



## Support for carers

**Guest: Nik Cook**

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### **Jess Thompson - [00:00:15]**

Hello and welcome to this interview. My name is Jess Thompson and I'm the director of psychology at the Optimum Health Clinic. And today I'm joined by Nik Cook, who's a psychology practitioner at the OHC.

Welcome, Nik, and thanks so much for joining me today.

### **Nik Cook**

Pleasure. Great to be here.

### **Jess Thompson**

So Nik's experience of chronic fatigue syndrome prior to joining the team at the Optimum Health Clinic was as a carer for his wife, Lisa, who suffered with chronic fatigue syndrome and is now recovered.

There's actually a case study interview with Lisa's psychology practitioner, Nikkie Foster, which gives the practitioner perspective on Lisa's recovery, which people may also be interested in watching in conjunction with today's interview.

So Nik supported her on this journey and on last year's Fatigue Conference did an interview giving some tips about the best way to provide this much needed support. And we're now revisiting this as there are some things that Nik now feels he may have done differently.

So, Nik, for those people who didn't see last year's interview. Can you give us some background about Lisa's experience of chronic fatigue and just go over the five main things you focus on as her carer.

### **Nik Cook**

So Lisa's illness and her subsequent recovery was, it was a long process. And like a lot of people who I've now dealt with, as time passed by doing the course, doing the course and working with clients, there are so many factors that contributed to her illness.

She was working in a high pressure job at the BBC, she was training for a marathons, she was going out partying, her father's estate blew up and she had to deal with that, she got diagnosed with a little tumor on her pituitary gland. So there was so many things going on.

And, yeah, it was, looking in hindsight, it was probably a very slow gradual decline over maybe sort of 4 or 5 years. And then there was an instant of she got Epstein-Barr, and her father's estate, and that was what really pushed her over the edge.

**Jess Thompson - [00:02:18]**

OK, the final straw?

**Nik Cook**

Yeah, there was a couple of things going on at that time, and then she got very ill.

**Jess Thompson**

Sounds quite a lot of boatload to contend with.

**Nik Cook**

Yeah. I mean, so now that I'm aware of that boatload model that we work with, if I look back on what was going on in her life, in our life. Yeah, I think like a lot of people who I've now worked with and they fill out that boatload, that sense of, OK, it's not that much of a surprise. Almost realization and relief at seeing that, OK, this has contributed to it. It's not that much of a mystery.

So, yeah. That's been quite an interesting experience in hindsight as well. And then, yeah, she battled against having chronic fatigue. Both in terms of trying to keep on going, and she went through a lot of boom and bust cycles. She'd get herself going, have a few weeks off work, get back into it.

But she also really battled against the diagnosis. When she was told she had it, it was a case of, I don't want to have that, that's not real. People don't get better from that from that.

**Jess Thompson**

OK.

**Nik Cook**

And there was a long, quite a long period where it was, sort of it wasn't even mentioned. And finally she came to this place of more acceptance and wanting to do something about it. And that's when she went to the Optimum Health Clinic, did the 90 day plan, worked with Nikkie. And yeah, came out the other side.

A lot of changes in her life, in our life. So we moved up to the Peak District. She changed from working in journalism and PR to, some people might not think this is lower stress, but for her it is, working as a teacher.

**Jess Thompson**

OK, yeah.

**Nik Cook**

And is now, yeah, fully working and touch wood fully recovered. She's even back doing very gentle exercise and running, but very much in a way now that she just enjoys the running, rather than saying, I need to do a marathon in 3 hours, 30 or whatever. So her whole mindset has changed.

And that's how I came to the clinic. And that she changed so profoundly as a person and made so many changes. So I actually felt slightly left behind in our dynamic as a couple.

And my first degree is in psychology and it's something I always wanted to go back to at some point. So I started looking at master's degrees in sports psychology and various things. But they were all incredibly academic and research focused rather than practicum focused.

And it was actually Lisa who said, well, isn't the answer staring you in the face? Which was the practitioners cause. So, yeah, I did that over probably about two or three, about three years I think in total, getting it all done. And then yeah, came out the other end of it and was fortunate enough to then get a position working with the team, which has been fantastic.

**Jess Thompson - [00:05:32]**

And we're delighted to have you.

So what were those five things when you were Lisa's carer? Talk about those five main areas that you really focused on as her carer and how that helped her.

**Nik Cook**

Yeah, I mean, I think I did some things better than others. I made a lot of mistakes, and that's what we're going to be getting on to later. But, yeah, the sort of things that I think I did do fairly well. The first one was asking for help. And it takes quite a lot of doing, that, putting your hand up saying, I'm not coping with this.

**Jess Thompson**

Yeah.

**Nik Cook**

And particularly during that period where Lisa was really ill. I was trying to balance work as well and looking after her. And I was very fortunate in that we have Lisa's mom, who just came up and lived with us. And it wasn't just practical support that she gave, so she'd do the laundry and things like that, it was also, it was somebody for me to have a bit of a moan to, have a bit of a bitch to every now and then.

Because when Lisa was having those really dark days, she could be a really hard person to deal with and she would lash out at those people nearest to her, so that would be me and her mom. And, you know, we'd sit in the kitchen sort of saying, who's going to go and deal with the devil upstairs next? Things like this. And that was just really, really valuable. I think if you have got any, whether it's friends, family or whatever, just putting your hand up and asking for help.

And then a step on from that was then asking for help at the clinic. And people who have dealt with this, people who have recovered from this and people who know how to move on into recovery. So that was the first one.

Yeah, the next one was finding things that we could do together that weren't necessarily chronic fatigue related. And this was something actually that I was quite bad at, initially. I very much buried my head in the sand when Lisa first got ill. And even as she was going through her recovery, I would go off and spend a lot of time on my own, whether I was out on my bike or things like that. It actually took me breaking my leg to really realize the value of, to both of us, of doing things together.

So whether it was just slobbering around watching boxset. Or one of the things we really started doing when I broke my leg, when Lisa was starting to get a bit better by that stage, was going out for a little drives in the car, driving as close to the top of a hill we could get to, and then just walking the rest of the way up together and sitting on top of a hill together.

**Jess Thompson**

Yeah lovely.

**Nik Cook - [00:08:27]**

And those are actually really happy memories now, even though I had a bust leg, and Lisa was still ill, those moments together were really, really special.

**Jess Thompson**

Yeah, it sounds like it was quite a lonely experience for both of you initially, while you buried your head in the sand and she was battling with her own demons herself. So it took for you to break your leg for you to actually find those things that you could come back into connection with.

**Nik Cook**

Yeah, definitely.

And yeah, we had some really good times during that period. And we look back on it fondly now, which is really quite strange.

**Jess Thompson**

It sounds like separation in a way, emotionally, while you were both dealing with the enormity of her illness, followed by a real sense of coming back together again.

**Nik Cook**

Yeah, and it did give us that sense of, yeah, we can we can beat this together.

**Jess Thompson**

So you came together as a team at that point rather than two separate people dealing with the same thing, yeah.

**Nik Cook**

Yeah. But equally, I do think that as a carer or a partner, that giving, and this is the third tip we came up with, giving yourself space is vital. And giving yourself space and time away from your partner's recovery without feeling guilty. It's really, really important.

And this was another aspect that Lisa's mom was great on. You know, she could see me getting all stressed, uptight about what was going on and she'd say, look, she's fine with me, just go out on your bike, enjoy yourself, sort of go and have some space, go and regroup yourself. And, you know, by doing that, you'll be able to look after her better going forward. Now, you don't want to get into a point where you're burying yourself and also developing, building up some resentment. You don't want to go to that place. You need to give yourself that time and that space.

And also, Lisa's mom would say, go and meet your mates at the pub. She's fine with me, you know. So it's letting that go and giving yourself that space is really important.

**Jess Thompson**

It's like the analogy we often use of the oxygen mask on the airplane. So when they say if the oxygen mask comes down, you need to, and you've got a dependent with you like a child, you need to put your own oxygen mask on first. And it sounds like you just needed some encouragement from her mum to really do that. Make sure you were taking care of you.

**Nik Cook**

Yeah, definitely. Because I think you do take on a real identity as a carer and I know that this was something that I struggled with as she got better, it was switching back from carer to husband. And I

think in that time when I was in full carer mode, actually, sort of saying, handing her over to someone else or not being around was actually really quite difficult. But it's something I had to do for my own mental well-being. It's something else.

**Jess Thompson - [00:11:25]**

Yeah.

**Nik Cook**

And then the next one and something again, that applies to some people not to others, but we talk about the different types of tiredness and that for Lisa, that changing her environment was just so important and just such a useful thing. And that that whole period when I had the broken leg us getting out and up on the hill and things like that. And it was always a bit of a balancing act, sometimes she'd say, oh, I don't know if I've got the energy for this. And sometimes I didn't get it right. Sometimes I did sort of push her and we went and it wasn't great. But more times than not, that little change in environment was really important for her and made a big difference.

But even just getting her from the bedroom into the sitting room made a massive difference to her. Changing the light, we changed the lighting in the bedroom and that made a big difference to her. And then, I guess the ultimate changing environment we had was, and again this was when I was still rehabbing myself from my broken leg, Lisa was still quite ill, we decided to move house. Because Lisa really came to associate the house that we were in, and we loved that house, but she associated that with being ill.

And actually, even though it took a lot of energy and effort to move house, and they say it's one of the most stressful things you can do, I would say it was probably the turning point in her recovery, was us moving house.

**Jess Thompson**

Yeah. And it's interesting that you're talking about how sometimes you got it right and sometimes you got it wrong. Sometimes changing the environment seemed to help and other times it felt like too much.

And I guess that brings to mind the importance of being able to identify what type of tired you're feeling, which is something you work with clients to do.

**Nik Cook**

Yeah. Which I think if I was now going back with the knowledge and experience I have now, I would have done a lot better.

**Jess Thompson**

Hindsight. Great.

**Nik Cook**

Yeah, exactly. Yeah, it's always good.

And then and the last of the five was being, and I still do this wrong, which is being an objective recovery guide.

**Jess Thompson**

I didn't think about that.

**Nik Cook - [00:13:42]**

Because, well I think when you're in it, it's really hard to see out of that moment. So when Lisa was having a bad day or a not so good day, particularly as she was starting to get better, she wouldn't necessarily see that she was having maybe one bad day a week at that point rather than three or four bad days a week, which she had been having six, seven months ago.

And just by being able to say, actually, look you're in a much better place now than you were then. And having sort of being able to objectively say this is not just me giving you false positives, this is what happened. I actually, I kept almost like a recovery diary for her.

**Jess Thompson**

OK. Was that helpful?

**Nik Cook**

Yeah, really helpful. Just being able to say, look, you had this many bad days then and even now, so she'll come to the end of a hard term at school. I mean, last term was weird with everything that was going on.

**Jess Thompson**

For all teachers.

**Nik Cook**

Yeah, exactly. And she got to the end of the term and she needed a couple of days in bed. And there's still a lot of, there's still a bit of normalization of tiredness going on with her, in that, that sort of tiredness when she has to go to bed, when she has to sleep can be scary for her. Am I getting ill again, etc?

And again, it's just pointing back and saying, OK, but, you know, when you were doing your teacher training the year before you'd get to the end of the term and it would whack you out for three or four days. Now you're having one day of sort of bounce and then you're back into it. So it's, yeah, I think being able to provide the objectivity is really, really useful.

**Jess Thompson**

Yeah, that kind of one step back perspective really to remind the person just how well they're doing. Because, when I had chronic fatigue, I think you very quickly normalize your progress. So it becomes very normal to be able to do this amount so any less feels like a real step back. So having someone to say, actually two months ago or three months ago this was the picture you were looking at, it would be really helpful.

**Nik Cook**

And I think, and I'm noticing that working with clients as well, that coaching aspect of what we do is, you know, it's almost as important as the actual pure psychology aspect of what we do. Giving that step back objective opinion, objective feedback of what's going on.

**Jess Thompson**

Absolutely.

**Nik Cook**

Because I know with Lisa as well that she still doesn't remember an awful lot. She doesn't remember how bad she was.

**Jess Thompson - [00:16:32]**

The brain's deleted those difficult memories.

**Nik Cook**

Which you know, there's a positive to that. But there's also the negative because it also means she doesn't remember how far she's come.

**Jess Thompson**

Yeah. So you're there to remind her, which sounds like it's a really helpful thing.

**Nik Cook**

Yeah.

**Jess Thompson**

So let's move on now then to what, now that you've been a practitioner with us for a while and obviously you've been working with many people with chronic fatigue syndrome, what would you do differently now, do you think, with the experience that you've got? Or what would feel different?

**Nik Cook**

I think it's almost like we, I mean, we use a tool with clients, a process for clients, called timeline, timeline work, where we'll go back to a period in their lives and we'll say what resources would help you, would help you then get through that period in your life?

And it's similar to that I think, in that this knowledge and learnings and resources that I have now, if I could take back to then, I think it would have been better for Lisa, and also better for myself.

And I don't know if it necessarily would have meant she would have recovered quicker. But I definitely think that we would have, it would have taken less out of us, her recovery. And it would have been less of a battle, I think.

So the first one yeah, it's confidence in the tools and the recovery process. You know, now I've not only witnessed Lisa recovering, but also the patients that I'm working with in the clinic. And the recovery stories that there are and just seeing that the tools and the techniques and the program do, work. Yeah, and just, I think when I was back then, you're clutching at straws. And everybody's promising you the answer.

So you go and read a book on mitochondria and supplementation. You go and read a book on graded exercise therapy. And Lisa did all of these things and she tried all of these things.

And also you get the input from the medical profession as well. You know, Lisa went to see her endocrinologist who found the little tumor. That's the answer. And by the time she came to the clinic I was probably in a place where I was thinking, oh, it's just another, it's another false hope, it's another straw we're grasping at. And it took me a long time to come round and see that what she was doing and the tools that she was using were actually beneficial.

**Jess Thompson**

Yeah, it sounds like you've been hopeful so many times with so many different things and then just not being able to build the evidence with those things that actually it was going to work. Whereas when you were going through with Lisa with the Optimum Health Clinic program, you were both gradually building evidence towards that sense of confidence really, that this works. And now you've got that you've got so much more evidence, but not having that then, that must have been hard.

**Nik Cook - [00:19:51]**

Yeah, it was, it was really hard. And I think we were both in that sort of position. I mean, I remember when Lisa went down for her weekend at the clinic for her 90 day, she went to stay with her mum. And I got a phone call from her, and I can't remember what day it was, and she was just saying, I don't know if this is going to work, it's so much information, it's so many things to take onboard, there's some quite strange stuff when she's talking about the EFT. I just don't know. And I was just thinking, oh, no it's another one. But yeah, we persevered.

**Jess Thompson**

Yeah, and stuck with it. And I guess you must've built some evidence in order to stick with it. I guess you must have built some evidence quite soon or even during the program that this was something that made sense.

**Nik Cook**

Yeah, I think what really, really helped with Lisa and really, really turned it with Lisa was the fact she was working with Nikkie. And it was somebody who had been there, done it, come out of the other side. And I think that resource within the clinic is just, it's invaluable. Absolutely invaluable.

And that gave me, I was probably slower and later to come onboard, which is, we'll get on to the next point in a minute, but yeah, that made, I think that made a massive difference to her.

**Jess Thompson**

Sounds like having that really comforting companion that she found in Nikkie on that recovery journey, like you say, someone who'd been through it themselves and used the tools that Lisa was being taught, to get there.

**Nik Cook**

Yeah, definitely. Yeah, yeah. Definitely.

Yeah. And then the next one is engagement. So, I would actually have engaged in what she was doing more fully and more quickly.

**Jess Thompson**

Perhaps there was a sense, initially, of being hard to engage with her because you didn't really understand it. You hadn't been on the course yourself.

**Nik Cook**

Yeah, there was that. And I think also, if I'm honest, there was also a sense of, OK, they know what they're doing, or at least Lisa thinks they know what they're doing, they can deal with this now.

**Jess Thompson**

So perhaps a bit of relief in there?

**Nik Cook**

Yeah. And so, you know, I felt I haven't got the energy to throw myself into this. I'm just going to let them get on with it for a bit.

I was totally oblivious to a lot of the things she was doing. I mean, I remember this week or so after she got back and I was lying in bed one morning, I was thinking, is she humming Happy Birthday to herself? What is she doing?



**Jess Thompson - [00:22:34]**

Let's explain what that is for people wondering. Talk us through what that is.

**Nik Cook**

Yeah so, it's part of, actually one of the older, fuller EFT tapping recipes.

**Jess Thompson**

Yeah. Emotional freedom technique.

**Nik Cook**

Yeah. And yeah, so she was lying in bed, sort of tapping on various parts of her body and humming Happy Birthday and I was just thinking, what on earth is going on here? Why is she also, why is she taping now, stop, choice and coach, which is part of the stop process, which is another process we use, on our kitchen floor?

**Jess Thompson**

It must have been very confusing.

**Nik Cook**

Yeah, it was really confusing. But now having come to use those tools myself while I was doing the practitioner training, while I was learning how to use them and obviously now using them a lot with clients, I think by learning them and working through them with her, using them myself, I wouldn't have, I could've have facilitated her recovery. But I also would have really helped myself.

**Jess Thompson**

Yeah.

**Nik Cook**

Because when I look back to some of the thought patterns that I ran while I was caring for her, having a resource like the stop pattern. Some of the emotions that I went through having a resource like EFT would have been so useful to me, as well then.

**Jess Thompson**

Well it was an enormous journey for you too.

**Nik Cook**

Yeah, yeah definitely.

**Jess Thompson**

It's hard for the person suffering with CFS, but it can be equally hard watching the person you love suffer.

**Nik Cook**

Yeah, definitely. And I know as I did start to engage more as Lisa got better, particularly with the stop process, we would run that on each other while we were out walking the dog in the morning. A very changed and tweaked version of it, Lisa found worked for her. But yeah, and it was just really, really

useful. And I think if I'd come to that point earlier, I could have saved myself quite a lot of work that I had to do with myself and on myself after Lisa recovered.

**Jess Thompson - [00:24:43]**

Yeah, that's really interesting. Yeah.

**Nik Cook**

Yeah. And the next one and this is something that comes up again and again with clients, I notice. And I was speaking to a client yesterday and she was saying that, my mother just keeps on saying things that are just too optimistic for me, they're too false positives. She just doesn't get it.

And I think going back, if I could give myself more of a sense of empathetic realism I suppose, it's hard to describe it. Because often the knee jerk reaction is, I know you're fine, you're going to get better, it's all OK, you're just having a bad day. All of these sort of very glib, cliched platitudes. That actually now looking back, would have caused parts of her immense stress. Just by me saying that. Because that wasn't where she was at that moment.

I think realizing that and having the confidence in the process again to allow somebody and just to sit with them and just to be with them and with how they are, rather than trying to fix. Because fixing, you waste a lot of energy trying to do that.

I almost see myself now rushing around like this fly, trying to sort of make sure everything was in place. And it just wasn't helpful to her and it wasn't helpful to me at the time.

**Jess Thompson**

So actually really creating some space to sit with the actual feelings that were there. However distressing, however difficult, and it's something that we know, as psychology practitioners, is so important, you know, that ability to just sit with the feeling that's there without trying to change it or make it go away.

**Nik Cook**

Yeah.

**Jess Thompson**

Yeah. So that's something you would do more of if you were to do this again?

**Nik Cook**

Definitely. And I think again, if I had, if I'd engaged more and had more knowledge of the tools, and what she was doing, then I would have been a far better resource to be able to do that for her and for myself as well.

**Jess Thompson**

And is that something that you think that Lisa could have helped you with? So do you feel that perhaps was she a bit resistant to talking you through what she was doing and why she was tapping or singing Happy Birthday or?

**Nik Cook**

I think there was a degree of she didn't necessarily have the energy to explain what was going, what she was doing and why she was doing it.

**Jess Thompson - [00:27:35]**

Yeah.

**Nik Cook**

And I think she probably, she was probably also sensing in me that maybe I wasn't at a place at that time when I was, would have been open to it.

**Jess Thompson**

Yeah.

**Nik Cook**

And. You know, we probably needed to meet in the middle a bit on that.

**Jess Thompson**

Yeah. But perhaps even something for those people listening that are kind of caring for people that have got chronic fatigue, perhaps even just that kind of process of reading the material, going through the, may have been enough for you to feel a bit more engaged with it.

**Nik Cook**

Even just two hours of watching some of her video on what EFT is, what the stop process is, what the maladaptive stress response is.

I think by gaining that understanding. It wouldn't have been a lot of investment on my part to actually become, be a lot more resource than help in her recovery.

**Jess Thompson**

But it does sound as though, at the time actually, you really did need to create that sense of space for yourself. So it's, I hope you're not too hard on yourself.

**Nik Cook**

No, well that actually segways very nicely into my final one. Which is a bit more sort of kindness to myself. And because, you know, I was pretty hard on myself during that period. And again, taking on that carer role as opposed to a husband, it was hard. And I did get that pretty wrong. I was hard on myself and I ended up having to do a lot of work after Lisa recovered to dig myself out of that hole.

**Jess Thompson**

What sorts of things did you kind of, what kind of thoughts were you having about the way that you were caring for Lisa that maybe weren't so helpful?

**Nik Cook**

It was more once she'd recovered actually. It was again, so it was letting go of that carer role. I think, Lisa knew and accepted she'd recovered before I knew, before I accepted that she had recovered and that I could, that part of me that was a carer could stand down.

And I was very wary about her doing things very overprotective about her doing things and causing myself quite a lot of stress during that period, and wasted quite a lot of energy and probably annoyed her quite a lot as well.

**Jess Thompson - [00:30:12]**

Well, it sounds like there was a period when she was unwell when you actually kind of, as you said earlier, sometimes pushed her too hard, said, come on, let's do this. And then perhaps through that experience then became really quite cautious. So even when she became confident, you still had that sense of caution.

**Nik Cook**

Yeah, definitely. Yeah. And I think yeah, just that, in the same way that we talk to people about when they're of the latter stages of recovery and they're balancing boundaries and so they're increasing what they're doing, they're increasing their capacity. And we talk about doing it in a very stepping stone way, so that if you do go that bit too far, you're only going, it doesn't matter because it's only a stepping stone too far, you can step back, rather than jumping over a big river.

And it's a similar sort of thing I guess, the position that I found myself in, in that I think I probably tried to leap too quickly from carer back to husband. You know, sort of yeah, she's better, and that just didn't sit and there was part of me that just wasn't right for. I think I should have just been a little bit more progressive and yeah just slowly sort of allowed us that transition.

**Jess Thompson**

Yeah. So in terms of kind of being kinder to yourself, you're saying that you would, if you did it again, you would be kinder because you were so hard on yourself, how would you kind of advise someone to do that? How would you work with someone, a carer, to help them to be more kind to themselves?

**Nik Cook**

I mean, I ended up, I mean, I think it was also part and parcel of the fact that I was doing the practitioner's course. So during the course of the practitioners course we obviously do a lot of work and stuff on each other. And also we're encouraged as practitioners to obviously look after ourselves from a mental health perspective as well. So after Lisa recovered, I actually did a lot of work with a therapist myself.

In hindsight, I would have done that whilst she was ill and while she was recovering.

**Jess Thompson**

Yeah. So you would've recognized that you really needed that support then.

**Nik Cook**

Yeah. And I think that would have made a huge difference. And again, that's sort comes back to you know, I was good at asking for help from Lisa's mum, on very practical level, and yeah she was somebody to talk to. But having somebody, I think to talk to. You have that distance, you have that professional knowledge, you have that knowledge, would have been really, really valuable.

**Jess Thompson**

Yeah. Well, thank you so much, Nik, for joining me today to talk about this. I know there's lots of people out there who will be in that position of caring for someone with a fatigue related condition. And as you've described, it's actually a real journey for the carer, too. And I think you're talking today about those things you would have done differently, is really going to help people.

So thank you so much for joining me.

**Nik Cook**

Thank you. Enjoyed it. Thank you very much.