



We Have Nothing to Fear ?

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"We have nothing to fear but fear itself," declared history's most famous polio survivor. But, for those who are disabled, there's a lot to fear. Having treated people with disabilities for more than 35 years, let me tell you about disability's "Fundamental Fears," ways to stare them down and send them away.

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

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 disabling conditions end in death. But, the overwhelming majority of physical disabilities - for example PPS -- 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, were more afraid of becoming disabled than they were of death. One reason is that looking disabled announces vulnerability. Bill, a paraplegic 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!" However, 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. A more common disability-related vulnerability is the fear of 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. Abuse was dished out not only by strangers -- nurses, doctors, physical therapists -- but also by parents, siblings and neighbors. Polio survivor Molly was welcomed home from the rehabilitation hospital by a neighbor scolding that 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 survivor Jim: "Fear in the pit of my stomach has been there for as long as I can remember. Why? Because I had polio, that's why."

Polio survivors' fears are nowhere more evident than in our research showing that changes most obvious to family members -- assistive devices, buying special equipment and home modifications --

were the most often rejected in spite of their being the most effective in decreasing PPS symptoms. About 10% percent of those treated at The Post-Polio Institute refused any assistive device. 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 is far better to feel good than to "look good" by trying to hide your disability by rejecting the assistive devices you really need. To quote one abused polio survivor who *did* accept assistive devices to treat his PPS, "I limp. I'm a gimp. Get used to it!"

Helplessness & Homelessness. "I cried only once after being diagnosed with PPS. I was terrified that I would no longer be able to earn a living and would become a burden to my family," said one PPI patient.

People with new disabilities often expect the worst -- that they will become helpless invalids and unable to work -- rendering themselves and their families destitute. Even polio survivors who have worked for decades, but are now being pummeled by PPS, are terrified of retiring 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 nearly half of those who wanted to end their lives were motivated by a fear of becoming "a burden on others."

First, even people having severe disabilities work. 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. (and if you pay the policy premium, that 60% is tax-free!)

Third, if you don't have long-term disability, Social Security Disability Income is available. Although SSDI only pays about \$2,000.00 a month it provides Medicare two years after you are approved. But please don't believe the rumor that "everyone is denied SSDI on their first try." A complete protocol to apply for SSDI accompanies my 2003 Social Security Ruling for PPS in the POST-POLIO LIBRARY at PostPoliInfo.com. But, even before the Ruling, in the 30 years since the PPS regulations were released, we have had *not one* polio survivor who followed the protocol denied SSDI.

Dependence Creates Independence. That Oregon report found that the most common motivations for suicide were 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." You certainly don't have to like PPS. But accepting new symptoms and making changes to manage them puts the control of your body and your life in *your* hands. As Dr. Nancy Frick said, "There is ***always an alternative*** to deal with any problem."

However, fear of dependence and being a burden often arises when polio survivors need to ask family members for assistance. We've found that family members don't feel burdened; they actually want to help. The true burden on family members is seeing a loved one in pain and losing function, *not* being asked to vacuum the rug. Since our studies show that family support increases polio survivors' acceptance of new symptoms and decreases depression, it's vital that family and friends be allowed to help with physical tasks and that those having a disability feel valued regardless of reduced abilities. As one polio survivor wisely reminded us, "We are human *beings*, not human

doings." It is a wonderful contradiction that the more disabled you "look" -- the more assistive devices you use and the more you ask for help -- and the less you're abusing your body, the better you will feel and function and the more *independent* you'll 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 but from Eleanor Roosevelt: "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."