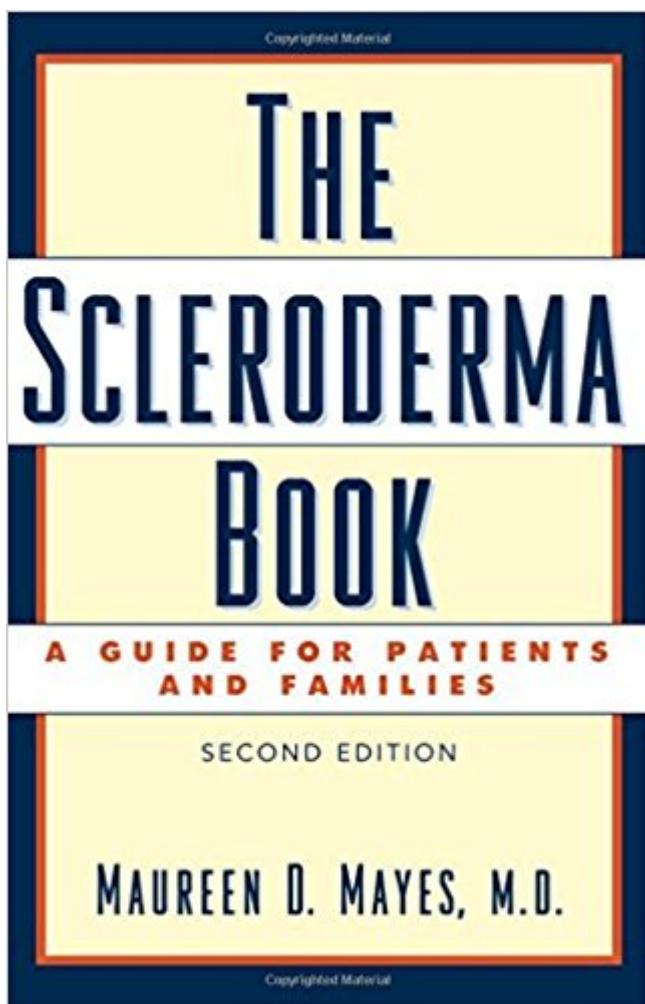


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# The Scleroderma Book: A Guide For Patients And Families



## Synopsis

The Scleroderma Book has long been considered the leading source of information for patients suffering with this disease. Now comes the Second Edition of this highly respected volume, extensively revised by Maureen Mayes, M.D., the leading authority in this field. Writing specifically for patients and their families, Dr. Mayes draws 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. The new edition has updated chapters on the genetics of scleroderma and on new treatments for complications of this disease. Touching on virtually every aspect of this disorder, The Scleroderma Book provides a reliable source of information and reassurance for patients of any age and no matter how severe their form of the disease. Endorsed by the leading national advocate group, The Scleroderma Foundation

## Book Information

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## Customer Reviews

"Dr. Mayes' book is the ultimate resource for patients and their families seeking to gain a better understanding of this complex disease. Her compassion and dedication for her patients is evident throughout the book, from her easy-to-understand description of scleroderma and its manifestations, to more personal subjects such as depression, lifestyle changes, and patient-physician relationships. She promotes further understanding by the use of case studies that patients can easily relate to. If education is the key to alleviating anxiety, making patients more effective partners in their care, and providing a more positive way of coping with scleroderma, then every patient, family member, caregiver, and friend needs this book." --Carolyn Weller, RN, Vice President Education & Research, Scleroderma Foundation

"This is a comprehensive but easy-to-read book that I would recommend for all people with scleroderma and their families to read, and then use as a reference. Dr. Mayes has provided a thorough description of the multiple aspects of scleroderma and addresses questions about symptoms, investigations, treatment, and coping with scleroderma. I rate it a 10 out of 10!" --Dr. Janet Pope, MD, MPH, FRCPC, Professor of Medicine, Rheumatologist, Epidemiologist and Scleroderma Specialist, St. Joseph's Health Care, University of Western Ontario, London, Canada

"This easily understandable book describes the background of scleroderma and how scleroderma can affect a person. It is of great value to patients who have been recently diagnosed with the disease and also to those who have suffered longer. The last section, on coping with scleroderma, although short, should be particularly useful for patients learning to live with scleroderma." --Daniel E. Furst, MD, Carl M. Pearson Professor of Rheumatology, Director of Clinical Research, David Geffen School of Medicine at UCLA

Maureen Mayes, M.D. is Professor of Medicine at the University of Texas Houston Medical School, where she directs the Scleroderma Clinic. She is a past president and director of the National Board of Directors for the United Scleroderma Foundation, and serves on its Medical Advisory Board.

Our doctor recommended we read this book. I found that there isn't much information in it that I didn't already know from reading the internet. Would not recommend buying if you can use google.

This is a good introduction to Scleroderma by a leading expert in the disease. It is simple and straightforward and generally accurate. It is particularly good as an introduction for new patients and

their family.

Book is written in lay mans term not all that medical jargon. I totally will recommend for family members to read.

Everything you need to know, on a very rare desiese, that even the Drs. do not know much about. Helps you navigate your care better. Is current , has been updated with the new studies. It was recommended as the BIBLE for new patients to go by.

Dr. Mayes clarifies many things about scleroderma. The book is extremely well organized, kept patient and family friendly and explains every term and process one might not be very familiar with. I have appreciated the book immensely and recommend it to anyone with or interested in this disease. I wish Dr. Mayes would write an update.

I found this book to be a good resource for information.

I was just diagnosed. I felt the need to find out what "it" was. This helped me to have a better understanding of the "what". I feel better equipped to take charge of this disease.

Reading other reviews I was confused as to what to expect. Yes, you can google everything and a lot will come up. Remember however that when this book was originally written, it was when hardly any info was available. Dr. Mayes literally wrote the book on Scleroderma when no one else did. She has it all in one place for you. The internet sometimes especially for newly diagnosed can be very scary. I remember just googling and thinking I was dying in less than 10 years. I recommend this book and cannot wait for Dr. Mayes to update it again.

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