

Coping with PSC for Caregivers

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“There are only four kinds of people in the world – those who have been caregivers, those who are currently caregivers, those who will be caregivers and those who will need caregivers”.

*Former First Lady Rosalyn Carter
(2007)*

Common Challenges for Caregivers

- Dealing with guilt, disappointment, frustration, and fear
- Feeling hesitant to ask for help
- Coping with uncertainty
- Managing and fulfilling multiple changing roles
- Juggling increased responsibilities
- Emotional and physical isolation
- Managing stress and burnout
- Making time for your own health and wellbeing
- Keeping patience, faith and courage

Warning Signs of Caregiver Burnout

- Increased fatigue; you feel constantly exhausted.
- You neglect your own needs, because you're too busy or don't care anymore.
- Your life revolves around caregiving, but it gives you little satisfaction.
- You have trouble relaxing, even when help is available.
- You're increasingly impatient and irritable with the person you're caring for.
- You feel overwhelmed, helpless, and hopeless.

Tips to Prevent Burnout

- Learn as much as you can. Knowledge is power.
- Don't try to do it all alone. Accept help.
- Know your own limits and set boundaries.
- Accept your feelings...you have a right to them.
- Confide in others.
- Make time for yourself. Take a break.
- Seek emotional support.
- Believe in yourself.
- Stay mindful of the need for a balanced lifestyle.

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 support
- Exercise
- Medication

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

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

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.

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

Finding Balance

To keep your perspective



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

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”

On-line Caregiver and Family Resources

Caringbridge: Free password protected “create-your-own-website” that enables you to keep a journal of your loved one’s progress, and maintain a guestbook for friends and family to send their support. <http://www.caringbridge.org>

Carepages: Another free password protected “create-your-own-website” to inform family and friends about your loved one’s progress. You can upload photos, art, and the latest news. The site includes patient stories and tips for caregivers. <http://www.carepages.org/>

Caregiver and Family Resources (cont.)

Well Spouse Association: This non-profit organization offers a site for well spouses to connect with others and to find tips to manage their role. A support group is available on line as well in some localities. There is an annual conference and the group puts out useful publications; a newsletter (subscription) is also available.
<http://www.wellspouse.org/>

Transplant Experience: The website leads to the "Caregivers' Connection" that provides resources to transplant recipients and their caregivers. Membership enrollment is free. You can receive a newsletter of support, videos, and literature that provide information through each stage of transplantation. This site discusses the impact of transplantation while giving specific coping strategies.
<http://www.transplantexperience.com/>