

Elaine Furst, RN, BSN, MA
SoCal Chapter

LIVING WELL WITH SCLERODERMA



WHO IS HERE TODAY?

INTRODUCTION

- What does living well with scleroderma mean to you?

HIGH ANXIETY REDUCES LEARNING

- ❖ Breaking a big problem down into smaller pieces make it easier to look at, and easier to digest.



THE MOBILE PRINCIPLE

- ❖ A family or closely connected group is like a mobile:
When one part is affected,
all parts are affected



“WHO’S IN CHARGE HERE?”

- ❖ Control or controlled?
- ❖ Who decides?
- ❖ What you can do, what you can’t do
- ❖ Thinking outside the situation



WHAT ARE YOU COPING WITH?

(LISTING THEM MAKES THEM MORE OBJECTIVE)

- ❖ Fear
- ❖ Guilt
- ❖ Grief/loss
- ❖ Anger
- ❖ Pain
- ❖ Disability/change in body image
- ❖ Loss of income/increased outlay
- ❖ Constant doctor's visits, esp. the first three years

WHAT ARE YOU COPING WITH?

- ❖ Physical difficulties:
 - ❖ Stiff skin
 - ❖ Raynaud's
 - ❖ Hand deformities
 - ❖ Digital ulcers
 - ❖ Dry mouth/small mouth opening
 - ❖ Dry eyes
 - ❖ Joint pain, joint stiffness
 - ❖ Fatigue
 - ❖ Pain
 - ❖ Fibromyalgia
 - ❖ Reflux and gastric difficulties
 - ❖ Breathing problems
 - ❖ Kidney problems

THOUGHTS ABOUT LIVING WELL

- ❖ A chronic disease flares and goes into remission; sometimes you do all the right things and it still flares. Don't beat yourself up about it.



THOUGHTS



- ❖ It takes effort to take care of yourself. Fatigue and pain sap your strength makes it hard to make the effort, BUT.....
- ❖ If you don't make the effort, you'll get sicker.
- ✘ Get help if you need it.



THOUGHTS

NO
NEGATIVE SELF
TALK, EXCUSES,
OR GIVING UP
ALLOWED HERE.

- ❖ Stay away from negativity
- ❖ Learn to assert yourself. Say what you mean and mean what you say. It takes a lot less energy and keeps the relationships clean.

THOUGHTS

- ❖ You need a team: professionals, family, advocates, good friends, support group



THE EFFECTIVE PATIENT- DOCTOR RELATIONSHIP

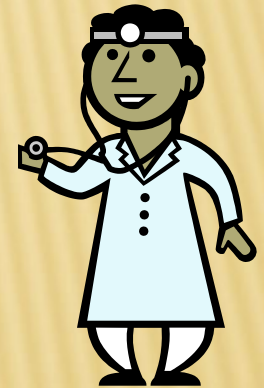
.....is a partnership where both doctor and patient share in the responsibility for the patient's care.

PATIENT EXPECTATIONS OF DOCTORS

- ❖ Information and education
- ❖ Answers/Teamwork
- ❖ Reassurance
- ❖ Planning for the future
- ❖ Referrals and networking
- ❖ Medications
- ❖ Hope

AN EFFECTIVE DOCTOR'S EXPECTATIONS OF PATIENTS

- ❖ To ask questions
- ❖ To listen to answers
- ❖ To share concerns
- ❖ To follow advice or....
- ❖ Discuss doubts about it
- ❖ To be a partner in your treatment



TIPS FOR THE NEXT APPOINTMENT

- ❖ Write questions down beforehand.
- ❖ Tape or take notes during your appointment.
Or take someone with you who can.
- ❖ Keep track of medicine responses, side effects, symptoms, etc. between appointments.

WHAT IS SUCCESSFUL COPING?

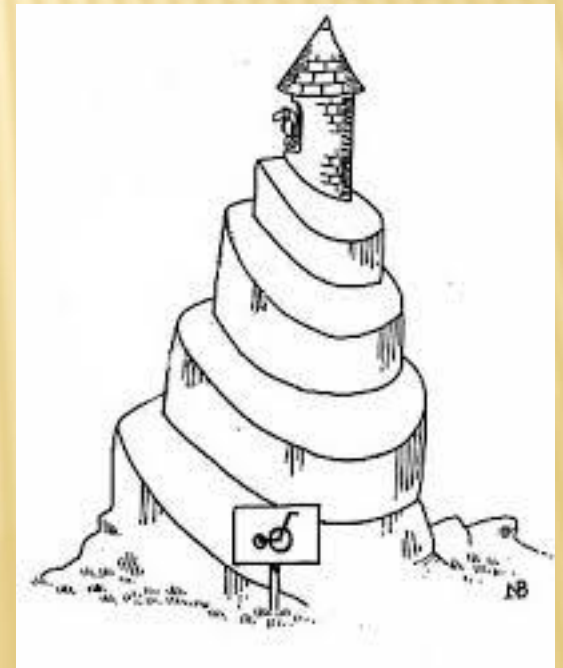
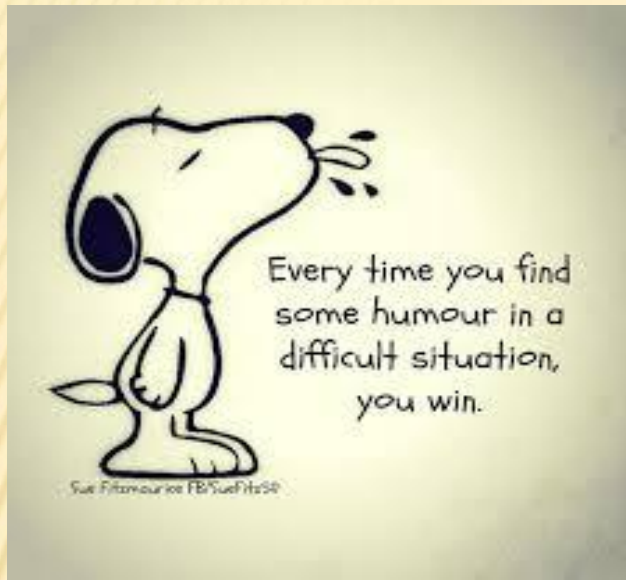
- ❖ Continuing to function in daily life while taking care of yourself and the disease
- ❖ Recognizing abilities and disabilities
- ❖ Integrating needs of the disease with needs to maintain real life

SUCCESSFUL COPING

- ❖ Ability to have fun, maintain relationships, give and receive support
- ❖ Being satisfied with yourself and how your life is unfolding; being able to make changes as necessary
- ❖ Seeing scleroderma as part of your life, not taking over your life

WRAPUP

- ✘ What do you want to change?
- ✘ What are your resources?
- ✘ Who is in charge of your life and your illness?
- ✘ What is the best thing you do for yourself?
- ✘ What do you want to stop doing? What do you want to start doing?
- ✘ Who can help you reach your goals?



And hug!