Creating your own CRPS Toolkit:

“Nurse Beth's Tips and Strategies with CRPS and Flares”

Presented: RSDSA Conference
December 8, 2017
Nurse Beth has NO actual or potential conflict of interest in relation to this presentation.

Nurse Beth’s presentation comes from a unique position as both a nurse and a CRPS patient. It is intended for educational purposes only and does not replace independent professional judgment.
About Nurse Beth

THE PERSON......

* Married 33 years ago to a wonderful man, while still in nursing school (FYI: chronic pain, CRPS NOT taught in nursing school)
* Have 2 terrific adult kids and new son in law
* RN since 1984 in Critical Care, ER and Asthma & Anaphylaxis Education
* Nurse Beth has unique perspectives, great sense of humor and determination, all of which are helpful living with CRPS
About Nurse Beth

THE PATIENT......

* Work related injury almost 11 years ago
* Left ACL tear post slip/fall requiring surgery
* Immediately post op, had severe, relentless, electrical sensations of unexplained burning pain, changing an “ambulatory procedure” to a 5 day admission on PCA pain pump!
* Took 6 months to be diagnosed & begin my CRPS journey
* Developed: CRPS type 2 Left leg/foot initially
* Progressed: CRPS type 1 Right leg/foot
  * Arms
  * Nose, mouth
* Osteoporosis
* Gi dysmotility
* Dysautonomia
Nurse Beth wants you to **IMAGINE**......

* Your skin is SO sensitive, that a simple touch, a hug, a shower, or clothing causes excruciating burning pain

* Having tormenting pain from:
  -- **Vibrations:** (riding in a car, music)
  -- **Noise:** (ringing of a phone, volume of TV/radio, loved ones voice, child’s instrument)
  -- **Temperature:** (the heat from lying next to your spouse/partner, fluorescent lights, or changes in temperature or barometer)

* Feeling your skin as Fire & Ice
Despite CRPS, Nurse Beth DEVELOPED......

*A few new abilities & comic relief

“Really, how is that possible?”
Nurse Beth’s developed **NEW SKILLS, I CAN....**

* Turn **blue**, burning and cold: like you’re limbs have turned into an ice glacier in the Arctic Circle.

* Turn **red**, burning, HOT: like you’re stepping on hot molten lava or turned into a human lighter.......
Nurse Beth’s developed NEW SKILLS, I CAN....

* Turn red and blue, like the 4th of July

* Develop brain fog, like a machine out of order
Nurse Beth’s developed **NEW SKILLS, I CAN....**

* Look **Shiny** and wet, as if you just got out of a shower or turned into a newly waxed floor

* Develop lattice looking skin: *livedo reticularis*, like an abstract geometric design or trellis
Nurse Beth’s developed NEW SKILLS, I CAN....

* Develop **red HOT** nose, like Rudolph red nose reindeer lighting the way

* Develop unusual **swelling**, as if I have camel humps retaining water
If nurse Beth had a **MAGIC WAND**

to eradicate CRPS I would gladly share.....

**AFTER** using it first!

**BUT till then..........**
Nurse Beth’s….. TOOL KITS

* Depends on the situation:
  * Every day
  * Overnight
  * Travel
  * International
  * Hospital

*In conjunction with my “pain management plan and team”

Expect the UNEXPECTED & PLAN AHEAD!
Before deciding on a TOOLKIT …

**EVALUATE**: Potential Activity & Options

Plan ahead to assess:

- Time Involved
- Weather conditions
- Temperature considerations
- Tolerance, energy, stamina level (rest, sleep)
- Mode of transportation needed
  - (Can I drive with pain or on meds?)
- Mobility challenges
  - (wheelchair, scooter, cane, crutches, need assistance ambulating/transfering?)
- Medication & Compounded Specialty meds
  - (cold or room temperature?)
- Dietary restrictions
- Assistance & support requirements
- Noise, vibration, lighting considerations
- Medical equipment
  - (TENS, SCS, Intrathecal pain pump, etc)
- Personal equipment (hypo-allergenic supplies)
- Medical documentation needed
- **What are YOUR needs?**

MINIMIZE OR DECREASE CRPS FLARE

*Believe in YOURSELF!*
*Have Faith You CAN do it!*
*Be patient!*
*Just Breathe!*
*Relax*

http://www.theacpa.org/Relaxation-Guide

Believe in YOURSELF!

Have Faith You CAN do it!

Be patient!

Just Breathe!

Relax
WHY does Nurse Beth have a TOOL KIT?

* Empowerment
* Control over the “unexpected”……
* Liberation of fear

* Courage and Independence
* Expand “short-term” goals
* Improve quality of life while managing chronic pain
* Found my own strength in spite of pain

What’s my pain level? Honey, I only have two types of pain: tolerable or intolerable.
WHO does Nurse Beth think needs a **TOOL KIT**?

Anyone with a chronic persistent condition such as CRPS.

If pro-active with asthma, diabetes etc. why not with chronic pain conditions like CRPS?

“CRPS is a **REAL MEDICAL CONDITION**”
**WHAT is a TOOL KIT?**

*Practical tools which can improve **compliance & safety** of your individual medical needs, regardless of flares*

***Organizes** your individual medical management of medications & documentation for **easy access***

*Provides **confidence** knowing you have what you need & or use **regardless** of where you are*

*Can build your doctor-patient **communication***

*For me, it’s like an umbrella. If you bring it, you won’t need it, but if you don’t, you will **definitely** NEED it.*
Nurse Beth’s EVERYDAY Tool Kit

Medical documentation including:

* Contact info of all physicians including your “pain management team”
* List of daily medications (topical, patches, liquids, pills)
  List of prn (as needed) medications
  List of nutritional supplements, Rx and OTC
* List of specialty compounded medications
* List of medical conditions
* RSDSA information
  (Hospital Guidelines, CRPS card, Tips for Managing CRPS)
  Aids to validate & educate others
Could use a tool belt, but not comfortable or practical...

Rather consider a secured bag or container for documentation & medications organized & accessible
Nurse Beth’s EVERYDAY Tool Kit....
also includes:

* Modified Yoga (chair, floor, couch when able)
* Flip flops (closed shoes painful)
* Wheelchair & cane
* Our puppy (therapy)
* Cream/lotion (allodynia creates dry, itchy skin)
* RSDSA bracelet or Mediband®
**Vitamin C:**

Study shows **Vitamin C** reduces the prevalence of complex regional pain syndrome after wrist fractures. A daily dose of 500 mg for fifty days is recommended.

[https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2861029/](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2861029/)

*Prior to CRPS- daily multivitamin

*With CRPS*-additional support may be needed

* Before surgery and or procedures I increase Activate-C Immune Complex
Calcium

D3

Prescribed powder blend
- Co-Q10 (ubiquinone)
- Acetyl-L-Carnitine
- Pyridoxime (B6)**
- Creatine

**B vitamins:**
- Riboflavin
- Thiamine HCL (B1)**
- Methcobalamin (B12)**
- L-ascorbic acid (C)

Can be helpful with neuropathy

Reverse Osmosis water filtration system
Nurse Beth’s EVERYDAY Tool Kit…. also includes:

* Umbrella
* W/c Accessibility
* TENS
* Heating pad
* Poncho or sleeveless coat (burning skin, can give me chills)
Nurse Beth’s **OVERNIGHT** Tool Kit....

Also includes:

- Neck pillow
- Food, water (hydration) gluten-free/minimize especially during high flare days
- Nebulizer
- My own towel, washcloth (used my own detergent)
- Soft blanket
Nurse Beth’s **OVERNIGHT** Tool Kit...
also includes:

*Flip flops*

*Adaptive, soft clothes*

*Medications in cooler bag*

**LDN:** low dose naltrexone suspension

**Ketamine** Troches

*TENS*  
(transcutaneous electrical nerve stimulation)
Nurse Beth’s TRAVEL Tool Kit....

* **TSA** disability “**Notification Card**”
  
  **ie** “CRPS full body, left eye, face. Extremely painful especially to touch”
  
  [https://www.tsa.gov/sites/default/files/disability_notification_card_508.pdf](https://www.tsa.gov/sites/default/files/disability_notification_card_508.pdf)

* **TSA Cares**, passengers with disabilities & medical conditions call #1-855-787-2227 at least 72 hours BEFORE

* **Passenger Support Specialists:**
  
  TSA officers trained to screen passengers with disabilities, medical conditions, traveling with medical devices, needing security accommodations
  
  I ask for: Passenger Support Specialist OR Supervisory TSA Officer
  
  [https://www.tsa.gov/travel/special-procedures](https://www.tsa.gov/travel/special-procedures)
Nurse Beth’s TOOL Kit…
also includes:

America the Beautiful-National Parks & Federal Recreational Lands Access Pass
(Free access to National Parks)
https://store.usgs.gov/pass/access.html

A **lifetime pass** for US citizens medically determined to have a permanent disability, severely limiting one or more major life activities.
Nurse Beth’s TRAVEL Tool Kit....

* Jet Blue Special Assistance:  
  https://www.jetblue.com/travel/special-assistance/

* Wheelchair, boarding, & disability seating  
   I ask for **specialized seating**: bulkhead  
   removable armrest  
   larger seats

* I take w/c up to plane, and **remove** foot/leg pedals before attendant brings to cargo area

* I Keep **all my medications** in my carry-on bag to avoid lost luggage. Temperatures inside the cargo hold could damage your medication

* I Bring a **few days extra** of medications, in case my return is delayed.
Nurse Beth’s TRAVEL Tool Kit….
also includes:

* Ask about accommodations (airport, rent a car, hotel, activity, restaurant, etc)

* Umbrella to shield the sun (protect burning skin)

* Rental car shuttle (w/c accessible?)

* Transport, standard or all terrain w/c

* Small fridge in hotel room/handicap room
* Medical **documentation**, stating what medications & or medical supplies you will be carrying on board & any specific traveling considerations from doctor.

* **Insurance** for trip & medical coverage including medical evacuation coverage

* All **medications** in labeled original containers kept inside clear “zip lock” bags

* All medications & medical devices in carry on (backpack)

* **IPAD/cell with language translator**

Check product adaptor use
* AC adaptor/converter for medical devices (US 110 Italy 220)
* Wheelchair: NOT a transport chair
* Is there a Special Assistance Lounge prior to flight?
* Copies of: Credit Card, ATM, Passport, drivers license, health insurance (Discover had 0% transaction fees vs. Visa had 3% fee)
* Notify credit card company & bank of travel plans

Should have had frequency converter for heating pad “blew a fuse”
**Nurse Beth’s HOSPITAL Tool Kit…..**

**ALLODYNIA & HYPERHIDROSIS**
Can cause skin to be super sensitive

You can ask for **Hypo-allergenic**:
- EKG electrodes for cardiac monitoring
- Tape
- Linens including: sheets, gown, towels, blankets
- Disposable soft wash cloths, self sudsing, no rinse
- Portable fan (if able to tolerate)
Nurse Beth’s HOSPITAL Tool Kit....

* Flip flops, NO hospital socks for me
* Wear my own pajamas
* Sign above bed “DO NOT cover patient with sheets”
* Bed by wall to prevent accidental bangs
Nurse Beth’s **HOSPITAL** Tool Kit...

Decrease **TRIGGERS** with and without IV Ketamine, used Sunglasses in dark cool, room

Due to **ALLODYNIA**: used a plush blanket

No peripheral access left: **MID-LINE PIC LINE** inserted, saved on frequent needle sticks & more trauma
PLAN AHEAD!

To avoid obstacles, consider which tool-kit to use by evaluating....
<table>
<thead>
<tr>
<th>Challenges</th>
<th>Solutions &amp; Tips</th>
</tr>
</thead>
<tbody>
<tr>
<td>Walk vs. walking</td>
<td>*Do what you can, utilize mobility device, park close or be dropped off, acceptance, strategize, “short term goal”</td>
</tr>
<tr>
<td>Medications</td>
<td>*Insulated cooler for compound creams/meds. (compound cream soothes more if cold) *Have ALL and ENOUGH meds in one place like a zippered bag, medical letter *Baggies/pill box instead of med bottle EXCEPT when flying *Prepare ahead, never be caught off guard, bring own food/drink</td>
</tr>
<tr>
<td>Food</td>
<td></td>
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<tr>
<td>Accessibility</td>
<td><strong>Call ahead</strong>, is there elevator, special seating, ramp, bathroom *TSA cares Help Line 72 hrs before leaving <strong>Passenger Support Specialist</strong> 1-855-787-2227 <a href="http://www.tsa.gov/traveler-information/travelers-disabilities-and-medical-conditions">www.tsa.gov/traveler-information/travelers-disabilities-and-medical-conditions</a> *Smart Traveler Enrollment Program FREE <a href="https://step.state.gov/step/">https://step.state.gov/step/</a></td>
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<td>Weather limitations</td>
<td>*Black wheelchair very HOT, get lighter color *Umbrella to shield sun</td>
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<tr>
<td>Pain limitations</td>
<td>*Limit activity BEFORE, hydrate, nutrition, <strong>REST, meditate</strong> *Pre-medicate, acupressure, heat pad, elevate, gentle stretching *Adaptors IE push handle extension *Provide down time, couple therapy</td>
</tr>
<tr>
<td>Care-supporters limitations</td>
<td></td>
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<tr>
<td>Driving limitations</td>
<td>*Back up driver or RESCHEDULE *FREE Handicap parking permit Form <strong>MV-664.1</strong> from city, town, village hall NOT DMV. (don’t need to own car or be registered driver to obtain permit) OR plates $28.75 fee *NYC Street parking MUST have “city permit” NOT valid outside NYC (718) 433-3100 <a href="http://www.nyc.gov/html/dot/html/motorist/pppdinfo.shtml">http://www.nyc.gov/html/dot/html/motorist/pppdinfo.shtml</a> *Set <strong>time goals</strong> to travel (distance increases pain/discomfort)</td>
</tr>
<tr>
<td>Stamina vs. cost</td>
<td>*Rest periods, allow PLENTY of time, PACE yourself *Not a good day, change date OR do what you can *Find <strong>discounts</strong> within town, county, state etc</td>
</tr>
</tbody>
</table>
Nurse Beth is **KIND** to herself!

* Take at least 15 minutes everyday to “just be”

* Surround myself with encouraging energy

* It’s a constant work in progress

* **Insight Timer-Meditation** App: FREE in the app store
  Accessed online or mobile app

* **Headspace Meditation** and Mindfulness: 10 FREE sessions for 10 minutes
  Accessed online or mobile apps

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