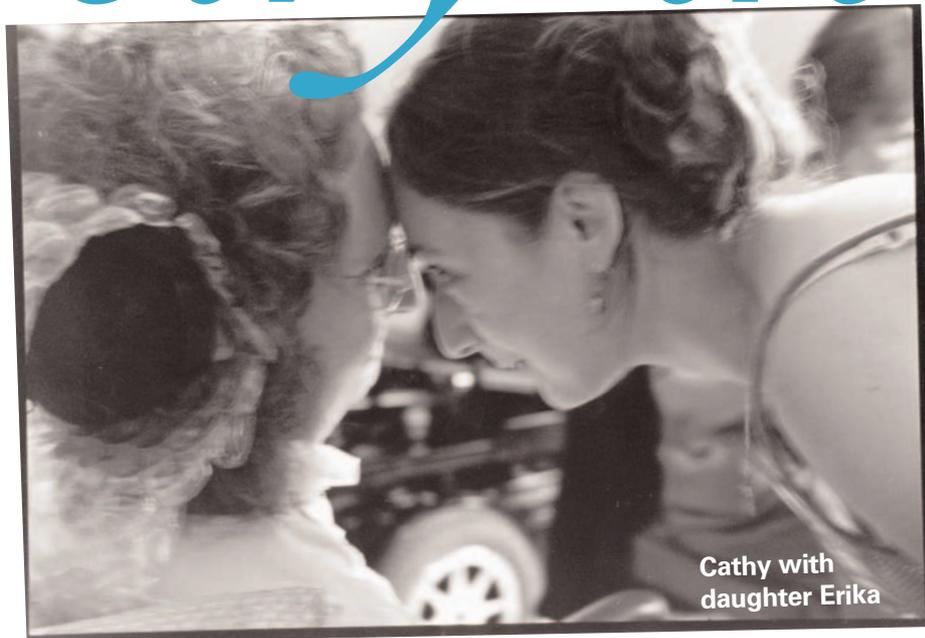


Poetry in

Not even a paralyzing neurodegenerative disease like ALS can keep Cathy Wolf from writing poems that inspire

By Orly Avitzur, M.D.



Cathy with daughter Erika

Cathy Wolf never really wrote poetry before she received the cruel diagnosis, before she became quadriplegic, before she required a ventilator just to breathe. But as amyotrophic lateral sclerosis (ALS) shrank her physical world, the horizons of her mind have expanded. Poems became her way to keep in touch with friends and, later, to express her feelings. Now she writes about almost everything: the disease that has caused inexorable deterioration in her muscles, the daughters she cherishes, the pets she loves.

“Some poems are cathartic, some are fun, others are reactions to political events, or personal statements,” she explains.

All are therapeutic. Small wonder that Cathy Wolf, who has a Ph.D. in psychology from Brown, does her best writing in the early morning hours when she can't sleep. Just as ALS robbed her of her ability to speak, poetry has given her a new voice.

She writes poetry the same way she communicates with her family: on a computer, using a scanning keyboard and a movement-triggered headset device that selects one letter at a time. Her career as a computer design engineer, developing assistive technologies for people with disabilities, would ironically prove beneficial for herself. After it became too difficult for her to type, she found contraptions that helped suspend her hands over the keyboard so she need move only her fingers. When her fingers lost their dexterity, she began using a speech-recognition program. When her voice became too weak, she rigged a mechanism using her big toe. Now she uses a specialized apparatus that consists of an onscreen keyboard and a switch sensitive to her slightest head movement. The keyboard scans each row until she finds the one with the right letter and triggers the switch, then scans each column until she gets to the letter itself and again activates the switch.

As slow and tedious as the process is, Dr. Wolf calls on the patience and persistence that predated her ALS diagnosis in 1997. She was 49 when “the first inkling something was wrong came in a modern-dance class when I couldn't flex my left foot.” As a runner training for 10K races on the roads of Katonah, N.Y., she soon



FAMILY PORTRAITS Together in 1998, and in 2004 at Erika's wedding

Emotion

noticed pain in her left calf. A staunch liberal who's lost none of her activist '60s defiance, she was at first in denial about ALS. But she would need a wheelchair by 1999, a ventilator by 2001.

Still, she continued to defy the odds: While most ALS patients do not survive more than two to three years after diagnosis, she is in her 10th year with the disease and, at 59, looks forward to the arrival of her first grandchild.

She traveled to her daughter Erika's wedding two years ago in her adapted minivan, having organized a list of essentials to pack — ventilator, oxygen canisters, monitors, a laptop so she could converse with guests — and arranged for a hospital bed in her hotel room. And just this May, she organized Erika's baby shower as thoroughly as she does fundraisers for ALS

and muscular dystrophy.

"My mom has always had incredible strength and a lot of energy," marvels the younger of her two daughters, Laura.

"Nothing is a big deal anymore, and we are more mindful of the good things in life," Erika says. "It has also brought out the dark humor in our family, and in a good way, where we don't get upset about most things."

That dark humor resonates in Cathy Wolf's poems, which run the gamut from bleak to silly. Her husband, Joel, likes her poems about their four cats best, because they're funny and goofy. Oliver, a gray tiger-striped tabby that loves to sleep in her bed, is the subject of "Touch" — one of four poems chosen to speak here for a poet who has lost her voice in body but not in spirit. NN

THE REAL ME

*Amyotrophic lateral sclerosis
That was my solemn diagnosis
I asked the doctor, "Do people die?"
He said, "Yes," I started to cry
Eight years later, I'm a quadriplegic
If you told me then I'd not have believed it
"I will always run, I will cross country ski"
I would not believe it could happen to me
But life is random and disease doesn't care
If you're good or evil, or what you can bear
With legs of lead and arms of wood
I'd like to dance, if I only could
Where is the real me?
Am I a shell of who I used to be?
Like some wax museum figure
No, I am much bigger
The real me is in my heart and in my mind
In what I do that's kind
In the hearts and minds of others
Daughters, husband, friends and mother
Father, sister, in my writing
In my spirit, in my fighting
No, ALS is not the whole
The real me
Is in my soul.*

TOUCH

*I sleep alone now
Not by choice but by disease
The nurse sits in the far corner
Records my vital signs
Pulse, 78
Breaths per minute, 8
Not dead yet
A gray cat remains faithful
Curled at my feet
Or stretched long on my body
His furry warmth comforts me
Through gnawing nightmares
And the loneliness of 3 a.m.
He knows without knowing
The kindness of touch*

DREAM DANCING

*I dream that I'm dancing
I shimmy and twist
I'm the Queen of all dancing
Dancing is why I exist

I do the Pony
Mashed Potatoes too
I am dancing with Mercury
But ordinary boys will do

I feel like I'm flying
I dance until late
My mind's in my body
School work can wait

I awake with a smile
I've been dancing!
Cruel dream, you lied!
This broken body can't dance

But in my dream
I was dancing*

RESOLVED

*I refuse to die
I choose to defy
Prognosis (poor)
I will see
Daughters
 Graduate
 Marry
 Grandchildren
I refuse to die
I choose to defy
Prognosis (guarded)
I must
 Love
 Help
 Work
 Dream
 Eat chocolate every day
I refuse to die
I choose to survive
Prognosis (good)*