



The Scleroderma Book: A Guide for Patients and Families

By Maureen D. Mayes

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An autoimmune disease in the family with Lupus, Rheumatoid Arthritis, and Polymyositis, Scleroderma afflicts hundreds of thousands of people in the United States. And yet there are very few sources of information for men and women with this disease. Now, in *The Scleroderma Book*, one of the nation's leading authorities provides a comprehensive guide written specifically for patients and their families.

Dr. Maureen Mayes has drawn on her extensive experience treating scleroderma to provide up-to-date, practical information that will help patients manage their symptoms and improve their quality of life. Dr. Mayes begins with an easily accessible description of the basic facts, distinguishing between the many manifestations of the disease, ranging from localized scleroderma (small patches of hardened skin, most common in children, which tend to clear up over time) to systemic scleroderma, which can attack the lungs, the kidneys, and the blood vessels, and can be life threatening. Equally important, she offers sympathetic and reassuring advice on matters that often concern patients, such as the best course of action for those who want children, what to do if the disease affects your sex life, and what *you* can do to help your doctor treat your illness more effectively. The book concludes with a good-humored, frank discussion about how to cope, day in and day out, with an uncertain future--how to be a "person living with" scleroderma, not a "victim suffering from" it.

Touching on virtually every aspect of this disorder, *The Scleroderma Book* can be used as a reliable source of information and reassurance for patients of any age and no matter how severe their form of the disease.

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The Scleroderma Book: A Guide for Patients and Families By Maureen D. Mayes Bibliography

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Editorial Review

From Library Journal

Scleroderma is a rare, incurable autoimmune disease that strikes between 4000 and 8000 people annually, though estimates are sketchy owing to variable presentation. Few books on the disease have been published. A rheumatologist and professor of internal medicine, Mayes has been treating scleroderma patients for over 20 years. She gives a thorough overview of the processes that lead to such complications as Raynaud's phenomenon, esophageal reflux, hypertension, and skin changes in both the localized and systemic forms of the disease. Chapters on the main organ systems that can be involved (respiratory, cardiac, gastrointestinal, and renal) cover diagnosis and specialists. Also included are chapters on sexuality, pregnancy, and coping. Mayes emphasizes the variable nature of the disease, which requires an individualized approach to treatment. The tone of the book is empathetic and nonalarmist. Surprisingly, no comment is made on the media-hyped "cure" minocycline. Appendixes include criteria for diagnosis, support groups, resources, and a glossary of terms. Recommended for public libraries and hospital consumer health collections. (Index not seen.) ALisa McCormick, Jewish Hosp., Cincinnati
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From [Booklist](#)

Mayes has been treating scleroderma patients for almost 20 years and combines her clinical experience and medical knowledge in an informative, accessible book. Neither the cause nor the cure of the autoimmune connective tissue disease is known. She describes the two main types of scleroderma; discusses who is likely to get the malady, which affects the whole body, as well as sexuality and pregnancy; and zeroes in on such organs as the kidneys, GI tract, lungs, heart, joints, tendons, muscles, and nerves. Frequently scleroderma and Sjogren's syndrome go together. Good symptomatic treatments are available, but they need the context of a first-rate doctor-patient relationship to be really effective. Mayes gives practical suggestions for coping with the rarely fatal, though discomforting and frustrating, disease, and she debunks three harmful myths often thrown at scleroderma patients by others or themselves. Appendixes list sources of additional information and include a well-chosen glossary. *William Beatty*

From Kirkus Reviews

A little understood disorder, scleroderma is a particularly thorny medical problem: neither cause nor cure is known, and the disease presents in multiple guises. This slender, sympathetic guide sets out clearly and comprehensively what is known about occurrence and treatment. Rheumatologist Mayes (Wayne State University School of Medicine) brings nearly 20 years of practice to bear here; she defines scleroderma as an autoimmune disease (meaning the body's immune system attacks its own tissue as though it were a foreign invader) that affects blood vessels and connective tissue. It can occur in localized or systemic form and, as Mayes repeatedly points out, is a disease characterized by exceptions". Mayes discusses who gets scleroderma (women much more frequently than men; it doesn't seem to run in families) and the myriad ways it can affect the body (from thickened, tight skin to kidney failure). Possibilities for treatment and symptom control are laid out, and Mayes attends to psychological and social issues of living with such a variable disease. She is impatient with the current fad of considering disease as an opportunity for growth: "Getting a diagnosis of a chronic, possibly debilitating disease is not good news, and no matter how you rephrase it, it is very difficult to see it as an opportunity." But she is clearly sympathetic, admiring the courage of those struggling with this disorder. A sound resource, both informative and practical. -- Copyright ©1999, Kirkus Associates, LP. All rights reserved.

Users Review

From reader reviews:

Allen Brown:

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Troy Ethridge:

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Marylouise Potter:

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