

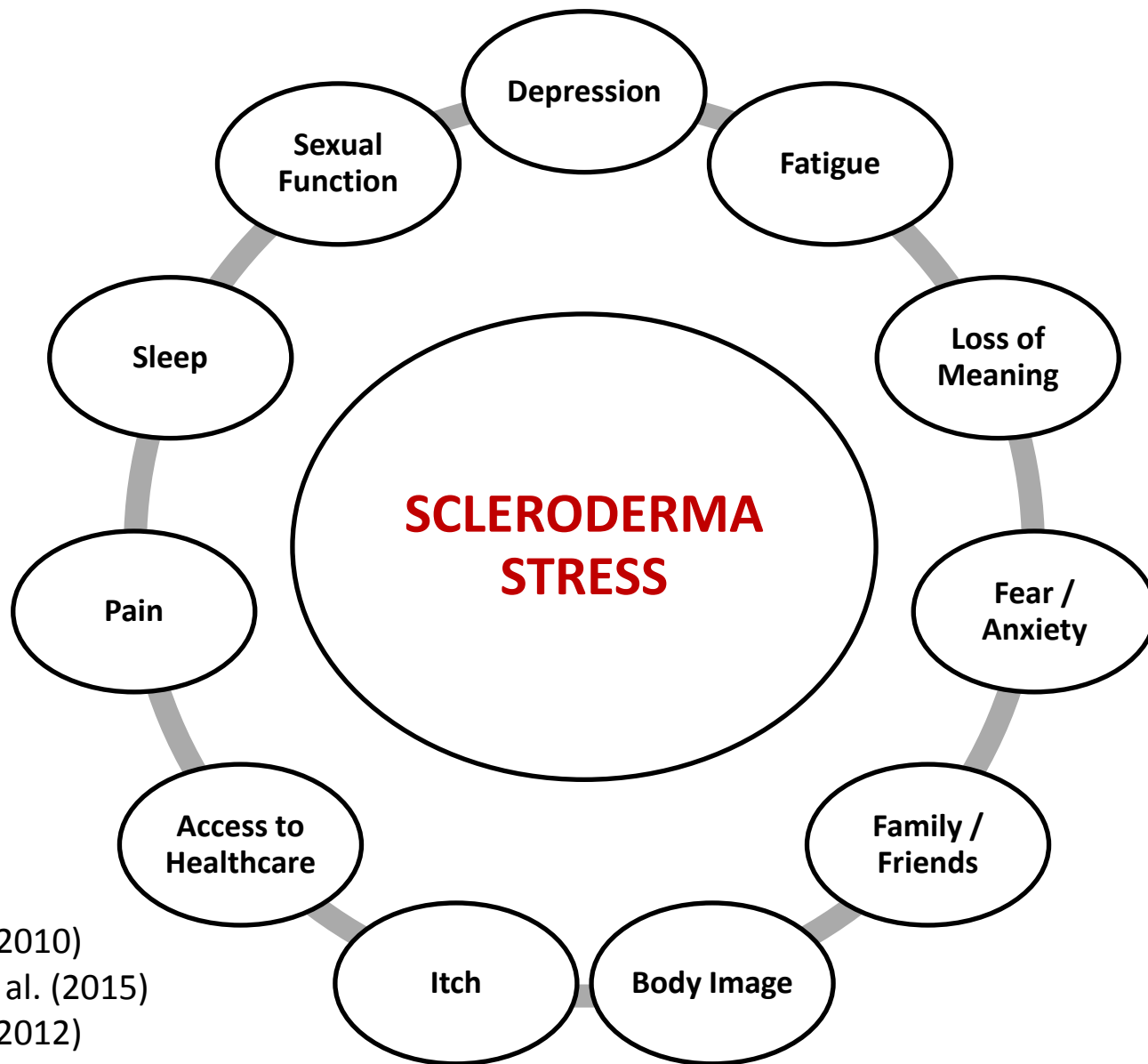
Living with Scleroderma

Education forum for those affected by scleroderma

STRESS, COPING, & SCLERODERMA:
Activity & Meaning

Joseph R. Pellizzari

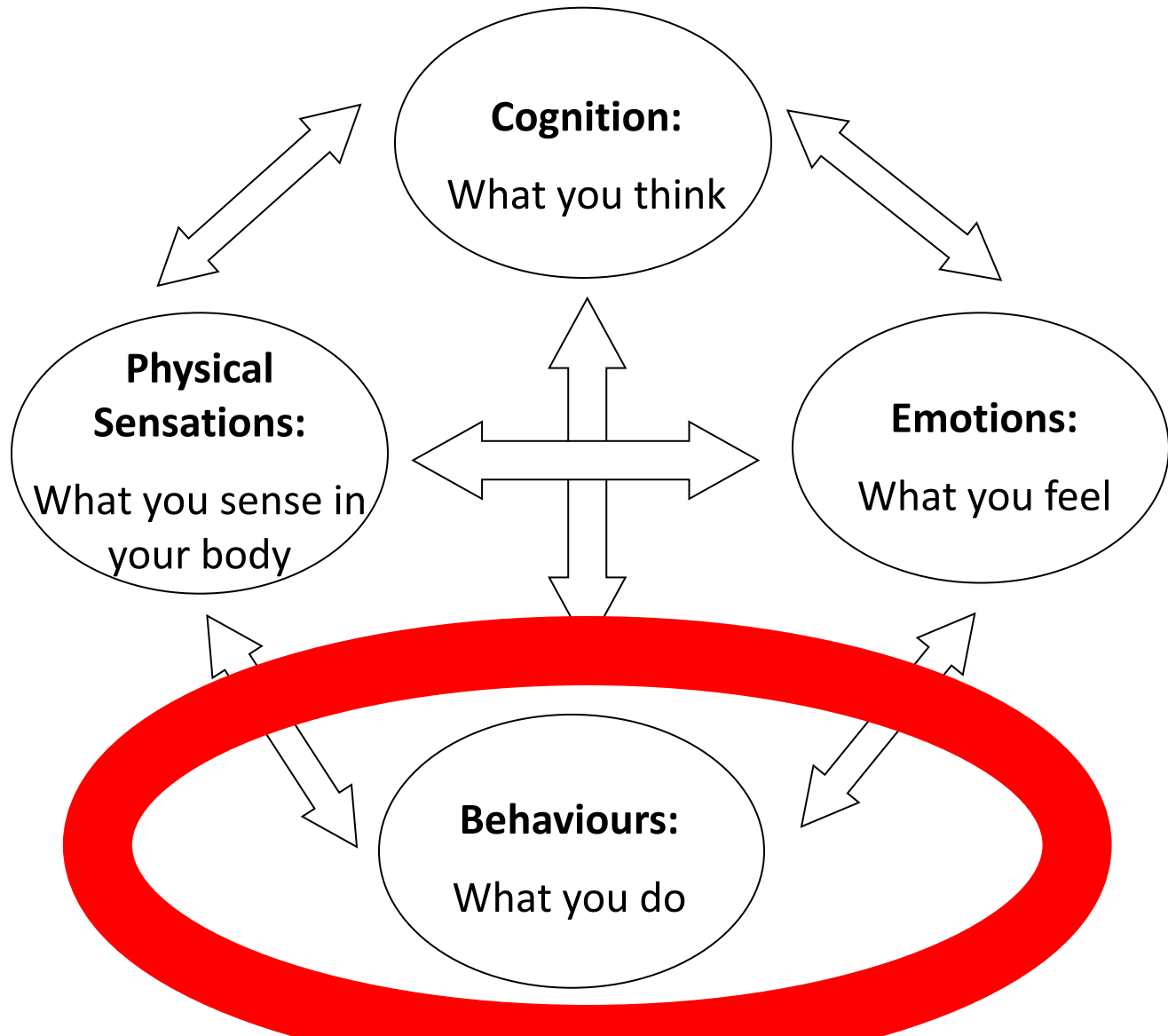
Ph.D., C.Psych.



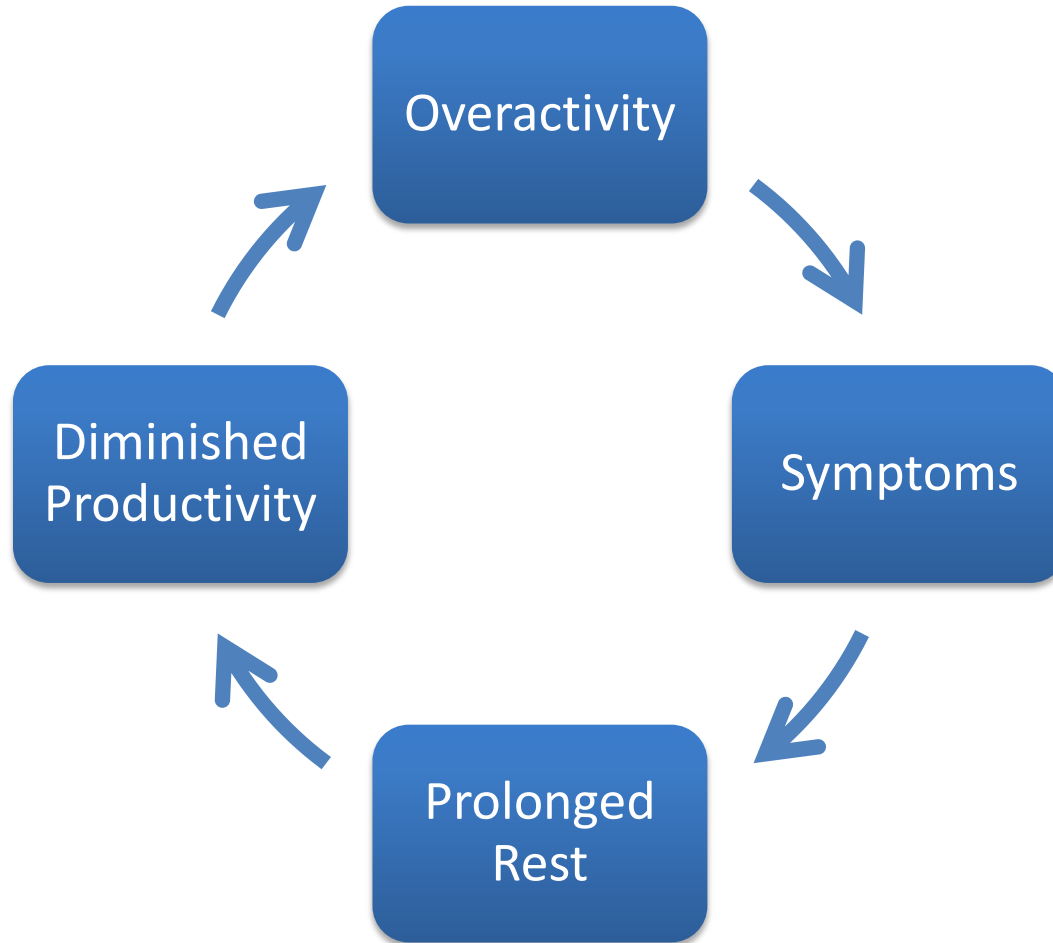
Thombs et al. (2010)
Kwakkenbos et al. (2015)
Newton et al. (2012)

Cognitive Behavioural Therapy Approach

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Behaviours: What do you do?



Behaviours: What do you do?

Activity Pacing:

..... is the regulation of activity level and/or the rate in the service of an adaptive goal or goals (Nielson et al. 2013)

..... is an active self-management strategy whereby individuals learn to balance time spent on an activity and rest for the purpose of achieving increased function and participation in meaningful activities (Jamieson-Lega et al. 2013)

Nielson, Jensen, et al. (2013). Activity pacing in chronic pain: Concepts, evidence, & future directions. Clin J Pain 29.

Jamieson-Lega, Berry, Brown. (2013). Pacing: A concept analysis of a chronic pain intervention. Pain Res Manag 18.

Behaviours: What do you do?

- Time-Based Pacing
- Conservation of Energy

How to break the cycle? With TIME-BASED PACING!

- Time is the key to good pacing!
- This means taking breaks from activity based on time intervals, and **not** on how much of the job was completed.

Examples of NOT pacing	Why is this a problem?
Doing a task to the point when you feel depleted.	If you are active to the point of physical exertion, you've been active too long.
Doing all tasks in the morning and reserving afternoons for rest.	Wearing yourself out in the morning will require prolonged rest in the afternoon, and therefore maintain the cycle.
Doing only one load of laundry at a time; before you used to do two or three.	Pacing based on the completion of a task can still result in over-exertion.

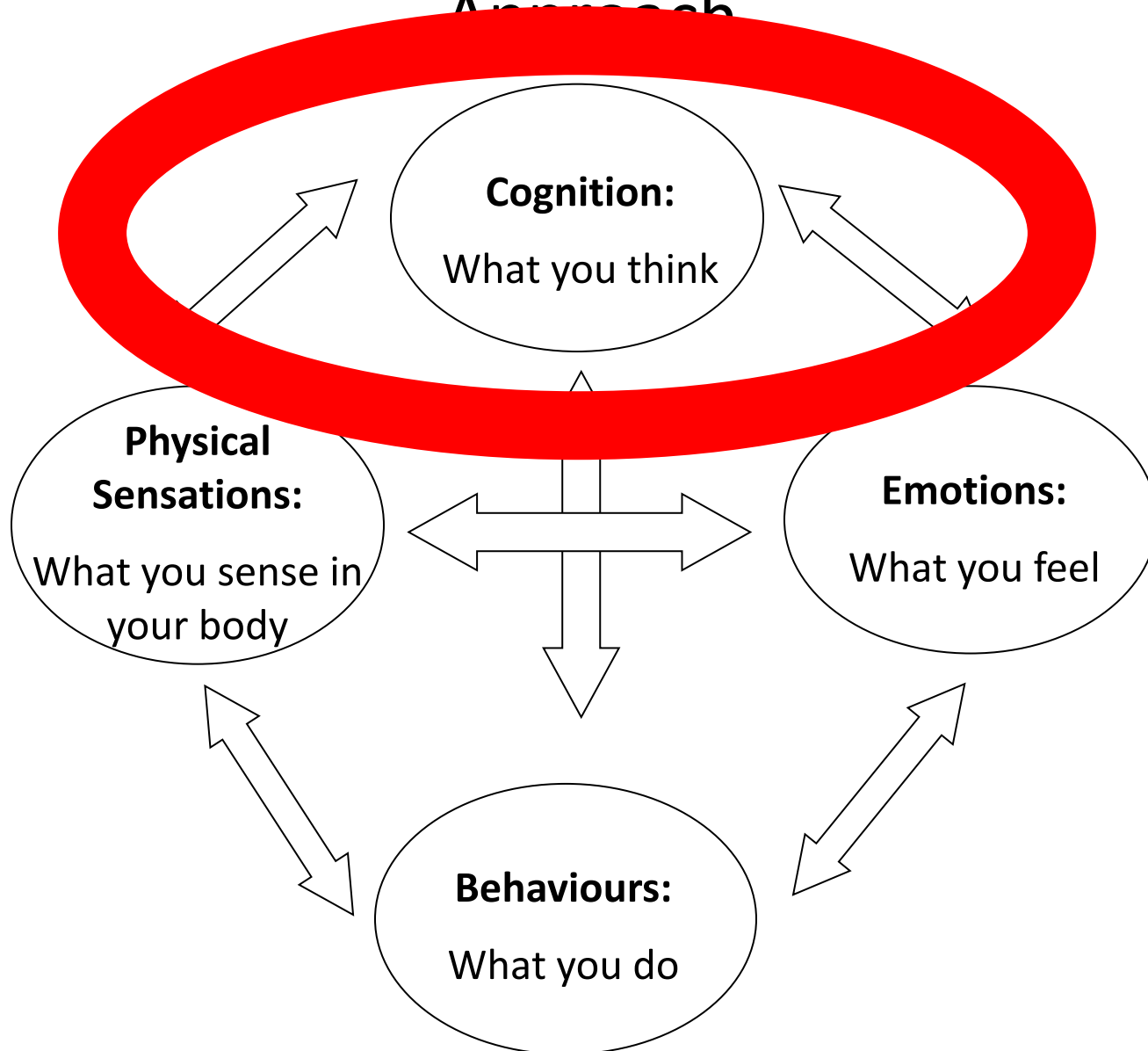
Now, here is an example of time-based pacing:

- If you know that you can be active at a specific task (e.g., grocery shopping) for 15 minutes **BEFORE your symptoms worsen**, then you would break the task into short active periods – 15 minutes at a time.
- Shop for 15 minutes... Rest... then shop for another 15 minutes.
- This means that you must stop and rest after 15 minutes even if you're not finished. Alternate a time of activity with a time of rest, until you finish your task.

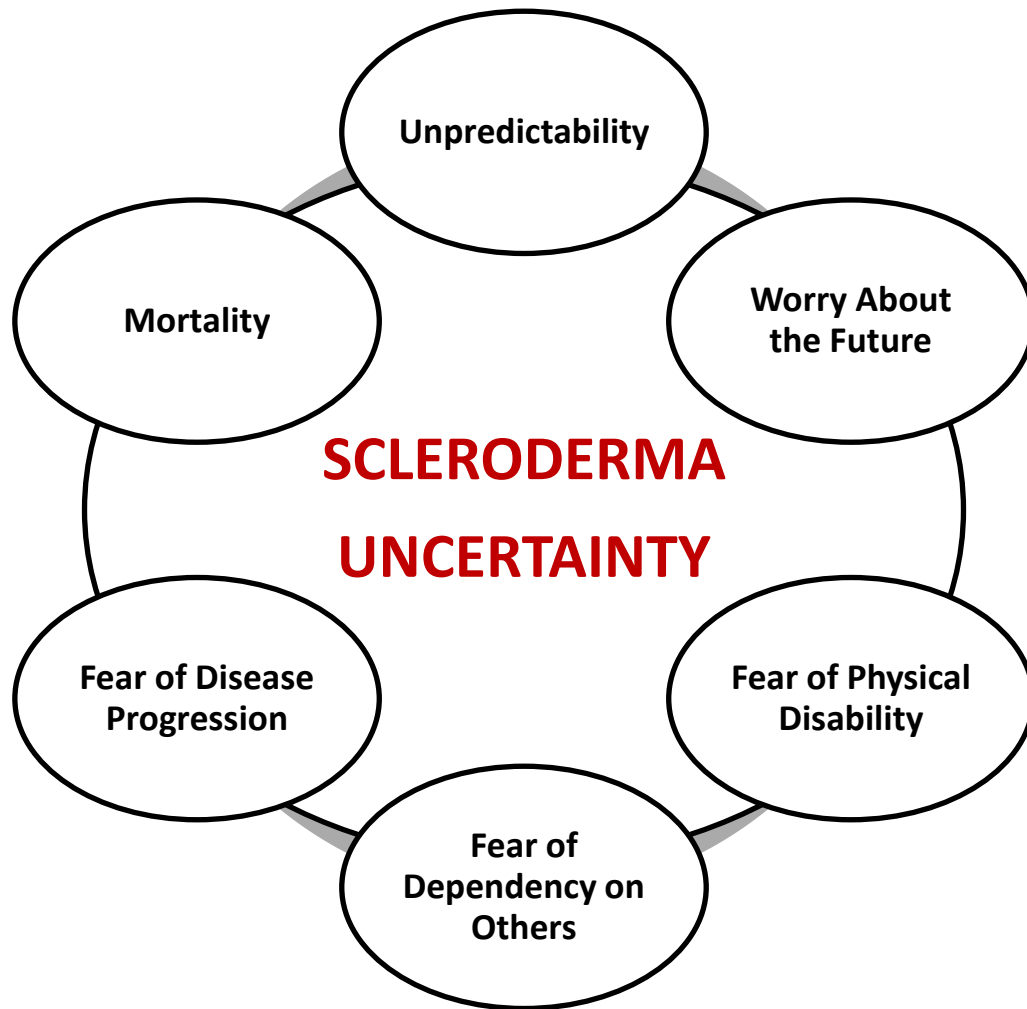
Activity... Rest... Activity... Rest... Activity... Rest...

Cognitive Behavioural Therapy

Approach



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Kwakkenbos et al. (2015)

Intolerance of Uncertainty

- Unhelpful Thinking

Crystalballing	e.g. “They’ re not giving me any information, so obviously my condition is getting worse.”
Catastrophising	e.g. “Uncertainty about the progression of my scleroderma makes life intolerable.”
All or nothing thinking	e.g. “If I am not 100% sure that this will help me manage my scleroderma, then what is the point in trying?”
Setting unrealistic expectations	e.g. ”I <u>should</u> be able to organize everything in advance.”

Coping with Uncertainty

- Identify and Modify Unhelpful Ways of Thinking
- Purposeful Planning:
 - increases sense of control
 - counters procrastination
 - consider activities that will give you a sense of pleasure or achievement
 - consider trying something new

adapted from Dugas & Robichaud (2007); Sage, et al. (2008)

Coping with Uncertainty

- Mental Relaxation
 - e.g., pleasant imagery, mindfulness-based meditation

- Healthy Distraction
 - pleasant distractions (e.g., conversation with a friend) or activities that require concentration (e.g., completing a puzzle)

adapted from Dugas & Robichaud (2007); Sage, et al. (2008)

summary

- To counter fatigue & depression:
- stay as active as possible:
 - consider how you do what you do
 - pacing & conservation of energy
 - consider what you do
 - activities that promote accomplishment, pleasure, and meaning in life

summary

- To counter illness uncertainty:
 - identify & change unhelpful ways of thinking
 - consider healthy ways of coping
 - mental relaxation exercises
 - purposeful planning
 - healthy distraction

Resources

The Johns Hopkins

Scleroderma Center

Living with Scleroderma

The following Scleroderma Educational Program was developed by behavioral psychologist Dr. Jennifer Haythornthwaite and Johns Hopkins Scleroderma Center director Dr. Fredrick Wigley to help patients learn about the physiological and psychological effects of scleroderma.

1. Introduction
2. Raynaud's Syndrome: Finger and Skin Care
3. Pain & Fatigue
4. Gastrointestinal Tract
5. Living with Scleroderma
6. Psychological Impact of Scleroderma
7. Heart, Lungs & Kidneys
8. Alternative/Complementary Therapies for Scleroderma

<http://www.hopkinsscleroderma.org/patients/living-scleroderma/>

Positive Coping with Health Conditions

A Self-Care Workbook



- Relaxation
- Managing Worry
- Activating your Life
- Solving Problems
- Managing Depressive Thinking
- Managing Anger
- Relationship Building



<http://www.comh.ca/pchc/>

Blisker, Samra, Goldner,
2009

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