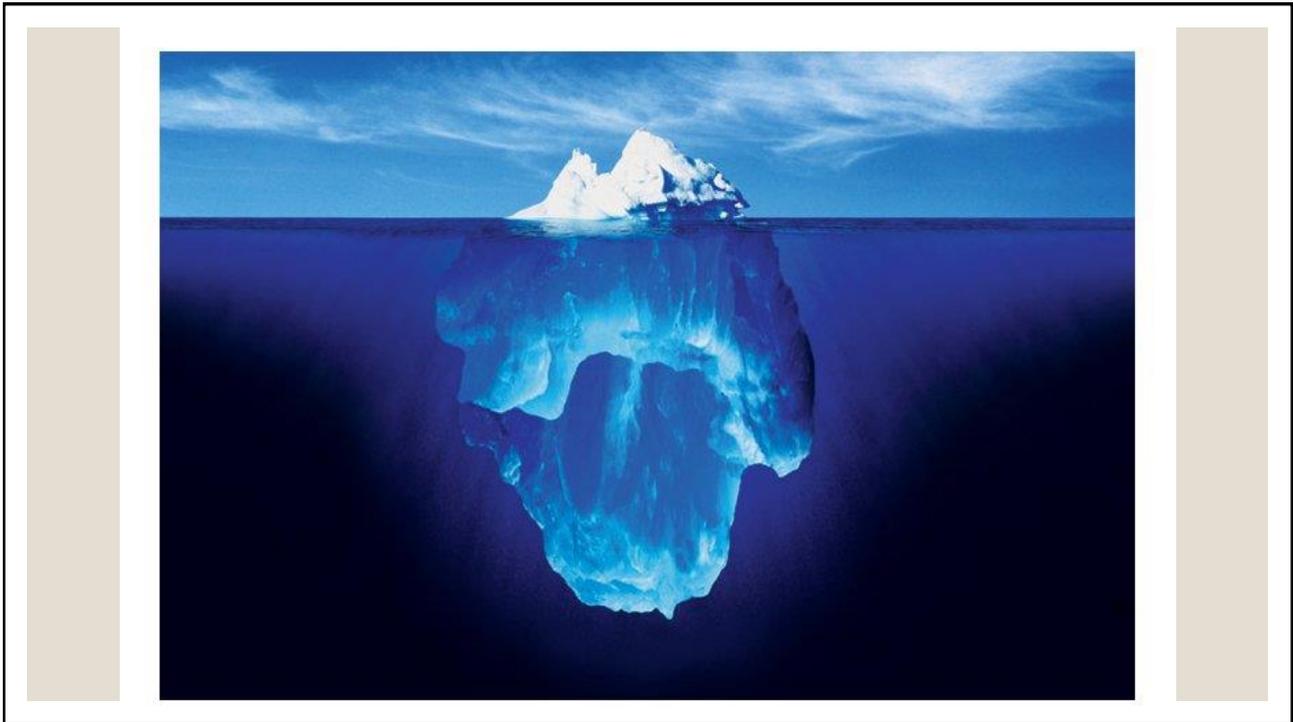


Navigating the Impact of CRPS on Caregivers

RSDSA Facebook Live
July 28, 2022
Leanne Cianfrini, PhD

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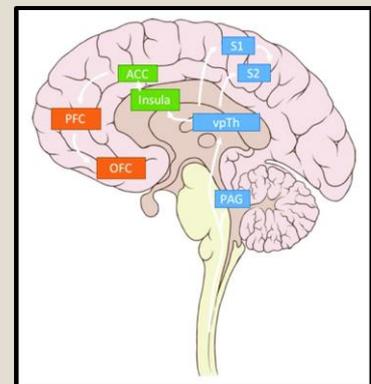
THE PAIN STARTS IN MY HUSBAND'S LOWER BACK,
THEN IT TRAVELS UP HIS SPINE TO HIS NECK,
THEN IT COMES OUT HIS MOUTH AND INTO MY EARS.
AND THAT'S WHY I GET THESE HEADACHES.



3

Basics to Remember About Persistent Pain

- Persistent pain vs. Acute pain
- Chemicals such as **hormones** and **neurotransmitters** can amplify the pain message
- The central and peripheral nervous system can get **sensitized**
- Persistent pain by definition also impacts **emotional suffering**

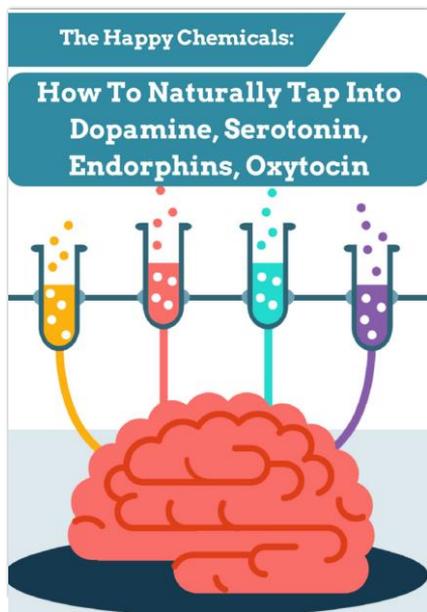


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Basics to Remember About Persistent Pain

- The good news is that the brain and nervous system can be re-trained to normalize (“Neuroplasticity”).
- We need a large toolbox - no one treatment gets us complete relief.
- Zero pain might not be realistic - don’t chase that mirage with medications and invasive treatments.
- Emphasize function as an outcome rather than focusing only on pain reduction.
- “Self-Management” is the key for long-term control and quality of life.

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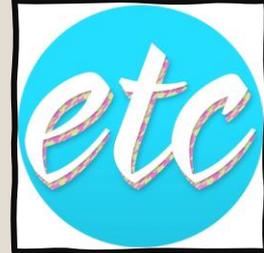
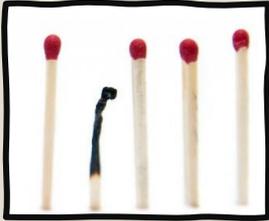


Access the “Medicine Cabinet in the Brain”

- Meditation
- Hugs / Pets
- Engaging in a creative hobby
- Exercise
- Sunshine/ Nature
- Create new memories
- Achieving small goals
- Laughter

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The Challenges of Caregiving



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- **Survival instinct** - triggered when we or our loved ones are in danger
- Opportunity to develop **resilience**
- **Empathy**
 - Cognitive & Emotional
 - Not natural to everyone
 - The "empathy trap"
- **Patience**
- **"Silver lining"** - What have you learned from this experience that you might not have known otherwise?

The Beauty of Caregiving

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**"WHAT YOU
RESIST,
PERSISTS."**

C. G. JUNG

Acceptance

- Not giving up or giving in, not a passive resignation of defeat.
- Recognizing that the more we avoid or fight the situation, it's still there and can even grow stronger.
- Instead: softening, embracing, "sitting without judgment" of the situation "in the moment"

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Relationships

- Mutual respect
- Rules and clear boundaries
- Creating time for each other, balanced with your individual pursuits
- Honesty about feelings
- Privacy



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"I" STATEMENT



GoodTherapy.org

Communication

- Problems become smaller if you confront them, rather than dodge them.
- Passive / Aggressive / Passive-Aggressive / Assertive communication styles
- Use "I" statements rather than "You" accusations

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Communication

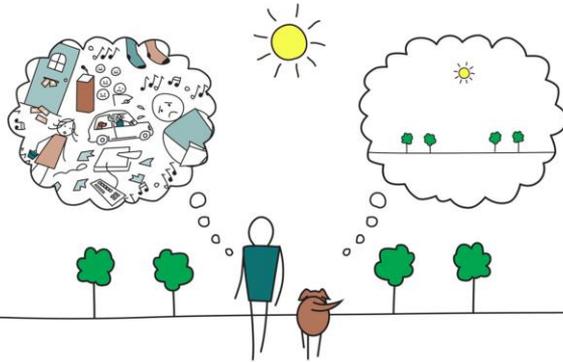


Addressing suicidal thoughts

- Don't be afraid to ask if you notice warning signs - this does not "put the idea into their head"
- Listen deeply - serious and should not be ignored
- Show empathy, not shame or guilt
- Get medical help if imminent; new National Suicide and Crisis Lifeline

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Self-Care



Mind Full, or Mindful?

But, how could I possibly find time for myself?

- Are you acting out of pity (see loved one as a victim you must rescue) or compassion?
- Your self-care benefits the person you're caring for as well.
 - Pacing
 - Delegating
 - Acknowledge your strengths
 - Talk it over
 - Nurture your body - nourishing food/ hydration / movement / sleep
 - Feed your soul - mindfulness, gratitude

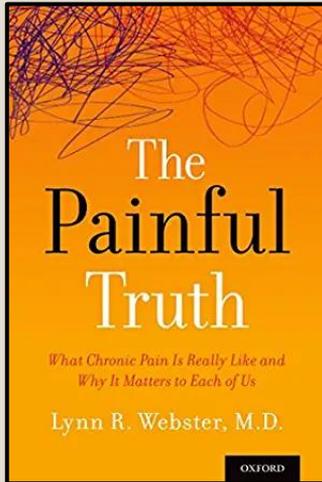
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Summary/Recommendations

- Don't try to be Super Caregiver
- Do allow yourself to grieve the loss of your old routine
- Do know it's okay to share your struggles, even with your loved one
- Do "address the elephant in the room"
- Don't over-attend to pain behaviors
 - Don't ask about the pain every day
 - Don't rush in to offer help unsolicited
- Have a sit-down meeting to re-set dynamics/boundaries if necessary
- Do use "I statements" to communicate
- Do try a team approach
- Don't isolate yourself
- Do take care of your own health
- Do practice self-compassion
- Do go have some fun

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Resources for Further Support: Pain

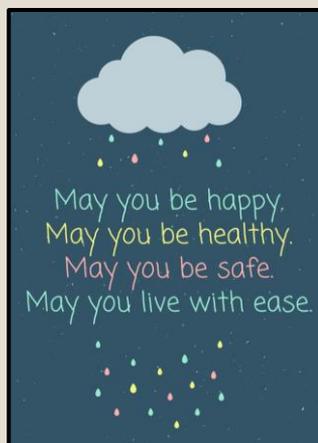
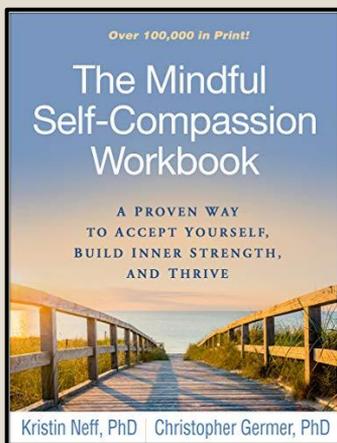


"Understanding Pain" on [Tamethebeast.org](https://www.tamethebeast.org)



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Resources for Further Support: Self-Compassion



Two recommended meditations :

- **Loving-Kindness Meditation** (for self-compassion, empathy)
- **Mountain Meditation** (for strength in the face of chaos)
 - YouTube
 - Apps such as Calm, Headspace
 - <https://drronsiegel.com/recorded-meditations/>

<https://self-compassion.org/category/exercises/>

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Resources for Further Support: Podcasts +



<https://painbc.ca/>

<https://www.spreaker.com/user/painwaves/painwaves-episode-family-caregivers-of-b>

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Resources for Further Support: RSDSA / RSDS.ORG

Treatments

Treatment for CRPS/RSD must be individualized. No one treatment will work for everyone. Most treatments and medications were developed to treat other chronic pain syndromes and may not be covered by your **insurance**.

Treatment for CRPS may be difficult. The goal is to seek pain relief and to restore function.

Treatment methods are continuously evolving as research and clinical practice provides new evidence and insights. For example, it was once thought that sympathetic nerve blocks were a diagnostic tool and a curative procedure. This has been disproven over time.

Some current treatment methods that may work for you are:

- Use of anti-convulsants
- Use of TCA antidepressants
- Physical and occupational therapy (including graded motor imagery and mirror box therapy)
- The anesthetic Ketamine
- Steroids in the acute phase
- Nerve blocks
- Spinal cord stimulator
- Warm water therapy
- Calmare therapy
- Hyperbaric oxygen therapy
- Use of opiates (may be considered controversial)



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