

Living with RSI during the Acute Stage - Crucial Tips for Survival

by Judith Kay

If you are suffering from any of the following - tendinitis, thoracic outlet syndrome, cubital tunnel syndrome, and/or nerve damage in one or both arms, then you are in a lot of extreme pain (up to levels of #8, 9 even 10), and you must pay attention to it.

Hopefully you have found a physical therapist, PT masseuse or doctor and/or a team of people who are working with you to get you better. I hope it includes hands-on deep tissue massage, rest, and, later, a conservatively-designed exercise AND stretching program, one that is catered particularly to your body. You need all of the above to get better.

Meanwhile, you have to live and survive. To do so requires drastic change of life patterns, and full acceptance that you are in bad shape and that this is your main focus right now— doing everything you can to get better, whatever that means.

Folks, I have been through it. At one point I was unable to play my beloved guitar for five years straight. I am serious - dead serious - about the following things I'm telling you. First and foremost:

1 MAKE ALL THE FOLLOWING MAJOR LIFESTYLE CHANGES LISTED HERE BELOW, TO ACCOMMODATE THE CONDITION;

2 SURRENDER TO THE FACT THAT YOU ARE REALLY INJURED AND CAN GET WORSE IN ONE SPLIT SECOND WITH JUST ONE WRONG MOVE

3 KNOW THAT YOU MUST HAVE PART-TIME/TO FULL TIME HELP IN ACTIVITIES OF DAILY LIVING for your entire recovery period which could range from six months to several years. YES! (Think of how many years it took you to get into this miserable state... would you really expect to get out of it that much quicker?). If your spouse or a close family member cannot or will not provide this kind of help, you will have to hire someone. **Trying to use your hands, when they are hurting, is a disaster... don't do it.**

Stop doing what makes you hurt, and you may have to stop it for a long time

Most importantly, as Dr. Pascarelli used to say - "Stop the offending activity!". And that offending activity is, sadly, any or all of the following: playing your instrument, typing on the computer keyboard, writing by hand, drawing and any other fine motor activities that you do with your hands. Yes, life really sucks when you are going through the acute pain stage of RSI, but **you would be a fool to ignore the symptoms** and try to carry on your life as usual. Face it - you are debilitated by this condition, and life is not "normal" during this time of therapy and recovery.

For pain

-Just stretching can often relieve pain and also swelling; lay on the floor, on your back, and put your arms in a V-stretch over your head; stay like that for 5 min. or 20. You will be amazed at how the pain/swelling lessens.

-Ice is about the best pain reliever, and it is free; use it often throughout the day, and for as long as you feel is the right amount of time; but **DO** be careful afterwards, and allow the iced area to come back to room temperature gradually, before you do anything with (or ask anything of) that hand/arm etc.

-If you are out in the public and there is no ice available, go into the bathroom and run cold, cold water from the faucet over your arm. You will get some relief.

-For swelling that won't quit, you need compression. The old trick that hand therapists have recommended for years is to take one of those stretchy Isotoner gloves, turn it inside out and wear it. After a while you will need a break from it, so take it off as needed. Elevation helps of course, but the glove alone is surprisingly effective. I used to sleep with it on every night during the really bad bouts.

Tips for personal grooming, during acute injury

1 cut wash cloths in half, a full-size wash cloth drenched with water is much, much too heavy to hold onto and will hurt your arm or could actually re-injure you

2 do not attempt also to use a heavy, full sized bath towel to dry yourself during this time; instead just use a hand towel, which works fine; instead of a bar of hard soap which is very hard to handle, use liquid body wash

3 even washing/drying hands can hurt - when you dry, dab cloth on stationary hand, to avoid pain

4 GIRLS, of course no holding onto the hair dryer with bad hand - just allow hair to air-dry during this time!

Women - Dressing for Acute RSI

- wear pants that have elastic waist band; avoid zippers and buttons
- wear all of the "accouterment" that might have been given to you by physical therapists/doctors for the hands (Isotoner glove, individual finger wrappers, carpal tunnel brace, squeezing brown arm wrap etc.) and plan to use, especially when you are out in public, so that people know not to grab your arm
- wear dresses, skirts, tops which have no buttons
- wear slip-on shoes rather than ties
- when have to wear sneakers, do not tie them; simply loop the laces around and around so they stay out of the way
- put in one pair earrings with someone's' help, and then they will stay in during your entire recovery; they must be ones you can sleep with because changing earrings is out of the question

Men - Dressing for Acute RSI

- wear pants that have elastic waist band; avoid zippers and buttons
- wear slip-on shoes rather than ties
- when have to wear sneakers, do not tie them; simply loop the laces around and around so they stay out of the way

STOP ACTIVITIES

The following things are most likely **out of the question** while injury is acute (which can be months);

- 1 Driving GET HELP
- 2 Preparing food GET HELP
- 3 CAUTION -if you have, or suspect you have, nerve damage, then DO NOT engage in: periods of pinching (for even more than a second), handling papers, nor static holding onto items (for more than a split second or two at a time) - these activities are **extremely detrimental** while the hand is in any kind of tentative state!! GET HELP paying bills and dealing w/ papers in general.
- 4 Handwriting, learn to use your other hand (I DID IT - IT'S POSSIBLE) or get someone else to write
- 5 Typing - purchase and use voice recognition software only
- 6 Laundry, dishes, cleaning, food shopping and all household chores GET HELP
- 7 Shaking hands with people (always wear something over your hand/arm when you go out in public so that people will be less likely to grab onto your arm, which is guaranteed to re-injure); also hold your arm in a protective position so that people know in advance that you're hurt; I like to place my hand on my chest, in the same area as if I were holding a baby; when going to embrace someone, I often put my hurt hand behind my back
- 9 Lifting anything (seems obvious but must be stated here)GET HELP
- 10 Folding things like blankets; also hanging up clothes on hangers and manipulating hangers generally, very bad GET HELP

NOTE Be prepared to ask for help in public, and do not be ashamed about it. People are amazingly willing and anxious to help you (w/ lifting items, opening doors, etc.).

Diet during recovery

4 Eat a well-balanced and especially HIGH-PROTEIN DIET - look, your muscles are in a process of total rehabilitation, so believe me you need to eat meat, cheese and eggs every day during your recovery time. Save your vegetarianism for later, not now!

General tips - changes of behavior for life now, and down the road

- 1 VERY IMPORTANT -regarding the telephone. Don't ever hold onto a telephone receiver again. Get a really good headset, and wear it all the time you are on the phone. You will wish you had always used this, even when your hands were good.
- 2 When something falls, do not attempt to catch it, for instance a knife in the kitchen - allow it to fall and jump away from it during the process
- 3 Watch out in a restaurant; people will hand you heavy plates to pass around and you must not grab hold of them even for an instant
- 4 -Occasionally use a wrist splint, yes - but **beware of over-splinting** - this can lead to the disastrous and dreaded RSD, something I've had to go through several times, and believe me you don't want to go there.

Dealing with friends and family who just don't get it

A dear friend of mine who has had chronic fatigue syndrome for some 25 odd years once told me that in our culture you must either "get over your illness/condition in about three weeks time, or just die". Those are the two things that most Americans can deal with... something that is over with quickly, or death. They have a really hard time with conditions that linger and linger, but unfortunately RSI is one of those.

So be prepared for strange and seemingly hurtful comments and behaviors on the part of your friends and family. Quite a few might rally at first, being available to help you with this and that. But when it drags on, and unfortunately it usually does, all of a sudden those people will fall away and not be there for you anymore. Please know that they really don't understand this condition, partly because it is invisible and you look "fine". They won't believe the pain level that you say you have had or are in, and they simply will be incredulous that perhaps you cannot hold a fork or brush your own hair.

They won't know what to say, and will probably say something stupid, as a result. During the 5 years that I was unable to play the guitar, at least 20 or so people told me that "I guess you will have to start playing the guitar with your feet now, ha ha ha ha..." and each of those folks actually thought that he/she was the first person to say that, and that it really was funny. I always looked at them, aghast, that they had said that awful thing to me, but inside I knew if they understood how deeply hurtful it was, they would never have said it.

Sometimes it is best not to talk about your condition at all with most people, or to say it is going fine, and let that be the end of it. You may even find yourself consoling others, to make them feel better that you are in this terrible state! Hopefully, there will be a few souls whom you can turn to and "vent" when you need to, but it will probably only be a few, so just know that this is the reality, and it's part and parcel of the already tough-going, during your recovery.

General notes, in summary

You will make mistakes, and you will have setbacks, this is inevitable, until you really learn your condition and learn your body. The setbacks will cause you emotional, as well as physical, pain. You will need to talk to somebody about this to relieve the stress and sadness... back to the friends/family - are there any you can talk to who will listen, and offer empathy? [Spouses, by the way, are usually the least-equipped for this, since they are in their own denial about your condition, and/or are just plain angry about it]. If there is no one, consider finding a professional psychotherapist because your grief is deep... especially deep because playing your instrument was your identity, and now you have lost your identity in addition to your ability to carry on as a normal human being in the activities of daily life. Take time to grieve your loss, and look to fellow sufferers (ones you may meet at the therapist's office or online) for moral support, because they really do understand what you are going through!

In 20 years time I have now gone through three major episodes of RSI, each sidelining me for a minimum of eight months, up to, as I said, five years. SO, how did I get through the emotional pain of my various bouts with RSI ?

Well, as I said before, I put lots of signs up all over my house to help me remember what my goals are - what to do and not do -- and one of my favorite ones is this one - Concentrate on what you can do, not on what you can't!!

At one point it hurt so bad to even hold a book and read (and turning pages was excruciating) that I put the book in a holder and read it that way. It was in Portuguese, a language which I had been studying because of my strong interest in bossa nova music. During one of the worst periods of my injury, I dictated the English translation to large sections of that book into a recording machine. A friend of mine typed it up into the computer. I ended up using those sections in a course that I was teaching on Brazilian music at the University of Delaware. It was a difficult project, but it was something I could do without hurting myself, and I threw myself into it, totally enjoying it, since it helped me take my mind off of my constant pain.

Be kind to yourself. You will find your own ways to cope, and new interests along the way... and, it is endlessly wonderful and reassuring to know that the body wants to heal!

I hope these tips will prove useful for you... don't give up, if all goes well you will play your beloved instrument again and be back, and you will never ever take it for granted again.