



B12 revisited - Ref151

with Tracey Witty

16th March 2021

TRANSCRIPT

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Steven Bruce

Today I've got one of our repeat offenders back in the virtual studio. I've had Tracey Witty on the show before, last time she was actually in the studio with me. And she's going to talk to us about vitamin B12 deficiency. Now, normally my guests are the great and the exalted of the medical world or elsewhere. But Tracey, Tracey, you're just a woman, aren't you?

Tracey Witty

I'm just a woman.

Steven Bruce

Tell us about yourself, Tracey.

Tracey Witty

Well, I started my closer look at B12 deficiency nine years ago, last month, when somebody close to me was sectioned with this deficiency. And from then I decided I needed to try and get information out to both clinicians and people with B12 deficiency, so that they didn't experience what my loved one experienced, but also what I experienced when I found that I was B12 deficient. So I started B12deficiency.info in order to create a hub really, so that that would provide good information in amongst some of the rubbish that's written out there about B12 deficiency.

Steven Bruce

But you were a cabinet maker first of all, I believe, weren't you?

Tracey Witty

I trained as a cabinet maker and upholsterer and so I have no medical training whatsoever. I kind of learned by researching. And as most patients with B12 deficiency find they know an awful lot more about their condition than their doctor does, unfortunately.

Steven Bruce

And I introduced you in a very rude way, but there was a reason for that wasn't there?

Tracey Witty

Yeah, in trying to help a patient in Lincolnshire, I was communicating with a district nurse who told me that I was just a woman. And of course, I agreed and said, yes, I am just a woman, but I'm a woman who's trying to help you to help your patients. So it's quite common that as a lay person trying to give out medical information to somebody who doesn't, hasn't learnt it or doesn't understand it, that they kind of get a bit upset about that. Naturally, probably.

Steven Bruce

Yeah, it's salutary for all of us, isn't it to remember that whether we're male or female, we are just people who happen to have one level of information in our brain about a given topic, whether or not we've got letters after our name, you're going to have some letters after your name, I imagine in a year or so time, aren't you?

Tracey Witty

Well I started a PhD, this time last year and so hope to be completing in a couple of years or maybe three.

Steven Bruce

And there's no prizes for guessing what the topic of your PhD is. But to be honest, I mean, it shouldn't matter. But I suppose it does to an uninformed audience, to the doctors that you speak to, to the nurses who speak to, it will actually lend some credibility to your standing as an advisor on this topic, won't it?

Tracey Witty

I think it does, people view you differently. And it wasn't something that I ever thought that I needed to do or even wanted to do. And it was somebody, a friend of mine who's a professor of psychology in Australia, who really persuaded me to look at doing this. And she was the one who, you know, pushed me into applying, and I'm so pleased I did and I've got a fantastic, really lovely supervisor who is very open even though she's a doctor herself, but her background in mental health nursing, who's been a dream to work with.

Steven Bruce

Good. Well, I know, you know, when you last came on, we had lots of viewers for that. And I knew that so many of them were knocked out by information, which they had no idea about the scale of the problem with B12 deficiency and there's so many different aspects of that problem. Should we run that video that you asked me to share first of all, just to give an idea of how bad it can be?

Tracey Witty

Yep.

Steven Bruce

Justin, over to you.

Speaker 1 in video

Patients were coming in, that were very symptomatic, and the physicians would not test them. And I tried to educate the staff and the physicians I worked at a teaching hospital, and they just wouldn't test the people.

Speaker 2 in video

Pediatrician Dave Carr was told he was suffering from a rare incurable neurodegenerative disease. He was about to die, demented, blind, deaf and in a diaper, before he was correctly diagnosed with a vitamin B12 deficiency, a condition that would have been easy to prevent and inexpensive to treat, if it had ever even crossed his mind. Dr. Carr did not know that low B12 was shrinking his brain and demyelinating his nerves. He did not know that masked B12 deficiency damage can look just like MS or Parkinson's or Alzheimer's or autism.

Speaker 3 in video

There's no way in the world in the year 2005 that a vitamin deficiency can do something like this.

Speaker 2 in video

And yet, B12 deficiency causes serious problems ranging from fatigue to depression, to memory loss, to heart disease. What your doctor doesn't know about vitamin B12 can hurt you.

Speaker 3 in video

Low B12 levels are associated with a progressive cerebral atrophy. It's not a placebo.

Speaker 1 in video

The neurological manifestations well precede the hematologic manifestation.

Speaker 4 in video

Well, let me simply say you can't live without it. A vitamin B12 deficiency, if left untreated, results in death.

Steven Bruce

So Tracey, I mean, the main subject of that film there, that clip from the film and we'll share the link to the full video, because it's available on YouTube. The main subject there was a pediatrician, so he's a fully trained medical doctor, and yet he was unaware of this, so, you'd have thought wouldn't you that their training would cover the signs and symptoms of B12 deficiency.

Tracey Witty

Yeah, especially since he'd be seeing children with symptoms of B12 deficiency. But the general understanding is that B12 deficiency really doesn't affect anybody except women over 60. So oftentimes, they're not looking for it in children. They're not looking for it in men, and they're certainly not looking for it in adolescents. So for Dr. Carr, you know, this was a really scary time. And as you can see, he now just walks with crutches. And has been permanently damaged by not knowing about B12 deficiency.

Steven Bruce

Yeah, you say he should have known about it because he's treating children. Is it more common in children? Is it something we should look out for in children?

Tracey Witty

Sorry, what I should say is actually every single discipline of health care, whether it's pediatrician, gynecologist, gastroenterologist, each person doing medical training, or nursing should know about B12 deficiency because it affects every single body system. It affects both sexes and it affects all ages.

Steven Bruce

I think the conclusion we came to after last time was that basically everything is down to B12, isn't it? Or potentially everything is down to B12, even low back pain.

Tracey Witty

It does sound like that. And obviously, not everything is down to B12 deficiency, but what would be really key is that, you know, if it was part of a full blood account would be really helpful. I think, because our doctors don't necessarily understand all of the symptoms and certainly the mental health side of things, then it's not on their radar to click a tick box on a blood test form to test for it.

Steven Bruce

Can we go back a bit to basics on this. And apologies to you in the audience if I'm covering stuff that you think is old hat but B12 deficiency and folate deficiency are often sort of lumped together, aren't they? Are they the same thing? Do they manifest the same way?

Tracey Witty

They're very similar overlapping symptoms. But the distinct differences are that folate is the big sister to B12 really. B12 deficiency can cause neural tube defects like folate deficiency does, which is why women are told to take folic acid or some kind of folate during pregnancy. But B12 deficiency is much more complex because it must be given in injection form if there is a problem with the stomach. And if there is or if there's some problem with the stomach or your inability to absorb it from food, it can't just be given in tablet form. Whereas folate can be given in tablet form.

Steven Bruce

So what is B12 deficiency actually doing? We talked about pernicious anemia last time, but that's not the same as B12 deficiency either, is it?

Tracey Witty

Well pernicious anemia is just one cause of B12 deficiency. It's often believed by doctors to be the most serious but actually, it's just one cause. Everybody with B12 deficiency has similar symptoms, the treatment should be the same unless it's because you're a vegan and a vegetarian. And the only reason you're deficient is through dietary lack. And then every cause, every B12 deficiency, regardless of the cause is serious. It's all pernicious, you will die without B12. And whether that's because you've got the autoimmune condition, or whether it's because you've taken Metformin for diabetes, which has stopped you absorbing B12 from food, or whether you've had a gastric bypass, or whether it's a genetic reason or very low stomach acid.

Steven Bruce

So summing up the causes of B12 deficiency that you've mentioned some drugs, you've mentioned some genetic conditions, inherited B12 deficiency, or is it? I'm forgetting my terminology because I want to...

Tracey Witty

Pernicious anemia did you mean?

Steven Bruce

No. Intrinsic factor. That's right. It's the failure to be able to produce intrinsic factor, isn't it, which is the genetic component?

Tracey Witty

Well, that's the lack of intrinsic factor to unbind and transport B12 through to the small intestine. And there can be genetic reasons for B12 deficiency as well, there are TCN2 genes, which is getting the transport of B12 from the blood into the cells, methylation issues with B12 and folate can also cause problems with B12 and folate deficiency, and it's said that about 40% of the population have these genes.

Steven Bruce

Okay, Ron has anticipated what was going to be my next question, because I think it's a really useful thing. One of the things that on the NHS guidelines, the NICE guidelines, doctors are recommended to do is to carry out a full blood count. And he's saying, why is it not part of a basic blood test, but I think you've got a fairly good answer to that.

Tracey Witty

It should be part of a full blood count. And I think sometimes doctors rely on the mean cell volume, on the mean cell hemoglobin to indicate folate and B12 deficiency. The problem is with that if there's a coexisting anemia, that will push those levels down, so that the MCV and MCH will look normal. And of course, if you have supplemented with folate, then, if you had macrocytosis, so large red blood cells, which can be an indication of B12 and folate deficiency, those, if you supplement with folate it can normalise the size of those blood cells. So it would be really helpful to have B12 as a tick box on the full blood count, yes, as part of the full blood count.

Steven Bruce

Don't I recall from our last discussion that you were saying that it's all very well testing for it, but they test in the wrong way, and they test for the wrong range of B12.

Tracey Witty

Well, the serum B12 test has its limitations. And there are lots of documents. If you, I have a page on the site called what to do next and point four on that page leads the reader to documents which show the reader that the serum B12 test should be, a within range result on the serum B12 test should be ignored in a symptomatic patient. So what they realise is that their own B12 test tests active and inactive B12 in the blood. And the inactive B12 can't be accessed, and the body doesn't recognise it, but it's circulating. And there is an active B12 test, but that's not gold standard either. So really what our doctors should be looking at is the clinical picture. And not just reliance on blood tests.

Steven Bruce

You mentioned that folate supplementation will actually normalise the size of the red blood cells. Does that cure the problem?

Tracey Witty

No, it doesn't. But I think in the past it certainly was seen to have, that it was thought that that did cure the problem. That's just changing the size of the red blood cells. You can't supplement folate and expect it to correct B12 deficiency, they're totally different vitamins.

Steven Bruce

It's not been uncommon in medicine in the past, has it to assume that a change in a marker is actually fixing a problem?

Tracey Witty

That's right.

Steven Bruce

It is just a marker. Some more questions for you. Victoria says she's a vegan and her doctor recently refused a B12 tests as part of a full blood count due to COVID. Not sure why she says.

Tracey Witty

That's outrageous. And I think the problem, what lots of people experience during COVID if they were B12 deficient and receiving injections, some GP practices, unfortunately, were telling people they couldn't have their B12 injection, but they could come in and be tested, test their B12 levels to see whether they actually needed their B12 injection. Well of course, you're as close to the nurse, having a B12 injection as you are having your B12 tested and that was being used in order to tell people that their levels were within range and that they no longer needed B12 injections. So if you are vegan or if you are suspicious of B12 deficiency, then you shouldn't really be refused that test.

Steven Bruce

That's an interesting philosophy isn't it? You're allowed to come in so that we can test you for B12. But no matter what happens, you're not going to get an injection.

Tracey Witty

Totally bizarre what happened last year. And lots of people were just put onto tablets and told that they no longer needed injections, it's completely bizarre.

Steven Bruce

But also, maybe I'm leaping ahead here, doesn't that fly in the face of the NHS guidelines to doctors on what you should do to support someone who's B12 deficient? Because they never come off injections surely.

Tracey Witty

Well, NICE guidance does say that, you know, unless you know that it's a proven dietary lack then injections should be given. What should happen is if you are diagnosed with B12 deficiency, you should be given a loading dose of every other day injections. And that should continue at that frequency if you're neurologically affected for as long as it takes for those symptoms to stop improving. But what generally happens for people is that they're given two weeks of loading doses. So six injections. And then they're simply told we'll see you in three months.

Steven Bruce

Right. And I think the guidelines say that even once you come off the every other day injections, you should be getting them every three months regardless.

Tracey Witty

Yeah, and the problem is with that three months is that that really doesn't suit most people. I have a weekly injection from my GP, and I've had that for years. Most people who are on the three monthly might find that, you know, even after a couple of weeks, they're really struggling to cope. But often are told, well, we'll see you in three months. And there's no alternative. Some people can get them eight weekly, but it really comes down to what your relationship is like with your GP, how much your GP understands

about it, and really, the ability of the patient to really push home that they need more injections. And that is one of the things that I come across really with the site is that lots of patients really struggle to challenge their doctors.

Steven Bruce

Well, and Victoria, I think it might be the same Victoria has come back with another question saying, would you suggest they get private lab tests? Or is it enough to go to their GP? And I guess the follow on from that is, well, how's that conversation going to go?

Tracey Witty

Well, I would say, Victoria, lots of GPs won't accept private tests, they'll say they've not been done at our lab. But in your situation, then I would say, look, if you're not going to test me and I'm going to pay for private tests, will you accept these results and treat me on the basis of them. Because for an individual, forking out money for a private test, just to be told, well, it's not been done at our lab, we're not accepting them, after they've refused you testing already. It's outrageous.

Steven Bruce

And there are some pretty good, very reliable, respectable labs out there, aren't there. Do you have any that you recommend or that you use yourself?

Tracey Witty

I don't, I don't use any, I always say to patients, please go and get a serum test from the GP, get a baseline, have it in your notes. And that's the way you can fight for a diagnosis. Because private testing is outside of that. And naturally, people do go down that route, because they are frustrated and they're anxious and really impatient to find out what's happening, get to the bottom of it, but it is a primary care issue. This is for your GP to treat. And therefore, my advice always is, even if you've had private testing and those tests have come back, and there's something amiss, then to just make sure that you have a record of this test in your GP notes.

Steven Bruce

Right. The other part of my question was is, how is this conversation going to go with the GP? If you come up with a GP who says, I don't accept those results, they weren't done by us. Or who says yes, it's all very well, I know, you've been looking at Dr. Google on the internet, but I don't think it's a thing you should be worried about. How do you approach that?

Tracey Witty

Well, I would always, I've had lots of arguments with lots of doctors and with my own doctor, previous doctors, the point is that you are the expert of your body and you have a right to help and care from your GP practice. I always go to the website of the GP and I look at their policies. And I often use their policies against them when I'm trying to help patients, because they'll often say things like, you know, we will provide this care, and, you know, see what's in there, go back and demand the test. And in fact, if you can't get any sense out of the GP, then go to the practice manager and say, I don't understand why I'm not being given this test.

Steven Bruce

Do the practice managers have any real influence in that regard?

Tracey Witty

Some do and certainly that's where I start oftentimes because you can't necessarily reach the doctor straight off. But starting with the practice manager and saying, you know, can you explain to me why I'm not being given this test, can you put in writing why I'm not being given this test that often yields some kind of response.

Steven Bruce

How's it worked for the people who are in touch with you because I would imagine that by now in a wide range of GP practices near where you live, they all know about Tracey Witty and they quiver when they hear your name. For an ordinary person going along trying to do this, it's probably a little bit more scary and intimidating. You have all the facts.

Tracey Witty

I think the problem is for patients is that we've all been brought up to think that we're handing over our control to somebody who has wider knowledge than we do. And unfortunately, it's not always the case, but lots of problems, female problems, menopause, lots of things, but certainly with B12 deficiency, the patient often knows more. So a lot of what I do is try and help to empower women. It's usually women that come to me. Empower them to know that they know their body better than anyone else, they are the expert of it and to just stand their ground and to say, you know, this is something I need to have treated and ought to be tested for. But it is tricky and especially when people are often very cognitively affected and they may be depressed, they may be apathetic, they may be really, really struggling to function. So it is bloody tough trying to fight with somebody when you are literally fighting for your life too.

Steven Bruce

Yeah. Coming back on the laboratory's thing, Nita has said that Doctors Laboratory or Genova Diagnostics in London are both good labs. And we've had some other labs recommended in the past, which I can't remember off the top of my head. You mentioned menopause a minute ago, and Wendy asked whether the incidence in B12 deficiency in women over 60 is that due to menopause?

Tracey Witty

No, I think that's probably more related to lower stomach acid or the fact that you're just kind of, you know, you're running out of reserves of B12 or maybe even drugs that you're on, maybe for other conditions.

Steven Bruce

Right. So is it actually more prevalent in women than it is in men and to what degree?

Tracey Witty

I think there is more prevalence in women, purely because they have children. And if you have a child, then your B12 cupboard, if you like, is being accessed by that child because there's no other way of that child accessing B12 and then mothers who have nitric oxide during pregnancy, if your B12 deficient that

completely inactivates your B12. So that's an effect on it. And then as we age, we have less stomach acid. And on and on, really, but I think it does affect far more women than men, but not to say that men aren't affected, if they take drugs that cause B12 deficiency, PPIs, acid suppressants or Levodopa for Parkinson's, there's all sorts of drugs that cause problems with people being able to absorb B12 from food.

Steven Bruce

I wonder if there's also perhaps a greater recognition of B12 deficiency because in the process of childbirth, they will probably be tested more rigorously, maybe men aren't being tested to the same degree.

Tracey Witty

Maybe so. And also I think that men are less, well, as I understand it, men would rather not go to the doctor's as easily, as readily as women would.

Steven Bruce

Yeah, possibly. I have heard that and again, I don't know whether it's true or not. Somebody will no doubt tell me shortly. Let's go back to some of the causative factors here. Jess has sent in a message saying that he or she sorry, Jess, I don't know which one you are, has heard, I'll call you they in keeping with our recent broadcast on gender equality. They have heard that conflicting ideas on B12 deficiency through diets. Some say that it's through soil degradation and others insisting is more likely if you don't consume dairy or meat. Any ideas Tracey on what it is in the diet that causes it?

Tracey Witty

Well, B12 only comes from animal products. But it's a fact that it comes from cobalt in the soil and there are certain areas of the UK that doesn't have a lot of cobalt in the soil. So animals reared on that ground then are given boluses to make sure they have enough B12. But there are no plant products that contain B12. There was a time, somebody I worked with down in Devon where they have been advised as a vegan to take spirulina and seaweed because it contained B12, but this is not correct. These are B12 analogues which the body can't use and doesn't recognise.

Steven Bruce

Yeah, I remember you mentioned this before, it's just, run me through again, what do you mean by a B2 analogue?

Tracey Witty

Is it just, it's not active, it can't be used. So, in your circulation of your blood, you have active B12 which might be 20% of what is in your blood, so 80% of your serum B12 test may be recording inactive B12.

Steven Bruce

Right? Oh, hence why again, the serum test is not necessarily accurate.

Tracey Witty

It's not but the beauty of having the serum B12 test means that you can use the documents that state it has limitations, you can use those to help the doctor to understand that the clinical picture is of utmost importance, the BMJ and Nicas, the haematinics essay, and NHS choices themselves have produced information on this.

Steven Bruce

Right. Now Steven is asked, if a patient is taking a B complex supplement, how long would it take before they should have a B12 tests to see if that's a problem?

Tracey Witty

So the person is deficient, but then they've taken an oral supplement is that?

Steven Bruce

Sorry, how long should they stop supplementing before they take the test was the question, apologies Steven.

Tracey Witty

Here's the thing really, and truly, if you think you might be B12 deficient, people do take supplements, unknowingly, thinking that that will help and that will supplement what they need. But they say to leave it around four months to be clear of supplements to get a clear test. Now, to my mind, that is just painful. If you've taken supplements, you don't want to be suffering for another four months, just in case you get a clear test, I would suggest under those circumstances that you go to your doctor, and that you say I want to be tested. But I have supplemented. So I need that noting on the lab form so that they can look at that, alongside my result.

Steven Bruce

How will those supplements distort the test?

Tracey Witty

Well, it will look like you've got a healthy level of B12. And you turn over a red blood cell in about 120 days. So for around four months, you could look like you've got a really good level of B12. But that's nothing, there's no indication of what's happening at a cellular level. And if your patient is severely symptomatic, then it's quite clear that, you know, often young patients with family history, they're symptomatic and then they've gone and taken a supplement. So it's skewed the results. And so people will say we need to stay off those for four months before, but that person's suffering. So they need to go and get it sorted straightaway.

Steven Bruce

But doesn't, again, I'm struggling to get to terms with this. I mean, it will look as though I've got a healthy level of B12. But I haven't. So what is it I have got that's making it look that way? Is it another analog?

Tracey Witty

Well, it's just that the B12 has gone in to the system but you've not got the equipment to take that through to the small intestine or to unbind B12, you know you can't unbind B12 from food, an oral supplement they say you can get 1% by passive diffusion, what's 1%, you know, it's not going to heal the nerves, it's not going to make you feel great very quickly.

Steven Bruce

Okay, Sally has asked whether sublingual B12 supplementation is all right if you can't get an injection.

Tracey Witty

Sublingual B12 suits some people, it's usually in the form of methyl cobalamin. It doesn't do anything for me. But some people do report that it's okay for them. It's not, there's not an awful lot of research on the sublinguals. And it is an absolute fact that injections are the most efficient and most effective form of administration of B12.

Steven Bruce

Okay, and Jess says so you don't get cobalt from eating vegetables with soil on them. This is what I've been told lately. Good to know. So Jess is saying that's good to know. Sorry I thought that was going to be a question. I saw the question marks in there.

Tracey Witty

Yeah, I'd always wash my veg before I ate a load of mud, personally, but yeah, you can't tell. You wouldn't know.

Steven Bruce

In terms of diet broccoli always gets a good press. I think broccoli is good for B12 as well though, isn't it?

Tracey Witty

Oh, yeah. I've been told that before. She just needs to eat some broccoli. And I also have, I think last time we had the really sad blood results from a patient who, her B12 level was below range. She should have been treated and the doctor just simply circled it and said advice leafy green veg and that poor patient was permanently damaged and in a wheelchair. And what I would say actually, and I think this, what I would love is that in the future, we can make B12 injections available over the counter in this country. Because most of the countries around the world allow people to buy them from pharmacies and self inject. And what many people do who don't necessarily want to fight with their doctor because they're not well enough to is that they do source their own B12 from generally German pharmacies and treat themselves in the absence of help from their GP.

Steven Bruce

Can you get injectable B12 from a German pharmacy?

Tracey Witty

You can, you can buy that perfectly legally for your own use. And of course, in the UK, there are lots of clinics and hairdressing salons and beauty salons that can provide you with a B12 injection because of

an MHRA, what should we say, loophole where they can call it a supplement, they're not allowed to use the word deficiency, they can say it's a health boost. So that's how they get around it.

Steven Bruce

Okay, those injections, they're intramuscular?

Tracey Witty

They are licensed for intramuscular in the UK, but most people who self inject use, well, I say, some people use subcutaneous needles and that's what I use.

Steven Bruce

And the dose is how much?

Tracey Witty

One mil.

Steven Bruce

Right. So it's one milligram. Every other day I think you said earlier on, is that right?

Tracey Witty

Yeah, that's the loading dose. And that's what generally people are started on. And then, like I said, that frequency should continue for as long as it takes for neurological symptoms to stop improving. And that could be some time, I know people who are still on that frequency. It's all dependent on how long you have been without B12, what your level of damage is and each person is the expert at how much they should have.

Steven Bruce

So you said you know some people who've been on that loading dose, but you didn't say for how long? I'm guessing it's quite a long time.

Tracey Witty

Yes, some people are in need of far more B12 than others.

Steven Bruce

Justin's asked whether there are any adverse effects from B12 supplementation.

Tracey Witty

There is no known toxicity of B12. It can be used in huge doses. So that five grams can be given to a newborn child to treat cyanide poisoning. But there is, in rare occasions, anaphylaxis to either the cobalt itself or the buffer solution. But that is very rare. But for the B12 itself there is no known toxicity and hasn't been for, I think its 50 or 60 years of use.

Steven Bruce

Okay. And I imagine there are some people out there using fairly high doses on.

Tracey Witty

Yeah, yeah.

Steven Bruce

We got more stuff on the diet. We always get lots of stuff on diet from osteopaths and chiropractors. Tish has asked about plant sources of B12. She seems to think that we're not getting anything in plant products. I think that's quite true. Are all vegetarians and vegans going to become deficient if they don't take supplements? And how do complete vegetarians and vegans ever get B12 if they don't take supplements?

Tracey Witty

There are no plant sources of it. So you need to supplement properly. If you're a vegetarian and you're eating dairy and you're eating eggs, then you're getting some B12. But it is something that you need to keep your eye on and supplementing properly with a good quality B12 will help enormously to keep symptoms at bay. But if you're becoming ill, if you are experiencing symptoms - a lot of people do veganuary and then they start to notice symptoms that they've never had before then, you know, you can put it down to B12 if it goes when you start eating animal products again.

Steven Bruce

There was one study years ago and it's apocryphal I remember it being mentioned to me when I went through osteopathy training, that there was a group of complete vegans who did not suffer from B12 deficiency. And as I recall, what they found was that there actually bugs in their food that they were eating without realising it. I don't know how big the bugs were or what the bugs were but, so there is hope for complete vegans after all.

Tracey Witty

Maybe so.

Steven Bruce

Victoria says she apologises for sounding stupid, but can't you just take B12 anyway to be on the safe side?

Tracey Witty

You could, but I think that the key thing here is that if you're vegan, but you've also got pernicious anemia, or you've got low stomach acid or you're taking another drug, then you might be B12 deficient not just because of dietary lack and that's the key. You know, if you're taking a supplement and you're thinking okay, I'm supplementing B12. But actually you've got a latent deficiency for another reason then it's really key to get a baseline test and just kind of keep your eye on your symptoms. I know that sounds that I'm trying to cover all bases there, but just avoiding it in your diet does not mean that you can't have it for another reason.

Steven Bruce

Right. Okay. I've just seen a question or observation coming from Jeff. He's put this much more eloquently than I did a moment ago. Thank you for that, Jeff. He says he's heard that microorganisms that live in

and on plants can produce B12, which we can live on. He's asked whether that's true or not, I'm saying It must be because I heard it years and years ago, I don't think you knew, did you, Tracy?

Tracey Witty

I don't know about those. And I think, you know, if you're vegan, and you're really healthy, and two, three years down the road, you're still really healthy then you're getting something from somewhere. And who knows where that is. There's so many, now I work with the vegan society to do the page on my site and have unfortunately worked with a lot of individual vegans who become B12 deficient. And the one thing we all want to do is live and function well. And if you feel well and you're looking well and your friends around you are saying you look well and you're doing great, then that's marvelous. But if there's any indication of ill health as a vegan, then B12 might be the culprit.

Steven Bruce

Okay. Myles has asked about lysosomal vitamin B12. Can it be transported into the bloodstream through that mechanism?

Tracey Witty

Yeah, liposomal B12, it's a bit like with the sublinguals, you're bypassing the stomach, you're using the mucosa. There are different forms of B12. So methyl cobalamin is an active B12. And touted by a lot of natural therapists to be the best form. But actually, it doesn't suit everybody. Hydroxocobalamin is the form we use on the NHS and you can get liposomal forms in hydroxo. And so that might be a really good one to try for people who are interested in it. And so I'm not discounting the fact that these do work for some people, but they don't work for everybody, but they will raise levels regardless of whether it works or not.

Steven Bruce

Okay, we're gonna have to get off the topic of diet and nutrition in a second and move on to something else, but Claire says she thinks it's weasels in the flower. I don't think it's weasels, Claire. Manuel says it's B12 in miso and adequate source.

Tracey Witty

Miso? I don't know. Is miso soya?

Steven Bruce

I have no idea, someone who knows about these things will tell me, no doubt Claire will come back because she knows well. What I promised people in my email that went out earlier on today or Ana's email that went out early on today was that we talk about some of the success stories that you've heard with B12 deficiency and you deal with an awful lot of people who come to you for advice and so on. Have you've got any of those that you want to share anonymously, obviously?

Tracey Witty

I can tell you about my mum, because she doesn't mind me telling about her. She was a nurse. So when I first started in this game, she kind of thought that's interesting, but didn't really think it applied to her. So even though I could see it a mile off, that it was affecting her, she wouldn't have a bar of it until she hit

rock bottom. And that's the point where she let me help her. And let me write to a doctor about it because mum had had her B12 level tested and she was within range around 323. And at that point, she was apathetic, depressed. She wasn't able to walk far, her breathing was affected. Her bladder was affected, various symptoms. So I wrote to her GP and said, look, I know she's within range, but look at these documents and I run this website and we have methylation issues in our family and please, could you try my mum, a trial of B12 injections. So her doctor wrote back to mum and said, your daughter's written to me, are you happy to try this? And mum said yes. And she literally, in the first two weeks of having her B12 injections and a good level of folate, flowered, absolutely flowered. And she then said to me, oh, my God, why the hell did it take me six years to listen to you? And she says now that she can't believe how well she feels, that she feels more well than she ever has. So, and I honestly in my 50s feel more well than I ever have because of our genetic problems, we've all in our family had been struggling with this from an early age.

Steven Bruce

Right. So this leads me on, I think, to talking about what we might look for, not just in our family members, but when someone comes to us in clinic, what are the sorts of clues, the indicators that might make us start to think that we should look down the B12 route.

Tracey Witty

One of the key things is that people might be, when they're coming to see you, they may have problems, they may have an ataxic gait, they may have physical radiculopathy or widespread pain. They may have a scalloped tongue or cracked corners of their mouth. They may be very pale, they may have real weakness in the muscles. They may have prematurely graying hair or hair loss. There's so many symptoms. And I suppose, because you're taking a good history, then you're going to hit upon things that a GP may not have time to spot, but the visual clues are how they walk, do they experience dizziness and the pallor and not everyone's pale, not everyone loses weight. But there are some distinct physical clues that you can see in somebody the minute they walk in the door.

Steven Bruce

I think there's one which struck me from the NHS list, I think, which is particularly bilateral paraesthesia in the legs. Now if we end up seeing somebody who's got bilateral nerve symptoms in their legs, we start to get warning bells ringing in our heads. And we'd be thinking then, well, if there's any loss of sensation, maybe we're starting to think is there a cauda equina problem, which I know is out of your field. But I mean, it's going to be hard sometimes to differentiate the musculoskeletal condition from this nutritional deficiency, isn't it?

Tracey Witty

Yeah. And I think, you know, if you've got one symptom of B12 deficiency, you've got a handful. So we, on the site, there's an app, we produced an are you at risk app. So even a quick flick down that for the patient might indicate that there are an awful lot more things going on there than are visible at the time. So the numbness and tingling can be a key symptom in patients, their fingers and the toes.

Steven Bruce

Right. Okay. Manuel has come back with some information about miso, thank you, Manuel. He says it's soya fermented with a mold - koji, with byproducts including methyl cobalamin and lots of umami. So there we are.

Tracey Witty

Alright, well, it tastes alright then. But if you've got methyl cobalamin in and that's been added in, then you can get some B12 from it.

Steven Bruce

Going back to the business of overdosing on B12. Lots of people have been asking about that. You answered that question earlier on, but they're also asking whether there are any contraindications to taking B12.

Tracey Witty

Some people when they start on B12 experience a kind of rash or acneiform rash. That has been said to have been the homocysteine, which is an amino acid, which rises to a toxic level, that that is a good indication that that's leaving the body. Now, I have no paper that backs that up. But it used to be on one of the big 12 websites. So what is key about that rash is that once you have a good level of B12, you don't get that rash anymore, I experienced it and my family members have experienced it too. And you can get that anywhere on your face, chest in your scalp. That goes when you've got a good level, good constant level of B12.

Steven Bruce

Okay. Tim says that you've mentioned low stomach acid on several occasions already. What are the typical symptoms of low acid?

Tracey Witty

Low acid and high acid have the same symptoms. And so unfortunately, when somebody goes to the doctors with heartburn and these kinds of things, then they're often given antacids, without actually checking whether that is low stomach acid or high stomach acid. And because the symptoms are identical then it's really tricky unless you look deeper into what this is. But if you're an elderly person, then generally speaking, your stomach acid lowers as we get older.

Steven Bruce

And the symptoms that they're going to experience would be?

Tracey Witty

With low stomach acid? I can have a look.

Steven Bruce

You got a cheat sheet?

Tracey Witty

I've got a cheat sheet. I've got an iPad here. They are very similar and it's very tricky for doctors to differentiate between the two but I know that they are the same as high stomach acid.

Steven Bruce

We're still getting loads of questions about diet coming in here and nutrition.

Tracey Witty

Low stomach acid symptoms: cramping, nausea, constipation, heartburn, acid reflux, halitosis, loss of appetite. Gastric reactivity.

Steven Bruce

Right? Okay. Martine has asked about Metformin and other medications that stopped B12 absorption? Will they always cause a deficiency in the long term?

Tracey Witty

I think prolonged use of these drugs do cause an inability to absorb B12. So, I think doctors are, fingers crossed, they're becoming more and more aware of acid suppressants and Metformin causing problems. So it should be on their radar to test people who've been on those drugs for a certain length of time. I mean, it should be from the beginning of course.

Steven Bruce

I had a question about nitric oxide as well, I can't remember who's asked this one. What's the actual mechanism whereby nitric oxide suppresses B12 absorption?

Tracey Witty

It doesn't suppress it, in activates B12 in the body, completely inactivates it.

Steven Bruce

Yep. Do you have the mechanism, how does it do that?

Tracey Witty

It takes it from, can't remember the name, it's stage one to stage two, something like that? I don't remember, do you want me to look on my iPad?

Steven Bruce

No, no. We can all do that. But I suppose the question that arises for me is well, people don't take nitric oxide unless they're doing it illegally in recreation, they don't take it very often or very frequently. So presumably, the effect of nitrous oxide is short lived?

Tracey Witty

Well, it can be unless, if you take nitrous oxide, say recreationally or even in during pregnancy, and you have not got an undiagnosed deficiency, then, if you've inactivated, all B12 in your body, then you can rebuild that when you start eating food with B12 and then you've got no other problem with it. If you've

taken B12 recreationally to the point where you are, you've had a problem with your heart and you are not getting any better, then it may be that there was a latent B12 deficiency there and you're not able to just build those reserves up again, you will need B12 injections.

Steven Bruce

Alright. Ron wants to get a bit personal here. He wants to know what your symptoms were when you went to get yourself tested, what made you do it.

Tracey Witty

I realised when researching for my loved one that I had many symptoms, I'd had multiple, early miscarriages. I had problems with my bladder and my bowel, my memory. My memory loss was the problem for me, the scariest symptom for me, I felt like I'd be one of those people who they might say, oh, she's got early onset Alzheimer's, I literally worried about it, I had difficulty recalling names, names of things. So the fridge wouldn't be a fridge anymore. It'd be the big white box that holds the cold things or using lots of words to describe simple things.

Steven Bruce

Right. Was that immediately obvious to you that it was B12 or were you just scared that there was something weird going on?

Tracey Witty

I know, I think because I had my baptism through this loved one, then I had read an awful lot of information. And it dawned on me one day that oh God, this is a family thing. So it did, kind of gradually crept up on me. And when I was tested, I was lucky that in my area, the reference range is 220 to 700 I think, so my level was 216. And I was just in under that low reference range. So it meant that my fight to get treatment in the first instance wasn't a problem at all. And I have to say that within the first two weeks of getting treatment, I found that so many, like the blurred vision I'd gone to the optician for who couldn't find anything wrong, that corrected within those first two weeks, my bowel and bladder corrected within those first two weeks. But of course, once they tried to put me then onto monthly I just was not coping.

Steven Bruce

Really. Interesting, you there gave a range of tolerance for B12. Wendy asked earlier on, what's the baseline figure for B12. And you said it was 220 a moment ago, has it changed?

Tracey Witty

That's in my area, but every single area has a different asset kit. So in Lancashire, their low reference range used to be 110. In North Wales, it's 150. In South Wales, it's 130. So it's ludicrous really that there may be certain areas of the country where people really struggle to get a diagnosis because they don't necessarily understand that these serum B12 test has its limitations, so they don't know that B12 is the culprit, but they're just sent off down a different route to find out what else it might be. And by this, I mean, the patients are sent off down the different route, but also the doctor is too.

Steven Bruce

I don't understand that because surely in NICE guidelines somewhere or in the clinical handbook, which is used by every doctor in the country, it must say what the bottom number in the range for B12 is?

Tracey Witty

Well, they're saying anything under 150 should be treated, but each primary care trust might have a different algorithm for how it should be treated. So Gloucestershire, I think, is pretty bad. I did blog about their ridiculous ways of diagnosing and treating.

Steven Bruce

Are they improved as a result?

Tracey Witty

No.

Steven Bruce

Right. I'm so sorry, I did interrupt you there. And I apologise, but I'm intrigued. What are their ways of diagnosing and treating that differ from anyone else's?

Tracey Witty

Well, they, I think they suggest that tablets should be given at a certain level and some say, oh, just retest in three months, or only people with pernicious anemia can have certain injections. I mean, I might be mixing the Gloucester thing up with some other areas, because every single trust seems to have a different set of rules about how they do or don't treat and even different GP practices. One GP in a practice might want to treat the patient but the head GP says no.

Steven Bruce

Yeah. I wonder why they would do that. Well, I would think it was Wendy earlier on asked how much B12 injections cost. Is this a vast drain on the NHS resources?

Tracey Witty

No, it's very little. When I first started the petition to try and make B12 available over the counter. I think there was 69 pence and then that cost went down to 55 pence. And I think the last time I checked, they weren't doing per ampule cost, they were doing per box, which is five ampules. I think it was one pound 85 per ampule at that point. So the cost is very little and of course to buy from Germany, it's about 60 pence an ampule, so you can buy 100 ampules for less than 60 euros or around 60 euros.

Steven Bruce

Right. When I looked up the B12 deficiency on the NHS websites and so on I was expecting to find some NICE guidelines which stipulate what people should do. But there aren't any NICE guidelines that I could find there, there is just a page about B12 deficiency, but it's not a formal NICE guideline, which directs doctors how to behave, or am I wrong?

Tracey Witty

It's the Ccare summary. But lots of, sometimes when people are battling with their doctor, their doctor will say, well, they're just guidelines. I don't have to follow them. So it is all really tricky. There are so many different barriers to treatment and diagnosis of B12 deficiency.

Steven Bruce

Okay, an observation here from Anna. Anna says her daughter had GI symptoms for a while, I didn't know what the symptoms were. And Anna was worried that she'd have vitamin deficiencies. So took a list to the GP for testing. Interestingly, her B12, was incredibly high and had to be monitored for a few months. Her levels lowered again as the GI symptoms improved. Apparently certain bacterial overgrowth can produce it.

Tracey Witty

Yeah, I think there is documentation about SIBO can look like you've got a high level and then they do look for an underlying pathology of B12 without any supplementation at all, if that's very high. But of course, I think, is it parasites, certain parasites synthesise B12 as well, so it can look higher than it is.

Steven Bruce

And that is of course, we mustn't confuse that with the business of can you overdose on B12. Without supplementation if you've got a high level of B12, there must be something else going on that's causing is the message there I think, isn't it?

Tracey Witty

Yeah, I mean, unfortunately, some of our doctors kind of mix that bit up with, so they'll test somebody for B12 having given them an injection the day before or on the same day, test the B12 and then say, oh, my goodness, you've got too much we need to stop, it's dangerous. And lots of doctors do believe that it's dangerous, if you are over 2000 when you're already on treatment, but of course, it's not at all, you'll always be quite high if you test the day after you've had an injection. And for some time after.

Steven Bruce

David says, do you have any comments on topping up with hydroxocobalamin such as liposomal form if the B12 injection frequency is inadequate.

Tracey Witty

No, if the liposomal form is working for somebody, then I would, you know, take it, if it's helping the person. You know, in an ideal world, we'd be able to buy our own B12 and be in control of our own treatment and have it as in when we need it because we are the expert. Unfortunately NICE, Ccare's guidance assumes we're all the same, that we've all been diagnosed at the same level of deficiency and that we all have the same lifestyles and that we all are the same size. You know, it's ludicrous to think that anybody's treatment is identical.

Steven Bruce

Case's asked whether IBS and celiac increase your likelihood of B12 deficiency.

Tracey Witty

Well, IBS can be a symptom of B12 deficiency. And celiac, of course, causes malabsorption of lots of nutrients. So many people with celiac are B12 deficient.

Steven Bruce

I think Crohn's specifically is a cause of B12 deficiency or can be, isn't it?

Tracey Witty

Crohn's, ulcerative colitis, all sorts of things that affect the bowel. And if you've had your terminal ileum operated on, if you have atrophic gastritis, anything that stops you absorbing nutrients can lead to B12 deficiency.

Steven Bruce

Okay, Ian's asked what the app is, I think he's referring to your website. So your website is...?

Tracey Witty

It's B12 deficiency.info. And there's an app page on there. We have a monitor app as well for patients who can monitor the severity of their symptoms, the website will be updated over the next few weeks. So it'll look a little different and be less text heavy.

Steven Bruce

Well, yeah, I'm glad to hear that you know that you're still pushing the information out through the website, because last time I remember you said that if people are having problems getting through to the GP, I think you offer some support in that regard, don't you?

Tracey Witty

Yeah, I do. I do offer personalised help to, you know, people come for all sorts of reasons, whether it's that they want me to contact their GP for them or whether they want help with just understanding the condition because oftentimes, they've been given very little, or very confusing information from their GP or from another support group. So often what I'm doing is unraveling incorrect information and helping the person on the right track to recovery.

Steven Bruce

On that same note, I mean, I'm not sure if I didn't ask this question properly last time. But Ruth has asked if you could run through again what you said to the GP in order to get your mother treated.

Tracey Witty

I, what I always do, and what I think most people should do is always put down the clinical picture. So in our family there, you know, my grandmother had B12 injections, my mom's mom, and then I listed her symptoms. And I listed and I noted down her B12 level, which was within range but then I also added the documents 1.4 on the What to Do Next page to state that this should not be ignored in a symptomatic patient. And then I simply asked, could they have a trial of B12 injections to confirm the deficiency and she was very lucky, really that her doctor was open to this. And providing links to the website actually helped the doctor to do some research beforehand.

Steven Bruce

Yeah, maybe that's a key element there isn't it, is letting the doctor know beforehand what it is you're concerned about and providing that resource. Because that means that they didn't have to go away and look it up or rely on the basis of half an hour's training during their medical degree. Again, this is all, it's important stuff for us, it's not just communicating with a patient but it's also communicating with fellow healthcare professionals in the wider arena. But I think there's also, there's a certain amount here of listening to our own patients, isn't there and seeing beyond the musculoskeletal thing that they may have come in with or maybe listening to the person who comes in with them and picking up clues as things which might indicate a B12 problem.

Tracey Witty

Yeah, and I think one of the very common first presenting symptoms can be depression or chronic fatigue. And I think that the worst thing about the NICE guidance is that there are certain do not do recommendations and one of those is do not test for B12 deficiency unless anemia is present or something. I did blog about this a few years, I think was 2013. But those do not do recommendations stop people from being tested even and it's just bizarre.

Steven Bruce

Yeah. Victoria's asked, she asked ages ago actually, what you would recommend in terms of high street supplements, is there a spectrum of quality for B12 supplementation?

Tracey Witty

There is like anything, really, I use all active active B-vitamins. So I use a company called Health Leads in Wales, and they don't have any magnesium stearate or any weird fillers and stuff in their supplements. So a good quality supplement's always going to be better than something that you buy for a quid from Wilko's.

Steven Bruce

Right. Okay. And Solgar and people like that, that sort of the the mainstream providers of supplements, are they any good?

Tracey Witty

Yeah, I mean it's always a case of suck it and see, they don't suit everybody and just in case of trying them seeing what suits you, every supplement has a different milligramage and, or microgramage. And so it's about finding something that suits you. Now for me, I don't tolerate any folic acid. So I take active B-vitamins and methyl folate. But methyl folate can be tricky for people if they can't cope with that methyl donor in there. So folinic acid might be better for them. But folic acid, for some people is really tricky. And they can't convert it. But it's not necessarily widely understood by our GPs.

Steven Bruce

But what you said makes it actually quite difficult for anyone, doesn't it? Because if we have a patient who we think possibly has B12 deficiency or they think they have, not only are they going to try and get the dose right, but they've also got to go and try and get the brand right. And in amongst all that they've

got to decide how long am I going to give this before I go and see the GP and complain that something's not well?

Tracey Witty

Well, under those circumstances, if you as a practitioner had somebody come to you and you think they're B12 deficient, then I would suggest, the best thing for them is really to, if they could take a look at the website and follow the pathway to getting tested. First of all, if they possibly can with their GP and I fully appreciate that they may not want to do that or it may not be possible for them, certainly given the situation we're at the moment. So then testing for B12 in a private way just so they know, now the point is that if that person doesn't want to work through their GP in any way and wants to sort themselves out, then it doesn't matter or not, you know, where you get a test from, you can get a private test and you can selftreat privately by buying from abroad if you want or having your first B12 injection at least from somebody medically trained with an EpiPen just in case there's a problem with anaphylaxis.

Steven Bruce

Is that a possibility?

Tracey Witty

Anaphylaxis? Yes, it is very rare. But yes, it is a possibility. It never happened to me. And certainly, when I had my first injection, I don't think the nurse was aware that that could be a possibility. You're not told to sit and wait there. Let me just see if you're okay, you're given the injection and off you are, off you go. So it is rare, but it can happen. So, you know, if you are going to embark on treatment on your own, then it would be advised that you get your first injection at least, at the very least from somebody who's medically trained who has an EpiPen, just in case. But if we can make B12 injections available over the counter, then who's to say that osteopaths and chiropractors can't help people in this regard with that at least their first injection, as it comes to buying supplements, it's like buying food, you do your research, you look at reviews, you find the best thing that suits you, it might be that the one that you've always had is great for you. For me, it took me a bit of trial and error, trying certain things to see what suited me. And I think people become much more able to discern what's working for them once they've got a good level of B12 and the cognitive function is returning. You know when you're taking things, how they make you feel. If high dose folic acid is making you feel nauseous, then ditch it and try something else.

Steven Bruce

Okay, do you find that many people, is that a silly question, are people genuinely prepared to inject themselves? I know so many people who are scared stiff of needles, let alone injecting themselves.

Tracey Witty

No, I think it's a terrifying thing for lots of people. And it's not just terrifying because you're injecting yourself. It's because you feel like you're doing something wrong when you're not doing it with the understanding of your doctor. People feel like they are doing something bad, that they are almost doing drugs. Of course they're not, it's a vitamin. There's no other way of getting it for most people then via injection, so it's a really nerve-racking thing. One good thing that happened during COVID is that some really good doctors produced little films for their patients and provided them with the ampule so that they could safely inject at home. And that, you know, for so many patients with a real freeing and a real feeling

of having control back in their lives and being trusted by their GP to look after themselves. So the thing with B12 is certainly with hydroxocobalamin. It stings like hell, it's not a pleasant thing to do. And I've only ever in all the years I've been having B12, given myself one injection. And that's because my husband who normally gives it to me was away. And it made me sweat. And I really didn't, you know, I don't want to do it again. I'm frightened of injections, it stings. So in order to make me feel comfortable, he tells me he's going to take a run up, and he's given me an injection, just to make me calm.

Steven Bruce

Right, okay, not sure how calm I'd feel about that. Do you know what it is in the injection which causes that anaphylactic reaction in some people? It's surely not B12.

Tracey Witty

Well, it could be, cobalt is the iron and if you're allergic to cobalt, and some people are, then that can be the bit that causes you the anaphylaxis. Now, I think it's in Thomas's where they do help people with an allergy to cobalt, even though when you need B12 it comes from cobalt, so they have a desensitisation program to help people to have the injections. I don't know how that works, or how many people use it, but there is a program for that.

Steven Bruce

Right? Okay. We got an observation sent in by Lucy a little while ago, she's talking about a patient of her own, she says was refused her an NHS B12 because she was unwilling to allow her levels to drop enough to qualify for it by their standards. She got a private injection and is now self-administering. She's lived with this for a long time and knows how she feels when her levels are quite low. It's a good result for the patient. But it's a sad result for the NHS when that happens, isn't it?

Tracey Witty

It is and you know, just, it's bizarre, can you imagine saying to a diabetic, can we wait until you're nearly dead before we give you some more insulin, it wouldn't happen. And yet, time and time again, this critical nutrient that sustains life can be restricted, and even withdrawn totally from people who need it. It is absolutely outrageous. I completely understand why that person has decided to self inject, they have more control over themselves.

Steven Bruce

The pediatrician we saw in the video at the beginning of the show here, do you know how long it took him to get to that sort of vegetative state that we saw him in this chat?

Tracey Witty

No, I don't and it doesn't discuss it in the film. Alyssa Leonard who made the film met with Dave Parr and I think there was a photograph taken at the time. And like I say who's so lucky that a friend of his recognised what it could be, but they said severe neurological, neurodegenerative disease, which is what it looks like when it's far gone.

Steven Bruce

And you mentioned Alzheimer's earlier on, are there any other diseases which it might mimic that we might or GPs might mistake for...

Tracey Witty

MS can be a misdiagnosis, bipolar, psychosis, Parkinson's, there's a lot of them. Bipolar, fibromyalgia, chronic fatigue syndrome. There are so many and even when you say those names, like we say Parkinson's, you know there's a tremor with that. Lots of people with B12 deficiency have this benign essential tremor, which goes very quickly with B12 injections. Bipolar, a lot of mental health symptoms and diagnosis. And they've got to that stage, but they've never had a physical cause ruled out. And so anybody who's presenting with depression or psychosis or suicidal ideations should be tested for B12 deficiency.

Steven Bruce

Right. You said, I thought I could see a tail wagging in the corner there, was it an ear flapping? You said that it could mimic the symptoms of MS, does it go as far as producing the sort of plaques that you would get in MS?

Tracey Witty

Yeah, if you had an MRI scan and you have lesions, I think I am right in saying that in B12 deficiency, they are symmetrical and in MS, they're scattered.

Steven Bruce

Okay. So there is a possible clue there in the diagnose, would that perhaps go unnoticed in a conventional assessment, they'd see the plaques, they'd see the lesions and say, we know what this is?

Tracey Witty

Yeah, certainly. I mean, I think that's the point. If you are not fully versed in understanding that that could be a misdiagnose of B12 deficiency, then you are naturally going to decide that it's MS. And the same with Alzheimer's or dementia, you know, cognitive decline in B12 deficiency is common. But if you're not coupling that up with other symptoms that the patient has, and you're, you know, you're looking for Alzheimer's, then that's what you might get diagnosed with.

Steven Bruce

There won't necessarily always be other symptoms will there, I mean, presumably it could present with one or a few of the things that you've mentioned.

Tracey Witty

Yeah, absolutely. Everybody, I mean, even in my family for each of us, family members, and Damian, my husband as well is B12 deficient, we all have different symptoms. And sometimes you could have three or four. And not necessarily no, some people who might have really low B12 levels, but don't have any symptoms. And then therefore, if you haven't got any symptoms, then don't require treatment until you are symptomatic if you like, but every single body system is affected from head to toe. Its manifestation in each person is completely different.

Steven Bruce

And what are the visual symptoms that people might suffer from?

Tracey Witty

Premature graying.

Steven Bruce

So I meant ocular, if you like, I mean eyes.

Tracey Witty

The damage to the optic nerve, when you consider that B12 deficiency affects your nerves, so Leber's optic atrophy is something that can be treated with B12, but not cyanocobalamin, because that can worsen that condition. But so yeah, the nerves of the eye can be affected. And that may be, like I said, when I had blurred vision and I'd gone to the opticians having had 20/20 vision, he said there is nothing wrong with your eyes. And yet, I'm saying well, why is this page moving? Why don't these words stay still? So oftentimes, when people have certain symptoms, they'll go to see the optician or whoever it is, and they'll say there's nothing wrong, I can see nothing.

Steven Bruce

Okay, Kathy's asked whether you see many cases or you hear of many cases of B12 deficiency in children. We mentioned them briefly at the beginning.

Tracey Witty

Yeah. Cases in children are really tricky. I've been at appointments where GPs have said to the child, who's clearly B12 deficient, would you like injections? Now what nine-year-old is ever going to say yes, I'd love injections. Yeah. Do they hurt? Yes, please sign me up. You know, a lot of doctors don't want to test for B12 deficiency, because they don't want to draw blood from a child because it'll hurt the child. And then they don't want to give injections because it will hurt the child. But of course, children get B12 deficiency.

Steven Bruce

Yeah, and what sort of things does a child complain about? Or is it something that parents notice rather than the child mentions?

Tracey Witty

Well, the red flags to look out for is, there are all sorts of things, again, depression, fatigue, could be autistic-like withdrawal, could be OCD tics could be, the manifestations are similar to the adult ones, but then there's things like developmental delay, a small head growth, smaller person, floppiness in a baby. And it is really heartbreaking with children because, you know, they haven't got the time to hang around for a specialist appointment. And often GPs are afraid of treating children, they want the backup of a pediatrician, or a neurologist or somebody else to say, it's okay to treat this child, because they feel concerned about it being a child and it being injections. But of course, it is a primary care issue.

Steven Bruce

Yeah. So again, parents have got to be alert for this and maybe just a little bit more forceful if they think it could be a problem.

Tracey Witty

Yeah, I think it's really tricky, because, as I understand it, if you have a child who is presenting with autistic-like traits, or ADHD, then the school will often point this out and then the school will have a mechanism for taking people down this pathway. And if we could teach the teachers or the people who point this out that B12 deficiency might be a differential diagnosis and it leads to check that out first, it may help the parent enormously, because if you can treat B12 deficiency in a child quickly and easily then there is less chance of permanent damage. But of course, that child's nervous system is still developing so there is a chance of permanent damage in a child.

Steven Bruce

You mentioned tics a moment ago and Rachel sent in a question a little while back saying could B12 deficiency be misdiagnosed as Tourette's.

Tracey Witty

Tourette's possibly, I mean, I've not read a lot of papers on Tourette's, but certainly, you know, tics, OCD, all these kinds of things. If you've got just Tourette's and there are no other symptoms on there then, you know, maybe not, but have a look at the other symptoms. Usually when people have one, they have got a few others and some that they don't, you know, you wouldn't be surprising. And the weird thing is that the list I have on the site, you would have seen Sally Pacholok and Jeff, Dr. Jeff Stewart in that film, they're the people who wrote Could it Be B12 and I use their research on the website. Now their symptom list is huge, but it's not exhaustive. And there's symptoms that don't appear on that list that people find just miraculously go. So they are the most common symptoms, reported symptoms, but there are symptoms that aren't on there that you know that people experience that just are remedied with B12.

Steven Bruce

I feel this is the point where I really need a long case history from somebody telling me about their experiences because you look as though need to drink some water.

Tracey Witty

Moth there down my throat or something.

Steven Bruce

We've got about 10 minutes left so if you can bear with us just for a little while, it would be great. Victoria says she's just found out that Superdrug do a B12 injection service and they will accept a private test. Were you aware of that?

Tracey Witty

Well, I had seen that Superdrug do it and I did try and ring them, actually, I think that Superdrug, if I'm right, and I could be wrong, is, they will give injections to people who are diagnosed who have a below range test. I mean, hopefully they will accept people who haven't got a below range test too. But I've not

actually spoken to them. But great, if you can get B12 from anywhere in this day and age, because, you know, it's becoming harder and harder to get your doctor to give it to some people then go to Superdrug.

Steven Bruce

Good idea. Adrian sent a question, Adrian, nice to hear from you. It's nice to hear from everybody. But I actually trained as an osteopath with Adrian. So and I haven't seen him come up on my question list before. Adrian says can it cause sleep disturbances and insomnia?

Tracey Witty

Oh, yes, it can. I forgot to say that was another one of my...

Steven Bruce

I remember Adrian from training, I'll bet he already knew that he was a brightspark, then. Is that prominent? So one of the first symptoms you might experience?

Tracey Witty

For some people. I mean, for me, it was, but also, and I'm sure Adrian realises this too, is that menopause can really screw up your sleep too. So if you happen to be just finding that you've got a deficiency alongside perimenopause or menopause, then your sleep will invariably go to pot.

Steven Bruce

Okay. Vladimir has said that he has been placed on a methyl B supplement by his nutritional therapist. It's a good quality supplement. And he finds it's making him very sleepy. Not a bad thing he says. But sometimes he's sleeping around nine or 10 hours per night. Is that relatively common do you think?

Tracey Witty

I suppose I would say to Vladimir, really, methyl cobalamin does suit some people. Now a nutritional therapist will often sell a supplement rather than say, perhaps try and find injections. And I say that in the kindest possible way that may not be that they really understand that injections are the best way of getting B12 into the person. So I would suggest that trying B12 injections might be a really good option there and see if it has the same effect.

Steven Bruce

Okay. He says methyl B is that the same thing as methyl cobalamin? Is that what is called?

Tracey Witty

Methyl B12. Yeah.

Steven Bruce

I see, of course, right. Vanessa says is there any research based on B12 treatment and bipolar depression being resolved?

Tracey Witty

There's masses of research into mental health and B12 deficiency catatonia and B 12 deficiency. And like I say my own family member had a diagnosis of bipolar, but it was B12 deficiency. So yeah, and I think, you know, as I said earlier, if you have a mental health diagnosis, you're often pigeonholed, and a physical cause may not be ruled out.

Steven Bruce

That's fascinating. So often on these shows I am reminded, you know, we've done shows on different aspects of health before, and we've had people on the show talking about mental health. And we've talked about vitamin supplementation, deficiency in other contexts and so on. And I just think sometimes we ought to get you all in the room together and put all these thoughts in so we can come up with a single show with a comprehensive diagnosis. Maybe we'll think about that once we can get people back in the studio. I wouldn't want to do it via zoom or teams, I'm afraid.

Tracey Witty

There is some brilliant researcher, I think it's Abram Hoffer, who wrote about vitamin B3 and schizophrenia. So a lot of the B vitamins are connected to poor mental health in low ranges.

Steven Bruce

James has asked what kind of bowel and bladder symptoms are associated with B12 deficiency.

Tracey Witty

You could have access diarrhea; you could have constipation. You could have a constant need to go to the loo.

Steven Bruce

That's just to urinate, to pee? Yeah.

Tracey Witty

Yeah. So it affects the nerves and it affects the nerves in all sorts of ways. So it may well be constipation or diarrhea.

Steven Bruce

Right. Now, you mentioned Sally Pacholok a moment ago, and you mentioned the book Could it Be B12, to which the answer is obviously, yes. Tell us a bit more about Sally because she's actually produced a feature film on B12, which is very watchable. Not least because it's the nurse taking on the medical world, isn't it?

Tracey Witty

Yeah, Sally's story is fascinating. Alyssa Leonard was the person who made the film, Sally Patcholok, which is based on Sally's life story, although inaccurate in the sense that it's done in a Hollywood way, in that the handsome male doctor finds Sally's deficiency, when in actual fact, Sally discovered her own deficiency. And she first worked as a paramedic and then went on to be a nurse. And Sally discovered her own deficiency, I think she was in her early 20s. And just couldn't believe that nobody knew about it.

So she went on to write a book and would always talk to her colleagues and the doctors about, have you checked B12? Have you checked B12? And they actually raised an injunction against Sally and tried to stop her getting her book published. And you can see this played out in the film. So it's a really good starter. There's a couple of unfortunate things in the film in the sense that the vegan person, there is a vegan person in there who, I think she commits suicide. But there's a bit in it, where if they'd have given the vegan person the oral supplements, rather than the, sorry, I'm spoiling it for people if they want to watch it, but there are some anomalies in the film, which are unfortunate, which could have been done better. And there's also a bit in the film where Sally is shown putting her dad in a home so that they can educate these elderly people in the home about B12. But Sally did look after her father till he died in her home. I would have been affronted by that if the film had been made about me.

Steven Bruce

I think we have to give Hollywood its license so don't we, because so seldom the real stories find their way onto celluloid accurately. We've got a little bit of time left and I have been asked whether restless legs are also a symptom of B12 deficiency and I'm gonna guess the answer is going to be yes.

Tracey Witty

Well, it can be, but I would look more towards magnesium deficiency for that.

Steven Bruce

That's the first time I've heard you say that it might not be B12 to a question. It's always B12.

Tracey Witty

It could be.

Steven Bruce

Indeed. Jen says, does it affect more age groups than others? She has an older gentleman who came to the clinic only today with multiple joints and muscular pain and who was seriously depressed.

Tracey Witty

Yeah. And as we get older, the fact of the low stomach acid and different levels of drugs and we're aging anyway, then yes, they say that more people over 60 suffer from B12 deficiency and of course, it does affect men too.

Steven Bruce

Yeah. Okay. I love this question. Kendall says, how effective is Marmite? I don't think he's talking about subcutaneous.

Tracey Witty

I don't know how effective Marmite is, but I won't give up my injection for a jar of Marmite.

Steven Bruce

Yeah, I suppose what you said earlier on, didn't you that, you know, if it's a dietary lack that's the problem, then diet might be the cause. But so often it isn't.

Tracey Witty

Yes, that's the problem.

Steven Bruce

Sophie would like, if you can do it in a couple of minutes for you to explain the Metformin cause more fully.

Tracey Witty

Well, when you're given Metformin as a diabetic, it affects something in the stomach. So they're then unable to absorb B12 from food. So, but also with type one Diabetes, which is autoimmune, oftentimes, they you know, you collect autoimmune condition. So you might have pernicious anemia as a coexisting deficiency. And the problem is that with diabetic patients, because diabetic neuropathy is looked for, it's often put down to diabetic neuropathy rather than being B12 deficiency neuropathy caused by either a coexisting pernicious anemia, or Metformin, which is stopping the absorption from food.

Steven Bruce

That's really useful stuff to know, very useful. I don't have time for this one, I got time for this one. Richard says, can you recommend a home testing kits? But I guess you really ought to go back to those labs that we mentioned earlier on, shouldn't he?

Tracey Witty

Yeah, I mean, I really don't have a lot of, I've never done that myself. But I heard Blue Horizons mentioned, MediChecks, Genova Diagnostics. You guys will probably know better than me which testing companies are better.

Steven Bruce

We recommended MediChecks in the past, they had a good reputation. And I'm sure there'll be lots of others who can come up with other labs. What about transdermal patches, any good?

Tracey Witty

Weird way to get B12 into the system. It's not known for transdermal. Some people do say, oh, I have them in between my injections and I feel better. Now, I don't know that there's an awful lot of research on these patches and for a lot of people, it's just money down the drain.

Steven Bruce

Maybe it's nicotine. We come to the end of our schedule time, Tracey, thank you very much. I just wanted to finish up by mentioning again, Sally Patcholok, is the lady who wrote or co-authored the book, Could it Be B12. I'll send out the links to those. And also to the movie because the movie, it is very watchable. And it's a very nice way of sort of reabsorbing a lot of the information that Tracey has given us this evening. Tracey, your website?

Tracey Witty

B12 Deficiency.info, yeah. And there's a film page on the site, so you can access those videos on the film page, too.

Steven Bruce

Yep. And of course, if you need help with B12 deficiency with patients or you want to refer your patients some help then I'm sure, Tracey, with nothing more than a PhD to keep her busy will be more than delighted to answer all those emails and inquiries. So I introduced you, Tracey, I said you were just a woman because that was what you'd said, a district nurse had called you and I'll leave it to you to judge because clearly there are very few people, certainly in this country who could tell you more about B12 than Tracey Witty. I don't think she needs a PhD in order to convince others but maybe she needs the PhD to get a foot through the door of some of the GPs' clinics. Tracey, it's been great talking to you. Thank you for coming on the show again. And I'm sure, when you've got your PhD I'd be delighted to get you back and hear how the research went.

Tracey Witty

Great. Okay.