

# Patient Power

## *Barby Ingle*

Best Selling Author of RSD in Me!

Motivational Speaker

Pain Advocate and Educator



*Issues surrounding pain management*

*Patient rights & responsibilities*

*Empower patients to become a self-advocate*

*Pain in perspective to life*

*Patient Communication w/ caretakers and healthcare professionals*

# BARBY'S STORY

**2002**

- Car Accident (Whiplash)

**2003**

- Shoulder Surgery
- 1<sup>st</sup> Rib Resection
- 5 collapsed lungs

**2004**

- 1<sup>st</sup> Rib Resection (*again*)

**2005**

- Dx with RSD after seeing 40+ healthcare Pros
- Began Radiofrequency Ablations & Nerve Blocks

**2005-2008**

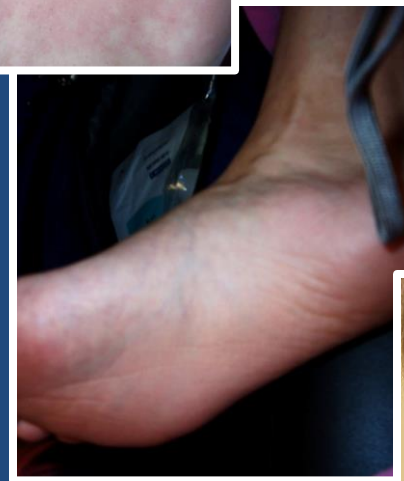
- Radiofrequency Ablations & Nerve Blocks

**2009**

- Diagnosed w/ full body RSD
- Awaiting Ketamine Procedure
- Released RSD in Me!
- Have been seen by over 100 healthcare professionals

**2010 - 2014**

- Received Ketamine Procedure and 5 booster treatments!
- I am now in “remission”



# Issues Surrounding Pain Management

Access to Medications

Getting timely and appropriate treatment

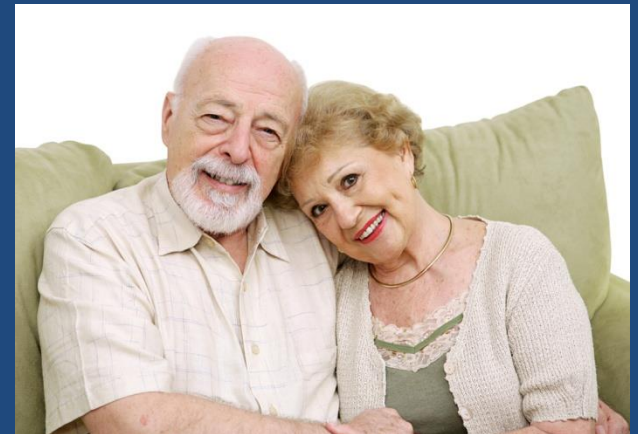
Under-treatment and Over-treatment

Medical specialties

Procedures

Physical approach

Psychological approach



# *Empower Patients To Be A Self-advocate*

1. Take a deep breath.
2. Think about what just happened.
3. Think about what you want to be different.
4. Speak clearly and slowly. Start by saying something like, “I would like to talk with you about...”
5. Let the other person speak.
6. Don’t expect immediate results.
7. Ask someone to help. Asking for help is also advocating for yourself!



# *Patient Rights*

- Accurate and easily-understood information
- Choice of providers and plans
- Access to emergency services
- Taking part in treatment decisions
- Respect and non-discrimination
- Confidentiality (privacy) of health information
- Fair, fast, and objective review of any complaint you have against your health plan, doctor's, hospitals or other health care personnel.



# *Patient Responsibilities*



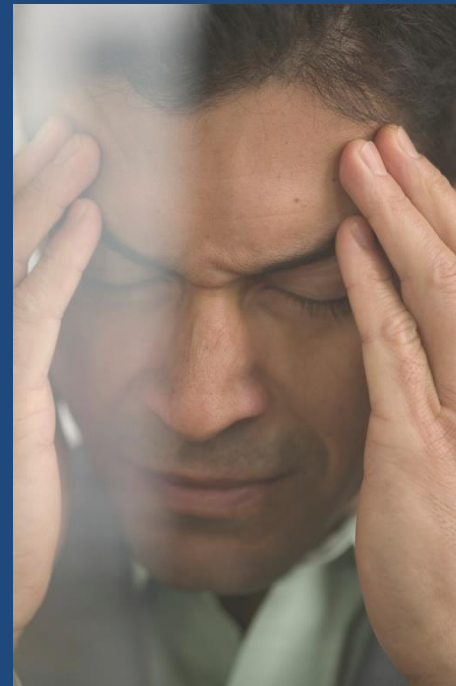
- Patients should expect to take on some responsibilities to get well and/or stay well.
- Patients are expected to treat health care workers and other patients with respect.
- Try to pay medical bills.
- Follow the rules and benefits of your health plan coverage.
- Having patients involved in their care increases the chance of the best possible outcomes and helps support a high quality, cost-conscious health care system.

# Understand The Symptoms

The more you understand the symptoms the better you can care for the person in pain.

The onset of symptoms may be rapid or gradual.

- Aching
- Burning
- Crushing
- Dull
- Electric
- Feeling as if your on fire
- Sharp
- Stabbing
- Throbbing
- Tingling
- Spasms
- Tremors



Hypersensitivity- Something as simple as a slight touch, clothing, sheets, even a breeze across the skin on the affected area can cause an extreme amount of pain to the patient.

Pain can also be increased by sounds and vibrations, especially sharp sudden sounds and deep vibrations.



# Understand The Symptoms

- Immune system functioning
- Body fatigue
- Coldness in the affected extremity
- Low-grade fever
- Skin rashes/Sores
- Swelling & Sweating
- Depression
- Short-term memory problems
- Sleep Disorder/Insomnia
- Visual disturbances such as blurriness, dry eyes
- Permanent damage to muscles and joints
- Bone Changes
- Color/Skin Changes
- Increased Tone
- Movement Disorders
- Nails/Hair
- Dizziness
- Tinnitus
- Irritability





# HOW PAIN AFFECTS DIFFERENT ASPECTS OF LIFE AS A PAIN PATIENT.



*Pain in perspective to life*  
**PAIN EFFECTS YOUR MIND BODY & SPIRIT!**



Make Conscious Decisions To Work Through The Life Changes Chronic Pain Brings On A Daily Basis



# *Patient Communication W/ Caretakers And Healthcare Professionals*

**Increasing your communication for better treatment and pain relief.**

- Become the expert of your pain
- Start a pain journal
- Write your questions; take notes
- An important point regarding communication is having a shared understanding of goals.
- Be assertive and listen to other side
- Take someone with you
- Take responsibility to reach goals



# Patient Communication W/ Caretakers And Healthcare Professionals



10– Worst Pain That You Can Think Of

9– Can't Do Any Regular Activities  
Because Of Pain

8– Strong, Terrible, Horrendous

7– Unable To Do Most Actions  
Because Of Pain

6– Dismal, Stressful Upsetting

5– Unable To Do Some Actions  
Because Of Pain

4– Distressing , Unpleasant, Bothersome

3– Can Do Most Actions W/  
Rest Periods

2– Mild Aggravating Pain

1– Pain Is Present But Does Not  
Limit Actions

0– No Pain



# COMMUNICATION TIPS



## Medication

Daily	Med's When Needed	Bad Reaction to these Meds's
Folic, 1 pill, daily Synthroid, .05mg, daily Welbutrin, 300 daily Neurotin, 300 mg 3xday	Ambien Bonine Ketorolac Lidoderm patches & Lotion	Iodine Oxycontin Topamax Dar-v-cet

## Recent Issues

**Neurotin-** Started Neurotin on 1/10/06 @ 300MG (night) wk 1, (then move to - 300 mg (M & Night) wk 2, - 300 mg (M, N & night) wk 3 and after)

## Recent Tests/procedure

Radio Frequency Treatment- January 13, 2006

## Continuing Issues

**RSD-** Pain (Arm, fingers, shoulder, neck, face), Eyegraines, migraines, dizziness, short term memory problems, vision hearing problems, balance problems.

**Weight Loss-** Since starting Welbutrin in Aug 05, I have gone from 131 lbs and 36% body fat.

## Past Surgeries

1999- Hysterectomy, Endometriosis, 2001- Right Knee Surgery, Torn Meniscus and MCL, 2003- Right Rib Resection, Thoracic Outlet Syndrome

Given to: Dr. Siwek, Dr. Hummel

# Newest Information on Neuroinflammation

## *They can see Pain*

*in the brain*

*in the glia (activated flight/fight nerves)*



*Pet Scans*

*Functional MRI's*

*Blood Testing*

*Antibiotic*

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