



Support for carers session 2

Nik's story

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Alex Howard - [00:00:13]

Welcome to the Fatigue Super Conference. Often the unsung heroes in healing journeys are those which are on the sidelines which on one hand one might say they're not suffering as much because they're not going through the physical symptoms. I would argue sometimes they are suffering as much and on some situations are suffering more watching their loved ones in incredibly difficult life circumstances and often feeling disempowered, clueless, like a ship without a rudder, not really knowing how to help, what to do, how to be the best support. And for this series I'm talking with Nik Cook who is the husband of a former patient of The Optimum Health Clinic, who has I think quite an interesting set of perspectives in a sense that obviously his journey as being Lisa's husband and support through that.

He's also more recently been going through our Therapeutic Coaching Practitioner Training Program, which has given some additional elements perhaps to the understanding, and before we started recording this, Nik was saying that, of course if he paid for that program before, he might've had a few more strategies and tools to support. But in this session, we're going to explore Nik and Lisa's story but primarily from Nik's perspective and we'll follow the narrative of the journey that they went on, but really some of the key lessons that Nick learned along the way. And I think it'll be a combination of lessons learned at the time and lessons discovered in hindsight that he wishes he'd learned at the time, but Nik, welcome back and thanks for joining me again on this session.

Nik Cook

No problem. Glad to be here.

Alex Howard

So this time I get to ask the questions.

Nik Cook

I'm feeling a bit more nervous about this.

Alex Howard

Let's start from the beginning. As we... Actually we touched on in a bit in the last session. You were asking me about it. But the process of getting a diagnosis of fatigue. And obviously, we're talking to a broad range of fatigue in this conference and for some people this might just be a relatively mild fatigue that just impacts the quality of their life, for others it could be a very severe Chronic Fatigue or fibromyalgia or any situation. But for you guys, when Lisa got her diagnosis, that can be a bit of a double-edged sword, that can be quite an emotional roller coaster. So maybe talk a bit about what, perhaps the circumstance but also how that was particularly for you at that time?

Nik Cook - [00:02:47]

It was a fairly drawn out process. In that Lisa had not been right for a long, long time. So periods of being able to manage everything and then just periods of crashing. And we went through a load of traditional medical pathways. And then an endocrinologist found that she did have this pituitary tumor which involves a matter excrete a lot of prolactin hormone, which had a big impact on her and then the medication she had to take for that. And there's a lot of instances like that where we'd be...

Somebody would say, "Oh, it's this." And we'd say, "Oh that's going to sort it." I remember going to see the endocrinologist and feeling absolutely elated afterwards that we'd got to the bottom of why she had all of these issues in that she was going to take this medication and it was all going to be fine. And then it wasn't, because then the medication hit her and she still wasn't fine. So then she took a month off work and she got better in that month, but then the moment she went back again, it all kicked in again.

So eventually it was a doctor that I knew from a sports background. He worked with a lot of pro cycling teams said... No, did some blood work with her and said, "Look, there's nothing on the blood work. But based on everything you told me, this looks like the burnout fatigue that I see a lot of time with elite athletes and it's a very similar condition. I think you have some form of Chronic Fatigue."

And I think both our reactions quite similar to that, and Lisa was very much, "No, I haven't got that. I'm not having that. That's not happening." And I think I was, I was a bit like that thinking, "Oh, no. Everything I've read about this, everything I've known about this, and it's all you don't get better from it, it's a life sentence." So you'll have people who won't believe you actually got something wrong with you and I just went to this spiral of catastrophizing how this was just going to unravel our lives and that there was no way out of it. And then I think we both stuck our heads in the sand for a bit about it and it all really came through ahead. We were actually on holiday in Holland.

And Lisa was actually having a bit of an up. Which tended to happen, so she would have these ups and we'd think, "oh, she's fine". There's actually nothing wrong with her. And yeah, we were on a holiday in Holland with her mom, and we went out I think for half an hour bike ride, flat bike ride, it's Holland.

Nik Cook

And she was laid out for three days after that and the year previously. She'd been, we'd been on holiday in France and she'd been riding Tour de France climbs. And so she was just absolutely laid out flat for this one bike ride, we were walking to the Pancake House down the coast and there's a slight incline and her 77 year old mother was going on this incline faster than she was, and both her mom and I said, there's something really wrong here. We need to sort this. And I think that's when she also realized that there was something probably wrong

Alex Howard

I think part of what can be so difficult in that situation is that we're so used to going to medical professionals, getting a clear diagnosis, getting a clear treatment path. Even if that treatment path is one that's not to full recovery. But a sense of these are the parameters of what you can expect and these are the things we're going to do and these are the likely outcomes that will come from doing that, and I think often that uncertainty and that being left in the dark really is I think can be almost quite traumatizing for both parties going through that experience.

Nik Cook

Oh definitely. It's that not knowing, and I think the default reaction to not knowing is to think that the worst is going to happen. So you're faced with this black hole and you think, "Well, it's not going to be good. What's in that black hole?"

Alex Howard - [00:07:12]

Yeah. So how do things unfold from that point? So you, in time, you've got this diagnosis that Lisa didn't like so didn't count. I guess that that was a realization in time that actually really this is what's going on.

Nik Cook

Yeah, and I think yeah, I have some real clear memories of the whole process and one of them is that conversation with her mom starting in Holland and the next one's actually on the way, journey back from Holland. Just Lisa on her phone researching everything there was to research about Chronic Fatigue, ordering books left, right and center, buying up Holland & Barrett online. I think she read, I've forgotten which of the nutritional books it was, but she read one of the nutritional books on the journey home and just ordered everything on that list, and she just... You see, it was almost like this mania of...

Alex Howard

For those outside the UK, Holland and Barrett, is one of the High Street Health Food stores. So I guess it's a Planet Organic equivalent or Whole Foods equivalent in the US.

Nik Cook

And I just got this feeling that I had to at that point, take a little bit of a stand back and just, it was obvious she needed to go through this. I think even if she didn't get to the bottom of it herself, there was part of me that felt good that she was actually engaging with what Dr. Willard said. That it was this Chronic Fatigue and... But then there's another part of me that was thinking, "You're just scatter gunning at this. We need to take a more measured approach and a more little logical approach."

Alex Howard

Well, I think that's one of the challenges as well, isn't it? The person that's going through being ill has this sense of being completely out of control and powerless in terms of what's happening, so what you don't want to do is try and force them too much down certain paths, but also you are going through it together, and I wonder how you guys navigated that, wanting to give her the freedom to make her own choices whilst also perhaps having some different opinions sometimes.

Nik Cook

I found that quite hard. Lisa is quite a force of nature. And the thing is, again I think that has been, it was a contributing factor to her illness, was her very high achiever type personality. She's always worked on that, the more you put effort into things, the better the results are going to be. And I could just see that she was just expending so much energy into trying to find her cure for this. And I have this feeling in the back of my mind that I knew that it wasn't going to be a simple fix. But whenever I tried and say, "Are you sure you need to be taking all of these things? Are you sure you need to be doing this, are you sure that's going to work for you?" The reaction wouldn't necessarily be hostile, but it was, it was quite a difficult phase.

And we felt it very much. It was all, to be honest, it was all on us because at that point we weren't seeking any outside expert advice or talking to anyone or whatever. And so for that reason one of the biggest weights of my mind was when Lisa did sign up for the OHC, because then suddenly there was somebody else involved.

Alex Howard

Yeah, and before we come to that I'm also curious as to how it was, you mentioned, Lisa's mom.

Nik Cook - [00:11:21]

Yeah.

Alex Howard

Because when we talk about carers, it's obviously it's not just intimate partner it can be if there's lots of different conservation's that it could be parents that are caring for it could be children. It can be siblings. It could be close friends, could be romantic partners, but how is it Lisa and her mama. How was it for you and Lisa's mom. How did that dynamic work?

Nik Cook

Lisa's mom was absolutely invaluable. If it hadn't been for her, I don't know if we would have got through it to be honest. And it's much for the support she gave me as for the support she gave Lisa. During that first diagnosis period but also then once it was actually probably at her most ill, Lisa's Mum effectively came up and lived with us for quite a long period of time and she would happily take a lot of the flak that Lisa would be giving out. She would take that time to sit with Lisa she would take the being shouted at, but she would also... She gave me that space which then she was also this objective standing board of that I had as well, all the feelings I was going through and she was just an absolute rock.

And I think one of the main things I would say to anyone who's caring for somebody with fatigue is that you need somebody else.

Alex Howard

Yeah.

Nik Cook

Not necessarily in situ like I was so fortunate to have, just somebody who you can talk to, you can off load to, you can balance things off. Because that was just absolutely, that was a lifesaver. It really was.

Alex Howard

It sounds like it was an enormously important role and I can imagine also at times I imagine, quite frustrating. I have a very good relationship with my mother-in-law but I do find it after a set amount of time I want to be on my space. So I wonder how that was for you in a sense, that knowing that your mother-in-law was a really important part of the picture in terms of the support network, but I would assume that also at times probably quite frustrating that wanting Lisa to be well once you've got to do things together and wanting to have your own space. How did you navigate that?

Nik Cook

It's not necessarily a normal situation to have your mother-in-law living with you effectively. But again, I'm really lucky that she's actually very low maintenance, very independent, she gets on with her own thing. So that wasn't so much of an issue and to be honest, I can only really sense I only really had positives from it, and it's quite interesting now that when we do spend time, like, we're going to be staying down there this weekend, for example, in her flat. And undoubtedly, she will wind me up and I think that's actually a really strong indicator of where Lisa is in her recovery and where we are as a couple in her recovery and that we now have a lot of much more normal.

Alex Howard

That's a sign of progress.

Nik Cook - [00:14:41]

I know! Yeah, exactly. I remember this huge sense of relief when she would come to stay. It's almost dread when she would go and I'd be then on my own with Lisa. Particularly when Lisa was at her most ill.

Alex Howard

I know that you've mentioned before that there were, of course, there were times when Lisa would have got frustrated. She would have got pissed off, anyone going through a situation like severe fatigue that doesn't is probably in denial. I can sense their healthy way through it is sometimes there's gonna be some blow ups, but how was that for, you mentioned that Lisa's mom was getting some of that, but I'm sure you were getting some of that as well. How was that? Seeing someone in so much frustration and having to also be the intimate portion of that.

Nik Cook

That was really hard. There were days when... There were days, there were weeks when Lisa would be effectively bed-bound and this wasn't the girl I fell in love with, this wasn't the woman that I married. And she was so angry and frustrated but in such a strange resigned way, it's almost as she didn't have the energy to be angry and I remember her saying one day, "I wish I was dead, but I can't be bothered to do anything about it."

Alex Howard

Wow.

Nik Cook

That just hurt so much. When she would get frustrated. Inevitably I would say the wrong things, I tried and be positive when she was in no frame of mind for me to be positive or I'd be negative or realistic when she wants me to be positive. I'd get some reaction and it was incredibly hurtful and that's where having that objective standing board and her mother really helped in that I could say, "Listen, Lisa said this today" and her mom would say "That's not really her talking. That's the illness talking, she knows she can say these things to us because she loves us and she feels comfortable saying these things to us."

To an extent, I almost then in a number of mechanisms to protect myself, almost separated off ill Lisa from Lisa.

Alex Howard

Interesting.

Nik Cook

It was the analogy that I almost used, don't know if you're almost familiar with the film The Exorcist.

Alex Howard

Only very vaguely so you've got to give me more than that.

Nik Cook

It was almost like this demonic possession and that there was this part of her that was this incredibly angry, lashing out, but it wasn't really her.

Alex Howard - [00:17:51]

Yes.

Nik Cook

I had to take those things that this demon, for want of a better word, was throwing out. But I also had to not take them to heart as much as possible.

Alex Howard

I think that's a very helpful way of separating it, right? Because in a sense if it's your lover, your wife, your intimate partner, the person that you committed your life to which is angry, frustrated taking out to you that's very painful and if you can separate that, I think it's the first time I've heard it described in that way, but I think it's actually very good. I think you can separate it in that way you can still love her. It's a little bit like we're parenting, right? It's that you can love the child but dislike the behavior. If you can separate those two pieces, you can respond with love whilst also have certain levels of boundary of how you limit the impact of the behavior.

That sounds like a really good strategy. I suppose what I also wonder is, at that time, and I know that perhaps with some of the deeper insight that you've gathered over the years and for doing the course since, I'm sure that there are some other pieces that you might want to add as well, but at the time what else were you doing to take care of yourself, right? Obviously having Lisa's mom there was a support, were you making time, I know cycling is a great love of yours, were you making time to go and do that, to spend time with friends? How was your life outside of the being carer thing?

Nik Cook

That's going where this is mom was invaluable. For me, getting out for four, five hours on the bike is my release. And having her there, it allowed me to do that guilt-free.

Alex Howard

Right.

Nik Cook

Lisa wasn't... She didn't need 24-hour surveillance or 24-hour care as such, most of the time she was in bed either asleep or trying to read when the brain fog wasn't too bad or watching their box sets or whatever so I could have gone out when Lisa's mom wasn't there but I didn't want to almost because the guilt that I'd feel about doing that would be too great and it was similar with going out and seeing friends as well in that, I would feel bad and I want to be out with Lisa.

Alex Howard

Yes, and that's tricky if you're used to going out as a couple, right?

Nik Cook

I think we both became a lot more isolated as a couple during that period and it was hard to manage that and I think one of the things that you do really notice with fatigue is that it's really hard from a social perspective and undoubtedly, we did lose friends because of it. At the beginning, when Lisa was first ill, you'd have friends who would be near ask you, you'll be asked out to things as normal but you keep on having to say, "No we can't." And eventually people stop asking.

The other difficulty is it's such a subtle and insidious illness and that if she was feeling good on a Friday afternoon, we might try and walk down to the pub, and people would see her out and about, they would see her but they only see her because she was having a good five six hours. No, they wouldn't see her the rest of the week. Because it's not a tangible illness. There's nothing that people

can see and you do have these little ups where you are okay, and you are able to do something. Our friends circle was very much based around cycling, running and things like that. That made it difficult as well. We did lose friends.

Alex Howard - [00:22:19]

It's an important point you raised as well, that the fluctuating nature of fatigue is such that it's quite difficult for people to understand because normally people assume, you know, you break your leg and you are at a certain stage of that recovery process which is fairly consistent and most conditions are like that. Whereas with fatigue, because it can be so fluctuating and up and down and there can be so much cultural misunderstanding in a sense to what's happening there that ultimately the people that we most need support from, our close friends and family, often they can be the people that are the least helpful because they don't really understand what's happening.

Nik Cook

Ironically, when Lisa was actually at her illest I did break my leg.

Alex Howard

That must have been an inconvenience.

Nik Cook

Oh yes. And I think Lisa actually found it really frustrating that I suddenly got this support from people, when I had this broken leg. And she verbalized that, she was saying, all these people are coming around and doing this and this and this, and that didn't happen for me. That was quite interesting. And I think quite difficult to handle them. In the up side of me breaking my leg, was that we actually had a really nice period of time when we were both effectively house-bound. I think it gave me a lot of empathy at that time and we could do things together because we were both incapacitated.

Alex Howard

I think if there is something that is... It's interesting, actually. I've had a number of patients say over the years that one of their loved ones who had suddenly become much more empathic and understanding because they've had terrible flu for five days or a week or something and they suddenly realized how awful it was possible to feel and then they'd be, "Oh my God, is that how you feel the whole time?" And like, "Oh my God. How have you done that for the last year." Or five years or whatever it is. There's something about that empathy that comes from having had one's own experience.

Nik Cook

Yeah, definitely. During that time, I had the thing I love doing most, going out on the bike. I had that taken away from me for five months, I think it was. And suddenly I realized, "Wow, this is what happened to Lisa." She used to love riding a bike. She used to love running. And I suddenly have an idea of what it was like but the difference was I had this incredibly structured rehabilitation process in place. I had a physio who is telling me, "Right. In 12 weeks are going to be taking that cast off. In 16 weeks, we're going to have you on an exercise bike and we're gonna have your pedaling through a full range of motion." And I knew exactly, and I had to know these targets whereas, like I said, Lisa was this black hole of unknowing about was she ever going to get better, was she ever going to get back to normal life?

Alex Howard

Yeah, which is obviously incredibly unsettling and I know that you... Just back up at you mentioned then there was a point where you found OHC or the Optimum Health Clinic, what was, and please

don't be polite, just tell me how it is. What was that like for both of you? Often I think what can happen is that the one that's suffering can be the one that does the research and understand it, sometimes those around them can be quite skeptical and cynical. Was that your experience? Might not have been your experience.

Nik Cook - [00:26:12]

Yeah. No, I think definitely, definitely to start with, I probably did bury my head in the sand quite a lot and I didn't want to read, particularly when Lisa was going through her manic self-diagnosis and self-treatment phase, I didn't want to read all the books that she was telling me I should be reading. Because I just didn't feel it was honing in on what the problem was. And to start with, with the OHC, I was probably similar as well. As I said, there was this big sense of relief that somebody else was dealing with her.

But I was still thinking, I remember being, when I was a student, I lived with medical students, and I remember one of them coming home and saying, "oh we learnt about ME today, it might exist!"

Alex Howard

I think that's about the size of it in medical school.

Nik Cook

Yeah. And I come from a very rigorous scientific background. And so I was myself quite skeptical and I remember she went down for the first...

Alex Howard

90 Day Programme...

Nik Cook

90 day, yeah. I remember getting a phone call from her saying, "Oh, get me out of here, it's a load of people sat in a room doing nutty tapping stuff." And then I was thinking, "Oh man, this isn't going to happen either." But then I think as I started, as I think Lisa embraced it and found the bits that worked for her and found some things that worked for inside particularly when she started working with her therapist, I started looking and reading through material she was getting and I think that was a real turning point in that once we were both singing from the same hymn sheet.

It made a massive difference and we had that, not that we were attacking this from the same place, but we were at least coming, conveyed in the same direction on it.

Alex Howard

Yes, although I think one of the things that can be quite interesting at that stage, is that the one that's going through the program starting to develop a new vocabulary in a sense and you mindset a new way of doing things a new way of not doing things and I sometimes hear that the experience of those around them is that suddenly everything they do and say it's wrong because they're not they're not they haven't had that same training and also it's so nuanced of what's appropriate each point. Did you find that challenging, being someone that was trying to support someone on a program that you weren't indoctrinated into the world in a sense?

Nik Cook

Oh, definitely, and though I remember lying in bed one morning and I could hear this humming. You feel the bed by source of slightly vibrating and she was humming Happy Birthday to herself. Well that just lay there would be what is going on? And it's only when I said to her were you humming that she explained what she was doing. She did have this totally new mindset and she was trying to... I

remember her saying, "right, I can't overly stimulate my parasympathetic nervous system. So we're not watching television after X clock at night and we're not watching anything that's horror or overly violent drama. And we're basically only watching rubbish comedies".

Alex Howard - [00:30:07]

So basically nothing that you as a guy wanted to watch.

Nik Cook

Exactly and I got to go with this but there were definitely times when I was thinking, I really don't know what's going on here.

Alex Howard

Just for the uninitiated. I think I just explained the happy birthday piece. Otherwise, I might get you would think this is kind of crackpot. So as part of Emotional Freedom Technique, which is the... In fact we have one of the interviews in this online conference with Doctor Craig Weiner talking about EFT and that one of the parts of that sequence is that we do a set of strange things are eye movements and counting and that sort of thing. We all say get me with a hum something and often. It's happy birthday. You have a nice happy birthday and there's a logic around the switching between different sides of the brain in different folks that so there's a reason why we do that but I think it looks genuinely crazy for people on the outside, but don't necessarily and I'm initiating.

Yeah, definitely take you and you're it lying in bed in the morning.

Alex Howard

Noted. Also as things started to change and improve Lisa. It's rarely. Is it a straight line of recovery. Normally it's a the few steps forward as a step back. It's five steps forward three steps back the step to the left step to the right. It's a process of evolution and there's lots of nuance to what's most helpful at different stages. How was that for you guys in terms of almost like you suddenly get a sense of oh my God, we're on the right track and then it could be a sense of a deflating. Oh, we're not. How did you guys navigate that? How was that for you?

Nik Cook

I think I saw that better than Lisa saw it.

Alex Howard

Interesting.

Nik Cook

In that I think she actually whether it's a protective mechanism or she just genuinely didn't remember. I don't think even now I don't think she remembers quite how ill she was? And I also don't think she remembers that whenever during her recovery, she introduced something new whether it was going to do half a day's work at the local radio station or whether it was starting to lecture at the University again, there would be a bounce back and so she would also automatically go into I'm getting ill again. I'm never going to get better. I can't cope with this.

Whereas I would remember how this pattern had been and I'd be able to say actually no, when you did this last time this happened and then the most recent example of that was when she started doing a student teaching.

So the first week of being a student teacher she came home every afternoon and probably slept for four, five hours before when she got home so should get home say three four o'clock and she'd sleep

until 8:00 that evening. Yeah, I'll have some tweaking about that again. And for the first week should that every evening and at the week and the weekend should just crash completely.

The next week, probably three out of four weeks three or four weeks days one day weekend. She slept next week. It was probably one or two. And it's been a case of reminding her that has been a cycle throughout and it's just the way her body needs to adapt to it. And I think it's also having that and maintaining that objectivity. But making sure that it's realistic objectivity is a really, really important role that you.

Alex Howard - [00:34:07]

Well, I think that that's one of the as you say one of the really helpful roles that you can play as a carer that you can, in a sense because you're not quite so physically and emotionally impacted by the ups and downs, one of the things that people often forget is that when someone crashes physically they also crash emotionally because the whole capacity to produce hormones is often diminished in that period so one is producing less cortisol one less adrenaline less dopamine or whatever else so it isn't just physically one's exhausted, their mind their emotions will tend to go down with it. So it becomes quite hard to be objective when one is in a crash and also memory is State dependent. So the state were rain will help us access the memories that link to that so that's why when we are in love. We remember all the things that I like that we love and when we're in a state of anxiety, remember all the things that were worried about.

So when you get someone goes into a crash it's often quite hard to actually see it from an objective point of view. And that's one of the real values of someone on the outside such as yourself who is able to go. Well, actually I can see more of a clear trend here. So it sounds like the doing that and helping Lisa to see that was something you were able to do. That was really supportive.

Nik Cook

Yeah, and it's not a flawless process you have to time it so there are definitely times when Lisa might be having a crash and if you suddenly saw safer or actually work this time must have then you're going to get a bad reaction to that. So you've got to judge it and I'm and that there have been times when I go into that that cycle of oh God your you are getting ill again. You're not going to get well again, and I think that's where having particularly having done well, what about working on the practitioner course, I've learned some strategies for myself that allowed me best cope when I'm getting into that mindset.

And also that it was ironic who's during the recovery phase really the that I actually sought that therapeutic help myself I think in hindsight it wouldn't have been imported would be a very good idea for me to commit to have done that much earlier, but from my own point of view the the the issues that I really had were during recovery rather than during illness.

Alex Howard

So say a bit more about that the as she sometimes I think what can happen is as someone starts to improve it's almost like as the what the people around are able to get somewhere where someone said a crisis. Everyone around is in a state of my god with it's like a stress response. We have to deal with the crisis. That's almost that as we start to see that the crisis is although they might still be ill. We're coming out of this progress. We're moving forwards the somehow everyone calms down a bit and relax as a bit and there's actually more contact of one's emotions and it's almost like so it's like someone is in a war zone and handles it completely seemingly okay, comes back from the war zone and then has PTSD we weren't signs and they were there but it's when they're safe enough to feel it. Suddenly that stuff starts to get felt. Was that some of your experience or something?

Nik Cook

I think that there are a few areas in it a few issues. There was an issue like that you come out of firefighting mode. And you also, you have more time to engage with your own feelings and emotions,

you're not giving so much of your emotional energy to this other person. So you have got bit of time thinking, "How am I feeling about this?" I think there was also quite a sense of doubt and worry about is she really getting better? Can I back down? Can I stand down? So there's that. There's also I probably developed a real identity as a carer as a caregiver and had a role doing that, and it's a big role in my life doing that. I think identity with that. And there's probably this perverse part of me that didn't want to give was scared of giving that up. Would I still have a part in Lisa's life when she was better? She had little well-being cliched genuinely transformed as a person. So a lot of the stuff she had done.

Would I still have it but this part to play in her life?

Alex Howard - [00:39:15]

Yeah, it's like who are we as a couple? Yeah the other side of this as well right that there's a it's almost like you had to adapt to her being ill and that was a hard transition, but then you almost got a comfort zone that okay, now I know where I stand with this. But then you have to re adapt in terms to her to her getting well, which I think in in some ways almost more and more threatening adaptation in a sense because when someone gets ill, at least it's like well, they're dependent upon these so I've got some power in this Dynamic, for better or for worse and then if she starts to get well, it's like well, who is she on the other side and do I have a place in this relationship? And what is she's a different person but she's still Lisa. But yeah, I often think that there's a rediscovering of each other in a relationship on the other side of something like this.

Nik Cook

Oh no, definitely, and I think we're still to a point going through that stage and still working through that stage and yeah, we're still coming out the tunnel I'd say. So we're definitely heading towards the light but it's although no so ostensibly, physically, this is there. I still think as a couple we're still having to work at it and I think we're both aware. That was all her time to work at it and I think as I say for me seeking again seeking that help. Lisa's mom and then there's the therapist as well, asking for help and actually getting it, was really, really important for me.

Alex Howard

I'm sure and I think one of the things that's also just to make it even more explicit, one thing I think it's also quite challenging. Is that often on the recovery path, the one who is on that path is having to evolve and change as a person, they're becoming more aware of their unhelpful patterns there perhaps cultivating more than positive patterns they're reassessing their life, what's important, and for the one that's caring for them, most of their focus tends to be going into being caring being supportive being impacted by I'm sure but one's own self development isn't necessarily happening.

And normally you do get, you get it challenges in relationships. When if you've got two people that come in and they're connected as are the same and then we talk about a dance of change that one of them suddenly moving off in a whether it's up or down left or right talking my point but once evolving and changing and the other one is left with, one of three choices, do you join that person in the new dance, do you try and pull them back to the old dance? But that's not a good idea the new dancers what's facilitate your recovery or there's the risk of dancing different dances so it's and wondering how that process was for you in a sense of recognizing that hang on, this is changing. Did you feel that you wanted her to pull her back or was it just a recognition? Actually, I need to go on my own journey here.

Nik Cook

I think it's more the latter, but it was actually it was so I'm trying to get my head around time scale. So yes, it must have it came to a head, it would have been Christmas 2017 or so I just wasn't in a good place at all. I was just a feeling, that was when Lisa was really starting to get well again, then but mentally I was just I wasn't happy with the work I was doing, I wasn't feeling challenged I was just feeling directionless really and it was actually Lisa who said to me look, what do you want to do?

What can we do to give you that interest and that's when we started looking into a changing career or changing what an augmentation of career rather than changing career.

Yeah, maybe doing, no that's from start looking at maybe doing a Masters in sports psychology, but and that's eventually where we when we came around to doing the practitioners course to give me something notes to work towards and to allow me to develop them, it was almost having that permission from Lisa in a way to say I'm okay, you can do this now.

Alex Howard - [00:43:52]

Yes. Yeah. Well it in some ways. Also I suppose your life was somewhat on hold whilst you were supporting her, right? So there's was a double whammy that one hand. She's evolving and changing and you're not but also you've almost actively paused your life because you're prioritizing being available for her recovery. And I think that's also very common that certainly that the times that whatever reason I have contact with those that are caring for people that is part of the frustration that can also build up that it's that one's life one is not able to self actualize their own life because through the love and care of this other person that's having to take priority and that does have its own impact over time.

Nik Cook

Yeah, we often talk about an open way talk to Lisa about I've been juggling balls in that there's a number of balls that she's potentially gotten her like she's got work, she's got social, she's got exercise and it tends to be at the moment where she is she can probably do two out of three balls at a time and one has to be potentially put aside or she has to bring in a sleep ball to help over scoffs. Yeah, and I'd say that to her but then taking a step back, I didn't really apply it to myself as well.

And for an awful long time, I had my work as one ball, my cycling and racing as another ball, and I had Lisa looking after Lisa as a ball and those of that was my three balls and there wasn't any scope for anything else. Although my work had to remain as one size a ball. It couldn't grow. It couldn't change I couldn't add something else in and it was only when I got that not to say actually you can put me to one side now for a bit as as a carer that I could consider bringing something else. And so I think there was all that it was always going to stagger. I think she was always going to have to develop herself and change and evolve herself first and then I was always gonna have to have a little period of catching up.

Alex Howard

Yeah, but I think the fact you were able to navigate that together I think was really important which also brings me to a question around what helps you guys, what supported the communication between the two because they must have been quite a bit of moments of self awareness and insight but also quite a bit of dialogue I would imagine to discover those things what's helped that?

Nik Cook

I think Lisa, as part of her change and evolution, written as I think she engaged much more of her own emotions and was a lot more a lot more mindful, she did a lot of mindfulness work and meditation as I thought and I think that generally makes her a lot more aware of what's going on around her. So I think she was much more aware of the, something wasn't right with me and I think and reciprocally I think she encouraged me to talk more and become more involved so I think we benefited each other during that time, but it was also that made me going and seeing a therapist. I think also me doing the practitioners course, I've gotten in touch with a lot of issues...

Alex Howard

It's good for that.

Nik Cook - [00:47:47]

Exactly and I think that's really helped and I think having... And also going back to Lisa's mom. She is this for both of us a real conduit of our feelings in that she thinks the world of both of us and she will she's somebody who can both of us can talk to and I think it's as a couple we've come out of more coming out of Lisa's illness much stronger and much we communicate so much better.

Alex Howard

That was one of my one of my closing questions to you. You've obviously talked about the immense challenges that you guys have been on the people what anyone goes on through this Journey and yet I often think about depth of friendship. Let alone relationship is created by shared experiences. And that's why we can have friends from 20 years ago that we haven't seen in 20 years, but because he went on a crazy backpacking adventure through wherever together work with ended up sleeping rough the three days that we've still got like this bond and connection that's being created through that. I think the same is true. When you go through as a couple that if you're able to navigate them together, there's also a real gratitude and depth of bond. I'd love to hear a bit about what's the gifts have been for your relationship through this.

Nik Cook

Yeah exactly. But, and she has said it before, for her she says I'm guessing Chronic Fatigue or whatever was one of the best things that ever happened to her, it was a real wake-up call a real, what made her stop it made us stop assess. And gave her a reason and a need to change and evolve positively, to look at what she was doing career-wise etc etc and I think it and it did the very much similar thing slightly time liked with me. And as you say that shared experience, no one's ever going to be able to take that away from us, and the fact that we still got through that together. Yeah, and it created a lot of other positives and going back to one of the one of the really important things that did work when Lisa was ill was environmental change for her.

I really... And this is also when I had my broken leg as well the number of times we had jump when I was actually able to drive and because they had no automatic get in a car and drive up a hill and maybe total of 20 yards to the top of the hill and then also the from environmental point of view, Lisa was very much started to associate the house that we were living in with being ill, and that was a catalyst for us moving out and although we didn't move far, yeah, it was a really positive thing for us to do together.

And so I think there were happening so many plus sides of Lisa being ill and coming, getting through Lisa being ill and we're definitely stronger, happier and I think not necessarily physically healthier, but definitely mentally healthier a couple because of it.

Alex Howard

Yes, and I think you make a really good point there about and I notice I missed off our plan before but the value of changing, we talked about different types of tiredness of some health clinic in one of the forms of tiredness is environmental tiredness where one gets drained by simply just being in the same space and sometimes changing environment can give its own freshness in terms of energy that that's one of the ways that of course a carer can help is if someone has the energy to do it, is never something to be imposed, but somehow the energy to do it to go for a drive or to go and be somewhere different with knowing that that different environment it's still going to meet the various needs in terms of rest and quiet and food, whatever they may be but that can be another way of just very practically being able to help.

Nik, a question that I know is gonna be a lot of people's minds, is your mother-in-law available for hire?

Nik Cook

There are downsides to her as well. But yes, she's London-based so she's right there!

Alex Howard - [00:52:28]

So is there anything else you wanted to put in here before we just wrap up in and set up for the next one.

Nik Cook

I think the biggest lesson I think I learned I've learned is to ask for help. And not take all on your own shoulders. And whether that's friends, family or a paid professional, you need somebody who you can talk to and lean on. And I think I was lucky in that as I said, I had Lisa's mom and then I had some professional help as well. And I think I could have in hindsight actually benefited from more help, particular professional help even earlier in during recovery just to give coping mechanisms and help with what you're going through and although it can see I can probably seem slightly selfish in that you're not the one who's going through the illness. Yeah, the illness that is put on you and the drain that is put on you and the feelings that you have to deal with, those feelings of guilt and all those negative feelings. So if you've got some way and somebody to help you deal with those, you're just going to be a better carer and be able to give better care because of her.

Alex Howard

It is one of the things that we have such a strong emphasis on with the practitioners at the Optimum Health Clinic is their own self-care and it's something that I find that most practitioners that join us. Don't really get it until about four to six months into the job. I have a personal crisis a mini personal crisis make it up and get all that stuff that they talked about. Maybe I should start following the advice but there's there is something that is if we don't take care of ourselves, we are simply this is not a spread this has multiple marathons that you have to do as a carer that if you don't take care of yourself you end up being less support and in and in danger of being a drain on that person and so I think you're right, and it does take a certain amount of courage and vulnerability sometimes to go I'm human and I need some help and hopefully it's all three. Hopefully it's friends, it's family and it's a professional. But even if it's one or two out of those three that's at least a great starting point.

Nik Cook

Definitely. Yeah.

Alex Howard

Great! Nik, thank you so much for being so willing to be so open and vulnerable in terms of this. I think it would have been really helpful for people and I'm looking forward to in our third session together, we're going to take some of the key things from this and perhaps a few other pieces and be a bit more prescriptive in terms of some of the key principles and some of the key ways that carers can take care of themselves, be the best support they can for the person they're supporting and some of the tips and lessons.

For now, thank you so much for your time and your willingness. I really appreciate it.

Nik Cook

No problem at all.