

Factsheet Still symptomatic after treatment

1. Contrary to what most physicians believe, the symptoms of Pernicious Anaemia do not disappear once replacement therapy with Vitamin B12 has begun.
2. The Symptoms of Pernicious Anaemia vary from patient to patient, not only in terms of what the patient experiences but also in the intensity of the particular symptoms. This is true in the run-up to receiving a diagnosis but, and nobody really knows why, also after treatment has been started and the anaemia corrected.
3. The Pernicious Anaemia Society is working with clinicians and clinical researchers to promote research into why patients should be still symptomatic and to date there appear to be two main hypotheses: the first of these is that the patient has developed brain lesions when he or she was deficient in the vitamin (see Hooper 2015). This means that the patient will be permanently affected by the disease. The second train of investigation involves some very complicated bio-chemistry associated with genetic barriers preventing the cobalamin (B12) from entering the cell and the mitochondria in particular (Yue 2015).
4. The continuing symptoms of Pernicious Anaemia can be mild, which means the patient simply has to develop a coping strategy to deal with his or her condition, or severe which can and often mean that they will have a debilitating effect and will mean the patient has to make some life-changing decisions. This will involve any employer making reasonable adjustments to the patients working conditions.
5. The symptoms most commonly reported by patients already receiving treatment include the following (though it has to be remembered that different patients experience these at different intensity): continual tiredness, constant fatigue, memory loss, nominal aphasia, difficulty remembering everyday words, mood swings, irritability and anger Issues, sudden bouts of diarrhoea, low or loss of libido, desire for Isolation away from bright lights, noise and bright lights.
6. Physical symptoms can be irreversible and include: numbness in arms and legs, paraesthesia (pins and needles), electric shock like shooting pains (Lhermitte's Sign), unusual gait, inability to walk (Sub-Acute Combined Degeneration of the Cord Secondary to Pernicious Anaemia).
7. Many patients with Pernicious Anaemia also have low iron, folate and magnesium due to gastritis. If patients do not feel well after treatment it could be due to another deficiency.
8. Pernicious anemia is often found together with other autoimmune disorders, like type 1 diabetes, hypoparathyroidism, Hashimoto's thyroiditis, Addison's disease, vitiligo, and Graves' disease. If patients do not feel well after treatment it could be due to another auto-immune disease.

References

1. Hooper, M; What You Need to Know about Pernicious Anaemia And Vitamin B12 Deficiency Hammersmith Health Books; London; 2015
2. Yue et al: Structural insights into the MMACHC-MMADHC protein complex involved in vitamin B12
3. Trafficking; Journal of Biochemistry and Molecular Biology; Oct 2015