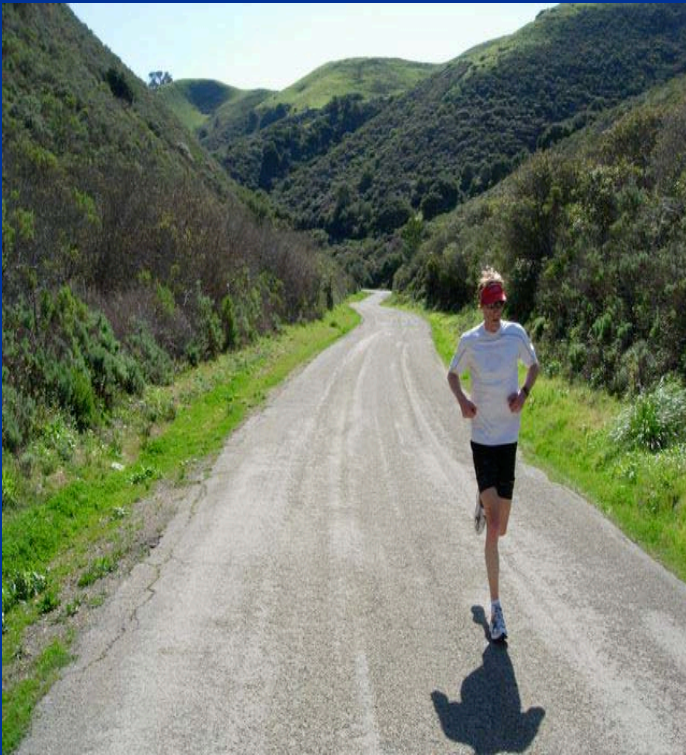


# Coping with PSC for PSC Patients

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# Living with PSC and the road to transplantation: “A psychological triathlon of stress”



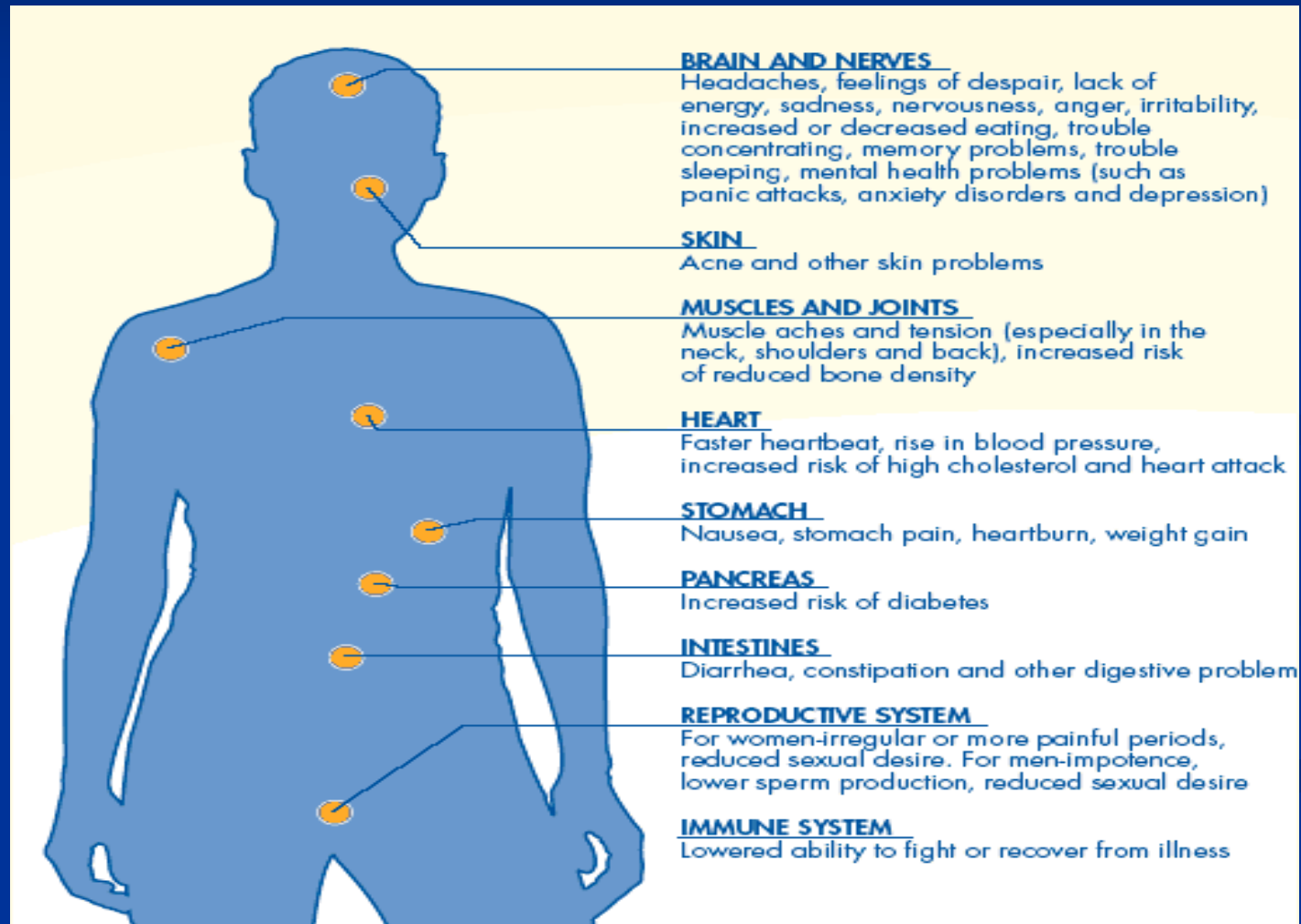
1. The physical burden of the illness and it's treatment on the individual and their family.
2. Emotional factors: unpredictable course, uncertainty, disability, altered role status.
3. Direct impact on the brain by the disease and medications to treat the disease.

# Stress Response

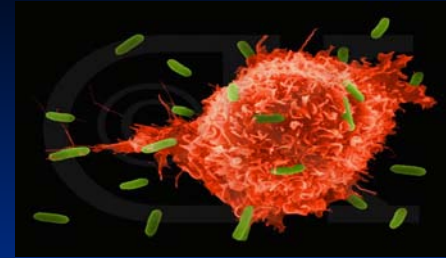
- Stress is the physical, mental, or emotional tension caused by an event.
- Stress triggers the “fight or flight” response—an automatic physical response in your brain and your body that effects how you think, feel, and behave.

# Effect of Chronic Stress on your Body

Mild stress can be motivating, but chronic high stress can lead to physical and mental health



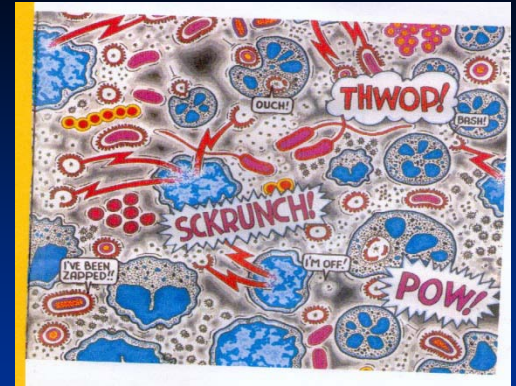
# Stress and Your Immune System



- Chronic, long-term stress can **suppresses** the immune system.
  - Lower body's ability to fight or recover from illness
  - Slower recovery from surgery
  - Higher risk of infections
- The immune systems of the elderly and those who are sick are more at risk to stress-related changes.



# Chronic Stress



Chronic stressors – such as those which change your sense of self or social role, feel beyond your control, or seem endless – are associated with the most global suppression of immunity.

The longer the period of stress, the more the immune system shifts from making adaptive changes to making more potentially detrimental changes.

Reference: Segerstrom & Miller, 2004. Psychological Stress and the Human Immune System: A Meta-Analytic Study of 30 Years of Inquiry. Psychological Bulletin, 130(4).

# Stress management is as easy as remembering your ABC's

## **A= Awareness of physical tension or mental stress**

- Scan body for any signs of muscle tension
- Identify negative and unhelpful thoughts and emotions

## **B= Breathe**

- Deep relaxed breaths to relax the body and mind
- Meditation, guided imagery, progressive muscle relaxation

## **C= Choose how you want to cope**

- Problem-focused for controllable events
- Emotion-focused for uncontrollable events
- Try to balance any negative/unhelpful thoughts

# Ways of Coping

## Controllable vs. Uncontrollable Aspects of a Problem

### Problem-Focused coping

- Problem solving
- Gathering information
- Decision making
- Resolving conflicts
- Setting goals
- Asking for help

### Emotion-Focused Coping

- Rethinking the situation
- Reframing thoughts
- Acceptance strategies
- Seeking emotional support
- Exercise
- Medication

What **NOT** to do: **Passive avoidance**



# Anger, Assertiveness and Clear Communication

**Anger:** A normal, healthy emotion that can motivate you, or alert you that something is wrong.

**Assertiveness:** Saying how you feel and what you want in a respectful way. “Win-win.”

## Steps to being assertive:

- Use “I” statements to state what you want/need
- Be empathic: Balance your understanding of others with expressing your own needs
- Be a good listener...and others are likely to listen too.

# Seek Support

Social support is the emotional, informational, and tangible benefits we get from our relationships.

## Types of social support

- **Emotional**: companionship, encouragement, friendship, love, laughter
- **Informational**: advice, knowledge, professional help
- **Tangible**: household help, financial support

## Benefits of social support

- Helps you to feel less alone with a problem
- Buffers the negative effects of stress
- Helps you to think about a situation differently

# Mindfulness

To help accept the uncertainty of the future



Mindfulness is “being in the moment”

- **Observe** using your senses
- **Describe**
- **Participate** fully
- **Be non-judgmental**...practice acceptance
- **Focus** on one thing at a time

# Walking the Middle Path

Living Life Fully while Accepting the Realities of the Moment



- Acceptance & Change
- Flexibility & Stability
- Nurturing & Challenging
- Moving from “either-or” to “both and”

# Finding Balance

## To keep your perspective



- Family
- Friends
- Job
- Health
- Recreation
- Relaxation
- Sleep
- Diet & nutrition
- Spiritual

# Summary:

## 10 Simple Steps to Reduce Stress

1. Maintain good nutrition
2. Exercise regularly
3. Rest when you need to
4. Be assertive
5. Make time with family and friends
6. Accept help from others
7. Counter negative thinking with more realistic/helpful ideas
8. Problem-solve things within your control
9. Learn to accept things outside of your control
10. Reach out to help someone else



# Winning the Triathlon:

Active “training” will improve your outcome

- Be informed
- Set realistic goals/pace yourself
- Seek support
- Share your feelings
- Maintain healthy outlets
- Faith and spirituality
- Mental health treatment



# Online Resources

**American Liver Foundation:** [www.liverfoundation.org](http://www.liverfoundation.org)

- Connecticut ALF Division, North Haven, 203-439-0888
- CT PSC Partners, North Haven, 203-439-0888

**UNOS:** [www.unos.org](http://www.unos.org)

- Transplant Living: [www.transplantliving.org](http://www.transplantliving.org)

**Online PSC Support Groups:**

- Yahoo: <http://health.groups.yahoo.com/group/psc-support/>
- Facebook: <http://tinyurl.com/pscpartnersfacebook>
- Caringbridge: <http://www.caringbridge.org>
- Carepages: <http://www.carepages.org/>

**Yale Stress Center:** <http://yalestress.org>