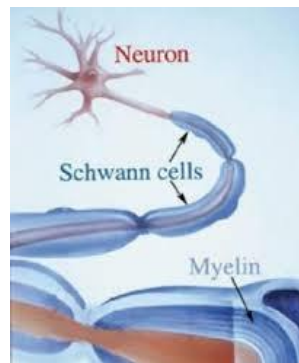


The Pernicious Anaemia Society's Information Library

PAIL 2

**SUB-ACUTE COMBINED DEGENERATION OF THE CORD
SECONDARY TO PERNICIOUS ANAEMIA**



This leaflet is for information only and is not intended as a substitute for professional medical advice.

Your doctor is the best person to advise you and you should discuss any of your symptoms with him or her.

INTRODUCTION

There are two major problems in diagnosing Pernicious Anaemia. Firstly the symptoms are *insidious* – they don't suddenly appear but gradually emerge sometimes over a very long time which means it can, and often does, take many years before the symptoms are experienced by the patient to the extent that medical advice is sought. Secondly the symptoms of Pernicious Anaemia are many and often vague and not only do they manifest themselves in different degrees of severity but also physicians often associate them as indicators of the patient having a wide variety of other diseases and medical conditions. These two problems with the symptoms of Pernicious Anaemia can, either individually or together, lead to the patient receiving a late diagnosis – and this can and does lead to damage to the patient's nervous system.

A patient with Pernicious Anaemia who has yet to be diagnosed and treated will be deficient in Vitamin B₁₂. Vitamin B₁₂ is not only needed to produce healthy red blood cells that will transport oxygen around the patient's body, but it is also needed, along with various other substances, to maintain a healthy nervous system. Left untreated the Vitamin B₁₂ Deficiency leads to damage to the insulation that surrounds nerves. This 'coating' is called the Myelin Sheath and its purpose is to speed up nerve impulses. Severe B₁₂ deficiency over a period of time leads to the Myelin Sheath wasting away – Demyelination. When the Myelin sheath withers away due to lack of Vitamin B₁₂ then the diagnosis is Sub-Acute Combined Degeneration of the Cord Secondary to Pernicious Anaemia (SACDC). The transmission of signals along nerves is compromised or entirely lost and left untreated the nerve will ultimately become useless.

SYMPTOMS

The Nervous System can be divided into two main divisions – *Peripheral Nerves* and nerves associate with the *Central Nerves* found in the spinal cord (central nervous system).

Symptoms of damage to the Peripheral Nerves (nerves of the skin):

- 'Pins and Needles' (paresthesia) especially in fingers and toes
- Heat sensitivity (symptoms worsen or reappear upon exposure to heat, such as a hot shower)
- Odd sensation in legs, arms, chest, or face, such as tingling or numbness (neuropathy)
- Burning sensation in legs and feet (Grierson Gopalan Syndrome)

Symptoms of damage to the Central Nervous System (damage to the spinal cord):

- Awkward Gait (strange walk)
- Stumbling – the need to hold on to something when walking
- Difficulty coordinating movement or balance disorder
- Inability to stand up straight with eyes closed
- Loss of dexterity

- Sudden ‘electric shocks’ running down the body following a sudden forward head movement - Lhermitte's sign - (also called the Barber Chair Phenomenon)
- Blurriness in the central visual field that affects only one eye, may be accompanied by pain upon eye movement
- Double vision
- Loss of vision/hearing
- Weakness of arms or legs
- Cognitive disruption, including speech impairment and memory loss
- Difficulty controlling bowel movements or urination
- Irritability and lack of patience

Patients will experience some or all of the above symptoms but to varying degrees of intensity. The symptoms are very similar to those of Multiple Sclerosis which leads to many patients being investigated for that condition and, in some cases initially being diagnosed with MS. But it is the absence of healthy levels of Vitamin B₁₂ combined with the above symptoms which leads medical professionals to diagnose SACDC.

CONFIRMING THE DIAGNOSIS

The doctor will conduct simple tests to determine the extent of the damage to the patient’s nervous system including the *Sharp/Blunt Test* where a sharp and then blunt object is placed on the skin and the patient has to differentiate between which of the two objects are being used by the doctor.

The *Finger to Nose Test* is also used to determine the extent of the nerve damage by asking the patient to slowly touch their extended finger to their nose to evaluate coordination.

Tuning Forks can be used to provide more information about the damage to the nerves as will the patient’s ability to walk ‘heel to toe’ and will help the doctor to determine the extent and type of damage that has occurred to the patient’s nervous system.

Nerve Conduction Tests can also be used which involve tape measures and electrical signals that will allow doctors to determine the extent of the damage to the central nervous system.

A *Magnetic Resonance Image* scan (M.R.I.) is sometimes used to ensure no other medical conditions exist.

Defining the Diagnosis

So what exactly does ***Sub Acute Combined Degeneration of the Cord Secondary to Pernicious Anaemia*** mean?

Sub-Acute refers to the fact that the problem is not acute (short-term) nor is it chronic (long-term) in that now any B₁₂ deficiency has been corrected hopefully no *further* damage will occur. Thus the condition is not chronic in the sense that the cause of the problem has been identified and hopefully some nerves will repair themselves. (There is some evidence that the use of one particular type of artificial B₁₂ – Methylcobalamin – can and does promote repair to the damage caused to the Myelin Sheath by low B₁₂ levels – but Methylcobalamin is not licensed for use in the UK or North America).

Combined means that both the peripheral and central nerves have sustained damage.

Degeneration means that the nerves have not continually renewed themselves as they are supposed to do and have withered away to some extent or other.

Of the Cord refers to the spinal cord – the super-highway through which nerve impulses travel.

Secondary to Pernicious Anaemia means a product of, or caused by way of, Pernicious Anaemia.

Patient Experiences

The patient with SACDSC will experience all the difficulties of Pernicious Anaemia as well as some, or all, of the following:

- Difficulty in performing daily tasks such as washing hair in the shower or putting on underwear or hosiery - this is due to the balance problems encountered.
- Walking in the dark. Because the patient's internal balance mechanism may be damaged the sufferer will use fixed objects to focus on in order to compensate for the lack of internal balance. These objects are not visible in the dark and so the patient encounters problems when walking.
- Shoe-staring – not a style of music but the need to look at the ground when walking as the ground provides a fixed object on which to focus. This can lead to posture and back problems.
- Inability to run or jog. The nerves are simply unable to transmit the signals needed fast enough from the brain to the muscles.
- Tripping, stumbling and falling – this is especially true if the peripheral nerves in the feet and lower legs are damaged. The patient is unable to feel any obstacles or potential obstacles. This is especially true when walking in the countryside where brambles, ivy and vines are particular problems.
- Extreme vertigo associated with heights. Looking at a void, over a cliff or to the side of high bridges for example, means that there is no focal point on which to concentrate which leads to giddiness and a feeling of vulnerability.

Treatment

In the UK the British National Formulary – the reference work that doctors refer to that states how medical conditions should be treated – advises that where there is any “neurological involvement” with Pernicious Anaemia then the treatment should be a 1mg/ml injection of Hydroxocobalamin (B₁₂) “every other day until there is no further improvement”.

Unfortunately there are two problems with the patient who has neurological damage getting the treatment he or she should be receiving. Firstly not many doctors are aware that the BNF makes the difference between treating Pernicious Anaemia and treating Pernicious Anaemia where there is any neurological involvement. Secondly, some doctors are reluctant to identify some symptoms being experienced by the patient as being due to neurological issues. These include the memory loss, forgetting everyday names for things (nominal aphasia), mood swings, irritability etc. These are as much due to neurological involvement as any numbness, balance problems and pins and needles but some doctors are reluctant to consider them to be so.

SUPPLEMENTARY TREATMENT THERAPIES

*You should always tell your doctor you are considering any of the following and any other additional and complementary therapies **before** you embark on any alternative treatment programme.*

Many sufferers report that their peripheral nerve damage improved after attending regular back massages and hot stone therapies. Others benefit from having a Jacuzzi or Sauna.

Using running machines that begin slowly and progressively speed up to jogging or running speeds can be of benefit but only if the machine is provided with handrails that the user can hold onto. **Again, this should not be attempted individually but should be supervised and assessed by a professionally qualified Fitness Consultant.**

Meditation can also help to focus the brain and relieves stress, worry and anxiety that the patient may be experiencing on diagnosis. Mental exercise and stimulation such as crosswords or puzzles have also been shown to benefit some patients. However, on 'fog days' this will be a real struggle for the patient.

For Further Information see

Pernicious Anaemia: the forgotten disease. The Causes and Consequences of B₁₂ Deficiency by Martyn Hooper. Hammersmith Health Books 2012

Could it be B₁₂? An Epidemic of Misdiagnoses by Sally M. Pacholok and Jeffrey J. Stuart; Quill Driver Books 2011

If you have any concerns, please visit
www.pernicious-anaemia-society.org
or call us on 01656 769717.

Ends

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