FINDING AND MAINTAINING SUPPORTIVE RELATIONSHIPS

Living With CRPS
By
Sharon Weiner
RSDSA Board Member/VP
President, Living With RSDS Inc.
The relationships:
- Our relationship with our self
- Our relationships with those who care for us or who we care for
- Our relationship with our children
- Our social relationships
- Support relationships
“When one is out of touch with oneself one cannot touch others”

Anne Morrow Lindbergh
Relating to us

- Why do we feel like we are a different person since we started our endeavor with CRPS?

- Guilt and Anger
  - Why do feel guilty over something we did not have control over?
  - Why are we so angry and who or what really are we really angry at?
  - Why do we feel we need to prove something?
  - It is not all about us-
Relating to us

- How do we forgive and move on?
- Who am I now?
- Find what you like and find a way to do it
- I never said this was easy
- Is it depression?
- Getting professional help
Spouses, Caregivers, and Others

- Change in dynamics
  - Changes in power or responsibilities
  - Lack of intimacy – emotional and physical
  - Find ways to reconnect
Spouses, Caregivers and Others

Communication - it goes both ways
- Make time to talk
- Divide and conquer responsibilities
- How you say it matters as much as what you say
- Keep it simple
- Be honest
- Be creative
- Practice active listening
Spouses, Caregivers and Others

- Find common ground
- Respect each other’s issues
- Do what works for you
- Compromise is not a bad word

Our Fears
- Rejection by our partner
- Pain associated with physical contact
- Failure
- Medications
Relationships

- Serious problems:
  - Neglect
  - Alcohol
  - Drug issues
  - Emotional or physical abuse
  - Lack of support system
  - Getting help
Caregivers Need Support too!

- Keep in mind that a caregiver may have had a major change in their life too.
- Caregivers are entitled to time for their pursuits as well and need down time
- Find a support system- caregivers need support too.
- Remember it is not easy for a person to watch another in pain and be unable to do anything
Children and CRPS

Parents with CRPS

- Age appropriate info
- A child’s imagination will make what ever it is you are not telling them worse then it is
- Get them involved; children like to help
- Involve teachers, counselors, daycare etc.
- Create a support system for you and them
- Teens and parents with CRPS
- Be present and involved
Parents of Children with CRPS

- Trust your child and listen to them
  - Be their advocate
  - Educate yourself
- Determine what is “normal” for their age before chalking it up to CRPS
  - Take care of yourself
  - Be their parent
- Be aware of the feelings of siblings
Use technology
Use calendars, filing or color coded systems
Plan a head – projects, dinners, tasks etc.
Use the tools of convenience
Make a list of what can be done to help
Ask for help!
Use your support system
Delegate
Our Social Networks

“

The most I can do for my friend is simply to be his friend”

-Henry David Thoreau
Our Social Networks

- Who are our friends? Who is not?

- Keeping our social world going?
  - How much do we share
  - Expressing our possible limitations
  - Communication is a two way street
  - It is not all about us – there are other people involved
  - compromise
Social Networks

- How much is too much support or is it control?
- Understanding things may change
- Find new things to learn and do or do what you did a different way
- Dating With CRPS
  - Tell you new or possible partner the basics
  - Answer any relevant questions
  - Keep conversations positive…but truthful
  - Stay interesting – be involved in the world
Social Networks

- Dating cont.
  - Accept help and set limits
  - Obtain and advocate and an ally
  - Show appreciation
  - It may take some time—no different then anyone else dating
  - Be honest of what your commitment is
  - Watch for any disturbing concerns
  - Don’t over compensate
Using Social Media

- It is a great tool but real people matter too.
- Understand it is a tool and understand it’s limitations and pitfalls
- Don’t let social media become your only social life
Support

- Are support groups helpful
  - Opening up in person
  - Navigating on-line groups
- Starting your own support group
  - Medical professionals
Verbal vs. Physical

- Verbal is sometimes considered worse - it is harder to prove and more emotionally damaging
- Either sex can be a victim of abuse
- What is verbal abuse?
  - Being called names, using words to shame
  - Always yelling at, threats to intimidate
  - Blaming the victim, feelings are dismissed
  - Manipulation, always feeling bad
They say a person just needs three things to be truly happy in this world. Someone to love, something to do and something to hope for.

Tom Bodett