

Pernicious
Anaemia
Society



The Pernicious Anaemia Society
Information Library

Sub-Acute Combined Degeneration of the Cord Secondary to Pernicious Anaemia

This information is for guidance only.

Any symptoms and treatment regimes should always be discussed with your doctor.

Sub-Acute Combined Degeneration of the Cord Secondary to Pernicious Anaemia.

Pernicious Anaemia has two main characteristics that can often lead to a late diagnosis. The first of these characteristics is that the condition is insidious. It can take many years before the symptoms of the condition are experienced to the extent that medical advice is sought. The second is that the symptoms of the disease are often associated with other medical conditions which often lead medical practitioners to suspect the patient is developing, or has developed, a quite different disease. These two characteristics, on their own, or together, can lead to a late diagnosis or even a wrong diagnosis and this means that, left untreated, Pernicious Anaemia can lead to irreversible damage to both peripheral nerves and the central nervous system.

Not only is vitamin B12 essential to maintain healthy red blood cells that can efficiently carry oxygen in the blood, but also it is needed, along with other substances, to help maintain a coating around nerves called the Myelin Sheath. This coating helps speed-up the electrical impulses that travel along the nerves. When the Sheath is destroyed (demyelination) the nerve signals are seriously compromised and the damage is often permanent. However, there have been cases of the sheath repairing itself and the patient makes a full recovery.

SYMPTOMS:

The first set of symptoms are shared with those of Pernicious Anaemia namely:

Extreme Tiredness, Fatigue, Lethargy.

Fogs—lack of clarity in thinking and understanding as if everything is being experienced in a fog.

Breathlessness—not panting for breath but taking sighs and deep breaths.

Confusion—owing to the fogs.

Memory Loss-short term.

Inability to recall names of objects and people-this leads to frustration.

Repetition of questions.

Mood swings and general irritability and impatience.

Tear Jags - unaccountable crying or wanting to cry.

Brittle nails.

This list is not exhaustive but it includes the main symptoms that members of the society have identified as being the commonest ones experienced.

Sub-Acute Combined Degeneration of the Cord Secondary to PA Symptoms will also include:

1. Peripheral Nerve Symptoms (the nerves felt by the skin).

Numbness in areas such as the feet, legs and arms.

A sensation of swelling as if an area of the body is bigger than it is.

Inability to differentiate between hot and cold.

2. Central Nervous System Symptoms (damage to the Spinal Cord):

Awkward Gait (strange walk).

Stumbling.

Loss of Balance-the need to hold on to something to walk.

Inability to stand upright with closed eyes.

Confusion and disorientation.

Memory Loss.

Irritability and lack of patience along with frustration.

Patients will experience these symptoms, maybe just one or perhaps all of them in varying degrees.

These are symptoms that lead many doctors to suspect that the cause to be Multiple Sclerosis or other associated diseases. But it is the link between the absence of B12 and the Nerve Damage which leads to professionals diagnosing Sub-Acute Combined Degeneration of the Cord Secondary to P.A.

CONFIRMING THE DIAGNOSIS:

The doctor will conduct simple tests to determine the extent of the damage including the Sharp/Blunt test where a sharp and then blunt object is placed on the skin and the patient has to differentiate between the two.

Tuning Forks will be used to provide more information about the damage to the nerves and walking 'heel to toe' will help determine the extent and type of damage.

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

M.R.I. Scan. This is sometimes used to ensure no other medical conditions exist.

Finger to Nose Tests—to determine the extent of the nerve damage.

DEFINING THE DIAGNOSIS.

Sub-Acute refers to the fact that the problem is not Acute (short-term) but 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.

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

De-generation means that the nerves have not continually renewed themselves as they are supposed to do and have withered.

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 Sub-Acute will experiences 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.

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.

TREATMENTS

Members of the society have reported positively on various treatments that can help the patient manage their condition:

Note—any course of treatment should only be started with the full support of your doctor.

As well as **more regular injections of B12** than the normally administered tri-monthly intervals (as either Cyanocobalamin or Hydroxocobalamin) the patient should also regularly have their Folate, Iron and Potassium levels checked with their medical practitioner.

Massage - many sufferers report that their peripheral nerve damage improved after attending regular back massages. This should be discussed with your doctor before proceeding with this course of action.



Gym sessions - 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 - this helps 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. On *fog days* this will be a real struggle for the patient.