

Parkinson's Disease and the Family

A NEW GUIDE

Nutan Sharma, M.D.

Elaine Richman, Ph.D.

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Introduction

Ken was embarrassed by his father's funny gait and slow way of talking. His dad, though, had a way of making everyone think that he was managing just fine.

Marissa was one of the first people Sue told about her husband's diagnosis of Parkinson's disease. What Sue wanted most was the unconditional support of a friend with whom she could share her worries.

Parkinson's disease (PD) is a chronic and progressive condition that affects not only the person with the disease but also his or her loved ones. Everyone reacts differently to a diagnosis of PD—the person with the condition, the spouse, children, extended family, coworkers, and friends. No one can tell you how to feel or how to behave, but as you talk with more and more people about Parkinson's disease, you will find common threads in everyone's experience.

We recommend that you embark on your journey with Parkinson's disease by gathering information. Start with the basics: anatomy, symptoms, course of the disease, psychological aspects, and so on. There will be a lot of decisions ahead, and they are best made when you know the facts. Families say that a search for facts gives them comfort and a sense of control. If you are new to Parkinson's disease, you will soon see that you have _____

joined a large community of passionately supportive health care providers, researchers, families, and advocacy groups.

Modern medicine has made tremendous strides in the last century, contributing to our increased lifespan and an improved quality of life for those with chronic illnesses. Our knowledge of the human body and how it malfunctions has grown exponentially. The result is that highly skilled, knowledgeable, and compassionate care is available from highly trained medical professionals. The difficulty, however, is in how to convey this knowledge and the wide array of potential treatments to people affected by the disease.

The goal of this book is to provide straightforward information to the general public about what is known about Parkinson's disease and its treatment. This book is meant for people with Parkinson's disease and their friends and family members. We do not live in isolation, despite the ubiquity of television and the Internet, and it is important for everyone involved in the life of someone with Parkinson's disease to understand the illness. Fortunately, we no longer live in a society where people are afraid to discuss disease. Knowledge is essential to minimize fear. We hope that the information in this book will help make people less fearful about Parkinson's disease and more likely to become actively involved in their own treatment or that of a loved one.

The first several chapters contain medical information, in plain English, that describes what we know about the causes of Parkinson's disease and the many aspects of its treatment. They also contain practical information that should help answer some of the most common questions that arise about daily life: questions about driving, travel, work, intimacy, mental health, alternative medicine, and so on. The patient anecdotes that are found throughout the book illustrate the problems faced by many families coping with the diagnosis of Parkinson's disease.

As a movement disorder neurologist, I (Dr. Sharma) have had

the pleasure of developing long-term relationships with many patients and the people closest to them. It is a great joy to hear news of family weddings, the birth of grandchildren, and other special life events. People with PD generally live with the disease for many years, and so I have met and spoken at length with many family members and friends of my patients. I count among the greatest privileges in the practice of medicine the opportunity to work with whole families, to coach them in coping with illness, and to help them live as active and independent lives as possible.

Throughout this book, we have tried to address the concerns of friends and family members as well as those with Parkinson's disease. We have tried to shed light on what the diagnosis means to everyone within the family unit and explore what the responses and fears of others may be. It is our hope that this book will serve as a springboard for family talks and for open and meaningful discussions between patients and physicians.

