

# POLIO PERSPECTIVE

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**Yet Another Tightrope to Walk**

**By Millie Malone Lill**

There are several pages on Facebook that are devoted to polio survivors. I belong to so many of them that I actually lose track of which page is run by which administrator, which are closed pages meaning that no one but members can see the posts, and which are not. Every morning, I check all the pages to see what my polio friends are up to.

The other day, one of the administrators, who happens also to be a friend, told me that they'd had to ban someone from their page. Why? Because he was a devotee or possibly a wannabe. Are you familiar with these terms? I was, vaguely, because of an incident that happened many years ago, but hadn't run across it lately.

A devotee is someone who is sexually attracted to people with disabilities. The person who had been banned spoke of one woman's braces as 'jewelry for her legs.' A wannabe is someone who is not disabled but wishes to be.

This raises interesting, even puzzling questions. How do you know if the person you are dating is a devotee? I have no answers, but lots of questions. We already have to walk that narrow line between doing enough to stay mobile, but not so much that we burn our diminishing supply of motor neurons. Now we also have to be careful about who we date. We want to have someone in our lives who understand our disability and is not turned off by the fact that we wear braces or use assistive devices, but we do not want someone to whom the braces and/or devices is the turn on!

I did a bit of research on these two subjects. I had already met a wannabe. This woman claimed to have PPS, but she had no fatigue, no pain, no atrophying of muscles, no limp, nothing to show any kind of disability. I don't like to judge people on these things because some of us don't show physical signs of a disability, but then again, we do have some signs. Either being easily fatigued or having a limp, or perhaps one limb smaller than another. Something. This woman did not. She wanted braces on both her very healthy looking and acting legs. You could crack walnuts on the calves of those strong legs of hers! Yet, despite being able to go from 6 AM to midnight for 11 days in a row,



This equipment generates alternating high and low pressure, which causes compression of the thorax, i.e. air is pressed into and squeezed out of the lungs, the body is so-to-speak forced to breathe. For a long time, I spent 24 hours a day in this monstrous metal box, the body hermetically sealed, with only the head outside. A narrow cuff wrapped around the neck prevented air escaping from the chamber

I was about 4 years old when they started turning off the unit for short periods at a time to see how I reacted. I quickly panicked, was scared to death, felt helpless. But one day I gasped desperately for air and miraculously, I managed to squeeze vital oxygen through the larynx into the lungs. So I learned the so-called "frog breathing" method , a strenuous, arduous way of breathing without the support of my paralysed diaphragm. It took years before I managed to stay outside the iron lung for more than two to three hours a day.

There were about 15 children in the polio ward, sometimes more, sometimes less. Most of those who were hit as badly as I was, died . It was commonplace for me that a child was taken out of the room and never came back. But I wanted to live - and the small group of us that was left, wished to be kept busy.

A teacher was employed and we were enrolled in the 'hospital school' . With the 'school bag' (a typical German way of starting the first day at school, this bag was filled with sweets and cookies) we - the six to eight year olds started lessons , 2 to 3 hours a day, depending on how long we could stand it; we were taught reading, writing and arithmetic .

I was 14 years old when I was able to leave the hospital. A life without people in white coats was unimaginable for me, but I was curious to see the world outside.

*Living in a Home for 11 Years*

In 1969 the Pfennigparade (an equivalent to the American March of Dimes Foundation) finished building a home in Munich for polio survivors . Children from all over Germany who were disabled by polio were looked after and cared for in this home. As we were not really ill any longer the hospital was not a suitable place for us in the long run.

My parents gave up their apartment in Puchheim, moved into the Pfennigparade home and we learned to live together as a family. I got my own room which for me was beyond all imagination, I had not even dared to dream of that. The iron lung was my bed, but otherwise the room was not different from any normal child's room. I enjoyed my own space with all my heart, at least during the day.

The nights, however, were disastrous. I had never slept alone in a room and therefore was easily frightened. With an improvised battery-operated bell my father connected my iron lung to their bedroom so that I could let them know when I needed anything. I rang the bell over and over again. I needed to be certain that my parents really heard me, that they were there, that I was not alone. No more was there an undisturbed night for the family.

As the sleepless nights never seemed to end, it was decided one day that I should sleep in the respiratory ward of the Pfennigparade home. This proved to be an extremely good



over the years I actually stopped suffering in that way. A relationship, partnership or marriage was not for me.

After many years – when the wall around my heart seemed indestructible – I met her:

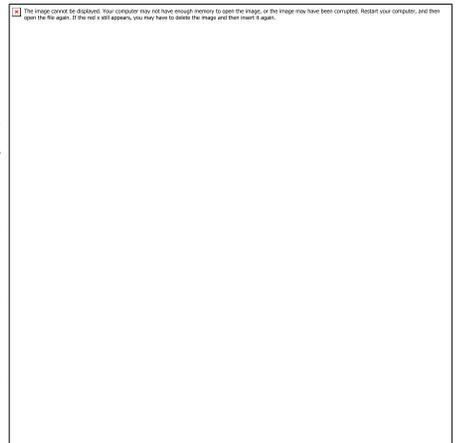
The woman that I once dreamt of.

We met on the Internet, this fantastic, imaginary world in which all people are equal, anonymous, and usually have only fictitious names. And yet there is spontaneous sympathy or antipathy towards these ‘bodyless’ beings in the Cyber World. Today when I think about it, the first brick in my wall started to crumble when I entered the chatroom with my psydonyme "little frog" and a lady "onnlein" welcomed me with "Hello little froggy" . We talked , that is to say, wrote for hours, we got on so well right from the start and we really liked each other. Even when I revealed to her that I was disabled there was no change in her natural friendly way of talking to me. Soon our nightly chats became so important to me that I caught myself more and more waiting impatiently for the time “onnlein” actually came online. When one day she casually mentioned that we should meet offline I suddenly panicked that I might have fallen in love in spite of my laboriously built wall and there was the fear of having to cope with another disappointment, fear of the feelings that have always been connected with suffering. Encouraged by a friend whom I had told about my internet acquaintance, I decided to meet her.

This meeting made my indestructible wall crumble like a house of cards.

The first visit was followed by others, brought us closer and then we really felt that the affection we had for each other in the unreal world of the Internet, now had become reality: We love each other.

One can imagine that a partnership with a person like me is not easy. I need and I receive assistance 24 hours a day, which means that 24 hours a day a carer is at my side. I'm used to it, but for Karin this was something entirely new. She had no experience whatsoever with any type of disability and of all people she came across me who as far as physical disabilities were concerned, had pretty much the most to offer. But right from the first day she was very interested in everything that the carers did for me , and watched each step carefully. To put on my jacket was the first action she wanted to do herself. This was followed by other things like brushing my teeth, get me dressed completely, lift me into the wheelchair and so on. She wanted to learn to deal with my disability all on her own so that every now and then we could be together without a carer being present. Today we are both a great team, able to deal with the situation on our own and be close to each other for longer periods of time.



But unfortunately we will never be able to live together as a couple. As she is healthy –

luckily - and has a job, but doesn't earn a fortune we cannot afford an apartment together. My basic social security income would be canceled if she moved in with me and the round-the-clock assistance I receive from the carers would be cut...

## **DEAR PAIN**

By Donna M. Kidner

First off, this should be sent directly to your "complaint" department, because I have some major "bones to pick" with regard to the way I have been treated and despite numerous attempts to contact your customer service department, little has been resolved.

On the one hand, some would say you are to be commended because you have been quite consistent over the years we've done business together, but let me tell you, I would add that you've exceeded any previous notions I may have held about the "product" in question.

Are you aware of the power you have to completely turn another's life around, inside and out, sideways, backwards? Do you meet with your colleagues, depression, sadness, anxiety, and devise more ways to torment your "victims"? Oh, sorry you must think of us as "customers".

Did it ever occur to you that most folks, were it in their power would gladly in a heartbeat put you completely out of business for all eternity?

I would lead a national campaign to do so, if you would consider allowing me a break in the action long enough to pursue such a worthwhile endeavor.

But as it is now, most if not all my energy revolves around "survival" and that is a full time job thanks to the likes of 'you',

I do not expect any response as I realize you most likely gained as much pleasure from this litany as you do when you dispense your daily doses. Many others I know share my displeasure and disdain over your existence in our world.

May someone far stronger than I, find the way to destroy you one day so that we all can live, love, and again contribute and have renewed purpose and a greater quality of life.

signed,

unthankfully yours,

P.S. no need to sign my name, you are fully aware of who I am for we have "spoken" often, have we not?

## WEB CORNER

### **Disabled rights pioneer Lord Morris of Manchester dies**

<http://www.bbc.co.uk/news/uk-england-manchester-19253539>

### **For those of us watching our weight:**

[http://www.dietsinreview.com/diet\\_column/01/know-your-portion-sizes/](http://www.dietsinreview.com/diet_column/01/know-your-portion-sizes/)

### **All kind of crutch accessories:**

<http://www.fetterman-crutches.com/accessories/index.php>

### **"Village" groups help elderly live in homes they love:**

[http://www.washingtonpost.com/realestate/village-groups-home-alterations-help-more-elderly-people-keep-the-homes-they-love/2012/07/26/gJQAvMEHCX\\_story.html](http://www.washingtonpost.com/realestate/village-groups-home-alterations-help-more-elderly-people-keep-the-homes-they-love/2012/07/26/gJQAvMEHCX_story.html)

### **I want one of these wheelchairs!**

<http://www.universaldesignstyle.com/mobi-electric-folding-wheelchair-concept/>

### **Forgetfulness: Knowing when to ask for help**

<http://www.nia.nih.gov/health/publication/forgetfulness-knowing-when-ask-help>

### **Ask Dr. Maynard**

<http://www.post-polio.org/edu/pphnews/PPH28-2spr12p10-11.pdf>

### **A blog about pain and fatigue:**

<http://lindaonwheels.wordpress.com/category/pps-pain-and-fatigue/>