

# "Have You Heard of Scleroderma Before?"

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Many people may not have heard of the disease 'scleroderma.' If you have, perhaps, you're not sure what the disease is or to what extent someone living with this disease has to endure on a daily basis. In general, patients with scleroderma may seem to you as just having thickened skin that appears more shiny and smooth than most people's skin. However, this disease can involve other organs including lung, heart, kidney, and muscles, just to name a few. Because this disease also can have symptoms that lead to diminished functionality due to things like fatigue and malaise, it is important for us to learn as much as we can in order to provide love and support to those suffering from this ailment.

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# Scleroderma

is a heterogeneous group of conditions where the term means thickened or hardened skin due to an excess of collagen fibers. It may affect skin and adjacent organs or it may affect a person systemically. Within the systemic involvement group, patients can have limited cutaneous or diffuse cutaneous type of disease where the description relates to the extent of skin involvement.

This disease affects more Americans and has more devastating impacts than most of us are aware. The prevalence rates of scleroderma-like conditions range from 4 to 489 cases per million individuals. There are higher rates seen in the United States and Australia than in Japan or Europe and in African Americans than Caucasians. The overall mortality rate for scleroderma patients is approximately five to eight-fold higher than the general population. And, those with certain characteristic of the disease have a higher risk of mortality, including but are not limited to, greater areas of skin involvement or pulmonary hypertension.

The general symptoms include, but are not limited to: malaise, fatigue, and joint stiffness/pain, loss of strength, insomnia, skin discoloration, and muscle soreness/pain. The systemic manifestations of SSc are diverse. Most prominent are abnormalities of the circulation (most notably Raynaud phenomenon) and involvement of multiple organ systems, including the musculoskeletal, renal, pulmonary, cardiac, and gastrointestinal systems, with fibrotic and/or vascular complications.

Due to its potential effect on multiple organ systems, the pre-treatment evaluation includes a full work up to determine the extent

of organ involvement to tailor treatment for all organs involved. Most patients live with the fear of this disease affecting not just their body, but also their jobs, personal, social life, and ability to continue with activities they enjoy. As with many diseases, the diagnosis of scleroderma is not just a diagnosis of a disease that needs treatment. The diagnosis may also lead to dramatic changes in a person's life. Therefore, it is imperative that treatment for those with scleroderma be based on a team approach where education is at the forefront for the patient, his or her family members, and anyone that may be impacted by the disease diagnosis.

The various treatment options available for those living with scleroderma are too diverse to go into detail for this article. However, there are many drugs on the market which can target various symptoms that may occur depending on the organs is involved. For my scleroderma patients, I work with them to make sure basic nutritional needs are met for their body and implement acupuncture, supplemental regimens, and mind-body therapies to help these patients regain some of their functionality, energy, and quality sleep.

As with any disease state, it is important to keep in mind our bodies are better equipped to handle the stress of battling a disease state if it is not running on empty. Therefore, foundational components, such as vitamins and minerals, are necessary for basic cellular functioning and should always be optimized in all patients with chronic diseases.

The stress on the body is constant and significant when it comes to living with chronic diseases. The constant stress on the body may

lead to adrenal fatigue in the long run and adrenal health is important in our overall wellbeing and health. As an example, adrenal fatigue tends to worsen the inflammatory status of the body and usually magnifies the symptoms of the disease, making disease management more difficult. So, for patients who are living with chronic diseases, you should check with your doctors about evaluating your adrenal status as well as making sure the fundamental building blocks of cellular functioning are optimized.

For those of you who know of someone living with this disease, or perhaps it's you who is living with this disease, keep in mind there are specialists, groups, organizations, and loved ones who are armed and ready to help you live a full and fulfilling life even with this diagnosis. One of my favorite quotes from the World Health Organization is:

"Health is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity." ~World Health Organization, 1948

Even with this diagnosis, there are still ways to continue enjoying physical, mental and social well-being. As I mentioned before, there are various healing modalities available to patients today, both from conventional and complementary health practitioners, which can help you to increase functionality and well-being. Through your family, friends, national organizations, doctors, and neighborhood community groups, you may indeed find all the resources you need to maintain an acceptable level of physical, mental and social well-being our would be happy with. Remember health is not just the absences of infirmity, but it is more about the quality of the life you live.

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