Tools and Tasks for a Better Day

Presented by

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The basics: Thinking Differently

1. Having CRPS/CRPS or being a caregiver means having to look at life differently.
2. Saving time and energy and finding less painful ways of accomplishing life's tasks means more energy and less pain.
3. We need to remember we are the generals of our own lives and to use the army of tools and resources at our disposal to our advantage
4. We often concentrate on what we can no longer do but the list of what we may be able to do is possibly longer.
5. We also need to remember not to judge ourselves by others – what works for one may not work for another.

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Relationships: Family First

1. Maintaining a good relationship takes work!
    a. Empower Yourself!
    b. Hurt vs. Harm
    c. Just because you are ready to talk about it that does not mean they are ready to hear it
    d. Do not let having CRPS/RSDS define you

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Relationships: Family First, Cont.

2. Do not expect everyone to understand your condition.
3. Don't be afraid to take on new roles or redefine a relationship.
4. Find new ways to interact and use all the means at your disposal
5. Communication is huge!

- Do things for yourself when you can and make sure your family and friends do not smother you with help
- Do something you love even if it hurts a bit but let it do no harm! Do not let fear of a "little" more pain make you miss some of life's most important moments.
- They may be empathetic but unless you have the same condition they cannot truly understand. Some things unless experienced cannot truly be understood. So focus on the practicalities of living with the condition.
- Understanding may come later
- Chronic pain can make a relationship difficult! Some relationships may change and we may need to find new ways to relate to the people in our lives. DO not define yourself by what you cannot longer do.
- Technology has certainly helped! Can't visit Skype!
- It may seem obvious and basic but so often overlooked. Keep in mind this is for everyone! Just because we need to "talk" does not mean others may be ready to hear it. Make time when everyone is and can be ready.

Steps for a better relationship

1. Seek out effective pain and stress management –may seem redundant but less pain = less stress on the relationship
2. Empower yourself – do things for yourself and make sure family and friends do not smother you with help.
3. Hurt vs. Harm – do something you love even if it "hurts" a bit but let it do no "harm". Do not let the fear of a "little" more pain make you miss some of life's most important moments.
4. Give up expecting others to understand your condition- yes the can be empathetic but unless you have they have the same condition they cannot truly understand. Some things unless experienced cannot truly be understood. So focus – the practicalities of living with the condition
5. Don't be afraid to take on new roles and redefine relationships

6. News flash: ‘chronic pain can make relationships difficult”. Some relationships may even fade away (that happens sometimes any way) but we may just need to find new ways to relate to the people in our lives. Do not define yourself by what you can no longer do! Find new things to do.
7. Find New Ways to Interact: use all the means at your disposal! Technology certainly has helped.
8. Communicate: it may seem extremely obvious and basic but sometimes the most overlooked. Keep in mind this goes for everyone. Just because we may need to “talk” does not mean others may be ready to hear it. Make time! When everyone has time to decompress from the day and can really communicate.

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Caregivers Need Care Too

1. Being a caregiver is made up of many tasks
2. Asking for help is a sign of strength not weakness.
3. Break down the tasks! Delegate!
4. Write down your concerns and share them with someone.
5. Make time for yourself – you deserve it!

- Asking for help means you may have a better grasp of the situation
- Be proactive with problem solving, it’s a lot to take on!
- Make time for you – you deserve it!

Getting help for Caregivers

1. Why is it so hard to ask for help? What’s a good response to the statement, “Call me if you need me?” Despite the fact that family caregivers are drowning in responsibility or are really confused about what the next step ought to be, they often respond “no thanks” when help is offered.
2. Asking for and accepting help is a complex issue. Obviously you first need to admit that having some help will make a real as well. Then you need to define what help you need. Which tasks or chores would be the easiest to ask others to do? Which do you really want to do yourself? And which, if any, can you afford to pay others to do? If this just sounds like more work, know that it doesn’t have to be an overwhelming task but rather just a way to organize the thoughts and information you already have. Ready to give it a try?

Here are six steps to getting help as a caregiver

1. Recognize that care giving, like any job, is made up of lots of individual tasks, not all of which are of the same importance. Some tasks take a few minutes; some may take many hours. Some tasks are easy; others require some skill and fortitude. The challenge is to know the difference.
2. Recognize that asking for help is a sign of strength and not of weakness. It means you truly have a grasp on your situation and have come up with a proactive problem-solving approach to making things easier and better.
3. Create a list of the tasks that need to get done in any given week, or at least those you are most concerned about, such as balancing your responsibilities at work with taking mom to the doctor and Susie to soccer practice, bathing and dressing your husband, cooking, cleaning, etc. When you see how long the list is you’ll quickly understand why you are so tired and don’t have time for yourself.
4. Group your tasks into categories such as personal care tasks for your loved one, transportation, household chores. You can group your tasks into only a few broad categories, or many specific ones. There’s no right or wrong way. It’s all a matter of personal preference.
5. Write down your caregiving worries. Where will we get the money to pay for John’s medications? Who will care for Mary if I get sick? Where can I find a daycare facility that provides transportation? Seeing them in black-and-white helps diffuse some of their emotion. It also allows you to think more rationally about your concerns and understand how getting help with some of your tasks might lessen the stress. It can provide the basis for deciding which tasks you might ask a neighbor, family member or the church to help out with, which you are willing and able to pay someone else to do and which there a public programs for assistance.
6. Share your lists with someone you trust before you actually reach out for help—a friend, therapist or clergyman, perhaps. The intent is to first get comfortable with idea of talking about your need for assistance and hopefully get some encouragement and good ideas in the process. Then take a deep breath and actually ask someone to help with one of the tasks on your list, or ask for guidance in resolving your most persistent worry. Start with something small, especially if you are looking for hands-on assistance or something that requires someone doing you a favor. Don’t get discouraged if you get rejected at first. It sometimes takes perseverance.

Just remember—the effort is worth it because the goal is better care for your loved one and yourself.

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Pain and Parenting

1. Have an open dialogue with your children – age appropriate of course!
2. Children need to be reassured about what is happening.
3. For school aged children keep their teachers and counselors involved and offer them counseling if needed

Parenting issues

1. For the purpose of this presentation we will discuss the parents in pain. The birth of a child is a wonderful and joyful event but to a pain patient it can be a whole new set of concerns. How can I still parent? And yes there is a difference if it's mom vs. dad in pain (any feedback?) The most important thing to remember about parenting with pain is to have an open dialogue and communication (age appropriate of course). This helps children understand their parent's' limitations and why their parents are different then their friends parents.
2. Young children have active imaginations and if let to their own devices who knows what they may think. They need to know they cannot catch your pain!

3. School age children think in black and white so give realistic answers even if it's not an "I do not know". They also function better with a routine and knowing how things will get done – as in how I will get to school or who will make my lunch etc.
4. Adolescents are the roller coaster of parenting to begin with! Answer their questions as honestly as possible and do not be afraid to ask for professional help if needed. For them too!
5. Children of all ages need to be reassured about what is happening. The bigger part of parenting with pain is our own guilt that we are short changing them somehow because of our limitations. I was once told when I was scared about caring for a second child and maybe not being able to give enough – that how would the child know? The child would only know how much they were loved and cared for! Not so much the how! Yes we may have to do things different and maybe a few less things but pick what matters and make it count. We need not to beat ourselves up for what we cannot control and do what we can – read a bedtime story, watch a game, make a dinner together (they can cook later for you!). It's the quality of time not how much and how much we do. And being different is what helps make the world an interesting place. You may be surprised at how proud your child may be of you handling such a difficult issue!

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Dear Doctor

1. Keep a journal
2. Ask to fill out paperwork ahead of time
3. Get your questions and concerns together before your visit
4. Bring pen and paper!
5. Be honest; it works or it didn't.
6. Ask questions! Take help if needed!
7. Keep a list of medications and supplements
8. Bring your research - just don't tell them about it
9. Second opinions Doctors are not all know.

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Home and Hearth

1. Use lists for groceries, tasks etc. and keep them on the fridge
2. List the 3 things you need to do each day; that is your goal
3. Break tasks into smaller components
4. Use message boards
5. Give a specific task to anyone who offers to help!
6. Plan for emergencies.. They do happen and extra care may need to be given to those less mobile.
7. Everything has its place.
8. Use available technology

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Taking care of the home

1. ORGANIZATION
   a. Color code
   b. Have each person in the family have a “color” and a corresponding folder for paperwork and marker for events on a larger
   c. Have one person do the finances
   d. Recycle unneeded paperwork asap
2. UNWANTED EVENTS
   a. Video tape your home and put the copy in a safety deposit box
   b. Keep important papers
   c. together as well
   d. Have an emergency phone or contact list – not on a cell phone
   e. Keep an info book: insurance info, combinations of kid’s bike locks etc.

Every day thoughts:

1. Lists are great!
   a. It sounds simple but making a list each day of the three things, you must do and then a list of three things you would like to do. Those are your goals for the day. It amazing how good it feels to check done tasks off a list!
   b. Lists can be used everywhere in your life leave a list for groceries on your fridge or house hold tasks someone needs to do. We know how well our memories may be and that adds to our frustration and pain.
   c. This works well with our questions and concerns for our doctors as well.
2. Plan a head

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Use all those kitchen tools!

1. Timers
2. Right angled kitchen tools
3. Jar openers electric
4. Bag openers
5. Skid free bottoms or pads
6. Holders to keep pots on place
7. Wide handled tools
8. The right tool for the task
9. Bread makers
10. Quick recipes 5 ingredients or less!
11. Heat gloves vs. pot holders
12. Paper plates!
13. Wider glasses and lighter weight
14. Have stool to sit on
15. Small step latter
16. Crock pot

Kitchen

1. Keep commonly used items at waist height, so you don’t have to reach
2. Large knobs on appliances and cabinet doors requiring manipulation
3. Long handled cleaning appliances, (e.g., brooms, dusters, sponges)
4. Long-handled "grabbers" for removing items on high shelves or picking up items from the floor
5. Sliding shelves or turntables on kitchen shelves so the patient does not have to reach into cabinets to access items at the back of a shelf

Cooking

1. Come up with easy to make recipes that are still good for you
2. Crock pot cooking is a great way to have a good meal and easy to prepare
3. Split larger food items or food needing to prepared in Tupperware
4. Cook larger batches and freeze for another night's dinner
5. Right tool for the right job
6. Precut fresh or frozen vegetables to reduce prep time

Bedroom

1. Blanket support frame so that the weight of blankets or sheets do not rest directly on the feet of a patient
2. Install blackout curtains for a place in your house you can retreat to for those moments of breakthrough pain, migraines, etc...
3. Keep commonly used items close to the bed for easy reach (remote control, medications, cup of water, reading materials)
4. Keep the floor from being cluttered to avoid tripping and falls
5. Keep your room ventilated, being too hot or too cold can interfere with quality sleep
6. Make sure your mattress is comfortable and use pillows that provide more or less support as needed
7. Nightlights in the bedroom and any other rooms where the patient may walk if they awaken during the night
8. Visit American Sleep Academy online at yoursleep.aasmnet.org for ideas

Laundry

1. Do smaller loads
2. Wear wrinkle free clothing
3. Downy Wrinkle Releaser small items
4. Use a lingerie bag for smaller items (e.g. socks)

Cleaning

1. Do work as you can, 1 or 2 tasks a day
2. Know that it is ok if everything is not perfectly clean and tidy
3. Break jobs into smaller components
4. Delegate
5. Task lists for family members

Bathroom

1. Dry with smaller towels so the weight of the towel doesn't wear you out or drag across painful areas
2. Grab bars in the bathtub, shower, and next to the toilet
3. Tub or shower bench
4. Use a hairdryer stand
5. Toothpaste tube key
6. Use an electric toothbrush
7. Use Epsom salt baths to relax

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Health and Beauty

1. We have the right to look good!
2. Medications may wreck havoc on our hair skin etc. use proper products.
    a. Hot oil weekly or use a dry shampoo; same goes with skin and chapped lips (e.g. Vitamin E)
3. Use sun screen – 30 SPF or higher- medications can make us sun sensitive
4. Dentists are important! So are other annual checkups!
5. Look into beauty tools, aids and products that may make your routine easier
6. Medical Concerns

Medication strategies:

1. Streamlining even the smallest of tasks can make life less stressful and run easier. Arthritis Magazine offered a few suggestions in this department.
    a. Review meds with your doctor. Do you need them all? What about time released vs. a short acting version? Can I cut down on any? We should probably all do this review periodically. What is the best way to refill/renew? Automatic? Online over the

        phone? What about refill reminder to avoid running short? Learn new procedures and legislations pertaining to your medications. All of these suggestions can help cut down on time and stress.
        b. Learn what each medication does its side effects. Are they worth it?
        c. What vitamins do you really need? Can a multi vitamin take the place of many vitamins? Are you duplicating? Maybe food is a better source?
    2. Supplements – are you self-medicating? Ask if you really need or have you noticed any improvements since you started it. Make sure you note supplements when asked what medications you take.
    3. Exercise and weight control – keeping our weight under control may be difficult do to your personal situation but look into what done. Less weight may reduce your need for some medications.
    4. Organization: Do you use a daily or weekly dispenser? Why open all of those bottles so many times! Especially with supplements and vitamins that may need to be taken numerous times during the day
7.

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Wearing clothes can often be painful

1. Wear what works!   Soft lose fitting in natural fibers are often the best
2. We are temperature sensitive so be prepared and dress in layers;
3. There are tools that can help button, zip and pull on socks! Give them a try.
4. Shoes – get what works and use Shoe Stretch spray if needed to break them in.
5. When dressing to be out in the cold – use a "heat wrap" used for back pain to keep your body warm! Mittens are easier then gloves and even better with hand or toe warmers.
6. Invest in Downey Wrinkle Release – no ironing needed
7. Don't just shop in one department – try men's, larger sizes, maternity, and whatever works.
8. Use a coat rack to hang coats instead of hangers. So much easier.

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A little exercise can go a long way…..

1. Do what you can! Even 5-10 minutes a day.
2. Walk yoga, aqua therapy, swim, Pilates. Tai-Chi -movement without causing more pain! Check out new equipment that limits your weight impact on joints...
3. Take your vitamins or recommended supplements. Make sure there are no issues with your medications.
4. Stay hydrated and eat a healthy diet – read some of the health magazines and their recipes! Gluten free has been recommended as well as anti-inflammatory diets.

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Relieve a little stress..

1. Find a support group – that goes for caregivers too.
2. Get counseling
3. Meditation, bio feedback or even a bath
4. Research for resources: financial, medical, medications. Every little bit helps.
5. Learn to ask for help lighten your load of responsibilities
6. Take time for yourself. You deserve it. Do something for you.
7. Empower yourself. Be your own advocate.

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A good night's sleep

1. Keep a dark room – no light - use an eye mask if it helps. Use black out curtains or liners.
2. Noise – keep it a minimum.
3. Sheets can make a difference! Use quality and high count. Put pillows to work.
4. Magnetic mattress covers have been known to help
5. Use scent to help – calming scents sprayed onto pillows or sheets
6. Try melatonin – Super Snooze has other sleep aid herbs as well
7. Calming bath or mediation before bed
8. Be aware of the temperature in your room
9. Keep pad and pen around for those thoughts you do not want to forget

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Fun and Entertainment

1. Yes, we can have some fun! Yes, there are times when we just can't but there are times we can try. Here are some ways to get through the event:
    a. Plan for pain but try not to let it ruin the day
    b. Pace, plan and Prioritize. Rest the days before and have no plans the day after.
    c. Watch the alcohol and your meds!
    d. Communicate Thank the host early on in case you are tired and need to leave early.
    e. Take time during the event for a time out. Even if it is your event. A few minutes of rest will work wonders.
    f. Listen to your body! There is no one saying you need to party the night away, when you are tired and have had enough leave. You made it that was the point
    g. Dress comfortably. Bring a wrap in case it's cool or a scarf to use a s sling in case your hand or arm hurts
    h. Ask if your table or seat can be away from the music or doors
    i. Plan ahead on how to answer all those questions about how you are doing.
    j. Dance if you want to! We are allowed to enjoy ourselves!
    k.

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Being Mobile

1. WALKING WITH AID; Canes can assist with balance and gait issues
    a. All canes are not created equal
    b. Check for height adjustability
    c. Fold up? Portable?
    d. Handle or arm support?
    e. Good rubber bottom to avoid shoulder pain?
    f. Walker or roll aid
    g. Portable seats

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2. DRIVING CONCERNS
    a. Handicapped parking permit! Always!
    b. Special auto needs
    c. Scooters? Own or rent?
    d. Wheelchairs?
    e. Electronic locks and car starters
    f. Emergency kits
    g. Electronic controls
    h. Specialty bikes

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Traveling

1. HOTELS
    a. Book directly
    b. Check all amenities
    c. Explain situations and requests
    d. Take a virtual tour
    e. Ask about local attractions and deals
    f. Plan and plan again!

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2. TRANSPORTATION
    a. Plan from start to finish
    b. Let the airline know you have special needs
    c. Use a wheel chair at the airport
    d. Car rentals: can they fit a wheelchair or scooter
    e. Bring Placard!
    f. In The Car
        i. Apply for your handicapped parking placard and keep it in the car
        ii. Car doors that are easy to open and close, keyless entry vehicles and push button start
        iii. Special key holders
        iv. Electric seat positions with buttons that are easy to manipulate
        v. Have the dealership modified controls to facilitate driving
        vi. Keep a pillow and blanket in the car at all times
        vii. Keep an emergency kit in the trunk in at all times (jumper cables, fix a flat, first aid kit)
        viii. Extended mirrors to help with view – less twisting and turning
        ix. Use your cruise control
        x. Add a thickening steering wheel cover or attach a steering wheel knob to make steering easier
        xi. Driver Rehabilitation Specialists at driver-ed.org

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Traveling,

1. AIRPLANES
    a. Bulkhead seats have more legroom
    b. avoid sitting on the aisle
    c. Move around and stretch
    d. Take a medication to relax if needed*
    e. Keep your meds with you

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2. AIRPORT CHECK IN AND OUT
    a. Wear shoes that can be removed easily
    b. Check for size of carry on
    c. Let staff know about your concerns and mobility
    d. Snacks and water
    e. Know regulations

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Vacation tips

1. Plan ahead – for anything and everything!
2. Prioritize your sightseeing
3. Give yourself days and time to rest
4. Call attractions ahead and see what policies they have for disabled (special lines and seating and policies for renting equipment
5. Let your family do some things without you – do you really need to go to the water park?

6. Changes to our routines may cause flare ups are prepared to build in down time.
7. Cancellation policies
8. Health care coverage
9. Extras such as hot and cold packs and medical info

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A few other things

1. Give concerts a try – just check out the handicapped seating and regulations.
2. It is best to leave medications in their original containers.
3. International travel may require more extensive planning & have different regulations country to country
4. Make a list of everything you need to do and pack a head of time. This will reduce a lot of anxiety the closer you get. Check lists are a great idea.
5. Check out vacation cancellation polices. Also cancellation insurance policies.
6. Who knows when a major flare up may happen. And remember not to beat yourself up if this happens. This is a difficult topic and concern with RSD patient's .Our in ability to predict how we will feel months from now. Just remember the world does not stop because we are in pain

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What we like to do…

1. Try not to give up on hobbies. Review what information or options are available in that field that can help you possibly find a new way to do it.
2. Break a project down. Who says we need to do it in one hour or one day?
3. Plan it out. Who can help with what?
4. Find a new hobby. There is still so much we can do.
5. We become forgetful due to pain, lack of sleep medication or just too much multi tasking; Focus on one thing and keep pen and paper handy (or use technology) for all those other ideas.
6. Join a group. Be it a support group, book club or other type. Socializing is important.
7. Technology is wonderful but so are people.

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"You look fine" and other Comments

1. At least it's not fatal
2. But you don't look sick
3. I read about this new product that cures ...
4. I used to have chronic fatigue too – I just got active & it went away
5. If you got more sleep, you'd feel better
6. It's all in your head
7. I've heard CRPS/RSD is just a diagnosis they give when there's really nothing wrong
8. My friend has back problems and still manages to work
9. You just need to get a job or hobby to take your mind off the pain
10. We all get more aches and pains as we get older, it's probably just a touch of arthritis

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Good Reading :

- *A Survivor's Story: Life with RSD* by Stephanie Gardner, Ms. Edwards and Dale Lundy
- *Chronic Pain: Reflex Sympathetic Dystrophy, Prevention, and Management* by H. Hooshmand

- *Defeat Chronic Pain Now!: Groundbreaking Strategies for Eliminating the Pain of Arthritis, Back and Neck Conditions, Migraines, Diabetic Neuropathy, and Chronic Illness* by Charles Argoff and Bradley S. Galer
- *In the Blink of an Eye* by Mary Jane Gonzales
- *Invisible Pain, What You Can't See is Real!* by Kristen Baker
- *Living with RSDS:* Your Guide to Coping with Reflex Sympathetic Dystrophy Syndrome by Linda Lang and Peter Moskowitz MD
- *Medifocus Guidebook on: Reflex Sympathetic Dystrophy* by Inc. Medifocus.com and Elliot Jacob PhD.
- *No, It Is Not In My Head: The Journey of A Chronic Pain Survivor From Wheelchair To Marathon* by Nicole Hemmenway
- *Pain Banishment: Don't Manage Your Pain, Banish It Completely* - Even When Nothing Else Works by Donald Rhodes and Patricia Boeckman
- *Positive Options for Reflex Sympathetic Dystrophy (RSD): Self-Help and Treatment (Positive Options)* by Elena Juris
- *Power Through Pain: Living with Reflex Neurovascular Dystrophy* by Elizabeth Elster
- *ReMission Possible: Yours, If You Choose To Accept It* by Barby Ingle
- *RSD In Me!: A Patient And Caretaker Guide To Reflex Sympathetic Dystrophy And Other Chronic Pain* Conditions by Barby Ingle
- *The Patient's Guide To RSD: Know why RSD causes devasting pain and suffering* by Dr William Edward Ackerman III
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Additional Resources:

1. **Organizations**
    - RSDSA
    - RSDHope
    - Power of Pain Foundation
    - National Care Givers Association
    - Medic Alert
    - Local Support Groups
    - For Grace
2. **Websites**
    - www.rsds.org
    - www.caresalliance.org
    - www.crpsadvisory.com
    - www.patientawareness.org
    - www.powerofpain.org
    - www.rsdawareness.org
    - www.rsdhop.org
    - www.rsdinfo.com
    - www.rsdla.net
    - www.rsdnation.com
    -
    - www.rsdrx.com
    - www.stoppain.org
    - www.uspainfoundation.org

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1. Yes, many of us "look" fine but it takes an enormous amount of energy to appear that way. It is up to us –CRPS/RSDS patients to be our own advocates and educate those we come in contact with.
2. By taking steps and utilizing some of the tools and tasks we have mentioned or come up with your own you may have a better day and be able to do just that.