

Scottish Parliament - Petition: PE 1408

Petitioner - Mrs Andrea MacArthur

15th December 2014

Here are my comments in reply to the Scottish Government's recent response to my petition:

I must admit, I find this whole process deeply frustrating. Several times now I have reiterated our concerns about the present diagnosis and treatment of Pernicious Anaemia/B12 Deficiency and each time the points I made were either not acknowledged at all or no satisfactory explanation given as to why patients cannot be treated symptomatically, at least until medical research catches up with the evidence as to why so many people are presenting with this condition and requiring ever increasing levels of treatment to deal with it. I am fully aware that research is greatly lacking into this condition but this must not be used as an excuse to leave patients suffering and deteriorating further when the means to treat them effectively is already available, safe and inexpensive.

I welcome the fact that the BCSH Guidelines have been considered and that the Scottish Haematology Society will be asked to condense them into a form suitable for clinical use. It is therefore crucial that the contents of this guidance be relevant and fit for purpose so that individual patients can be treated in accordance with their particular need. I am more than willing to meet with the SHS to discuss with them the main issues that patients are facing.

At the moment, there does not seem to be any particular dedicated source of information from which GPs glean their knowledge of how to treat PA. Some do indeed take it from the BNF whilst others seem to make it up as they go along and, once it has been agreed that a patient should be given injections, the treatment varies considerably from one GP practice to another, and even between individual doctors within a surgery. Then there are practice nurses who interfere with the doctors' decisions and send patients away without their injection if they personally don't think it is justified. All of this leads to humiliation, distress, uncertainty and physical suffering, leaving the patient anxious every time they have to appear for an injection, fearing that it will be refused. This is not a rare event – we hear from people on a daily basis who experience this scenario.

I mentioned my concerns about the part of the BCSH Guidance that recommends:

'a pragmatic approach in patients with neurological symptoms by reviewing the need for continuation of alternative day therapy after three weeks of treatment.'

This, in effect, allows for only one more week of treatment than normal and cancels out the option for the patient to access this level of treatment on an ongoing basis until they have gained all possible improvement. GPs were not following it anyway but to have this restriction put upon the facility means that patients will not even be able to refer to it as an option. What has prompted this new advice to review after just three weeks? It's not as if doctors were forgetting to review patients and leaving them indefinitely on this level of treatment. No one was being offered it in the first place! Had I not been able to access this level of treatment myself, I would almost certainly not be alive today. Surely, the option of continued alternate day injections was included in the BNF because there was seen to be a need for it at the time.

Another part of the BCSH Guidelines states:

'Although there is little evidence that more frequent dosing is harmful, specific objective studies demonstrating clinical benefit are absent'

The Guidelines Working Group also say that they cannot make specific recommendations. Indeed, what guidance are GPs supposed to follow and whose responsibility is it to update it in accordance with new research etc? I'm puzzled why it is seen as permissible to further restrict treatment without evidence but not extend it when necessary. Clinical studies of benefit may not be available but the experiences of thousands of patients must surely be of clinical significance and regarded as a form of proof? The PA Society already has a properly conducted survey of almost 1,000 members, which is available to the appropriate department on request.

I would also be more than happy to provide those concerned with the link to the online support group I help run so that they can read for themselves the distressing stories posted day after day. This group now has almost 5,000 members and grows by up to 20 new members a day! It is also only one of several support groups in addition to the PA Society's support forum. This is how prevalent this problem is and it needs to be tackled as treating these patients adequately at the start helps prevent them continuing to develop worsening damage and be an increasing burden on the health service and benefits system, as well as permanently losing their health and careers.

Most people loathe injections and don't want to be frequently subjected to them but they know the enormous difference it makes to their quality of life, enabling them to function to at least some degree. There are so many other medical conditions where patients are treated in accordance with how their symptoms respond yet for some inexplicable reason those with B12 deficiency are all expected to respond in exactly the same way to the same minimal level of treatment.

It is encouraging that there is now a gradual awareness that all is not well when it comes to PA treatment but we need to take the bull by the horns and make some radical changes now to how the medical profession regards this condition and treats it. To do so is in everyone's interests.