Introduction and housekeeping

00:00
Hello everybody, welcome and thank you for joining us today. We are recording this, but only the panel's names and videos are visible. I just need to let you know that Becky's having some technical issues, so after the intro, she's going to go off camera for a bit, but she'll be back for her presentation. We're delighted to be hosting this free webinar on myalgic encephalomyelitis, or ME, and long COVID as part of our Learn About ME project funded by the Scottish Government.

00:29
and delivered by Action for ME in partnership with the ME Association, ME Action Scotland and Long Covid Scotland. My name is Clare and I'm Head of Services here at Action for ME. I'm joined by my colleague Avril, our projects and participation senior practitioner, who be collating your questions for our panel a bit later on. We're going to hear 10-minute presentations from three professionals with a wealth of specialist expertise.

00:54
Thank you to everyone who submitted questions in advance, which our panel have tried to address in their presentations. There's a chance to ask further questions in our Q &A at the end. Please submit these via the Q &A button, which you can also use to upvote questions from your fellow attendees that you're keen to have answered. We'd be hugely grateful if you can share your feedback about this webinar via two anonymous polls, the first one of which Avril is launching just now.

01:24
and the second will come at the end of the presentations. We'll also share a short survey, I promise it is short, it's just three questions, in the second half of the webinar. Your feedback helps improve what we do and helps us apply for funding to reach and support more patients and professionals. So I'll just introduce our panel and then we can get started. First of all, we're going to hear from Dr. Nina Muirhead.

01:52
who's a British specialist surgeon in dermatology and has lived experience of ME. She has written the CPD module that we promote as part of this project and is really highly rated by those that take it. Nina will then hand over to Dr. Robin Kerr, who was a full-time GP partner in the Scottish borders for more than a decade. He now continues to work in general practice, but also leads his local rapid cancer diagnostic service.

02:20
and offers UK wide online consultations for patients with ME and long COVID via Action for ME. Our third panellist is Rebecca Sessions, a chartered physiotherapist with over 30 years of clinical experience with Action for ME and independently. She's current quality and clinical governance lead at IPRS Health and also has lived experience of ME.

Dr Nina Muirhead

03:02
Looks like I've got my work cut out for me this evening. From the poll, it looks like not many people on this call are confident in diagnosing ME and I can understand why. I have ME and I'm a doctor and I didn't recognise it in myself for many months. I then saw 13 different doctors before I got a diagnosis. I had a diagnosis from my GP and that was incredibly helpful.

03:31
And so if you learn nothing else from this evening, please learn that being a GP and diagnosing a patient is life-changing. And please gain the confidence and hopefully some of the tips that you learn this evening will help. And if not, there's also the online CPD learning.

03:57
So ME is defined as a neurological illness, it's multi-system and it's characterized by this thing called post-exertional malaise where symptoms are exacerbated following exertion and it can be cognitive or exercise that's causing the exertion. Other main diagnostic criteria are unrefreshing sleep, severe fatigue or exhaustion,

04:27
which limits functions so people can't work or study as normal. And also cognitive impairment. And what patients need is recognition and a formal diagnosis. And then mainly support and support can be practical but also pharmacological. And Robin and Becky will be providing some more information on that later. But I'm going to start with Beth's story. This has been popping up in the news

04:55
a lot over the last month. Beth is an athlete and is Olympic standard and unfortunately is currently in bed 22 hours a day. She's stoic, she knows what fatigue is like, she knows what muscle aches are like, but she had no idea what hit her when she got ME. She said it felt like she was a few days from death.

05:24
And these are all quotes directly from Beth in some of her recent interviews that she's been doing for the media. She's just left the house five times this year. She's been in bed for 22 and a half hours a day. She only gets up to eat and use the bathroom. Conversations, bright lights or sounds can trigger a crash lasting days or in severe cases, months.

05:54
It's life decimating like I can't even put into words. It feels as though my entire body is shutting down. It feels like you're a few days from death. Your body just can't produce energy properly. It leaves you with so many symptoms. I can't even list them. Well, I have attempted to list them and this is a list of the commonest symptoms. And you'll notice that

06:22
doesn't actually really make the shortlist. A lot of patients will present with a lot of odd, seemingly unrelated symptoms, sore throats, muscle aches, but also feeling hot and cold, tiredness, fainting, nausea, change in sort of day-night orientation where they can either...

06:49
be waking early, waking in the middle of the night or not falling asleep properly, waking unrefreshed. So if a patient comes with a lot of bizarre symptoms, please don't assume they're depressed or anxious or just a little bit of a hypochondriac. Please just dig deeper and ask about the four main key cardinal symptoms. If you carry on Clare.

07:16
So ideally an early diagnosis should be suspected in children after about four to six weeks and certainly after three months of symptoms in adults a diagnosis should be made. So if someone comes and they've just had symptoms for a month or two please make sure to follow them up bring them back to clinic after another month with the aim to making a formal diagnosis because people will start to struggle with

07:45
being believed in the workplace, being supported in education or even getting help if they're a mother, a busy mother at home or have elderly parents. If you've got dependents and you can't cope with your day-to-day activities, then support is needed. So the four key symptoms to ask about are fatigue and this is crushing fatigue where you are too tired to complete your day.

08:15
or you're weak. Unrefreshing sleep, post-exertional malaise, so that's worsening after minor exertion, so it can be having a bath or shower, can wipe someone out for a couple of days afterwards, and cognitive impairment. There's another diagnostic symptom as well, which is orthostatic intolerance, but is often not picked up, but is easy to pick up because a patient's heart rate can increase significantly on standing.

08:46
So management is supportive and Becky Sessions will be talking about that later this evening. Mobility aids and care can be provided to help the patient to conserve their energy. Pacing and rest and managing energy are the key ways of managing ME and also regular review for other comorbidities. So one of the sticking points.

09:12
for diagnosis of ME is the fear that once diagnosed the patient will stop getting help or management or will lose hope because ME can be a chronic disease which doesn't really improve. However, if the patient does get a diagnosis, they can get support to manage their energy and actually are more likely to return to the workplace than if they're given exercise as an option.

09:40
So exercise will push them into this post-exertional malaise even more quickly. And Robin will talk about the pathophysiology of that. So the key to support is telling them not to push through and ignore their symptoms when they're exercising, but also supporting with medication for sleep, pain, orthostatic intolerance, and often antihistamines can be quite helpful as well.

10:09
So I've done some qualitative research on this and this was from direct patient interviews of 10 different patients and Beth Dobbins' statements were almost exactly mirrored by the patients that I interviewed which was prior to her being public with her account of the illness. Patients often say that they were too ill to continue or they got ill, they tried to

10:37
go back to work, they tried to get back to normal, but then started getting symptoms.

10:45
The symptoms can sometimes last for days or weeks at a time. Neck stiffness, headaches, feeling like you might die comes up quite often. And I don't think people are exaggerating how that feels. I certainly went through days of such severe pain that I was just concentrating on getting from one breath to the next. And having had two children and gone through labour,

11:15
I would say that the ME pain was worse and it was very, very difficult to cope with. And it can be quite shocking to know that someone is in bed at home with no support, no medications and being in worse pain than the labour pains. So please don't underestimate when these patients are complaining.

11:44
they can be really, really ill. And the tendency is in reality is to underestimate how ill you actually are because people are survivors. People want to minimize the trauma that they're going through. They don't tend to exaggerate. So please take patients seriously. Just two more slides from my point of view. And that's...

12:14
really kind of giving you some ideas of what to ask the patient, what fraction of your pre-illness capacity are you functioning at and how many hours a week can you function and be useful. So it might be that just two or three hours a day or two or three hours a week can be obtained with sort of work and concentrating or maybe not at all. It may be they can only speak for five minutes a day. What happens when you engage in normal

12:44
trivial exertion, whether it be physical, mental or emotional. How long does it take to crash? How long does it take to recover?

12:59
So this is a resource that I've created. Please use the PRN, the QR link to get to study PRN. They have a variety of courses and actually the MRCGP Applied Knowledge Test case examples are their most popular revision resource. So we have provided this for free and it is one hour of CPD and it gives you a certificate which looks like this following slide.

13:27
So, oh, well done, Clare, you've done yours. Fantastic. So, please do this because after tonight's presentation, you can go online, do this very quickly. It's 10 case-based MCQs and you'll have a certificate to show for it and that can pop in your portfolio. It's always helpful for appraisal. So, please do engage with that if you can.

13:55
Carry on.

13:58
So we did some quality of life research which is published in the BMJ which shows that across the board ME-CFS patients have a significant impact, particularly on physical activities, pain mobility and self-care compared to the normal population. And when we looked at family members quality of life, which is on the next slide, we saw that actually the family members were also significantly impacted.

14:26
And compared to lots of other disease areas, family members of patients with ME were significantly impacted at a statistical level in a lot of the domains. So it not only impacts the person with ME, but their parents, their children, and their loved ones. And they often feel worried, frustrated, sad.

14:56
and find it difficult to cope. They're hugely impacted with holidays, activities, sex life and having any time for themselves. So it takes a lot to support these patients and their families.

15:16
So I'm going to hand over to Robin now. Thank you.

Dr Robin Kerr

Thank you very much, Nina. I think that was really helpful, and I hope our audience is now more comfortable with the concept of diagnosing ME. I think if you're going to be comfortable in making a diagnosis, it would help to understand what you're diagnosing. And therefore, I'm going to talk a bit about the pathophysiology. I picked this picture quite intentionally.

15:44
I absolutely do not have all the puzzle pieces, but I'm going to show you how it looks like they're fitting together. There are absolutely gaps. Okay, that this puzzle is incomplete. There are a lot of people contributing to it and hopefully this will continue to advance. But I think our knowledge from medical research of what ME is is actually probably better than is made into mainstream practice yet.

16:11
And so well done everyone who signed up for the webinar. You'll get to be the more advanced ones out there. So you can go back and spread the word to whatever you want.

16:26
A few studies that I want to highlight so that we can improve our understanding. ME patients have reduced exercise capacity on day two, controls capacity increases. So this is in a laboratory setting. People with ME were put on exercise bikes and pushed to VO2 max.

16:52
The same was done with healthy controls. Now the healthy controls did what you would expect human beings to do with practice. They got better when they came back on day two and repeated the process. The ME population got significantly worse. They could not replicate that effort on day two. Their effort was worse than the controls on day one.

17:18
but it got worse again on day two. And so this is not an illness of psychology, as it's been mislabeled in the past. This is first of several bits of biological evidence showing that these people are ill on a physical level. Next slide please, Clare.

17:42
Another study here showing that ME patients with an elevated blood lactate at rest are at higher risk of more severe post-exertional malaise. So we know from Nina that post-exertional malaise is one of our four core criteria in making the diagnosis. And this paper is telling us that people with ME are running with a high lactate at rest. So they are already

18:12
tipping into anaerobic at rest. That's why brushing your teeth, making your tea, going to the toilet, having a conversation, that are stuff that healthy people take for granted is

like mile 26 of the marathon for people living with ME. We've got on the left here the Krebs cycle. So hopefully you'll remember your high school biology. And we've got lots of oxygen.

18:41
and we're in aerobic respiration, we're very good at making energy and we get a return of 36 ATP. When we don't have a lot of oxygen and we're going anaerobic as these people are, our production of ATP is very poor, only two, and our production of lactic acid is far higher. And that's what we're seeing in these ME patients. Next slide please Clare.

19:13
Oh, back one, please. Super, thank you. The reduction in VO2 max in long COVID patients is from a peripheral rather than a central cardiac limit due to impaired capillary oxygen extraction and not deconditioning. Apologies for the wordy sentence. Let me just break it down. So the VO2 max is what we're already measuring in those initial exercise studies.

19:42
In this particular study, there was a venous catheter put into near the right side of the heart to measure what was coming back. And in doing so, the researchers found that in the ME patients, and there's been a same study done on long COVID ones as well, oxygen is not being extracted in the peripheral circulation to the muscle bed to a cellular level. The oxygen isn't making it out.

20:09
of bloodstream, it's coming back to the heart having not been extracted. So we know that people with ME have a lower threshold to go anaerobic. We know therefore they're dropping their VO2 max when you ask them to repeat an activity. We know the ones with higher lactate are the ones that are more symptomatic. And now we're getting clues that they're struggling to get oxygen out of the bloodstream and into their cells and into their mitochondria, hence why they are anaerobic.

20:38
And so then we have to think right next bit the jigsaw, why are they not getting oxygen out of their peripheral circulation? So next slide,

20:53
I missed a slide, let's go forward one a second just so can get my bearings. There we go, sorry, back one a second, sorry, just bear with me. So these studies, what they're doing is they're offering a potential explanation for post-exertional symptom exacerbation or post-exertional malaise suffered by ME and long COVID patients. I'm not going to major in this because Becky will.

21:18
talk very well about pacing, the crux of this is that living with this condition, these people, their body is a bit like a smartphone that just charges to 20 % overnight. So I'm hoping that all of our audience, you charged 100 % overnight and then you go about your

day and it slowly tracks down. But if you've only got 20 % and it takes 5 % to get washed and 5 % to get dressed and 5 % to make your breakfast.

21:46
your battery is down to nearly nothing before it's even nine o'clock in the morning. And so this is a way of trying to understand what it's like to walk a day in their shoes because you might not have any or long COVID, but you've probably had to get by when your phone's not got much battery and there's no plug nearby. And you've got to be very tactical about how you use energy. And in those circumstances, you might follow a sports team. You could still go into the sports app.

22:15
But rather than using a lot of battery watching the match highlights, you use just a little bit of battery checking the score. And that's how these people have got to live. And that's what pacing is in a nutshell. But as I say, Becky will do it better than me. Next slide, Clare. And so what could be a peripheral cause for this reduction VO2 max? That's where I was getting my thoughts jumbled up. So now we're back on track.

22:41
what could be going on that means people can't get oxygen out of their bloodstream and into their cells and into their mitochondria to do aerobic respiration and instead they're going anaerobic. Well, peripheral endothelial dysfunction in ME and chronic fatigue has been demonstrated that in ME and long COVID we have studies showing that the people that have the higher markers of endothelial dysfunction

23:10
are the ones that are the most symptomatic. Next slide please Clare. And so here's one of those studies. just want to remind everyone that's sitting going, geez it's a few years since I was at university, what's the endothelium again? That's the purpose of this picture. So the endothelium is the inner lining of our blood vessels. our knowledge has advanced with...

23:35
Long COVID, where we know that the virus gets into endothelial cells via ACE receptors, makes the endothelial cells inflamed and makes them persistently inflamed so that the endothelium then struggles to do its various jobs properly. Look at the job of the endothelium on the next slide. Because as I was saying already, markers of endothelial damage in ME and long COVID correlate with a higher symptom burden, higher exercise tolerance.

24:05
So yeah, next slide please. So what does the endothelium do? It's a barrier on a membrane. So we're trying to get oxygen out and we can't because the barrier is inflamed and can't do its job properly. It has a role in vascular tone. And this is where Nina was talking about autonomic dysfunction. So you've got your sympathetic nervous system fight and flight, and you've got your parasympathetic nervous system rest and digest. And they're meant to be fairly in balance.

24:34
But because the parasympathetic fibres are embedded deeper into the inflamed endothelium, they're more susceptible to the inflammation stopping working properly. And so you end up with a situation where there's too much fight and flight and not enough rest and digest. And the classic description of being tired but wired. Our endothelium also has a role in clotting. An inflamed endothelium is releasing markers that have us thinking that in error.

25:03
with cut ourselves and so it promotes coagulopathy, it hyperactive platelets and particularly in the long COVID population it promotes micro clotting which can be just the right size to block the smallest capillaries in the body and therefore impair that oxygen exchange problem even further.

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Endothelium is involved in host defence and we'll talk about the role of mast cells in host defence and mast cell dysfunction in ME patients in a subsequent slide. obviously anything where you've got prolonged vascular inflammation is going to lead to organ complications as well.

25:41
So a little bit on pharmacological symptom management. This is what I am comfortable doing in general practice. And I realize that I am also someone that consults an ME every week and has invested a chunk of my career in trying to do this well. So I appreciate you might not be coming at this from a position of comfort. This is meant to be a gentle introduction because

26:10
Otherwise these are a cohort of people that aren't blessed with lot of services. And you know, if you're to sit down with them and say, look, I've got this medicine, I cannot promise it will work for you, but there is some evidence behind it. Here's the risks, here's the potential benefits. As we do so often in general practice, it doesn't always need to be

26:36
You know, we can deviate off script if we think it's going to help people. But anyway, I wanted to give you a script to follow so that hopefully you feel a bit more comfortable with this. So we'll look at the autonomics first of all, autonomic dysfunction. Picture there summarizing how people with autonomic dysfunction might present. So postural presyncope, palpitations, chest pain, memory and cognitive problems, shortness of breath, IBS type stuff, disproportionate tiredness.

27:06
nausea, myalgia, headaches, insomnia. And so your average autonomic patient can take up to seven years to be diagnosed. And for most of those seven years, they've been told they're anxious. And with that kind of infographic there, you can perhaps

understand why they have unfairly been labeled as anxious. But if you're now empowered by this and you see that combination of symptoms in someone that you're already thinking has ME,

27:35
then I would very much empower you to go looking for autonomic dysfunction. And we do that with the NASA Lean Test. And yes, it's named after the space agency, because lo and behold, if you end up in zero gravity or spinning around at goodness knows what g-force, you can experience autonomic dysfunction as well. If you go to the Bateman Horn website, there is a great four-page handout. It explains to patients exactly what to do. And my

28:05
way of doing it is to send them home with an automated blood pressure cuff because to do a proper NASA lean test you need them supine for at least 15 minutes minimum ideally longer and only then do you stand them up for the 10 minutes that follow and I don't think there's any GP out there that's got the time for someone to lie 15 minutes flat in their room before the consultation really even starts

28:31
and we certainly don't have the small talk for 15 minutes of that when we're otherwise busy and got lots of other stuff to be getting on with. So send them home, get a willing partner spouse relation to do the test with them and the Bateman Horn web link talks them through exactly what to do. If you're seeing postural hypotension, that is a form of autonomic dysfunction to treat. The thing you most commonly see is pots.

28:59
P for postural because it's related to standing up. O for orthostatic, our medical word for saying gravity is trying to take blood from their brain to their boots. T is for tachycardia, which you all understand. And S is for syndrome because it can cause all those things you see on the left-hand side of the screen. And if we find a sustained heart rate rise of over 30 beats per minute, POTS has got to be very, very, very, very near the top of your differential and gives us something to potentially treat.

29:28
Just got a picture there of dependent acrocyanosis, which you'll see in a proportion of people with autonomic dysfunction. Again, you can't write that off as anxiety. You can't write that off as psychological. Just a wee marker there that this is very much a biological illness. Next slide, please, Clare.

29:50
So I'm conscious of time and I realize I'm going fast, but if I've engaged you to a degree of interest here, POTS UK is a great place to read, to do this thing on the right hand side called POTS on a Page. So a guide for GPs on how to look what it is, how to look for it, how to diagnose it, and how to treat it. And so at the very least, you want them to be very well hydrated. You want them to be increasing their salt consumption.

30:19
Pots UK has got stuff in recumbent exercises, but just stressing the point Nina made before, graded exercise therapy has been completely debunked in ME. It's gone, it's out. It was nonsense in the first place. You're not gonna make people who drop their VO2 max every time they exercise, exercise back to health. well, biological evidence that this is bad, research evidence this is bad.

30:47
but recumbent exercises gives them something to do to try and improve muscle tone in the legs to try and help if they can do it without triggering PEM. Stop trigger meds, which the pots in the page summary, I'll give you a guide on that there. Consider rate limiters. Generally my go-to is bisopril or 1.25 milligrams, once daily, that you can then titrate up to symptomatic response and tolerance.

31:17
There are other options prescription wise, but as I say, I wanted this to just be an introduction to try and get people comfortable with it. There's also compression garments, so not flight socks because they're too baggy. want class two or class three compression that has to be prescribed so you get your DN or your practice nurse if the person is able to come into the practice to measure.

31:41
them for the right size of compression garment. The evidence base is in waist-high, so tights. But if that is intolerable, then they're better off with some knee-high kind of football sock type things. And some people respond very well to that. And suddenly, they can get up and about and be upright without all these symptoms. Touch a little bit on mast cell dysfunction. And then I'll be.

32:07
Passing on to Becky. So next slide. So mass cell dysfunction. The mass cells are embedded in this inflamed endothelium and respond to the inflammation going on around them by bursting open and releasing their contents into the bloodstream. And one of the main chemicals they release is histamine, the allergy chemical. And so you end up with this kind of variety of histamine-driven symptoms. So kind of ENT-type stuff with the kind of

32:35
you know, sneezing, nasal congestion, post-nasal drip, throat, itchy eyes, might even be kind of wheezy, flaring asthma, all sorts of cutaneous stuff, be that itch, rash, hives or tachycardia. There's an overlap with the kind of cardiovascular stuff and the POTS symptoms. You'll see a lot of GI stuff that would otherwise be labelled as IBS.

33:05
They can have, you know, people with kind of seen a lot of people post COVID that have got sort cystitis type stuff, but it's actually, you know, it's not an infective driven thing. It's mast cells and histamine irritation of their bladder. And so time and again, I then I'm

having the kind of the risk benefit conversation with people to see, there was this study done in London and long COVID patients and in the

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the study that gave them high doses of two different antihistamines. And apologies if you know this already, but just in case there's anyone in the audience that doesn't, in our body we've got histamine one receptors, which are typically covered by the antihistamines we can buy over the counter, and histamine two receptors, which are only available on prescription in the UK. And in the study, they gave them high doses of both. So they blocked histamine one receptors and they blocked histamine two receptors. And in this study of debilitated long COVID patients,

34:02
20 % of their symptoms went away completely and 52 % described some benefit. So there's an over 70 % chance that if you think you've got an ME patient with symptoms suggestive of mast cell disease or a long COVID patient with symptoms suggesting a mast cell disease, that you're going to be able to give them some symptomatic benefit with an off-license prescription, yes, but...

34:29
I mean, it's anti-histamine, so it's low risk for potentially high reward. And so I hope that gives you some ideas that you might want to take back to your own practice, because you've probably signed up for this, because you've got people that you're maybe feeling a bit hopeless with, or a bit, where do I go next? Screen them for autonomic dysfunction, and strongly consider a trial or treatment for mast cell disease, if this slide here is resonating with you.

34:58
Thanks so much Robin. Becky over to you.

Becky Sessions

So hello everybody I'm Becky. I'm specialist ME Physio here at Action for ME. In the next 10 minutes I want to share how Physio can help people with ME.

35:25
and why that help looks quite different really from the rehab many of us were trained in. So if I can go on to the next slide please, I'm gonna start off with talking about recognising PEM in practice. So we obviously have learnt what PEM is, it's the flare up of symptoms that comes on usually 24, 48 hours after doing some form of activity, whether that's cognitive or physical or...

35:55
anything like that, but I really want to focus on what that looks like in the room because for me, if you take one thing from today, let it be the pen. it's clinically, it's delayed, it's out of proportion and it's slow to recover from. And the trigger, like I said, can be physical thinking, talking, emotion, noise, light, anything like that can count. And it's really easy to miss if you just ask somebody how they're feeling on that given day.

36:25
So the question that really unlocks it is about the day or two after they've had something that they've had to do. So I tend to ask what happens after they do more than usual, how long it takes to get back to where they were and what kinds of things set them back. And people have often not been asked that before and the answer can be a real moment of recognition both for us as clinicians but also for them as a patient.

36:52
I mean, on our side, we would notice sort of boom and bust patterns and the symptoms, like Robin said, being driven by being upright. But telling me also, it can be a crash after something like an appointment with us as well. that's the reason why really, I think, recognising PEM in real life is really, really important. So what I'm going to do is go on to the next slide.

37:21
you know, what does physio do really if it's not exercise? So it's quite a lot really, but we really have had to turn training on its head. So Robin showed that the reduced capacity in ME isn't deconditioning, you know, so the use it or lose it logic just really conventional rehab just doesn't apply here. So, you know, your conventional rehab is aiming to build capacity through fixed increments.

37:48
With ME, the first aim is stability. So we want fewer crashes and we want to protect the baseline. So rest really isn't something that's earned after effort. It's something that we plan in in advance and it is part of the treatment. So success isn't more reps, it's fewer crashes and more of what matters to the patient really, which is why goal-based measures.

38:17
are really, really important and they don't need to be big goals for the patient. They need to be small and achievable for them and setbacks are not to be pushed through, you know, their information for us together and then we can reduce, we can rest and we can review. So yeah, and I'll just echo as well that the NICE guidelines are clear that programmes based on fixed

38:42
incremental increases like graded exercise should not be offered in this circumstance. So next slide please. So as Nina mentioned, we've got aids and adaptations that we can recommend to patients. I've had quite a lot of patients say to me all while I was a bit worried about whether I should use a wheelchair when I'm out, am I going to decondition or I'm worried about what people think.

39:06
things like that, but actually it can be a really good way of reducing the amount of effort somebody has to put in and reducing the amount of PEM they get afterwards. But also other things like shower stools, walking aids, any aids really that are going to help with day-to-day life. Next slide please. So the ME Physio Toolkit. So here's what it looks like in practice. We start by finding a baseline.

39:35
What's sustainable on a hard day? Not a good one, a hard day. Pacing diaries are really useful. Heart rate data can help some people see their limits a bit more clearly. Pacing means that we're obviously breaking up tasks, we're breaking up physical and cognitive activity, and we're stopping ideally before any symptoms arise, not when they arrive.

40:00
and then rest is taken before it's needed, it's planned, it's regular and it's low stimulation. For people who've got ME, very often lying down and listening to an audiobook isn't true rest, watching TV isn't true rest, it needs to be sort of lying down, very limited stimulation for it to be a true rest.

40:25
Orthostatic intolerance, obviously one of the parts of physio is practical, helping people do tasks seated or lying, budget their upright time across the day and it can free up a surprising amount of energy actually. We can also support with pain, sleep, breathing patterns and positioning. And then for the people who are at the right severe end of the scale of ME, it's gentle positioning, protecting the joints and the skin.

40:54
minimal handling and supporting the family and carers really. So the aim throughout is stability first, any increase is small, flexible and only from the stable baseline. Next slide please.

41:11
So, society's expectations around rest are quite a hard one really to go over. People carry a lot of guilt, a lot of fear of being seen as being lazy or you look alright or know past experiences of not being believed and many have lost roles that were the central to sort of who they are as a person. So the first thing that we offer is belief.

41:37
simply just by naming PEM as real and physical can be a huge relief. Secondly, language, giving people words like, rest is part of my treatment, helps them hold boundaries with others and with themselves in fact. Practically we can give letters supporting reasonable adjustments at work or at school, bringing family and friends into the plan just so that everybody pulls in the same direction.

42:07
And psychological support does have a place, but that's more with the adjustment and the grief that comes with the illness alongside of energy management, not framed as a cure. And then my next slide says it all really, rest isn't giving up, it's protecting the baseline. And I'll pause on this because it's the message I want people to hear that have ME and I want them to hear it from professionals. Rest isn't giving up, it's protective.

42:36
And what often the most useful thing we give people isn't a technique, it's permission. And it's permission to stop before they crash. Permission to say no and to put their health first without having to apologize. Next slide, please. So ME rarely travels alone. We know that you can get autonomic dysfunction. We know you can get mast cell activation. And alongside those, we often see things like hypermobility,

43:05
breathing pattern disorder, fibromyalgia, chronic pain, migraine, sleep problems, gut problems, low mood, anxiety, you know, they all go hand in hand. And the low mood and anxiety can often be a consequence of living with a poorly understood illness rather than the cause of it. So two main points for practice. First, every one of those things that I've just mentioned has an energy cost.

43:32
So recognising and treating them as well can free up real capacity from the ME side of things. And secondly, just to point on diagnostic overshadowing, new and changing symptoms still need proper investigation. can't just be put down to the ME. And I think that's just really important to be aware of. Next slide, please.

43:58
So just a little bit about multidisciplinary teams really. So many of the new Scottish services are AHP led and so like the different mixes will vary from team to team. But very often it's the GP that holds the diagnosis, co-occurring conditions, medications, fit notes, those things. Physio tends to be helping with the energy management or the static symptom support.

44:25
daily function, equipment, those sorts of things. And then like I touched on before, psychology is more to do with adjustment and coping alongside other care. And then there are things like dietetics, speech and language and social care, which can be really essential with people who've got severe ME. The main principle here is to use the same language about PEM and pacing so people don't get mixed messages. And remember that every appointment costs energy. So where we can combine

44:55
and coordinate, it gives the patient the best chance really of maintaining their energy. And next slide, for those of you who are setting up or working in the new ME and long COVID services, just a few practical points, I'm not gonna teach you to suck eggs, but obviously phone, video consultations are easier on the patient, nine times out of 10, home visits, shorter sessions.

45:22
and expect that the assessment itself might trigger PEM and maybe build in a gentle check in a few days later. Avoiding exertional tests that can cause a crash and go for things more like the patient specific functional scale to tell you what matters to the person. And that's the one where they choose up to five activities when they rate it on a scale of 0 to 10. So for example,

45:47
they may say showering without needing to lie down afterwards, they can do that a three out of ten, you know, something like that and those scores holding steady each time you see them can be a sign of a good outcome itself and that things are a little bit more stable and there's less crashes. Other things to think about are the environment, if a patient is coming into you, quiet, low light, somewhere to lie down and a flexible cancellation, rebooking.

46:17
schedule. And then the last slide from me are my three things to take away from today. So one is to ask about PEM every time. Ask about the day or two after, not just how someone is today. The second thing is stability before progression. No fixed increments. Protect the baseline first and any increase has got to be small, flexible and very symptom led.

46:45
And then number three, every contact costs energy, including hours. So design care and services around that.

Thank you very much. Thank you, Becky. And thank you, Nina and Robin.

End of presentation