

The perioperative management of patients with ME and Long COVID

Podcast transcript

00;00;00;00 - 00;00;32;23

Dr Anton Krige

Welcome to this episode of Anaesthesia on Air, the podcast from the Royal College of Anaesthetists. My name is Anton Krige and I'm a consultant, intensivist and anaesthetist at Royal Blackburn Teaching Hospital and an honorary professor with the local medical school. I'm also heavily involved in research within the NHS and the management of patients undergoing high risk major surgery.

00;00;32;26 - 00;01;05;00

Dr Anton Krige

today we're going to be discussing the topic of, ME and its implications for anaesthesia and how, a patient resource document was generated by the Royal College of Anaesthetists along along this topic. I'm joined by Doctor Charles Shepherd and medical advisor to the association. And Helen Baxter, an advocacy worker for the 25% ME group.

00;01;05;03 - 00;01;41;08

Dr Anton Krige

The background to this work is that over a period of years, the Royal College of Anaesthetists had been approached by multiple ME sufferers, inquiring as to how anaesthesia would impact them and that the information around this had been extremely limited. This has resulted in the college, setting up a working group and the project to generate patient information and a patient resource, to support patients who have ME and are going to undertake the surgical journey.

00;01;41;10 - 00;02;12;27

Dr Anton Krige

I've got involved with this after seeing an advert in the Royal College Bulletin. looking for a clinician who would take on the lead role in this project. as already explained, I'm, I've been a consultant anaesthetist for over 25 years, and, my personal journey involved having one of my one of my three children, my middle child develop very severe ME when she was eight years old, and that lasted for three and a half to four years.

00;02;12;29 - 00;02;43;11

Dr Anton Krige

with her losing most of her primary school years spent at home with home schooling, etcetera. She's thankfully now back to full health and absolutely thriving. incidentally, she qualified for the England School's cross-country championship recently and has won a couple of league races. So she's gone from the extreme opposite. so that's been a great personal driver for me to get involved and trying to put something back to this patient group.

00;02;43;14 - 00;03;13;23

Dr Anton Krige

combining both my personal knowledge of the condition and seeing it firsthand, along with my years of experience and knowledge, as an anaesthetist. So we how this how this project unfolded is that it started off by doing a thorough literature search to sort of identify what the actual evidence is around the impact of ME and anaesthesia. And in short, there is almost nothing in the literature in terms of evidence base.

00;03;13;25 - 00;03;49;10

Dr Anton Krige

And the next step in this whole project was to organize a focus group meeting and to do something that is quite novel for information documents developed by the Royal College of Anaesthetists in making use of lived experiences. By, individuals who'd actually experienced, both having severe ME and undertaking a surgical journey and they, they formed the underpinnings of the sort of question and answer format of the patient resource.

00;03;49;13 - 00;04;30;06

Dr Anton Krige

And these patients then also gave very valuable feedback on the draft documents that were, generated off the back of the focus group meetings. This podcast now forms one of many social media launches of this patient resource document. And at the time of this recording, the official launch is going to be the following day. So some of the, some of the, key points that really were highlighted by our focus group and the lived experiences were really just highlighting more the things that didn't work so well for patients.

00;04;30;08 - 00;04;53;07

Dr Anton Krige

That really gave us a focus where many of these patients felt that there seemed to be a general lack of knowledge from both surgeons and anaesthetists about the condition in general, and that their condition wasn't taken seriously and wasn't really acknowledged as an actual medical condition, with a lot of lack of understanding around the impact that it could have, from surgery and anaesthesia.

00;04;53;10 - 00;05;26;19

Dr Anton Krige

Despite their concerns, they also felt that it wasn't really listed as an actual co-morbidity at pre-op assessment visits, and there wasn't any real adjustment made for it. And any particular planning around their ME Other themes that arose were patients experiencing severe crashes of their ME after anaesthesia, taking longer to come around, not receiving any particular special monitoring.

00;05;26;22 - 00;05;56;18

Dr Anton Krige

they, they saw that there was a lack of any written notes about the, their specific needs and, and any real communication between the different hospital groups. particularly features were being very sensitive to bright lights, sounds and strong smells around the emergence from anaesthesia and some had to wait for many hours on the day of day of operation, which has a big impact in their ME when they have a very limited energy envelope.

00;05;56;21 - 00;06;24;09

Dr Anton Krige

and some felt they were discharged too quickly while they still have quite significant fatigue. Many of them experienced changes to the patterns in their condition in the in the, weeks and months afterwards, with crashes being quite frequent and changes in pain levels and heart rates and blood pressure and so on. So all of this gave us a lot of ammunition to start to work on this patient resource.

00;06;24;12 - 00;06;44;18

Dr Anton Krige

So with that being said, I now want to really bring Helen into the conversation. with her particular experience around advocating for these patients and, and their sort of experience in NHS care. Helen, what would have been some of your experiences around these themes?

00;06;44;20 - 00;07;10;21

Helen Baxter

Thank you. Anton. Yes, I do recognize the experiences we heard in the focus group. People's experiences of NHS care really does vary. I mean, some do receive good treatment and and feel supported, but others really don't. Their ME is quite often just dismissed. And it's important to

mention that some people with ME/CFS will have difficulty accessing primary care, let alone secondary care.

00;07;10;24 - 00;07;31;09

Helen Baxter

And as we know it can be hard to get a GP appointment. But that becomes much harder when you need a home visit and that can have a knock on effect. It can lead to people presenting late to primary care with symptoms, and the knock on effect of that is that they may require more complex surgery. It's worth saying that some GP's may never encounter someone with

00;07;31;11 - 00;08;11;24

Helen Baxter

ME/CFS, and medical education at both undergraduate and postgraduate level, is woefully lacking. So the doctor may be unsure how to support patients with ME/CFS and if they are unsure, I would suggest looking at the NICE guidance on ME. There is also a CPD module online about ME so you can access that as well. People with ME/CFS have also previously experienced stigma quite often and I found from my personal experience of advocating for people with severe ME/CFS that they're quite wary of approaching allied health care professionals because they expect to be dismissed.

00;08;11;26 - 00;08;41;08

Helen Baxter

so as an organization, just like you, we're regularly approached by people, people in our case with severe or very severe ME/CFS. And I'll point out that the charity is called the 25% me group because at any one point, it's estimated that 25% of people will be housebound or bedbound. So they're categorized as having severe ME. But they come to us asking for information about anaesthesia, both themselves and something that they can give to their surgical team.

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Helen Baxter

But up until now, there really hasn't been much to offer. So I'm really pleased to see the ME/CFS and anaesthesia document has been produced. And combining that anesthetic expertise and the experience of people with lived ME/CFS who had anesthetics. I think that's a really good move.

00;08;59;19 - 00;09;27;14

Dr Anton Krige

Thanks, Helen. That's fantastic information. And you know, from what you said there, I can really empathize with all my colleagues because until I had, a personal trigger to get heavily involved in researching ME in my 25 years as an anaesthetists I'd probably only ever encountered 1 or 2 patients with ME presenting for anaesthesia and surgery. So it's quite natural that colleagues feel ill informed around this and therefore vulnerable.

00;09;27;17 - 00;09;48;20

Dr Anton Krige

So I think this is a huge step forward in raising the profile in education. moving along, Charles, I wonder if we could bring you in to just give all listeners a bit of a better insight and education on what ME/CFS actually is and how we would define it and what resources they can access.

00;09;48;22 - 00;10;10;00

Dr Charles Shepherd

Thank you Anton. As you introduce me, I'm a doc with both personal and professional interest in this subject dating back, just over 40 years. when I developed this illness, like many people, I was a very fit young adult. I was working in hospital medicine at the time. I got a very nasty dose.

00;10;10;01 - 00;10;33;29

Dr Charles Shepherd

of Chicken pox. It was a chicken pox encephalitis, actually, from one of my hospital patients, and went down with all the, key symptoms of this, of this condition. But no one could give me a diagnosis. No one could give me any sensible advice on management. and I'll come to a description of this, this illness in a minute. but I'd just like to say how grateful we are.

00;10;34;05 - 00;11;02;28

Dr Charles Shepherd

To the ME association for working with the Royal College of Anaesthetists on preparing this patient information for people with ME. It's a very important precedent. And we, as part of the NICE guideline and this part of a Department of Health initiative called the DHSC Delivery Plan for people with ME/CFS. we desperately trying to improve, medical education of health professionals on this subject.

00;11;02;28 - 00;11;23;10

Dr Charles Shepherd

So I think this is very important precedent to work together with, with patients, charities, to produce this information. As I say, I've 40 years experience of this. When I left medical school in

the early 1970s. the Middlesex Hospital, I was told this was hysterical nonsense. ME [unclear] disease. Go away. Forget about it.

00;11;23;10 - 00;11;49;00

Dr Charles Shepherd

You won't see a patient with it. And in 40 years of dealing with this subject, my colleagues, many of my colleagues in the medical profession have been involved in a debate which has involved uncertainty, disagreement, skepticism, sometimes even hostility towards this subject. And this debate has gone on as to what we call it, how we define it, what causes it and how we manage it.

00;11;49;02 - 00;12;24;29

Dr Charles Shepherd

And this has had a very negative, negative impact on the patients with this illness. It's led to people not being diagnosed. It's late diagnosis, misdiagnosis. And equally it's led to bad management in many cases or no management at all. But fortunately I think we are now changing. we've got a new NICE guideline. there's a link to it, in the, information booklet, which was published in 2021, as part of the committee that produced this new NICE guideline.

00;12;25;02 - 00;13;02;08

Dr Charles Shepherd

And it sets out very clear recommendations on what to do if you suspect someone has got ME, they're not recovering from a viral illness, which is the normal, route into this illness. We've got this DHSC delivery plan, which is covering education, implementing the NICE guideline and, research as well. And then we've got recognition from the Medical Research Council that this is a very genuine medical condition, which is very disabling and requires proper biomedical research into cause, and treatment.

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Dr Charles Shepherd

quick background information then on, on what this is, what this illness is and how it presents. We think at the moment the epidemiology suggests that there's roundabout at least 250,000 people with this condition in the UK. But interestingly enough, new research paper came out last week from the University of Edinburgh Chris Ponting's group.

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Dr Charles Shepherd

looking at a different way of, estimating the epidemiology and prevalence. And Chris's, work is suggesting that the true figure is probably nearer to 400,000 people in the UK. And part of that, I think, is, is the reflect that at the moment, Covid 19 is possibly the major trigger factor for ME/CFS at the moment in the UK, and so we've got quite a lot of people with long Covid who are now being transferred into a diagnosis, of ME/CFS [...] this figure of 250,000 as, as Helen said, we've got a wide range of severity in this illness.

00;14;10;12 - 00;14;37;07

Dr Charles Shepherd

at the severe, very severe end. we've got people who are obviously housebound, bedbound and may even be tube fed. But for most people with this illness, the other three quarters, they are, not housebound, but it is an illness which is having a severe effect on all aspects of quality of life for them. they're not able to work, they're not able to to participate in education.

00;14;37;10 - 00;15;05;02

Dr Charles Shepherd

And as Anton indicated, a significant proportion of people with ME/CFS are children and adolescents, and it has been estimated that ME/CFS is, one of the commonest causes, if not the commonest cause of long term sickness absence, from school. As far as the actual illness and its presentation is concerned, most people as I have described and I think that's probably what happens with Anton's daughter.

00;15;05;04 - 00;15;31;03

Dr Charles Shepherd

Fit young adults or children and adolescents, they get a viral infection, they don't recover. And that's what happened to me. And the the main key presenting features of this illness, the diagnostic features which are used in the NICE guideline are this very debilitating fatigue, which is activity induced. It can be induced by both physical activity and mental activity.

00;15;31;06 - 00;16;02;01

Dr Charles Shepherd

Linked to that is is what we regard as the key diagnostic feature, which is what we call post exertional malaise. So in very simple terms, if someone goes to the limit of what they can do physically or mentally on one day [or] gets very near to that point, they have a delayed period. And the following day they have a severe reaction, a relapse of symptoms and general ill health.

00;16;02;04 - 00;16;24;16

Dr Charles Shepherd

following that, exertion on the previous day. they have cognitive dysfunction with short term problems with short term memory, concentration, attention span. It's called brain fog. If you're following the debate into long Covid, it's just the sort of, problems that they, the people there have, they have non-refreshing sleep is a very diagnostic feature.

00;16;24;16 - 00;16;52;03

Dr Charles Shepherd

So even though they may be getting perfectly good night's sleep, they feel no better the next morning. A particular importance to anaesthetists is the fact that they have disautonomia. They have a problem with the autonomic nervous system control, particularly of pulse and and blood pressure, but also, bladder and bowel sometimes. And this can result or does result in most people having what we call orthostatic intolerance.

00;16;52;03 - 00;17;35;18

Dr Charles Shepherd

That's an inability to remain standing for, for any sort of period of time. And also a significant minority, particularly again in the children and adolescent sphere of this illness have postural orthostatic tachycardia syndrome where there's an increase in pulse rate, in response to standing and that that's particularly relevant obviously in, in anaesthesia, because some of these people may be on, fluid expanders, they may be fluid cortisone, they may be on beta blockers to, to reduce pulse rate, or they may be even on a drug like [unclear - Midodrine?].

00;17;35;20 - 00;18;03;12

Dr Charles Shepherd

So that's an important consideration when when assessing these patients. finally, in relation to symptoms this illness has a wide range of symptoms. so I think in particular importance in relation anaesthetics and anaesthesia, is the fact that they have cognitive dysfunction so that they may have difficulty, maintaining and information processing, being told what what's going on.

00;18;03;15 - 00;18;33;20

Dr Charles Shepherd

They have the disautonomia autonomic nervous system dysfunction symptoms. As Anton has mentioned, they are often particularly at the severe end are very sensitive to light and sound. they have problems with, temperature regulation, possibly due to a hypothalamic involvement, in this illness. So, the, they're not good in cold or hot environments. And that's obviously something of a relevance, in both surgery and anaesthesia.

00;18;33;23 - 00;19;03;03

Dr Charles Shepherd

and finally, they are particularly sensitive to drugs which act on neurotransmitters. And one of the things we put into the NICE guideline, was to always be very careful with these drugs and start with a low dose and work up gradually. so if they're on antidepressant medication, if they're on, analgesic medication, which involves, neurotransmitter function, then that is something that they may well be sensitive to.

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Dr Charles Shepherd

And the other drug that they do seem particularly sensitive to, which is particularly relevant in dental anaesthesia is adrenaline. And our dental advisor at the ME Association recommends that where possible they should be given, an adrenaline free, anesthetic if they're having any dental work. so that's, that's my quick round tour of what ME/CFS is, Anton.

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Dr Charles Shepherd

I don't know whether you want to pick up on anything. there that we've missed out.

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Dr Anton Krige

No that that was perfect, Charles. I think some of the, particular implications around anaesthesia. I think it's really important that disautonomia component, particularly because some of the medications they may be on, as you alluded to, will have implications to anaesthesia or certainly need to be, thought about by the anaesthetist. you mentioned Midodrine, which anaesthetist won't encounter very often, and that's sort of a chronic medication to help increase blood pressure.

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Dr Anton Krige

the fludrocortizone may require anaesthetist to, give additional steroid during anaesthesia because they're on some long term fludrocortisone. One one of the other medications that isn't used very often but could, can be used in some cases. This disautonomia or [...] is pyridostigmine. And that also has implications because that can affect the neuromuscular blockers that are used during general anaesthesia.

00;20;40;17 - 00;21;14;04

Dr Anton Krige

Sometimes. And different categories of neuromuscular blocking drugs are affected in different ways by people who are on chronic pyridostigmine and you already mentioned the beta blockers, which obviously we would need to be aware that they impacts on heart rate. and an associated medication that sometimes is used for these patients is something called ivabradine, which again an anaesthetists wouldn't very often have encountered because it's usually only used quite uncommonly in cardiac disease.

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Dr Anton Krige

so that's really useful information.

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Helen Baxter

We can also find that some of these patients are on unlicensed medication as well. Things like low dose naltrexone and also nimodipine. So that needs to be factored in that they are using them off label. And also a number of supplements as well. People with ME can be taking those supplements.

00;21;39;22 - 00;21;53;09

Dr Charles Shepherd

But they may be obtaining these off label drugs, not from their GP. Their GP may be unaware in some cases that they're on low dose naltrexone because they're getting it from an online pharmacy.

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Dr Anton Krige

Yes, and low dose naltrexone is an important medication to raise because firstly the anaesthetist in the hospital they won't find that in the British National Formulary because it's an off license compounded medication, it is a very safe medication and a very interesting medication, but there are implications for anaesthesia. just very briefly, this this drug is in a micro dosage of the.

00;22;21;21 - 00;22;56;11

Dr Anton Krige

Well known drug called naltrexone, which is used in it, which does appear in the British National Formulary. And that's conventionally used to help patients withdrawal from chronic opiate use, you know, possibly heroin abusers, etcetera. but it was discovered by accident that it has other possible beneficial effects when it's used at a much smaller dosage. So the normal dose of naltrexone is 50mg, but typically the dosage is used as low dose, naltrexone is anything from 0.1mg up to 4.5mg.

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Dr Anton Krige

So it's a maximum of sort of a 10th of the standard dosage. and these very low doses modulate the immune system, and they interact with the natural release of endorphins, our natural painkillers in the body and interact on the, on the opiate receptors. and that's where it has an implication for anaesthesia, because if somebody is on this medication right up to surgery, the morphine type drugs we give during the perioperative time may not work effectively.

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Dr Anton Krige

So it potentially will worsen their analgesic experience, and it simply needs a person to stop taking their low dose naltrexone two days before they're going to need any acute pain relief using fentanyl, morphine or all the other usual opiate painkillers. Some of the other conditions that do occur more commonly in these patients in the general population, which may also have some impact in anaesthesia, is one of these is we do see more hypermobility.

00;24;06;06 - 00;24;31;06

Dr Anton Krige

I don't know if you if that's something you come across, Charles, but Ehlers-Danlos syndrome and hypermobility is has been seen more commonly. And at the more severe end, these patients may have greater risk of joint dislocation subluxation when we move them around after they're under general anaesthesia. And we need to have awareness if we're going to do certain positionings during surgery.

00;24;31;12 - 00;24;52;25

Dr Charles Shepherd

There's certainly some research evidence, particularly from a, well, a long standing position in the States. Peter Rover is very interested in this, subject. on an overlap with hypermobility syndromes, in particular EDS. So, it's it's something we come across fairly, fairly commonly.

00;24;52;27 - 00;25;01;24

Helen Baxter

Yes. And as an advocate, it's something I hear people regularly saying that they are hypermobile even though they've got very severe ME.

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Dr Anton Krige

And that's why it would be very important for the patient to sort of inform us which particular joints they, they are more hypermobile in, and we can take extra care during the anaesthesia to safeguard them against any, any sort of accidental injury to those joints.

00;25;19;22 - 00;25;38;11

Dr Charles Shepherd

just, because of just this, the other drug that people quite often obtain online and that GP's are probably not aware of, is melatonin. am I right in thinking that doesn't have any particular implications for anaesthesia?

00;25;38;13 - 00;26;08;02

Dr Anton Krige

no. That shouldn't have any any effect on anaesthesia itself. in fact, there's actually been a very recent large and randomized, controlled, trial, multicenter study to see whether melatonin preoperatively was better at reducing anxiety in children than benzodiazepines and that studies just recently concluded. so it's been used intentionally in that context as a pre medication in children.

00;26;08;04 - 00;26;38;09

Dr Anton Krige

and we certainly on my intensive care unit, it's one our first line, thing to prescribe as a prescription medication version of melatonin on ICU patients to help sleep over night. And certainly is it's a natural, sleep sedative and far better than any, any of the pharmacological options for helping people sleep.

00;26;38;12 - 00;26;42;03

Dr Anton Krige

So I'd far rather they use melatonin than anything else.

00;26;42;06 - 00;27;13;01

Dr Charles Shepherd

Anton can I pose a question which which is quite commonly raised, with us and which we don't have an answer to. And I know probably there isn't a set answer to this, but it is a common question. And and that is, is there any particular anesthetic regime which is going to be more suitable for people with a condition where they've got muscle weakness, problems with neurotransmitter medication?

00;27;13;04 - 00;27;16;02

Dr Charles Shepherd

is that.

00;27;16;05 - 00;27;47;07

Dr Anton Krige

So the, the answer is it depends. And it would have to be completely individualized. So really when for all patients if there is an option to do the surgery using a regional anesthetic technique only. In other words, upon numbing the body region involved, that that would be the the better way to go. And completely avoiding the general anesthetic drugs altogether.

00;27;47;10 - 00;28;13;26

Dr Anton Krige

And that would just eliminate any of those risks. as we know, in this, if the patient is already had previous anesthetics and they clearly had an adverse reaction to particular medications, it would just be common sense to avoid those next time round if they're completely general anesthetic naive then the anaesthetist would be best placed to use what they usually use.

00;28;13;28 - 00;28;40;09

Dr Anton Krige

obviously eliminating drugs that would interact with things we already mentioned. You know, for instance, those treatments might be on for Pots, taking into consideration the impact of those drugs and how they might interact with with various anesthetic drugs. but in the end, it would really need to be individualized. And it really depends on the type of surgery and what anaesthesia is required for that surgery.

00;28;40;11 - 00;29;08;18

Dr Anton Krige

and tailor it accordingly. The particular items you mentioned earlier around, drugs that affect neurotransmitters. I mean, that's quite broad in a sense, because all the drugs that we would call induction agents, in other words, the ones that induce sleep and unconsciousness, they're all interact with neurotransmitters, in a sense. They they're working on Gaba transmission in the brain and, and various other receptors.

00;29;08;20 - 00;29;32;09

Dr Anton Krige

So indirectly, all of them would fall into that category. And ultimately they need a general anesthetic. We would need to use one of them. We've got to get them off to sleep to do it. unless there is an option, as I said, to do the entire operation under a spinal block or some other form of regional block. Now that that is the default in the NHS for people having, for example, hip and knee replacements.

00;29;32;11 - 00;30;01;06

Dr Anton Krige

That's what that's the way that we'd have it done anyway. And then there'd be no need for any of those medications. the, the avoidance of adrenaline. that would only really come into where, where they, where we would usually use certain local anesthetic to have adrenaline mixed into them. And that's where you referring to dentals, where the local anesthetic that the dentists use usually is mixed with adrenaline

00;30;01;08 - 00;30;25;28

Dr Anton Krige

It both reduces the toxic dose of a local anesthetic, but also it causes less bleeding locally, where they inject it. There are a few scenarios where we also use that combination in the operating theaters, but of course that that can be avoided if if we know the patient has a problem, it all of these interactions though aren't true allergies because of course we can't be allergic to adrenaline.

00;30;25;28 - 00;30;58;10

Dr Anton Krige

We release adrenaline all the time. It's a natural substance. We'd be dead if we are allergic to it. So none of these are true anaphylaxis or true allergic reactions. But what I, what I personally suspect is going on is that these patients are experiencing something that's more recently been, discussed in the literature and something called mast cell activation, where a very it's a very early component of their immune system is, is mast cells which identify threats, etc..

00;30;58;13 - 00;31;29;12

Dr Anton Krige

And these mast cells can release up to 400 different mediators and many of them are vasoactive mediators. And I suspect many of these negative reactions to various medications, because those particular substances have triggered their mast cells to release different chemicals. and that's the same, probably the same mode for whereby these patients get negative reactions to certain chemicals, perfumes and any number of other things, food intolerances, etc..

00;31;29;14 - 00;31;50;19

Dr Anton Krige

And there's a lot of growing literature on this whole concept of mast cell activation, including it being shown to be highly prevalent in patients who who generate long Covid or get, other types of Covid symptoms. And I don't know whether that that may be something you've encountered in the literature, Charles, or on mast cell activation.

00;31;50;21 - 00;32;02;03

Dr Charles Shepherd

Yes. again, it's it's another one of these conditions which seems to have a significant overlap, with, ME/CFS. Yeah.

00;32;02;06 - 00;32;20;07

Dr Anton Krige

And, and can certainly these mediators can induce a lot of these changes like changes in heart rate, blood pressure, etc.. that there are just so many different mechanisms involved in all of this happening variably from one patient to another and, and simultaneously.

00;32;20;10 - 00;32;35;25

Helen Baxter

But we often find that actually mast cell activation disorder is very rarely diagnosed, even when it's quite obvious that the patient has got, say, hives or gastrointestinal problems. But actually it's not diagnosed and it's not treated unfortunately.

00;32;35;25 - 00;33;03;15

Dr Anton Krige

It is lacking profile. Absolutely. Helen. And I think it's, it's still thought of as a rare condition of course. One of the original conditions which doctors are taught about is systemic mastocytosis, which is very, very different. And it's actually, a malignant malignancy of these mast cells, whereas mast cell activation syndrome is very, very different.

00;33;03;17 - 00;33;27;20

Dr Anton Krige

It's, it's nothing to do with the cancer. It's got to do with instability of these mast cells. And the the newest literature suggests it's as common as 14 to 17% of the population. Most of those obviously experiencing it very mild symptoms. But you're right, it's it's actually a very common, condition. And really the symptoms are multi-system.

00;33;27;23 - 00;33;38;06

Dr Anton Krige

They're not just the sort of classic allergic symptoms. So, I suspect it's behind a lot of the negative reactions to medications in these people.

00;33;38;08 - 00;33;43;18

Helen Baxter

But unfortunately, like with ME/CFS, it's very much dismissed by healthcare professionals.

00;33;43;25 - 00;34;11;00

Dr Anton Krige

Absolutely. there is just a very slow and long and knowledge translation gap between what we generate in, in the literature and in research into it becoming, a common, common knowledge within the system. But hopefully this podcast is going to go some way to trigger people to do a bit of research and self-education around these different topics.

00;34;11;02 - 00;34;36;24

Helen Baxter

We were discussing the role of melatonin. Now obviously that's consultant prescribed normally, but what we sometimes find is that patients go into hospital they're on melatonin and their consultant overseeing their care in hospital thinks, oh, this patient looks really sleepy. So they take them off the melatonin. And that, of course has a massive knock on effect to them they're then not sleeping at all in an environment that's not suitable for them.

00;34;36;26 - 00;34;44;28

Helen Baxter

so I would urge, you know, caution around altering medication regimes whilst you've got patients in hospital.

00;34;45;01 - 00;35;09;01

Dr Anton Krige

And that's that's a great point, Helen. And, you know, my, my outlook on this is as an anaesthetist is, you know, you you try and keep a patient who's coming from surgery. You try and maintain everything that they normally get unless it's going to directly, negatively interact with the acute treatment in hospital. And then you add whatever they need for the surgery on top of that.

00;35;09;03 - 00;35;44;08

Dr Anton Krige

And that that particularly comes around to another item which we commonly encounter with ME patients is a large proportion of them will experience fibromyalgia, sort of generalized body pain and particularly muscle pain and, and soft tissue pain. And certainly my daughter experienced that throughout. in fact, she was that sensitive that just going on a car journey, the vibrations of the car on the road would give her a lot of pain, and she needed to really sleep on a nice mattress that helped reduce ME, etc., etc..

00;35;44;10 - 00;36;14;11

Dr Anton Krige

So as a knock on effect to that, some of these patients will be on chronic pain medication to help deal with their fibromyalgia pain. which may include chronic opiates, gabapentin, amitriptyline, all the other standard chronic pain medication used by chronic pain clinics. and that we'd need to be aware of because we need to factor that into planning the optimal, acute pain package for them whilst in hospital and certainly in my own pre-op clinics.

00;36;14;11 - 00;37;02;21

Dr Anton Krige

What I'd ideally do when I encounter any patient who's a chronic pain patient is include our acute pain team in in my, pre-op report in terms of the plan for that patient's journey. so they already have awareness of them ahead of time, know when they're coming in for the surgery and what we really want to do in line with talking about melatonin is similarly, we want to make sure that they maintain all their chronic pain medication, ideally use regional techniques as part of

their pain relief, interim perioperatively, because we know that these patients who are already used to chronic opiates using morphine and other drugs, using that as the only form

00;37;02;21 - 00;37;26;21

Dr Anton Krige

of pain relief postoperatively is quite difficult. They can end up needing much, much higher doses than other people. If they're really tolerant of morphine type drugs. so we'd ideally come up with a pain plan that that accounts for that. and that's, that's, that is also one of the, the points raised in our patient resource. And, and points towards that.

00;37;26;23 - 00;37;51;13

Dr Anton Krige

And all of this really comes under the whole umbrella that we want this entire interaction at the pre-op assessment clinic to be what we call shared decision making. And that's a more modern concept within anaesthesia. And it's got information about this in the Royal College website. And it's a reference and link from the patient resource. and it's really it's about a team approach.

00;37;51;16 - 00;38;18;01

Dr Anton Krige

It's about the clinicians together with the patient and the surgeon coming up with the best decisions for that patient in the first instance, whether it's a good idea to actually go ahead for surgery, weighing up their individual, cost benefit analysis. and that's taking into account, how important is the surgery in terms of what quality improvements could offer against that individual?

00;38;18;01 - 00;38;42;01

Dr Anton Krige

ME patients may be risk of the ME getting worse, which is unpredictable. But nevertheless if the surgeries may be a minor problem. It might not be worth the risk. Clearly, if it's a cancer surgery, it's a completely different risk benefit analysis. So that whole concept of shared decision making is crucial. Any any comments from Helen or Charles along that.

00;38;42;04 - 00;39;09;25

Helen Baxter

I think there's lots of simple things that anesthetic anaesthetists and surgical MDTs can do to make a really big difference to the experience people with ME/CFS have, and the NICE guideline does provide guidance around hospital admissions and I think perioperatively you need to

consider whether you need to see that person, that patient in person, a telephone call or an online discussion is probably much less tiring for them.

00;39;09;27 - 00;39;41;12

Helen Baxter

And if they find communication difficult, providing they're happy, speak to someone who knows them well. So a family member, partner, friend, home care worker or an advocate just to gather that information, ask whether they have a care and support plan in place. Unfortunately, a lot of ME/CFS patients don't. But as you said, Anton, use that shared decision making to enable you to put personalized plan in place and that will then allow you to make the reasonable adjustments you need when they come into hospital.

00;39;41;15 - 00;40;01;11

Helen Baxter

I mean, if it's essential for the person with ME/CFS to come into outpatients, ensure that you've got a quiet space with low lighting where they can rest. Bear in mind if the person's ME/CFS is at the more severe end of the scale, they're going to be coming in in a wheelchair. And for those with severe ME/CFS, they're going to be arriving on a stretcher.

00;40;01;14 - 00;40;21;00

Helen Baxter

So you're going to need somewhere quiet to put that, and you're going to be they're going to have to be able to access toileting facilities. And if you need to do a number of tests, perioperatively, try and do them in one visit or the minimum number of visits, because some of those people who are very severely affected are just too ill to leave their homes.

00;40;21;03 - 00;40;44;09

Helen Baxter

So a trip to the hospital is a huge demand on their energy. NICE has a phrase which I find is very useful to bear in mind when you're dealing with people with severe ME/CFS and that is risk assess each interaction with a person with severe or very severe ME/CFS in advance to ensure its benefits will outweigh the risk.

00;40;44;11 - 00;41;10;00

Helen Baxter

So for example, worsening the symptoms to the person. For example, for people with very severe ME/CFS, think about discussing things with the person's family or carers on their behalf if

appropriate, whilst keeping the focus of the engagement on the person with ME/CFS, I think that's a really important part of the NICE guidance. you should be really thinking about that as the anaesthetist or the surgical MDT involved.

00;41;10;00 - 00;41;13;04

Helen Baxter

Looking after this person.

00;41;13;06 - 00;41;50;28

Dr Anton Krige

That's that's fantastic points Helen, and fortunately targets of modern pre-op assessment clinics are to provide where possible a lot of our assessments remotely now. And certainly that is one of the few positives out of Covid. It is that it actually hastened that movement to remote, pre-op consultations. And routine practice when we do see patients in a consultant anaesthetist led, higher risk pre-op assessment clinic in person, we we would always, encourage them to bring along, either their, their partner or friend or whatever.

00;41;50;28 - 00;42;13;04

Dr Anton Krige

So we usually have a second person in the room. And I think again, that's really important. Yeah. That we've got a second person who can listen when there's brain fog and difficult to retain information. Somebody else has also taken on, on board, to, to help explain it later on and repeat back that information. And Charles, I think you had some comments.

00;42;13;06 - 00;42;39;10

Dr Charles Shepherd

Just just one quick comment. Helen's just emphasized the importance that we put into the NICE guideline on on caring for people who are coming into hospital. And there is as Helen indicates a separate section of the NICE guide on that. just one particular point, which I'll pick off as well from what we put in said, being very cautious about the, about the pressure of touch.

00;42;39;12 - 00;43;04;12

Dr Charles Shepherd

and that's particularly important to people who are bedbound severe end of the spectrum. just quick points on on pain in that ME/CFS. I didn't include my in my list of, diagnostic symptoms because it was not one that we, classified in the NICE guideline as a diagnostic feature. But pain is a very important symptom in this illness.

00;43;04;14 - 00;43;41;04

Dr Charles Shepherd

But it's interesting in that not everyone with ME/CFS has pain, probably about 25% of people have no pain at all. It's very minimal. I personally have never had any pain as part of ME/CFS, but at the other end of the spectrum, pain can be the most, intrusive and disabling part of this illness. And it's worth noting that people with pain and then ME/CFS may be on different steps of the analgesic ladder, so they may well be starting off with low dose amitriptyline, a low dose tricyclic, and then moving on to gabapentin, pregabalin.

00;43;41;06 - 00;44;04;19

Dr Charles Shepherd

And there will be a few people, who have really got very severe problems with pain who are on an opiate pain reliever. So that's worth taking note of. And we did, in the NICE guideline link the management of pain in ME to the NICE guideline, on neuropathic pain.

00;44;04;22 - 00;44;42;29

Dr Anton Krige

Perfect. And I think we've we've given quite a good discussion there around most of the sort of pre-op components that have actually been covered really well in the patient resource document that's being launched. perhaps a few of the the items that we cover in the document around the day of surgery itself, and some of those we've alluded to there in, in the, the, the list of common symptoms for these patients, many of them voiced about their sensitivity to noise and light, and their concerns around the theater environment itself.

00;44;43;01 - 00;45;23;21

Dr Anton Krige

And this is important, again, for the patients to inform us about during that pre-op assessment, because we can we can from from the pre-operative clinic, we can advise the anaesthetist who's going to be involved in the day of surgery, the surgeon, etc., that these are particular issues for this patient and and the way operating lists work nowadays in the NHS is that at the start, very start of the operating list, there's always a team brief where the whole operating list is discussed with the entire operating team, and this will be anything up to 8 or 10 people.

00;45;23;24 - 00;45;49;04

Dr Anton Krige

It'll be the surgeon, their assistant, the consultant anaesthetist, anesthetic nurses, etcetera, etcetera. And the list is essentially planned for the day. And with each patient they'll go through what that patient's issues are, what what's required for the operation, what the anesthetic plan is and then particular problems, allergies, etc.. And this is a perfect moment to raise things to say.

00;45;49;04 - 00;46;05;17

Dr Anton Krige

This particular patient has ME.

Helen, did you have any further comments to add to, what I was discussing around, changes that could be made for the patient on the day of surgery? to minimize the impact of their ME.

00;46;05;20 - 00;46;28;14

Helen Baxter

When it comes to the day of surgery itself, find the patients somewhere they can lie down where it's quiet and dark. So minimize the stimuli, allow them to bring someone with them and let that person stay with them. And if they normally have care, allow that caregiver to continue to provide the care both before and after the surgery, because that minimizes the energy expenditure.

00;46;28;17 - 00;46;56;19

Helen Baxter

because the care can be provided through familiarity and the caregiver can respond to that person's cues, and they can also advocate for that person. In recovery find that quiet corner with the low lighting for these patients, and keep external stimuli to the absolute minimum. And remember that many people with ME/CFS, suffer from chemical sensitivities. So avoid wearing scented beauty products or smelling of cigarette smoke.

00;46;56;22 - 00;47;21;01

Helen Baxter

when you're back on the ward after recovery, provide a side room where possible away from the noise and the bustle of the ward. Keep it dark and use minimal lighting. For example, looking at the patient and examining the patient. I mean, I know of instances where bloods have been taken just using the light from a mobile phone and listen to what that patient needs and make those reasonable adjustments.

00;47;21;03 - 00;47;32;07

Dr Anton Krige

Helen and Charles, any any final thoughts that, that you'd like to share with the audience around ME and its implications with anaesthesia?

00;47;32;09 - 00;48;00;28

Helen Baxter

Okay, so my key take home message would be really listen to that patient. Listen to what they tell you. Make those reasonable adjustments and also believe that patient and make them realize that you believe those symptoms that they're telling you. And that way you will gain their trust. They'll probably provide information like the NICE guidance. So take that away, look at it and use it to make those reasonable adjustments that they really do need.

00;48;01;00 - 00;48;04;15

Helen Baxter

And it will make their journey so much easier.

00;48;04;18 - 00;48;25;02

Dr Charles Shepherd

Yes, I'd really just like to second what Helen has already said. And I think, you know, it's a big ask because we're, you know, all doctors have got vast amounts of things to do not to look at. But I would urge any anaesthetist who is looking after a patient with ME to at least have a look at the key points in the NICE guideline.

00;48;25;02 - 00;48;34;24

Dr Charles Shepherd

It's very easy to, to, look at and pick up what what's going on with these patients.

00;48;34;27 - 00;49;08;04

Dr Anton Krige

So in closing, I'd just like to thank all of our guests, Doctor Charles Shepherd and Helen Baxter. thank you for your time, both of you. And for this really interesting discussion we've had around, ME/CSF and its implications for anaesthesia and in particular, really to to act as a launch and create awareness of our patient resource around CSF and anaesthesia, which is being launched, the day after this recording.

00;49;08;07 - 00;49;34;21

Dr Anton Krige

if you haven't already, please make sure to subscribe to Anaesthesia on Air, available via all the major podcast channels. And have a look at all the links that will be provided with this podcast. Both links to the patient resource, NICE guidance, and all other relevant links in related to this topic. And finally, thank you for listening.

00;49;34;23 - 00;49;58;08

Speaker 4

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00;49;58;08 - 00;50;02;04

Speaker 4