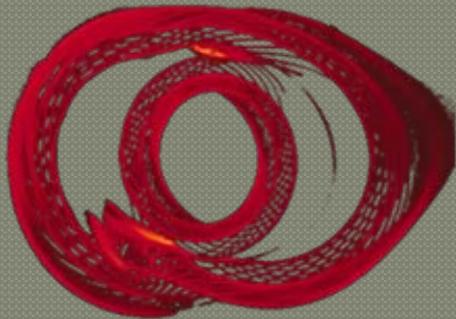


How Do I Deal with Life and PSC?

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You Are More

MORETHANILLNESS.ORG

The Silver Thieves



- ◉ *The Spoon Theory* by Christine Miserandino.
 - Meet the Silver Thieves.
- ◉ What happens when we try to defeat the silver thieves?

Solution:

- Accept thieves (PSC) as a reality.
- Work *WITH* instead of *against* PSC.

Acceptance ≠ “Giving In”

- Acceptance is...
 - Accepting what is,
 - Choosing to tolerate the moment,
 - A repeated commitment to accept,
 - Shifting away from willfulness to willingness,
 - Letting go of blame and judgment,
 - Accepting personal responsibility.

Goal: You are more than PSC

- ◉ Encourage working and dealing *with* PSC, life, & each other instead of fighting.
- ◉ Emphasize importance of keeping PSC from being the center of your lives as PSCers & Caregivers.
- ◉ Review some key psychological and sociological factors to keep in mind.

Ways Illness Can be Viewed

- “PSC has become my whole life” or “I am my PSC”
- “PSC causes problems in my life, but it is not me.”
- “Because of PSC, I appreciate life more & no longer take things for granted.”
- “PSC is my life and I turn it into something more...”

Problem with PSC as Central

- Unpredictable & largely uncontrollable.
- Allowing self-definition to revolve around any single facet of life.
 - around chronic, progressive illness, quality of life progressively worsens.
 - around unpredictable, uncontrollable part of life, then life begins to feel unpredictable/uncontrollable.

Alternative

- Strive toward expanding self-definition.
- Strive for incorporating things in life that...
 - Bring you a sense of mastery, pleasure, and variety.
 - Are in your control.
- Enlist the help of others to allow you *time* for other things in your life.

(Note: Especially important for caregivers!)

Things in your control

- Self-care
- Information seeking
- Partnering with healthcare team
- Pleasant activities
- Skill-building
- Social connection
- Turn attention to positives
(negatives don't need any special attention!)
- Freeing time by asking for help
- Managing time
(sometimes)

A few key issues

- ◉ Fatigue
- ◉ Insomnia
- ◉ Irritability
- ◉ Attention / concentration
- ◉ Withdrawal / isolation
- ◉ Communication problems
- ◉ Depression
- ◉ Anxiety
- ◉ PTSD
- ◉ Sexual changes

Reducing Blame and forming collaborative relationships

Problem: Blame & anger toward healthcare providers.

Those coping well tend to...

- View providers as human and use assertive collaboration.
 - Prepare questions/ideas. Take notes.
 - Bring advocate.
 - Seek to be “pleasantly persistent” but willing to be more forceful when needed.

Distractibility / Poor Concentration

- ◉ Practicing mindfulness and clearing the mind.
- ◉ Reducing extraneous stimuli.
- ◉ Frequent mini-breaks.
- ◉ Attend to sleep.
- ◉ Lists, reminders, organizers.

Communication problems

- Recognize that fatigue, insomnia, concentration problems, etc. all...
 - Reduce patience & increase irritability.
 - Polarize thinking & reduce creativity.
 - Activate stress hormones.
- Work towards calm, slowing of responding, listening, and “gimmicks” to increase awareness.

Fatigue

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

Insomnia & Fatigue Self-care

- 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 / large meals before bed
- Cool temperature
- Reserve bed for sleep
- Set worries aside

Depression

- ◉ Depression 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.

What you can do...

- ◉ Staying active.
- ◉ Address what you think-feel-do.
- ◉ Reduce isolation.
- ◉ Emotional & Practical support
- ◉ Build Mastery
- ◉ Talk with healthcare provider

PTSD: Complication of Transplant

- Triggered by trauma, but largely biological. **NOT** a sign of weakness or willfulness.
- Symptoms:
Avoidance, Re-experiencing, Hyperarousal

Those most at risk:

1. Parental caregivers of pediatric patients (~50%).
2. Adolescent patients (~30% & related to poor compliance & complications).
3. Pediatric patients. (~50% but not as predictive of long-term problems; more often successfully treated).

Pleasant Activities Lists: Make When Feeling Well

- Relaxing
- Going to a movie in the middle of the week
- Listening to music
- Recalling past parties
- Buying household gadgets
- Laughing
- Listening to others
- Making jigsaw puzzles
- Soaking in the bathtub
- Taking care of my plants
- Repairing things around the house
- Reading for fun
- Spending time with friends
- Remembering beautiful scenery
- Working on my car (bicycle)
- Wearing sexy clothes
- Doodling
- Exercising
- Having quiet evenings
- Sex
- Singing around the house
- Making a gift for someone
- Painting

What Role Will PSC Play for You?

- ◉ Accept that PSC causes problems in your life, some of which you can address.
- ◉ Look for ways to appreciate what you can and place PSC in perspective.
- ◉ If PSC is you or your life, turn it into something more.

Dial 211 in most states for support

Types of Referrals Offered

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

Crisis Hotlines:

- 800-273-TALK (8255)
- 800-SUICIDE (784-2433)
- 877-SUICIDA (Spanish) (784-2432)
- 800-799-4TTY (4889) (Deaf/Hearing Impaired)

Online Resources

<http://www.suicidepreventionlifeline.org>

<http://www.samaritans.org>

<http://www.samaritansusa.org/>

Seeking Help

- Many see this as “giving up independence”
- Reality: Independence is a myth for *everyone!*
- Able to have more choice and independence if help with simpler tasks.
- Others won't know to help if you don't ask.

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: Biology

PSC *may* impact sexual desire, arousal, and performance

- ◉ Normal stress response
- ◉ Hormonal changes
- ◉ Sleep disturbances
- ◉ Depression
- ◉ Medications
- ◉ Nausea/Pain or otherwise feeling sick

Sexual Well-being: Results

Pressure to perform (from society, partner, or self) or functional problems may lead to...

- ◉ Withdrawal from partner
- ◉ Disappointment in self and depression
- ◉ More sleep problems
- ◉ Performance problems

Coping with Sexual Problems

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

- Practice open dialogue with your partner.
- Discuss with your physician.
- Re-assess what is important to you versus what society seems to expect.
- Re-conceptualize intimacy as a whole mind/body experiencing.