



PUBLIC PETITION NO.

PE01408

Name of petitioner

Mrs Andrea MacArthur

Petition title

Updating of Pernicious Anaemia-VitaminB12 Deficiency understanding & treatment

Petition summary

Calling on the Scottish Parliament to urge the Scottish Government to review and overhaul the current out-dated and ineffective method of diagnosing and treating Pernicious Anaemia/VitaminB12 Deficiency.

Action taken to resolve issues of concern before submitting the petition

1. Featuring in a major newspaper article in 2009. This raised awareness of the general symptoms and alerted many people to what may be wrong with them. It brought many personal responses and increased membership of the Pernicious Anaemia Society as a source of valuable information. www.pernicious-anaemia-society.org
2. Contacting the Scottish Parliament through my MSP in 2009, achieving responses from a Speciality Advisor which confirmed what we know to be the present but flawed understanding of how best to diagnose and treat this condition.
3. Adding my support to various e-Petitions at Westminster, lodged by the Pernicious Anaemia Society or members of it.
4. Personally appearing in a professionally produced DVD by the Pernicious Anaemia Society this year and which makes clear the failings in the current diagnosis and treatment of this condition.

Petition background information

I submit this petition due to my personal experience of and concern at the major failings in the diagnosis and treatment of Pernicious Anaemia/Vitamin B12 Deficiency. This condition is no longer a simple result of patients having gastric antibodies which prevent them being able to absorb VitB12 from their food or having a diet which excludes the foods which contain it.

There appear to be other reasons for an occult deficiency, many of which do not result in a depleted serum level. 'Occult' deficiency refers to the dictionary's description:

Medicine (of a disease or process) not accompanied by readily discernible signs or symptoms.

There are many cases of patients having experienced long-term, serious and permanent damage to their health, typical of that associated with untreated Pernicious Anaemia (PA), but they do not necessarily have any of the haematological markers,

such as a low serum B12 level, macrocytosis (enlarged red blood cells) or gastric antibodies to the stomach's parietal cells or the Intrinsic Factor they produce and which are crucial for the absorption of B12.

Other possible known reasons for a hidden deficiency are:

1. A problem with transcobalamin (a carrier protein to which B12 needs to bind).
2. A methylation cycle defect where B12 interacts with other substances which enables it to be metabolised.
3. Treating a folate deficiency without first identifying a coexisting B12 deficiency. This may correct the haematological signs of macrocytosis (ie - bring their MCV level back within a normal range) and will mask the B12 deficiency allowing it to remain hidden in the background and continue to cause neurological damage.
4. There are also quite a few patients for whom it is never known why they need a considerable level of B12. I am one such case but have now identified a probable reason as being mercury poisoning from the high number of dental amalgam fillings I had from a child. There are many patients who have received diagnoses of Fibromyalgia, Chronic Fatigue Syndrome or ME, however, since there is no option to test for environmental toxicity within the NHS, only those who can afford to pay privately are in a position to have this possibility explored. This is the route that I have had to go down.

An undiagnosed B12 deficiency over many years causes devastating health problems, many of them permanent, and the patient is often unable to hold down employment yet is unable to receive any assistance as they don't have a diagnosis of any condition. Despite serious permanent damage to my own health, my serum B12 level was still well within the normal range and this is one of the major concerns with the current diagnostic tests. I responded immediately and spectacularly to VitB12 injections but have continued to need them extremely frequently (3 a week) rather than the 3-monthly frequency to which most patients are restricted, regardless of whether it is controlling their symptoms.

I was already off to a good start in that I have excellent GPs, one of whom saw me before I began to deteriorate and who believed what I was telling him and had at least some documented and visual evidence of my decline. I have never been diagnosed with PA and no longer even believe that is what I have, however, I came across the term 'Pernicious Anaemia' by chance while browsing the internet and, purely out of curiosity, looked to see what it was. It was the recognition that I had almost every one of the advanced symptoms of it that I approached my doctor and asked if I'd ever been tested for it. Incredibly, and after 13 years of seeing various specialists, I hadn't ever been tested. However, since my serum B12 was still within the normal range even after all that time, it would probably have been dismissed as a reason and that is what I am trying to get over to the medical profession that patients are slipping through the net due to the unreliability of the test. Although I have said that I don't now believe I have PA, there is no doubt that the treatment I was given saved me from what I expect would have been death within the next few months. It literally saved my life and bought me time to search for the true reason for my excessive need for B12 and folic acid.

I explained to my doctor why I was asking about B12 deficiency and it was agreed that it was reasonable to test me for it and, by the time the result was received, I had already discovered from my own research that a result which fell within the 'normal' range did not necessarily mean I did not have the condition. Since my doctor saw I had all the advanced symptoms, he was happy to let me try B12 injections but this is not at all typical of the vast majority of members who relate their stories on the PA Society website forum. There are even quite a few who have tested as being deficient yet are still denied injections as they don't have antibodies or their doctors think they "are not very deficient".

Again, although my response to the treatment was dramatic, it was very short-lived and I could not last more than a couple of days before the return of major symptoms. I admit I was a challenge to my doctors but they rose to the occasion and, I presume, after checking out for themselves the safety of such a high level of treatment, they allowed me to remain on it. My very frequent need of B12 may sound like an exception

but, sadly, it is not. I read stories all the time of others struggling on the standard treatment but not being allowed whatever level of B12 keeps them stable. In essence, most doctors are basing all their clinical decisions on an out dated and unreliable test. Those who have their treatment decided on the results of this test, rather than their symptoms, are left with the options of either continuing to deteriorate or seek other ways of obtaining treatment. Quite a few of them consult private clinics or buy their own supplies from the internet or mainland Europe (where it is freely available in pharmacies) and learn how to self-inject.

Where I am also an exception is in having doctors who treat me as an individual and I have so far come across maybe only two other people in the UK whose doctors treated them symptomatically. This is despite the British National Formulary (section 9.1.2) making provision for those with neurological symptoms to be given an injection on alternate days until they gain as much improvement as is possible. This can take years and, I presume, has to also mean that they are not then allowed to deteriorate again by having their injection frequency reduced to a level which is insufficient for that individual person.

I have been extremely fortunate to have a doctor who listened to and believed me, allowing me trial injections despite a 'normal' serum level and, once confident of the safety of this, agreed to let me have whatever amount keeps me stable and this is another area which is fraught with problems. I am an exception. Doctors are simply not believing their patients, either those that have been diagnosed with PA or those presenting with symptoms that B12 helps them at all or that that they need more frequent injections than are currently offered. Rather, most patients are at some point offered anti-depressant medicine which is not appropriate, is more costly and does not address or halt the worsening symptoms and damage that the patient is experiencing.

I would say that, in almost every case, the reason why doctors routinely offer anti-depressants is because no other reason can be found for the patient's symptoms and that doctors underestimate the diverse range of seemingly unrelated symptoms and damage which this condition causes. It is known that both B12 and folate deficiencies can cause a form of depression but it is usually resolved as soon as the deficiencies are effectively addressed. For this reason, anti-depressants will not have any effect on the physical, emotional or psychological symptoms of vitamin B12 deficiency.

We, as in members of the Pernicious Anaemia Society as well as the society itself, cannot understand why the Health Service is so reluctant to prescribe this treatment which is extremely safe, very cost-effective (each ampoule costs the NHS just 50 pence!) and is much safer than giving the patient other types of serious medication and investigations to simply try to manage their symptoms rather than address them and prevent further damage.

This is not a condition which is affecting just a handful of patients in Scotland. For example, and taken from the Scottish Government's own prescribing data for 2011, around 109,000 patients were identified as having Pernicious Anaemia and it cost the NHS in Scotland over £800,000 to treat them. Astonishingly, half of that cost was spent treating just 9% of the patients concerned and, worse still, this was using the least effective form of treatment available, oral Cyanocobalamin tablets.

The reason why patients should be given injections is because they are unable to absorb their B12 in the stomach or intestinal tract. It is claimed that perhaps 1% of these tablets may be absorbed through passive diffusion but, in reality, they are completely ineffective and will not manage an actual B12 deficiency, unless it is solely due to a dietary lack, as in veganism. However, taking these tablets will elevate the serum level resulting in the doctor assuming all is well. Some (but not all) patients get a degree of benefit from high-strength Methylcobalamin sublingual tablets but these are not available on the NHS and are still nowhere near as effective as an injection.

Added to this is the fact that many patients are not included in these figures as they never get the length of having their deficiency identified and, for those who do, it is not necessarily recorded as PA, particularly if no gastric antibodies are present, and so these official figures are only the tip of the iceberg. Then there are those who are denied treatment and whose only option is to buy their own supplies from abroad,

either by internet from Germany or Australia, or in person in several mainland European countries where it is freely available without prescription from any pharmacy. They then self-inject, often without any instruction or guidance. A few have even resorted to asking for help at a Drug-Abuse Centre for needles/syringes and tuition in self-injection.

In summary, the following changes have to be introduced:

1. Doctors need to be made aware of the most common set of symptoms experienced and be able to think of B12 deficiency as one of the first options to explore. This is often the last thing to be checked, if it is checked at all.
2. The diagnostic tests need to be overhauled and more reliable forms of testing used. This would include adopting a new Active-B12 Test (Axis-Shield Diagnostics) which has now recently been made available at a private clinic in the London Area. The existing options to test Homocysteine and Methylmalonic Acid (MMA) levels should also be routinely used. At the moment, these tests are rarely used.
3. Some patients show no haematological signs of a deficiency but have all the advanced symptoms of one and any patient in this position should automatically be offered trial injections, regardless of apparently 'normal' blood test results. (In my own case, there is virtually no other doctor who would have even considered treating me due to all the above tests showing normal results).
4. Other important levels should be checked and addressed where necessary, particularly folate and ferritin, and other coexisting conditions considered, such as hypothyroidism and adrenal insufficiency, which are very common. At the moment, most doctors are unaware of the importance of particularly folate, and are misinterpreting the British National Formulary guidance which warns against giving folic acid without first checking B12 status. Despite the presence of a folate deficiency, some doctors are wrongly withholding folic acid supplementation until the patient has had their initial course of aggressive B12 treatment and thereby vastly reducing the effectiveness of the injections which cannot be absorbed without sufficient folate. This usually leaves the patient in an even worse state of health leading the doctor to assume the injections are not helping and even in cases withdrawing them.
5. Each patient should be treated symptomatically as each responds differently to the condition and its treatment, as is true of every condition. Those who need much more frequent treatment to keep stable should be given it and the option of being shown how to self-inject which frees up surgery time and resources and is much more convenient for the patient.

I urge the Scottish Parliament to listen to what patients are telling you and work with them, and groups such as the Pernicious Anaemia Society, to make the management of this condition more efficient, effective and cost-effective. This can only be in everyone's interests both from a health perspective and in savings on the NHS budget.

Unique web address

<http://www.scottish.parliament.uk/GettingInvolved/Petitions/PE01408>

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1

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