symptoms, which sound painful, debilitating, isolating. So, living with these conditions, you have ME, you lived with it. I don't know if you want to talk about your own personal experience or that of people that contact the ME Association, but what is it like?

**Russell Fleming:**

For me, I've had me for 23 years. I was living and working in Jersey. I was working for Lloyd's Private Banking. I was an investment manager. Loved it. It was a 14-year career, it was brilliant. Had a great social life as well. Went on holiday abroad, picked up a nasty virus, was ill, came back into hospital. And for me, it felt like the virus never left because my symptoms just continued.

So, even though the tests proved that the virus was no longer there, for me, it was like I was locked into these symptoms. And the symptoms were, basically, I couldn't function, I

couldn't get back to where I was before. So, like everybody else, I pushed myself, I tried to get back to work. I had several attempts at work, they didn't work out.

And in the end, my parents had to come out to Jersey and pick me up and take me back here in Cornwall, and then followed, I think, six or seven years of me not accepting it. I refused to accept it. I wanted anything but ME because-

**Chantal Boyle:**

Did they diagnose you with ME after the six months, did they?

**Russell Fleming:**

Yeah. So, I got a diagnosis of post-viral fatigue syndrome at around six months, and then, at 12 months, I think, maybe I saw a different doctor or something, I can't remember. But he diagnosed with me with ME. But at that time, 20 years ago, there was a lot of stigma. A lot of doctors, a lot of medic medics, a lot of media were all labelling me as yuppie flu. And of course, I was working in finance and I was dealing stocks and shares. Anyway.

**Chantal Boyle:**

Well, that would be part of the reason why you didn't want to accept it, right?

**Russell Fleming:**

Yeah.

**Chantal Boyle:**

The stigma, which-

**Russell Fleming:**

But also because as you know with your work, having a largely an invisible condition. The only thing that people could see was how it was affecting me. They couldn't take a view inside my body to see it for themselves any more than I could. But the number of times I remember wishing for broken legs or broken bones so that people could just see what I was feeling.

**Chantal Boyle:**

Yeah, give you some compassion.

**Russell Fleming:**

Yeah. Well, it was just because I got fed up people asking me how I was feeling, and trying to describe what it was like, and my descriptions were never enough, do you know what I mean? Especially when all the headlines were "Yuppie flu, yuppie flu. It's not real, it's not real. It's all in the mind." Ah, it's awful, it was awful.

And I will say that, particularly with the new NICE guideline, but in general, I think we've turned the corner, at long last, on all that rubbish, especially with Long COVID. I think Long COVID's helped too. Although, at the conference I attended last week, some of the clinicians and the researchers were still not happy with some of their colleagues who were still trying to psychologise Long COVID when they knew damn well that it was very real.

**Chantal Boyle:**

Yes.

**Russell Fleming:**

Anyway. So, for about six, seven years, I really struggled, and I struggled mentally. It really affected... I lost all confidence-

**Chantal Boyle:**

Is that the biggest battle, your mental health with it?

**Russell Fleming:**

This is it, I'm not sure. I liked to think, at the time, that if the diagnosis had been something else, I might have coped better mentally.

**Chantal Boyle:**

Yeah.

**Russell Fleming:**

At one point early on, they were convinced it was a brain tumor. And while that was upsetting in and of itself, I could cling to that. It was evidence of something. So, I think the hardest part for me, and it's not necessarily the same for everybody else, we're all different after all, but one of the hardest parts for me was the mental health side of it because depression and things like that were totally new experiences to me.

And I attempted to take my own life at one point, and dealing them with psychiatrists and people like that, and all they would say was, "Well, you've got to pull yourself together," and, "You're obviously not trying hard enough," and-

**Chantal Boyle:**

Oh, no.

**Russell Fleming:**

Oh, yeah.

**Chantal Boyle:**



Oh, no.

**Russell Fleming:**

It's appalling.

**Chantal Boyle:**

I hope these therapists are not like that anymore.

**Russell Fleming:**

No. Some of the therapists today, they hear the examples of what it used to be like for people with ME and they can't believe their profession was like that. And it's the same with Long COVID, unfortunately. I think Long COVID is showing up some good practices in the NHS, but then, it's also highlighting some of the remaining bad practices, unfortunately.

So, over time, things improved. One of the best things I did, actually, was, when I was well enough... Because ME's, for a lot of people, it could be a fluctuating condition, but most of us, I'd say, spend the first months at least, or years in my case and in other people's cases, that the severe level where we can't do very much. So, that's the biggest challenge to mental health.

Then, hopefully, and again, this unfortunately doesn't happen for everybody, you'll find the swings in severity of your symptoms will stabilize, and then it provides you a bit of a foundation on which you can stand, not stand literally. Then, hopefully things will slowly improve, again, over a period. And it's all relative to the individual to what I was able to do yesterday, to what I was able to do last month.

So, eventually, I went to part-time college, and it was great because it gave me some structure, and mum and dad used to drive me back and forth. Then, I did that, and then I went to university in Wales, and again, because I thought it would give me some structure. And it was a degree that I was really quite interested in, Ancient History.

And there was no pressure on me to perform. I wasn't 18. It wasn't like, oh, I need to get a degree to get a job. It was quite relaxed. I was an adult. I approached it differently. But it had its own challenges. And I got infected by the flipping viruses from all these germ-ridden children.

**Chantal Boyle:**

They are the most unhealthiest places, aren't they, places of education?

**Russell Fleming:**

Oh, was it freshest flu? Oh, nightmare. Anyway. So, that was a good experience for me, and I highly recommend it to anybody. Going back to university as an adult, it's completely different. Anyway. So, that was quite good. But I had some relapses, as I said, and then I

tried to attempt work again. But even though I was applying for jobs that were well below my qualifications and my skills, I couldn't manage them.

I remember I was on the night staff at Asda, because I thought working nights would be a bit less onerous, but that was a nightmare. My God, it's like slave labour. Don't know how anybody does it, let alone somebody with ME. So, that didn't last long. Then, I was-

**Chantal Boyle:**

Quite a physical job I should imagine, isn't it?

**Russell Fleming:**

Yeah. Yeah, my God, it's like piece work, isn't it? It's, "Why haven't you opened that? Why haven't you done that?" I was, "Go away! Leave me alone." Anyway. Then, I was admin assistant at a special-needs school, which I really enjoyed. It was really good, that. But again, I couldn't do it. I remember one of the duties I had was to count the dinner money every day. Do you know what, I could not get the totals right, and it was driving the others in the office absolutely mad because they had to recount everything I did. This was a competence thing.

**Chantal Boyle:**

When you think you were an investment banker. Yeah. But you were an investment banker, and it's not like you weren't good with numbers.

**Russell Fleming:**

I know. I know. So, that was another thing, trying to deal with that. God, talk about embarrassing. I started boosting my online presence a bit and teamed up with a few people that I got to know who also had ME, and we started covering the science and we started tweeting and joined them and we helped create a forum. So, that was a quite interesting diversion because I'm not a scientist at all by background, but it was quite interesting to work with other people who understood the science a bit. And we were all patients as well, so that was good.

And it got us involved with some of the researchers, and we were able to blog about them and try and raise the profile of ME research a bit better, which we did. That was great. Then, the DME Association got in touch and asked me to produce a few reports for them, which I did, and then that led to a part-time role as website and social media manager. Then, that went into communications manager, and now head of communications, working full-time from home.

**Chantal Boyle:**

Congratulations. That's-

**Russell Fleming:**

Thank you.

**Chantal Boyle:**

... quite a journey you've been on in those last 23 years.

**Russell Fleming:**

Yeah. Ups and downs, ups and downs. But it is all relative, isn't it? Because I can sit here and I can look back on it... And funnily enough, I think two years ago I wrote an article ,Surviving ME, and I said, on the last podcast I was on, if I'd written an article 10 years before that one, it would've been totally different because it would've been all about struggling and...

So, it's all about perspective, isn't it, and relatively relativity. If I wrote something today, I can talk, in all honesty, about improvements and stability of symptoms. I still have a fantastic support network around me so that I can focus all my energy on work, which is what I've chosen to do. And I couldn't work if it wasn't for them.

**Chantal Boyle:**

You have, presumably, flexible working conditions. You work in the mornings, don't you?

**Russell Fleming:**

Yeah. I still struggle massively with bad sleep. I don't know anything about it, but it just completely flummoxes me. Even after all these years I haven't figured out a way of doing it properly. So, the most I can sleep is four hours, if I'm lucky. But invariably it's one or two hours. And what I've learned over the years, I suppose, is that I just don't keep tossing and turning, I just get up and get going. So, inevitably, I usually start work in the early hours and then finish around lunchtime, but I take a break or two in between.

**Chantal Boyle:**

Do you sleep in the afternoon, Russel?

**Russell Fleming:**

Yeah, yeah, yeah, yeah. In fact, my afternoon sleeps are quite often the best sleeps. That's the biggest chance I've got of having some interrupted sleep. But I have epilepsy as well.

**Chantal Boyle:**

Okay. And that's a result of ME?

**Russell Fleming:**

Yeah. So, that was diagnosed after the diagnosis of ME because I was having these seizures. But touch wood, that's the one thing that, with medication, it's reduced the frequency, and I don't get them half as often as I used to. But now they tend to hit me at night. But there's

other things about nighttime disturbances, as I refer to them. You get these awful night sweats and the terrible nightmares.

And I used to get, thankfully I don't get it anymore, something called hypnagogia, and it's a paralysis that occurs just as you're waking or just as you fall into sleep, and you don't know that you are still in sleep mode. You think you're awake, and it can lead to hallucinations. And I used to get these hallucinations of giant insects in my room. Oh, it was weird, absolutely weird.

**Chantal Boyle:**

Do you think that was related to any medication that you were-

**Russell Fleming:**

Oh, I don't know.

**Chantal Boyle:**

... prescribed, or you just don't know?

**Russell Fleming:**

I actually didn't think about... I don't know. It went on for so many years though.

**Chantal Boyle:**

Yeah.

**Russell Fleming:**

Yeah. I don't know. It's weird. Like last night, I couldn't sleep last night. All I could do, and this happens quite a lot, is, I wasn't dreaming, it felt like I was just thinking, just thinking. I had my eyes shut. I was just thinking away. I wasn't stressing, I was just pondering things, but I couldn't get into deep sleep. And that's the problem, I can't get into deep sleep and stay there.

**Chantal Boyle:**

Insomnia is torture.

**Russell Fleming:**

Oh! It's funny though, well, it's not funny-funny, but this is a thing with ME, you are either sleeping too much or you're sleeping too little. It's either or. There's no compromise in between. Usually, in the early years or the early months or the early years or when you are having a relapse, your body is needing you to sleep a lot longer. Then, when you are more stable and maybe you've experienced some improvements, in my experience anyway, you seem to have switched from too much to too little.

**Chantal Boyle:**

When you are working, you are connected to people as well, aren't you? It's a connection. It's not so isolating and with only one thing to think about, which is your condition and health.

**Russell Fleming:**

It's true. Work, it's completely given me... I've always gravitated towards things that give me purpose. So, when I was ill and disabled, going to college, going to university, trying to find jobs that were the right fit, setting up the forum, doing all the research studies, things that would take me out of myself, and I think that's an important part of acceptance, isn't it, and trying to motivate, because nobody wants to be unable to sleep and worrying about how ill they are.

Nobody wants to be sick in bed worrying about how old we are. Sometimes it's unavoidable, but if you can find these distractions, let's call them distractions, I think it does unclog your brain, and it's a relief to any mental health problems.

**Chantal Boyle:**

So, what therapies are there? So, if we talk about what's actually available now as opposed to what NICE say we should be providing patients, what therapies do exist?

**Russell Fleming:**

Well, unfortunately, again, it's often a question of trial and error. So, in my early years, once I've gotten over the acute phase, I spent an absolute fortune on any and all therapies and treatments that I could possibly find because I was convinced there had to be something that would work. And of course, nothing did, and I was worse off for it.

So, if you go on the internet, there's a lot of people out there claiming that their product or therapy will provide a cure or will provide recovery. And you've really got to be careful, you've got to try and approach these things objectively. If anybody's out there offering a cure, then I'd say that they're talking out their backsides.

If people are offering you a product or a therapy that hasn't been backed by gold standard science, then I'd leave it alone. Both I and the charity, we don't judge people, because we've all been in this desperate situation ourselves. So, if you find something that you think helps... We are just publishing our magazine, and I was doing the editing this morning, and there's an article in there from a lady with Long COVID who's found hyperbaric oxygen therapy to have been really helpful for her, and it's fine.

It might not be for everybody. There's no scientific evidence that suggests it could be, but things of that nature. It doesn't even have to be therapies, does it? If people find that things they can do for themselves at home work are felt to help them, then great. I think it's a question of finding something that works for you.

**Chantal Boyle:**

You were listening to the Sunflower conversations with Chantal. To find out more about the topics discussed in this podcast, details are in the show notes.

Just thinking back to when you were at work and talking about your invisible disability, what do you think about the Sunflower?

**Russell Fleming:**

Oh, yeah. So, I think having a card to explain what your illness is is very useful. We get asked a lot about, do we as a charity provide lanyards, because some people like wearing them on the bus and things like that, or the train. We always direct them to you. So, I think, for people who want to be visible, it's great. Not everybody does. Some people don't want to be forced to explain what's wrong with them. They don't want to stand out from the crowd, I suppose. But for those that do, it's great.

**Chantal Boyle:**

And what support is the ME Association giving to people?

**Russell Fleming:**

So, the main service for support and information that we provide is called ME Connect. It's a 365-day-a-year telephone helpline, email, and social media messaging service. During the pandemic, the calls to ME Connect and the use of the emails, et cetera, rose about 40% in the first year of the pandemic, and then, another 40% in the second year of the pandemic, and the levels have held reasonably well since the pandemic.

So, we're talking about five to 6,000 people a year using the service, which is pretty good for a small charity of our size. We also provide the largest range of information literature on post-viral fatigue syndrome, ME/CFS, and Long COVID. We have the most acknowledged expert on ME/CFS in Dr. Charles Shepherd as our medical advisor. He's supported, in turn, by a team of other specialist advisors, from benefits advisors to employment advisors to dieticians.

And we also operate, obviously, really good social media. We have engaging discussions, and I think most people who use our social media find it very helpful. Then, for members, we have ME Essential Magazine. As I said, I was just putting the next one to bed this morning. And we produce ME Medical Magazine which goes out to healthcare professionals.

At the tail end of last year, we sent some key information packs to every GP surgery in the whole of the UK Channel Islands, Isle of Man. We're the only charity to have done that. It told them all about the NICE guideline, et cetera, it told them about similarities and differences between ME and Long COVID.

And we got other things coming up in the pipeline. Christmas, just this Christmas, we were the only charity that didn't ask for donations. Instead, we asked our members to nominate their unpaid carers that support them, and then we sent hampers to randomly selected carers, which-

**Chantal Boyle:**

Lovely idea.

**Russell Fleming:**

... did go down very well, yeah. So, I want do that again. Because carers are so busy caring, we don't hear enough from carers, and it can be hard to reach them, sometimes. But it was a delight to see the photos of carers receiving the hampers and reading their stories.

**Chantal Boyle:**

And you've said how important having a support structure is, so...

**Russell Fleming:**

Yeah. And finally, we are one of the few charities that invests directly in research. So, we review any grants from researchers wanting to look into ME/CFS or Long COVID, and then we directly fund it. So, we're supporting the UK ME/CFS biobank at the London School of Hygiene and Tropical Medicine, and we've been doing that since 2011.

We've just supported two studies by Nicola Claque-Baker and her team of physios for ME, one of which they went out and they monitored the physical recordings of people in their own homes. So, it was a way of trying to quantify... So, if a person with ME at home isn't able to leave their bed or can only sit up in bed or can only walk for a certain few steps, et cetera, Nicola was able to go in and attach recording devices to them that monitored heart rate, that monitored breathing, that did all of that so that we can try and quantify the actual effect that ME does have on people. That's quite interesting. Then, a second study, they're looking at using heart rate monitors to see if it's an effective way of pacing.

**Chantal Boyle:**

I know.

**Russell Fleming:**

But they were two quite good studies. Then, we've got a big campaign, hopefully going to start in May, which we can't say too much more about, but it's going to be a big attempt to try and reach more people. So, on Facebook for example, we know we're followed regularly by about 30,000 people. We know that if we get a really good post out, it can reach 250,000 or more people.

But what we want to do is to try and get in touch with people who might have symptoms but don't yet have a diagnosis, we want to get in touch with more people with Long COVID, and we want to try and bring them to the charity so that they can benefit in terms of getting the right diagnosis, in terms of learning how best to manage their condition. So, that's something we hope to launch in May.

**Chantal Boyle:**

Yes, quite a lot that you...

**Russell Fleming:**

It's a [inaudible 00:44:25] how I remember it all.

**Chantal Boyle:**

I know. You're not even reading off a list. Finally, what do you recommend for anyone who's listening that has ME/CFS and isn't sure where to seek advice? You've just said such a lot that you are doing, I would imagine-

**Russell Fleming:**

Oh, I think... Well, one of the first things you can do is get in touch with ME Connect, so that's our support and information service. So, you can do it either via email by sending us a private message on social media or telephoning the helpline. Like I say, we're open 365 days a year. Make initial contact. We can put you in touch with local support groups.

I think one of the best things is to get in touch with somebody else who's got the same condition or the same symptoms because just trying to cope alone is incredibly difficult. Obviously, if you are acutely affected, then I suggest that, if any carers or family members or friends are listening, then they get in touch on their loved one's behalf because it might be too difficult for the affected person to do so. But make that initial contact with us and we'll try and help you.

**Chantal Boyle:**

Fantastic. Thank you. Thank you very much for your time today, Russell.

**Russell Fleming:**

Thank you, Chantal.

**Chantal Boyle:**

If you are interested in any of the advice discussed in this podcast, please follow up with your GP or healthcare practitioner.

**Speaker 1:**

If you'd like to share your Sunflower story or conversation, please email [conversations@hiddendisabilitystore.com](mailto:conversations@hiddendisabilitystore.com). Find out more about us, or listen to this recording again, by checking out our insights page at [hiddendisabilitystore.com](http://hiddendisabilitystore.com). You can also find us on Facebook, Instagram, Twitter, YouTube, and LinkedIn. Please help, have patience, and show kindness to others. And join us again soon. Making the invisible visible with the Hidden Disability Sunflower.