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PARKINSON'S DISEASE



Dear Friends,

Being a mother with Parkinson's has not always been easy. Do I avoid a class trip so as not to embarrass my child or go along and make him feel special? How much do I tell my children about the disease? How open am I with their friends? What do I say the future holds? There are many questions...

Some of them are answered in good books for children about PD – Rasheda Ali's book, "I'll Hold Your Hand So You Won't Fall" and "Shaky Hands" by Soania Mathur." Check them out, whether you are a parent or a grandparent.

Here are some poems I wrote for children but never published, and two brief vignettes from my children's teenage years. I hope you enjoy them.

DON'T WALK PRETTY

Sometimes I don't walk pretty anymore
Yet sometimes I'm bounding out the door.
The fluctuation is quite dramatic,
The physical problem symptomatic
Of a crazy disorder called Parkinson's.

Sometimes my legs can't move, they're frozen

Sometimes my feet point inward – toes in

Sometimes no one seems to be able to hear me

Sometimes younger children look at me and fear me

Because of a crazy disorder called Parkinson's.

Sometimes I'm put in the awkward position of comforting others about my condition of deciding on the spot, do I tell them the truth? Do I handle it differently for adults than for youth? Questions arise from this crazy condition called Parkinson's.

But by now I've had it for quite a while
And I just tell it like it is, with no frown, no smile
And hope that with whomever I share my thoughts
That person will benefit from my talk,
and ask any question that pops into their mind
about any neurological problem of any kind.

BACK AND FORTH

In the morning my mom moves in a jerky way
And a while later she acts more like me
And hours after that, the stuttering moves come back,
and then later still, they dissolve and she's free!

I know my moods shift from time to time
But my body doesn't change like hers does
Will this happen to me when I reach fifty-three
Or by then will this disease be unheard of?

Sometimes I feel sorry for her
Other times I'm frustrated with her slow pace
I want my breakfast, my clothes, my shoes;
I can't find my homework, she's making me late

Her mood is better when she can move
And that means so is mine
But we do this dance, this see saw of sorts
All the time, all the time.

PD?

What, oh what, tell me, what is PD?
Is it a party dress, play doh for me?
A pizza delivery, a pretty daisy,
A polka dot, a puppy dog gone crazy?

What, oh what, tell me, what is PD?

A perfect day, potato dumplings to eat?

A private detective, a prom date,

A prairie dog, a president's debate?

Are you tired of all this speculation
I hope not for there's more to this collaboration
Between the letters P & D, not let us think
Is it pitch dark, a poisonous drink?

How about a poodle dog, a primary doctor, A police department. A prima donna, A double play, a pistachio dessert, What is this PD, is it fun, does it hurt?

Well it isn't really fun, and sometimes it may hurt But you take what is dealt, what's hidden or overt, And with rhyme, music, words, dance and song We battle our Parkinson's Disease, on and on!



And from teenage years, here are two personal stories for Mother's Day...

My older son was hanging out around Union Square in NYC with some high school friends. One of them saw a picture of Michael J. Fox and started to imitate him. Everyone else joined in, (except my son), all moving dyskenetically and laughing as they did so. My son raised his voice: "Hey man, that's not cool...my mom has Parkinson's"....total quiet; total stillness. Someone changed the subject and they all moved on.

It took guts – especially for a teenager – to stick up for his mom. That was one of the best Mother's Day presents I ever had.

This next one has no relation to PD, just to being a teenager:

I was riding on the number 4 train with my younger son. He was late for school. I said to him, "What punishment do you get at school when you're late?" He looked at me and said, with total seriousness, "The punishment has begun." "What do you mean?" I said. He replied, "I have to ride the train with my mom." I loved that too – his humor and affectionate barbing which I gave him right back.

Happy Mother's Day,
Pamela Quinn
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