



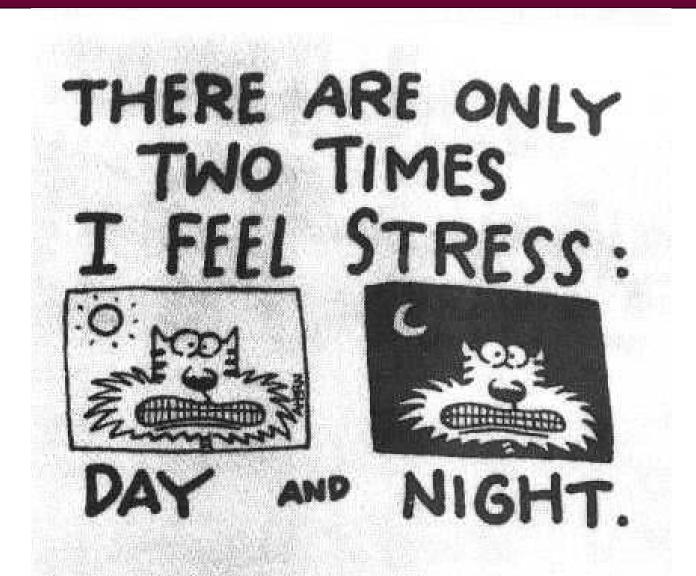
# Coping for PSCers: Making your life more than PSC

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## Why learn about coping?

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Symptoms or fears of the unknown loom...

- "PSC has become my whole life" "I am my PSC"
- "PSC causes *problems* in my life, but it is not me."
- "Because of PSC, I appreciate life more and no longer take things for granted."
- "PSC helps me put things in perspective."
- "It could be so much worse..."
- "PSC is my life and I turn it into something more..."





Our bodies are built to respond to physical and psychological demands...

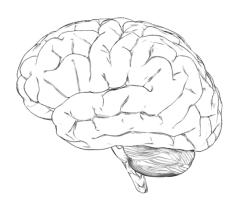
...at least in the short term.

- Demands place *stress* on body & mind.
- When stress is temporary, our physical and psychological response helps us meet those demands.



# Effects of *Acute* Stress on the Brain





Facilitates rapid decisions to look for, prepare for, and act on threats

- Narrows our thinking
  - Focuses our attention
  - Reduces rational thought
  - Promotes emotional thought
- Restricts range of emotions (fear, anger, & related)
- Reduces creativity
- Reduces social judgment



Stress response doesn't fit PSC



Demands of PSC are usually ongoing rather than acute

- Physiological Changes
- Unpredictability and uncertainty
- Hard to find ways to focus on action

Result? – Chronic and recurrent stress

Body Mind headaches worrying frequent infections muddled thinking impaired judgement taut muscles muscular twitches nightmares fatigue indecisions skin irritations negativity tress hasty decisions breathlessness loss of confidence accident prone more fussy loss of appetite irritability loss of sex drive depression drinking more apathy insomnia restlessness alienation apprehension smoking more Behavior Emotions



# Styles of Coping



#### Engagement

- Problem-focused
- Fighting spirit
- Positive reinterpretation
- Meaning making & benefit finding
- Social support
- Seeking alternatives
- Socially-oriented, emotion-focused coping

#### Disengagement

- Avoidance
- Wishful thinking
- Self-blame
- Resignation
- Substance abuse
- Blaming others (e.g., healthcare providers)
- Isolating, emotionfocused coping



# Myth-busting



• Myth 1: Avoidance/denial is always unhealthy.

 Can be adaptive in short-term, just like other aspects of stress-response system

- Engaged styles can be overwhelming early on
- Myth 2: Problem-oriented coping always best.
  - Best for controllable, solvable problems
  - Accepting what can't be changed very important



## Myth-busting



- Myth 3: Working through your emotions is always valuable.
  - Inward focused emotion processing can sometimes lead to disengagement.
- Myth 4: Feeling sorry for yourself is always harmful.
  - Occasional "pity parties" can simply be a sign of honesty to oneself.





Problem: Many PSCers find reasons to blame and maintain anger towards healthcare providers.

Why does this Happen?

REDUCING BLAME AND FORMING COLLABORATIVE RELATIONSHIPS



Approaching Healthcare Providers



Those coping well tend to...

View healthcare providers as flawed humans who wish to help, while recognizing that some are more flawed than others and not all *can* help.



Collaborating with your healthcare providers



- Proactive, assertive collaboration.
  - -Come prepare with questions and ideas.
  - -Have an advocate and take notes.
  - Seek to be "pleasantly persistent" but be willing to be more forceful when needed.
- Seek second opinions and be open to alternative perspectives.
- Build assertiveness and communication skills.



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### Fatigue, Sleep Problems, Depression, Relationships, Sex

#### COPING WITH A FEW COMMON PSC CHALLENGES







- Very common and real struggle
  - Although can interact with psychological factors, it is not "all in your head"
- Inflammatory process: likely changes in cortisol, melatonin, etc. that influence mood, sleepwake cycle, and more.
- General influences: sleep problems, dehydration, nutritional deficiencies, too much or too little exercise, too much work...

Sleep problems often have similar causes



# Fatigue and Sleep



- Practice acceptance
- Treat illness
- Physical activity
- Balanced Nutrition
- Hydration
- Avoid alcohol and unnecessary drugs
- Seek balance
- Brief naps and siestas

#### Good sleep hygiene

- Caffeine moderation
- Minimize light & sound
- Avoid exercise or large meals before bed
- Cool temperature
- Reserve bed for sleep
- Set worries aside



#### Depression



- Depression is NOT a sign of weakness.
- You do not have to be sad to be depressed.
- Many of the symptoms of PSC, IBD, and depression look the same.
- Help is available.





- Staying proactive and *active*
- Address what you think-feel-do
- Reduce isolation and seek support
  Emotional and Practical support
- Build Mastery
- Talk with your healthcare provider
- Consider other professional help (as long as you remember they are human, too)



## Relationships



- Practical barriers when symptomatic
- Not wanting to be a burden
- Challenge accepting help
- Irritability
- Physiological effects on social judgment and emotion regulation
- Challenge of invisibility of illness



# Sexual Well-being



- PSC may impact sexual desire, arousal, and performance
  - Normal stress response Hormonal changes
  - Sleep disturbances
- Depression
- Medications Feeling sick
- Pressure to perform (from society, partner, or *self*) or sexual problems may lead to...
  - Withdrawal from partner
  - Disappointment in self and depression
  - More sleep problems
  - Performance problems





As before, accept what can't be changed and address what can be...

- Work towards an open dialogue with your partner.
- If medications or depression may contribute, discuss with your physician.
- Re-assess what is important to you versus what society seems to expect.



# Dial 211 in most states for support



**Types of Referrals Offered by 211** 

- Basic Human Needs Resources
- Physical and Mental Health Resources
- Work Support
- Support for Older Americans and Persons with Disabilities
- Children, Youth, and Family Support
- Emergency Suicide Prevention

Other National Suicide Prevention Hotline numbers:

- 1-800-SUICIDE 1-800-SUICIDE (1-800-784-2433)
- 1-888-SUICIDE 1-888-SUICIDE (1-888-784-2433)
- 1-877-SUICIDA 1-877-SUICIDA (1-877-784-2432) (Spanish)