



PERIPHERAL NEUROPATHY

WHEN THE NUMBNESS, WEAKNESS, AND PAIN WON'T STOP

AN AMERICAN ACADEMY OF NEUROLOGY PRESS QUALITY OF LIFE GUIDE

Norman Latov, MD, PhD



A GUIDE FOR PATIENTS AND FAMILIES

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Peripheral Neuropathy

*When the Numbness, Weakness,
and Pain Won't Stop*

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Dedication

This book is dedicated to the memory of Mary Ann Donovan, a dear friend, and founding president of the Neuropathy Association, whose caring, courage, and grace inspired and brought hope to people with neuropathy everywhere.

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About the AAN Press Quality of Life Guides

IN THE SPIRIT OF THE DOCTOR-PATIENT PARTNERSHIP

THE BETTER-INFORMED PATIENT is often able to play a vital role in his or her own care. This is especially the case with neurologic disorders, for which effective management of disease can be promoted—indeed, *enhanced*—through patient education and involvement.

In the spirit of the partnership-in-care between physicians and patients, the American Academy of Neurology Press is pleased to produce a series of “Quality of Life” guides on an array of diseases and ailments that affect the brain and nervous system. The series, produced in partnership with Demos Medical Publishing, answers a number of basic and important questions faced by patients and their families.

Additionally, the authors, most of whom are physicians and all of whom are experts in the areas in which they write, provide a detailed discussion of the disorder, its causes, and the course it may follow. You also find strategies for coping with the disorder and handling a number of nonmedical issues.

The result: As a reader, you will be able to develop a framework for understanding the disease and become better prepared to manage the life changes associated with it.

ABOUT THE AMERICAN ACADEMY OF NEUROLOGY (AAN)

The American Academy of Neurology is the premier organization for neurologists worldwide. In addition to support of educational and scientific advances, the AAN—along with its sister organization, the AAN Foundation—is a strong advocate of public education and a leading supporter of research for breakthroughs in neurologic patient care.

More information on the activities of the AAN is available on our website, www.aan.com. For a better understanding of common disorders of the brain, as well as to learn about people living with these disorders, please turn to the AAN Foundation's website, www.thebrainmatters.org.

ABOUT NEUROLOGY AND NEUROLOGISTS

Neurology is the medical specialty associated with disorders of the brain and central nervous system. Neurologists are medical doctors with specialized training in the diagnosis, treatment, and management of patients suffering from neurologic disease.

Lisa M. Shulman, M.D.
Series Editor
AAN Press Quality of Life Guides

Foreword

NEUROLOGISTS WANT TO HELP patients adjust to—and live with—chronic neurological disease. Peripheral neuropathy is one such condition, which may be caused by many different diseases. One of the most common diseases associated with neuropathy and the current trend of rampant obesity in the United States is diabetes mellitus. However, there are at least 100 other conditions that could lead to neuropathy. Another disease that can lead to neuropathy is Guillain-Barré syndrome, which is a model of those diseases induced by an abnormal immune response. In Guillain-Barré syndrome the patient's immune system attempts to protect the body against infectious bacterium or virus and instead attacks the nerves of the patient. Other so-called “autoimmune” neuropathies are common, and vitamin deficiencies or endocrine diseases are some other factors that can contribute to neurological disease. The word “peripheral” differentiates these conditions from nerves of the brain and spinal cord, which make up the “central nervous system” (CNS). The word “neuropathy” is derived from two Greek words, *neuro* meaning “nerve” and *pathology* meaning the “study of abnormality.”

Peripheral neuropathy may be a mild annoyance or a life-threatening condition. Weakness of the legs may cause difficulty in walking and weakness of the hands can interfere with daily functions such as eating and dressing. Sensation can be impaired leading to an abnormal feeling of numbness and tingling. The bladder can be affected and there may be abnormalities of blood pressure or the heartbeat. Each of the component sets of symptoms can be mild or severe. Some are amenable to treatment and some are resistant. It is my hope that patients who read this book would be able to better understand their illness and available forms of treatment.

The chapters in this book follow a logical progression: defining terms, describing the structure of nerves and how their functions can be distorted, defining symptoms, how the diseases are diagnosed, the dif-

ferent causes, and treatment. This information will be useful in helping patients understand the nature of their symptoms, why specific diagnostic tests are done, and what options are available in the treatment of their disease. The patient will feel better informed and, in many cases, will want to take a more active role in plans for treatment with their neurologist. The book culminates with a unique section of stories written by patients themselves, a dose of reality. These stories are told from the perspective of people living with the disease, in the hope that their experiences will be useful to others.

Dr. Norman Latov is an expert on autoimmune neuropathy and all other aspects of neuropathy. He is devoted to helping patients with neuropathy and he was the driving force behind the formation of The Neuropathy Association, an advocacy organization that works to improve care and provides patients with the latest information in the treatment of their disease. This book is another example of Dr. Latov's commitment in helping the patient to gain a better understanding of the diagnosis and treatment of their disease.

Neurologists are physicians who are trained to care for patients with neuropathy. It is therefore fitting that this book is being published as part of a series of books by the American Academy of Neurology that are written by experts and designed for patients, not physicians. This book will be useful in helping the many thousands of people who have incurred various symptoms of neurological disease and provide them with information on the care and treatment of peripheral neuropathy.

Lewis P. Rowland, MD
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Preface

IF YOU ARE READING THIS BOOK, chances are that you either have peripheral neuropathy or know someone else who does. Otherwise, you probably would have never heard of it. Although neuropathy is common, estimated to affect 10–20 million people in the United States, most people have never heard of it, and it is difficult to obtain information about the disease.

This book is intended for people with neuropathy, their families or friends, and those who care for them. It reviews what we know about neuropathy, including its causes and manifestations, and what can be done about it. The book also includes stories written by people with neuropathy, who were willing to share their personal struggles with the disease in the hope that their experiences will help others.

Norman Latov, MD, PhD

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CHAPTER 1

Introduction: What Is Peripheral Neuropathy?

*P*ERIPHERAL NEUROPATHY REFERS to any affliction of the peripheral nerves. These nerves span the body, similar to wires in an electrical network, and connect the skin, joints, muscles, and internal organs to the brain and spinal cord, which make up the central nervous system. *Peripheral* refers to the fact that these nerves lie outside the central nervous system, so that they are distinguished from central nerves.

The symptoms of neuropathy can vary, but they constitute a limited repertoire. If you talk to ten people with neuropathy, you may hear ten different sets of symptoms, but if you ask another 100, you will probably hear the same ten. The symptoms can be subtle at first, with numbness or tingling in the toes, a sensation as if you are wearing socks and gloves, or that you are walking on sponges or rolled-up socks. You might step on a sharp object or cut yourself, and realize that you do not feel

If you talk to ten people with neuropathy, you may hear ten different sets of symptoms, but if you ask another 100, you will probably hear the same ten.

any pain. Alternatively, you could experience burning, stinging, or shooting pains in your feet or all over your body, with the pain sometimes so severe that you cannot sleep or think about anything else. Your gait may stiffen and become less fluid, or you might find that your stance

is widened or that you tend to lean against a chair or wall when standing, to maintain your balance. Buttoning a shirt, turning a key, or tying your shoelace may become difficult, or your legs might be too weak for you to get up or walk. These seemingly diverse symptoms are all due to peripheral neuropathy. To understand why this is happening, it is necessary to have some understanding what the peripheral nervous system does and how it works.