

# Secrets to Recovery: A film about ME, CFS and Fibromyalgia

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# Alex Howard - [00:00:00]

At my lowest point of ME, after being virtually housebound for two years. I promised that if I ever recovered, I would help others. When I recovered five years later, I made good on that promise and I set up the Optimum Health Clinic. In the thirteen years since then, we've worked with thousands of patients in over 35 countries, and that's only the beginning of our story.

ME, chronic fatigue and fibromyalgia affects millions of people around the world. And behind every statistic is a real story of suffering and challenge. What started off as my story has become our story.

# Person 1

It was terrifying. I didn't know what was happening.

# Person 2

I just felt so exhausted all the time.

# Person 3

Every day was miserable.

# Person 4

I literally couldn't get out of bed.

#### Person 5

I desperately didn't want to listen to my body.

#### Person 6

I didn't know what was wrong with me. I was alone in the world with this problem with no answers.

#### Person 7

I wouldn't say a death sentence, but it certainly felt like a life sentence.

#### Person 8

All I wanted was to hear about people who have been this ill and got better.

# David Butcher - [00:01:45]

Well, you know, my life before I crashed with ME/Chronic Fatigue was characterized really by excitement and high energy. I was a chief executive three times. I worked on turnaround businesses. I did two start up businesses. And what I loved about that very long career was the sense of challenge all the time. You know, I guess I'm a bit of a high achiever, what you'd call a type A personality. And I always love new challenges.

## **James Alexander**

Before I got ill, I lived a really active lifestyle. I used to love mountain biking, going downhill, dirt jumping, really dangerous quite a lot of the time. I used to love skateboarding, anything that was giving me an adrenaline rush. I lived a really active lifestyle.

# **Claire Jones**

I started playing musical instruments when I was seven years of age. I played the piano, the violin and the harp. And continued to study these instruments all the way through my childhood, and it became apparent to me very early on that my passion and my drive was all in music really. So I embarked on a journey to audition then for the Royal College of Music in London and then the Royal Academy of Music to do my master's degree. I did actually audition for the position of royal harpist for Prince Charles. I became his harpist for four years and in that time, I got to do wonderful things like, I performed 180 times royalty and one to one for her Majesty the Queen, played at the royal wedding for William and Kate as well. So some really fantastic memories. Loved every single second of it.

# **David Butcher**

The build up to crashing with ME/Chronic Fatigue started with my wife being diagnosed with breast cancer. And she went on a horrific journey, first of all, recovering after lots of, you know, radiation, chemotherapy and then the cancer coming back. And, you know, it was a horrible illness. She had multiple tumors. So I was caring for her and my daughter 24/7 for five years. And in parallel to that, my dad was slowly fading with Parkinson's disease. And I was going to see him as often as I could and, you know, supporting my mom. So I had that kind of double whammy of two terminal illnesses within the family.

#### **Claire Jones**

I started to realize something wasn't quite right, really, with my body and how I was feeling really in my early twenties. I had shingles when I was sixteen and I would sometimes get quite, sort of full on viruses or illnesses, which would kind of strike me down for a few weeks. And then I'd kind of go back a hundred miles an hour again and try and live my life as full as possible.

#### **James Alexander**

When I got ill, there were two starting points. There was a starting point of when my health was declining and I didn't really realize it yet. For example, I couldn't really get up for school. I was always late for school, I was always extremely tired. But at that point in my life, I associated tiredness with laziness if it meant I was cycling with friends I was extremely tired. I kept going because that meant I was lazy. I never really associated tiredness with anything other than that's what you're meant to feel at bedtime kind of thing. It was, tiredness was something for lazy people.

#### **David Butcher**

I was just focusing on what I needed to do to support my wife and my daughter and my dad. And in that process, of course, I completely lost sight of myself. I just buried all those emotions, all that anger and anxiety and frustration and the general emotional trauma of knowing that I was going to lose my wife and my dad. I just buried all that.

### James Alexander - [00:05:26]

When I started to really get ill was when my body had had enough of me ignoring it, it was about age seventeen. And I started to have panic attacks out of nowhere. That's when I knew something was wrong. I was tired all the time. I was starting to have panic attacks. This obviously led to a decline in mental health as well. I was depressed. I just didn't feel good anymore. And the more that happened to me, the more I wanted to be isolated from the world.

# **David Butcher**

When I stopped working in the financial services world, I took up drumming. I did loads of lessons and workshops and so on. And eventually I put my own band together as a kind of a blues band, a blues rock band. We had a terrific gig at The Bull's Head in Barnes in Southwest London, which is a very famous jazz and blues venue. And, you know, we had a fantastic time, but that was really the sort of tipping point, I think, because what happened was there were two bands booked on that occasion. We were the support band and we were due to play for an hour. And just shortly before we started playing, the guy who ran the venue told us that the headline act had pulled out for whatever reason. And could we play a second set? Well, you know, we had enough material to play a second set. But I can tell you, by the time I got to the end of the first set, I was pretty depleted. And so it really was a question of running on empty for playing that second set. I did it and it probably sounded all right. But inside I was just burning energy that I didn't have, and that was the straw that broke the camel's back.

# **Claire Jones**

I started getting really sort of, well, painful feelings in my body really throughout my muscles, like sort of little electric shocks kind of thing, that kind of feeling. Aches that were really beyond your normal aches and pains. Fatigue that would just completely floor me, really. I just felt so exhausted all the time. All these things kind of led me to believe that maybe I was just run down or just, you know, I'd get over it. I just thought completely that I'm just a little bit tired and I'd maybe have a week off and think, right, I'll be fine at the end of that week. But that end of the week never came. It was just so, consuming really, and that I ended up being taken A&E by my husband, Chris. And, at that point, they couldn't quite find what was wrong with me. And whilst I was there, I had a seizure in hospital and they kept me in then for some time to try and see what was wrong. From there on really my life completely changed.

#### Jess Thompson

When I first noticed symptoms, I actually started with what felt like a tummy bug, which me and the children all had. And that for me then developed into what felt like quite severe flu-like symptoms. So I started to be very hot, very cold, had a temperature, sore throat. And throughout that I continued trying to go to work and look after the children. I used to find it really difficult to take time off or let go of any of my responsibilities. So for about a week, I continued to try to go to work with these awful flu-like symptoms until one day, came home from work and literally collapsed as I came through the door. And the symptoms really got much worse from then on.

#### **James Alexander**

The first time I had a panic attack I was in sixth form college. And, you know, I wasn't feeling very good like always. I was extremely affected by the fluorescent lighting, especially. I think it was around lunchtime at sixth form. There was a really crowded room in the cafeteria and everything. All of a sudden, just this feeling of ultimate dread came over me. I just couldn't, I just found it difficult to breathe. My heart rate went up and I just had to get out. I walked out. I kind of sprinted out of the college and sat on the bench. And I called my mum and I said, I can't do this anymore. I feel too awful. I don't know what's wrong with me.

#### **David Butcher**

The thing that caused the crash was actually one night in on a cold, wet February evening. My daughter had a chest infection and it was pretty bad. So I took her straight to the hospital. We had to

wait five hours for her to be seen. And during that period, I started to feel as though I was getting the flu. I was sweating. I had a headache. I couldn't breathe properly and I was absolutely exhausted. So I literally laid down on the floor in this waiting room with my daughter sitting next to me, and I fell asleep for five hours. And then after she'd seen the doctor, we managed to get back to the car. I was shaking. Cold sweat. I was panicking. I managed to somehow drive home, went straight to bed of course. That was the beginning of ME/Chronic Fatigue. I was then completely flat out in bed for six weeks, barely able to summon the energy to crawl to the loo.

# Claire Jones - [00:10:13]

Being diagnosed with Chronic Fatigue was really quite a shock really at the beginning. I don't think it quite sunk in really at the very start you know. At that moment when that consultant said you have it, I mean, I don't think I really let it sink in straight away.

I think the lowest point for me was the point where I ended up in hospital and I was not able to move. I was completely under somebody else's care, constantly. My husband, my mother, they were constantly my carers, really, I wasn't able to do anything for myself. And having spent so many years being so independent and so driven, my dreams were coming true, you know I was living the dream, really. And then, bang this happened. I couldn't have felt more sort of emotional. I felt really, just as if, I mean, my life had been robbed from me really. It was completely the lowest point, really, that I can think of in my entire life. And I just felt, I was scared. I was really worried that I wouldn't be able to: A. Play the harp again and B. Would I ever recover enough to be able to kind of, well recover my career really? Because it's the type of industry that you do need to gradually be still out there performing and playing, which is all I wanted to do.

# **David Butcher**

My very worst day in this nightmare three years of this illness, was the day I thought I was going to die. There was a moment when, and I'd just taken a few supplements, including a drug for dealing with the wrong bacteria in the digestive system, there were a few moments when all of a sudden I felt as though this massive, dark, damp blanket descended over me and covered me in darkness. I felt physically unable to move. I couldn't even move my hand to my phone on the bedside table. I was so petrified. My daughter happened to come in to see me at that point and she could see I was in a terrible way. She offered to call an ambulance and then at that moment my mind kicked in and I started thinking about the problems that I would have to go through, which was, of course, creating more stress. I would have to make the call. I would have to make the explanation. How could I explain this situation I was in? Would that justify an ambulance? How long would the ambulance take? How am I going to be feeling in the interim?

#### **James Alexander**

The worst thing about being ill for me was the constant visits to GP's with my serious symptoms. To the point of me pleading with them. My life was going nowhere. I literally saw myself living isolated on my own until I was into my thirties, potentially forties, and no one giving me any answers or indications of what would be wrong with me. So on top of all these symptoms that I was experiencing, from hypersomnia to insomnia, extreme fatigue, extreme muscle weakness to the point where my grandma was a lot stronger than I was, and I was in my twenties. My mom had a breakdown and I no longer had anyone to turn to. There were no GP's that I could turn to. There was no one in my family that I felt like I could turn to anymore. I was alone in the world with this problem with no answers. So that was probably the lowest point of not wanting to live anymore, being suicidal. That was the lowest point of ME for me. Living every day and not wanting to be there.

#### **David Butcher**

Yeah you know, this was an incredibly difficult situation for my daughter, Charlotte, because she was only eleven when my wife died. So she was actually six when my wife was diagnosed with breast cancer. So it was actually at the age of six that she started to realize that she was going to lose her mom. But then a year after my wife had died and my father had died, and they both passed away at

pretty much the same time, I, of course, became ill myself. So I felt terrible that I wasn't able to be there for my daughter, who desperately needed some parenting, even just from a single parent. But at that point, she was losing the parenting from me as well.

# Jess Thompson - [00:14:31]

The worst day or the worst time when I was unwell was within the first six months when I literally couldn't get out of bed and my husband had to start working from home and taking care of the children. And he would have to, for example, feed me water from a cup and carry me to the bathroom. That was the hardest time, I think, just not even being able to, sort of even chat to my children, really. I had to be in a really dark room with no noise. I couldn't bear any light or any sound. And hearing life going on outside the bedroom door, kind of hearing my children, knowing that actually what they really wanted was for me to be there with them was desperately awful.

# **David Butcher**

Yeah and, you know, the worst thing about being ill is this feeling, especially for someone like me, is just feeling completely out of control, not understanding what is causing this illness. Not getting any help from so-called experts, let alone GP's. And, you know, the sense that there's no end to this, the sense of despair because you think, how am I ever going to recover if I can't even figure out what the problem is? If I can figure out what the problem is, then I can develop a strategy to deal with it, which, of course, is my business experience coming in. But I couldn't even figure out what it was.

# Alex Howard

One of the things that I found most difficult was just the absolute lack of understanding on every level of society, really around ME/Chronic Fatigue. So from doctors in the medical world and specialists, to teachers at school, to friends and even to some family members. All that really did to me was just make me feel another step isolated, and another step into this abyss of I am on my own and no one else gets this. No one else understands it.

#### **Claire Jones**

I remember being in Wales with my parents. And, you know, if you imagine people do tend to book you quite far in advance for concerts and performances, sometimes years. And I remember there was one big kind of occasion that I'd been looking forward to for so long. And it was a really good profile thing. And I just remember just thinking to myself, if I have to step out in front of all those people, I will fall apart. I will completely fall apart. And I just remember trying to explain that to my family and say, I can't do it. I can't do it. And one member of my family sort of turned round to me and said, "well, maybe if you do do it, you might just feel better for doing it, you know?" And I just completely, at that point, at that stage, it just wasn't at all possible. And that's probably the most disappointing bit for me, is, you know, again, I hate letting people down. And that was one big thing I had to change really in the way that I think.

#### **David Butcher**

The thing with this illness is that nobody really understands, apart from those people who've been through it themselves. And so you go on this journey where both doctors and specialists and even friends and family slowly become distanced from you. And of course, that just adds to your sense of isolation and despair. People start to believe that you are just complaining. They start to believe that you're making things up. They start to not listen to your own theories of what you think is going wrong. Because it's all new stuff for them. It's not anything they've learnt from conventional medicine or the NHS.

So this just adds to the loneliness and the despair. But, you know, when you go and see GP's who kind of dismiss you and are disrespectful to your intelligence, disrespectful to the fact that you've been listening to your own body for months and you know your own body better than they do, and tell you that you've just got depression and that this is what's causing this illness and please take some anti-depressants. This just creates a fundamental sense of isolation. And I remember saying to my mother at one time, I really feel that the NHS, wonderful though it is in so many ways, has abandoned me.

### James Alexander - [00:18:39]

All these things, I would try these one step cures, and if they didn't cure me, I wouldn't bother. And I went through these years of trying these one things at a time, even though I was looking elsewhere at that point for a few years, I gave up. I really did give up on ever finding a cure because no one in my life knew anything about health and what I was going through. No one, the friends I knew, know what was going on. No doctors seemed to understand what was going on. The last GP I saw, he said that all the symptoms were extremely serious. He was saying this isn't normal, but they don't fit a particular pattern for him to be worried about something serious. So at that point, I was just losing hope every GP visit. Every GP visit was another nail in the coffin for me. It just made me feel worse each time because they weren't giving me any answers.

# **Claire Jones**

I think as soon as I realized I had to accept that I had this illness and it was an illness and it's a real one. I started looking at the recovery pattern, then, you know, what we needed to do. And really, I was in my right mind to be able to even think of what needed to be done next, really. My family took over because I needed such full time care. You know, having a bath was an absolute big task for me at that point. I couldn't do it myself. Somebody had to bathe me. Somebody had to feed me.

# **David Butcher**

I was talking to my daughter Charlotte, and we both felt that I needed some support with managing my anxiety. In a sense, I needed some support with my head because I got into such a desperate place with this illness, not understanding what was causing these terrible symptoms. And she did some research and she discovered the Optimum Health Clinic and Alex Howard. And then I read up on that and I realized that the OHC specialize not just in the nutritional therapy and the functional medicine, that I had the benefit of from a functional medicine specialist. But more importantly, for me, at that time, they specialized in all the psychological therapies that they developed to specifically support people with this horrible illness.

#### **James Alexander**

If anyone had suggested to me that everything I was experiencing in my life up until that point, from the panic attacks to the fibromyalgia pains to the constant fatigue, to the constant changes in my sleep, the idea that that would be caused by a psychological component was something that was insulting to me. These physical pains I was having in my arms, my legs, and the constant fatigue were anything to do with my mind. I would be insulted at the idea.

#### Jess Thompson

When it was first suggested to me that psychology, my own psychology, played a part in how ill I was. I was really angry. And it wasn't until I came to the Optimum Health Clinic and really was helped to understand that they aren't separate. What's going on in your mind is not separate to what's going on in your body. Then that started to make more sense.

#### **Alex Howard**

The early days of starting the Optimum Health Clinic was a pretty wild journey. Having been through seven years of my own illness and writing a book about my recovery. And whilst I was ill and I gradually started to improve. I'd managed to get to university and study psychology and then did many other qualifications in various forms of psychotherapeutic work. And also with the knowledge I'd built up around nutrition. I felt like there was an opportunity to do something to help people that just wasn't there. I basically wanted to build the clinic, which I'd longed for to exist in the time that I'd

been ill. And that didn't just mean in terms of treatment and kind of intervention, but also in terms of ethics, in terms of placing the patient care beyond profit and commercial success of just building something that was for the people, by the people, which I know sounds a bit cheesy, but that really has always been the vision.

# Helen Lynam - [00:22:37]

So here at the Optimum Health Clinic, the nutrition approach is about food, of course, but it's much more than that. It's a functional approach looking at how your body is functioning. So if you go to an allopathic NHS doctor, they're going to be looking very specifically at things being broken. Here at the Optimum Health Clinic we're looking at a much broader picture of different functions in your body, all not quite working as well as they should be. And what that adds up to is this lack of energy.

# Alex Howard

We see any chronic fatigue, fibromyalgia and that group of illnesses a bit like a puzzle. And that puzzle has a number of different pieces. You need to identify the pieces and put those pieces together in the right order and the right way. We see a big part of our role of helping you solve your puzzle, our years of experience, having worked with so many thousands of patients in whatever it is, over 35 countries, we have got pretty good solving people's puzzle and helping them understand their experience.

# Jess Thompson

So for some people, it may be an immune system issue that's the main puzzle piece. And there are other aspects that will go around that. For other people there may be structural issues, there may be digestive issues, and there will be the psychological issues. So the achiever type, for example, may be a piece of their puzzle that we need to work on, or perhaps the helper type or the anxiety type. And perhaps one of their puzzle pieces may be trauma that will help to work with.

#### Helen Lynam

So chronic fatigue is really complex. There's lots of different things going on for everybody. And everyone actually has their own unique story of how they got into chronic fatigue and how that chronic fatigue is actually expressing itself. So we often find that people have a history of repeated viral infections, there's tests that we have available to us where we can do some testing to see what is still active and what there might be history of. And then we can work through diet and through supplements to help support the immune system, get it back into balance. It's not about boosting or suppressing. It's about getting balance to the immune system.

#### **Claire Jones**

I started then by having an appointment first of all, just a quick chat with one of the practitioners just to see whether they thought they could help me. And I got going with Jess, the psychologist, and then I got going with Tara as well on nutrition. Looking back now it's one of the best treatments I've ever had because, you know, it just completely makes you understand and be aware of your everyday life, of how you are and the way that you're wired.

#### Jess Thompson

Working with the maladaptive stress response is a critical part of our work with patients at the OHC, because until a person's nervous system is calmed down, actually, they're not going to get well. You need to be in a healing state in order to recover. One of the first things that we work with in the maladaptive stress response is a person's thoughts, because beginning to understand that our thoughts impact our physiology is key. So learning how to become aware of your thoughts and whether those thoughts are helpful or unhelpful in terms of either turning up the stress response or turning it down is key to recovery.

### James Alexander - [00:25:45]

My life wasn't going to change unless I changed it myself, so I decided to take my ego away and go. Psychology may play a role, nutrition may play a role, these factors may play a role. So I changed my diet and then I had a discussion with Alex and I decided to give it a try. Psychology with Emma because I felt that I could relate so much of what Alex was saying. Maybe this could potentially help me, potentially this could be something that plays a role in my recovery. And that's when I began talking to Emma. And within the first 20 minutes of talking to Emma, I was realizing all the things I've been bearing and all the thought patterns that I had that were detrimental to me covering.

#### Alex Howard

One of the reasons why we offer free 15 minute chats is we know that if someone is considering treatments with the Optimum Health Clinic, they're going to have all kinds of questions. And we believe you should get the chance to get those questions answered before. I mean, yes, risking time and money, but actually risking your hope, pinning hope on something. If we don't think we can help you, we will be the first to tell you. And if we think we can help you, we'll explain how we think we can help you, why we think we can help you, and what the steps towards that would be.

#### Helen Lynam

So what we found over the years is that there really isn't one quick fix, sometimes we are very fortunate and there might be a fairly simple answer for them, but that's a very unusual situation. Normally, it's a complex situation where we're putting pieces of the jigsaw together. And as we do that, it's important that we take our time.

#### **David Butcher**

That was the next key building block in my recovery, because I made contact with the OHC. I talked to Alex and I had a number of sessions with Alex. And that made, that gave me the tools effectively to manage my body, to heal itself, to manage my mind, to manage my anxieties, to support the body, to be able to heal itself. And that was a huge secret to my recovery.

#### Alex Howard

After reaching my lowest point, having been ill for two years at this point, I happened to have a conversation that really quite radically changed my life. I spoke to my uncle, who was a little bit like Gandalf in Lord of the Rings. He wasn't there very much, but when he was there, he always just seemed to come at just the right time and have just the right words of wisdom. And we had a conversation, a couple of conversations in an evening, which was probably no more than an hour in total of time. I wouldn't have been able to concentrate on a phone call for any more than that in a day. And he asked me a series of questions. He said, on a scale of 0 to 10, how badly do you want your situation to change? And I was like, well, that's a ridiculous question. I would do anything. Maybe I wouldn't like take a saw and chop my arm off, but I would do basically anything.

And he also asked me to make a list of all the things I thought I could do to change my situation. And on that list was I started to read a little bit about things like meditation and yoga and nutrition in terms of health and all that. So I had things like that on that list. And he then asked me how many hours a day do you spend doing those things? And the answer was zero. And of course, I had all kinds of excuses. Like I didn't have any energy. I was just trying to get through the day. I was 18 years old at the time. And then he asked me the question which in a sense was the question that put everything in context. He said, how many hours a day do you spend watching television? And at this point I was watching about seven hours television a day. And I realized by the time I was 18, I virtually had a PhD in soap operas. But it wasn't the vision that I have for my life.

And so my uncle helped me realize that if I wanted it to change, then I was going to have to change. And from that point, and it was the beginning of a five year journey of self discovery and of healing and recovery, I started doing things like limiting my television to no more than two hours a day, to practicing meditation, yoga every day, to learning about nutrition. I went on to read over 500 books on health and healing. And it became an obsession that became my life. In a way now I can see I've not always been healthy, but the level of intensity that was driving it was a desperation that if I don't find a way to change this, my life is over. And it yeah, that was just a fuel that was even through periods of complete exhaustion and complete incapacitation was a fuel that really made, for what seemed to me, the impossible to become possible.

# James Alexander - [00:30:41]

Taking my ego away was one of the best things I ever did for my recovery because I started trying everything and if it was beneficial to me, I would carry on doing it. And if it wasn't beneficial for me, I wouldn't be upset that I wasted time because I was wasting time anyway. Um, but yeah, that was a turning point for me. I took the ego away and did things that could possibly contribute to a healthy body.

# **David Butcher**

One of the great things about having this kind of type A personality, this kind of high achiever personality is that it's very true. I realize that those types of personalities are amongst the most prone to crashing with ME/Chronic Fatigue in the first place. But at the same token, the other side of that coin is that, that mental approach, that is at the base of being a high achiever, is also a key to the recovery.

# Jess Thompson

One of the things that almost all of my patients resonate with is a feeling of being tired but wired. And I think the wired feeling is an extremely important thing to pay attention to. What that's demonstrating is that their system is operating in a state of high stress. We refer to this as the maladaptive stress response. And often a person's body will get stuck in a state of high stress and they'll normalize this. And it can lead to some of the symptoms and certainly can turn the volume up on nearly all symptoms.

#### **Claire Jones**

I inevitably started doing things a bit too soon I reckon. It's part of my nature, my personality. I just was ready to push myself. I do remember one concert in particular, I was feeling quite in pain at that point, still having some pain in my body. And at the end I remember meeting and greeting the guests. And it's all a haze really, because I was so knackered and tired and fatigued after it all, I couldn't actually put one foot in front of the other. And Chris, my husband had to literally carry me. It's a very difficult moment where you're transitioning from being very ill to sort of being on your way to being better, but you're not there yet.

#### Jess Thompson

A key aspect of recovery is really learning to listen to your body, to not push it too far and to work within your current level of capacity, mentally, emotionally and physically. It's important to recognize that some people will have become unwell through a tendency to push themselves too hard. Perhaps they've got quite an achiever tendency happening and they tend to use the same approach to try to get well. What we teach people to do is, rather than following that pattern of behaviour, is to really listen to their body, to tune into what's really going on for them, what feels right, what level of activity is going to be OK, and to work within that.

#### Alex Howard

After I started on this path of my own kind of healing journey. I realized quite quickly that I needed sources of inspiration. And so I went to the local library to try and find books by people that had recovered from ME/Chronic Fatigue or fibromyalgia and that kind of group of policies. And I couldn't find any. That was kind of scary in itself. I didn't want to go to a support group. I didn't like the idea of being supported in being ill, I didn't want to meet other people that had the illness. I wanted to hear of

people healing themselves.

And so I started reading books by people that had overcome physical illnesses. To me, it became my oxygen almost. It was a thing that kept me, almost literally kept me alive. And I took a lot of inspiration from those stories. And it's part of the reason why is, as the years went by and I ended up setting up Optimum Health Clinic, it felt so important to put out recovery stories to people and not the kind of miracle recovery stories which we obviously see Optimum Health Clinic someone comes in and we just hit the right few things straight away and it has a big result. But to try and show the journey that people go on. Something like this film is a great way of capturing the fact that for some people, it's years and years of finding their path. And supporting people and getting access to that feels really important. And also making as much as we can available through things like 'Secrets to Recovery', our YouTube channel, Facebook page. Where those that are unable to afford to come to the clinic, can still benefit from those resources and that information. And so we try to be as prolific as we can of just sharing those ideas and sharing that wisdom.

# Jess Thompson - [00:35:07]

When I first heard positive stories about people getting well, that was my first sense of a kind of glimmer of hope that actually I wasn't going to spend the rest of my life in bed and I would be able to do the school run. That's amazing to think that now, that was my goal, that was all I wanted back was just to be able to do the school run. That would have been enough because everything had been taken away. And then a family friend actually heard about the Optimum Health Clinic. And back then there was some kind of CDs that were available of recovery stories. And I would lay in bed listening to the recovery stories and that really, for me was the beginning of my own recovery, because without that hope that you can get better, you don't do anything about it.

And that for me, just gave me a sense that it's actually possible to get well from this. I felt really very inspired by it. I realized that it was going to involve some quite hard work on my part. I think up until that point, I'd been really hoping for someone, a doctor, someone to give me some medication that would make all of my symptoms go away. And I started to understand that actually a lot of this recovery process was going to be down to me. And that in itself was quite empowering.

# Alex Howard

The patients that we work with, which are the most challenging for us. They're the ones that we learn the most from. I think patients usually appreciate the fact that not only do we hugely care, but we want to crack the case. We will do everything that we can. So, yeah, we're always learning it's a path of constant, never ending improvement. And we learn together. It's a collaborative process between us and the patients that we support and work with.

# Jess Thompson

We found that there are as many different versions of ME/CFS, fibromyalgia as there are people who suffer with them. And this means that we have created a very individualized approach that's integrative. So there isn't one answer for this illness. Every person needs a different combination of approaches in order to get well, which is why we have a psychology department and nutrition department in order to help people to understand their specific puzzle pieces that they need to work on for their recovery journey, which will be different for each person.

# Helen Lynam

So one of the things that people find quite puzzling when they have chronic fatigue is this delayed fatigue. So you think you're OK, you get through the day and actually you're fine. But then the next day or perhaps even two or three days after that, you're hit by it and you realize that actually you did too much. And of course, then it's very difficult to address it because you have to slow down, but you wish you'd known earlier if you could have slowed down. The way we work with that, that we've been doing for the last 11 years, is by testing mitochondrial function and understanding how the mitochondria works.

So we do actually have a blood test that we use which tests mitochondrial function, and it's looking at it in several different ways. So it looks at the ATP production, which is the energy that you've produced from scratch, but also it then looks at ADP to ATP conversion. So this is energy recycling and actually 60 to 70 percent of the energy we use every day should be made through recycling. But some people can struggle with that a lot more than others. And sometimes that's affected very much because there can be blockages on the membrane of the mitochondria. Those blockages can be anything. They can be all sorts of different toxins and metals. But they interfere with the release of the energy ATP into your cell to be used or ADP going back into the mitochondria to be recycled. So if there are any toxins blocking, it's important that we find out what those are and we can support the elimination of them.

# James Alexander - [00:38:42]

During the time where I was building up my fitness again and I realized that everything I was doing was actually helping me recover, I was building up my fitness very slowly. I would go for 20, 30 minute bike rides. I didn't want to push it. I knew that in the past when I pushed myself, that it only resulted in me relapsing or feeling worse for it. I realized that I had like a method where I do something and then for the next two, three days, I would check back in my body and how it made me feel. And I built up very slowly, very gradually because in the past, if I had any glimpse of any kind of energy, I would go right. I've been waiting for this moment to have some sort of energy. I'm going to do something. And then I burn that energy back to square one. So I understood that I had to be very patient and being impatient actually made the journey a lot longer.

So the analogy I use is the iPod. You wouldn't ever put your iPod into the computer and go, oh, it's 10 percent charge now, I'm taking out, I'm going out for the day. I was like, right in terms of iPod, I always leave it until it's like one hundred percent, at least or 80, 90 percent. And I did that with my energy. I would check back with my energy and I would, in the early days of when I felt like my body was actually craving for exercise for the first time, I didn't actually do any exercise. I just conserved my energy like I was charging an iPod and that's when I started to build up my fitness, when I realized I was 80, 90 percent of the way there.

#### Helen Lynam

So we're interested in adrenals because one of the important hormones that the adrenals produces is the cortisol hormone. And this is part of our circadian rhythm. It gives us our get up and go. So cortisol should be high in the morning as we rise and then as the day goes on the cortisol levels should drop. So when we go to sleep at night, our cortisol levels should be low. If they weren't low, we would have a level of stress hormones and of course, then we would actually not be able to sleep. So then what do we do about it? Well, it depends on the results. If you've got a high cortisol output, there's things we can do to bring your cortisol levels down. And then if you've got low cortisol, there's things we can do to help increase your cortisol levels. And sometimes we find people are producing enough cortisol, just at the wrong time of day. And then there's other things we can do to help get your cortisol more equally distributed. And that will be through supplements, through lifestyle as well as diet.

#### **David Butcher**

I went through the usual history on pacing. I thought I could just fix myself by doing exercise. So I did that. And of course I repeatedly crashed and had many major relapses. Then I went to a cognitive behavioral therapist who completely ignored my history and my current state of ME/Chronic Fatigue and said, here's the schedule that you've got to work to. And so I tackled that religiously, religiously for a week. And of course, that just sent me on another massive relapse that took a couple of months to recover from. So when I got through all that and I had, for example, a specific pacing strategy, then I was incredibly disciplined about it.

#### Helen Lynam

Pacing is probably one of the most important things we do. Just as we expect and want you to pace

your life. We're going to pace how we work with you and how quickly we do testing, how quickly we change supplements, how quickly we make changes to your diet. Because what we want to be sure that we've got for you is a sustained recovery, one that's going to really stick with you, not one that's just going to get you through the next few months. But then have you come back. We want you well for life.

# Jess Thompson - [00:42:17]

One of the things that's quite unique about the Optimum Health Clinic is that we've identified that there are three clear stages to recovery and there are different approaches that are important for each stage. So what helps at one stage may actually hold you back in another stage. Stage one is crash. And this is where actually there's no energy at all in the system. So it's where I was at the beginning of my illness, completely bed bound unable to do anything.

Stage two is called tired and wired. This is where you feel exhausted. But there's also a sense of kind of feeling of wiredness in the system. And this is the maladaptive stress response when that's really playing out.

Stage three is the reintegration stage. This is where you're beginning, you've got a baseline of activity, and you're beginning to gently bounce the boundaries to reintegrate back into life.

#### Alex Howard

Sometimes you can do the right things in the right way at the wrong stage of recovery. That's a big part of what I was figuring out of my recovery path. And we help patients to do in a way that really does make sense.

#### **James Alexander**

The first like glimpse of recovery was something that I experienced on a step back. It took her like a relapse of symptoms to understand that I was progressing. And even though it was a step back and I was upset about that, I realized that what I was doing was working and it was going to take some time to heal. It may take me two years. It may take me two years. I didn't care. I knew it was a way out. It was like being in a cave and seeing that one speck of light that you can work towards.

# Jess Thompson

After the first few appointments, I began to really get to grips with the fact that the way that I was thinking about my illness was creating a huge amount of stress in my system and that that was really blocking me from making any progress in my recovery. So I worked really hard with the techniques that I was taught in order to calm my nervous system down, because I hadn't understood before at that point that if your system's not in a calm state, it can't get well. I'd been trying all sorts of different supplements and things that we bought for ourselves, really. And Anna then suggested that actually all of those supplements, I wouldn't have been absorbing them because of the state my system would've been in.

And when I got to a point where she felt that my nervous system had calmed down enough, she suggested that I started with the nutrition side of the clinic to start to give my body back what it was so depleted. And it wasn't really until I was doing both sides that things started to really change. I started to be able to, for example, kind of be downstairs more, which sounds really not very much but for me it was huge. I became less angry at seeing people walking past the window. For a long time when I was very ill just seeing people walking I used to feel so upset by, because I couldn't do it. And I started to get a sense of things really shifting and changing. It was slow. It felt, you know, I learned how to be patient through this process, because it was slow, not every day was a kind of gradual curve of getting well, but gradually over time, the spaces between the really difficult ill days got longer and the really ill times got shorter. And I started to be able to really work towards doing the school run, which had been my whole aim.

# Claire Jones - [00:45:33]

I think it's quite hard to sometimes put a moment in time down on paper. When did I actually feel fully recovered? It was a long process over a good couple of years of trial and error, moving forward, moving backwards, moving forward again. But I actually do remember looking back in hindsight, at a few moments and it was probably around the 2015 mark where I sort of felt I was living life again. I was actually doing all the things I wanted to do. And, you know, especially when you realized you can't do them anymore when you're ill. So I think one of the biggest memories I've got is going to the gym. And it's funny to think about that because I always felt just really exhausted, more exhausted than everyone else when I went to the gym and looking back, it was because I had the illness and that was draining on your body and I wasn't able to keep up with everyone else in that sense with the stamina. But I remember doing a workout and just feeling like, "actually I feel great after that workout" and I'd never, ever felt like that ever before. And so I do remember feeling that and being very pleased about it and just something very normal, very everyday. And it's just amazing how you appreciate all those little things, all those little moments really that make it all worthwhile.

# Jess Thompson

The first time I drove the boys to school was such a huge day for me. I did have to work a lot on my thought patterns beforehand. About how was I OK, well enough to do this? Would this make me feel more ill? But my overriding thing was just that this had been my aim from the first few weeks of being unwell to get back to being able to do this. And even though it seemed like a very small thing to other people, you know, mums and dads do the school every day and for some of them, it's a real hassle. They don't really want to be doing it. For me, this was just such a huge achievement and just the whole process of helping them in the morning and getting them in the car and driving them to school. I felt like I had climbed a mountain when I got there. And I actually sat for a long time in the school car park, just holding on to that moment of, I've done it. I've taken the children to school.

# James Alexander

The turning point for me, when I realized that everything I'd been doing up until that point was working was probably when I took the dogs for maybe half an hour, 40 minute walks every other day, and I realized, hang on a minute, there's no way in hell I could have done this like 10 months ago. There's just no way. Realizing that I had gone from someone that was suicidal every day to actually quite content. I was being able to actually do some form of exercise and I was waking up feeling refreshed, I was like, I don't feel like shit anymore. Every day isn't a struggle.

That was the point where I realized that my effort had paid off and at that point I realized, hang on a minute, when I'm playing guitar, I never expected to be good straight away. I always understand that there was going to be a long process of practice and everything before I got to a stage where I think I'm playing and I actually like the sound of what I'm playing. It was at that point where I realized why, for so long I was stuck in the mindset, thinking that I could overcome this in just such a simple manner. But my hard work made it so much more rewarding. That all my hard work had paid off until this point and it was only up from here. And at that point it just, it was like a landslide.

# Alex Howard

I knew that I had reached the point of recovery when I could absolutely use my body in the way that a normal person would do without thinking about it, without having fear about it, without trying to hold back a bit of energy or prevent relapse. And what that looked like for me was progressing from doing yoga to being able to go for a run and just really just like run hard on my body. And by this point, I'd moved to north London. I knew I was at the final stages of recovery. And I went for this run from where I was living at the time in Crouch End up through Alexandra Park and up to the top where Alexandra Palace is because it was a big hill, and I went all the way up the hill. I was fit enough in terms of fitness at the time, but you know, I felt like Rocky. I got really emotional as I was running up that hill because it was seven years to get to that point.

And it had taken me to places that I thought I wouldn't get out of. Everything in my life was different at that point. My relationships, what I value to be important, my sense of self-worth, self belief, and to

feel like I come through the other side and I could live the life that I wanted to. It was such a feeling of freedom and release. And it was also such a feeling of like, I can do anything now.

And for me, I mean, that was also, that was the kind of place, the kind of energy from which I started the Optimum Health Clinic. I wrote my book '*Why Me*' about my journey of recovery because I wanted other people to be able to read a book about ME/Chronic Fatigue, like I've been able to read about other illnesses. And it was just having been through that, the only thing that seemed important was setting up the organisation, which I dreamed that existed in the years that I had been ill.

I have an immense respect for anybody who becomes ill with this illness. The journey that you need to go on to get well demands a huge amount of kind of personal investment, personal resourcefulness and learning a huge amount about yourself to get well. I think that it's a really challenging illness to be diagnosed with. There's a huge lack of understanding about it. And what we're here at the OHC to help with is to show that we do understand this. We've been here, we've walked these steps, we've navigated this journey. And we can help people to do the same with a deep level of understanding and empathy for what they're going through.

# Claire Jones - [00:51:46]

So I was approached by Alex at the Optimum Health Clinic to become the patron of the clinic, and I'm so overwhelmed and overjoyed to be associated with the clinic because it played such a massive part in my recovery. And anybody who's had treatment at the clinic will know that they put their heart and soul into every single part of that journey. They look after you like you were a family member. They put you through everything, they give you every bit of information that they can to help you to succeed in your journey. I remember talking to Alex at the Optimum Health Clinic and just talking about how I felt pre illness about recording and all the energy and the vibe that you have before you go and do something like that.

And then, of course, the illness happened and now on the other side actually producing something brand new, but very raw and very personal and from a different place, really, because this album has such a big, deep meaning to it because of it being my own journey. You know, stamina wise, it was quite a challenge again, but I was completely fine with it. I built up to it and got ready for it emotionally. It was just like pouring everything out. I felt very emotional at several points because you are emotional about it because it's you, it's your personal story and it's very close to you. And music is a funny thing. It's a very raw and emotional part of everyone's life really. Music can mean, so many things to so many people. And it really has such a power to heal.

#### James Alexander

I went to a festival and I booked a hotel room for the wrong day, and I went there that night and I realized I'd booked it for the wrong night and it was for two, three weeks ahead of that the night I wanted it for. And I realized this is an opportunity for me to test where I am at this point. And it may have been a bit much at that point. It was a bit of a gamble possibly, but I was like, I'm over a year into recovery. I'm going to try. I'll take it easy. And I took a friend with me and we cycled to Bristol and it was around 80 miles there, and it was about 80, 90 miles back.

And the journey, it was everything I had wanted for the years that I was ill experiencing. And I loved the fact that it was such a long bike ride because it was like just enjoying the whole journey. It wasn't an effort or anything. It was just so enjoyable that I was making up for all those years that I missed exercise and yeah, the bike ride to Bristol was something, that was the point where I was like I am 100 percent cured. I can do anything now. And it's an amazing feeling to after having that taken away from you for so long, to be able to go out and do that. It is an amazing feeling, especially when you've earned it. You've spent years or doing whatever you can to recover and then you've achieved that, then it's like, right, I've achieved that now, I feel like I can achieve anything I put my mind to now.

#### **David Butcher**

Yeah. You know, playing the drums is actually a fascinating thing to do if you suffer from ME/Chronic

Fatigue and to do that as part of your recovery. It's fascinating because playing the drums is immensely demanding both physically and mentally. Physically, it's obvious, you know, you are using a lot of different muscles. Mentally, it's even more challenging because you are having to listen to the music that's being played around you. You're having to listen to the other musicians, the bass player, the singer and so on. And you are having to provide the bedrock of time. You know, you're having to segment the time, compartmentalise the time so that everyone knows where they are. So the amount of mental concentration that's required as well as all the physical coordination is huge. But you're also getting the mental therapy because you're, every beat you hit, you're thinking, wow, that is another beat that's telling me I've recovered fully from this horrible illness.

# James Alexander - [00:55:55]

It was at that point of my recovery where I realized that I was done. 100 percent recovered. I didn't feel, I felt less fatigue from 160 miles of bike riding than I did from walking up the stairs at my illest. It was when my mom asked me to hold one of the curtain poles above my head and my vision blacked out. I was extremely weak. My shoulders felt like I've been shoulder pressing 200 kilograms and I needed the whole day to recover. And it was when I did that bike ride, I looked at the contrast from that hard time getting up the stairs to 160 miles on a bike and feeling amazing. I realized that everything I'd done had worked. All my hard work and paid off, and I deserved what I had got. If I'd just taken a pill if that even existed. I don't think I would have appreciated it as much. But it was at that point and I was like, I've come a huge way. It's like looking down a cliff and seeing myself at the bottom and realized that I'd got to the top and it felt amazing.

# **David Butcher**

There were two final pieces to my full and complete recovery, the first one was kind of re-engaging getting back into the world as a parent because, of course, I'd been ill for three years and my poor young daughter Charlotte had effectively lost her dad for that period. So, you know, re-establishing, rekindling that relationship, that emotion, that engagement was absolutely crucial. All of a sudden I was able to take her on the school run, pick her up, go to school events, watch her playing the piano, watch her in a play. It was like being reborn emotionally. It was like starting the whole thing afresh, you know, with my daughter, after so many years of being absent.

#### Jess Thompson

It wasn't just my story. It was my family's story. And as a result of me being as unwell as I was for so long, we're actually much closer, I think than we would have perhaps been if I hadn't have been unwell. My children have learnt a real sense of empathy, compassion, understanding and maturity that they may not have had if this hadn't happened. And my husband has seen me at my very worst, my very weakest, my most vulnerable. And also he's so proud of my strength.

#### **David Butcher**

The second piece was re-engaging my brain because for so many years, all I've been doing was focusing on my condition. I hadn't been using my skills or experience to help anybody. So re-engaging my brain, using my skills to help the Optimum Health Clinic was how it worked out. And that was tremendously important because that gave me a reason to get up in the morning, you know. I remember being asked to create a strategic plan for the Optimum Health Clinic. And the fact that every morning I got up and started using my brain just made a massive difference to me, that was the final piece of my recovery.

#### **James Alexander**

My life now is, if I want to set out to do something, I have the physical ability in my body and my mind to do that, whereas before I was always limited, I always felt handicapped. I felt like if there was something I could do, I couldn't do it. You know, I'd watch that same YouTube video of someone doing calisthenics. I was like looking at them and realizing that that's something out of my reach. Now, if I go, you know what I'd like to do that. I go and do it. I can do things now. So now normal life, I can do what I

want to do. That's not taken away from me anymore. And I have no excuses now.

# Claire Jones - [01:00:04]

Well, life at the moment is better than ever. I'm really glad to say I'm enjoying every single moment, physically feeling great and emotionally, psychologically, everything is working genuinely as it should work, feeling pretty good in general. And the great thing is I've just given birth as well to little Cadi, Cadi Haf which means pure sunshine in Welsh. So she's got a lovely Welsh name. And there was a time I think especially in previous years where I felt, I genuinely felt I would never, ever have the energy to be able to have a child really, to give birth, let alone look after a child, you know, 24/7 and have all the responsibility that goes with that. And it's sort of odd to think that really when I look back now to think I wouldn't be capable of it and and now it's here and I'm doing really well with it and I'm coping fine. And of course, everybody has their challenges and lack of sleep but I'm coping with it very well and have lots of support from my husband and my family and things. And so really, it's just living life day by day, appreciating every single moment that I have and full health and really just spreading the word that there is come back for ME and it is possible to make a full recovery.

# **David Butcher**

And I guess the final, the icing on the cake of my recovery story is, is meeting my adorable wife, Meray, and falling in love and getting married last September. I mean, that is an extraordinary turnaround story that is beyond my wildest dreams. I mean, not only at one point did I not think I would ever recover from ME/Chronic Fatigue but, you know, it was beyond imagination that I would ever meet someone and fall in love and have a new family and a whole new life. So that is now just an utterly extraordinary experience and it's a much more fulfilling experience. Of course I loved my wife before, but what ME/Chronic Fatigue has done for me is it's turned me into a completely different person. I'm so in touch with who I am. I'm listening to my body. I'm in touch with my feelings, I'm managing out my anxieties. I mean, I'm a completely transformed person. And so to meet someone and experience love and happiness again is kind of, you know, a million times more intense than it was before. You see it's just incredible. Incredible.

#### Song: Freckled Angels by Ren

Could I have just a day where I get to see your face? I would laugh and you would skate hanging out by the pier cave, chasing dreams, freckle faced, no inhibitions, acest mates, tell me everything's okay, you never meant to go away and I need something to hold on to, and I wish I could hold on to you, cause I will never ever forget you, and bet, I know you'll be soaring through because freckled angels laugh the hardest and their hearts, they are the largest with their wings, they fly the farthest, so I know you're gonna be okay, freckled angels live the longest and their minds, they are the strongest, all their friends, they are the fondest, so I know you're gonna be okay. Could I have just a sec? Please pull me out of this wreck. Crack a joke and tense your pecks. Act the fool, but with excellence.