

HEALTH & MEDICAL CONDITIONS > CHRONIC FATIGUE SYNDROME

Chronic Fatigue Syndrome

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1. Introductions and websites_groups

Kia ora, I'm Amanda Gillespie and I am a school counsellor and have actually participated in similar things to this in my counselling capacity. But today what brings me to this space is my son Andrew who is 14 who two years ago, well actually not quite two years ago, probably 19 months or so, he became very unwell and it took us close to six months to find out that he had in fact had a virus that then has progressed now into CFS-ME. And in that time it has been something that has taken over my life, taken over my family's life. And so through my professional role as a counsellor I've been able to liaise with some people that have enabled me to be part of this.

And so I'm here today as a parent and wanting to advocate for other families in my position and for the young people that are struggling with this debilitating illness. Okay, so my name is Warren Tait. I've been a biomedical academic scientist for the last 55 years really at the University of Otago. And 32 years ago, my... 14-year-old daughter came down with a mystery illness which we later found was ME-

CFS. And so I have another close family member with it now. So I've lived as a ME family with this really pretty well every minute of every day for the last 32 years. As a biomedical scientist, I tried at the time to start an ME-CFS research programme.

And I've been doing that ever since. And I've been doing that ever since. And I've been doing that ever since. And I've been doing that ever since. But none of the mainstream investment agencies really saw ME-CFS as a real disease. And so I wasn't able to get funding. So I started a research programme about 10 years ago, mainly funded by donations from families and people who want to see researches done. And the aim of that was to try and see if I could find a biological basis for the disease. And the aim of that was to try and see if I could find a biological basis for the disease. And the aim of that was to try and see if I could find a biological basis for the disease.

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molecular signatures in the DNA and also in the immune cell proteins for ME-CFS and now I've published quite extensively in the international literature and last year published a holistic model really to try and understand what ME-CFS and also long COVID is and I'm now also working on long COVID and doing comparative studies between ME-CFS and long COVID and since the lockdown really since the pandemic I really field maybe three or four queries, phone calls and emails from individual patients each week and I try and answer each of those just to you know provide some put some service back into the ME-CFS and now long COVID community.

Hi everybody I'm Tom Harris I have ME-CFS and long COVID. And I just want to start off on behalf of the ME-CFS community to give a massive thanks to Professor Tait, Warren for all that you've done and keep on doing. A huge appreciation also for Amanda and everybody involved and put here. I'm just here to give a little bit of added lived experience. I'm also on the board of one of the New Zealand support charities for ME-CFS, and I hope to just be able to tip in occasionally but mostly enjoy and listen. Thank you.

2. How is ME_CFS diagnosed

This sounds like a really simple question, but I know it's not always, which is simply, how is CFS-ME diagnosed? Okay. So sadly, as yet, we don't have a simple molecular diagnostic test for ME-CFS that's available in your community chempath laboratories. And that means clinicians have to use clinical case definitions to try and get a diagnosis. And there's probably three of those that are commonly in use, more modern ones. The first one is the Canadian Clinical Consensus, which was published in 2003. And I must say, when I first read that, I thought, this is tremendous. It just actually described my daughter's illness.

Then that's been updated in 2011 to give the international consensus, clinical consensus. And then in 2015, the Institute of Medicine of the Academy of Sciences in the US came out with their own kind of variation of that to try and make things a little bit simpler. So ME-CFS would be recognized as an important disease. I have to say, Ros Vellings, who's been the major... The clinician in New Zealand who's diagnosed ME-CFS has used predominantly the Canadian Consensus clinical definition, which, as I say, I think is good both for clinicians and also for research. There is, of course, a tool test for orthostatic intolerance that clinicians can use in their rooms when they see patients, which will help them.

And I think it's a good thing that we've developed with the diagnosis, this is where you can get a patient just to lie down on a bed, and then after about five minutes, in theory, if you've got one of these beds, you can tilt the bed up, but alternatively, just get them to stand up or even lean against a wall and look to see whether if their cardiac output stays the same or not. And if their heart rate goes up and blood pressure goes up, then there's some evidence of orthostatic intolerance. And so that's an indicator. It's not an absolute test, but it's an indicator that the person might be suffering from ME-CFS.

I'd just add to that. So I have ME-CFS and have a diagnosis, but I don't have orthostatic intolerance. So it's very common and many people have it. But for those of you who don't, I think very roughly, the general question... The general criteria is trouble with brain fog, tiredness that is not relieved by rest, and post-exertional malaise, which we might talk about a little bit. But I guess in simple terms, everything you do makes you unreasonably tired and you crash. That's a rough gist of the kind of criteria that you'd be looking at.

3. What to do while waiting for a diagnosis – “wondering what if”

So if you are a parent that thinks your child might have ME-CFS, and I know that there are time frames often involved. So when we, you know, for my son, there was a period of time where we discovered he had cytomegalovirus. So we believed that it was just him dealing with that to begin with, that he should move through because it's much like glandular fever. However, there was a point when we

started thinking this could be ME-CFS, but we didn't have a set diagnosis. Are there some things that, yeah, that we should or shouldn't do as parents of a young person in this time when you're wondering if this could be the case?

Absolutely, I think there are, and largely this is from my own experience and the things probably I didn't do that I should have done or I started doing. Partway through the illness. So one of them, I think, is if you suspect that your child may have ME-CFS, is to start a daily diary and just keep a record of what happens every day during the illness. I mean, as Tom said, is know the core symptoms, you know, severe fatigue, the brain fog, which is, of course, the first time I heard that was when my daughter used the term, to me, she said, I've got brain fog. You know, now it's common, the common term for the sort of loss of memory, inability to just compute in the way that we'd normally do.

You know, my 14-year-old daughter was a great, wrote poetry and was a great little writer and she couldn't write. Knowing, you know, that the effect on sleep, the need to sleep long, I think my daughter slept for 14 or 15 hours in theory. At the first stages of her illness and yet awoke as though she hadn't slept at all. In other words, it was unrefreshing. Hypersensitivity to the senses, sensitivity to light and sound, you know, she had to live in a darkened room. And, you know, as a typical Kiwi male who used to want to bang her nails in the weekend when I was home, I couldn't do that for three or four years because it was like torture to her, just that normal.

So be sensitive to that. Watching television, you know, most young people, of course, you know, glued to their devices and whatever. And yet with this disease, it can be quite difficult. You know, the stimulation one gets from watching television. So that's a kind of signal. So watch out for sudden onset of allergies. You know, my daughter became allergic to every food item that she ate. She ate a lot of food. She ate a lot of food. She ate a lot of food. She ate a lot of food. She ate a lot of food. She ate a lot of food. She ate a lot of food. She ate a lot of food. She ate a lot of food. She ate a lot of food.

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She and my wife had to go through and just you know work out was there a flower that she could possibly have without getting a massive swelling in her abdomen and that turned about to be rice flour so we designed or my wife designed a diet which she could actually have without too much effect and she still basically has that diet 32 years later I have to say

4. What not to do!

what shouldn't you do and the big mistake I made is that well parents you know when they see a love child who's kind of lying on the ground like the animal kingdom they try and get them up and get them moving and get them going and whatever and there was a little bit of that but my daughter also loved school and loved network and she wanted to continue to go to school even though she she shouldn't have and and I I knew instinctively you know we shouldn't have been taking her to school but we did for about two or three weeks when she was really not able to and fortunately her chemistry teacher used to work with me so he would bring her home at 10 30 in the morning at midterm break each day you know and until we gave that up so really as a parent I think just recognize affirming that the illness in as positive a way as possible and I know that's impossible but not trying to you know get your child to do to the to the don'ts as well exercise don't don't exercise it's one of the hardest the most counterintuitive things you think oh exercise is good for you it helps you when you're down all you've got to do is push through and exercise is good for you it helps you when you're down all you've got to do is push through and exercise is good for you it helps you when you're down all you've got to do is push through and that that took me probably about three years to fully accept that and still hard as everyone with MSFS knows but yeah rest rest rest can I just add a comment to that at the end before we move on and that is that just to talk about my daughter's experience initially she was able only to walk about five or ten meters from her bed to the shower sit down in the shower get back and then would have to take about three hours to recover and I think that's a really good point and I think that's a really good point and I think that's a really good point and I think that's a really good point and I think that's a really good point and I think that's a really good point so clinicians said to me one thing you must do was keep her doing some exercise so we had a young colleague of mine his wife was a occupational physiotherapist and so she came up had my daughter lie on the floor lift her arm and lift her leg and whatever for about 15 minutes and it took her about three days to recover from that so you know I can endorse that in our experience Tom Yeah structure in our experience Tom Yeah and I'd like to also just Worrn hearing um your experience with the regret Yeah and I'd like to also just Worrn hearing um your experience with the regret feel with pushing your daughter I can certainly say the same feel with pushing your daughter I can certainly say the same when my son was first done while he was starting high school at the beginning of last year and he did six days at school he even participated in Pe despite me sending him with a note saying he wasn't to do Pe but he said I just want to be like all the other kids and now six days he was running on something um but eventually it was very clear he couldn't he couldn't walk around the house and every day he started getting dressed and we we had to stop him but i've i've known of some other young people where they are so determined to try and carry on and we inadvertently are encouraging them to even um you know his

heart rate my son's heart rate he had a watch and it was it was scarily high his heart rate and we were telling you know the medical people that this was happening and no one ever said to us well don't do that if walking around the block makes his heart rate go that high don't do it nobody said that so you know i just i think it is yeah it probably can't be emphasized enough um i still look back and wonder if we hadn't pushed him those six days could he have figured out a way to gradually do a little bit of work last year could he have had some success um i don't know but it is we definitely you pushed him very hard and and it did not go well um but i just see again and thank you tom and warren for your input with that because i know there'll be lots of families hearing this and and it is important um

5. Working with the clinician

The other thing I would say is that try and be in control of the dialogue with your clinician. Now, that's very hard as well when you're just emotionally traumatized as we were as parents. But often the clinician is struggling as much as you are to understand the disease. And so it's got to be a partnership. And if you've got a clinician who is understanding and empathetic, don't have to know everything, then you can form a good partnership. But so many ME patients and families haven't managed to find that in New Zealand over the time that I've known about the illness. And that's very sad. I really hope just to chip in, as I'm sure we all do, that with long COVID, there'll be a bit more empathy from clinicians and also families and friends and things.

6. Medical appointments

So, in terms of medical appointments, is there any advantage to regular medical appointments? I know for myself at times I feel like I'm putting my son through a lot of, you know, the energy that he uses for these appointments. And we've come up with different strategies to try and minimize the impact of them. But, yeah, I'm really curious, Warren, from your perspective, is there benefit in regular appointments given the strain that it can place on young people? Yeah, totally resonate with that question. What I would find is that when we had a regular appointment, we'd wait in the waiting room for about 20 minutes or so, and my daughter's energy would just spiral down.

So she was a real mess when she went in to actually see, you know, the doctor. So what I started doing was ringing up when there were regular appointments, the receptionist saying, look, I'm going to call you back in a minute. Look, will you ring us when she's five minutes from being able to see her, and then I'll bring her down. And so we did that. Receptionists didn't like it at all, but it made a huge difference. For doctor's appointments, it was even worse. Hospital doctor's appointments, we had one where my daughter was, ended up lying on the floor after an hour waiting, and she saw it was an endocrinologist, you know, that was, she was, referred to.

I saw the notes afterwards. He said she was a highly nervous young woman. The reality was she was a completely exhausted, spent person who had been waiting for an hour for the person to arrive, you know. So I would say, you know, one has to be very cautious about the value of these visits unless you know they're going to offer something. My daughter actually had pancreatitis attacks and had hospitalizations, and one of the critical things there is that hospitals are like a nightmare for people with ME-CFS, you know. In the mornings, the shades go up, you can't sleep, you know, as you need to. So one night, there was a night, when we were in, there was a night nurse I got talking to who seemed malleable.

So I'd found a storeroom down the corridor from the ward that was empty and would fit my daughter's bed. So I said, can we shift her bed down in there? So she can be in a darkened space and get a good night's sleep. And so somehow the nurse agreed. And I think they discovered my daughter about midday the next day, you know. But that was the one night she got asleep. And so, you know, these are really important. It's an important question you raise. And this is where, as a parent, I think you have to kind of have some degree of control. Yeah. Can I ask you a question? Can I ask you a question? Can I say, just going to, one thing which has come out just recently in the Victoria University of Wellington survey, and it was looking at the impacts of COVID, and they had a section on long COVID.

I don't know if you've read that. But there was a quantitative survey from long COVID patients. And what they said is about their doctors. They want their doctors to show empathy, affirm their illness, have much more confidence in themselves, have much more knowledge and understanding of the illness, and be more proactive in formulating a management strategy. You know, if clinicians are kind of starting to do that, then maybe these visits will be, you know, more meaningful for families. And to jump in there, I personally have always found medical appointments really, really draining, unfortunately.

My current GP, I really like him. And so it's better with him. So the importance, you know, the personality of your GP. But I should mention, I listened to a podcast recently, a family sharing their experiences. For them, they found it really helpful to have, I think, a monthly checkup. And they used it for their GP, helping them with a self-management plan. And it was like a check-in, an external person checking in. I think they were on the Care Plus system, which I'm not sure if everyone's, you know, able to get on that, but can

pay for some of that. And if you didn't have the money to go every month to your GP, even with, say, a community services card or something like that, that could make it cheaper.

I guess you could come up with another individual who could sort of serve that role for checking in. We might talk more about self-management plans in a bit, I guess. But that's my two cents. Yeah. I could add a couple of things, too, really. One of the problems with, you know, health practices now is you often don't get to see your own doctor, you know. And that's a disaster for ME patients. I think they've got to have their own practitioner who understands them all of the time. Another point, I mean, I think that it's important to have the regular appointment, as you said, at some point at frequency, because ME people get other illnesses as well.

Right. Right. Right. Right. Right. Right. Right. Right. Right. Right. Right. Right. Right. Right. Right. Right. Right. Right. I mean, the danger is that doctors can say, oh, well, it's just their ME, and they might have some other thing that needs, you know, dealing with and treating. And so that's important. And I had a third experience with a medical student when I was teaching a third-year med class. She realized from my lecture that she had probably had ME-CFS. And so she went to see a clinician. And she came to see me afterwards and told me about this. And she said her clinician and her came to an agreement.

She would take a list, you know, three pages long of all the things that were wrong with her and she needed to work out. And the clinician would say, look, I can't deal with that in a 15-minute thing. Let's do the first four things on your list. What's the most important first four? And then in the next appointment, we will actually go down to the next thing. And for her, I mean, for this med student and the patient, and she's had to withdraw from medical school, unfortunately, you know, this was very helpful. So I don't want to just be, you know, denigrating clinicians, but there needs to be a partnership and an understanding.

Yeah, and it sounds like just having, like, I think that's a really good point. If you have actually a regular appointment, whether it be monthly or whenever, you are going to see that same person. And I think that continuity, and I've got to say, we were lucky at, you know, we have an amazing GP, but we also, we've learned to send him journal articles and email. He's given me his email address, which is a dangerous thing to do. But, you know, he reads the emails and he makes appointments at the end of the day when he actually has no one else afterwards so that he knows he has time. So I think, but that did come from us really pushing for that as well.

And I think, you know, I guess as a parent, I suppose I've learned it is not my natural state. I want to trust medical professionals because I know I'm not one. But I have learned to trust myself more and to push and ask, you know, and send the research and not feel silly for sending it to them because they actually have every single time not seen it and been interested. So, yeah, I think maybe it's just a helpful thing to put out there for anyone else who might be wondering that as well. Thank you.

7. Cognitive ability - its reversible!

The great thing in terms of cognitive ability, too, is that it's reversible. You know, my daughter, who was a great little mathematician, couldn't do any maths or anything like that. And when she started to get transitioned into what we call the chronic phase of the illness from her acute three or four years, I sat down with her and I realised that everything was in her brain. It just had to be unlocked. And so we went through a year's syllabus just step by step. And it was amazing that you could just unlock the broken circuits or reconnect them. And she had it all there still, you know. So that was a great relief to me as a parent to realise this is not an irreversible disease, you know. That is really heartening to hear.

8. The history of ME _ Chronic Fatigue Syndrome

There is, obviously, there's a growing number of long COVID cases, and that is something that obviously has a strong link in with CFSME. Would you be able to explain what the connection is between CFSME and long COVID? Good. Sorry, there's a bit of noise outside in the corridor. I hope it's not interfering with you. I was struggling a little bit to hear that. Yeah, so let me first define kind of the history of ME-CFS. It was probably first reported in the 18th century BC by a Babylonian philosopher, a description of a disease which sounds very much like ME-CFS. And then we know that almost certainly the mother of nursing, Florence Nightingale, had it, was it 250 years ago?

And then the father of evolution, Charles Darwin. But people still... People started reporting on this in about the 1930s. And initially, it was reported as a result of infectious disease outbreaks that were isolated, geographically isolated, involved a few hundred or thousand people and gave rise to a post-infectious disease syndrome, thought to be viral. So, but of course, subsequently, and from two of those, that's where the name ME-CFS came in. Myalgic encephalomyelitis from an outbreak in the Royal Free Hospital in London in 1955. Chronic fatigue syndrome from an outbreak in an inclined village in Nevada on the shores of Lake Tahoe, a village of 900 people.

And so the term chronic fatigue syndrome came about. It wasn't really amazingly until 2017 that the international community sort of accepted. They'd used... They'd used the term ME-CFS to encompass both the UK, European names and the US ones. So it's an umbrella term, really, that encompasses these infectious disease outbreaks. But what we found in the last 10 or 20 years is that you can get ME-CFS from other causes as well. And about 20% of the cases come from another major stressor in one's life. If you're a... If you're a susceptible person, and maybe we'll... We can talk about that in another minute or so.

And so, for example, major surgery can give rise to ME-CFS. If you work, you know, on the land, in the agricultural sector, agricultural chemicals, toxic chemicals can give rise to ME-CFS. And in my University of Otago young woman study group, patient study group, there was a young woman that had constant... Childhood abuse. And that came into ME-CFS. So 80% of the cases probably viral from a viral illness, post-viral, and 20% from other causes. Now, of course, these have drip-fed. So 20% of the cases of ME-CFS today are probably from glandular fever. That is Epstein-Barr virus. And they drip-feed into the community.

So today we think... 45,000 people with ME-CFS in New Zealand. Because it's accumulated, and for the large majority, unfortunately, it's a lifelong disease. So we just keep adding up more and more cases.

9. Long Covid

So the difference between that and long COVID is that long COVID comes from just a single viral infection, which is, of course, the SARS-CoV-2 virus of the pandemic. And that's unique because we've never had a pandemic like this before, which has given rise to 680 million cases worldwide. And so that has generated many cases internationally of post-viral syndrome. And it's really brought it to the attention of all clinicians around the world, communities and countries. And so that's the unique difference. It is an ME-CFS-like illness. And interestingly, the first COVID outbreak in 2003, which was only 8,000 cases, I was amazed at that worldwide because we were scared it was going to come to New Zealand, that gave rise to post-viral fatigue syndrome cases.

Which fitted under the umbrella of ME-CFS. So long COVID is an ME-CFS-like illness. And we can see that with the World Health Organization came out with the clinical case definition in 2021. And it's very similar to that for ME-CFS. Of course, having arisen from only a single virus, a specific virus, there are some unique features like the loss of taste and smell, skin problems. If you're interested. And singing as I am, the professor of voice contacted me from the university because he's got long COVID and he's lost his ability to sing properly. And so that's another one unique to the cold virus.

But mostly the 100 or so symptoms that ME-CFS people have recorded are found also with long COVID. So it's very similar to that. In my own case, with our research, we've looked to see whether long COVID people have, the same molecular signatures of ME-CFS, that is immune inflammatory signatures in their immune cells. And we've shown that they do. And we've got a big data set, which we're analyzing now to see whether there's the same changes in the epigenetic code of the DNA. And I'll bet my life on the fact we're going to find the same. So it is an ME-CFS-like illness. And you may realize that some people now are talking about long COVID as becoming ME-CFS, when you get to six months, which is a strange kind of way of talking about it.

But it relates to the fact that, unfortunately, the World Health Organization said three months was the limit when diagnosis could be made. For ME-CFS, it's, of course, six months. And most people get their diagnosis maybe a year or two after they've had it, not just at six months. So what we're looking at now with long COVID is that when we get a virus, we're going to 50% of people recover within 10 days to two weeks. Another 20 or 30% might take a month to two months. And some people take even longer time. So those people that are being reported as perhaps, you know, thankfully recovering from long COVID now, I think of those group of people that with their MS would have recovered within the time before their diagnosis was made.

So in that way, I don't see it's a difference. I just see it's a difference applied by the way we define the two diseases now.

10. Acute and Chronic phases

One of the things I was wondering about, in terms of the severity of chronic CFS-ME, you've mentioned, Warren, you've referenced the chronic phase and the acute phase. So I guess wondering, there's two parts, I suppose. One is, how do I know how bad my son's ME-CFS is? Because I've never felt like that's been measured in any way, other than myself measuring it. And then also, how do I know what phase he's in? Because again, that's something that, while I've read things about that, it's never been referenced in a medical context either. No, no. That's an excellent question. And really, I'm very happy.

I hope to give you some good news, really, on that. Firstly, I think severity, functionality is the thing. In other words, if my daughter can only walk five to ten, ten meters to a shower, you know, then it's high degree of severity. If she has lost her ability to interact socially, it's high severity. If she can't do any educational things, it's high severity. And if it's an adult person, of course, if they can't work, then

it's high severity or can't do any work. So functionality is the first rule of thumb, you know, asking yourself, what is the... Functionality. And as you've said, there's the acute phase, which in our case lasted for three to four years, really.

But the good news is that my daughter always thought she was going to get better. And when she started to feel that she could do a little bit more, that she wasn't quite so affected. Of course, she was raring to go. You know, we had to kind of try and dampen that down a bit. And so it was like a road to Damascus experience for the family. You know, when she got out of her bed and could come downstairs, you know, she largely lived in the upstairs. There was a bathroom and she had a bedroom there. And that was her thing. When she came downstairs for the first time, it was an amazing experience. But it was generated.

It was generated from her, I have to say. And she wanted to get better. And that, you know, was an amazing thing. You know, I felt totally helpless through all of this period. But, you know, just seeing that she could generate some of this.

11. Alternate therapies - Reiki and meditations

There's one other thing that I could mention, and that is that giving them something that they can themselves help to move to that thing, I think, is important. And although we tried to get it from the clinicians and couldn't get it from the clinicians, we had a Reiki teacher come up to the house who was prepared to come up every day for a couple of weeks and teach my daughter how to do Reiki on herself. So that when the symptoms were the most severe, and often they were, she suffered a lot of pain during the night and whatever, she was able to do that for herself and help. To control her illness to a certain degree.

So giving the power to the person who's ill, and Tom might want to comment on that, was extremely helpful. And I have to say, she became very spiritual from that, not sort of necessarily religiously spiritual, but spiritual as a person, which was a coping mechanism which she had to deal with the day-to-day ongoing illness. And the ups and downs. Yeah, just to jump in there, definitely I can associate with the spiritual thing. For me, I haven't had experience with Reiki, but just in an attempt to try and calm my whole overstressed system. Even though I didn't necessarily feel that kind of stress like when you're running around, but just very clearly.

You know, sensory. Stimulation and everything like that. And also measured with my smartwatch, which was kind of telling me that my stress level was 100%. So for me, I use things like, I really enjoy a little meditation app, Yoga Nidra, which is just lying down, no stretching or yoga. And we can provide a link to this in the PDF summary of the talk. And when I was feeling it. So I. I was a little bit more moderate, less severe. I did some very gentle Tai Chi exercises. That would be too much for some people. It involves standing and moving their arms. But that was helpful for me. And one of the biggest struggles that I found was a sort of envy, jealousy of.

Normally, I would say I'm a very positive person. But through this, of course, you have that huge feeling of missing out on things. And I started. I started to feel resentment when good things were happening for my friends, which is a horrible feeling. Nobody wants to feel that. And for me personally, the way I dealt with that was doing loving kindness meditations, which is a Buddhist thing. And the key thing there is you remember that everybody suffers at some point in their life sooner or later. And so we're all in the same boat from that point of view. Many people hide it and don't share it.

And when you think about it, you don't want anyone to experience that. So just reminding yourself, oh, yeah, OK, so I'm not as alone in my misery as I might have thought. So, yeah, we could maybe provide some links to that. But, of course, I would also just add everybody's on their own journey. That's what worked for me. Everybody has to find what works for them. Can I just add something to that? My daughter now meditates every day. And finds that very helpful. So all of you said, you know, I totally resonate with. But just one other thing. And you talked about stress, but feeling all over the place.

And, you know, you could tell maybe your heart rate was up and things like that. So in the acute phase, my daughter would most of what is at night. And so my wife would sit up with her most nights, really. And we would try and deal with this. A couple of times it got so severe, we actually did get young doctors to come up. To the house. And they measured everything. And her blood sugar was all over the place. And her temperature. I mean, all of her homostatic mechanisms were just all over the place. Which I think was what you were referring to, that kind of stress, you know. And they said, look, they were really nice young people.

And they said, we don't really have anything except we could put her out, you know. So my wife met a woman who had a practice called Healing Hands. So one night when it was really. She rang up this woman at 3 o'clock in the morning who came. And I'm a biomedical scientist. I believe in evidence-based medicine, you know. And I was just totally shocked. This woman put her hands just very close to my daughter. And for about 20 minutes, she managed to calm all of her disturbed physiology down. You know, all of her homostatic mechanisms just kind of receded and went back. And my daughter just went off to sleep, you know.

So this altered my whole perception of how broad we have to be in looking for things that can help, as you say, each individual patient. It may not be the same for everybody. To give them a better standard of, you know, living and to give them hope. So thanks for that, your sharing of that. Thank you, Tom. I know one of the things. That makes me think about when you share that, Tom, is, you know, I

have a really close relationship with my son. But he doesn't like talking about his ME-CFS. He doesn't want that to be the focus of our conversations. And he also doesn't want his mother to tell him what to do.

So I know that for you being able to share that, I feel that that's a really helpful thing for young people to hear it from someone else. Who understands how they feel. I was actually going to say who's young, but I can't quite claim that anymore, get it? Almost young.

12. Believing your going to get well - good outcomes

And the other thing, Warren, that when you said about your daughter believing that she was going to get well and recover, that really struck a chord for me because my son truly does believe that, and I'm going to get emotional, so I apologize because he truly believes he is going to get better. And that's one of the things that I find the hardest to face, how to have those conversations with him. Yeah, yeah, I understand. And, you know, we felt very desperate, I mean, back in the stage that you're at, because, you know, my wife, who was, she's microbiologist, but she'd also done a nursing qualification, was nursing cancer patients at the time.

She would say, you know, these aren't as sick as our daughter is, and we couldn't see an end to it, you know. And in some ways, I have to, so I felt very guilty because I thought if someone said to me, your daughter's got cancer and she's got two years to live, it would have been easier to cope with because, you know, you would have known what the pathway was and you could have adjusted. You know, I'm ashamed to say that, but that's how I felt at the time, you know. The good news is, and we might talk about this, but is that when you go into the chronic phase, you know, I can tell you, there's not enough time, but I can tell you lots of really uplifting stories about what my daughter has done with her life and struggled, you know, two steps up, one step back, many conversations in the middle of the night to me from afar, you know, but really positive things.

Yeah, that is really good to hear. And I think having that belief and what I really liked what you said as well about letting the young person lead when they're feeling better. I think for me, that means trusting them to tell you when they're feeling better and not pushing them, which I think is probably quite a struggle at times in families where you just, as a parent, want to make them better. Because if we do believe that they do want to get better, then they're going to get up the day that they feel better and that they can, and then it's just working on how to manage that. Maybe it's because I've been fortunate to have a daughter, not a son, who's more communicative.

Yeah, I think that's a really good point. I think that's a really good point. But what my daughter said, you know, when we went to the transition phase, she said, we've developed a very unhealthy relationship. And she wasn't being mean or nasty about it. She was just being realistic. She said, I would like to leave home and establish myself, you know, she was about, I guess, probably 18 then. So we can have a better healthy relationship and I can lead. And I think that's a really good point. And I think that's a really good point. grow. And, you know, I mean, in some ways, it was very hard to hear.

But on other hands, it was, I was ecstatic to hear her say that, you know.

13. The causes of ME_Chronic Fatigue Syndrome

um in terms of the you know the causes um of mecfs and and just any i mean like warren you're clearly across all of the research that's that's you've been part of and that's taking place um yeah is there anything that would be beneficial to share in that space yeah i mean i i now have gradually come to a view about this illness which is it's it's a complex illness and so difficult for clinicians and and people affected because really what it is it's the individual's body physiology responding to a particular major stress it's not like diabetes when i go with pre-diabetes to my clinician they really are treating the disease rather than treating the person almost whereas mecfs requires treatment of the and and focus on the individual person and i've come to that in part from the fact that my research we've you know i've got a very homogeneous group of young university women their course of disease is the same their degree of functionality is the same they're very impressive young women when all of the studies we've done on them they they are unique individuals they have differences in the molecular responses that are going on in their body so um yeah so so that's a sort of a critical thing i think about core the cause and the susceptibility of people to get this disease is it's a mixture of i think you know we've done a study last year a quantitative survey so we've concluded that it's nature and nurture that is to say um there's a familial component i mean that came out very strongly for our survey there's one recent publication which from the uk which now has said there's a very strong genetic connection so that's sadly what you inherit from your you know parents and family that you have a more of a susceptibility but it's also your previous personal health history gives a susceptibility as well so these things are very similar to what we've done in the past so i think that's a very strong component of what we've done in the past so i think that's a very strong component are causes for the particular individual and then uh the illness response you know relates to kind of basically how what you are as an individual so we talked about exercise before for example these five university women who you know have a reasonable amount of activity they can do studies they generally take have to take a day off a week from lectures and they need a bit more time in exams but they're doing really really well when we did the post-exertional malady study on them um you know some showed their cardiopulmonary effects were quite

dangerous when when they did exercise and others were like very unfit normal human beings in other words their cardiopulmonary parameters reacted like that so they're individuals really and i think that's the critical thing people talk about um and i've done kind of a detailed investigation just published on this i mean really subtypes comes down to each individual what i think subtypes are important about is if we can link a therapeutic option to a kind of a group of people you know within the me community so this is the best therapeutic option for them maybe a different therapeutic option for someone else because we know that for a lot of people it's going to be a different therapeutic option for example um you know things like vitamin b12 which is helpful to many me cfs patients my daughter made her illness worse um pregnancy for example a natural physiologic phenomenon my daughter had the best year of her me life when she was pregnant whereas other women there's you know their symptoms get a lot worse and some have no change so it's a kind of me cfs disease like a third a third of a third we're seeing a lot of people who are having a lot of problems with their symptoms and some people get benefit from things some people get no effect and some people you know their illness gets worse and just to add a little to that um i found it really helpful understanding that me cfs long covid is considered a multi-system disease um so it's affecting all these different parts of your body it might be the brain the blood vessels the metabolism um all these different things uh just even when you know it's a real thing it can just be really helpful to hear that again that it's it's not just in the head there's evidence of things like uh in long code potentially microclots i think they call it in the blood but also heart heart pumping things like that i know warren's done some stuff on the microglia the immune system in the brain there's lots of different uh evidence that has been found on things like the brain uh just a little bit um but yeah i think it's really helpful and i think it's helpful to hear that again that it's things um so just for all those people out there who still have that little bit of self-doubt which is so hard to get rid of there really is so much physical evidence it's just the hard thing i guess is knowing what's the fire and what's the smoke uh what or if it's just shifting the whole body into a kind of unhealthy but manageable thing and then figuring out how to shift that back and definitely we were talking about de-stressing things that seems to be one way to put yourself in the right situation for for helping all those different systems um potentially get to a better space

14. The impact on mental health

So clearly when looking at diagnosing ME-CFS, I know in my own experience that there was, at every turn to begin with, mental health was the go-to assumption in the medical. One of our early medical interventions was in the hospital when my son woke up one day and couldn't walk, which clearly to us seemed like a medical issue. But through the process of being in hospital, after an MRI came out clear, it was put down to anxiety and mental health and we were given a psychologist referral. And I know that even now my son is very... very sensitive to any link to mental health because of the impact of that on him.

So I'd really be curious to find out from you, Warren, what you see as the impact of CFS-ME on mental health and also that, to me, it can be a little bit of a chicken and egg situation. So, yeah, just if you could elaborate on that. Well, the important thing is that ME-CFS, most of the symptoms are neurologically based. That means the brain and the CNS are misfiring a bit. I mean, they're not regulating body physiology properly, the homeostatic mechanism. So, you know, this is kind of real. And what I've done, if I can just say a little aside, in my research in the 10 years, I looked at people and they were looking at one thing or another.

And what I wanted to do was to do a holistic study where I followed individual... patients on all of their physiology so we could understand them. And basically, we can, you know, publish now this holistic mechanism to understand what the disease is all about and the interaction between peripheral body system in the brain and CNS and what mechanisms might be involved. So we accept that it's a neurologically based disease. I mean, it affects sleep, cognitive ability and whatever. Of course, that means that some patients will have some secondary symptoms which can, you know, put in the realm of mental health.

Like anxiety, for example, is not an uncommon symptom. It's not one of the core symptoms. It's one of the many symptoms that some people can face. But I get very angry when, and clinicians have told me this. You know, from around the country, why do you believe patients? You know, they're just suffering from anxiety. So, you know, I have... Not much gets me angry, but something like that gets me angry. People can get depression. It may be reactive depression because, you know, they're getting fed up with knowing what, you know, and they look ahead and say, when am I going to get better and will I, you know?

And a lot of long COVID patients that have contacted me, they haven't wanted me to talk about what the future is because they're scared of, that I might say they're going to have ongoing disease for the rest of their life, you know? Now, I wouldn't do it that kind of bluntly, but they have difficulty facing that. So, that can be a reactive depression. I mean, I as a father had, and my wife, we had more depression than my daughter did with her illness. You know, we had reactive depression. It was very hard to take, you know? I was amazed how my daughter could be so kind of optimistic that she was going to get it.

So, well, you know, aspects of mental health are affected, just like having had COVID. You know, the whole country has had its mental health affected because of COVID and the disruption and the uncertainty in our lives now. You know, I feel much more unstable in my life now than I used to before COVID and climate change today. I had difficulty getting into work because there was a storm in Dunedin. So, patients with this, of course, are going to have, you know, some effect on their mental health, but it's not the dominant. And I've had

some horrendous examples of people getting into, under the realm of a psychiatrist who didn't believe in MECFS, and there's one at the moment who's in a private mental institution here in Dunedin, you know?

Who's just trapped away and isn't allowed to do things, and her mother wanted her to go on a micro-diet, and the overarching clinician sort of said, didn't think that would be any use at all. And the other thing is that MECFS, we haven't talked about this, have a high sensitivity to drugs or any medications, and that's a factor which has to always be brought in. And, you know, unfortunately, medications, medications that are classically used to treat mental health, like depression and things like that, they're dirty drugs in the sense they affect things. So, they're going to make, you know, ME symptoms a lot worse.

So, I, you know, I think one's got to acknowledge when there's things there to treat, and anxiety might have to be treated and whatever. But I think putting in the blanket, you know, when my daughter was, when they did the differential diagnosis and didn't, get anything at the end, then it immediately got put into the psychiatric or psychological base, you know, thing. And I talked to medical students about this, you know, and I mean, that's despicable that we're still doing that at this time. But we should be conscious of the fact that it can affect people's mental well-being.

15. Is remission possible _ – living fulfilled lives

In terms of the different phases of this illness, and, you know, I've heard of lots of people speaking about being in remission, and not, from what I understand, there's not a huge percentage of people that fully recover. How likely is remission, and, you know, is it possible to fully recover from this? And one of the things I'd add to that as well was I, you know, are there factors that, because obviously everyone is different, are there specific factors such as gender or age that play a part in that? Yeah. So, I mean, the official word for those that have been diagnosed with ME-CFS, you know, from the UK ME Association, who've done a lot of studies, is that for 95%, it's lifelong.

In other words, you have to live with the illness. That doesn't mean to say you can't have a constructive life. You know, my daughter's essentially done three tertiary qualifications, you know, taken a longer period of time. And so, she's still living with the disease every day, but she's got a constructive life. And I think that's where the emphasis probably is better. As I've said, with the long COVID situation, because of when the diagnosis was made, I think that's a total different confusion. I think we will see a proportion of long COVID people recovering, you know, and there's estimates coming out now, and they vary widely depending on which report you read, but it could be as many as 50% recovering within a year.

And so, you know, we don't really know the answer, but really what I'd like to do is to change the narrative. How do we go, how do we help people live constructive lives and get the fulfillment out of what they've got available to them? When I look at my young university woman's group, you know, they can walk around campus, they maybe go to one yoga session a week and half the time just lie there and do nothing. But, you know, that's good for them. They can go to most of their classes and whatever. Now, what's the comparison with their family? They're fellow students. Their fellow students go out drinking heavily as students do, don't live healthy lifestyles, you know.

So it's shifting living a healthy lifestyle back, you know. And as Tom has said, the meditation and things like that, healthy diets and things like that, which are good for all of us, you know, ME, CFS people are using it, and that makes their life, you know, better. And the important thing for people like me and also you know, clinicians and whatever is to try and find more strategies which will help patients, you know, get benefit and make their lives kind of easier to live in so they can do more, get more fulfillment out of it. That's how I like to see the kind of thing rather than talk about, am I going to go into remission?

Of course, there are examples of people who say they've gone into total remission, and they're really interesting people for me to study to see what's actually happened to their body physiology. I have to say that, but they're rare at the moment. Often people say to me too that I've recovered, and then I talk to them, so older people, and what I realize they've adjusted to living with their illness, you know. And incrementally it's improved, and they can do things. But when I ask them questions, you know, can you stay up late at night? Well, no. You know, can you do this? No. You know, they've still actually got the disease, but they've risen above it mentally to think they're able to do, you know, useful things and live normal lives, which is great if one can achieve that.

From my experiences, just to share my story, so I had chronic fatigue syndrome from when I was about 18 until 25. Tried all kinds of things that didn't work. Ups and downs for me. I was still pushing quite hard, trying to, I'm a musician, teaching and playing music. Probably I should have gone a little bit easier, and that might have helped more with the remission. In the end, I try, my dad's a microbiology background, and we wondered if it might have been from brucellosis, which is a bacteria that I picked up, blasted my body with antibiotics for six months. And amazingly, it did. It did seem to help me, but I got depression in the meantime for the first time ever, so I wouldn't recommend that to anybody.

I've taken it so easily. I moved back in with my parents for those parents who are wondering about the independence. It was great. I had my independent years. I came back home, just rested absolutely for balls a year and a half.

16. Treatment plan - management strategy

Available that, you know, like antioxidants, mitoQ, coenzyme Q10, which can help some people. We, you know, shown at the molecular level, you can show improvement in energy production, even if the people don't necessarily feel much better. There's drug therapies like low dose naltrexone, which is an anti-neuroinflammatory. And we think neuroinflammation is a major component. Of the ongoing illness. And then there's behavioral therapies. And I've recently just, because a patient alerted me to it, come upon the book by Annie Hopper called Wired for Healing. And the interesting thing, I hadn't heard of her, but I looked up on the internet and I discovered that she got, she had an injury.

So we'd come to the same thing. So I had a great deal of respect. So she's developed a system called dynamic neural retraining system, which is really acknowledging the brain is plastic. We call it neuroplasticity system. And when things go wrong and, and, and nerve connections get broken, they can be reformed and other parts of the brain can take over. And that's what she thinks has happened with her. And that's why she's been able to heal herself. So she wrote this book just to give other people possibly the opportunity to try it. Now, the trouble with most of the behavioral therapy things, which are very closed and whatever, they're incredibly expensive.

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And the thing she advocates is an incremental thing. You have to do this for an hour a day, every system for at least six months. And what I'm hearing of people who've got benefit from this is that they've done this and got incremental thing. And that, to me, makes a lot of resonance for this disease, you know. Not a quick fix, not something that will cure you tomorrow, but something that if you work on will improve your conditions and get you to a better space. And so, you know, I'm not necessarily advocating for this or her, but it is something which is a strategy which is worth, you know, looking at.

What I like about what you're saying there as well, Warren, is the idea of incremental improvement and making that the goal. Yeah. Rather than what I think so many people are, you know, trying, the goal being to be back to where you were before CFS, but rather just actually trying to look for incremental improvement. Yeah, so I think that strikes a chord with me in terms of finding a way to see some hope, see some improvement and find something that feels achievable. Yes. I just wanted to share with you guys. I think it's a really great kind of model of what a self-management plan might look like, that I read a recent paper by an Australian paediatrician, Catherine Rowe, and I'm reading it out, so I'll try and make it exciting.

Just really important that the child is believed and accepted. That's super important. And just remembering that there's this whole balance as they're growing up. Yeah. It's a lot of things that have gone off the rails in terms of their education, their physical development, their social networks, and their emotional balances. And so she suggests having a self-management plan for every week, which you could review monthly between the parent, the child, and possibly the school, if you have good school. And it might look something like you just try and include a little bit. No more than—if it causes PE.

No more than—if it causes PE. No more than if it causes PE. No more than if it causes PE. No more than if it causes PE. No more than if it causes PE. If it causes PEM, exhaustion, you're doing too much, but try to include some proactive social contact, so it might mean messaging someone online or you're reaching out to someone, whatever is doable, whatever that looks like to you. Proactive social contact, some academic and physical activity, and again, if it causes PEM, you're doing too much, it may not be possible, but even the smallest amount, and the last thing, a commitment to a child. a commitment to attend something enjoyable outside of home on a regular basis.

And again, I really do want to stress, if it causes PEM, if it's too much, then don't do it. But this is her suggestions. And really, it's about trying to learn to live with your illness, balance, still have some control. Control is so important for young people, for anybody, and just feeling connected to each of those different things. And one idea for the academic stuff, if the child is not totally housebound, it might look like taking less subjects at school to allow your child to progress with their friends. And that helps them with that social aspect. Of course, that would require school acceptance.

So anyway, that's just a quick summary of some ideas of hers. Again, you wouldn't want to be doing anything that triggers exhaustion. Or PEM, but just remembering how important dialogue between everybody involved is, giving the child a sense of control, the kid a sense of control, and that being believed and accepted and helped to manage in a holistic way. And I'll include a quick summary of that in the PDF summary we do as well. That's a fantastic summary of the whole discussion we've had today, I think, Tom, actually. Yeah, agreed. I think that sounds like a really good conclusion. Thank you.

17. Toms experience

hmm i'd be curious to hear about your experience as a parent as well amanda just very briefly i would say uh i so i had chronic fatigue syndrome for about seven years didn't have any depression and then with long covid i have had depression um i got i got the depression in between for other reasons um and um i think the big so so i definitely did struggle with depression it was exacerbated a lot by the long covid stuff and just picture as anybody but especially as a young person your social network your sense of purpose your future feels like it's just gone out the window uh for me the key thing was um i mean it's a whole shift and adjustment phase and recognizing that it is an adjusting time but you can get to a point of acceptance and okay this is the new the new way things are and this is what i can do and um this is kind of you know what i can work with and i think um you know uh working on acceptance and part of that is balancing of course hope is really important and striving and trying different things but actually equally important is sometimes just being like okay here's what i'm dealing with right now i have to accept it and thankfully the my background's in psychology research and there's a lot more awareness of that now than there used to be so if you were talking to a psychologist perhaps saying things like i really you know want to work on acceptance techniques or something like that might help also meditation is often good for that stuff but i'd love i'd love to hear um your experiences amanda with your story so

18. Amanda's experience

Yeah. And I mean, we've, what Warren mentioned earlier really resonated with me in terms of his struggle, you know, accepting, because acceptance is a really big part of this, I think. And I think, you know, the tension as a parent for me has been, how do I accept

this and also fight for my son to get the best possible care? And it feels like two ends of a very different spectrum that I, so, you know, we do compartmentalize a little bit and try and focus on the medical stuff when we do that. And the rest of the time, try and focus on acceptance and living out in his best life in the meantime, because there are still things to be grateful for.

But it can be very easy to lose sight of those. But definitely, I mean, my husband and I have struggled immensely. And being in awe of how my son accepts and deals with it, I guess, you know, and Tom, hearing your experience is so amazing. I worry sometimes that he is trying to protect us from his experience, because he is doing so incredibly well within himself. He's been offered antidepressants many times. I do not believe he needs them, and he does not believe he needs them at this point. But I keep that conversation open to ensure that if that ever does happen. Because when I think of my life being restricted the way his is, I can't help but imagine feeling depressed by that.

But he is, and I see it every day, is able to work within his limitations and live in that day. I think he doesn't get caught up thinking about the future. That is probably something that my husband and I do just think of, is he going to be able to do this? Is he going to be able to do that? But yeah, one. One of the things that I have struggled with, and I think he struggles with, and I'd be curious to hear both of your opinions, is trying to navigate other people's perceptions of your illness. And things like people saying, you look really good, and oh, you'll be better soon, or those sorts of comments that are no doubt coming from a good place, but are really hard.

And, you know, my son has got to a point where if someone says, how are you, he's very honest. And his response, and I love that, because he isn't fine, and that's what people expect him to say when they say, how are you? They expect him to say, I'm fine. So he doesn't say that, which I really admire. But I really struggle with that, you know, as a parent of someone with CFS, and then I know that's a real struggle for him. And that was a real privilege to hear you both speak about that. I, you know, I think you're the best people to... And Tom, you having sort of experienced that, I think it's interesting to hear that, really.

It's a difficult question to answer when you're standing on the sideline, you know, the mental health question, actually, I think.