

I WANT TO LIVE—NOT JUST SURVIVE: 11 years of ME/CFS
By Nina Lydia Olf

Sometimes I think I am through with life.

things that brought me joy, have
passed. There is no going back....

This new life is spent in cyberspace and in
imagination.

Sometimes my body won't move
no matter how hard my mind wants to get up and go...

What happened to my free-will?

No matter how many people tell me to push myself —knowing little
But meaning well— and it's hard for them
to see me walking one day
And in bed the next.

My grandson, who lives 2 thousand miles away
is the only person that makes my heart soar,
brings an ear-to-ear smile that is evident in every photo of me
looking at him—*my whole being is dancing again.*

I get to see him: 2x a year

And must have someone with me;

And the drugs, supplements, snacks, a pillow a taxi, TSA, change
planes, a taxi

And then after travel, the crash.

I want to be there. Yet I cannot go alone. And
I do not have the money.

My daughter's house is not big enough for me to stay

And I can offer little to my daughter who I had expected to be

A real grandmother for, someone she could count on.

I want to be a part of their lives...but how can I be?

My family remarks about how good I look

because they cannot see

inside of me.

Their expectations are inflated.

And I hate to let them down.

I try to hide my pain and exhaustion, do my best, to look okay.

I have been a writer and have loved children and dogs most of my life

Now without purpose I stare out of my window

And hope to see a large dog or a hawk in the sky.

No words can change these chronic illnesses or can

Give me back my self-agency or

independence and dignity

And so many people have it much worse than me,

In different dimensions, and I feel sad when it is a

young person, or a young mother.

My empathy for others

Does not discharge my own

Self-pity.

My life is too small

My daily pain and medical journals

Are getting harder to decipher...

It is official: ME/CFS and Fibromyalgia

Are recognized

By the NIH and the AMA.

The fifteen-minute appointments with MD's are scheduled

to satisfy the HMO's obligations to maximize profits for its

shareholders and

Leaving little time for doctors to read new guidelines.

*“And be careful not to say too much at your next appointment
You don't want to act as if you know more about your condition
Than the doctor does...”*

My last crash wracked me with pain for 6 weeks
And I never know how long I can stay out of bed
Or when I will be back in bed.

What happened to my free-will?

Some days I want curses to come out of my mouth like snakes
I want to spit out my guts and lay my fiery brain on the street,
throw my aching glands into trashcans.

It is
as if
my life
has been
stolen

Those who know me,
barely

see my shadow

There is no cure, only ongoing loss:

Having to beg for pain pills

Canceling plans...not making plans

Suicide is not an option!

I love my family **so** much; *I could never*

take my own life; that is, until I cannot bear it anymore...

I keep my old tennis rackets...with

A fantasy that I will play again.

"Try to forgive yourself for being ill..."

I say to myself; but it doesn't work...

And each year I get worse...

Those who do not live with me, take care of me,

Or are at the receiving end of my wrath

have no idea.

My partner takes care of me
And sometimes I hate him for that
And I need him
And I am bored with him
And he covers my expenses
And he must be SICK OF THIS.

How will I find a way

to accept my life,

Find joy?

I want my health back!

Find a way

Help me find a way,

Until there is some, medical, breakthrough.

US patients have way more insight into this condition than the so-called experts