Nursing IN PRACTICE

Pernicious anaemia patients suffering needlessly

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"Many patients of pernicious anaemia are being undertreated and are suffering needlessly", says Martyn Hooper, Executive Chairman of the Pernicious Anaemia Society.

Pernicious anaemia affects half a million people in the UK and is treated by injecting the sufferer with vitamin B12.

"Many patients need more regular injections than the usually prescribed three-monthly treatment. Some patients' doctors are happy to let the patient devise their own individual treatment regime, but other doctors refuse to sanction more frequent injections and this causes needless suffering", he says.

or consent of their family doctor", says Mr Hooper.

Patients who need more frequent injections, but are unable to receive them, suffer from extreme lethargy and tiredness, irritability, mood swings and lack of concentration.

"Some patients live just one month out of every three – some for as many as 40 years" says Martyn. "The injection costs pennies and it is impossible to overdose on the teatment as it is a water based protein that is excreted in urine."

Pernicious Anaemia Society

What do you think about the charity's claims?
Your comments: (Terms and conditions apply)

"I live in the 'lucky country' and am able to buy my B12 without a prescription. So I can have my shots as often as I like. I was diagnosed 18 months ago and had a dangerously low level, my GP was shocked that I still had the energy to go to work full time on shift work as a registered nurse. I am 46 years old and was told that I probably had the disease for a few years undiagnosed. 2 other GP's ignored my symptoms and just told me to lose weight! But I knew there was something seriously wrong and finally found a more thorough and caring GP. The relief I get from lethargy and lack of concentration with each shot is amazing. I found that I was feeling dreadful waiting for my 3 months and feel much better on 2 monthly shots. All this has also taught me a lot about what to look for with patients with these symptoms. This is not a disease they spend any time on when teaching nursing. So to all the UK people having so many hassles with your GP's and getting access to your supplies etc, I feel so sorry for you. It's just not right. Make your next hoiday destination Australia and stock up while you are here! Best of health to everyone...." **- Karen Flynn, Brisbane**

"There is an overlooked factor here which is that treatment with sublingual delivery of B12 is proven to be as effective as injections. Perhaps patients should now simply ask for B12 lozenges to avoid the hassle with the nurses, painful injections? If they are refused they should simply buy them from a reputable source which may be cheaper than a prescription charge in any event." **- Joanne Wilson, UK**

"I completely agree with Mr Hooper's claims. It is time the NHS listened to the evidence that people's lives are being compromised by injections which are not frequent enough. On bad days I cease to function properly and have to rearrange plans/cancel arrangements. I am only 35 and a mother of two

for an answer and a large dollop of luck. The improvement I experienced was nothing short of a miracle but I soon realised that I needed far more treatment than is licenced. I have excellent GPs who have done everything in their power to give me the best treatment but their hands are tied due to the shambles of diagnostic and treatment guidance. In effect, it is a huge struggle to be listened to at all, another massive fight to be treated and downright impossible to receive the amount of treatment that your body is telling you it needs. This is a major failure of the NHS to give even the most basic care to a group of patients who have, after all, a life-threatening condition. This whole issue drastically and urgently needs completely overhauled, in consultation with the very people who are being ignored despite having a condition over which they have no control." **- Andrea M, Scotland**

"I couldn't agree more with the PAS. Having suffered for almost a year and being diagnosed with PA, I am struggling to hold down my job because I only manage to be well for about 6 weeks and I then gradually get weaker and weaker and end up off work. My doctor is against anything other than 3-monthly injections - saying the haematologist wouldn't condone it and that I should have sufficient levels of B12 and that it is psychological to think anything else." **- A King, N Yorkshire**

"There's absolutely no doubt in my mind that this is the case. It seems that nothing has changed in the last 25 years, when my Mum was diagnosed, until now. She has since told me how no one understands and no one including professionals really knows about the illness. I believe I am developing PA. It should be noted that I put up with many symptoms such as breathlessness, general fatigue, fluttering heart and so on long before I put two and two together and wondered if I may be developing it. Because of Mum, the penny dropped that this may be the reason for the way I was feeling. Her sister, my aunt also has it. Their father had it too. Lo and behold, my B12 was well below the minimum and has remained there for the last year. In my doctor's own words, 'A haemotologist wouldn't bat an eyelid at that level'. So the question really has to be WHY NOT!!? When do we start talking malpractice? I fully accept that a family history, no matter how strong, does not mean that I have it but this does not explain the fact that no one feels the need to treat the symptoms I have which can be explained by my low B12!! I have recently been referred to a haemotolgist by my doctor who 'cannot attribute my symptoms to low B12.' Can't you? And yet these are known and recognised symptoms of low B12." **- L Nugent, Scotland**

"J Walker's comments do not apply to my case or that of my father. With conventional B12 treatment we both stay on the very low side of the 'normal' ref range used by the labs. My father's serum B12 was still under the labs ref range of 'normal' after three months of

"I totally agree. I have been diagnosed PA for two years and cannot cope for more than 6-8 weeks. I have to beg for an injection and one nurse is willing but the other sends me away. Since awareness week I can now have two-monthly hydro but have permanent nerve damage to hands and feet through nhs incompetence and neglect. I feel very angry as I had to leave my job and exist on benefits." **- Sonia Martin, Manchester**

"I agree with Mr Hooper's comments. Others that do not have pernicious anaemia have no idea of the debilitating effect this illness causes in everyday lives. I am one of the lucky few and my neurologist here in Spain has allowed me to have injections every fortnight ... which really helps and I feel so much better than I did. It is such a cheap drug I cannot understand why it is withheld so much by some doctors." **- M Hendricks, Spain**

"Virtually anyone with PA will agree with Mr Hooper's comments and any of us who have been in contact with the PA Society will know what an invaluable source of information and practical support it is - information that for many sufferers is not forthcoming from GPs and consultants. I have PA and was initially put on the standard 3-monthly injections treatment regime, despite indications from another GP who treated me initially that 2 monthly would be better. I questioned this as I was still not feeling 100% but was told by the GP that 3 monthly was plenty. Fast forward 3 years on from diagnosis date and I queried with one of my practice nurses whether
it was possible/necessary to have more frequent injections. The nurse said that 3 monthly is enough and that it was just a psychological need that people felt to have more frequent injections. Obviously I went away thinking I was a wingeing hypochondriac so suffered in silence. Another 6 months down the line and I queried my annual blood test results with the nurse and found out that I had been below the lower limit for the last 2 years - no one at the practice had picked up on it.
This then prompted a rather panicky referral to the consultant again (at extra cost to me) who simply advised I go on monthly injections. This experience simply re-inforces my view that the reference ranges are fundamentally flawed." **- Mark Tweedale, Lancs**

"Gosh it is such a relief to realise I am not the only one in this boat. I keep sneakily making appointments a week or two early each time as I feel so terrible after 7-8 weeks. I wholeheartedly agree with Mr Hooper's comments. Furthermore my elderly nan has just had to go into a home for respite care as she has suddenly massively gone downhill with walking/balance/depression. They have done blood tests and she is mildly anaemic - I had to ring my mum last night to make sure the doctors are testing her B12 level as to me everything smacks of a B12 deficiency. I hate to think that she could be needlessly suffering when it is such a simple thing to put right when caught early enough. I have been toying myself with trying to obtain vials from the internet and learning to inject myself. At 38 I find

the arrogance of my doctors ignorance about PA that annoys and worries me." **- Mick, UK**

"My mum was diagnosed with PA over 20 years ago. I have watched my beautiful, clever Mum gradually become a difficult and now demented and confused old lady of 90. Throughout this time for the month after she had the B12 injections she was a different person and more like the person we loved. Eventually, with three-month injections it was obvious it was just a case of catch up and we were lucky if the effect lasted 2 weeks. About three years ago after I had called the GP several times and they were sick of us and had no more answers, it was agreed to let my Mum have injections every 2 months which was great at first but we are now back to catch up again. In fact I think late diagnosis and inadequate treatment of PA has been responsible for my Mum's decline into dementia. There is much talk of research into alzheimers and dementia in old people and it seems to me that this country could save themselves alot of money by treating this lethal but emminently controllable disease correctly. The NHS needs to understand that the cheapest is not always the most cost effective! They also need to understand that these sort of illnesses is misery for a whole family not just one patient and presumably can often causes medical problems for those caring for sufferers." **- Marilyn Magill, N Yorkshire**

"In reply to J Walker, East Sussex, no, it is not a pyschological issue. It is hoped that when one is taking B12 inejctions for PA, their level is high. If not, they are not responding. The problem is that some people require a higher B12 level than others. This is why the World Health Organization has never been able to place a "safe upper limit" on B12. They, in their wisdom, are aware that each person may require a different B12 level. The reference levels for B12 are very outdated and need to be updated to one that is more realistic. A lab in the USA uses a reference guide for B12 levels as 725–2,045 pg/ml. That is a more realistic reference level. Members of the PA Society have proven that more frequent injections when needed have improved neurological damage and alleviated suffering. It comes down to quality of life as opposed to just existing. No one should just have to exist. Diabetic patients inject on demand, why cannot PA patients do the same? Both kinds of injections are life-sustaining. And yet for most PA patients, doctors will treat according to standards that will just keep PA patients alive, rather than trying to improve their quality of life. However, for some very unfortunate people, lack of treatment and diagnosis has caused their death." **- Pat Kornic, Canada**

"I have PA and agree with Hooper. Luckily my condition was caught in a less serious stage and my GP agreed to B12 injections as often as I needed them. I do not understand why the UK has this terrible system that leaves patients suffering. B12 is a very cheap, safe treatment, and like diabetics we can easily learn to self-inject. It would save the health

I'm so tired, hands and feet tingling, palpitations, chest pain, tinnitus, poor memory span, depression to mention a few. Unless you have pernicious anaemia you dont know what it is like! I can't last 3 months and either need to change my doctor or find my own supplies." **- Alison, Cheshire**

"This is a great problem in my country. I was diagnosed in June, but my doctor thinks it's hype and didn't want to treat me. I have had a camera down and up to check if there was something going on in my guts. Had 10 injections in 5 weeks and then no more. I was feeling so much better and as soon as my doctor stopped the injections, I felt worse again. Went to another specialist in a hospital, who prescribed 2 injections a week for 6 weeks and afterwards one a week for 2 months and after that talk about the results. Back to my doctor, but she didn't want to give this treatment to me. So all and all it took me half a year. Now I have a new doctor and he is giving me 2 a week for 5 weeks and after that he wants to give me less. I think it will be problematic again. But I have already decided that I will go abroad, buy my own stuff and find someone to inject me. What does an honest person have to do to be able to have a normal life? Everyone...don't give up...keep on fighting, although it's hard. It's our life and we deserve to be able to feel good!" **- Hiske, The Netherlands**

"My GP recently decided (without even bothering to look at my records) to challenge the diagnosis made 16 years ago with blood tests, a schilling test and a full neurological exam, including CAT scan. She says she will decide if I have PA and will only continue my treatment if she decides my consultant was right. Who the hell do these GPs think they are? The Pernicious Anaemia Society were amazing! I have now changed my GP and hope that I won't have any more problems. The distress caused by this thoughtless GP (my mum had PA and died from premature dementia at 58) has caused terrible stress. Something needs to be done now and I applaud Martyn and his volunteers for everything they are doing to raise awareness of these issues." **- Annette, Solihull**

"If a blood test is taken from a person on B12 injections then the level is always higher than the top of the range so is this more of a pyschological issue than a physical one?" **- J Walker, East Sussex**

"I agree with Mr Hooper's comments. I am one of the fortunate people whose doctor is happy to give me monthly injections. I recently tried having the injections five weeks apart and found that I felt extremely tired and my memory and cognitive functioning began to deteriorate. I am now determined to have the injections every month as I do not wish to experience again the terrible lethargy, shortness of breath and memory and cognitive impairment I suffered before diagnosis and treatment. I believe it is malpractice when doctors allow patients to experience debilitating and life-threatening symptoms instead of

to eight weeks. Also, I feel it should be one of the standard blood tests which are given as the norm. Early dianosis would save the NHS a lot of money in later years." **- Evie, Cornwall**

"I wholeheartedly agree with the comments made by Mr Hooper. Diabetics are not made to wait until they collapse before they can have another injection, why should people with PA lose huge chunks of their life, and suffer failing relationships/lose their jobs because they need a simple water-based injection? It is most important that GPs and nurses are brought up to speed on these matters. Why do we in the UK always seem to fall short in comparison to Europe?" **- Ali Hodges, Dorset**

"I fully support the Pernicious Anaemia Society's push for improved health care regarding B12 injections. I can see no reason why a doctor should refuse a patient a protocol of treatment that can improve their quality of life and help them to remain in the workforce. I consider it unethical to allow people to suffer continuing ill health when there is only a restricted treatment available." **- Jane Smith, Australia**

"The PA Society is better than some doctors ... it is true you have to fight to get your injections. Well done Martyn and the
PA Society ... please, please give us freedom of choice." **- June Andrew, Hull**

"The claims are correct. PA patients are having proper treatment withheld due to outdated medical "knowledge". This causes undue suffering and permanent nerve damage, which all can be avoided by teaching patients to self-inject on an "as needed" basis." **- Cory Day, USA**

"From experience I wholeheartedly agree with Mr Hooper's comments. After a few years of becoming so tired and lethargic after about 6–7 weeks of having my injection I decided to take matters into my own hands and my husband now injects me at around 7 weeks. I feel so much better and my quality of life has improved enormously. I have recently changed doctors and he has agreed to supply me with B12 and needles every 2 months – I am one of the lucky ones. When will the medical profession start listening to their patients?" **- Alex Critchlow, Berkshire**

"I wholeheartedly agree with Mr Hooper's comments. As a PA sufferer I have suffered unecessarily from a "one size fits all" mentality towards treatment. When I finally found a GP willing to treat me according to my symptoms (a rare find, believe me) I became relatively symptom-free and finally started leading a normal life. Vastly different from a couple of years ago when I started losing feeling in my feet and feared ending up like my grandmother. She had PA and ended up in a nursing home, demented with both legs amputated. All from a lack of a simple vitamin. I wonder how the cost of that nursing home compared with the cost

parents'
footsteps! But her GP sees no problem. It is time the UK followed some other countries and increased the acceptable lower level and gave treatment when it is needed. Time to educate all GPs that this is not just 'a vitamin deficiency', it is a matter of living not just being alive." **- Jack Dee, UK**

"I agree wholehearedly with the comments. I am only allowed the recommended dose allthough with nerve damage caused by late diagnosis I get 2 monthy jabs and have suffered for the last 4 weeks with the mentioned symptoms, and also nerve pain. No matter who I have spoken to in UK, from GPs to consultants, they won't budge on the guidelines." **- Maureen Gray, Scotland**

"I agree with the comments. It's a vitamin and excess is excreted. It's criminal to withhold adequate treatment from patients fo no good reason." **- C Day, USA**

"There is not enough understanding of PA in the UK, and I definately agree that patients need to be taught to self inject. I myself am B12 deficient and waiting on final diagnosis but having had my 6 loading doses I feel some improvement, although I am not due for another injection until Feb '09...in my own opinion and my own experiences this is too long to wait." **- Caroline, Cheshire**

"I agree with the claims made by Mr Hooper. Its been 8 years now since I was diagnosed with PA, I spent 6 years on "conventional" three monthly hydroxocobalamin jabs and lost one month out of three, and developed metrological problems. I just was a washout, unable to concentrate and living in a demented fog; time meant nothing and my family suffered as just driving down the road would leave me exhausted and dizzy to the extent I had to more or less stop on the road if I had gone round a round about. Having relatives abroad I found my own B12 supplies and learned to self-jab, it's taken two years but I am now just normal, with far more frequent B12 (cyanocobalamin) jabs, no regular ups or downs and able to do what any other my age can. My blood tests are only now "normal", it's taken 8 years, I feel it's not acceptable that others in the same boat are not able to get back their quality of life by these stringent (possibly out of date) BNF guidelines. Treatment guidelines in other EU countries recommend more frequent B12 jabs, maintenance once every two months being the general "norm" for hydroxocobalamin, even the manufacturer recommends one every two months as a general guide, so why are UK PA patients expected to cope with less frequent B12 jabs than other EU PA patients?" - **M Dafforn**

"I absolutely agree with Mr Hooper's comments. I think all pernicious anaemia patients should be taught to self-inject, look at the money that wouild be saved by not having to go to

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