

Statistics

- Can be scary
- Can be based on old research
- Can be wildly inaccurate
- Can lead you to assume the worst
- No single statistic takes into account what makes *you* unique
- So you can decide that all statistics do not and will not apply to you

Journal thoughts/feelings (include dates)



Statistically I Have Been Dead for Over 5 Years



Scleroderma is Different in Everyone

Mortality Rates

Life has a 100% Mortality Rate.

This can cure your scleroderma!

A vintage advertisement for Snake-Oil Liniment. The text reads: "A Guaranteed CURE FOR RHEUMATISM WHETHER ACUTE, CHRONIC, SCIATIC, NEURALGIC OR INFLAMMATORY 50c a Bottle." To the right of the text is a detailed illustration of a rattlesnake coiled around a human figure. Further text on the right says: "PREPARED FROM PURE RATTLESNAKE OIL. THE ONLY COMPANY IN THE UNITED STATES THAT MAKES THE GENUINE ARTICLE. 50c a Bottle." At the bottom, the words "SNAKE-OIL LINIMENT" are printed in large, bold, capital letters.

Scleroderma – Important Notes

1. There is no cure for scleroderma (yet)
2. Scleroderma is chronic --- that means it will be with you for the long haul
3. Symptoms can go into remission or diminish over time and come back (particularly during times of high stress)
4. When symptoms diminish, it does not mean that you are cured
5. You should also pay attention to changes in your body and see a doctor if you have changes

Cognitive Concerns

Often people with a new diagnosis might also notice cognitive problems

Attention is the first step in forming memories---if you are distracted and thinking about other things (like a new diagnosis) you will be more likely to forget things

Depression and/or anxiety do not help matters

Fatigue can play a big role in adding to problems of attention and concentration

Scleroderma rarely has a direct impact on cognitive functions---but it has an indirect impact

Awareness Takes Time



You may feel as though you are in over your head---or at least up to your knees. Be patient with yourself.

Things to Avoid

- Smoking
- Drinking alcohol
- Cold weather
- Eating late at night
- Rabid animals
- Walmart

Internet Chat Rooms / Health Sites

Do you think really healthy people spend all their time in internet chat rooms?

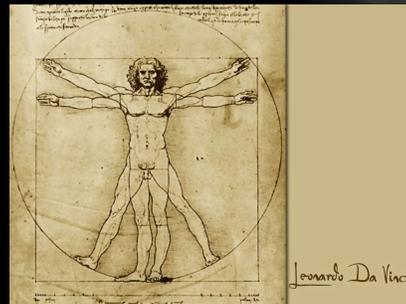
It can be a good place to learn more about different aspects of a disease or ask questions about weird symptoms

But...it can be an overwhelming place as well

Don't spent too much time there...it's too easy to become overwhelmed.

Inspire.com is excellent---but you still need to pay attention to how you feel. If you feel stressed...unplug.

Stress Affects the Body



Types of Stress

Acute Stress — stress that is momentary or short-term causes an increase in heart rate and stronger contractions of the heart muscle, with the stress hormones — adrenaline, noradrenaline and cortisol — acting as messengers for these effects. In addition, the blood vessels that direct blood to the large muscles and the heart dilate, thereby increasing the amount of blood pumped to these parts of the body and elevating blood pressure. This is also known as the fight or flight response.

Chronic Stress - a constant stress experienced over a prolonged period of time, can contribute to long-term problems for heart and blood vessels. The consistent and ongoing increase in heart rate, and the elevated levels of stress hormones and of blood pressure, can take a toll on the body. This long-term ongoing stress can increase the risk for hypertension, heart attack or stroke.

American Psychological Association

Awareness

Being aware of changes and different situations can help you make adjustments to handle stress better

Too Much Stress is Bad



What is Mindfulness?



Become Aware of Your Body

- Listen to your body
- Pay attention to any changes in your body
- Do not panic when something changes or feels different
- Stress will make it worse
- Sense your body as objectively as possible

What is Mindfulness?

mind·ful·ness

ˈmɪn(d)l(ə)lnəs/

noun

1. the quality or state of being conscious or aware of something.
2. a mental state achieved by focusing one's awareness on the present moment, while calmly acknowledging and accepting one's feelings, thoughts, and bodily sensations, used as a therapeutic technique.

Mindfulness – Key Thoughts

- Remain Calm
- Look at Situations Objectively
- Consider Bodily Changes as Something Happening---(Not Just Something Happening to You)
- Review Different Sensations Objectively

Deep Breathing Exercise

1. Breathe in through your nose (as if you are smelling something) for about 2 seconds.
2. Pucker your lips like you're getting ready to blow out candles on a birthday cake.
3. Breathe out very slowly through pursed-lips, two to three times as long as you breathed in.
4. Repeat.

COPD Foundation

Relaxation Techniques

- Meditation
- Visualization
- Progressive Muscle Relaxation
- Yoga
- Deep Breathing

Exercise When You Can As Your Doctor Recommends



Deep Breathing

- Can be done anywhere---including in a job interview and when driving
- Gets more oxygen to your brain
- Stimulates the autonomic nervous system which lowers your blood pressure

Exercise Speeds the Removal of Stress Hormones

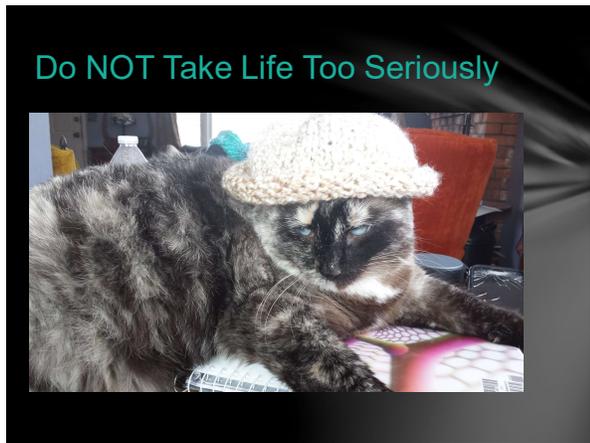




Our Challenges Build Us Up

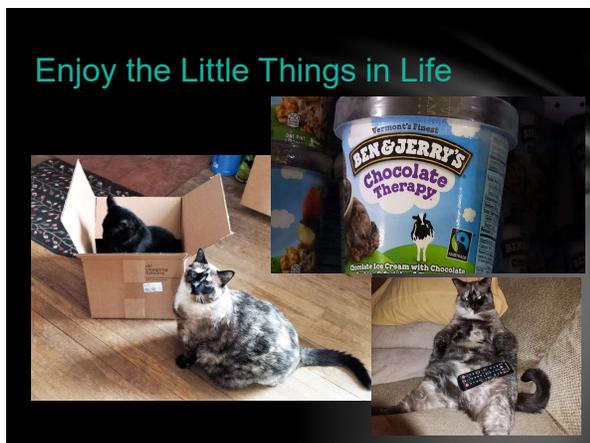
“The deeper that sorrow carves into your being, the more joy you can contain.” – Kahlil Gibran

Can you imagine your joy when a cure is found?



Finding Meaning

“He who has a *why* to live for can bear almost any *how*.” – Frederick Nietzsche



Remember...

SCLERODERMA



Relax Pray

Keep Moving

