

## Vitamin B12 With Tracey Witty

### Cast List

Steven Bruce  
Tracey Witty

SB  
TW

SB: Now, it's a bit unusual this evening. I've got a guest who is not quite in our normal mold. As you know, normally we have physios and we have osteopaths and we have chiropractors and we have medical consultants and the grace and the good and the alumni of the medical world. Well, tonight's guest is none of those things but she was recommended to me by one of our members, Archana Shah, which I'm very grateful. Thank you, Archana. And the reason for that is that if she's not the UK's leading authority on B12, she's certainly up there with them, and she's almost certainly the leading campaigner for equal rights for B12 if I can put it like that. And she's Tracey Witty.

Tracey, fantastic to have you with us this evening.

TW: Thank you.

SB: I forgot to say, of course, actually you are a cabinet maker, so quite diverse from and divorced from what we do in the physical therapy world. What is it about you and B12? Why are you into this?

TW: Well, my journey started back in 2012 and I was really researching for a family member who'd been diagnosed with bipolar, and I just felt that that diagnosis didn't really fit, so I used Dr. Google and dialed it down to being a

problem with either a thyroid condition or B12 deficiency. And it was, quite clear eventually, that it was B12 deficiency that was the problem.

In researching for this person I found that I actually had an awful lot of the symptoms, too, and so my journey began really in researching and trying to help out with the people in the same situation.

SB: Right. Why did you have to do the research yourself?

TW: There's not an awful lot that our doctors are taught about the B12 deficiency. I think on average they receive about half-an-hour's training on just pernicious anemia. Vitamin B12 is very different to a lot of the vitamins. It's quite complex and it has to be supplemented in injection form if people have a problem with their stomach, so it's not as simple as just taking a tablet.

SB: Yeah. And we said earlier on, we shouldn't in any way malign doctors for not knowing about this, because the fact that they only get 30 minutes in something which isn't specifically about B12 in their training just reflects the huge amount of stuff that they've got to study, isn't it?

TW: Exactly. And I think they've been done a great disservice by not being given the fundamentals about nutrition, really.

SB: Yeah. I suspect that many of my audience this evening, or our audience this evening, will be thinking, well to some extent, conventional medicine is driven down this drug-based model where there will be a drug that is the answer to the problem and they think along those lines, whereas vitamins are not proper drugs in many people's minds. But that's another story.

So, what was it that led you to the doctor and to Dr. Google? What were your signs and symptoms?

TW: My own signs and symptoms were, I was losing my memory at a fast rate. My bladder and bowel weren't behaving correctly. I had blurred vision whereas previously I had a really good vision. My hair had started to go gray quite early. I had numbness and tingling in my feet, and so, and also I had failed to conceive. I had problems with fertility. My symptoms were very different to other people that I knew, and I realized that there's just so much about this that hadn't-

SB: Sorry. Your symptoms were different from other people you knew. You knew-

TW: Well, the person I was searching for originally was, mentally affected.

SB: But at this stage you didn't know it was B12. You were just looking for what might cause these symptoms, weren't you?

TW: Well, it was a collection of symptoms for the other person that were mainly, well, premature graying and a lot of mental symptoms. Anxiety, depression and psychosis, and then following on, when I, more and more of my research and reading more about the symptoms, I actually realized that I had so many of them, which included infertility and the problems with bladder and bowel.

And it was that that then prompted me to go and get tested and I found that I, I was lucky in the sense that I came in below range on the serum B12 test.

SB: What's the correct range?

TW: The correct range, really, is moveable, in the sense that there is no... In the UK, anyway, we have no standard reference range. The reference range can be from 110 in Lancashire to 220 in Charnmouth where I come from. So, I was lucky that my result came in at 216, so I was treated without a real problem, but other people, who can be within range but highly symptomatic, and not get treated because unfortunately there's huge reliance on the blood result.

SB: There's been in fact, and I might as well start this, there's been a question already from a lady called Kim, who says, if I can read this. "I'm confused that the blood test for B12 measures total B12 in the blood, the active and inactive kind that the body can't use. I understand you can have normal blood test for B12 yet be deficient. So how do you know?" Many question marks.

"My vegan daughter," she says, "is often ill, yet when I told her to get the blood test she told me she had normal levels," and Kim actually says this is quite a worry.

TW: Yes. The serum B12 blood test is known to be inaccurate. It does test both active and inactive, and as much as 80% of that result could be inactive B12, analogs which the body can't use and doesn't recognize. There is an active B12 test but that's really not gold standard either. The best way is really, and there are documents on the website which state that the clinical pictures are of utmost importance. Reliance on just the serum B12 blood test would be not helpful for a patient who is symptomatic.

There are other tests that you could have alongside that, like the MMA, methylmalonic acid, and homocysteine. And homocysteine is an amino acid that rises to toxic levels, with low B12. So those tests used in conjunction with serum B12 and looking at the whole clinical picture would be a better way of-

SB: Are they 100% reliable?

TW: Homocysteine all together, really you're getting a better picture. Homocysteine reference range is around about 15 but an optimal level is about six. Said to be about six. So putting all those three together you'd get a

better picture. You can actually find clues in a full blood count on a mean corpuscular volume on a mean cell hemoglobin. But you've got to know that you are looking for that.

SB: Right. And what happens when someone goes to the GEP and is sent up for a full blood count, test? I mean, what do the GEP's look for? Do you know?

TW: If the GEP has B12 deficiency on the radar then they will send for a B12, a serum B12 test. But unfortunately if that comes back within range often it's just batch filed so the doctor may even, not even get sight of it. So when a patient rings up, like this lady, then they will be told that the test is normal. And what I'd advise in that case is go to a page on my website called What to do next and there's a-

SB: We'll put this up afterwards on our webpage, what is your website?

TW: The website is [B12deficiency.info](http://B12deficiency.info).

SB: [B12deficiency.info](http://B12deficiency.info)?

TW: Yeah there's a page on there called What to do next which really walks you through everything you should do and point four on there has a series of documents which state that the serum B12 test is inaccurate and a lot of doctors may not have seen these document. Some of them are NHS, Rich Medical Journal and NECAS. So there are key documents for-

SB: So in general than if a test comes back within what said to be normal range and I'll come back to that in a minute as well, I imagine that the GEP will instinctively start looking for other diagnosis.

TW: Yeah maybe so and that's the unfortunate thing, it can be misdiagnosed as so many different illnesses. Chronic fatigue, Fibromyalgia, Bipolar.

SB: So lets start with Fibromyalgia then. Which of the symptoms are likely to be mimicked by B12 deficiency.

TW: There's something called radiculopathy, which is all-over-pain. So then there's chronic fatigue, brain fog tiredness, so many of these symptoms can be down to B12 deficiency too. And of course not everything is B12 deficiency, it does share symptoms with Celiac Disease, Pyroluria which is Zinc and B6 deficiency. Thyroid problems. So not everything is B12 but it's worth ruling that one out because it's so simple to treat.

SB: Right. So what in terms if being simple to treat what route would you go to?

TW: If a patient is B12 deficient and they eat, they eat meat, fish and dairy, then there is a problem with the stomach. And the treatment for that is B12 injections. And that on the nice guidelines, if you're neurologically affected,

the treatment for that should be every other day injections for as long as it takes, for those symptoms to start improving. And only then go to a maintenance dosage of every two months.

SB: And is that the regime which, the regime which is followed in practice in-

TW: No, unfortunately not. What most patients are given is two weeks of loading doses so two weeks of every other day injections. So Monday, Wednesday, Friday for two weeks and then automatically they're put into a three monthly regime. For which there is no clinical evidence whatsoever.

SB: Right by which you mean there's no clinical evidence for that regime, for the injection-

TW: Yeah.

SB: The injections are proven to work-

TW: That's it. Yeah

SB: in cases where people can absorb B12.

TW: Yeah the injection regime of four a year is actually came about by a cost saving order that was carried out in the eighties.

SB: I can't imagine there are many gasps of surprise in the audience out there about that one.

TW: No and it was based upon district nurses going out B12 injections so 15 minutes per patient.

SB: Actually the cost is the staff not the injections.

TW: Yeah the injection is pence really. It's gone up now but it when I at the time I did the petition to try to get RB12 made available over-the-counter it was 55 pence per ampule so it's very cheap.

SB: People can self-inject presumably?

TW: Um, not many are allowed. My GP does allow me and lots of GP's do actually. But so many are not trusted to give themselves their own injection. Even though-

SB: Is it a proper needle injection? It's not one of these aerosol squirts injections?

TW: No, no it's a needle. It's a needle. But it does take up a lot of time obviously in surgeries if people are on every-other-day injections and generally speaking when it's tricky for the patient to get in and for the nurses to find

appointments then usually they can find a way of teaching the patient to self-inject so that they can do it at home.

SB: Where are the injections administered?

TW: If you go to the doctor it will either be in your arm or your bottom or your tummy.

SB: Right, so can I ask where do you inject yourself?

TW: Well I don't inject myself because I'm scared of it but my husband Damien gives me my injection in my arm.

SB: Okay we've got plenty of diabetics who will inject themselves-

TW: Yeah.

SB: Every single day. I mean in the stomach won't they?

TW: That's it.

SB: So it can't be that difficult to do.

TW: No, and I think if you're taught properly and the B12 itself is non-toxic so.

SB: Yeah. Well that's an important point isn't it? There's a range for B12. It has an upper limit on it but actually there is no dangerous limit for B12 from what you've said.

TW: No there is no known toxicity in over 50 years there's just never been a case of toxicity. There is, and it's why I'd caution people not to go out and just have injections if they've never had one. There is in rare cases a chance of anaphylaxis and that might be the reaction to the cobalt in the B12 itself, or the buffers in the solution.

So if you are, you know, like many people, really struggle to get diagnosed or treated. And often they will go to a private clinic or a private GP to get their first injection and then can buy from abroad and then inject safely at home.

SB: I don't know if you know of this chap but I'm a great fan of a UKGP called Malcolm Kendrick.

TW: Yes.

SB: He writes a lot about cardiovascular issues but he also writes about other health issues. And in his recent book which is called A Statin Nation, because he has a pet hatred of statins which he says are utterly useless in all but the smallest of cases. But he talks about vitamins and he says "It's a contraction

of vital aiming", which means they are essential for life. So, it's not as though you can live without them. But he says, if you look at the statistics for drugs prescribed by the NHS you will find a huge number of deaths and injuries and secondary problems as a result of those drugs. There are none for vitamins. No matter what you do with vitamins, you will not get any ill effects from them, so. Except for things you said might also be in the injection that might be causing that. So the idea that people shouldn't be allowed to take more B12 is like the question of, what's the rationale behind the GP saying you mustn't inject yourself or you can't trust people with needles?

TW: It is the law really that we can't-

SB: But diabetics do it.

TW: Diabetics aren't able to buy it over-the-counter. We can inject if we've got the permission of our GP. We simply can't buy over-the-counter. As you can't buy insulin over-the-counter.

SB: Yeah 'cause I think actually you can inject yourself, there is no law against that. The law would be rather buying-

TW: Yes. That's it. That's it. It's buying over-the-counter that's the problem. And I think that's the biggest problem we have in the UK. Because whilst our doctors have not been trained fully on B12 deficiency, they are inadvertently under-treating patients. So, while we've got that gap and that lack of knowledge, if patients were able to buy it safely from our pharmacies, then that would help so many patients who struggle currently.

SB: Why on earth, would the Medicines Control Agency control a vitamin?

TW: It's. It is literally because it's an injectable. It's because it's injected that we're not allowed to. And yet, most other countries in Europe and certainly, Australia, Canada, New Zealand, they can buy over-the-counter.

SB: Yeah. Okay. You'll like this question. Because although the person who asks it is has chosen to remain anonymous, she's owned up to being a vegan. And says as a vegan she takes B12 supplements. Takes them daily. Are these a waste of time? In other words, does she need injections of B12?

TW: Well if she's a vegan and she's able to absorb B12 through her stomach then the supplements will be hopefully helping her. The key there is to say, do you feel well under supplements? I, my feeling is that if you're a vegan and you're seriously low in B12 then you should be offered the chance from your GP to have the swiftest recovery which would be for injection.

SB: So the question for her is, is she actually suffering any health problems?

- TW: Vegans absolutely need to supplement there is no getting away from it. They are not eating any animal products. This is the only place you can get B12 from, is supplements, or injections. But it's also really important to remember that vegans may also have pernicious anemia or methylation problems or other problems related to the stomach. So might not just be that they are avoiding it in food.
- SB: Right. Okay. I seem to remember when Archana recommended you to us as a speaker. She did give me a bit of an email lecture on good and bad vitamin B12 supplements. Aren't there two types of supplement you can buy? One which is useful one which is not?
- TW: Well everybody's different.
- SB: I'm really sorry Archana, I should remember what you told me but I try very hard, but uh-
- TW: No everyone's different I do really well on Hydroxocobalamin which is the form that is used on the NHS. I have tried Methylcobalamin which lots of people say they do really well on, it does nothing for me. Cyanocobalamin is what was used here back in the 70s and is what's used in America and Canada in injectable form and some people say that they do better on that. That's mainly what was in tablet form given to you by the NHS. But it's very inferior in tablet form and they're usually entirely dosages of 50 micro grams.
- SB: This is making life really, really difficult for the GP isn't it?
- TW: Yeah yeah.
- SB: Because first of all, the signs and symptoms could relate to any number of other different conditions. And then the test for this isn't reliable without you sort of, correlating the clinical symptoms and other different tests. Serum tests in the blood. And now they've got to make a decision on, well you didn't work well on this particular version of the supplement, so should we try another one? Should we try an injection?
- TW: Well in a sense for a GP it's much easier because they have two options. If the person's vegan and they know that they can absorb from food, then a supplement, they can go out and buy a supplement. If they, if they have a patient in front of them that's chronically ill, whose is deteriorating, who has plenty of symptoms of B12 and they are slightly within range or whatever, then the best test for that patient would be to try injections and see what the result is. But there, generally speaking if anybody's in the GP surgery, chronically ill with B12 deficiency in a low reference range, injections should be the way to go.
- SB: Right. And if they work then it'll simply be a question of finding which of the other supplements does work for them after-



- TW: Well actually, well really I mean, I have B12 injections from my GP and that is all I need. I don't take supplements on top of that.
- SB: How did you get to do this then? If the common, if the normal treatment is once every quarter?
- TW: Because for me, my memory was failing and I was really struggling on even monthly. And most people do, you know there are so many people who really don't cope well on three monthly. And maybe you can cope well on that if you've, if you've not been deficient for long and you know, for any other reason. But all of us are so different. It's like saying that everybody needs the same amount of pain killer. Or everybody needs the same kind of chemotherapy. We're all different. We all need to be listened to as individuals and treated as per our particular symptoms. And I'm very lucky that, and it has taken me quite a fight to get to where I was with weekly injections, but it's done without a problem at all now.
- SB: Most people wouldn't do that would they? First of all they're suffering psychologically, mentally because of the B12 deficiency, they don't have your background in it. Because you've looked into it before you recognized the symptoms in yourself-
- TW: Yes-
- SB: Because of what you said before. So actually there simply going to do as they're told which might in some cases end up with them...being dealt with rather harshly by the NHS.
- TW: Yeah. I think the problem is that, the biggest problem I find when people contact me, is there is a real reluctance to challenge a doctor. Most patients don't want to upset their doctor at all. They don't want to question what they've been told. But actually when that patient is really suffering to function, they're not able to work, they're having their children taken away from them, then it really starts to get serious and that's when, you know, I will either help them, or somebody else needs to help them to actually educate their GP about what really should be happening.
- SB: One thing we haven't answered and not surprising that someone's asked this, is just how common is this in the general population? It's actually quite astonishingly high isn't it?
- TW: There are lots of different figures and of course we can't really know exactly but, there are five to twenty percent of the population. But there are so many reasons why you could become B12 deficient. For example, you're on a drug, metformin for diabetes, that interferes with your absorption of B12, as do acid suppressants. There are people with methylation issues which is said to affect 40% of the population. If you've had gastric surgery, if you've got Crohn's Disease, there are so many risk factors and so many causes of it.

SB: Which, of course people are not instinctively and their GP's are not going to associate with B12 deficiency I would have thought.

TW: No, and that is the problem really.

SB: So, before I've got a whole load of questions here already, which is jolly good, but before I get onto those, you mentioned to me earlier on your petition with 76,000 signatures-

TW: Yeah-

SB: How long as that been going?

TW: It's been going since probably about 2014 or 15, a long time-

SB: Okay, so it needs more signatures and what's the purpose of the petition?

TW: Well really the petition is to raise awareness of our problem. And the petition is really asking if we can have B12 ampules made available over-the-counter? And that's to fill in the gap really for patients who can't or don't feel they can challenge their doctor and are stuck on a three monthly regime, who don't want to buy from abroad. That petition has helped me to work with my MP to speak to different MP's about this and it still continues to be worked upon.

SB: Okay I've lost the question I was going to ask you. Yeah, this is one of our regular questioners. He's always, almost always first in with his questions. This is the second time in a row, second broadcast in a row where he hasn't made the first question. But it's Matthew Davis, Matthew, nice to hear from you of course. He asks, "Can treatment be obtained under private medical insurance? If self-treatment is administered, what's the arrangement for monitoring blood levels?"

TW: Well the point is really that if your GP or private GP will, treat you for this then that's fantastic. Sometimes there's a real difficulty with getting children treated, even by private doctors, with injections because, you know, there are lots of problems with doctors worrying about injecting children. I don't know whether your medical insurance would cover that. That would be something for-

SB: Are you aware of any medical insurance which does?

TW: I don't deal really with any kind of medical insurance but I'm sure that there will be, your particular doctor will treat it if you are deficient. But-

SB: I'm sure if it's recommended by a GP –

TW: Yeah, yeah. So you asked another part of that question. We just-

- SB: Um where's it gone. If you are self-treating, what's the arrangement for monitoring levels?
- TW: Oh on well monitoring levels. There's really little need to monitor levels if you are feeling well. The upper reference range of a continually tested person is really irrelevant once you're in treatment so there's no need to continually test the serum B12 level.
- SB: How the hell can it be that the reference levels for B12 can vary across the country? It makes absolutely no sense that those Yorkshire people are more stoic and don't need as much as we southern Nancys.
- TW: Well it really comes down to the fact that the assay kits are all calibrated in different way and no one person has the monopoly on which assay kit. So they really, each lab has a different reference range so in South Wales it was 130, North Wales is 150 and it's really unfortunate that in those particular areas there are so many more people probably walking around or dragging themselves around because the reference range-
- SB: Well that's weird isn't it. When you go and have your um....what's it the statins do with cholesterol. When you go and have your cholesterol measured, the reference range is the same across the whole country.
- TW: I know I know. It's really ridiculous.
- SB: And actually you're saying that the refere- the lower end of the reference range in many NHS areas is too high?
- TW: It's too low.
- SB: It's too low, sorry it's too low. So people who are actually deficient, are being missed.
- TW: Yeah Sally Pacholok in her book says that there is a gray-zone so between 45- anything below 450 should be treated. Actually there are people who, for example, say you've been supplementing before you've been tested with B12, you've been supplementing with not particularly great B12 supplement, then you tested. You will still be within range, and you may be much higher but actually your nerves aren't healing and there's plenty of research, on my homepage there is a document from the Netherlands that talks about the fact that a lot of supplements you might take, if you're just testing the blood and looking at the blood you're going to look fine. But actually the deterioration is continuing on behind. There's a journal I have on the homepage too of a young woman who had a sub-acute combined degeneration of the spinal cord but her levels looked perfectly fine after having supplements, oral supplements.

- SB: Well actually I might go to another question than the one I was going to ask because, somebody, Kim, might be the same Kim, Kim says that she uses B12 BetterYou oral spray, is it absorbable do you think? That's not the one I-
- TW: There's not an awful lot of research on the oral sprays or the sub-linguals really but-
- SB: Good because that was the question I meant to go for which was Dawns question is it best, is a sub-lingual B12 best if digestion-
- TW: They say it does avoid the stomach and gets in via mucosa and if they work for you fine, I find absolutely no benefit for them myself, but I do know that some people use them in between injections and can get by. If it suits you, that particular form of B12, and that spray or whatever does, then that's great. But they don't suit everybody and that's the key thing.
- SB: Now, going back to the questions in the order that I was going to ask them. Jess has sent in a question and I knew this one was going to come in from somebody. I thought it would be Archana sending it in but, Jess says "Hello guys, already very interesting thank you. You had a speaker, Nitu Bajekal a week, a while ago who was saying the big problem with B12 deficiency is coming from lack of nutrients in the soil and this is affecting non-vegans as well. What's your view Tracy on this? And what's the best source of B12 in diet assuming no gut or GIT problems?"
- TW: Well the best form is meat, fish, eggs, dairy, shellfish. Um, she's right in the sense that cobalamin or cobalt comes from the soil and there's certain areas of the UK which doesn't have a lot of cobalt. So animals farmed and fed on that land have to be given bonuses to make sure that they have enough B12. Soil depletion is a problem for everybody but actually that is a huge problem and so even if you're not a vegan, then yes there are going to be more and more problems I would imagine.
- SB: Okay. Perhaps I was misjudging that question 'cause the one I thought that Archana was going to send in was that, Nitu when we had her on, and Nitu is an Obs gyne consultant, but is heavily involved in diet, she was saying well if you have problems just take a Holland & Barrett B12 pills. I think some of the audience felt that that was a bit too simplistic for what could be a complex problem.
- TW: It, it really is. You know, for some people that will work. For some people. But its so, you know the pathway for B12 is really complex and if you've got a problem in any part of that pathway they're not going to help you.
- SB: Do you want to run us through the pathway?
- TW: Oh no.

SB: Hahaha

TW: Its called the enterohepatic pathway.

SB: I'm probably quite glad you said that. To be honest.

TW: Haha

SB: If you're a vegan or a veggie I'm asked do you test for stomach problems or just try tablets first?

TW: Well if you're a vegan and a vegetarian and you've got symptoms of B12 deficiency I would always suggest that you go into your doctor and talk to them about it and get tested. If you've got problems with your stomach, which are highly related to B12 deficiency then its worth investigating. And the thing is with B12, of course isn't the root of everything, but its really worth ruling it out.

SB: On your website you have got, you've got such a mass of information. But you've got a page which I think extends I think five times below the fold on the one site, which is a list of the conditions and problems that might arise from B12. And somewhere down near the bottom I'm sure I saw, an effect on, an effect on osteopaths. Which, presumably means that actually we are quite likely to see an influence on osteopetrosis with B12 deficiency.

Is that something that we ought to be asking patients who've been told they are osteopenic or osteopetrotic to have a look into?

TW: Well personally I would and I think that, as you say, our GP's have to learn so much stuff they may not actually realize this connection. But yes, if you have, you know have been given alendronic acid or something, for....this problem then its really worth getting your B12 checked because if you're going to then put B12 in and that helps the problem, then maybe the other drugs, you know, are not needed.

SB: How easy is it to get the test. I mean, could you just, could any one of the practitioners watching this to get in touch with a private lab and say I've got a patient and I need a B12 test?

TW: Yes, if your clients want to have lab testing, and I know that is used a lot with osteopaths and chiropractors, then using somewhere that Medichecks to get these tests for your patients would be really easy. And then using that patient, if they want to be treated, by their GP. Which would be the best way, really. Then those tests can be sent on to the GP, and used as part of their investigations.

SB: But of course, it means you've got to find somebody to carry out the tests which most of us can't do in our clinics. Because that involves, obviously,

injections, and most of us are not in a position to do that. Because we're not CQCE-

TW: To take blood, yeah.

SB: -covered and all the rest of it. So that still means finding either a private GP, or a private medical facility to do those tests for you. But, I can't imagine it's difficult to find those, is it?

TW: No, there are quite a lot of private companies who will give, who do test for this. I think if the patient went off on their own to do private testing, very often they are dismissed by the GP. If they were perhaps done by a chiropractor or an osteopath, through you, then that would be viewed differently. But often GP's want the blood at their own particular labs. Everybody's different. Every case is different. Every GP's different.

SB: Yeah, and they do sometimes need handling with kid gloves, because they are...

I'm not going to call them "precious", but they are very sensitive of their position in the medical hierarchy. That they are supposed to be the gatekeepers for all this sort of stuff, aren't they?

TW: I think generally speaking, they want the best for their patients. And the problem with B12 is that because there's such a lack of information that they've been given. And with our too, their information comes from another nurse, or the practice protocol, or a GP. And then the particular nurse, is then giving the injection will start to panic the patient by saying, "You can't have too much." Worrying about all sorts of things that actually don't matter. It is really tricky.

SB: I've had a couple of questions. An anonymous question, is about what is the correct injected dose? What's the correct dose for tablets, if you're just taking tablet supplementation?

TW: Well, an ampule is 1 ml. So that would be given, and I would say follow NICE guidance on that. If you're neurologically affected, every other day until the symptoms stop improving. And then it should be what the patient needs. Until you start failing again, you don't want what happens to many people is: they go for three months, but for a few weeks out of that they're not able to function. And you're keeping dropping all the time. What is optimum for you? I've found that my optimum is weekly.

SB: Matthew's asked. He's said his usual online vitamin supplier is listing loads of B12 tablets, up to 500 mg. Are they of no use at all? Is this again-

TW: 500 mg? Well, it may be. But again, if your particular set of genes worked with that particular form of B12, then that might suite you. Everybody's so

different. The different forms; people say that methylcobalamin is better. It's quite tricky to make hydroxocobalamin into a tablet, but some people have. And cyanocobalamin seems to be the inferior form. Although, having said that, some people rate it, and a lot of Americans and Canadians use this and are absolutely fine on it.

SB: An observation has been sent in by somebody. They do keep saying "anonymous". It would be lovely if you actually let us know who you are, provided there's nothing sensitive in what you say. But this person says they have a patient with radicular pain down her leg, similar to disk or sciatic pain. But actually it turned out to be a B12 deficiency. So, again, you talked about neurological involvement... What other neurological involvement might we see, do you think?

TW: Tinnitus, numbness and tingling. Oh gosh, I have to bring the screen up. What've we got?

SB: We'd love to, but we don't have it on a screen.

TW: Numbness and tingling...goodness me.

SB: In fairness, you could go through a long, long list, as long as your arm and leg, of all the things you might see with these. But they are all on your website, aren't they?

TW: Yes. They are.

SB: And the website is, again?

TW: [B12deficiency.info](http://B12deficiency.info).

SB: [B12deficiency.info](http://B12deficiency.info). And of course, we'll put a link to that up on the screen when we post the recording, along with all the other links that will support the discussion.

TW: The symptoms are separated out into neurological, psychiatric, cardiovascular as well.

SB: Matthew's asked: "Are you aware of a B12 blood self test service? I.e., from "thumb prick and post", or similar?"

TW: Yes, I have heard about them. Yes.

SB: And?

TW: Do I know who they are?

SB: Do you know who they are? Do you know-

TW: I don't know whether Blue Horizons do one. Viapath do an active B12 test.

SB: Who do?

TW: Viapath.

SB: Viapath?

TW: But that isn't... That does miss some deficient people, too. It's really tricky. I know that people who've had the serum B12 test who are screaming "deficient", and then I've had an active B12 test which has found them to be okay. But the symptoms really speak for themselves. So everybody is so different.

SB: Yeah, okay. Again, somebody here says, "If 450 is, what you say is, the lower end of the threshold for good health"-

TW: That's what Sally...yeah.

SB: "...does that mean that the 110 to 200 range is woefully lacking?"

TW: Yes, I think it is. And I think the point is: whether you're 600 or whether you're 250, the symptoms of each patient might be really extreme. So, reliance on the blood test itself is foolish. You've got to look at the symptoms.

SB: Again, an anonymous observation, or question: "My husband," says this lady, "has pernicious anemia. He has peripheral neuropathy, cognitive loss, and is unable to get out of bed. He's on monthly injections, but he doesn't seem to be improving. What else can be done? Or could it be something else?"

TW: Well the key thing there-

SB: I'm guessing that- Go on.

TW: Sorry. Because he has pernicious anemia, he's lacking intrinsic factors. So he can't take B12 through to a small insert, in testing for it to be unbound. Often what...

First of all, he probably isn't on enough injections because he's clearly neurologically affected, so he needs them far more frequently. But perhaps this patient also needs folate. Folate is the big sister to B12, and if there isn't enough folate, then you're not going to get the best from your injection.

SB: Right. Bloody hell, it gets more and more complicated. I was hoping it was going to be simple. So this chap who is on, what did we say, monthly injections should probably be on weekly or-



TW: If somebody is that poorly, they've still got neuropathy and cognitive impairment, then that person is neurologically affected. That person should be on every other day until their symptoms stop improving.

SB: Every other day?

TW: Every other day. This patient may have had a series of that frequency-

SB: So how does this lady sort of push to get this to happen then?

TW: Well, if she goes to the website and has a look at point 6 on the "What to Do Next" page, then that really will find her the documents, the nice guidance on there. But she really needs to read the rest of the page to look at what else that patient needs. I must say as well, if people are having frequent B12 injections it's really important to make sure your potassium levels are kept up, too.

SB: Right. So now we've got folate. We've got potassium.

TW: And iron is key, too. You need to have enough iron. But all the information is on that page.

SB: Yeah. Okay. What's the connection between anemia and B12 deficiency? Because you can have B12 deficiency without being anemic, can't you?

TW: You can, yeah. Pernicious anemia is the name for the autoimmune part of B12 deficiency. And because it says "pernicious anemia" some of our doctors mistake that with meaning you have to be anemic, there has to be a co-existing anemia, for you to be truly B12 deficient. But of course, the neurological changes can also precede the hematological changes. So it's really key, that even if the patient isn't anemic, they still need to be treated. There are a lot of documents and journals on the site about that particular question, too.

SB: Okay, so where are we going here? We normally make it known to our speakers that it gets very busy at the end of our 90 minutes, because that's when people start sending their questions in. I don't think I've ever seen this number of questions right at, at this stage of broadcast before. Medichecks can send a nurse to your home to collect a blood sample to test for B12. Alternatively, Medichecks have locations around the country where you can go to send patients too, and to collect blood samples for B12. Now, I didn't know that. I don't know anything about Medichecks at all. Do you?

TW: No. I mean, I don't really get involved in any supplements or any private testing. But I have heard of people use Medichecks and Blue Horizons, and they're just a couple of the names that I know. But that is a really good option for people who want to test. But what I would always say is that in the first instance, unless you're seeing a chiropractor or an osteopath, if you're

doing this on your own, don't just go out and get private testing. Go to your GP first and ask for tests. If you can bear to ask them for it. And then suggest to them that this what you want to do, and take their advice on whether they'll be accepted or not. Unless you're going to go down the whole route of having private treatment, too.

My aim with the site really was to try and help people to remain under the care of their GP wherever possible, so they are looked after.

SB: Yeah, okay. Somebody's sent in an observation here that you can do an at-home urine MMA test; for patients who are needle-phobic and prefer a urine test. On the American B12 website, they say a urine MMA test is more accurate. And the website is [www.b12.com](http://www.b12.com).

TW: That's right, yeah. This is Norman, and he uses SpectraCell test: gas spectrometer. And the urinary MMA is really useful, especially if you have children and you don't want to take blood from them. But again, always look out for what the reference range is.

SB: Right, but at least if you've got the results you can then compare with what you've told us should be the reference range, quite apart from anything else.

TW: Yes, exactly.

SB: Do PPI's affect vitamin B12? Proton pump inhibitors?

TW: Yes, they do. They can stop absorption of B12.

SB: Which drugs don't affect...

TW: I don't know really. There are quite a lot of drugs. And again, they're on the "Who's at Risk?", and the "Causes" page.

SB: So you mentioned antacids earlier on with-

TW: Acid suppressants. So anything ending in "-zole". So omeprazole, that kind of thing. PPI's. Metformin for diabetes; glucophage as it's called in America. There are drugs for gout. There are all sorts of things that can interfere with it. And of course, nitrous oxide in childbirth can inactivate B12.

SB: What is this "recreational use" of this on your website? You've given it a couple of other names I've never heard of.

TW: Yeah, over in America they call it-

SB: Obviously "laughing gas" is-

TW: Whippits.

SB: Whippits?

TW: Whippits. That's the American term for the little gas canister.

SB: Is that right?

TW: And you see those down on the ground. And that can totally inactive your B12, causing serious problems for anybody using that recreationally.

SB: Gosh. Who'd have thought?

TW: Or, as a midwife, or as a mother in labor.

SB: I've got a long question or statement here from Amy. Who says, "Thank you for raising the awareness of this problem." She had B12 deficiency while studying for her A-levels, but unfortunately it took over 2 years for it to be diagnosed. Which totally ruined her A-level course results. Oh, it's any old excuse for some people, Amy. She's recently applied to a new course, but been rejected due to her A-level grades being too low. Unless she can get a doctor's note "explaining my medical problems". Which they're unwilling to do, as it's only...ah, for heaven's sake...it's only a vitamin. "Thank you for all your work and helping educate to save others from struggling with this complex problem." Amy, I was clearly taking the mickey. I mean, that's disgraceful, isn't it?

TW: Yeah, and it really, really does. Like in Amy's case, it interrupts their lives. I've worked trying to help mothers get their children back out of care because they've been taken away from them. It can really destroy relationships when you consider how much this can affect people's mental health. It can destroy relationships with family members, with friends. It makes people very isolated, and it interferes with schooling. And the biggest problem, in Amy's case as well, is that many of our doctors think that this only affects women over 60. They really don't understand, and they're not taught that it affects fetuses, and babies, and small children, and on, and on. There could be any number of reasons that you'll become B12 deficient.

SB: If it's not a genetic condition, is there a typical age range at which it comes on? Where would be the most likely...

TW: They say around your 60's. For me, I was in my early 40's. And so many of the other people I know are in their early 40's.

SB: Predominantly women?

TW: Lots of women, but there are lots of men, too. I would say that it is probably more women, but there are so many men with this condition, too.

SB: Which leads us on to a question that has just come in. Somebody says they have an 86-year-old client that feels dizzy on walking, and all tests said E and T are negative. Hospital says it's age. Could it be B12?

TW: Yes, dizziness is one of the symptoms. Abnormal gait is one of the symptoms. Nominal aphasia, which is inability to recall names and words. It would be really handy to take that 86-year-old patient through the symptom list and just see whether there is a problem there. And then asking for a B12 test.

SB: So for whoever asked that question, if you go to Tracey's site you will find a list of all the things that could be associated with B12. And of course, it doesn't necessarily mean that there is a B12 deficiency, but you might try and correlate those with the other things that are happening with this 86-year-old patient, who I am told is male. And is a meat-eater, so dietary considerations are not a big problem.

TW: That's it, but also the one thing to remember is that as we get older we have less stomach acid. So less ability to unbind B12 from food. So there are lots of problems. We have an app on the website, which is 99 pence, which is our "Are you at Risk?" app. Which might be useful for some of your members to use since you could just click through, ask the questions. And then it will say whether you are high, moderate, or low risk of B12 deficiency, which might help in certain circumstances.

SB: So that's, I presume, a single app really, isn't it?

TW: When you say single use?

SB: Well I mean I'm only going to want to test, go through your list of questions.

TW: You can use it-

SB: If I were going to use it-

TW: Yeah, it is, it's cleared and then you can start again on it so if you wanted to use it for clients, it would be useful.

SB: Well there you go. That's a really useful idea, isn't it? So you could use this and just walk people through. You get them to it in the waiting room on an iPad or something, if perhaps you wanted to. On your website it's 99 pence. And she should be charging people per use, should you? Not per app.

TW: We have another app which is a monitor. A monitor app for people to use and grade their symptoms and see how they're improving, or declining unfortunately. But it's really something we wanted to do to try and help people to access information, and it directs people to the site, too.

- SB: If a person is low in B12, are they also likely to be low in other B vitamins? And does the GP test just for B12, or should they test for all of them?
- TW: It would be lovely if our GP's did carry out vitamin panels, but, no. Generally speaking, they will just test for B12. I do say on the site to ask for ferritin and folate to be tested, too. Of course, because B12 is part of a family of vitamins, then, yes. Generally speaking, we might be low in others. There's a condition called pyroluria which is zinc and B6 deficiency, which has very similar symptoms. What I do say on the site is that it's usually helpful for people to take a B-Complex alongside their B12 injection. But also take extra folate, which is vitamin B9.
- SB: Fiona Cockings-Mason wants to know if someone who's Celiac is more prone to vitamin B12 deficiency.
- TW: Yeah, anybody who's got an absorption problem, a condition like Celiac or Crohn's, is going to be more susceptible. Unbinding essential nutrients from food. So yes, if you're a Celiac really, hopefully she, or whoever she's talking about, has been tested. But if they haven't, I would certainly urge that they did. Look at the site. See if they're symptomatic, and then get tested.
- SB: Digressing from the questions for a moment, you've got some experience yourself...I'm being cautious how I phrase this...of some quite catastrophic failure on the part of the NHS where B12 is concerned, haven't you? Where a patient has had quite severe ramifications because they weren't diagnosed?
- TW: Yes.
- SB: Can you run us through that?
- TW: Basically this lovely lady contacted me. She had been tested for B12 deficiency. She was in a wheelchair, and what we often say is, "Go back through your results. You're legally entitled to all your blood results. Get copies of these." And what she found was that she had been tested for B12 deficiency. She was well below range. She was 150 in a reference range of 188, and the GP had simply noted on the test results, "Advise green, leafy veg."
- SB: So that could be what we've got on one of these slides here, which isn't going to come up, because it's being plain silly buggers. It doesn't matter, because that's actually the point of it. If I can get it to come up it will be very handy, but...
- So there we go. So that's the second one. If we went to the first one, there. All we've got here is the patient's notes, which has been slightly doctored so they all fit on the screen as large as possible. I'm sure Justin can bring that up so that it's full screen. But the first thing that I noticed is that there. The

range is 188-1069, isn't it? That's the acceptable range for B12 according to this particular thing. And the patient's at 115, so they're well down.

TW: Yeah, and no treatment at all was given.

SB: Apart from eating green veg-

TW: Advise green veg.

SB: Which is really quite handy; green veg is very good for you, but doesn't do anything for your B12.

TW: More folate than B12, unfortunately. And that is so tragic to think that this poor lady's now in a wheelchair and permanently harmed because not enough information was known by the doctor.

SB: Yeah.

TW: And I have repeatedly heard in mental institutions where patients are tossed. They're advising just to eat some broccoli, and that does cause you to hold your head in your hands because it's so ridiculous. It's such a fundamental understanding that it only comes from animal products.

SB: Yeah, and I suppose, again to reiterate what you and I said earlier on, we're not here to try and criticize the conventional medical world. If there's a failing, it's a failing to admit their lack of knowledge. They have got such vast knowledge, GP's, and they have to call it onto the fore at a moment's notice. But actually making a suggestion like this just reflects that they don't realize that they don't know.

TW: I think that's it, and I think that the heartache for a doctor who then learns that they've inadvertently harmed a patient because they have simply missed something so fundamental. It isn't their fault that they're not trained fully on this. The training really needs to be overhauled as far as lots of our vitamins and minerals go, but particularly B12 because it can be so devastating.

SB: Yeah. I flashed it up a second ago. Whoops, wrong way. What happened with, this is a second patient...

TW: Well this patient was psychotic, had very heavy periods, was very prematurely gray, was exhausted, hardly getting out of bed, and was so poorly. And even though, you see again, it was below range, it was suggest that they just took some vitamin D because on that Test 2 there was low vitamin D. The doctor really didn't understand the symptoms of B12 deficiency and carried out her neurological test. And because the person was not experiencing any numbness or tingling, or abnormal gait, the doctor really thought that this patient was absolutely fine. So even though they

were below range and should have been treated, it was totally dismissed because the doctor's knowledge was outside.

SB: Yeah, but if they'd have gone to the other doctor they'd have been within range because the last one-

TW: Exactly.

SB: -said the range was 180, and this patient, she's got 194 mg/L.

TW: Yeah, that's right.

SB: So she'd have been within range in one doctor's surgery, so they wouldn't have even thought about B12 deficiency. Even though this one-

TW: Back filed, and just put away.

SB: What happened to this patient?

TW: This patient was sectioned, and it took an awful long time to get correct treatment for that.

SB: That is utterly catastrophic-

TW: Yeah, it is devastating.

SB: -for something so easily fixed.

TW: Exactly. And it was really tricky to try and get the doctors and psychiatrists involved to actually understand that this was related to B12 deficiency.

SB: We'd say again, it just makes me reflect on the statistics you brought up earlier on, because you said 10-20% of the population, I think. Or somewhere in-

TW: Yeah, they're all sorts...

SB: Something like that. That's only the people we know who've been diagnosed. This person would have gone undiagnosed but for you personally getting involved. Now that's...

TW: The tragedy I feel, particularly with mental health, is that often they are never screened for physical ailments. You can be sectioned, and so many people with psychosis and depression, and anxiety. You'll see on the website, we have a particular mental health page. So many people are missed because they've been pigeon holed as a mental health patient. Even when I've spoken to people who work within mental health, who understand about B12, on their blood forms there's no tick box for B12. So, they're having to hand write

it on. If it wasn't having to be hand-written on, it may trigger the thought in the particular doctor to get that tested.

SB: Yes, okay. I've got one here which refers to an earlier question about the lady's husband. He suffered with Hashimoto's disease, onset twenty years ago. Is that relevant to the pernicious anemia?

TW: Yeah, many people with thyroid conditions are also B12 deficient. They often have very low stomach acid, so it's really, really pertinent that they go and get tested, too.

SB: Could it be any thyroid condition, or is it going to be thyroid hyperactivity?

TW: Hyper, hypo, Graves' disease, any of those.

SB: So any of them?

TW: Yeah.

SB: Okay. Somebody asked if you could talk about bladder symptoms a little, as he or she has a 25-year-old patient with uncontrollable bladder. And her sister has the same problem. Tests for both show nothing wrong with the bladder mechanics. Neither have had kids, but were still given info for pelvic floor problems.

TW: Well that was my problem, and it all corrected with B12. So, yes, definitely. Go and get B12 checked because it's the nerves. What happens in B12 deficiency is that you're nerves lose their fatty coating. And so any nerve, whether it's the central or peripheral nervous system can be affected. It affects every single body system, both sexes, all ages. So it's really worth getting that checked.

SB: And I know you said the B12 isn't the ultimate cause of everything-

TW: No.

SB: -but it certainly sounds as though it can be involved in pretty much everything, so it's a good one to rule out.

TW: But it is a crucial vitamin for us, and if your nerves, any nerve in anybody, can be affected. Me and my siblings, my aunts, we've all got completely different sets of symptoms. And it is fascinating when you see families affected in different ways. But yes, it can affect everything. But I'm not saying it is the cause for everything. Yeah, there's definitely other causes for things, too.

SB: May well have answered this question before I even ask it. Whoever it is says, "I have a patient who has a good protein-based diet, in her early 50's, with



tingling paresthesia, but predominantly on one side. She also has problems with balance and physical strength. Could this be a B12 problem?"

TW: Yes.

SB: All right.

TW: Yes. Definitely.

SB: Pretty much for every time someone asks, "Could this be a B12 problem?", we're going to have to say "yes", aren't we? Martin has asked a question. What does Martin want to say? Martin's asked: his local GP's would think it was insignificant to suggest a blood test for a B12 deficiency causing neurological signs. A patient would have to undergo a course of physio, and that would probably be that. Well we come back to what we said earlier. How do you convince the average GP to take this seriously? Particularly when there is still a subsection of GP's who regard all chiropractors and osteopaths as quacks?

TW: Well what I do for patient, I do give personalized help to people. And what I do, and before I start to do that, I would write letters for people. Basically, any patient coming in, finding the website, needs to do their homework. So you basically work your way through the symptoms and the signs, and note down any you have, the causes, and the risk factors. See if any of those strike a chord with you, and then you really do have to paint the picture for the GP. And I would always say if you can possibly get an email address, then send an email along with links, so that they can click onto the links, and just read for themselves about the problem.

SB: Website is again?

TW: [B12deficiency.info](http://B12deficiency.info).

SB: [B12deficiency.info](http://B12deficiency.info) because it is such an important resource.

TW: And I think one of the key things really, and what I do say to lots of patients, I have no problem challenging any doctor about anything really. And that's to do with my own experience of things. Now what I would say to this particular person is that ask the doctor if they were suffering those symptoms, would they think it was insignificant? The key thing here, you're neurologically affected. That's your brain being affected. It's not enough just to say that you've got a busy lifestyle, or a busy job, or you're a busy mum, or whatever. There's something going on for that patient, and they've taken the time to go to the doctor and just said, "Please, will you test me?"

SB: Any idea how much the test costs?

TW: I don't think it's too expensive. I have no idea really. For some reason I have my head around 2 pounds, but I have absolutely no basis for that.

SB: So it's not huge-

TW: It's not huge.

SB: The NHS doesn't have much of a-

TW: No, and I think the point is-

SB: -deep pocket these days.

TW: -regardless of what the tests cost, regardless of what the treatment is, which is minimal, what is the cost to society and the NHS as a whole for all these patients who are not treated for B12 deficiency? Who become heartsick patients? Who are then on numerous drugs that they don't need? Who always in the doctors'?

SB: Well they get sectioned for God's sake.

TW: Who are being sectioned and hospitalized for things that could all be avoided? It really does...

If in doubt, rule it out.

SB: I'm astonished. I had no idea about all this, but while we're talking I'm just thinking. Actually some of the things that you have mentioned, psychotic behavior, could have an influence on all sorts of problems within society, couldn't they?

TW: Yeah.

SB: And they could be. If this is the cause, sometimes it may be, we could resolve an awful lot of things if it's properly diagnosed. Someone asks, "Is there a difference between folic acid supplement and folate?"

TW: Lots of people do really well on folic acid; I personally don't. I take active folate. I cannot tolerate folic acid at all. It doesn't work for me. If you convert it, and you can use it properly, again, then use it. It's cheaper. I buy active folate and that suites me down to the ground. We've particular methylation issues in our family, and we all use methylfolate, and it worked like a dream for me.

SB: Vispi. I don't like you, Vispi. I really, really, really don't like you. Because Vispi has asked, "What is SE holotranscobalamin?" Did I say that right?

TW: Essy?

SB: Well, "S", "E".

TW: Holotranscobalamin?

SB: Yeah, I don't know what the "SE" part is. As one of the patients has low levels of this, with low levels of B12.

TW: Holotrans-

SB: If I didn't get that right, Vispi, please send in a followup. transcobalamin.

Tracey has since been in touch to inform us that Holotranscobalamin assay is an 'active B12 test'.

TW: So, transcobalamin. So it's a problem with transport of B12, so getting it from the blood to the cells. Yeah. So that would require injections. Yeah.

SB: And Vispi also asks, and this is a much easier question, for me anyway, "Does it matter what time of day you take your supplements, and should they be taken with food for absorption to be enhanced?"

TW: With B12?

SB: Mm-hmm.

TW: If they work for you, I think a lot of supplements would say, "Take with food." Some people find that taking supplements at night keeps them awake. Some people find that it helps them to sleep. So it's really, again, up to the individual with that.

SB: Gosh. People are annoyingly different, aren't they?

TW: Yeah. Personally, I avoid tea or coffee around taking any folate or things like that. Within an hour either side. And that's the same to be said for iron supplements. And also, I think, for thyroid.

SB: But food's okay?

TW: Yeah. Yeah.

SB: I was waiting for this question to come in, and I can kind of predict what the answer's going to be. "Could some of the symptoms of multiple sclerosis be similar to B12 deficiency?"

TW: Yes. Yeah. Yeah. They really can.

SB: The answer's always going to be yes.

TW: That's a demyelinating condition. And also, some GPs do ... or some doctors use B12 to treat MS. And there obviously is true MS. The lesions are, I think, slightly different in B12 deficiency. I think they're symmetrical. But there are people who have been misdiagnosed with MS, only to find that they actually have got B12 deficiency.

SB: Yeah. "How do you get active folate? What form is it in?"

TW: Methylfolate. But what I would suggest there, I don't promote any particular supplements, but I would read reviews, do your own research and find what suits you.

SB: Why don't you promote any supplements? You can say what you like on here. I don't care.

TW: Well, I think it's really because-

SB: Which are the crap ones?

TW: Well, I don't know. I don't use the crap ones. No, I think the point is for me, when I started the site, I was contacted by lots of people who wanted me to promote their supplements. And primarily with the site, I want people to ... I don't want to promote anything that won't suit everybody. And because they really don't ... Everybody is so different, it would be wrong of me to promote something that somebody's going to spend money and it's not going to suit them.

SB: I think probably part of that question is, I mean, are there some manufacturers whose production methods are likely to be less robust than others? Solgar, for example, have a pretty good reputation for most of their supplements, and I was told off the other for buying something from Holland & Barrett.

TW: I mean, it's really tricky. You might find that you like a particular vitamin C from somewhere and the more expensive one doesn't suit you. It is all so different. I wouldn't at all diss anybody's supplements or not.

SB: MS has cropped up again here. Another person mentioned MS as a possible misdiagnosis for us as well as for GPs. I'm not quite sure ... Oh, I see. That we could easily mistake it as an MS diagnosis in our own practices rather than just GPs missing it.

Some information here. Medichex does B12 test, or blood test, for 39 quid, apparently. "Boots will do a B12 blood for 39 quid," says Robin. Someone else says, "Private blood test on average 70 quid." So that gives us a bit of a reference range for how much we might spend if we're going to get these things done privately.

TW: That's it. And free from the GP.

SB: Sorry?

TW: Free from the GP.

SB: And free from the GP, if you can get the buggers to do it.

TW: Yes. If you can get it done.

SB: Here's another one. "I have been tested and have antibodies to intrinsic factor. Do you have any suggestions?"

TW: Well, has he got a diagnosis? Because you would assume that that would be pernicious anemia, and they should really be treated, it depending on what their symptoms are. If they're neurological, then it should be injections.

SB: Okay. And another one. "What about B12 sprays? I've used one and it's an oral spray which bypasses the digestive system. Is this much better than B12 tablet form regarding the body's ability to absorb?" I mean, are the sprays all sublingual, because we had a question whether they all were?

TW: Yes, they are. Yeah, they are. And again, if they work for you. They do nothing for me, but the next person they might do well for. The key thing with anybody taking supplements is, do they feel better? Are their nerves healing? Are they improving their brain fog? Can they walk normally? It really is down to you monitoring how you feel. Just sticking something in and not feeling any better isn't doing you any good.

Injections are proven. They're swift-acting and they really do work and they're very inexpensive.

SB: I've just had a question which I imagine is a bit tricky to answer because they've said, "How long after you start taking supplements would you expect to see an improvement?" I suppose we have to assume that you're taking the right supplements and it's the ones that work for you.

TW: For example, if you're on injections, the two weeks loading doses that people are given if they've not got neurological involvement-

SB: This it the every other day?

TW: Yeah. You can start to feel real benefit within a couple or three of those, but you really need to carry on. And I think it's really key that when you start to feel an improvement, you actually report that to your GP, that you feel well. I have known people who have had loading doses and felt really well on them, and then waited for their next three monthly and have gone right downhill and actually not said anything to their GP.

It's really key that you keep a monitor of how you're feeling. Note it down. Use the app if you want to. But some people can find real benefit in a couple of weeks, but that doesn't mean you're fully healed. You've got to carry on and see.

Some people find that the tinnitus is the first thing to go, or that their brain fog lifts or their depression lifts. Everybody's different.

SB: Okay. Which actually, what you just said brings us onto this next question, which is, "After diagnosis, does supplementation eventually correct the problem?"

TW: Well, you can reverse all symptom of B12 deficiency if it's caught early enough and it's treated aggressively enough. In children, that's slightly different. If you have a child who is not treated early enough, then their systems are still developing and then you can end up with developmental delay and real problems in children. You cannot reverse everything if it's not caught early enough then.

SB: I think the question was, would you need to carry on the supplementation forever or would you-

TW: Well, yes. If you cannot absorb B12 from food, then yes, you do. And then are some people who think, "Well, I feel fine now. I'm going to stop." And then they have a huge crash and they've got to start all over again. So yes. If you can't absorb from food, and that's the reason you're B12 deficient in the first place, or you're taking something that is stopping you absorbing it, then you must carry on. The treatment really is for life.

SB: Yes. Okay. Someone says, going back to what we talked about earlier on, that they're taking a B12 supplement and a PPI, proton-pump inhibitor. Is there no point in doing it at all due to interference with absorption?

TW: I'm assuming then that that supplement is oral, and no. There wouldn't be any benefit from taking that because the PPI is stopping you from absorbing.

SB: Right. So they would need to inject it?

TW: Yes. If they're taking that supplement because they've been diagnosed as B12 deficient then the GP should be giving the injections.

SB: Yeah. Would you expect a GP to know that?

TW: I would hope so. There are certain warnings on certain drugs about it lowering B12.

SB: Matthew has asked us if the B12 injection is subcutaneous or intramuscular, and are the syringes supplied pre-filled or to be drawn up from the

ampoules? And if supplied online, is it a complete kit or is any other equipment needed? Matthew's one for doing all this stuff, you see.

TW: Right. They're glass ampoules on there-

SB: He'll be out there with a pack on his utility belt with all this stuff for his patients.

TW: It is licensed, actually, in the UK for intramuscular. But most people who self-inject use subcutaneous and it's said to stay longer in the body like that. Personally, I use subcutaneous needles and there's less chance of you getting ... interfering with anything and I do fine on that. And most people who self-inject actually do use subcut needles for that. It is just drawn up from the ampoule.

SB: Right, okay. And what about antibiotics? Do they affect the uptake of B12?

TW: I think there is a particular antibiotic that ... Yeah. Is it fluoroquinolones? There are problems with some antibiotics causing B12 problems, yeah.

SB: Would we expect to see that in the BNF if we looked in there? Would it tell us that it affects B12, would you think?

TW: I don't know, is the answer to that.

SB: Okay. "Can you have too much serum folate? My mom," Says this question, "Has been having many varied symptoms and is receiving B12 injections every three months. Her serum folate has always been above reference levels and she's been prescribed folic acid daily for years. Her GP suggests stopping short-term as too much can cause confusion, irritability, et cetera. I'm now starting to think her B12 may not be right and not necessarily too much folate?"

So this person's thinking it may be the B12 that's wrong, not the excessive folate.

TW: And is she on folate or folic acid? And if it could be that the folic acid isn't suiting her. There is some ... I think in the guidelines, they mention giving folate at five milligrams for four months or something like that. I take my folate every week, and it's water-soluble like B12. But it might be that folic acid, if it is folic acid, might not be suiting her.

SB: Okay. It was mentioned earlier that the gas given during childbirth can inactivate B12, nitrous oxide. So any relationship between postnatal depression and the gas?

TW: Yes.

SB: And how long is B12 inactivated for? How does it recover?

TW: Well, if you can take in B12 from food, then you can replace that B12 that you've lost. It will take some time. If you are-

SB: And there's no reason why anyone shouldn't be able to just because they've had nitrous oxide?

TW: No. But if you're an undiagnosed B12 deficient mother, and that B12 is inactivated, then you are on a long road. And then if you go on to breastfeed-

SB: If you're already-

TW: Deficient.

SB: ... if you're already not absorbing it, I mean, would nitrous oxide affect that, then?

TW: Yes. You have completely wiped out any recycling supply. So therefore, if that mother then goes on to breastfeed, then that baby isn't accessing B12 either. So postnatal depression can be a result of an undiagnosed mother having their B12 inactivated. I have got a page on the site about fertility and pregnancy, too.

SB: Right, okay. And the site is [b12deficiency.info](http://b12deficiency.info). I'm going to keep on saying it because I want people to go there.

TW: Yeah. And there are some journals as well about the postnatal depression side of it.

SB: There's some links on the site that take you to the journals with the information as well. "Do PPIs stop other absorption from foods? So anyone on PPI should be having B12 injections?" That's two separate questions there. Should everyone on PPIs-

TW: If you are on PPIs and you're symptomatic to B12 deficiency, then go and speak to your doctor and let them know that PPIs caused this problem. I don't know how long it takes for the PPIs to cause a problem with B12 deficiency. That may be different in every person. But if you're aware of it, you're on a PPI, then make your GP aware of it and keep your eye on the symptoms.

SB: Interesting question, "What would cause B12 deficiency in children other than diseases like Crohn's and so on?"

TW: There can be inborn errors of B12 metabolism. There can be genetic reasons for it. There can be the reason where a breastfed child from a mother who's



deficient. Any number. And drugs again, of course. They give a lot of acid suppressants to babies in America, it seems.

SB: I've got a follow-up from Matthew here. Matthew says, "That's twice in four days." I don't know what he means by that. But he says he does not have a utility belt. He's too fat. That's entirely my own fantasy. I can assure you, Matthew, that I do not fantasize about you in your Batman suit or your utility belt. However.

"What's the difference between injections of cyanocobalamin and methylcobalamin?" Says Vispi. If you do this to me again and making me say these long words...

TW: Cyanocobalamin is, in the body, you have to get rid of the cyanide molecule, and then that should convert to hydroxocobalamin. Sorry, methylcobalamin and adenosylcobalamin. So, if you take methylcobalamin, that is an active form already. That's the difference. The methyl is active and the cyano has to be converted in the body.

SB: Okay. I read on your site, actually, that B12 is an antidote for cyanide poisoning.

TW: Yes, it is. It can be given in huge doses to a newborn baby, and all that'll happen is that baby will go pink. It is a brilliant ... It's only hydroxocobalamin, this one. That is a brilliant toxin scavenger and it should be used in anybody who's been poisoned with carbon monoxide, hydrogen sulfide. And there's an antidote page that discusses all this information, too.

SB: Gosh. And other things? Other toxins, other poisoning?

TW: Yeah. I mean, I've gathered together a lot of the journals there. But cyanide, there is a kit called Cyanokit because of the cyanide poisoning, but it's the hydroxocobalamin that's used in that kit.

SB: Yeah. Okay. "Could it be related to hypoglycemia?"

TW: I wouldn't say-

SB: Is this the one thing it's not related to?

TW: I wouldn't say necessarily, no. I mean, I would look at folate with that. But yeah. No. Not necessarily.

SB: All right. And someone asked, "Can the nerves heal?"

TW: Yeah.

SB: "At what point is it irreversible?"

TW: Well, again, it depends how long you've not been ... it's gone undiagnosed for and untreated for. You can reverse most symptoms. I haven't recovered all of my symptoms, and I've probably had a problem all my life. I used to have a pin sharp memory and that has been affected. But I have recovered an awful lot of what was wrong with me. My blurred vision corrected within a couple of weeks, and my bowel and bladder repaired very well. So you can. It just depends on how long.

Like the poor lady in the wheelchair is always going to be in a wheelchair, it sounds. So it really depends on the extent of your deterioration and how quickly and how effectively you get treated.

SB: What's the mechanism behind the blurred vision? Do you know?

TW: Well, it's nerves. I went to the opticians. They couldn't find anything wrong. But every time I looked at a page, it was moving. And the optician say, "There's nothing wrong." And that's often what patients get. They go for something and it can't be found. And I have to say, as well, because a lot of the symptoms are non-specific, it is tricky to find. And I think often it takes the patient to say, "Could I be B12 deficient? I've got these symptoms." Then the patient gets tested.

So it is tricky because so much of it is not spotted on a normal radar.

SB: Okay. There's another sad story that says in here that, someone says they had a patient who was B12 deficient, so presumably had been diagnosed, but then progressed to motor neurone disease. And the question is, "Could that be because they weren't supplemented properly with B12, do you think?"

TW: It's really tricky to say. You've got to look at the folate deficiency, B12 deficiency. Who knows why they went that far ... And it could be entirely unrelated. But the point is of accessing the right level of treatment for each patient.

SB: Yeah. There's praise. People have been bored listening to me, obviously, and they've been looking at your website [b12deficiency.info](http://b12deficiency.info) and praise is coming in. Somebody says here, reading the symptoms on your website, they've noticed their sister's had many of the listed symptoms. Tinnitus, orthostatic hypertension, geographic tongue, and has always been told there are no solutions to the individual problems. But at least five more of the other points apply to her, so they're thanking you for showing them such an inclusive list of things to work with.

Another one, this question has been asked before but I think people are really, really keen on this. "What language can we use to get tests done by the GP? Have you got any clever tricks, phrases, things that might actually get their attention?"

TW: I have got, if it helps people, a writing to your doctor page on the site. So using some of the information from there perhaps might help. But I think the key thing is, and often ... When I went to see my doctor and one of the doctors that I suggested I needed more B12 for, she didn't really ... she said, "I'm going to write to a gastroenterologist about you." And I said, "Hang on. What makes you think your memory is more important to you than mine is to me?" And it did make her stop and think. And she did then write it out.

And I think, you kind of have to not be afraid of asking your doctor these things. You're fighting, generally, for your life when you're B12 deficient, and some people are so poorly. And, at risk of being too emotional about it, I think you just need to ask them, "What would you do if this were you? What would you do if this were your child?"

I think it's really important for the doctor to understand how difficult it is for the patient to function, what their lives are like, and write that down in a letter or an email to the doctor. Take somebody with you who can support you, because it is often very difficult to ... Some people have real trouble ordering words and sentences, remembering what they want to say. Write it down, and take somebody with you for support, to ask this. But ask those questions, "What would you do if this were your child? I have seen this website. I've read the research. I understand that this could be a problem for me. Please will you look at it?"

And doctors now are becoming more and more receptive to it. I have spoken to a doctor who was devastated at the harm one of his patients had met with because they had been missed. Our doctors are human, and they want to do the best for us, and it's really tricky. It's really tricky for lots of patients to challenge their doctor, and it is a case of trying not to get too shout-y but making your point clear and putting the human into it, really.

SB: No, I don't for a moment doubt, and I'm sure none of the audience doubts, that 98, 99% of doctors have entirely the best interests of their patients at heart, but they are a little bit resistant to being told to do what Dr. Google has told the-

TW: I think that's it. And I think the point is, from my point of view, and I'm not medically trained, I have researched an awful lot, but I can see why somebody might be offended that a non-medically trained person is giving them information that they hadn't learned at university. So therefore, why is it important? I can understand that totally. But it's really key in this day and age that we need to...

SB: It actually proves to be very topical for one of our viewers called Stephen, who says that his GP was quite happy to include B12 testing when he asked it for himself earlier today. And thankfully, he didn't have to fight for it, but it

would seem, as he says here, that from this discussion, he's going to have to make sure the GP doesn't brush it under the carpet if he's just within range.

TW: It's absolutely key to get a copy of your results. You might be one point above and you need to then go and discuss this with a doctor.

SB: Interesting question, which I expect we know the answer to. This person was on the phone, so apologizes if we've answered this already, but we haven't. "On your webpage, it mention a symptom of impaired pain perception. Does that mean feeling less pain?"

TW: I think so, yes. Numbness. All the symptoms are from Sally Pacholok's book, so they are medical terms.

SB: We'll come back to her in a second, I think. Don't know who this. "I have B12 injections because I was ..." From the lady who has antibodies to intrinsic factor. Okay, that was written the wrong way round, I think. She was diagnosed with pernicious anemia, intrinsic factor's needed to absorb B12. "I have antibodies to the cells that produce intrinsic factor. My question was whether you could ask for a test for the antibodies to the intrinsic factor cells?"

TW: The trouble is that a lot of these tests have low sensitivity too. There's a testing page on the site and that talks about those particular tests. But if she knows that she's got pernicious anemia and she's being treated, in a sense, why put yourself through another test?

SB: Okay. Someone's just said that they've tried to download your app but it's charging 4.99 and she thought you said it was 99p?

TW: She's on the monitor app. There is another app for 99p which is the risk checker. So if she goes to the app page, she'll see two apps there listed.

SB: Okay. So the monitor app is the one you monitor your symptoms-

TW: That's 4.99, yeah.

SB: ... after your supplementing to see how you're progressing?

TW: Yes, yeah.

SB: The other one is to find if you're at risk from-

TW: Yeah, that's it.

SB: ... deficiency? Don't know who this is, but they're not sure if they missed this as the internet had a moment, apparently. "But what about spirulina,

seaweed, et cetera, for vegans? Is it only in meat and dairy as the animal food is fortified? Thank you so much again."

TW: I worked with The Vegan Society on their vegetarian page. Spirulina and seaweed contain B12 analogs. The body doesn't recognize it and can't use them. So don't take them thinking that that's giving you B12. It isn't.

SB: Okay. And someone says, "Are vegetarians intrinsically more liable and more susceptible to B12 deficiency?"

TW: Anybody, yeah, anybody who is avoiding certain foods, animal products in their diet, is going to be more susceptible than somebody who's eating meat, fish, eggs and dairy. By the same token, I've always eaten meat, fish, eggs and dairy and yet I have a problem with B12.

SB: And that was from Vispi again, so I mean, Vispi's taking the prize this evening for the most questions asked. Well, actually, a lot of the ones that didn't have names might've been from the same person. I don't know. But that's not a complaint, Vispi. I'm really pleased. Thank you very much for all those questions.

"Do you think there's a role," Asks somebody, "For B12 in chronic pain control, central sensitization, which tends to be hyper response to pain, hyperesthesia?"

TW: As a standalone treatment do you mean?

SB: Well, could B12 deficiency be in some way involved in an increased susceptibility to pain, or chronic pain?

TW: Yeah. I mean, chronic pain, yeah, is a key symptom for lots of people. There's so many people on different drugs that eventually they can come off because they are supplemented with B12 and their nerves are repairing.

SB: Okay. Dawn has sent in an observation of the online company Thriva. It's a private testing company that people can use directly or via referrals from registered practitioners, meaning osteopaths, chiropractors and others. So thank you for that, Dawn.

Someone else says, "They often recommend calcium supplement from seaweed as it's more bioavailable than that from dairy and chalk. Could this then be impacting on B12?"

TW: To raise the serum level, does she mean?

SB: That I don't know. I mean, could recommending a calcium supplement have any impact on B12?

TW: I would only see the connection there being if they're taking spirulina, and that's got B12 analogs in, then that might be raising the serum level.

SB: Oh, I see. So it'll show up in the serum level, but because it's not actually doing anything-

TW: Yes, that's it, yeah. If that's what the question is.

SB: We're getting close to the end of our broadcast, and so it's time for a few of the other thanks yous. Martin says, "This is a tremendously complex subject, so well done to you for fighting for what must feel like a constant uphill battle to educate people not unlike us." And actually, to get across a huge amount of information to people who've probably, in their medical careers, not just doctors but osteos, chiro's and others, they've probably dealt with this for an hour or so and not much more than that.

Again, somebody else, "Fascinating talk. Thank you. Would you happen to know if there's any evidence of neurological symptoms as a result of coming off antidepressants after 10 years, and is still suffering awful withdrawal 18 months later, including peripheral neuropathy and anxiety?"

TW: That was caused by the antidepressant?

SB: There's a bit missing in the middle of that question I think, and I'm ...

TW: I think if you've got peripheral neuropathy and anxiety, it's definitely worth looking at the symptom page and just checking whether, actually, there is an underlying B12 deficiency there rather than it being caused by a particular drug.

SB: Okay. What else have we got here before we ... What have we got? We've got a couple of minutes left. There's Monica. Monica, that's the first time ... I haven't heard from Monica for a while. Monica says, "There's a story of a GP who told his patient, 'Don't confuse your half hour of looking this up on Google with my five years of studying medicine.' To which the patient replied, 'Don't confuse your half day lecture you had on my condition with me having lived with it for 30 years.'" Which is probably not the approach to take with your GP if you can avoid it, but it does put it in perspective, doesn't it?

TW: I think the thing is that-

SB: Thank you, Monica.

TW: ... many doctors are aware that their patients are living with a condition, say diabetes, and know more about certain things than their doctors do. And I think that, very often in B12 deficiency, the patient knows far more because they've often found it themselves.

- SB: Yeah. Vispi's determined to keep up the statistics here and says, as you've mentioned, "People with B12 deficiency feel they have memory problems. What sorts of memory screening tests would you see as being important?"
- TW: I have no idea, really. I know for me that my memory was failing and I know that lots of other people have that as a particular symptom. I don't know how that would be best screened, really.
- SB: Well, interestingly, I was talking to a neurologist only last week with a view to getting that neurologist in to do one of these broadcasts. And I was thinking, having spoken to a number of our members and so on about maybe going back to basics for neurological testing and making sure we can do the tests properly and interpret them accurately. But we can then develop that, of course, and say, "Well, talk some more about how we would test properly for things like memory problems in B12 deficiency," and so on.
- So I'd be interested in hearing anybody's feedback on whether you think that we would benefit from getting a neurologist in and if there are other things you'd like to us to see in that regard.
- Couple of final questions, perhaps. "Is it better to have a B12 supplement or is a B complex just as good?"
- TW: Well, I wouldn't supplement at all until you've tested, if you feel that you have a B12 deficiency, because any supplement, even a tiny bit in a prenatal vitamin or a B complex, will skew results, and you want the best chance, really, of getting a clear result or a baseline result.
- SB: And you make that very clear on the website. Virtually every other paragraph is, "Don't supplement before you test."
- TW: Yeah. And it is hard, because if you have supplemented before testing, then it's really key that you let the GP know, let the nurse know that's taking the blood, and ask them to write it on the lab notes so that whoever's at the lab can use that in conjunction with your result.
- SB: Okay. I think this was from Siobhan, I'm not sure. But the comment is, "She's wonderful. I am literally full of wonder." So well done you.
- TW: Very kind.
- SB: And Matthew says, "Thank you for one of the best talks yet. The minutes have just flown by," and I can certainly echo that. "And I know all this fantastic information is going to be of enormous use to both my patients and family."

So that's all the questions that we've really had time for this evening. But I just have to echo that. Who would have thought that we would get so much

medical information from a cabinet maker? I'm put to shame by my lack of knowledge about supplementation, about B12 deficiency, and all this stuff. Tracey, it's just been brilliant. And then, this says, "90 minutes has just flown by."

Thank you so much for coming in.

TW: Thank you.

SB: We're going to send people to your website, which is [b12deficiency.info](http://b12deficiency.info), as we continually keep telling people, reminding them. There is a donate button on there to help you make this information more readily available, and we're going to put that on our website up with the recording.

TW: Thank you.

SB: But there's no reason why people can't go straight to the website and do that anyway. People can support your petition through the website?

TW: Yes, they can.

SB: And of course, as practitioners, there is a wealth of information on the website. I mean, the pages are huge about signs and symptoms and drug interactions and stuff like this. And I said at the beginning, you're probably the UK's expert on B12 deficiency.

TW: I don't know about what.

SB: I can't believe that there are many people, if any, that know more about this topic and I'm so pleased you came in. Thank you very much on behalf of everybody watching this evening.

TW: Thank you.

SB: And my final point, and this one's a really useful one for you. We have talked on a number of occasions this evening ... Well, I have. I bet Tracey has. About Sally Pacholok.

TW: Pacholok.

SB: Pacholok. Sally Pacholok, who is an American registered nurse who is a huge authority on B12 deficiency. When you claim your certificate, there will be a link there to the trailer for a major film that was made about Sally Pacholok. Well worth looking at. It brings out some of the things that we talked about this evening, and I for one am certainly going to download it.