

We Have Nothing to Fear?

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"We have nothing to fear but fear itself," declared history's most famous polio survivor. Well, that may be true if 1) you're a multimillionaire 2) have an executive job that pays the same salary whether you're working or retired 3) have the world's best medical care 4) are surrounded by eager servants and a coterie of men with guns sworn to protect you. But, for those who are disabled and aren't president of the United States, there's a lot to fear. Having treated people with disabilities for more than 30 years, let me tell you about disability's "Fundamental Fears" and ways to stare them down and send them away.

Death & Danger. I was amazed when I read a study that people without disabilities most often "thought of death" when they saw pictures of someone who had a disability. One enlightened insurance company sold their disability policies using the slogan, "Be Prepared for Disability, 'The Living Death'."

Since those who have disabilities are people first and disabled second, they too can see their own disability as a harbinger of death. But, disability isn't synonymous with death. Yes, some disabilities end in death. Others can potentially reduce your life span. But, the overwhelming majority of physical disabilities are *not* life threatening.

Holistic teacher Don Miguel Ruiz suggests, "Death is not the biggest fear we have; our biggest fear is taking the risk to be alive and express what we really are." However, for people with obvious disabilities, expressing what they really are can generate another fear. One study found that people with diabetes, which can lead to blindness and leg amputations, are more afraid of disability than they are of death. One reason is that looking disabled announces vulnerability. Bill, a para who lives in New Jersey, refuses to venture into New York City: "I feel like an easy mark, a guy in a wheelchair who can't run or fight. I'm a mugging waiting to happen!" But, Carla, who has cerebral palsy and *was* mugged, she believes as a direct result of her limp and cane, isn't letting fear keep her a prisoner. "I won't leave the house without pepper spray and my taser" Carla says. "C'mon muggers. Make my day!"

Abuse & Abandonment. Unfortunately, a more common disability-related fear than being attacked by a stranger is being physically or emotionally abused by someone you know. Our 1995 International Survey found that polio survivors reported 34% more physical abuse and 94% more emotional abuse than did those without disabilities. All that "extra" abuse was due to polio survivors having had "the dread disease" and looking disabled. And, abuse was meted out not only by strangers -- nurses, doctors and physical therapists -- but also by parents, siblings and neighbors. Polio survivor Molly returned home from the rehabilitation hospital to be accosted in the street by neighbor who said her wheelchair was "...upsetting people. You cripples shouldn't be allowed in public!"

It's stunning that the same polio survivor who promised, "We have nothing to fear but fear itself!" also said, "I'll walk without crutches. I'll walk into a room without scaring everybody half to death. I'll stand easily enough in front of people so that they'll forget I'm a cripple." Echoed polio survivors Jim: "Anxiety, inferiority, uselessness. Fear in the pit of my stomach is always there, for as long as I can remember. Why? I had polio. That's why."

These fears are nowhere more evident than in the research showing that changes most obvious to family members -- using assistive devices, buying special equipment, and home modifications -- were adopted by the fewest polio survivors in spite of these changes being the most effective in decreasing PPS symptoms. That's why about 10% percent of those treated at *The Post-Polio Institute* refuse any assistive device that makes them appear disabled. One patient told me she'd rather be dead than use a cane, saying "Why don't you just paint a bulls-eye on my chest and say 'Shoot the Cripple'?"

Despite Billy Crystal's old line, "It is better to look good than to feel good," it isn't! Be you a polio survivor, a para, someone with muscular dystrophy, MS, spina bifida or CP, it's better to feel good than to try to hide your disability and stumble, fall or crawl along without the assistive devices you need. To paraphrase a line from another abused and abandoned polio survivor, "I limp, I'm a gimp, get used to it!"

Helplessness & Homelessness. "The only time I ever cried after being diagnosed with MS was because I was terrified that I would not longer be able to earn a living and become a financial burden to my family," said Ray.

People with new disabilities often expect the worst -- that they will become helpless and unable to work -- rendering themselves and their families penniless and homeless. Even those who are disabled and have worked for decades can reach a point where they run out of muscle strength, are pummeled by pain, done in by fatigue. They are terrified to retire early, fearing that they will become their family's financial albatross. It's no wonder that a report on deaths under Oregon's assisted suicide law found that almost half of those motivated to end their lives were prompted by fear of becoming "a burden on others."

First, depending on your physical circumstances and education, even those with severe disabilities are working. That's what state vocational rehabilitation agencies and the ADA are all about - helping people with disabilities use their remaining abilities to earn a living.

Second, if you can't work any longer, your company may have a private long-term disability policy that typically pays 60% of your salary.

Third, if you don't have long-term disability, Social Security Disability Income is available; although SSDI only pays about \$1,500.00 a month it provides Medicare two years after you are approved. Please don't believe the Internet reports that "everyone is denied SSDI on their first try." A complete protocol to apply for SSDI that accompanies my Social Security Ruling for Post-Polio Sequelae, in the POST-POLIO LIBRARY at

PostPolioInfo.com. Even before the Social Security Ruling, since 1987 when Senators Bill Bradley and Tom Harkin helped me get the SSDI regulations for polio survivors released, we have had not *one* polio survivor denied for SSDI.

Dependence Creates Independence. That Oregon report found the most common motivation for suicide (about 66%) was fear of "loss of autonomy" and "loss of control of bodily functions." Poet Bonaro Overstreet said, "Perhaps the most important thing we can undertake toward the reduction of fear is to make it easier for people to accept themselves, to like themselves." To both accept and like themselves, those with disabilities -- both newbies and the old hands -- need to understand that loss of autonomy or control of bodily functions should not be reasons for taking the pipe. These changes, as well as other symptoms of disability -- and of aging itself -- are just variations on "The Burden Beguine," that dance between dependence and independence that polio survivors have learned to dance so well. As Dr. Nancy Frick frequently said, "There is ALWAYS an alternative -- physical or emotional -- to deal with any problem."

As people with disabilities lose function or age, they often get angry when others, especially family members, offer assistance. This anger is hiding a fear of dependence and being a physical burden. But, we've found that family members do not feel burdened, but actually want to help. The true burden is seeing a loved one in pain and unable to function, not being asked to vacuum the living room rug. Since our studies show, for example, that family support increases polio survivors' acceptance of new symptoms and decreases depression, it's vital that family and friends are allowed to help with physical tasks and that family members with disabilities feel valued regardless of reduced abilities. It is a wonderful contradiction that the more disabled you "look" -- the more assistive devices you use, the more you ask for help, and the less you abuse your body -- the better you feel and functional and the more independent you become. As hard as it is to believe, **dependence creates independence.**

"We have nothing to fear but fear itself?" Perhaps a more helpful quote comes not from Franklin Roosevelt but from Eleanor: "You gain strength, courage and confidence by every experience in which you really stop to look fear in the face. You must do the thing which you *think* you cannot do."

Set your browser to:

<http://www.PostPolioInfo.com> for Mia Farrow's POST-POLIO LETTER.

Go to the left side menu for information about the cause and treatment of PPS, including Social Security Disability information, surgical and dental precautions, The Post-Polio Library and random harvest e-books about PPS.

There are also post-polio support groups on Facebook, like THE POST-POLIO COFFEE HOUSE at <http://www.facebook.com/groups/148377278537482/>