# RSD POEMS

This poem was written by Mrs. Jackie McCombs. She had written it in the memory of her husband Henry who suffered from RSD.

### RSD? What does it mean?

It causes so much pain I would like to scream.

You wake in the morning and all the day thru.

It's constant, constant pain and nothing you can do.

In later stages...they say there is no cure.

We Pray they find one. That's for sure!

It's hard to deal with all that goes on.

Being in pain from dusk 'til dawn.

Anger, depression, mood swings, I could go on and on.

Then some doctors think. It's all a Con.

Drugs, drugs and more drugs ...you must take.

Starting from the moment, we awake. No one really understands what we have.

Too bad there's not a magic salve.

So, to all of you, who know how I feel, the ones who KNOW the Pain is real.

We'll stick together through thick and thin.

Hopefully someday in the end we will win.

Guess we just have to wait and see and pray they find a CURE for YOU and ME! It's not in our heads. The Pain is there.

Please Doc, show consideration, show YOU care.

Until there's a cure, we all must cope.

### So, DOCTORS...PLEASE LISTEN TO US, IT'S NOT FOR THE DOPE!!!!!

I hope you who read this know that I will keep you in my prayers. My Husband was a wonderful man who passed away Sept 15<sup>th</sup> 2001 from bladder cancer. I wrote this after visiting a doctor who acted like his pain was imaginary, I was so angry that I just put what I felt on paper. This is in Memory of Henry McCombs. My wonderful husband who was the greatest thing that ever happened to me. We have 3 sons who have also suffered because of this horrible disease. But they have all stood behind me and have stepped in to help their Mom. Take care all.

GOD BLESS YOU.

If you would care to write to me please do. Please just put RSD in the subject box. jmccombs26@aol.com

I WOULD REALLY LIKE TO GIVE THANKS TO ERIC FOR THE WORK HE DOES AND FOR THE OPPORTUNITY TO HIM TO SHARE MY POEM ON HIS WEB SITE. THANK YOU, ERIC. MAY GOD BLESS YOU AND KEEP YOU WELL!

Jackie McCombs

This poem was written by Heather Quinn. Heather is an RSD Patient.

Dear Family:

I've cut my losses and the ties; for this is the end of those of you that don't understand.

This pain and heartache that it's given to me is the path to the rest of my recovery.

There is nothing left to say or do, but take the next step.

Don't talk to me, call me or look my way.

I'm as invisible to you as you are to me every day.

As the world turns, I suffer.

Suffering equals my darkness and despair.

No ending and no beginning.

There I am stuck in the middle.

You'll never see my pain.

You'll never see my suffering.

I feel like I'm dying.

I feel like there is no reason to breathe.

There is no reason to love you.

There is no reason to think of you.

There is no reason to act or react.

Why for all that brings is heartache.

The world continues to turn as I suffer in my darkness and despair.

I see no ending, no light, but a new beginning.

I'm in the middle.

Sadness, anger, betrayal, loneliness and emptiness are how I feel.

Pain, hurt and sorrow is how I deal.

You'll never see my pain and suffering.

All dreams, plans and hopes are gone in the blink of an eye.

Now that I'm alone, you'll never see me cry.

I'm hurting so much and deep that I cannot sleep.

Lying there in bed, gazing into the air, wondering will I ever heal?

Free me, please free me from this pain.

Free me to know that I will never hurt again.

Free me to be myself and never lose sight of that.

I'm important.

Me, me, and me, that's all I want to see.

No one else matters to me, accept those that understand my disease.

To accomplish this, I'm forced to keep my heart under lock and key.

If you like you to contact Heather the author of this poem you can e-mail her at: <a href="https://html.ncbi.nlm.ncbi.nl

This poem was written by T.L. Tobac. T.L. is an RSD Patient.

#### **ROLLER COASTER - RSD**

Oh, twisted roller coaster I have been propelled

to live upon

destined to this contorted fate

not of my own volition nor deservedly

no fun ride

this roller coaster RSD

Reflex

attacking at will deceiving my psyche into thinking

though drug induced

recovery may dwell upon the horizon and that one day

we will stop at the station where I will depart

at last

to grab my shiny prize... remission

# Sympathetic

chugging chain to the crest

the sound tortures my brain as it abandons me

on the opposite side to another day of pain

Dystrophy

Destined to remain forever strapped

to this wicked ride praying for moments of peace

I am a prisoner of its clutches

comfort may come at any time

and just as quickly fade to be replaced

by searing pain spreading

and flashes of insane heat damp sweat

spasms

leg burning arms aching

and yet it starts again could it be at last? this time on the

up side of the Roller Coaster RSD

Reflex

sunny day happy ride pain sub side

drugs are working just for today

I anticipate a visit with my former self

(the one who doesn't ride the coaster)

## Sympathetic

hope wells up within this is it (excitedly)

could healing come at last? Does the shiny prize (remission) at last arrive into my hand? Dystrophy

dash it all to hell
the chugging chain begins
back at the wretched drop point

for that fleeting moment I thought I held the prize

but alas my palm lay empty

for this ride RSD never ends

hope ever remaining

some shiny dangling object whizzing by it with each lap teasing me

well out of reach passing it over and over

with each twist and spiral of the Roller Coaster

God

if this be your will

that I am destined to ride

I know you will be at my side and one day I pray

You will take me to the station.

T.L.Tobac 5/4/07

This poem was written by Darlene Brownell. Darlene is an RSD Patient.

#### Who Am I?

You can't see me you can't hear me. I'm the one inside of you, making you go crazy. All the doctors you have seen, they still don't know me, that's funny to me. And it's been over 100 years. And they still can't find me, those tests they take and pictures, there just wasting their time. I told you before they won't find me no matter how hard they try.

Indeed, I'm the one that makes you hurt all day long. I am the one responsible for your terrible burning pain. I love burning you with my flames, keep complaining no one hears you, no one cares. They can't see me they can't feel me. I'm the only one who knows what you're feeling because your body belongs to me now, and I have the power to make your pain spread. So, don't try to stop me, because you know what they will say, it's all in your head and how many pain meds have you taken today. Wow! There still saying that now, that's insane. I will leave you with nothing, no family and friends. I will keep torturing each and every day till the bitter end because people can't see your pain and that makes my day. I'm going to take my flames and burn you in the worse possible way, I enjoy those shooting pains I give you threw out the day. HA- HA don't you wish you were dead, because that's my intent. If your doctor keeps giving you those meds it's going to affect you and mess with your head. That's ok he's doing my job, the more suffering you have makes me want to stay. I'm not leaving so stop praying; wipe your tears this nightmare is just beginning. Yes, your really are a wake, I find that quite funny you thought it was a dream. It sucks to be you since no one understands. So, do me a favor and do yourself in. Ok, I will tell you who and what I am. My name is called RSD isn't that a nice name. It stands for Rapid Spreading Disease. So, tell that to all the morons you see.

And maybe one day they will try and stop me. By the way would you please stop changing my name.

If you like you to contact Darlene the author of this poem you can e-mail her at: <a href="mailto:darlenebrownell@yahoo.com">darlenebrownell@yahoo.com</a>

This poem was written by Cynthia Ward. Cynthia is an RSD Patient.

### I'm Not Like You

© 2000 ® By: Cynthia E. Ward

I'm not like you – you see;

I have a debilitating disorder

Called Reflex-Sympathetic-Dystrophy.

My days are precious and few;

If only I could do the things I used to do!

Although, I'm enthusiastic and optimistic my body is in constant pain;

Though I strive to find the best in me only fond memories remain.

Though each day is a struggle

I don't want to be classified as a casualty or a statistic

Because I think of myself as a survivor with a name.

Somewhere out there is a person like me-

Who is in constant pain or feels the same?

You are similar to me, but as of yet I don't know your name.

Although, I have a disability – I still have responsibilities.

Though I'm different I have needs just like you,

And I would like the opportunity to do the things you do.

Opportunities like being able to work and enjoy my leisure time;

Without total disregard,

Because even though I strive for excellence getting there is very hard.

Living with RSD is challenging everyday

So this is why I think the public

Should listen to what I have to say.

RSD is permanent damage to muscles bones and nerves;

Which drastically changes our lives.

We are special people who have had to endure unnecessary pain and strife.

There are no definite cures for RSD so we suffer every day;

Hopefully doctors will understand and find a way

To end the pain so the best part of our lives will return;

So, everyone educate yourselves so you can learn.

We will learn that everyone is valuable in their own special way;

Please listen to what I have to say!

I am a person with a heart, mind, and soul,

And Reflex-Sympathetic-Dystrophy.

If you give me the opportunity- I can be the best that I can be.

There will be many times which are very trying,

And even times when you feel like crying-

So, it's best to concentrate on the things you can do instead of the things you can't or are unable to do, because this will get you through.

I'm not like you- you see, because I'm just me!

Though, I have a debilitating disorder called Reflex-Sympathetic-Dystrophy.

Remember, I want the opportunities and privileges to do the things you do.

Though, I look similar –I'm not like you!

This poem was written by Christina Nowak. Christina is an RSD Patient.

### Refuse to Sanction Defeat

You toss and turn

Clenching your eyes

You bite your lip

To hold back the cries.

However, you lay,

There, is no relief.

The aching pain

Leads you to grief.

You curl your fingers

to form a fist,

But they barely bend,

they seem to resist. You

curse and you pray. The

cold creeps in.

The totality of pain

Did not yet begin.

Like a slave to his master,

you bend at its will.

Food is forbidden,

you mustn't be still.

Fighting the battle

Each day and night,

Yet when people are near

You better act right.

Hold back the pain

Flash a fake smile

Pretend you are normal

At least for awhile

This poem was written by Jenni Ford. Jenni is an RSD Patient.

### Too much pain from the RSD

I didn't ask for it

But it found me

Repeated surgeries gave it to me

I begged for them to take  $my\ arm$ 

They said they pain would still remain

I didn't understand then

But I do now it not just my arm

It moves like germ from infected to health area

Infecting that new area with pain

The doctor has done all he could

I hate pain medication but I have no choice

He put in a pain pump to ease the pain

But breakthrough pain still puts me in tears

I hate taking the pain pills

My nurse yells because I won't take it till

I can't stand the pain

I am not a druggie

I am in so much pain I want

To die because I know that the only way

To truly be free of this pain of RSD

By: Jenni Ford