

The following are my contributions to an ME/CFS awareness art project called “Creative For a Second or Two.” Please don’t distribute the works herein without my permission. If you would like permission, I can be reached at CFSupport-owner@yahoogroups.com.

Thank you!

Barbara A. Bell
2011

Life

This can't be MY life.
I don't know whose it is.
But it can't be mine.
My life is vital.
Vivacious.
Bursting with excitement.
Bustling with activity.
I'm going places.
This one is so tired
used up
flamed out.
The passion that burned
dazzling
alluring
is now ash
and anger
and sadness.
Mostly sadness.

THIS can't be my life.
My life is brilliant.
Luminous.
Shining.
I can see myself in all its lovely facets.
This one is so dull.
I can't see me at all.
No reflections.
Just shadows.
Shadow puppet.
No form.
No function.
I have no mirror
except what others see in me.

This CAN'T be my life.
My life is big.
Spacious.
Full of ideas.
Full of potential
for growth
for adventure

for achievement.
This one doesn't even fit me!
Look: it's too small.
Too tight.
Too confining.
My dreams won't fit in this.
How can I get anywhere
when I can barely move?
Bound in a body
that can no longer do.
Subject to the whims
of Orthostatic Intolerance
post-exertional malaise
painful slogs through the bog of cog fog
and the crush of gravity
that is surely far greater for me
than others without
this demolitionary disease
with the understated name
Chronic Fatigue Syndrome.
This can't BE my life.
My life is desirable.
Filled with adventure.
Romance.
Laughter.
I'm to be lauded
for my many achievements.
Not pitied
for my many heartaches.
My admirers should sigh with relief
perhaps applaud
when I master some great feat.
Instead,
they let out the breath
they didn't know they were holding
when they find out I'm still alive
or,
worse,
when they hang up the phone
after we talk
and breathe a sigh
of relief

that they're not me.

Can this really be my life?

A life of margins?

A life of letting go

of dreams

plans

expectations?

A captive existence

of walls and windows?

Am I consigned to watch the world

my colleagues

my friends

my hope for a family

all pass me by

all fade away

into the horizon of memory?

THIS is not the life I imagined.

But it IS the life I have.

I can't choose my limits,

but I will choose to thrive.

If this is how my life will be,

then I'll grow into it

around it

in spite of it

because of it

thanks to it.

I'll live it.

MY life will be

vital

brilliant

big

desirable

in a different way than before.

In an unexpected way.

A quieter way.
A still way.
A way I might have missed
if I had not crashed
and burned.

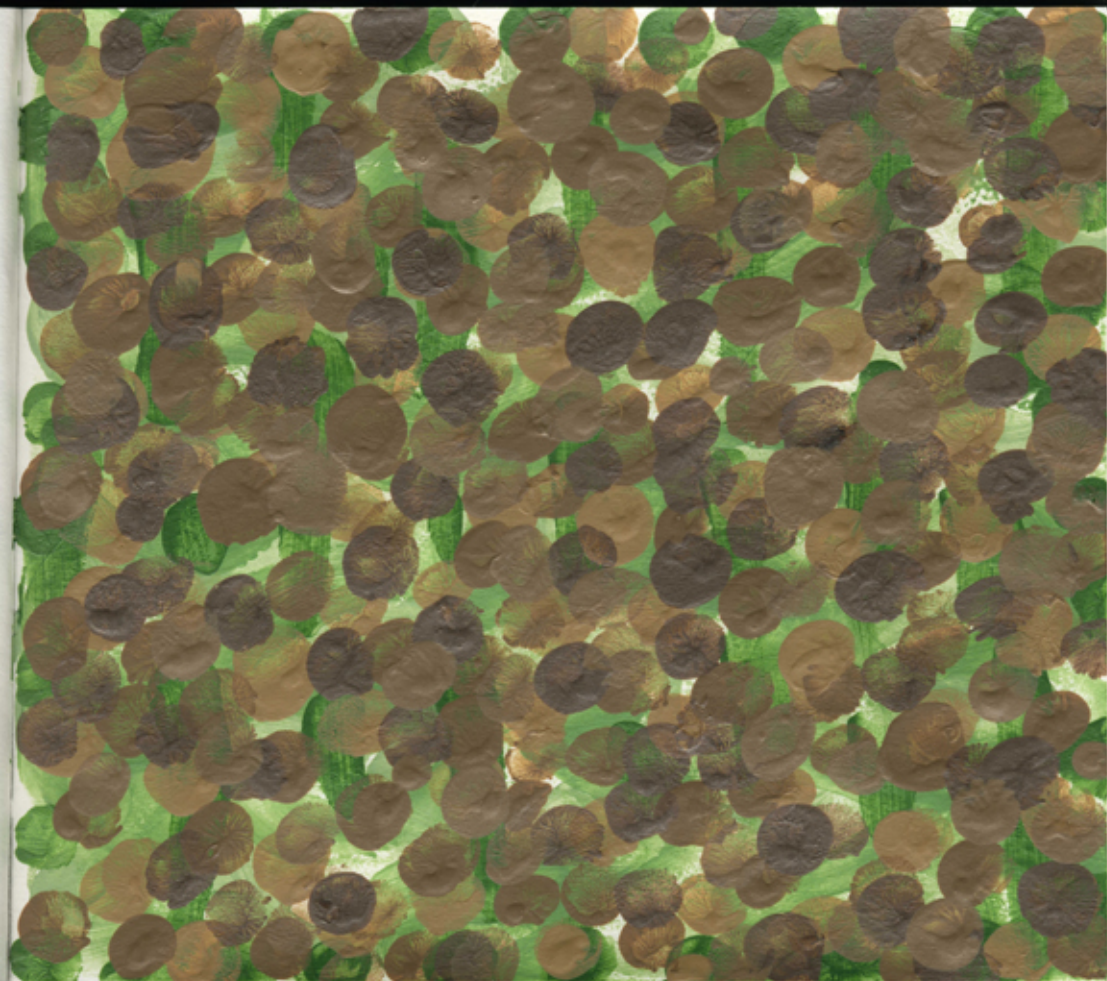
This vessel cannot contain my spirit.
It cannot limit my capacity
to adapt
to aspire
to adore
to thank my lucky stars
to have my life.

This will be my life.



"Before CFS"

Barbara A. Bell 2010



"After CFS"

Barbara A. Bell 2010

Art used to be easy for me. Now it's tiring and often frustrating. Like pretty much everything else. Physically and psychologically. I used to do beautiful things with beads. I could bead and watch TV. I could create and follow complex patterns. Now I can only do one thing at a time. If that. There are many days I don't have the energy to hold up my arms. That puts the kaibosh on creative pursuits. Many days I have too much cog fog to understand instructions or even keep track of a pattern. I went through a phase recently of trying to learn how to simplify. Create simpler works. I hoped I could enjoy simple stringing. I learned that I'd rather take a long time to do a more complex piece than force myself to create unsatisfying, simpler pieces. I embraced my need for complexity. Complexity is honest. ①

Life is complex. MY life certainly is. Someone without CFS might look at my average day and envy its apparent simplicity. I get up at 8:30-ish, have breakfast at 9-ish, putter on the computer (if I'm able), am back in bed by 11am to rest until lunch. Afternoons are spent caring for pets, watching TV, puttering with a craft (if I'm able), maybe making a phone call, in and out of bed. After a 5:30-ish dinner, I get an unwelcome surge of adrenaline. More TV, wishing I could DO SOMETHING while watching. No energy, but lots of awakeness. So strange to have adrenaline but rarely ^{be}able to use it.

On the surface my life seems simple. But it's a neverending stream of analysis and decisions. And it's pervaded by crushing, mind-numbing exhaustion. Like I have my own personal

field of gravity that's heavier than everyone else's. And the threat of post-exertional malaise is always looming. I do a mini cost-benefit analysis for every activity. Can I go to the drugstore and pick up my medicine? Not if I have to clean the turtle. Can I do a load of laundry so I'll have clean underwear tomorrow? Not if I want to balance my checkbook. Can I shower today? No, nobody's home to make dinner, so I'll need that energy to put a plate of leftovers together. *

I have no room for spontaneous activity in my life. My margin of error has shrunk to near-nonexistence. Every action has a physical consequence. That includes mental exercise. I have a hard time making people without CFS or FM ^{understand} that thinking is physical activity. The firing of neurons and mobilization

of neurotransmitters takes energy. For most people, that amount of energy is such a small portion of their reserves that they don't notice. But I have precious little reserves. And those reserves either don't refill or do so ~~so~~ slowly that I can hardly tell.

So even though I don't work, I'm not on vacation. I don't work because I can't. Every minute that I spend vertical is a discomfort. I keep to a schedule in hopes that it will somehow regulate my uncoordinated physiological systems. And because I have other factors to weigh, like medication schedules and reflux. I don't sit at home, watch TV, fiddle with crafts and lay in bed because I'm pampering myself. I do it because there's little else I can do. I WANT to be working. I want to go to a movie, or out with friends, or even on

a date. I want to have a day when I watch TV because I'm pampering myself, not because I'm trying to distract myself from pain and boredom. I'd love to read a book, but I can't hold on to a train of thought for more than a couple of sentences. I'd be delighted to make something with polymer clay, once a passion of mine. But I get post-exertional punishment from kneading a fresh lump of clay.

Yes, life is complex. No wonder it's a struggle for me to try to rein in my urge to make complex artwork. In a way, it's simpler not to fight it. Meet the desire halfway by deciding it's okay to do fewer projects and do them at a reasonable pace. After all, that's what I strive to do in all other areas of life. To figure out what my "energy envelope" is and find satisfaction working within it.

The pain of CFS extends beyond the patient. It affects those who care about us, too. They watch us decline from leading normal lives to being unable to perform simple tasks of daily living. It's baffling and frightening, especially when we have normal medical test results and no outwardly visible signs of illness. There's no test or treatment for CFS. The journey to a diagnosis is fraught with doubt that any physical condition exists. It's easy to believe it's all in our heads. We undergo behavioral changes as a result of physiological shifts combined with struggling to cope with what feels like an endless freefall into debilitation. Those who support us find themselves in the unexpected position of having a lot more to do and worry about than before. A two-income household may become single-income. An adult child may have to move back in with his/her parents. All parties involved labor under the pressure of managing their lives while navigating alien and unsettling terrain. So for all of you who extend your compassion and care for someone with CFS, thank you. You make a life-saving difference for us.

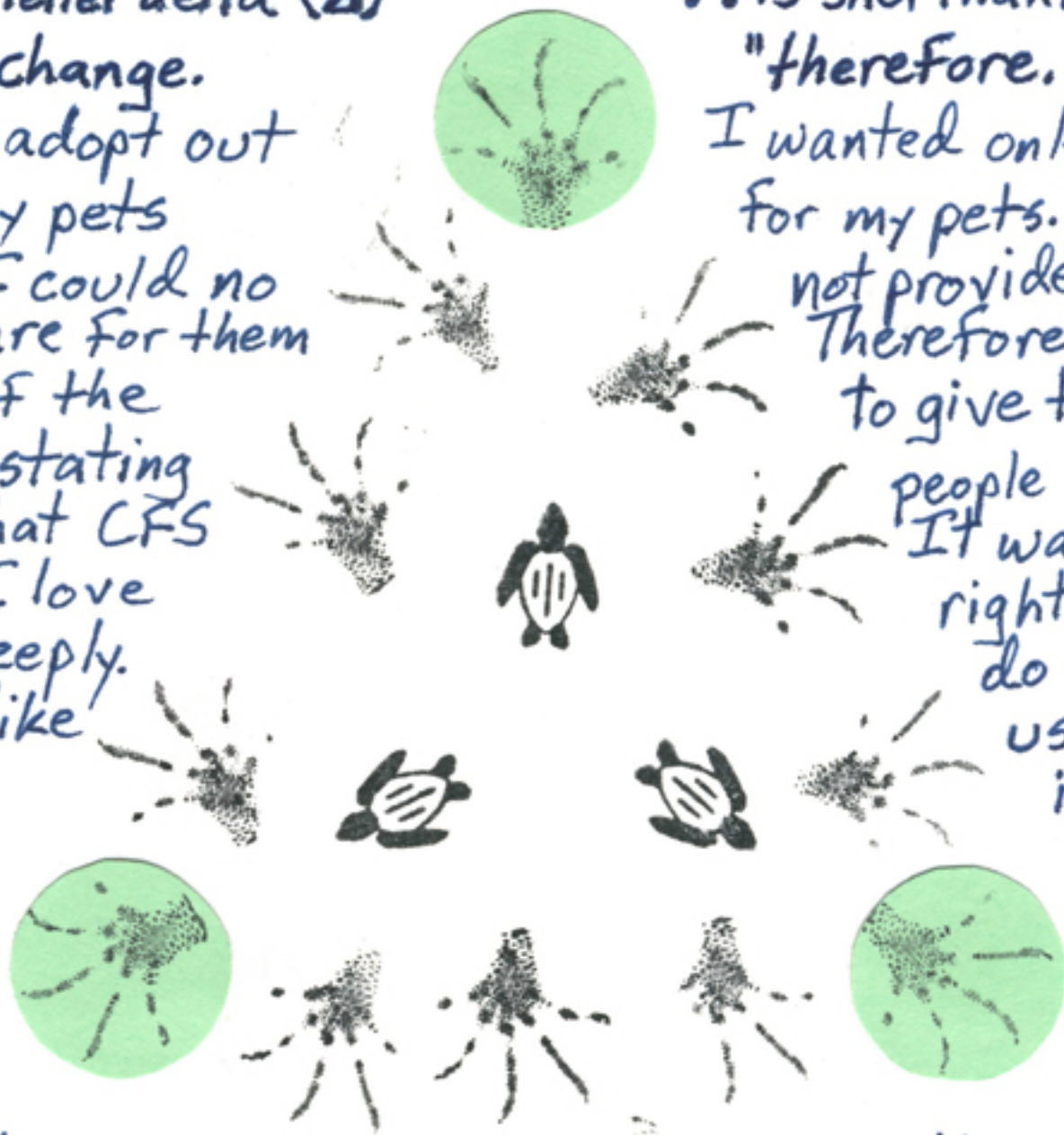
The greek letter delta (Δ) indicates change.

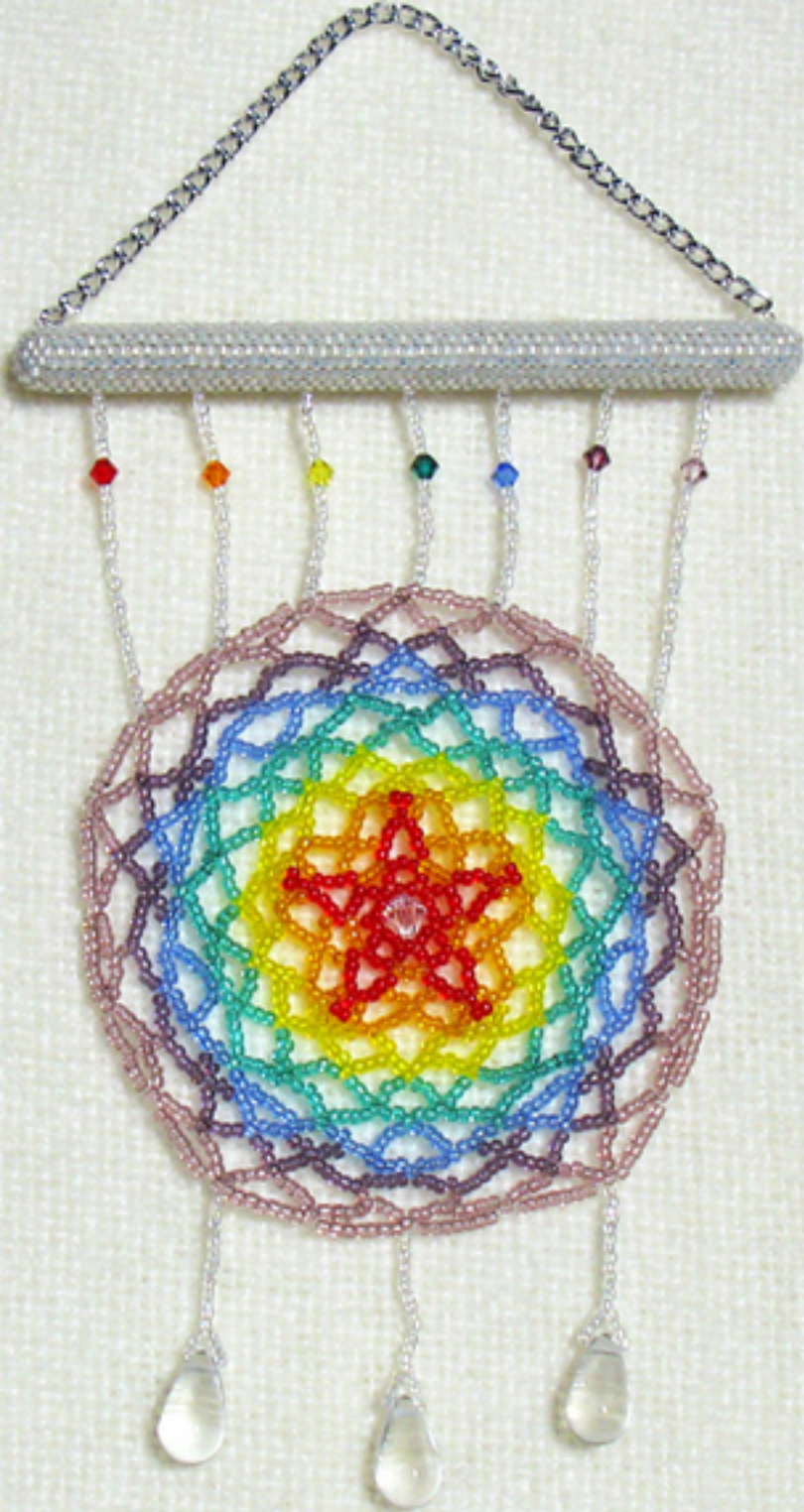
Having to adopt out most of my pets because I could no longer care for them was one of the most devastating changes that CFS brought. I love my pets deeply. They are like children to me.

\therefore is shorthand for "therefore."

I wanted only the best for my pets. I could not provide that. Therefore, I had to give them to people who could. It was the right thing to do for all of us. But it still hurts.

When drastic change happens, we can adapt to it or struggle against it in vain. It took some time for me to decide to adapt. I'm glad I did. It's hard, but struggling was harder.





I beaded this suncatcher as a meditation on mandalas and to practice having quiet creative time in which I only focus on the art project at hand. I didn't use a pattern. I just used a needle and thread and strung beads one at a time. I enjoyed *not* experiencing the frustration of being unable to follow written instructions or patterns. Forging ahead without a clear goal was liberating. Like everyone else I know with CFS, I was a high achiever before I got sick. I still have a strong urge to set ambitious goals and reach them no matter what it takes. So I took this opportunity to see what it would be like to just play with beads and colors with no specific end point in mind.

I left a couple "mistakes" in. They're unintended asymmetries. I kept them as reminders that even though life isn't neat and orderly, it can still be beautiful. In the big picture, the little oopses aren't noticeable. I find a bit of pleasure every day when I see rainbows on the floor and wall, sunlight bent through the clear center crystal. I like to put my feet on the ones on the floor, or step in front of the ones on the wall so they sparkle on my hands and arms. I like touching rainbows. I imagine they're the voice of the sun, translated by crystal.

CFS broke my heart. It changed everything. My world turned upside down. I lost my career and independence. My self esteem and self worth dropped. My self identity was challenged. All of us with CFS grieve a lot because we experience so many profound losses. Friends fade away. We become ~~the~~ increasingly isolated. We grieve our former lives. We grieve being able to take health and energy for granted. We get frustrated with our limitations. I know I do. Some days I don't have enough energy to hold up a fork.

Still, if I had to name one good thing that has come of this, I'd say it was getting stripped down to my basic self. I lost the energy (and desire) to hang onto illusions about myself and my life. I realize now that my former life was not perfect, that my attitudes and outlook affect my quality of life, and that I have the power to change my way of being. I'm reshaping my heart as it heals. In many ways, I'm stronger than before. Do those things make me glad I got CFS? No. But I'm working on getting there.

It's a healing journey.



Note: Since I wrote this, I *have* become grateful I got CFS. I'm not saying I'd rather be severely disabled than working. I'm grateful for the personal growth that has come from the situation. My inner life has changed for the better in ways that often offset the difficulties. It may sound odd to those who have not experienced life-changing, debilitating illness, but the cascade of catastrophes that it brought, and the silence after that storm, gave me/are still giving me the space I need to heal from the inside out. Learning to thrive in the midst of extreme hardship is really hard work, but its rewards are innumerable.