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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. [jmcombs26@aol.com](mailto:jmcombs26@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

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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 everyday.

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 site 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: [hz712002@aol.com](mailto:hz712002@aol.com)

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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 it's 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 subside  
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

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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 there 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 cant 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 no 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 ever 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. Bye 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: [darlenebrownell@yahoo.com](mailto:darlenebrownell@yahoo.com)

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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 everyday;

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!

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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

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