FOUNDATIONS OF MS NURSING

GLOSSARY

MS AUSTRALIA

MS Nurses Australasia Inc

IOMSN International Organization of Multiple Sclerosis Nurses

General MS Terms

Clinically isolated syndrome (CIS) is diagnosed when a person has experienced a single episode of neurologic symptoms. While not everyone that experiences CIS will actually go on to develop MS, about 70% of people will.

Epstein-Barr virus (EBV) is a very common viral infection that spreads through bodily fluids, especially saliva. Most cases of EBV don't cause symptoms. Other cases, especially in adolescents and young adults, can lead to infectious mononucleosis (also known as mono or glandular fever). Close to 100% of people diagnosed with MS have been infected with EBV.

Lhermitte's phenomenon are intermittent shock-like feelings in the neck and back, extending into the arms and legs. It is often triggered by bending the neck forward.

McDonald criteria are guidelines to help clinicians provide an accurate diagnosis of MS. They were first developed in 2001, have been updated several times to account for new information about the disease, and were last updated in 2024.

Myelin is a white fatty substance that surrounds the axon of some nerve cells. The myelin sheath forms an electrically insulating layer. It is essential for the proper electrical conduction of nerve signals along nerve axons. The production of the myelin sheath is called myelination.

Primary progressive MS (PPMS) is diagnosed in approximately 10-15% of people with MS. PPMS is characterised by a progressive worsening of symptoms and disability right from the beginning, without periods of recovery or remission. Relapses for most people are possible, but not common. Additionally, there can be periods of "plateau" where progression can stabilise for a period of time.

Pseudo relapse (or exacerbation of old symptoms) are symptoms not due to new inflammation or progression and generally caused by triggers such as infection, stress, heat, sleep deprivation.

Relapse is a period of worsening symptoms that can either be new symptoms or the return or worsening of existing ones that last over 24 hours and are usually persistent due to new inflammation.

Relapsing remitting MS (RRMS) is the most common form of MS. About 85% of people with MS are diagnosed with RRMS. It is caused by flare ups or exacerbations of the neurological symptoms of MS, also known as relapses, followed by periods of recovery or remission.

Radiologically isolated syndrome (RIS) refers to when a person presents signs of MS upon scans, despite not experiencing any symptoms nor having had a history of demyelination.

Secondary progressive MS (SPMS) is a secondary phase of relapsing remitting MS that can develop years to decades following the initial onset of symptoms. SPMS is characterised by a reduction in relapses and a progressive worsening of symptoms (accumulation of disability) over time, with no obvious signs of remission.

T cells also known as T lymphocytes, are a type of white blood cell in the immune system. T cells can be further divided into subcategories, including T helper cells, cytotoxic T cells, and memory T cells. Together they help form a full immune response against invading objects or microorganisms.

T1 and T2 are MRI techniques that use different timing between magnetic pulses to produce images of the brain and spinal cord. These techniques highlight different tissue features and are used to assess different aspects of disease. T1 and T2 lesions refer to lesions that are visible using these respective MRI methods. T1 MRI images supplies information about current disease activity by highlighting areas of active inflammation, while T2 MRI images reflect the overall disease burden, showing the total amount and extent of lesions, both old and new.

Test results

Evoked potentials are diagnostic tests done using stimulation of the special senses, such as seeing, hearing and feeling, to assess the function in these central nervous system (CNS) neural pathways.

Gadolinium is a contrast agent injected during an MRI to improve image clarity.

Lesion is an area of abnormal tissue or scarring (sclerosis) of the brain tissue, spinal cord or optic nerve due to a previous inflammatory attack.

Lumbar puncture is a diagnostic test for MS that involves removing and analysing a sample of cerebrospinal fluid (CSF), the fluid that surrounds the brain and spinal cord within the skull and backbone. It is also known as a spinal tap. The fluid is then examined to see whether there is a higher-than-normal white blood cell count and/or higher levels of antibodies (also known as oligoclonal bands due to the test carried out on the fluid).

Magnetic resonance imaging (MRI) is a medical imaging procedure. It uses a magnetic field and radio waves to take pictures of the inside of the body.

Neurofilament light is a blood and cerebrospinal fluid (CSF) biomarker for monitoring neuronal damage, reflecting disease activity, relapse risk, and treatment response.

Non-enhancing lesion is a lesion that does not light up during an MRI, following the injection of gadolinium. These are likely to be older lesions that indicate the person has had MS for a longer period of time.

Oligoclonal bands are bands of antibodies that are seen in a person's blood serum, or when cerebrospinal fluid (CSF) is analysed. They are an important indicator in the diagnosis of MS. More than 95% of people with MS have permanently observable oligoclonal bands.

Optical Coherence Tomography (OCT) is a non-invasive, rapid imaging test used in MS to measure retinal nerve fiber layer (RNFL) and ganglion cell-inner plexiform layer (GCIPL) thinning.

Pons is a part of the brainstem, a structure that links the brain to the spinal cord. It handles unconscious processes and jobs, such as the sleep-wake cycle and breathing. It also contains several junction points for nerves that control muscles and carry information from senses in the head and face.

Symptoms

Ageusia is the loss of taste functions on the tongue, which means you lose the ability to distinguish what is sweet, sour, bitter, or salty.

Allodynia is a high sensitivity to touch, resulting in intense pain even with minimal contact, and refers specifically to a painful response to a normally innocuous stimulus. Allodymia is a specific type of dysesthesia, which is the abnormal sense of touch.

Anxiety is the most common mental health disorder. It is characterised by constantly feeling or showing worry, nervousness, or unease about something. It can also cause fatigue, restlessness and hypervigilance resulting from excessive worry and/or fear, which in turn can affect the ability to concentrate, sleep and carry out ordinary tasks.

Ataxia is the incoordination and unsteadiness that result from the brain's failure to regulate the body's posture and the strength and direction of limb movements. Ataxia is most often caused by disease activity in the cerebellum (the part of the brain at the back of the skull).

Bladder dysfunction is a breakdown in the communication between nerves and the bladder.

Brain Fog is a common symptom of MS and is a term used to describe forgetfulness, trouble concentrating, and confusion.

Cognitive Impairment is the noticeable decline in memory, learning, language, thinking or judgment, and memory. Also known as brain fog.

Contracture is a permanent shortening of the muscles and tendons adjacent to a joint, which can result from severe, untreated spasticity and interferes with movement around the joint.

Depression is a mental health condition characterised by a persistently depressed mood or loss of interest in activities, causing significant impairment in daily life.

Dysaesthetic extremity pain is an unpleasant abnormal sensation such as burning, tingling, vice or band-like sensation. It may be worse at night or with physical activity and can occur anywhere in the body.

Dysathria is a reduced control of the speech muscles resulting in slurred speech. It is often associated with damage to the nervous system.

Dysesthesia is an unpleasant abnormal sense of touch. It can present as pain, such as allodymia, but it may also present as abnormal response to touch, such as burning, wetness, itching, electric shock, pins and needles, and can affect any body part.

Dysmetria is the lack of coordination of movement and is a subtype of ataxia. Dysmetria is characterised by when the limb undershoots or overshoots the intended position. It is sometimes described as an inability to judge distance or scale.

Dysphagia is problem swallowing, which can be a symptom of MS resulting from loss of control over the muscles controlling the pharynx or oesophagus (the tube leading from the mouth to the stomach), or loss of sensation of the pharynx, leading to disruption to the swallowing mechanism.

Dysphonia refers to abnormal voice production and may occur when neurological changes affect the muscles or nerves involved tin controlling the voice. This can include issues with pitch control and hoarseness of the voice amongst other symptoms.

Fatigue is a feeling of constant tiredness or weakness and can be physical, mental or a combination of both. It is distinct from and more debilitating than general feelings of sleepiness or physical tiredness. Fatigue is the most commonly reported symptom of MS.

Hypogeusia is a reduction in ability to detect sweet, sour, bitter, or salty tastes.

Incontinence is the loss of control of bladder or bowel function, resulting in involuntary leakage of urine or stool.

MS hug is a band of tight pain around the torso that can range from dull and achy to sharp and burning. The pain can sometimes make it hard to breathe, giving it the nickname "MS girdle."

Primary symptoms are the complications that arise as a direct result of damage to the central nervous system, for example, bladder dysfunction.

Secondary symptoms are the complications that arise as a result of these primary symptoms, for example, bladder dysfunction can cause repeated urinary tract infections.

Tertiary symptoms are the ‘trickle down’ effect of the disease, for example, problems with bladder control may cause people to withdraw from social interactions leading to isolation, depression and anxiety.

Uhthoff’s phenomenon is the worsening of MS symptoms when the body gets overheated, whether it be from hot weather, exercise, fever, or saunas and hot tubs.

Treatments

Autologous Haematopoietic Stem Cell Transplant (AHSCT) refers to a treatment scheme where a person's haematopoietic (or blood) stem cells are isolated from their bone marrow, before their immune system is removed either by chemotherapy. The person's own haematopoietic stem cells are then reintroduced back into their body to rebuild the immune system.

Disease modifying drugs (DMDs) or **Disease modifying therapies (DMTs)** are treatments which slow down or reduce the damage caused by MS, as opposed to symptom modifying treatments which work to control the symptoms.

High efficacy therapies are newer MS medications that are powerful in reducing MS activity and slowing disease progression but also tend to carry potential safety risks.

Low efficacy therapies are also effective in reducing disease activity but generally have more modest effects and may have longer-established safety profiles .

Therapies

Alternative therapies are treatment options outside the orthodox range, that may be used in place of conventional treatments.

Complementary therapies are a range of approaches to care aimed at enhancing quality of life and improving wellbeing, that are generally used in conjunction with conventional medical treatments.

Expanded Disability Status Scale (EDSS) is a scoring system for quantifying the impairment brought on by MS and includes measurements assessing weakness of limbs, tremor, speech and swallowing difficulties, numbness, bowel and bladder function and visual function amongst others.

Interferons are signalling molecules (cytokines) that are found naturally in the body. They are released by cells in response to the presence of foreign objects. Interferon beta can also be manufactured as a drug and is used as a treatment for MS; it is thought to act to reduce MS symptoms by modulating inflammatory signals.

Symptomatic therapies address specific symptoms of MS, such as incontinence, muscle spasticity, pain, or depression, improving quality of life by targeting particular challenges associated with MS.

Treatment switch is the practice of moving from one DMT to another. This may be due to inadequate disease control, adverse effects of the first treatment, changes in life circumstances (such as pregnancy planning), or a preference for a new DMT or method of delivery (for example subcutaneous injection).

IOMSN has reviewed this project that was developed by Therese Burke as a resource for MS Nurses. IOMSN has concluded that this project is fair balanced and accurate and is valid for educational purposes.