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IN RARE FORM

IN THIS ISSUE

Asking for Help: Why Does it Feel so Hard?

by Elisa Friedlander, LMFT

What Does Grief Have to Do with It?

It’s that time of year, when we tend to make more space in our lives for gratitude, giving, and even miracles. And considering the unique challenges of this particular holiday season, perhaps we’re turning toward these notions even more.

Yet even in non-pandemic times, the holidays can be difficult, especially for those dealing with loss of any kind. Feelings of longing or loneliness are especially highlighted in contrast to seemingly unending snapshots of togetherness on social media and television’s portrayal of the ideal.

Part of the fallout that comes from a CRPS diagnosis – and any condition causing high-impact chronic pain – is that we begin to see ourselves through the lens of what we did, and who we were, prior to life with intractable pain. In other words, we become involved in an intimate relationship with grief.

When we ask for help it can remind us (consciously or not) that we’re no longer able to do things we could do pre-diagnosis days, at least not in the same way. On a deeper level, needing help can remind us that we’ve lost a part of ourselves. No wonder the topic of asking for help is so weighted. Who wants to open up to feel that sense of loss? Who wants to be reminded about something that’s so hard to accept?

A Foundation of Self-Acceptance

A friend of mine who, gratefully, does not live with a pain condition, recently lost one of the most important people in her life, her precious aunt. Not knowing how I could possibly help (*do we really ever know what to do or say when somebody dies*?), I reached out to express my condolences, and asked if there was any way I could support her in this time of grief. She responded by saying she finds poetry to be of comfort and asked if we could read some poems together over the phone (if not for the pandemic, I imagine we would have met in-person, somewhere in nature).

As much as I love poetry (and all things related to the written word), it wouldn't have occurred to me to offer to help her in this way, and hearing her request gave me a surprising sense of relief. I couldn't bring back my friend's loved one, or take away that gut-wrenching sorrow, but I could - in a clear and concrete way – give her something she needed.

I also felt a sense of admiration. I don't know if she would have directly asked me for these poetry sessions if I hadn't reached out, but she responded, and did so with clarity and a quality that should always be a priority for people with high-impact pain - *self-care*. Ultimately, my friend's ability to make this request came from a place of self-awareness, as if to say, "*I need the comfort of poetry right now" and self-acceptance, which might sound like this: "I'm in a lot of emotional pain… I lost somebody I love dearly" or, "As hard as it is, I will feel these feelings of grief", or "I don't need to go through this alone".*

Challenges to Asking for Help

Most people have at least some skills to communicate their need for help. So, what gets in the way?

My friend had clarity about what she needed, but her response, and why it was so striking to me, was not the norm. Most people have difficulty identifying what they need from a loved one in the first place (which of course makes asking for help impossible).

Another barrier to asking for help has to do with feelings of vulnerability. As children, we didn't learn how to express our vulnerabilities (much less how to grieve, or how to ask for help). Underneath that vulnerability usually lies a sense of fear, so it's helpful to ask ourselves, "What am I afraid of?" For some, the fear is about appearing weak; others fear rejection or even abandonment. All of these feelings are amplified by the magnitude of physical pain and other symptoms secondary to CRPS.

We must also acknowledge our societal value of independence (and our hard-wired propensity toward it), and look to our family upbringing and cultural beliefs to understand our feelings and behaviors about asking for – and receiving – help. From that point, we can move to a place of self-acceptance and make choices that are in our best interest. Easy-peasy? Nope, it's a psychological process made more doable by – you guessed it, getting some help!

Chronic pain also tends to evoke feelings of guilt. If you feel guilty about asking for "too much" from people, consider one of the greatest antidotes to pain and suffering: being of service. Contributing to the world, even in small ways, connects us to humanity and gives us a role in repairing society. When we ask ourselves, "How can I be of service to others?" we show up more presently in all of our relationships and worry less about asking for help.

Like my friend did, we must allow ourselves to grieve and become open to self-acceptance. Only from that place can we become curious about what we need and ask for it, and we can best learn this through mindfulness practices (e.g., meditation, journaling, yoga). Mindfulness practices should be part of our daily lives, as they are the entrances to self-acceptance.

Asking for Help and Needing Help

Ask yourself if one of these statements resonates more:

"I don't know how to *ask for help*" or

"Asking for help feels awful because I don't want to accept that I *need* the help?

However related, distinguishing between these two issues is the place to start. Here are some tips for both that I hope you find helpful.

- Clear communication (begin from a place of "I…")
- Specificity (ask – in simple terms – for exactly what you need)
- Express gratitude (versus apologizing for needing help)
- Use your resourcefulness (access various means of support so you're not relying on only one person)
- When it feels particularly hard, shift to asking for help from a place outside of yourself. This, of course, is different for each of us, depending on our beliefs. We might ask:
  - *Please help me accept my pain levels today*
  - *Please help me find self-compassion in this moment*
  - *Please help me be okay with asking for help*

Where we might seek help for deeper inner-wisdom:

- prayer
- poetry
- angels
- nature
- journal writing
- G-d or a higher power
- a loved one who has passed
- the animal world (oh, the wisdom animals have to offer!)
- photographs
- the Universe
- the dream world

People who care about us want nothing more than to take away our pain. So, until a day comes when they can hand us the key to a cure, why not find ways to let our loved ones experience what my friend gave me – the chance to help in a concrete, doable way. These opportunities are sacred gifts, and who doesn't want an unexpected gift – especially this time of year.

Click HERE to read a bit about my life, and my personal story of how I redefined the notion of independence. Here is the link to my blog Happy Holidays!

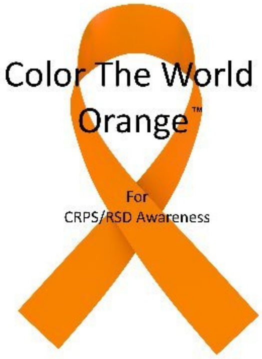
Facebook Live on Wednesday, December 9th

Join our next Facebook Live with Brad Yates on Wednesday, December 9th at 7p Eastern.

Brad Yates is known internationally for his creative and often humorous use of Emotional Freedom Techniques (EFT).

Yates is the author of the best-selling children's book "The Wizard's Wish," the co-author of the best-seller "Freedom at Your Fingertips," and a featured expert in the film "The Tapping Solution." He has also been a presenter at a number of events, including Jack Canfield's Breakthrough to Success, has done teleseminars with "The Secret" stars Bob Doyle and Dr. Joe Vitale, and has been heard internationally on a number of internet radio talk shows. Yates also has well over 900 videos on YouTube, that have been viewed over 31 million times. More info is available at tapwithbrad.com.

Color The World Orange™ Recap



Thank you to everyone who supported the 7th Annual Color The World Orange™. While the event was smaller than 2019 due to COVID-19 and the U.S. Presidential Election, it still went really well. More than 60 buildings in seven countries and more than 30 proclamations with supporters in North America, South America, Europe, Australia, New Zealand and Africa.

RSDSA on the Pain Exam Podcast

Our Jim Broatch and Beth Seickel, RN were recently on the PainExam.com Podcast with David Rosenblum, MD discussing their involvement with RSDSA, diagnosing CRPS, clinical education, and more. Click here to listen.

Does an Autoimmune Disorder Affect My Covid-19 Risks?

Patients with conditions like lupus and rheumatoid arthritis, who may take immune suppressing drugs, do not appear to be at greatly increased risk from coronavirus.

Read more here on the *New York Times* website.

CRPS Warriors Virtual Film Screening of The In-Between

Kristi Oen is hosting a virtual viewing of *The In-Between* on Saturday, January 9th.

Kristi is also hosting an interview with CRPS Warrior Mindy Bledsoe, the director and one of the main characters of the movie, on Wednesday, January 13th at 1p Eastern.

RSVP to watch here for $3 and click here to register for the Zoom interview.

Becoming Advocates for CRPS Warriors

Many people are afraid of advocacy because it sounds daunting and sounds like it can only be done by professionals or big organizations, but that is not so. Just by having CRPS/RSD, we advocate for ourselves all the time.

How?

- Did you ever argue with insurance for coverage?
- Did you ever have to go to multiple doctors to get a diagnosis?
- Did you ever have people doubt there was anything wrong with you and you changed their mind?
- Did you talk to your doctors and nurses about your medications and diagnosis?

If you said yes to any of those questions you are an advocate. The fact is that anyone can be an advocate. The power lies in each person. You are an important part of the equation.

That is why RSDSA formed an advocacy committee in November, appropriately for CRPS Awareness month. The Advocacy Committee goals are: to leverage our numbers as a group, to raise public, government and medical community awareness of CRPS and to advocate for laws, insurance coverage and medical care that takes us from being an orphan disease to the mainstream of care.

Our numbers may be small, but, together, our voice can be large.

Advocacy is having enough voices in concert that cannot be ignored. It is also having all those voices saying the same things with the right message, which amplifies us from individuals easy to ignore to thousands who cannot be ignored.

WHAT CAN YOU DO?

Our first step is a letter you can personalize and send federal representatives that introduces CRPS, yourself and a call to action for your representative. If each of us sends the same message with the same request to all our representatives, that message is hard to ignore. Click here for the sample letter.

The next step is we will host a RSDSA Facebook Live presentation on Thursday, January 27th at 7pm Eastern to share our goals and to get your input on how you can advocate.

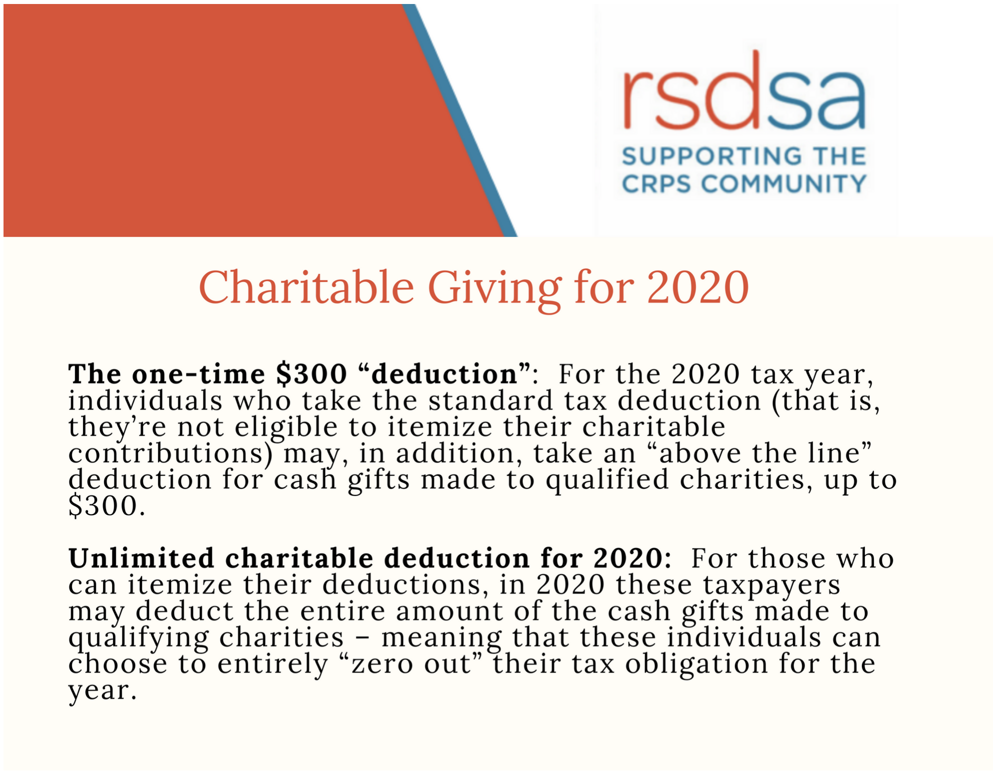
It is so much easier to speak your mind when the message is clear, with purpose and in a large and powerful chorus. With each of us working toward our mutual benefit, we can achieve great things. We can break through the barriers of lack of knowledge in the medical community, marginalization by the insurance community and invisibility within government.

As the founding members of the RSDSA Advocacy Committee, each of us contributes our individual experience in healthcare, medicine, government, and advocacy. Each of us as a community can elevate our status from orphans to advocates. One voice, your voice - one message.

We look forward to working together with you.
Jeri, Jim and Nancy

Treating the Whole Person: Optimizing Wellness Videos Are Now Available

Visit the RSDSA YouTube Channel to view our videos from our Treating the Whole Person: Optimizing Wellness virtual conference and be sure to subscribe while you're there!



rsdsa
SUPPORTING THE CRPS COMMUNITY

Charitable Giving for 2020

The one-time $300 "deduction": For the 2020 tax year, individuals who take the standard tax deduction (that is, they're not eligible to itemize their charitable contributions) may, in addition, take an "above the line" deduction for cash gifts made to qualified charities, up to $300.

Unlimited charitable deduction for 2020: For those who can itemize their deductions, in 2020 these taxpayers may deduct the entire amount of the cash gifts made to qualifying charities – meaning that these individuals can choose to entirely "zero out" their tax obligation for the year.

Word Up

Glutamate [glu·ta·mate]

Neurotransmitter which among other functions, stimulates areas of your brain so you can focus and learn new information. However, in high levels, glutamate is considered and "excitotoxin" which means they can overstimulate cells. There is speculation that this neurotransmitter at high levels causes the continuous misfiring of glial cells (nerve cells in the central & peripheral nervous system) which has been identified as a symptom of CRPS.

Support RSDSA When Shopping on Amazon

Shopping for holiday gifts in the coming weeks? Don't forget to start your shopping at smile.amazon.com so RSDSA can receive 0.5% of your eligible purchases!

Here's how to get set up on Amazon Smile if you have not yet selected a charity

- Visit smile.amazon.com
- Sign in to Amazon
- Under “Start by picking your charity” type in RSDSA or Reflex Sympathetic Dystrophy Syndrome Association and click search.
- We are the only option that will come up so once you see our name click “Select”
- On the next page when it asks “Yes, I understand that I must always start at smile.amazon.com to support Reflex Sympathetic Dystrophy Syndrome Association or (RSDSA).”, click the checkbox and then click Start Shopping

Here's how to get set up if you have already selected a charity that is not RSDSA

- Visit smile.amazon.com
- Sign in to Amazon
- If you have already selected a charity, on the left-hand side of the main menu you will see “AmazonSmile” with a drop down arrow. Click it.
- Click the "Change charity" button.
- From there, search for RSDSA or Reflex Sympathetic Dystrophy Syndrome Association.
- We are the only option that will come up so once you see our name click “Select.”
- You will then see in green "You have changed your charity to Reflex Sympathetic Dystrophy Syndrome Association (RSDSA)."

Send us a message or comment below if you have additional questions!

amazonsmile

End of Year Appeal

2020 has been a difficult year for everyone and yet, despite the pandemic of 2020 the RSDSA community has emerged stronger and closer than ever.

Community is profoundly important to those with CRPS. Living with a chronic disease, in constant pain, often unable to work or cut off from family and friends, community is the bright light that sustains us. It is your continuing donations that enable us to keep that light shining.

What did your dollars do to build CRPS community

- Facebook Live series – twice monthly presentations on the latest theories about and treatments for CRPS. Sessions were attended by as many as 1000 people and could also be viewed when posted to RSDSA's YouTube channel.
- Our first Virtual CRPS Awareness Walk – held in August, it was a testament to the commitment of our RSDSA community members who raised both awareness and funds in 40 states and 3 countries.
- Treating the Whole Person: Optimizing Wellness virtual conference – Four nights of pertinent information from CRPS researchers and clinicians. Followed by one-to-one networking that reached previously unconnected CRPS Warriors to become part of the caring community.
- *In Rare Form* – a new monthly mini-newsletter that updates the Warrior community on current research, news, CRPS initiatives and special events

How does your gift build community?

- $50 - Underwrites the cost of a sign language interpreter for two Facebook Live presentations.
- $125 - Funds a one-to-one monthly networking session to promote connection and inclusivity.
- $250 - Sponsors one child to attend Center for Courageous Kids Camp (CCK) for children in pain.
- $500 - The average grant to one family from the Jenkins Patient Assistance Fund. The Fund provides emergency financial aid to individuals with CRPS and their families.

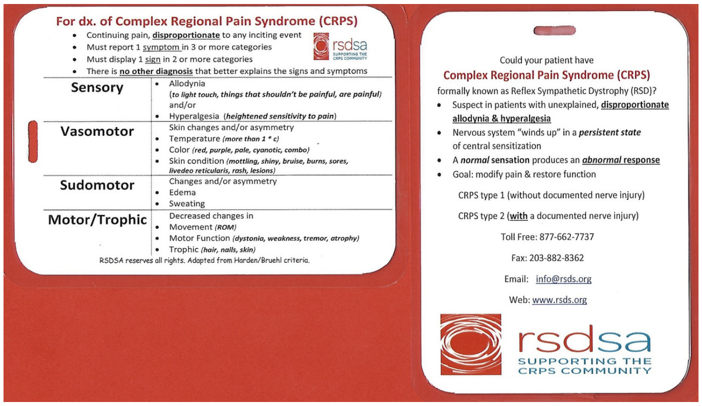
Your generous contributions to RSDSA help to banish the darkness that can easily overwhelm those who suffer alone without a community to support them. ***Please give a gift this holiday season and be the light of hope for our community.***

Thank you, with best wishes for a happy and healthy holiday season,
The RSDSA Team

Laminated CRPS Medical Reference Cards Are Available

Purchase one of our reference cards for $2 so you can keep information about CRPS handy in your wallet at all times!

Click here to purchase.



For dx. of Complex Regional Pain Syndrome (CRPS)

- Continuing pain, **disproportionate** to any inciting event
- Must report 1 symptom in 3 or more categories
- Must display 1 sign in 2 or more categories
- There is **no other diagnosis** that better explains the signs and symptoms

Sensory	• Allodynia (***to light touch, things that shouldn't be painful, are painful***) and/or • Hyperalgesia (***heightened sensitivity to pain***)
Vasomotor	Skin changes and/or asymmetry • Temperature ***(more than 1 * c)*** • Color ***(red, purple, pale, cyanotic, combo)*** • Skin condition ***(mottling, shiny, bruise, burns, sores, livedeo reticularis, rash, lesions)***
Sudomotor	Changes and/or asymmetry • Edema • Sweating
Motor/Trophic	Decreased changes in • Movement ***(ROM)*** • Motor Function ***(dystonia, weakness, tremor, atrophy)*** • Trophic ***(hair, nails, skin)***

RSDSA reserves all rights. Adapted from Harden/Bruehl criteria.

Could your patient have
Complex Regional Pain Syndrome (CRPS)
formally known as Reflex Sympathetic Dystrophy (RSD)?

- Suspect in patients with unexplained, **disproportionate allodynia & hyperalgesia**
- Nervous system "winds up" in a ***persistent state*** of central sensitization
- A ***normal* sensation** produces an ***abnormal* response**
- Goal: modify pain & restore function

CRPS type 1 (without documented nerve injury)

CRPS type 2 (**with** a documented nerve injury)

Toll Free: 877-662-7737

Fax: 203-882-8362

Email: info@rsds.org

Web: www.rsds.org

Happy Holidays from RSDSA!

On behalf of the RSDSA Board of Directors, staff, and volunteers, we want to wish you and your loved ones a very happy holiday season.

Additionally, Carolyn's Cards is back to spread holiday cheer! CRPS Warrior Carolyn McNoldy is ready to send cards and other small surprises through the mail to individuals with CRPS and their caregivers.

If you are a Warrior or know one in need of holiday spirit, email carolyns.cards2@gmail.com to receive some in the mail!

Please send us feedback!

Please send any suggestions or upcoming events of interest to our community to info@rsds.org and please consider a donation to rsds.org/donate.