



Neuropathy
Action →
Foundation
Awareness • Education • Empowerment

A Guide to Neuropathy

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The Neuropathy Action Foundation (NAF), a 501(c)(3) non-profit, is dedicated to ensuring neuropathy patients obtain the necessary resources, information and tools to access individualized treatment to improve their quality of life. The NAF increases awareness among physicians, appropriate institutions, the general public and public policy officials that neuropathy can potentially be a serious, widespread and disabling condition, which may be treatable when appropriate medical care is provided.



Our Vision

The Neuropathy Action Foundation (NAF) will be a premiere patient advocacy organization ensuring that neuropathy patients have access to individualized medications, IVIG and other treatments through patient empowerment and advocacy.

Our Goals

Patient Empowerment: The NAF educates and assists neuropathy patients on how to become informed advocates for their healthcare.

Public Awareness and Physician Education: The NAF actively supports programs that create public and physician awareness of neuropathy, the use of IVIG and other remedies to improve patient care through NAF activities and services.



What Is Neuropathy?

Neuropathy means disease or abnormality of nervous system. Neuropathies can be sensory, motor or autonomic. Sensory nerves give us information about the position of our joints, pain and temperature. Motor nerves stimulate muscle contraction and movement. Autonomic nerves control functions that our bodies don't consciously regulate, such as sweating, certain bowel and bladder functions, and heart rate.

Symptoms of neuropathy depend on both the type of nerves affected and the mechanism that causes damage to the nerves. The most common presenting symptom is the combination of numbness and tingling in the toes and feet. Less common neuropathies can cause weakness or clumsiness, and it may be difficult to do certain activities, such as raising an arm over the head, getting up from a seated position or walking up stairs.

If you experience such symptoms, your doctor will likely refer you to a neurologist, who specializes in the diagnosis and treatment of these disorders. Neurologists with specialized training in neuromuscular diseases usually have the most experience in the diagnosis and treatment of neuropathy. A neurologist should take a detailed history about the type of symptoms and timing, perform an in depth neurological examination and order various tests such as an EMG (electromyography) and nerve conduction studies. This will help determine the cause and best course of treatment.

The information that follows will give you a better understanding of different types of neuropathies, their causes, symptoms, treatments and outcomes. Remember that symptoms can be similar in different types of neuropathies, which can make diagnosis challenging. This is why a thorough work up is so important. Feel free to discuss this information with your neurologist.



What Does A Complete Neurological Exam and Workup Consist Of?

Complete health history: This includes questions about your symptoms, including type, onset, duration and location. Specific details about what brings on the symptoms, what relieves them and the types of sensations that occur serve as clues to the diagnosis. A complete list of medications should

also be provided in case the medication itself is the cause of the neuropathy.

Neurological evaluation: In addition to the history of the symptoms, the neurologist will also examine reflexes, strength and the ability to feel various sensations. Again, this aids in an overall diagnosis.

Blood tests: Certain lab tests can help determine the cause of the neuropathy. This may include tests for vitamin deficiencies, immune responses, blood sugar levels and the presence of toxins or infections.

EMG: An EMG, or electromyography, electronically measures and records muscle activity. This tells the neurologist the location of any muscle, nerve or neuromuscular junction damage as well as its cause.

Nerve conduction studies: This test measures the size and speed of electrical signals as they pass along the nerves. This tells the neurologist of any abnormality of the nerves. EMG and nerve conduction studies usually go hand in hand.

MRI: An MRI (magnetic resonance imaging) may be performed to rule out any other causes of the neuropathy, such as trauma or nerve entrapment and sometimes to show inflammation along the nerves.

Lumbar puncture: A spinal tap or lumbar puncture can determine the presence of protein and cells in the spinal fluid. This test is usually done if the doctor thinks the nerves are affected by inflammation.

Nerve, muscle or skin biopsy: A small piece of nerve, muscle or skin can help determine the cause of the damage. These tests are only done if the doctor suspects very specific conditions.



What Is Idiopathic Neuropathy?

Idiopathic means of no known cause. This type of neuropathy is very common, making up about a third of all neuropathies. This diagnosis simply means that the exact causative factor is unknown. This may sound confusing, but an experienced neurologist can tell you about the prognosis and treatments of this common condition.

Symptoms include numbness, tingling and pain starting in the toes and feet. Balance when standing or walking may be affected. There may also be muscle cramps. Once the neurologist rules out other

causes and identifies the neuropathy as idiopathic, a treatment plan is formulated, which usually consists of over-the-counter pain medications, as needed, and safety precautions due to balance issues and loss of sensation. The neurologist should also give reassurance that patients with idiopathic neuropathy have very slow progression and do not develop disability with time.



What Is Diabetic Neuropathy?

Diabetic neuropathy occurs in patients with diabetes mellitus who have uncontrolled blood sugar levels. Sensory, motor and autonomic nerves can be affected, so symptoms can include numb and painful feet, weakness, indigestion, constipation, dizziness, bladder problems and impotence.

Workup may include EMG and nerve conduction studies, blood work to check sugar levels and a thorough neurological assessment. Treatment depends on which nerves are affected and the type of symptoms and problems that the person experiences. The first step is to maintain blood glucose levels within normal limits through compliance with diabetic medications and diet. It is vital to prevent further damage and problems from occurring. Further intervention can include proper foot care, treating indigestion and constipation with medications and dietary management, possible antibiotics for any bladder infection and pain relief.

Charcot-Marie-Tooth (CMT) Disease is the most common hereditary disorder and affects both motor and sensory peripheral nerves. Symptoms include weakness and atrophy in the feet and lower legs and in the hands in more severe cases. Deformities of the foot result from loss of muscle bulk and changes in the shape of the bone structure. These are usually called “pes cavus.” Symptoms usually appear in the teenage years or early to mid-adulthood. Progression is very slow.

There are many different types of CMT depending on the part of the nerve affected. Some types of CMT are caused by damage to the nerve itself, other types are caused by damage to the coating of the nerve, which is called myelin.

Treatment includes physical and occupational therapy, use of leg braces and use of other assistive devices to facilitate safety and to help offset some of the deformities that can occur.

Hereditary Neuropathy with Liability to Pressure Palsies is a disorder that makes someone more susceptible to pinched nerves, like carpal tunnel syndrome. These patients sometimes sustain excessive damage to nerves from moderate trauma, like sleeping the wrong way on a nerve. Symptoms can last longer and occur more frequently than a limb just “falling asleep.”

Diagnosing a hereditary neuropathy may include a comprehensive history that reveals the episodes of



What Is Hereditary Neuropathy?

Hereditary neuropathies are genetic in origin, meaning that they are passed through the genes. Examples include Charcot-Marie-Tooth Disease and Hereditary Neuropathy with liability to Pressure Palsies.

numbness or weakness and nerve conduction tests that show a very specific abnormality. Genetic blood testing is used to confirm the diagnosis. Treatment consists of education about the risk factors, and ergonomic training to avoid pressure-related and repetitive movement injuries from everyday activities.

What Is Immune or Inflammatory Neuropathy?

There are conditions where nerves are “attacked” by someone’s own immune system. Several types of inflammatory neuropathies may occur. The two most common are Chronic Inflammatory Demyelinating Polyneuropathy (CIDP) and Multifocal Motor Neuropathy (MMN). There are also several variants of CIDP.

CIDP causes weakness and sensory abnormalities that usually develop over several months. The disease can stop progressing, and relapses and remissions can occur. The severity of CIDP can vary from mild to severe and it can affect any age group and either gender. Normally, CIDP is not painful, although some patients complain of unusual or troubling sensations.

MMN is a disorder characterized by weakness and muscle atrophy that usually affects the hands. MMN can cause minimal weakness in just a few muscles, or may be relatively severe weakness in all limbs. Because it only affects strength, but not sensation, MMN is sometimes mistaken for ALS (Amyotrophic Lateral Sclerosis, or Lou Gehrig’s disease). Unlike ALS, MMN is an immune neuropathy and responds to the same treatments.

In both MMN and CIDP the attack occurs against the myelin sheath, which surrounds the nerve and provides insulation for nerve conduction. The attack can also interfere with specialized “ion channels” in nerves that help electrical signals pass up and down the long processes. As a result, electrical impulses that carry the electrical signals are damaged.

The diagnosis of these disorders depends heavily on nerve conduction studies that prove nerve signals are abnormal. They also depend on a complete examination of the nervous system by a specialist who can recognize the unusual patterns of muscle weakness and sensory loss. A lumbar puncture is sometimes needed to check for high protein levels and, in rare cases, a nerve biopsy may be required. For MMN, a specialized blood test called anti-GM1 antibodies is useful if it is positive.

One common treatment for MMN and CIDP is called IVIG (Intravenous Immunoglobulin). IVIG is FDA-approved for both conditions. Insurance companies often have strict criteria that must be met in

order for IVIG to be covered. Many, but not all, cases will improve and the symptoms will decrease within a few weeks to a few months after IVIG is started. IVIG is given at intervals ranging from every two weeks to every other month. Responses tend to wear off so treatments need to be repeated.

Because diagnosis can be difficult, some doctors consider the first few treatments with IVIG as part of the diagnosis. Patients who do not respond probably have a different type of neuropathy. Since IVIG is also very expensive, and the diseases can stabilize, it is important that the neurologist check for responses regularly to determine whether ongoing treatments are needed and what doses are necessary.

A steroid called Prednisone is often used to treat CIDP as well. Prednisone causes more side effects than IVIG but also works well to treat the disease. Prednisone cannot be used for MMN, since it does not work for that particular neuropathy. There are other medications that can treat immune neuropathy, and these may be used when the condition is severe or difficult to treat.

Treatment of Painful Neuropathies

Pain is an important symptom of neuropathies that affect sensory fibers. The pain can be described as burning, lancinating, tingling, or shock-like. There are several medications that are specialized for managing nerve type pain. These include Elavil, Neurontin, Lyrica® and Cymbalta®, to name a few. More severe cases may require stronger narcotic medications.

Other Causes of Neuropathy

There are numerous other types of less common neuropathies that we have not discussed above. Neuropathy may be caused by certain vitamin or mineral deficiencies, medication toxicity such as chemotherapy, alcohol abuse, certain infections, and as a symptom of other systemic illnesses.



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