



Support for carers session 1

What is wrong with my loved one?

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Alex Howard - [00:00:15]

Welcome to the Fatigue Super Conference. This is going to be an interesting one, because in this session, I'm the one being interviewed. I was just saying to Nik, who's going to be interviewing me, that I realize it's rather easier being the interviewer. That's an unfair thing to say to Nik when I've, at this point, done dozens of these interviews for the conference.

But this is the first in a series of videos that Nik and I are going to do together. Really targeted at those supporting people suffering from fatigue and related conditions. The reason why Nik's going to be interviewing me is Nik's wife, Lisa, had her own journey with ME/Chronic Fatigue, so on the more severe end, let's say, of the kind of general fatigue spectrum. She was a patient with us at the Optimum Health Clinic.

And Nik then obviously was in a supporting/caring role for Lisa, and then went on, has been doing our therapeutic coaching practitioner training program. So Nik and I have got to know each other a little bit through that.

It was actually Nik that came to me and said, "I think you guys should do something, or we could do something together, really to give more understanding, more support for those caring for people with fatigue-related conditions." I thought that this online conference will be a good place to start some of that process.

So Nik, welcome, and thank you very much for being here.

Nik Cook

No problem at all.

Yeah, as Alex was saying, the main thing is it's given me an opportunity to ask those questions that I would've loved to have been able to ask when Lisa became ill, when we were sort of working our way through that entire maze of her illness.

I guess the first one is that I know when Lisa became ill, every doctor we saw seemed to have an answer. That answer was inevitably tied to their own speciality. That often gave us the great moments of hope, where they would say, "Yes, it's endocrinological, so we're going to give you that sort of cure." They just failed one by one by one by one. Is this something you often see?

Alex Howard

Yes, unfortunately. It can be more complicated than that, because I think you have such a range of perspectives. If you go down the more traditional medical path, often you can get met with one of two perspectives. Either a perspective wrong of, "I can't find anything wrong with you, therefore there is nothing wrong with you," or "There's something wrong with you and I don't understand what it is, therefore it's incurable or untreatable; there's nothing that can be done." A cynic might say that that's

the kind of arrogance of a traditional kind of allopathic or orthodox medical system; that we know everything there is to know, and therefore if we don't know what's wrong with you or we don't know how to fix it, then no one else does.

So you either kind of get those kind of perspectives, or what you were describing Nik, where you kind of go to your gastroenterologist or your endocrinologist or your cardiologist or whatever, and they look at it through a very specific lens, and they have the answers that kind of go with that particular lens. I liken it a little bit to, you go to the butcher's and you say, "I'm having a dinner party tonight. Do you have any suggestions? What would be good?" They'll say, "Well Nik, yes, we have some fantastic steaks in tonight or some great lamb cutlets," whatever it might be. Then you go to the fish monger and say, "I'm having a dinner party tonight." They say, "We've got fantastic lemon sole that's just fresh off the catch this morning."

People tend to see things through the lens of how they see it. It's not that they're necessarily even being cynical or skeptical or rejecting of other things; they're just not looking. I think that becomes incredibly frustrating for people that are used to suffering from more kind of acute medical conditions. Where you break your arm for example, and you go to accident and emergency or whatever, and they x-ray your arm and say, "Yup, it's broken here, and we need to give you some painkillers for the pain. We need to kind make sure the bone's set, maybe put it in a cast. Then come back in six weeks; we'll make sure that it's kind of healing as it needs to."

Those kind of specific things. Or if somebody has got a kind of clear medical condition like diabetes, it's like, "Okay, you need to be injecting insulin," assuming it's Type I diabetes. There are some things we need to do. But when you get something like a lot of the fatigue conditions - ME/Chronic Fatigue, fibromyalgia, Lyme - these things are multifaceted with multiple components happening in different ways. All of these systems are all interlinked, so something goes out of balance in one place, it affects something in another place. And that could be, I think, as you're describing, just very, very confusing.

It was 23 years ago that I first got sick. Then after having recovered after seven years and then spent, I think it's now 16 years, kind of specializing and helping people, I still find it... Doing this conference, I'm still learning stuff all the time. So I think for someone that's new on that journey, or indeed medics that don't see a lot of it, I think it's very confusing.

Nik Cook - [00:05:58]

And I think one of the things that we really saw is it's not that they weren't necessarily finding things that weren't right or were wrong. For example, the endocrinologist found a pituitary tumor and treated that. But then we were then left in the situation where we didn't know whether then the medication for that was contributing to this fatigue. There was any holistic approach or there wasn't any talking to other medical professionals or sort of engagement saying, "Actually, let's attack this from a wider viewpoint rather than this very narrow viewpoint."

Alex Howard

It's interesting. I think it's something that is, beyond even fatigue-related conditions, I think it kind of a systemic problem within much of modern health care. I can't speak so much about other countries, but I think it's probably true, but certainly in the UK. Even just looking at my mother and stepfather in their early 70s with various ailments and things that are going on. Just how little communication there'll be between the different people that they're seeing.

Actually, it takes a significant amount of self responsibility and ability to piece together things oneself. Sometimes, often, with fatigue-related conditions, it takes quite a lot of self confidence and ability to articulate oneself and to stand for one's rights and to be willing to... A lot of us can have a relationship to the medical world. I see this a lot in my parents' generation, of, "Well, they're the experts; they know. You shouldn't ever question it. If they tell you to do this, you do this." It takes a certain challenging of that and going, "Hang on, do you realize I'm doing this? And actually, this person said this." That's a big mindset shift for people, to take that kind of responsibility in that process.

Nik Cook - [00:07:55]

And I know you talk about a diagnosis of exclusion a fair amount. Can you explain more about what that is, and what you mean by that?

Alex Howard

Yeah. Firstly, I think we should say that the labels that we have for these conditions are not fit for purpose, I think would be a blunt way of putting it. We likely got the, certainly more in the US, one tends to get the Chronic Fatigue syndrome of the fibromyalgia diagnosis.

Here in the UK, people are more likely to get a myalgic encephalomyelitis or ME diagnosis. There's also beginning to become a bit more awareness around Lyme as a specific diagnosis. On the more nutritional therapy functional medicine path, people are maybe more likely to get an adrenal fatigue diagnosis. We have these different labels which are used in different ways.

But I think these labels, in and of themselves, I think are utterly flawed. I remember when I got diagnosed with Chronic Fatigue syndrome. Going to the doctor and saying, "Basically, I'm tired all the time. I haven't got the energy." Just going to the doctor's was a massive event; it was the biggest thing I'd done in a month, just to be able to go to the doctor's at that point and to get a diagnosis. I say, "I'm chronically exhausted." It's like, "You've got Chronic Fatigue syndrome." Putting the word syndrome on the end of what I've already told you, which is I'm chronically tired, is not a diagnosis.

There's been a lot of frustration and infighting and battles, really, even within the community of sufferers of these conditions around what labels we should use, around what diagnostic criteria that we should use. Certainly it's a little bit different for Lyme. Although with Lyme, there's a lot of questions around the testing there of getting a lot of false negatives. That's a whole other kind of piece. But certainly with ME/Chronic Fatigue, there are certain symptoms that one has to have, such as fatigue being one of the primary symptoms. There has to be no other explanation for those symptoms. If there's no other explanation and you have those symptoms, it depends upon which diagnostic criteria you use, whether it has to be for three months or six months. The diagnostic criteria we use here in the UK, it's six months adults and three months for children. But again, that's a whole other point of debate.

It's basically, if you have this set of symptoms, there's no other reason why you have these set of symptoms, then you get a diagnosis. It's called a diagnosis of exclusion because basically all you're doing is excluding other explanations for the symptoms. There is no biomarker at this point in time. It's something that we at the Optimum Health Clinic with our research work have been trying to push forward. The challenge is, there needs to be more recognition and definition of the subgroups, because we're not talking about one population that have all the same things going on. We would argue, and it's one of the things that I think will become clearer to people that have gone deeper into some of the interviews within this online conference, that there are subgroups around mitochondrial function. People where the primary cause of fatigue is they're not making energy on a cellular level. There are subgroups around digestive function. There are subgroups around adrenal function. Same with Lyme.

So I would place a fairly large bet, we would never find a single biomarker that effectively diagnoses this whole population. I think it's a series of biomarkers. The not having of that has all kinds of problems that go with it. Beyond the problems of not having clarity of diagnosis informing on treatment, it's also had a significant impact on influencing cultural perception of these conditions. Because culture and society is used to... You have, for example, something like cancer. You go and have various investigation. You get a diagnosis of cancer, and you can see that in various lab reports that support that. That lack of a biomarker is what's supported a lot of these ideas with fatigue that people are making it up, or it's not real, or it's psychosomatic in some way. It goes back to my earlier point that I think it's an incredibly high level of arrogance of orthodox medicine to say, "We don't understand what's happening, therefore it doesn't exist."

Nik Cook - [00:12:49]

When I look back, in hindsight, which is obviously a lot better, there were so many possible causes for her. There was an incidence of going to the fever when she's working at the BBC, there was hormonal imbalances from the pituitary tumor, medication to correct this, really stressful dealing with her father's state. The list goes on and on and on. My feeling now is that it was an imperfect storm of all of these factors interacting and contributing. Do you agree with that?

Alex Howard

I think so. This is where no two cases really are the same. Even though there are, we have certain maps, ways that we kind of piece together... Effectively, we see recovery as about having a jigsaw and you've got to have the right pieces to that jigsaw. It's kind of a similar thing in terms of someone getting sick in the first place. It's a series of things that come together. Rarely is it just one thing. There are instances, but they're rare, where somebody has a very significant thing that happens, be that a viral thing, maybe that's Lyme or co-infections. Or they have a massive emotional trauma if they come back from a war zone and they've got PTSD. That then has major impacts in terms of their energy levels and nervous system.

But normally what you have, it's like kind of loads on a boat, and you have a series of these different loads and it's no one load on its own. It's the cumulative effect. Another metaphor would be it's like straws on a camel's back. It's the final straw that breaks the camel's back, not the 1000 straws or 100 straws or whatever that came before. These factors can be many, many different things. They can be - I think we're going to come to this in a little bit - but certain kind of psychological factors that may be going on, and sometimes personality tendencies. They can be viral factors. They could be life events, something like what you were describing. These things together gradually kind of weaken the system.

I think one of the big challenges that happens then is, it's not just what causes someone to crash and become sick. It's also what stops people from healing. Suddenly, you've got this whole new strategy. Let's say someone's used to creating 100 units of energy a day, and they're used to spending a range of 80 to 100. If someone stays within that balance, then as long as it's been 100 every day, you've got a little bit of reserve. It's a bit like money. If you add 100 pounds a week and you spend 80 pounds a week, life's good. If you had 100 pounds a week, you spend 101 pounds a week, life's bad. Sarah Myhill talks about this in her interviews.

What can happen is that then, the amount of money you're earning or energy you're creating starts to go down. If you were creating 100 units of energy, you're down to 80 or 60 or 50. So people will say, "but I'm not doing anything, I've completely reduced my activity. I'm resting all the time." But if you're still out of balance there, maybe you're creating 60 and you're spending 70, you're like, "but I'm doing 30 less than I was before." Then you start to have this kind of stress of being ill; that you're trying to struggle with life with depleted resources. It takes energy to heal, and there's not energy that's then available to heal. Then you can get in a bit of a slippery slope, where you do last but you're still crashing and it's still too much.

There's the factors that built up to someone getting sick; what we call predisposing factors. There might be some kind of trigger, like some final straw or some big thing that happens. Then there's the cycles that people get stuck in when all these factors are kind of laid on top of them. Sometimes, you start to deal with those predisposing factors, but you also have to deal with where someone is at that point in time.

Nik Cook

I know when a doctor who happened to be a friend of mine, who is a sports doctor, he's worked with a number of pro cycling teams, he actually tentatively suggested the ME/CFS diagnosis. I remember her reaction to him saying that was actually quite sort of, "no, I don't want that. I haven't got that. That's not real." Is that something you encounter and see?

Alex Howard - [00:17:25]

Yeah, I think so. I think that there can be quite a significant trauma sometimes with diagnosis. There's been some interesting research that's been done on other medical conditions on how someone is told that they've got something, and the way that that's framed, the way that that's presented, can actually have an impact on outcome. Because it kind of determines how someone responds to it.

Again, I'm jumping ahead a bit here, but people will say that these conditions are psychosomatic. The thing that I always say is if you're going to make up a condition, you'd do better to make up one that society has more respect for, right? More likely to get some sympathy and some empathy if you choose better. It's just one of those conditions; there's so many cultural stereotypes around it. Be it kind of yuppie flu in the 80s; be it the comedy interpretations that people have about this. But it is not a diagnosis that people want to have. It is getting that diagnosis that people can be very defensive and go, "That's absolutely not me." Or it can feel like a temporary relief like, "At least I've kind of got a sense of what this is." Then there's often an overwhelming, one realizes that the path out is - at least in orthodox ways - is not a very straight forward or easy or even guaranteed path out.

I think, how one responds to that diagnosis, I think getting a diagnosis is important. There might be people that are watching this where their loved ones are almost self diagnosing and thinking, "Well, I must have this because I have all these symptoms that are going on." I would always very strongly encourage someone to go and make sure they have got a proper diagnosis. Because there are other conditions which are medically identifiable that can create all of these sorts of symptoms that, A) could be a path to a much simpler path out, and B) not tackled appropriately, could also result in things not being dealt with and things getting worse.

But if one has got this diagnosis, realizing that it is something that doesn't have to be a life sentence. But it is something where one is likely to have to take the bull by the horns and be the one that, or indeed, people watching them as the carers around people, that one's support network is going to play a crucial role in changing the outcome from just having to learn to live with a condition like this.

Nik Cook

I think one of the things I saw at that time was I really had to give her space and time to accept and come to terms with that diagnosis. There was no point in me trying to sort of push her towards... I instantly sort of saw it. The doctor actually recommended the OHC. I instantly started googling it and looking at it saying, "That looks great. You should go on that." She just wasn't ready at that time to do that.

Alex Howard

I think that can be common. When one is suffering with particularly severe fatigue, one feels a gradual loss of control in their life. If someone's used to having a career or going out with friends and family, having choices about what you want to do at the weekend, and suddenly you're doing less and less because your energy's getting less and less. The last thing that someone wants to feel is that, "and even now, I'm not in control of what happens next in terms of the recovery path". Particularly with teenagers, one of the real challenges can be that you want them to feel they've still got some control over their destiny and their life. But it's also getting them to open up to the potential that things can be different.

I've had a number of times over the years working with teenagers where I spend the first two, three, four sessions just trying to engage them in the idea of, A) accepting that something really is going on, and B) that they could play a role in being able to change that. But I know that when I was ill, I spent two years basically in hell; struggling to do an hour or two of schoolwork from home a day, barely able to go out, in pain, severe fatigue, often nausea, dizziness. I went through two years in hell until I had basically a conversation with my uncle where I said, "I don't want to live anymore." It wasn't that I was actively planning my suicide; I just couldn't face it. I was helped to realize that if I wanted the circumstances to change, I was going to have to be the one to change them. But I wasn't ready to hear that two years earlier. I can be quite stubborn by nature.

Although I had been doing a few things in those two years driven by my grandmother, ultimately when it really changed was when I took responsibility for that.

As you were saying with Lisa, you can't really enforce that upon somebody. You have to give them space and be patient, and try and light the flame or stoke the fire a little bit. Ways I think that could be helpful is people sending people links to interviews like this, sending links to other parts of this online conference. Books of people that have been through... My book's, I think, been a good source to some people, of reading a recovery story and identifying them in that. But I think, yeah, it's a tough one. I think particularly for carers or for friends and family, that if you can see some things that someone can do and they're not ready to hear it; you're seeing them suffer, you're suffering alongside them. It takes a level of patience and skill to navigate that.

Nik Cook - [00:23:05]

Yeah. I think in hindsight, I probably could have managed that situation better, but I just wasn't equipped at that time to do that.

You've already touched on the psychological aspect. I know with Lisa, it was one of the aspects of her treatment that initially she was really quite hesitant about, and sort of quite, "Well, that's in my head. Why do I need that?" But in actual fact, it's probably been the thing that's contributed most to her recovery, and it's the thing that she's used as ongoing as part of her sort of recovery.

But equally, we've got a friend who has quite bad fibromyalgia, and she won't even contemplate any form of psychological intervention because she thinks that's people saying, "It's in your head."

Alex Howard

Yeah, it's a really good point. There's an interview as part of this online conference with Nikkie, who's one of the psychology team at the Optimum Health Clinic. It's called - or at least it is at the moment; it might be changed by the time it goes live - at the moment, it's tentatively titled *Psychology is Physiology*. That's a really good one for people to check out, because in that dialogue, she talks about her... She was working as a physiotherapist, so was very much in the traditional medical model mindset. Talks a bit about her own journey to recovery and her understanding and realizing how the psychology and physiology interrelate. That's a good one to check out.

But just to give a few comments from my perspective around that. One of the things that's really important to understand is that the cultural way of talking about the role of psychology in a condition like this, is people's inference is that it's psychosomatic. That what someone's experiencing is not real; it's simply a case of it's imaginary in their head and they believe it's real. Which I would put in a similar category to phantom limping, where an amputee has had a leg removed for whatever reason and they still have pain in a leg that's not there. That's psychosomatic. It's not that the pain isn't real, and the brain's interpretation of that pain can have genuine suffering. I'm not trying to diminish that experience. But what's important to understand is this is not the same as that. This is not that someone has some kind of unconscious thought pattern around illness and therefore they're manifesting illness through that.

What we're talking about is psychology playing a number of different roles, and - as I think will become abundantly clear from this online conference - there's all kinds of physical processes that we see as being crucially important. But as we're looking at it right now from a psychology point of view, psychology plays a role in what we call these predisposing factors that I just loosely mentioned earlier. Things like if people are achievers by nature, where they measure their self worth by what they do and what they achieve in this world. Or if people are helpers, where their self worth is measured by what they do for others. If people have a sense of anxiety by nature, they tend to worry and be in a perpetual state of overstimulation in their thinking. Or if there's some kind of trauma that's happened but hasn't been digested and processed, and therefore it's triggering the nervous system.

These are what we call energy-depleting psychologies. They're ways of meeting the world, which are inherently draining and depleting. Would those factors alone cause someone to have mild fatigue? I

think they would. Would they be the primary cause of someone having a severe state of Chronic Fatigue? It's unlikely. It goes back to what you were mentioning earlier, Nik, around it's kind of loads on a boat. There's multiple factors.

But we have these predisposing factors. We then have, what I also touched on a little bit earlier, about this idea of the stress of living with a chronic illness. We at the Optimum Health Clinic, or OHC as people refer to it, call this maladaptive stress response, where a nervous system is in an ongoing state of overstimulation. That could be for a number of reasons. It can be because we're depleted in our normal energy, like our mitochondria are not functioning as they need to, so we're constantly using our adrenals to keep us going. This can be a physically induced state of sympathetic nervous system arousal of being overstimulated.

Or it can be that we've got this ongoing anxiety of what's wrong with me, why is it wrong with me, will I ever recover, should I rest, should I not rest, should I push myself, how will I feel tomorrow, how am I going to explain to this person that I can't do this thing I was going to do? This then creates this ongoing state of our nervous system being stimulated. When we're in that state, it's very difficult for the body to heal. There's, again, various places in this online conference, people talking about the impact of the sympathetic nervous system being on and not having that parasympathetic healing state. It affects digestion, it affects our hormones, it affects our sleep. There are people where just calming that down alone has a massive impact on the recovery path.

There are other ways that psychology can play a role as well. Just briefly, learning how to pace and listen to one's body is crucial. How much one does, and that not being a printout from a CBT practitioner that says, "This is what you should be doing each day," because that's just going from one's own pushing themselves to someone else's plan. It should be a list of things, so the constant messages and feedback from one's body. Learning to do that; learning to actually feel things, feel emotions, feel your body's communications. How to be one's own best coach. How to support oneself through the highs and the lows and the challenges. How to deal with these subtypes I mentioned. Defining one's self worth differently from just achievements and health.

There's a lot of these factors. It's not that any one of those things alone is like a magic bullet which then is the cause of recovery. It's that we need to ultimately break the habit where we are constantly pushing our system and doing too much. The body needs to be in a healing state where its own healing processes can happen. We're talking about recovery from certainly the more severe ends of the fatigue spectrum being as complicated as trying to climb Mount Everest. The nuance and the details and what each day the different decisions that need to be taken. So being able to be one's own best support. If you're only with a practitioner once a week or once a month, that's a lot of hours of decisions that need to be made that we're trying to coach and support people in how to best take care of themselves.

Nik Cook - [00:30:21]

I think that's a really good analogy, the climbing Mount Everest. Part of parcel of that is you go high, and then you come back down again. You go a bit higher, you come back down again. That's really what the recovery process felt like, and still feels like to a certain extent with Lisa. We'll make these progressions forward, and she'll make these progressions forward. But inevitably, they're usually then followed with a little slip back. It won't be quite back as far as she was, although sometimes they have been. But it's a constant back and forwards. It's not a linear process, by any stretch of the imagination.

Alex Howard

Yeah, that's right. That's very common. That's kind of going back also to what we were saying earlier on around this idea of people really have to become the captain of the ship of their own recovery. It's a fundamental shift in one's relationship to really the medical system and the medical world. It's good timing, us recording this conversation, because I'm, at this point, two thirds of the way through the other interviews that we've done.

I've just been to another one, James Maskill talks about the evolution, I can't remember the title of the interview, but it's basically the evolution of functional medicine and health care. He talks about the importance of the role of being responsible, really, for one's own recovery, and the role the community can also play in that as well.

Nik Cook - [00:31:45]

Yeah. I've really found that with Lisa, I think what I find one of the most positive contributions I'm able to make to her recovery is actually reminding her that this has been the sort of progression all the way along. When she's sort of pushed or bounced her boundaries a bit too much and she's having a little bit of a mini dip, I'll say, "Yeah, if you tried to do that six months, you wouldn't be having a mini dip. You'd be having a full-on crash." It's sort of that process of trying to maintain objectivity and just reminder.

I think there's been a lot of cases where she doesn't actually remember how ill she was. Whether that's her protecting herself or ever... As part and parcel of that, she doesn't really sort of have a clear timeline of her recovery in the same way that I have. I think providing that support and helping her to steer that ship is really important.

Alex Howard

It's funny; talking about climbing mountains. There's certain patients or certain moments over the years with the Optimum Health Clinic which are just stuck in all of our minds either because they're so emotive or powerful, or sometimes just because they're funny. I'm allowed to laugh at this one because the patient involved actually, at the time, was also working for our admin team so we kind of became friends as well.

He came into a session. I was like, "How are you doing?" He was like, "Terrible, as bad as I was a year or so ago again." As a practitioner, you're kind of sat there thinking, "Oh man, I wonder what's going on. He was doing so much better." This was a kind of throwaway comment, "What were you up to at the weekend?" "Oh, I climbed Mount Snowdonia." Someone that's gone from almost being housebound to climbing one of the tallest mountains in the UK. It's like, "I get that you feel terrible, but we have to have some context in terms of what's happening here."

I think that you're right. I know we'll talk in one of our subsequent dialogues around how you can be supportive to someone that's going through this. But I think you're absolutely right. Just that more objective outside perspective, which is very hard to do when you're just consumed by living in this incredibly difficult... I think most people would say they have been through fatigue, and particularly the more severe ends, will say it's the hardest thing they did in their lifetime. I think it's an important context to keep that in sometimes.

Nik Cook

It's no wonder, looking back, that if there were potentially so many factors involved in her illness, it's no surprise that no one treatment worked for her at all. Sort of that multi-factor approach was just so key.

Alex Howard

This is going to be a confessional moment for me. One of my biggest frustrations in the self help and natural health movement of the last 25, 30 years is this consistent theme that happens where somebody will be suffering from some kind of chronic illness, and often it's a fatigue-related condition. They will try a number of things along the way. They will go and do this one thing that seems to be this miracle answer for them. If we go back 25 years ago, that was often people doing an anti-candida program. Or over the years, there's been different psychological approaches, there's been different supplements, different... Fads is a strong word, but themes of things that have been popular at certain points in time.

You have a few people that go and do that approach and it's the answer for them. Then inevitably what happens is those people end up going and training in that approach. They end up going out there and saying, "This is the answer." The truth is, and I could say this, I think, fairly confidently having overseen the Optimum Health Clinic supporting thousands and thousands of patients in over 40 countries around the world, that there is no one answer.

There's rarely one answer for each individual, let alone one answer that's the whole picture for everyone. There are patterns and there are clues and there are key pieces and there are building blocks that everyone should be doing. But when we're going out there in the traditional germ theory model of medicine, where there's a pathogen and we need to find something to kill a pathogen. There's a single problem and a single solution, we end up getting just disappointed and frustrated and overwhelmed in that process.

Unfortunately that's fed by the simplistic perspective that a lot of books tend to take where they're presenting a particular approach. So inevitably they, in a biased way, take all the evidence that supports that approach. Nutrition's one of the best examples of that. If you would take the nutritional advice of everyone in the nutritional medicine world, you would not eat. I can tell you that every single food would end up... You take one diet and they say you can't eat these foods, so you take those ones out. Go to another diet and you can't eat these foods. You go long enough on that process, you will have no food left.

There's this kind of frustration that there's all these things offered as one answer. Actually what we have to do is, again, it goes back to being the captain of the ship of our own recovery. Working with skilled practitioners that are able to take a big enough distance from the jigsaw to not just be looking at a few pieces. As we were saying at the start, go to the butchers and say, "What should I have for dinner?" Because I can tell you now, they're not going to recommend you have a raw food dinner. You have to have this recognition of these different pieces. It's immensely complicated. If there wasn't so much suffering that's involved, I would say this is the most fascinating jigsaw in the world. But I wouldn't want to infer that there's a pleasure in the solving of that puzzle because of the level of suffering that people are going through.

Nik Cook - [00:37:56]

I totally agree. I know Lisa really went through, I've referred to it as her clutching at recoveries phase, where she was reading every sort of book on the planet. One case, I can't remember what exactly the book was, but it was a very sort of evangelical story of somebody following a graded exercise plan. That really appealed to her mindset of being able to make a spreadsheet of how she was going to increase her exercise daily, and this was going to sort it out, this was going to cure out. It absolutely wiped her out for about a week and a half. It was totally wrong for her.

Then she sort of started grabbing at every single nutritional book there was, and cutting things out of her diet. I think she bought up Holland Barrett, from a supplement point of view. Housing all these supplements into herself. I remember when she actually finally came to talk to the nutritionist and she told them what she had been taking. The nutritionist went, "You're obviously quite robust."

Yeah, she was looking for that single answer and it just wasn't there.

Alex Howard

Obviously it's completely understandable human nature to want to find answers. Indeed, people wouldn't find Optimum Health Clinic if they didn't have that drive to find answers. The challenge is, that drive to find answers often results in people self medicating so many supplements that all they do is have incredibly expensive poo, because it's just too much for the body to go and deal with.

I've said a few times on this online conference that one of my only real fears with this online conference is that someone might listen to all of the interviews, take everything that's recommended, and do all those things. Which is a terrifying prospect in a sense. That's where a really skilled practitioner comes in, and it's also where one's own capacity to piece together the jigsaw comes in.

You can do all the right things in the wrong sequence, and it will not work and make things worse. You could do nine right things and one wrong thing and it not work. You could do all the right things in too much and it could not work. That's where one really has to be patient, one has to be persistent, and one needs to be figuring out as they go along. I think we do a great job at the Optimum Health Clinic of fast tracking and simplifying that process. But it's still a process and it's still a journey that we go on with the people that we support, as I know that you know.

Nik Cook - [00:40:39]

Almost in summary, is it fair to say then that CFS/ME fatigue is an umbrella diagnosis, that in reality it's just describing a range of symptoms rather than one specific condition?

Alex Howard

Yeah. It's such an appalling diagnosis in the sense that we really do need, it's what the functional medicine world is certainly doing really well, looking at these interviews, it's interesting that people will notice if they go through all the interviews on this conference, that there are certain practitioners which come very much from a, in a traditional world, one would call it endocrinology perspectives. They're looking much more at hormones, blood sugar things like the thyroid. There are others that are looking much more at it from an immune perspective. They're looking at things like Lyme, co-infections, that sort of thing. Others looking much more from a kind of digestive perspective.

This kind of recognition and definition of different subgroups, different kind of systems, different parts of the jigsaw is what's happening in the functional medicine world. It's certainly the model that we've been using for the last 16 or so years here at the Optimum Health Clinic. But in a sense, you have to move beyond this idea of Lyme or Chronic Fatigue or adrenal fatigue or fibromyalgia or ME, to it's a set of processes that are happening in the body, and things that are out of balance that might not be... Like adrenals that are completely failed and you're in Addison's Disease, for example. But the sub ops were functioning, and that's having an impact on pap's digestion, and that's having an impact upon energy, and that's having an impact upon how the brain's function is. All these inter linkages.

It is fascinating, and it is complicated, and it requires that understanding of the jigsaw, the map, the picture, the sequences of how things work. I think the sooner people, in their own minds, even though the label can be useful to a point in terms of communicating to others, the sooner one can move beyond, "I have this label" to understanding these different factors of what's happening, you're then in a much more empowered place in terms of what do you actually do about it. Because knowing that you have Chronic Fatigue or Lyme or fibromyalgia doesn't tell you what to do; it just gives you a label of a set of symptoms.

Nik Cook

Yeah. When Lisa had got that diagnosis and once she had expected it, it was only really once she started her treatment with you guys that I felt we were making any progress at all. That actually we were going through methodically and working through what the possible contributing factors could be. Almost chopping those trees down one by one. That's what it felt like. It felt like sort of felling a forest.

Alex Howard

Yeah. Just to give people a sense of what's to come, Nik. I know we're going to do another session together exploring what one can do to support their loved one. I think that one will be a bit more collaborative, because I've got some questions for you on that because of you having been through that.

Nik Cook

I think it's mainly going to be the mistakes I made; what I could've done better. But yeah, that's what it's all about.

Alex Howard - [00:44:06]

We can share on that. Because as I know you know, as perhaps we'll come into in that dialogue, but my sister in law ended up with Lyme disease five or six years ago, so I also got to be the role of carer because she lived in my house for two and a half years. I will share with you, and we'll swap stories of how we made those mistakes.

For now, Nik, thank you for the great questions, and look forward to talking together on our next session.

Nik Cook

Look forward to it as well. Thanks very much.