

Living with ME/CFS Webinar – August 22 2023 – video transcript

Anne: Hello everyone and thank you for joining us. Welcome to this second Living with ME/CFS forum, where we share insights from issues that you have raised with us via our patient services and online forums. Before commencing, I wish to acknowledge the traditional owners of the land on which we meet and pay my respects to elders, past, present, emerging, and any here today.

Our conversation today will be with Emerge Australia's Medical Director Dr Richard Schloeffel OAM along with Kate Herbert, our Nurse Educator.

Richard has been treating ME/CFS patients for over 40 years and has a wealth of valuable knowledge and experience.

In addition to Kate's clinical experience in, paediatrics and communicable diseases, Kate lives with ME/CFS herself. Having staff who have lived experience of ME/CFS is something we really value and support at Emerge.

Kate will largely focus on the personal experience of someone living with ME/CFS, but will also draw on her professional knowledge. Richard will focus on the medical perspective. Both Kate and Richard are passionate about improving outcomes and management for people with ME/CFS and Long COVID. Richard and Kate will address some of the most common issues associated with adapting to living with the challenges and energy limits of ME/CFS.

So, before we start, here's a little bit of housekeeping. Please note this session is recorded, so please let us know in the chat if you have any issues. The recording will be available on our website in the coming days.

If you would like to enable closed captions, click on the show captions at the bottom of your screen and please feel free to engage with us in the chat. Given the many questions already before us, we are unable to answer further questions today but do feel free to continue to connect with us through the usual channels.

Our telehealth service is available to you as always. Just a reminder that all of the information discussed today is general in nature, and we do encourage you to speak with your trusted healthcare professional about anything specific to you.

So, Richard and Kate, welcome to you both and thank you so much for making yourselves available for this Q+A series.

So why don't we just kick off with one of the many questions we have before us and chat through the issues that these questions throw up? So, Richard, the first question is for you.

Richard: Yes.

Anne: From a doctor's perspective, how important is getting a diagnosis to helping people adjust to a life with ME/CFS? And also, what are some of the challenges?

Richard: Good afternoon, everybody. So my thoughts around ME/CFS is that it is a group of symptoms. It's a syndrome, and unless you've got a clear idea why you are not well, it's very difficult to get support. It's very difficult to be understood. And for many of you, it's very difficult to explain to family, friends, other doctors, healthcare practitioners, your workplace.

So getting a diagnosis of this condition, which is often a triggered inflammatory condition that happens after an infection, and we're now seeing it with COVID as well, people developing Long COVID, which may progress to ME/CFS, but other triggers set it off.

And if you're a practitioner, your medical practitioner is able to diagnose you with this condition, excluding other conditions. See, the thing is about ME/CFS, it probably is a diagnosis of exclusion in the first instance because we need to make sure there isn't something else we've missed. But then ME/CFS is a real medical condition with real symptoms, and the disease process is now defined to a certain extent.

And if you understand that and you've been given that information, then you've got something to work with, with your practitioner, with your family, with your workplace, whoever you're involved with, because it's very hard to explain if you've got fatigue, post-exertional malaise, brain fog, muscle pain, the multiple - 200 common symptoms of ME/CFS and Long COVID that don't quite make sense unless you've given these a label.

So from my point of view, your doctor or your practitioner, diagnosing - that is the first step to actually having an understanding of your illness and also learning how to deal with it and seeking support and hopefully seeking treatment that may lead to a better outcome. So part of what we do at Emerge and to give you some hope, is teaching doctors about this in our training programs. Because if your GP can diagnose this and help you on this journey, or your naturopath or whoever you're working with, that goes a long way for you to feel least heard.

Because one of the difficulties of ME/CFS, is that you look all right, but you don't feel all right. You've got all these symptoms and you're not diagnosed, you're not heard. That's a very lonely place to be. So I tend to think that diagnosis is paramount. And then that sets you on the journey to that sort of acceptance, but not necessarily acceptance of the disease, that you just become complacent with it, but acceptance in the general community.

And when you do seek help, you do receive it.

And I think that's very important because many of you would have experienced situations where you haven't been heard, you haven't been diagnosed, and that's very devaluing of your lived experience. It's with this illness, and this is a real illness - it's caused by inflammation. It's caused by cellular dysfunction and cellular failure.

And sometimes comes with all those cells not working - the fatigue and all the symptoms you have. So from a point of view of diagnosis, it is paramount and that's what we're working towards.

Anne: Thank you for that, Richard. So I just want to ask you one more question related to that, because, of course, we do recognise there are many challenges for patients in being diagnosed, but how important is it to be diagnosed early? Does that then have an effect in terms of how long people struggle with the disease or how seriously they can be impacted?

Look, there's two answers to that. If you get a diagnosis early with this condition, you're probably going to have greater opportunity to have positive outcomes with potential management or possible treatments. But also, you're not going to become so isolated, de-conditioned, lose your job, lose your relationships, not necessarily have any contact with your community, because you've got this illness, and that's a very lonely place to be. And the longer that goes on without any understanding of your illness, in a way, that's worse for you.

But look, if you're diagnosed when it's late with ME/CFS, it doesn't mean you won't have an opportunity to at least have a diagnosis and potentially have some management and treatment that can help you.

But as Anne says, getting diagnosed early is definitely helpful, especially with conditions like post-infection fatigue syndromes that lead to chronic fatigue syndrome, ME/CFS, such as Long COVID, because you can do things in the first instance to help people. But if you've had ME/CFS for many years or even decades, that doesn't mean you can't have a diagnosis.

And also, that doesn't mean you can't receive benefit as the science progresses in how we can help people.

Anne: That's great. Thank you, Richard. So, Kate, on the same theme, from your perspective of someone who has ME/CFS, how important was it for you to receive a formal diagnosis, and what were some of the challenges you experienced?

Kate: Yeah, I've been reflecting a lot on what Richard was talking about. So a formal diagnosis was validating, kind of, in some ways disappointing, because you're kind of holding out for, I've got this thing that you can give me this medication for that I can then get better and get on with my life. So it comes with a lot of mixed feelings. I was diagnosed very late. It took a long time to receive a diagnosis.

And I went from being a pretty typical story of someone very active with lots of things that I wanted to do in my life to very largely bedbound. I fluctuate a lot. So my symptoms sort of go like this with quite high peaks and troughs. And I think I guess one thing that diagnosis really helped with, and I think reflecting again on what Richard was talking about, is you can then understand how you need to manage it.

Because if you don't know what you're dealing with, you just keep trying to push through or you don't know what are the things that actually address the issues for that particular disease process or illness. So understanding post-exertional malaise took a long time for me to really understand that.

But having some grasp of that is very useful and very validating and gives me a little bit of steering, helps me explain things to people better, has people explaining back to me Kate, you're going into PEM, you need to stop - it creates that - lots and lots of benefits.

Your other question was about the challenges. Did you mean challenges in getting that diagnosis?

Anne: Yes.

Kate: Yeah. So I suspected for many, many years that I probably had it, but my GPs were not able to help and there wasn't a lot of information around.

They were like, well, yeah, you maybe have it, but it doesn't mean anything. It's a wastepaper diagnosis. There's no point me diagnosing you with it because there's nothing we can do kind of attitude. Then when I had another really large crash around 2013, there was a lot more social media around and community forums, and that's where I went.

Oh, and there was much more information sharing between patients than was enabled before. We were all just isolated in our own homes and not able to talk to each other. And now suddenly, we could all go, hang on, you're experiencing this? I found this. This is what helped me. This is the diagnostic criteria. This applies, this is how it works. These are the symptoms, this is how they're experienced. And that enabled me to then really advocate for myself, find a doctor who specialise in ME/CFS and get that formal diagnosis.

So it was a messy, long tiring, financially exhausting process. Yeah. It certainly wasn't a linear, easy process at all.

Anne: I'm sure that many people listening and watching today would identify with the struggle and the disruption that ME/CFS causes to your entire life.

Kate: That's it. You can feel like you're going along, you're getting somewhere, and then suddenly, bam, gone. The rugs pulled out, you're back in bed.

Anne: So we know that living with ME/CFS involves coping with multiple losses. The loss of your identity, your career relationships, your freedom, dreams, social isolation. If you're comfortable, can you talk a little bit about how you've personally experienced those types of losses and how you've learned to cope with them?

Kate: Yes, I was thinking a lot about this one and this might be my longest answer, and my apologies for that, but I did want to step through what I was thinking about.

Because obviously there have been a lot of losses. I've been able to keep my registration as a nurse, but I realise that many, many people can't. But I haven't been able to work in the career that I want. There's been a lot of time with being out of work and financial losses. You know, there are a lot of dreams that haven't been realised, haven't been able to fulfil, and that I've had to reframe and sort of kind of almost just reconstruct what my life looks like.

And that's a very messy process. But I think one of the kind of helpful ways to think about it is people might have heard of the stages of grief, because it is a grieving process for that life that you did live and for the losses that you keep on experiencing.

There's lots of different versions of the stages of grief, but I thought I might just kind of go through the five and give a little bit of an example of what it might look like at each stage.

What I do want to say, though, this is not like, oh, here you are at this stage, and then you end up at this stage.

It's more like this. It's big squiggles. It's not linear and it's not simple. So don't feel like I'm saying, oh, if you just step through these stages, it's really easy, and you'll just get to this point of acceptance and it's all la la. It's not like that at all.

But it does help you have a bit of a framework for thinking about what sort of help you might need now and also just accepting where you're at and accepting the emotional stuff that you might be going through.

And so the first stage is denial, that's that stage of this isn't happening. I'm going to keep pushing through. These are not the symptoms that I'm experiencing.

When I speak to other people, they talk about how they keep thinking that they might improve if they just make a little bit of an adjustment, have a bit of a holiday, they rest a bit. It's not really accepting that this might be a permanent sort of situation for them.

Stage two is often talked about as being anger or guilt. It's really infuriating when you lose your independence when you have significant levels of pain.

There's a lot of guilt over perhaps needing help, and we can often get in the way of letting other people help because of that. That loss of independence, that tangle of grief and guilt and anger over all that. It's not healthy to stay angry, but it's also not healthy to say, I'm not angry.

Shoving it down just means it's going to come up somewhere else. It's okay to go - this is "grrrr" right now.

But stage three is often talked about bargaining. So that might be thinking, if I had eaten the right thing or done the right type of exercise, I wouldn't be sick. We know that ME/CFS is not caused by lifestyle factors. It's not something you've done.

Stage four is often sort of depression.

Importantly, ME/CFS is not a psychological illness, but it's not uncommon to feel depressed or have sort of mental health issues as you adjust to massive life changes.

It could be you may just find that you've got a lot of lack of motivation. You feel really sad or flat or feeling hopeless or worthless.

Adjusting to coping with such monumental changes in your life. It's really difficult.

And that's where really good mental health support for me at different stages has been really critical. And I know Richard talks about this a lot. It's finding the right practitioner for you. It's finding the practitioner that understands the complexity of what you're going through and can work with you, with what works for you, for everybody.

So it's also okay to turn around. There's been a few times where I've turned around and gone, this isn't working for me. I need to find someone else. That's hard. You feel terrible, but in the end, it has to be something that works for you.

And the last stage is kind of like acceptance or hope or reconstruction.

And I think it's important to say acceptance isn't giving up.

It's about taking it day by day, engaging with what's happening with you now, accepting your limitations, but also planning your life around what you can do.

And maybe a little bit of hope thrown in there that things might improve with some help and intervention.

I've got a complicated relationship with acceptance and hope. That's really hard.

Anne: Well, the reality, Kate, is that as you said right from the outset, grief is not linear. You don't move from one stage to the other. You might get stuck on two stages. You might never get to acceptance.

It's what happens. And you work at your own level. And some people do get to that final stage, but a lot of people don't. But it to understand the process that you're going through. And sometimes it also helps people to understand why they're behaving in a particular way because. I think that's very true.

Kate: I think that's very true.

And I think there's a lot of dissonance as well. You can kind of feel like part of you goes, I accept where I'm at, I know where I'm at.

But there's this other part of you that doesn't feel like this is real. You don't feel like this is actually your life. You're like it feels almost like there's different parts of you and they don't quite gel.

Yeah. It's very strange space often and you're right, it can help. Yeah. It definitely explains some behaviour. Like, I've lashed out at people before and we've gone, actually, hang on, where are we at in this? What's happening to you?

Anne: Yeah. And taking time to look at why – is one of the things that I've noticed, and I'm a newbie to ME/CFS still, and there is enormous frustration and anger that is largely as a result of the fact that not being validated by their clinicians. They have not been listened to, they've not been heard, and they've been made to feel as though this is all their fault.

Kate: Absolutely.

Anne: So there's huge issues around anger management and frustration that are completely understandable apart from all the natural processes that someone who is grieving the loss of their previous life will go through.

Kate: Yeah, it throws up a lot of things that sometimes you can feel like you've just got on top of something, you're okay with it. You might have stabilised, you might have been able to work with your practitioner to get to somewhere medically and got a bit of function back.

And then something will just come along and go bam, and you're down again.

Anne: Thanks for that, Kate. So, Richard, what do you think about what Kate just discussed? What are your thoughts on this?

Richard: Look, I just totally agree. I mean, ME/CFS is a loss condition – you lose a sense of yourself, you lose a sense of control in your life.

You definitely find it impacts your work situation, your study, your interpersonal relationships, your friendships. It impacts any prospects of your present and your future. So that's enormous amount of loss and grief that's experienced when you develop this syndrome, which comes out of nowhere sometimes you may have had an intercurrent illness and suddenly you've got ME/CFS.

And the delay in diagnosis and the delay in actually validating your illness is part of that trauma. Because the journey of recovery starts when you're actually validated and when you're actually diagnosed and being supported in your grief and having good psychological support and good medical support and family and intimate relationship support comes about because you have a sense of empowerment, because there's a knowledge base around what this illness is.

And I think for a lot of people, the problem is they haven't had that validation from their practitioner or from their psychologist or from their medical specialist or even their naturopath. And definitely not from family, friends or society in general, because this hasn't been a mainstream illness with a guideline and a full understanding of the way this disease develops.

That leaves people in a very isolated place.

What we're doing today is about giving you hope, giving you validation, even if you are in despair or suffering. Because you not only have all these emotional symptoms, you're actually suffering physical symptoms that are very real.

You're in pain, You're in pain. It's not that you imagined the pain or if you've got headaches or you stand up and you faint and your brain's not working. I mean, all these are really valid symptoms that are real due to a pathological process of inflammatory response in your body that's causing all these multiple symptoms that you don't have control over.

You know, it's not only grief, it's fear.

Kate: That's so true, Richard. Very much so.

Richard: This illness, and I often say to people when I meet them, you are safe now. Because if you haven't got a sense of safety with ME/CFS this is quite a frightening illness.

And I think having people, the more people who understand this, from your close relationships to your workplace to your practitioners, that's a therapeutic process. And it also enables you to be in a space where you have some nurturing and not just dealing with your grief, but dealing with your fear.

I think that's the way I'd like to move forward with this, so the whole community, all Australia, all the world knows this is a real illness that is impacting huge numbers of people, and even more so since Long COVID and a recognition of your plight and supporting you is paramount.

Anne: Yeah, absolutely. Absolutely. So, if we turn our attention now to the major management technique with ME/CFS and that is pacing.

We know so many in our community have a difficult time getting others in their life to understand why they need to pace. Richard, what's an easy explanation that you would give to help others understand their situation and needs and the importance of pacing.

Richard: I think, look, what I'll do first is just explain what ME/CFS is.

If you understand exactly what's happening in your body, in your cells, you'll get an understanding of why pacing is essential. So part of the research and the international effort to understand this illness is we realise something

triggers this innate immune system where you become inflamed internally, which is not measurable in normal pathology.

So this is at a low level inflammatory response happening at the cellular level. Every cell has a functionality to produce energy. So you've got a biochemical process in every cell of your body to produce something called ATP. Now ATP is a fuel. It's like coal in a power station or fuel in your petrol tank for your car.

If you don't have any, it doesn't work well. What happens in ME/CFS?

Your cells aren't able to produce adequate levels of ATP because the chemical reaction that creates is disrupted because of this low grade innate immune response. If your cells aren't working - and the sum total of all your cells that don't have enough energy, enough ATP to power them - is that cell group is dysfunctional.

But the sum total of all your cells that is functional is the fatigue you're experiencing and the symptoms you also experience and the disease and organ and tissue issues that you've got leading to all your symptoms. So it's a cellular disorder. That's why normal blood tests don't pick it up.

It's happening at a much more finite area of your cell function. Now, when you do something, and if you're an ME/CFS patient who's severe, and that's housebound or bedridden, you've got to go to the toilet, that might be ten metres away, six metres away. You get to the toilet and back again, you're absolutely shattered, and you collapse if you get there. And you're not using a slipper pan.

That's very Severe ME/CFS. But it's because of your energy within your cells to get you up over to the toilet and back - not just the physical energy of moving your muscles, getting your circulation happening, making sure your blood pressure is all right and your brain function can actually enable you to get there without falling over or being distressed.

Well, that's not working properly. So as a consequence, you've used up that little bit of energy that your cells are able to activate your cell groups to do that you'll collapse. So if you're in that severe situation, I don't know how many listening to this are in that situation - you'll need help with all your care and all your activities because someone else's energy is going to look after you.

So pacing in that situation is very difficult.

If you're moderate ME/CFS, which is where you can get out of bed, you can sit outside. You might go for a little walk. You may be able to do one or two things a day, have an interaction. With someone who doesn't make you exhausted.

Find a point. Say 60% to 80% of what you feel you can do. And the moment you get to that point, feeling a bit tired you must rest. Because if you go, over that 80% of your normality with your cell function not producing enough chemicals to fire your cells to make sure all your cells are working will start to fail and you'll start to experience more of your symptoms that will cause you to have a crash.

And a crash literally is running out of fuel, ATP and the other chemicals that activate your cell function and you'll feel exhausted. If you're mild ME/CFS, that's someone who can get out, maybe do one subject at uni, but that's all you do. Maybe talk to one friend a week, maybe go to the shops once a week, maybe walk around the block a couple of hundred metres once a week, and that's mild.

You may find you have a little bit more energy, but if you go and do something, say two days in a row where you do something like walk around the block where you normally do it once a week, that may cause you to crash.

It's the same problem. So you're limited in your energy that you've got cellularly. It is determined by how much effort you put into what you do. And pacing is all about having a conscious recognition of how much you can do and how much you can't do. Now, that takes practice and education.

It's not me just telling you this. And if you can understand, it like a car. If you haven't got enough fuel in your car to get from here to your home, and you're in the shops and you can't get home, the car will stop before you get home. Well, that's what's going to happen to you.

If you overdo things. If you've got ME/CFS, you won't get home. You'll actually have a collapse and you won't get to the bed or whatever. And the fatigue you experience is unrelenting fatigue, unrelieved by rest. So it's not related to rest. It's not. You didn't make a choice to feel this.

It's because your cells, en-masse, aren't working properly. And the trigger to that is this innate inflammatory response. And when you do too much, you activate that inflammatory response, make the problem worse. So pacing gives you the ability to do a little bit each day or a bit more each day, and that's why graded exercise isn't beneficial because the graded exercise requires you to do more than you're capable of and you haven't got cellular function to do that. That's going to induce a crash.

So pacing all your activities mentally, physically, and your personal interactions - you need to be conscious of it and recognise the signs that I've done enough, now I have to stop. And even when you rest, you're not recovering. It's usually time that helps you recover because cells take a while to fire up and produce a little bit more ATP, this chemical to activate and other foods in your cells to be normalised.

So that's why it might take three or four days to recover from overdoing something. It's not because you're lazy or it's literally because you've run out of energy to have all those cell groups working, and your body's gone into almost like a hibernation phase until you recover.

I think that's how I would see why pacing is so important. It's based on your physiology that's disturbed.

Anne: That's such a good explanation, Richard. I've never heard such a comprehensive explanation that goes into what's actually happening at the cellular level in your body that requires you to pace properly. Otherwise, as you've said, the car will stop and you won't get to your destination.

Richard: Yeah. Thank you. If you understand that and if you can't do something one day and you can do it the next, that's okay. As Kate says, it's a disease condition that goes up and down. Some days you'll be better than others, and it's dependent on how much sleep and what you've eaten and what supplements or medication. It's dependent on your cell function. So all the things we do to support you, you've still got to pace.

Anne: Thanks for that, Richard. So, Kate, again linked to the issue of pacing, and we won't go into the specifics, but what do you wish someone had told you right from the start at the beginning of your journey? Were you informed about pacing? Were you informed about other aids that would be helpful for you?

Can you expand a little bit on that from your perspective?

Kate: I wish I'd had Richard's explanation. I wish I'd had that sort of linking the physiological issues with the symptoms and why there were those really hard energy limits and also that sometimes those energy limits can feel kind of flexible. So you can do something one day that then you're kind of like, oh, I did it one day and not another. Why is that? I think having an understanding of the physiology would have been really nice.

But what I do want to say is I wish someone had just said look, I did have the psychologist actually try and get me to do it and try and explain it to me, but I kind of wish someone had just said to me, look, it's really boring. And it's really frustrating because it sounds all very nice that if you pace, you're going to feel better. But I think it's very

frustrating to have to have a limit to put those hard limits on you. And it's really hard to go, I've got this much, but I'm only going to do 60% or 80% of this much.

That's hard because you're going up. Well, I've got that other bit there to play with, haven't I? So going and then resting is like you want to pull your hair out, you want to scream. You don't have the energy to scream. Um, but what I also wanted, I think the thing that when pacing was introduced to me, the big problem was it was kind of framed as a fix.

If you pace well and if you do all the right things. You're going to feel better and you're going to be able to function like a normal, healthy person. It wasn't said in that many words, but the implication and the feedback I was getting when I was coming back saying, I still can't do XYZ and I feel revolting was that I wasn't pacing well enough, that it was my fault, that I wasn't doing it properly.

So I think I wish I hadn't been told that. I wish I'd been told that pacing is not a cure, it's a management strategy only. It's a really essential management strategy only. But we understand that it's not some tick box now you can go on with your life kind of thing.

Yeah, I think the other thing I was really thinking about and I was talking about this with a friend on a holiday recently, so I got a mobility scooter, in the last twelve months. It took a long time for me to get there. I wish I had been encouraged to use mobility devices a hell of a lot earlier in my disease state, when I stopped being able to walk a couple of blocks. I wish a doctor had just turned around and said, get yourself a mobility scooter. Let's look at how we can get you a mobility scooter.

The ridiculous saying use it or lose it is kind of just - I am more active with that scooter because when I was up in Newcastle with some friends and they had a spare scooter, we were able to go out and do a few small things, which there is absolutely no way I could have done that without it.

So I wish that had been encouraged, too. I wish I'd been encouraged to use a shower chair earlier, even a walking stick.

I wish someone had talked to me about that internalised kind of ableism that we have, that I'm a young woman, I shouldn't be using a walking stick. I shouldn't be using a mobility scooter. I have to be bedbound to have use some sort of mobility aid. That's not a helpful kind of way to think about it, actually, I saw something online last night and someone was saying instead of going, how sick do you have to be to justify using one? Why not go, what could I do if I actually adopted this aid? What would my life look like if I actually had this assistance in my life? And I also do recognise that there are issues with accessing those things financially and that sort of thing. I guess I'm just more trying to bring up the conversation about examining what could you do if you used a walking stick or a walking frame or whatever in that situation, rather than not. I'm just trying to validate it a little bit more, I guess. Yeah.

Anne: So Richard. Have you seen benefits? So, to Kate's point, have you seen benefits in your patients when they've started to use mobility aids. Are there things people should be cautious of when thinking about using mobility aids? And do you get pushback from patients who will say, no, I'm not going to do that?

Richard: Look, I'll answer this in two ways, of course. The first thing I've been recommending mobility aids -25 years. Yes. So I'm very early to say, look, you need a walking frame, because if you get tired, you can put the brakes on and sit down. I don't care, if you're 20, but you can use this.

I've definitely encouraged wheelchairs because very early in the piece, because then my patient can come in, because if they can't walk into my surgery, their carer, their parent or their partner can wheel them into my surgery, and they're not going to collapse when talking to me because they've had to walk up down the ramp and from the car into the surgery and then they're collapsed.

So I was recommending walking frames, wheelchairs of late. I really don't recommend scooters. I recommend motorised scooters, but not two-wheel scooters.

We don't have a problem with you having a motorized vehicle like a little buggy or a proper -

Kate: Yes, that's what I'm referring to.

Richard: ...to get yourself around they're very useful for multiple patients of mine - that's part of the reason I'm in my surgery. I have lift access; I have disability parking at the lift.

They can wheel their device and there's often devices in my room scooters and whatever with the patients using them. And I'd say at least 30 or 40 of my patients have those sort of mobility aids. The issue comes to how do you acquire them? They're not cheap, they're expensive.

Where's NDIS? For you it is very difficult to get funding for these things, even though I believe if you've got a long-term disability, they should be funded and provided for you. And that's often difficult. Motorised wheelchairs are good as well. Again, the same problem is access, but if you've got sufficient funds to hire one or use one, they actually give you a different sort of perspective in life, because you can actually get out where you can't otherwise.

And often if you want something that can be folded up or put in your vehicle and driven somewhere, then you can go to the shopping centre or you can go to your doctor's surgery or go around a level area around the park. Even though you can't walk it, you're outside, you're enjoying nature or whatever appropriate places.

So these things are useful. And I think walking sticks can be useful because if you've got something, a mobility aid – people will treat you differently. Now, from my point of view, if you've got a mobility aid, most people will treat you with respect and support. I mean, you shouldn't be judged if you get something if you've got ME/CFS and start using it, which gives you a better quality of life, some people may do that, but in my world, I totally respect that.

That's something that's really useful. So for those of you who find walking limited, but you want to get out and if you're able to do this and you can acquire things, some sort of aid, use it. Walking frames are great if you go shopping, because, as I said, you can put the brakes on and sit down.

Motorised scooters are fine, but look, sticks are good because people oh, look, this person's got a disability. We'll assist them. You don't have to wait in this long queue. You go over there. Most of my patients have disability stickers for their car so they can in disabled parking.

If you've got ME/CFS, you can get a disability sticker. Because I know if you're driving around somewhere, and can't find a car park, the disabled parking is outside the door, I know where I want you to be. So that's a negotiation. Your doctor has to write it for you.

But my advice is ask them if you're disabled and you have ME/CFS and someone's driving you or you're driving yourself, which is not likely if you're moderate or severe. But some of my mild patients drive themselves. They all have disability stickers. So, yes, aids are really helpful. Stickers are really helpful.

Having carers with you are helpful. I encourage my patients to get out. And if they've got loved ones, carers partners, use it. Because isolation is a real problem in ME/CFS, and if you can actually have more interactions, it's better for you. But always remember only you have to pace yourself, even if you've got a mobility aid.

Kate: Yeah, I think that's a really good point.

Richard: Too much and you end up somewhere and you're exhausted. You have to be careful. You got to get home. Yes. You need to actually have someone with you who can get you back in the car and home rather than stuck somewhere.

Anne: Actually, I'm just reflect on something Richard, you were talking about. Did you want to no, I was just going to say could you comment on that? Because it's a really important point.

Kate: I think hang on. Comment on what?

Anne: On Richard just oh, about not doing too much when you've got an aid.

Kate: Oh, absolutely. I mean, you do still need to be very careful.

You know, when I first got my scooter, I went off to the Botanical Gardens with my husband and it was like, oh, this is fun. And then yeah, that didn't end well. I was able to get back to the car, I was able to get home, but then I was stuffed for a long time.

So because you're out and about if that is something that you are able to do, if you are able to actually take the scooter away from the property. Some people do just use things within the home as well to help them mobilise a little bit around the home.

But even then you are still doing things, you've still got the input of light, sound interactions, scent or climate, kind of changes. All those things impact on our energy. So it's still important to go just to take a little carefully and just test those things a bit more. And also even just sitting upright for some people, suddenly if you're sitting up in a chair when you've mostly been reclined or lying down in bed, that's a lot of postural muscle and energy that you're going to be using.

And those muscles - that's going to use a lot of your aerobic energy. And so you just need to be very, I guess, cautious about what you're doing. And I think probably the more severe you are, the more you're going to need to talk to maybe a professional about what's going to work for you and be safe for you.

I did also just want to reflect on something. I don't know if it's when you're a younger woman, but if you're using mobility aids like walking sticks or whatever, you tend to attract a lot of attention from people coming up to you and talking to you. And that can be a little bit challenging. So you may just want to be prepared for going just - warding people off a bit, going, oh you know, I'm just not very well, bye.

I don't need to talk. You don't have to explain yourself. I think that's the thing. You do not have to explain yourself to anybody. It is nobody else's business what you're using an aid except you, your loved ones, and maybe your medical providers.

Anne: That's a really good point, and it's something that we probably not think about because, you know, um, most people are quite understanding and empathic, you know, how. You'll always get the person that will come up to you and say, oh, are you okay? Can I help?

But people don't necessarily understand that this is your time for you to be independent.

That's just such a good point for people to understand that you may have to navigate that kind of social situation.

Kate: I ended up telling people when I was using a walking stick that I just hurt my foot.

I got so sick of it. I was like, I don't owe you an explanation. I'm just so sick of this. I don't have the energy. And they weren't being mean. You're right. They're empathic. They're just curious. But you've got to guard your own energy and your own emotional energy in this as well, and that can be challenging.

So yeah, I just hurt my foot.

Anne: So, we're coming to the last 10 or 15 minutes of our Q and A here today.

Richard, we've talked about pacing and mobility aids. What other things can doctors help their patients access or use? And in what other ways?

In what other ways can our clinicians help patients move further along their journey? It's so complex. I'm talking beyond medications because we know that the journey is so unique for everybody.

What are your closing remarks around that?

Richard: Look, I'll give this in three different fashions.

The first thing is you have a medical illness. And ME/CFS patients develop what we call comorbidities. They're illnesses that are a part of ME/CFS but actually have a genuine pathology.

Like 30% of you will develop underactive thyroid or thyroid conditions.

A large percentage of you will get metabolic syndrome and problems with weight gain,

Some of you will have adrenal fatigue, which becomes adrenal insufficiency.

You may well have multiple symptoms of pain and discomfort that are actually evolving with the illness.

So the first thing the GP needs to do is realise this is not a static illness and you may, as a patient present with ME/CFS, fatigue, post exertional malaise, cognitive impairment, pain.

But then you may have developed other conditions along the journey. So having a GP checking you to make sure that you haven't developed one of these comorbidities on your regular visits is part of that process that we do.

The second thing I think is really important with acknowledging this condition is actually putting in all the possible supports that you need as a patient for you to live in a reasonable way and supported by our community.

So that's as simple as, as I said, the disability sticker. But if you need to be on sickness benefits in relation to Centrelink, or have a pension form filled in, or if you're applying for disability pension and getting you through that, or doing your insurance claim, or giving you whatever it requires for you to have an income and some support through government or your work situation or insurance.

That needs to be supported by your GP as well. That's our responsibility.

And then the other thing that's really important to recognise as a GP is any of you who have got an illness referred to other allied health or particularly maybe a specialist doctor or whatever. Because ME/CFS is a diagnosis in itself. But you still develop all the normal things and have all the normal requirements of anyone else, whether they're healthy or not. And you need to have your regular checkups, women's checks, men's checks, or your skin checks, all those things that other people have done naturally without having ME/CFS but you're not unique.

You might be unique in the sense you've got ME/CFS but we as doctors need to look after all those aspects of your health, just like we would with our normal general practice patients.

And the last thing is being available. Having a GP in your life or a naturopath or your psychologist, your support person, is a really important link for you to have some degree of safety.

Feeling a little bit connected. Feeling heard and generally have a rhythm in your life that you can touch base with someone, so you don't get lost in your home situation, because it's very easy to become quite isolated with this illness. And all my patients are on a rhythm. I see them weekly in the first instance, weekly, monthly, three monthly.

And I had a patient, I had multiple patients today on their six-monthly visit. They're stable, they're on treatments and whatever. They're living with their condition.

If they've got ME/CFS and I provide medications, checkups and do all that, but they're at a stage where they're in this what I call quiescent phase of this condition where it's not necessarily evolving to anything else. But I'm still doing all those normal checks.

So I think that's what we provide as GPs, but also referring out to the appropriate people. Allied health specialists and other support, and as I said, the funding, financial side of this and government support, etcetera.

Does that sort of answer your questions? It's a pretty broad, it's essential.

Anne: Oh, absolutely.

Kate, what are your thoughts about what Richard just said? And is there other advice?

Is there any more advice from you as a patient that you believe would be really valuable to share on adapting to living with ME/CFS, or just sharing anything from your own personal experience that may be helpful for others?

Kate: Yeah I think Richard's right. I think looking to find those points of support in your life, what I call scaffolding or structure that you need to be able to keep checks on track to make sure that you're looking after yourself, that you've got those things in place.

Also, kind of the opposite to that. But I think what can happen, though, is that because even with really supportive doctors in your life, you can still keep kind of like you can get to this state where you're constantly trying to fix yourself or you're constantly trying to go to all the things, to do all the right things, to try and be the best that you can.

And I think there's definitely some benefit in that and there's times where you need to more intensively seeking support.

But I think there's also - I don't know if burnout is quite the right term to use, but sometimes you can also burn yourself out by this. Burnout doesn't cause ME/CFS. But I'm talking more about like burnout is kind of this state where the demands on you are more than the resources than you have to cope and sometimes managing chronic illness can really end up there because you've got so much going on, it can feel like a full-time job.

And I've personally hit points where I've felt extremely overwhelmed and have no idea what to do because I've just got all the things going on. And that's not just because it's ME. It's because a lot of external pressures that we have that mean that we don't have a lot of that support in this illness and in this society and that sort of thing. So it's a complex thing.

I guess what I'm trying to say is recognise, if you're starting to feel really frazzled and really over it and really like you're trying to do everything and fix everything and it's not working at that point, you really do need to step back, and you just need to take a breath and you need to go - for me, anyway, this is me. My journey has been going, I'm okay, I'm alive. What can I do next? What helped? What do I need if I don't know what next step I need to take, that's the thing I need. I need someone to help me make that next step.

That could be my GP. That could be a psychologist. That could be a really good friend.

I don't know if any of this makes sense. I guess I just wanted to share that because I think we can get really overwhelmed. It can feel like a full-time job and more just trying to cope with this. And then you can feel like you've got no room for you and the things that you love to do.

That can be hard when all the things that you love to do are no longer possible. So that's also part of that thing of letting go. When I really, really crashed, I learned to crochet. I am not a crafty person. I failed Home Ec. Every time my grandmother tried to teach me to knit, I was outside with the dog.

I'm not an indoor person. I'm not a sit still person. But I had to learn, learn to be, because that's where I was. And it didn't matter how hard I felt it. My cells were not giving me the energy to be a different person.

So that's my long ramble.

Anne: What an amazing conclusion. Kate, I love the fact that you failed Home ec(onomics) and learnt how to crochet.

Kate: and then I became obsessive with it!

Anne: That is about doing something really positive that ultimately gave you some joy.

I guess a lot of your story today is all about adapting and how we can cope, how patients can cope.

We're virtually four minutes away from closing, so Dr Richard Schloeffel, Medical Director of Emerge Australia, and Kate Herbert, Emerge Australia's Nurse Educator, thank you for your time and for your willingness to share your personal views and experiences.

Kate, thank you for your willingness to be vulnerable and share those vulnerabilities with everybody who's online because they all identify with what you're saying. And Richard, I'm sure that everybody wants a GP to be you.

Richard: I'm working on cloning myself.

Anne: And we do understand the difficulties that many of you experience in finding a literate GP, and we're working on easing that for you.

So we hear you, definitely. So, Richard and Kate, we so appreciate your participation.

So today was the second in our Q and A series of webinars with Dr. Schloeffel. Your stories of the lived experience of those with ME/CFS and Long COVID are so critical because your voices need to be heard.

So this is a platform where we can together explore the very pressing issues that you face.

For support in your journey Emerge Australia is here for you, so please feel free to call our 1800 Telehealth nurse service or email us with your questions.

We will always respond to your calls or your questions via email and please remember that.

For more information and to subscribe to the Emerge Australia newsletter, where we're going to let you know about our next Q and A, visit our website at www.emerge.org.au

Thank you to Richard, thank you to Kate, and thank you all for spending this last hour with us discussing what are the critical issues of your experiences.

So, thank you and goodbye. Thank you.