

COMMENTS ON THE SCOTTISH GOVERNMENT'S RESPONSE TO PETITION PE1408 RELATING TO PERNICIOUS ANAEMIA

The Response of the Scottish Intercollegiate Guidance Network to the issues outlined in PE1408 is welcomed and we would like to thank the Senior Management of SIGN for their efforts. We make the following observations to specific points made by SIGN:

1. *'SIGN also welcomes the Minster's invitation to the Pernicious Anaemia Society to work with NHS Inform to ensure that information on its website is up to date and appropriate'.*

The Pernicious Anaemia Society is happy to collaborate with NHS Inform to ensure that the website's information is accurate and appropriate.

2. *'Scottish Government asks practitioners to consider using a person centred approach to treatment based on individual patient's needs, whenever appropriate, rather than a strict timescale of every 3 months'.*

Whilst this request is welcomed it is unclear whether simply asking practitioners to consider using a person centred approach will be enough to alleviate the problem faced by many sufferers of Pernicious Anaemia in getting adequate treatment. There are a number of problems with simply asking doctors to treat the patient according to his or her needs.

- i. The science to explain why some patients need more frequent injections than others simply does not exist¹. Simply relying on measuring the amount of B₁₂ in the patient's blood does not explain why the patient feels his or her symptoms returning sooner than other patients. Some doctors believe the reasons are highly complex involving *receptors, analogues of B₁₂* or something that has yet to be identified. Consequently, because of the lack of scientific explanation doctors will be reluctant to provide the patient with a patient centred treatment regime.
- ii. The current treatment regime that is adopted by most, though not all doctors comprises of a replacement therapy injection delivered by the practice nurse every three months. Many doctors will consider more frequent injections as being extra demands on nurses' time and will be reluctant to depart from the three monthly regime because of this. It should be made clear that there is every reason to believe that once a patient receives treatment according to his or her needs then the repeated visits to the surgery asking for more treatment (which will usually be declined) that is made by the patient will cease. This will lighten the load on both the doctor who will not have to investigate any other reasons for the patient's symptoms and bring an end to patients taking time off work to attend a doctor's appointment and using up valuable consultation time.
- iii. There will be a need for some supervision of this request if it is to be meaningful. Consideration should be given as to what the patient can do if his or her doctor refuses to follow the new guidelines and who he or she can turn to if this problem occurs.

¹ The Pernicious Anaemia Society is currently working with three respected Clinical Researchers to address this problem.

3. *'The Scottish Government is fully committed to ensuring that people living with long term conditions receive the care and treatment that is tailored to their individual needs and this person centred approach is one of the ambitions set out in our Quality Strategy'.*

This recommendation is warmly welcomed. The impact on the quality of life for a great number of patients who do not have access to alternative treatments that are available in the private sector will be great. There are three types of patients who will benefit from a treatment regime based on their individual needs:

- i. Young people who are in education at any level. Currently, the Pernicious Anaemia Society has to deal with young people who are in primary and secondary education who display some of the symptoms of their condition before their next injection is due. Because the family GP will assure the education authorities that the child's B₁₂ status is healthy the child is often diagnosed as having 'behavioural problems' because he or she will not want to go to school, will not want to participate in lessons and will sometimes suffer mood swings and display frustration – all symptoms of B₁₂ Deficiency.
 - ii. Elderly people who do not have anyone to speak up on their behalf and who are unable to live a full life due to their treatment that is based on a textbook rather than their needs. This will lead to a reduction in falls and a decrease in the number of dementia cases being recorded.
 - iii. Members of the prison community who have Pernicious Anaemia and/or B₁₂ Deficiency. As one prisoner told the Pernicious Anaemia Society "it's easier to get heroin in here than to get hold of B₁₂"
4. *'We recognise that some people receiving treatment for pernicious anaemia experience a recurrence of symptoms prior to when their next injection is due - as we have advised previously we would expect them to be referred to a specialist for any further investigations that may be appropriate'.*

Whilst it is good that SIGN recognises that patients often experience the symptoms of their disease returning before the next injection is due we do not believe that there is the need to refer the patient to a specialist for any further investigations to take place. The symptoms of B₁₂ Deficiency are very specific and are recognised by patients as being due to their condition. With the treatment to treat the deficiency being so cheap and totally safe (there is no danger of overdosing) we would argue that there will be no need for the patient to be referred to a specialist. Simply prescribing another injection will usually be all that is required.

5. *'As noted during the debate we expect that the British Committee for Standards in Haematology guidance will also help guide clinicians with the specific issue of frequency of treatment'.*

The Pernicious Anaemia Society is pleased to note the above and looks forward to seeing the new guidance which will, hopefully, address the specific issue of frequency of treatment. Hopefully these new guidelines will endorse SIGN's recommendation of treatment regimes based on the individual needs of patients with Pernicious Anaemia. One simple way to address this problem would be for doctors to prescribe a *Therapeutic Trial* of more frequent injections based on the patient's need. Where such trials have been instigated the patient doesn't make continual visits to the doctor complaining of the symptoms and usually settles on a stable treatment regime to the patient and the GPs advantage.

6. Finally, we would again like to mention the usefulness of the Active-B12 Test in helping to diagnose a functional deficiency when the serum test has indicated a normal blood level. Very recently we heard from a member of the PA Society whose GP, despite the patient presenting with most of the symptoms of B₁₂ Deficiency, had refused treatment as the serum level was within the normal range and the GP stated he couldn't even consider it until the level had officially become deficient. The patient managed to persuade his GP to refer him to St. Thomas Hospital in London, which is the only hospital that provides the new test for Active-B₁₂, and it indicated a functional deficiency. His GP then agreed to commence B₁₂ injections that the patient immediately benefitted from. However, it had cost the patient £200 in associated expenses, and an inconvenient trip to London to achieve this. An alternative is that doctors order a *Therapeutic Trial* as outlined above. We would be interested to know if there are any plans to introduce the Active-B₁₂ test so that it can be made available for all patients. If there are no such plans please can this issue be investigated?
7. We would like to thank the Petition Committee and the Petition Committee's Secretariat along with the Minister for Health and Health Improvement Scotland for their work in addressing the problem of adequate treatment of Pernicious Anaemia. If we can be of any further assistance please don't hesitate to contact us.

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