

FROM

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and

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**Proceedings of the Ontario March of Dimes Conference on
Post-Polio Sequelae.**

Toronto: Ontario March of Dimes, 1995.

**THE CONTRIBUTION OF CHILDHOOD PHYSICAL
AND EMOTIONAL TRAUMA TO THE DEVELOPMENT
OF THE POST-POLIO PERSONALITY.**

Dr. Nancy M. Frick

Introduction: Jeannette Shannon

The violinist Itzhak Perlman once stated, " When you sit in a wheelchair, you lose your height and you become an 'it.' You are a disability." He went on to say, "I am tired of being a human interest story, a brave handicapped musician. I am a musician for whom life is not easy. But then, is life easy for anyone?"

**Our next partnership is with Dr. Nancy Frick, educator,
author, counselor and researcher specializing in the**

psychology of disability. She was one of the founding members of the International Post Polio Task Force and wrote the first article in the medical literature on the psychological effects of post polio sequelae. With Dr. Richard Bruno, she conducted the national surveys of polio survivors that documented the relationship between psychological stress, Type A behavior and post polio sequelae. Dr. Frick received Bachelor and Doctor of Humane Letters degrees from Baldwin Wallace College. She also received a Master's degree in Counseling from Drew University and did clinical training at the American Foundation of Religion and Psychiatry at New York Hospital, Cornell Medical Center. Dr. Frick created and is currently the Executive Director of Harvest Center in Hackensack, New Jersey, which provides consulting and education for corporations and people with disabilities, with special emphasis on post polio sequelae and compliance with the Americans with Disabilities Act. Her topic this morning is: The contribution of childhood physical and emotional trauma to the development of the post-polio personality.

Dr. Nancy Frick

Do you remember the old TV program Truth or Consequences? The master of ceremonies used to ask questions and if contestants answered them correctly, they got lots of great prizes, dishwashers and so on, and

presumably went home and lived happily ever after. But, if they answered the questions incorrectly, terrible things would happen to them. As you read on, you will be asked many questions about yourself. If your answers are incorrect, the consequences for you will be Post-Polio Sequelae (PPS).

The term "polio survivor" has been used in our community as if anybody who survived the acute stage of polio is a survivor. But I believe that there has got to be more to surviving than that. Surviving ought to mean more than just being alive, but feeling dead. Surviving should mean having quality of life and living without dread, without that clutching feeling in the pit of your stomach because you are so busy pleasing everybody else that you never get around to living your own life. I believe that being a polio survivor should include the possibility for inner joy and not just the tremendous pressure for success that so many people who had polio demonstrate.

I will link the origin of Type A behavior to events that occurred during the acute stage of polio and after polio survivors recovered from the acute stage. I will then show how Type A behaviors actually can cause post polio symptoms. But I am not going to stop there. I will present a plan that will help polio survivors stop being Type A, reduce their post polio symptoms and help them become true polio survivors.

Are You Type A?

Most people in the post-polio community have either heard or read that polio survivors have Type A personalities. If you had polio, do you believe that you are Type A? Take a moment and complete the brief Type A questionnaire that we use in our research and is included in harvest center's Computerized Assessment Program for PPS. For those who are either retired or on disability, please answer the questions as you would have answered them when you were still working. Consider yourself employed full time if you are a homemaker.

YES NO I usually wake up not feeling well rested.

YES NO I enjoy competition.

YES NO I consider myself to be hard driving.

YES NO I have a temper that is hard to control, a temper that's fiery.

YES NO I set at least one deadline a day for myself.

YES NO I set at least one deadline a week for myself.

YES NO It is very important for me personally to get ahead in life.

YES NO I usually spend less than five days on an average vacation.

YES NO I spend more than eight hours a week doing overtime work at home.

YES NO I have taken less than one vacation a year during

the last five years.

If you answered "yes" to five or more questions, you have the hard-driving, pressured, perfectionistic Type A personality. On average, people who did not have polio answer "yes" to four or fewer of these questions, while polio survivors answer "yes" to six or more.

If polio survivors are so Type A, the question is why and what difference does it make in terms of their being true polio survivors? To answer these questions, polio survivors have to go back to their original experience of polio. But, going back is a problem, because most polio survivors don't want to remember having had polio. Most say, "I had polio, I got over it and don't ever want to think about it again, thank you very much." But, polio is a pivotal part of any polio survivor's personal history and keeping it buried actually causes psychological damage. Yes, it hurts to think about it. But the only way to get a handle on why polio survivors are so Type A today is to remember and deal with the experiences they had yesterday and have so carefully hidden from themselves.

Polio: The Initial Terror.

There are many painful memories associated with the acute stage of polio. First, if polio survivors were old enough, they knew that they had been stricken by the "greatly feared disease." Polio survivors were the AIDS people of their

generation. Nobody wanted to have anything to do with them. Everybody was terrified of polio survivors, and even their families, for years. Second, if polio survivors were old enough to know that they had had polio, many thought that disability was likely and that death was at least possible, especially if they knew someone who had been disabled or had died from polio.

The Hospital Experience: Being Away from Home.

There is a third issue which is even more disturbing. There was the confusion and terror connected with polio survivors' being wrenched from their homes, dropped in a hospital and being left there for months or even years, while they received treatments that no one explained to them. Polio survivors went to the hospital, usually when they were very young, and lost their emotional support system.

- A Texas man had polio when he was five. When I met him he was 52 years old, a colonel in the United States Air Force, 6 feet 4 inches tall, extremely strong and was beginning to have PPS. He had completely repressed the entirety of his original polio experience until the day he heard me speak. While I was talking, it came back to him in a flood. I mean a literal flood because when he came up to talk to me, tears were streaming down his face. He didn't want to remember and when you hear what happened to him you will understand why.**

When he was five years old, he was taken 250 miles from home, admitted to a hospital and didn't see his mother for two months. When he he did see her again, she was on one side of a glass window and he was on the other. She couldn't hold him; she couldn't comfort him. Those who are parents know that when your children are ill, the one thing you want to do is to be able to hold and comfort them. He said to me, "I don't like how I feel about remembering being in the hospital and I don't like remembering how I felt afterwards either. All I will say is that it took me a lot of years to begin to like people, or trust them."

- A six year old girl from Ohio was so psychological traumatized by her hospitalization that she forgot what her sister and home looked like, lost control of her bodily functions and attacked the staff.**
- A man from New Jersey, who had polio at the age of five, was so overwhelmed by what happened to him when he got to the polio hospital that he forgot his name. For two weeks he remembers constantly asking every medical professional who went by, "Who am I? What's my name?" He lost the certainty of who he was in the hostile and sterile environment of that polio hospital.**
- A man in Florida, who had polio when he was four, had**

parents who were so displeased that he was ill, they admitted him to the local polio hospital and never came back. When he was twenty-two and old enough to discharge himself, he left the hospital on his own. He hasn't seen his parents to this day.

You may think these stories unusual, but they are not. Polio survivors were traumatized just by being in the hospital, especially if they were young. In his book *Loneliness*, Clark Moustakas says this about the childhood experience of being in a hospital:

Because of his inability to take care of himself in the all important functions, the possibility of being abandoned or left alone is the most serious threat to the child's whole existence. Of the many kinds of temporary abandonment, no experience is more desolating to a child than having to be in a hospital alone. The disrespect for the integrity of his wishes and interests, the absence of genuine human warmth, all enter into the loneliness of hospital life.

The Hospital Experience: Medical Abuse.

Not only was being in the hospital emotionally painful, physically painful things happened to polio survivors in the hospital. They had painful and frightening therapies. Many people were burned by hot packs. Many had the nightly experience of being splinted and there being no one willing to remove the splints when they began cutting into the skin;

being braced, having physical therapy in pools, even though they couldn't swim. Few polio survivors had their questions about these therapies answered. It was polio epidemic time. Who had time to explain things to children? The staff became angry when asked questions, sometimes responding, "You want to get out of here, don't you?" Think about the content of that question. Imagine how it would sound to a child; it was ominous. It seemed to mean that if patients didn't do exactly what they were told, they were never going to leave the hospital. Research has shown that failing to explain treatments and provide information concerning illnesses makes children think they are sicker than they really are, and allows their inherent fear of death to surface.

As if physical pain and terror weren't enough, polio survivors were abused by the medical staff. For years before I got polio, I had frequent nightmares and I would wake up in the middle of the night crying. My mother would comfort me. When I entered the hospital the nightmares continued. There was a night nurse at the hospital who did not like my crying and did not comfort me because I sometimes would awaken the other patients. When she came to my bed she would say in a very threatening voice, "You stop crying or you are going to be sorry." She frightened me for two reasons: I knew I couldn't control the nightmares and I didn't know what she would do to me when I cried again. Then, one night I found out. I awoke crying from a nightmare; she came in and said, "I told you not to do this or you were going to be sorry." She pulled me in my hospital

bed into a walk in linen closet, turned off the light, closed the door, locked it and left me there until morning. Such an experience can leave permanent emotional scars. Dozens of polio survivors have told us that they were locked in closets or placed in straight jackets to teach them to behave in a manner more acceptable to the hospital staff. There was the worst kind of abuse. Many polio survivors were sexually abused. One polio survivor was regularly sexually abused by someone on the hospital staff. Yet, she told no one about it. She said, "I was there, they had to take care of me, so I just felt that I had to smile and be a good patient and just grin and bear it."

Unfortunately, polio survivors were helpless, at the mercy of hospital staff, with a complete loss of control over their lives. Most polio survivors couldn't move. Some couldn't feed or toilet themselves. If those who had polio were to have their most basic survival needs met, they had to depend on the medical staff even if they were emotionally, physically or even sexually abusive. Normal, child like behaviors, such as crying and asking questions, were punished. Fears of abandonment by their parents made them certain they were totally dependent on a staff that behaved in ways that made them constantly feel, as one polio survivor described it, "As if I was in mortal danger." Polio survivors had little choice but to suppress their fears and follow their parents' well-meaning parting instructions, "Be good. Don't make any trouble and do everything you are told."

When a child forms a fear so strong and so basic at so young an age, the child takes that fear with him forever and applies it to every other relationship that is formed for the rest of his life. Many polio survivors learned to deal with the feelings of abandonment, loss of control, fear and pain by appearing happy, because it was too dangerous to examine how they really felt, and complying fully with any external expectations. Polio survivors learned to deny their personal needs, feelings, pain, and, worst of all, deny their own identity. This can be seen from a summary of The Good Chart written by the children on the polio ward at Baltimore City Hospital:

Listen to the doctors.

Obey the nurses.

Do not fight.

Do not be bad.

Be good in school.

Do your homework.

Do not talk at dinner or in school.

Little folks should be seen and not heard.

The Return Home.

That Good Chart became the prescription for proper and successful behavior when polio survivors returned home.

Polio survivors learned very young and very well how to stay out of mortal danger. But, returning home was no picnic, either. Many people remember being the one child in the neighborhood with whom no one was allowed to play because they might give everyone else polio. There are many documented cases of people actually crossing the street to avoid walking in front of a home where someone was known to have had polio. But, even if polio survivors were allowed to play with the neighborhood children or their former friends, polio survivors often couldn't keep up with them because of polio's residual effects. Or, polio survivors were ostracized or teased because they looked disabled or were in any way different. Many polio survivors became isolated, felt unwanted, unworthy and for some reason guilty. Many felt that they had done something terrible or they would never have gotten polio.

Another source of emotional pain polio survivors experienced is being stared at. For a child, being stared at is a torment. Many polio survivors learned to be afraid of children not only because they stared but also because of their endless questions. How do you deal with questions about your disability when you don't want to talk about it, when you don't want to think about it, when you don't even want to admit that you had polio? Because many polio survivors thought so little of themselves, at some level they felt the stares or impolite nosiness of strangers could reduce their value to nothing more than that of a momentary curiosity. Some polio survivors actually believed that curiosity could hurt them and, as a result, it did. Fear of

children and resentment of anyone who stared, made polio survivors feel even more alienated, unacceptable and different.

Getting Normal

But, there was hope! The idea was to appear as normal as possible. Get rid of those canes and crutches; get rid of those braces; get rid of that wheelchair and respirator! Get Normal! In the hospital, assistive devices helped polio survivors regain function. But in the community, braces, crutches and wheelchairs were obvious proof that polio survivors hadn't worked hard enough to have fully recovered. Necessary assistive devices were discarded as quickly as possible in order to look normal, regardless of the discomfort, fatigue, awkwardness, pain and actual danger in which polio survivors placed themselves. Why did polio survivors do that? Because polio survivors had to Get Normal.

Physical therapy was begun again when polio survivors returned home from the hospital, or begun for the first time for those who weren't hospitalized. Research had shown that there was no benefit to physical therapy for polio survivors after two years. Yet, many of them had therapy for decades after the acute polio. Why? To Get Normal, of course. One individual who had polio at age five was a triplegic wheelchair user from the time she had polio. When she went home from the hospital, her parents wanted her to walk,

even though it was extremely dangerous for her to do so. Physical therapy was continued until she left home for college. Although she could only walk a few steps with crutches, even though the danger of falling frequently was very real, her parents thought walking was better than using a wheelchair. And why was that? They wanted her to Get Normal.

Another client was beaten by his father as motivation to walk without braces. This particularly sensitive individual told his son, "I'd rather see you dead than a cripple." Now why would a parent who allegedly loves his son say that to him? To make him Get Normal.

Abuse by parents was usually less blatant. Few polio survivors left the hospital and returned to a house that was accessible Why? They had been in the hospital for months, sometimes even years. It wasn't a surprise to their parents that they had a disability. Yet, many polio survivors lived in houses that made it impossible for them to take care of themselves. Basic activities of daily living, such as bathing, dressing, going to the toilet, were impossible. Many were dependent on a parent who might consistently withhold help, or help only when it was convenient. Roberta Trieschmann tells the story of a girl who had polio who returned home to a very rejecting mother. She allowed her daughter to use a bed pan only three times a day: when she awoke, at noon and at 8:00 P.M. Beyond that this child was on her own - and she was in trouble if she had an accident.

Some parents accepted their child who had had polio. But, parents often showed their children that they were unacceptable if they appeared disabled. Abuse at home may explain the findings of a study of 100 children discharged from the Baltimore City Hospital polio ward. A number of patients actually wanted to go back to the hospital. This finding sounds unbelievable. But, could it be that the children who wanted to go back to the hospital were living in homes that were inaccessible where they were being abused by their parents?

Other parents abused their child subtly. For example, there were over protective parents who would not let their child out of their sight and say, "Oh no, honey, you shouldn't do that, you might hurt yourself." This sounds good to the neighbors; it sounds good to the family; but it wasn't good for the child.

If a child recovered physical abilities, which most polio survivors did, some parents tried to forget the fact that they ever had had polio by expecting them to equal or even to exceed their previous physical performance. We know of one family who took up hiking for the first time when their son came home from the hospital using crutches and braces. He climbed over rocks and hills because he wanted to be like the rest of his family. Other polio survivors say that they were expected to outperform their peers academically. Some polio survivors performed academically, not for themselves, but to

please everyone else. Any grade that was not an "A" meant that they were not perfect. And if they weren't perfect, they were worthless. It's amazing what polio survivors' conditioning caused them to do to Get Normal.

Still other parents, who were shamed by their child's disability but unable to deny it because of how visible it was, isolated their families from society. The mother of one man, who had a slight limp after his polio, restricted him to the house and would not let him leave the yard until he was eighteen years old. Many polio survivors experienced isolation which impaired their ability to develop social relationships. Also, and this is critical, if polio survivors parents' felt shame due to their disability, they learned to be ashamed of it, too. These polio survivors learned to expect that everyone they met would reject them. Their parents had rejected them; why wouldn't everyone else?

What did polio survivors learn from these experiences of dependence and rejection in the hospital and at home? They learned that they had better Get Normal and stay that way. They learned that they had better maximize whatever physical abilities remained, be smarter and work harder than anyone else. Then maybe, just maybe, they would be allowed to participate in society and be marginally accepted, but only if they very cleverly hid their polio. So, polio survivors became Type A overachievers and exquisitely sensitive to criticism and failure. They met the needs of everyone in their lives except themselves. Polio survivors

became extremely successful at everything they did on all levels: academically, professionally and personally. Furthermore, polio survivors discarded nearly all of the original assistive devices that they were given and learned to walk without them. They disappeared into society if they could. Those polio survivors who could hide it didn't want anyone to know that they had ever had polio. One individual said that polio survivors have gone beyond being Type A to being "Type E," doing everything for everyone every minute of every day. Why do you suppose polio survivors are Type "E?" To Get Normal, of course.

Polio Survivors versus The Vampires.

I have a name for folks who are Type A, and especially those who are Type "E," and spend more time worrying about what others think about them than they spend taking care of themselves: I call them Vampire Bait.

The world is full of people who want you to do anything they ask, who are eager to suck the life blood right out of your body. You remember that boy who went hiking with his family on crutches and braces? What was he? Vampire Bait. Instead of meekly complying so he would Get Normal, he needed a new inner voice. I am going to give you a new mantra to replace the voice in your head telling you to Get Normal. This is what that boy - what all Type "E" polio survivors - should say when people ask them to do things that are unreasonable, painful and actually dangerous: Get

Real! When your boss asks you to do his work and you do it; when your boss asks you to work late again, or every weekend, and you do it, what are you? Vampire Bait. What should you say to the Vampires? Get Real! Practice your new mantra, your new inner voice. Go home, look in the mirror, picture your Vampire boss, your mother, your neighbor and say, "Get Real!"

How many of you have had Thanksgiving dinner in your home for the last 87 years, inviting approximately 372 people to the meal? There are fourteen gourmet courses, all of which you must prepare yourself. Let's just say for the sake of argument that you decide it's time to start taking care of yourself, start treating your PPS, and you're not going to do Thanksgiving next year. So, you are sitting around the table with the 372 people you've invited, and you say, "Listen, is there somebody here who would like to make Thanksgiving dinner next year?" What do you hear? Stony silence. The roasted turkey is making more noise than your guests. The problem with which you have to deal at that split second is the voice in your head that says, "Oh, that's okay, I don't mind cooking because I hate to ask for help, I don't want to become dependent, I don't want to upset anybody." If you listen to that voice and make Thanksgiving dinner again and again and again, what are you? Vampire Bait!

Why do you keep doing Thanksgiving dinner again and again and again? To Get Normal, of course. Also, doing for everyone is a form of control. When polio survivors were in

the hospital, being treated by medical staff, they had no control over what was done to them. So later in their lives, having control became vitally important. When you hear the stony silence when no one offers to cook Thanksgiving dinner, another voice in your head says, "Thank God! Nobody can do Thanksgiving as well as I can. I am needed! I am earning my keep. I really am worth something. I have a right to draw breath."

It's time that polio survivors all Get Real. Remember, if you keep doing absolutely everything that you have been doing all these years, if you keep being "normal," why should anybody believe that you need help? Polio survivors must learn to say, "Listen, I have PPS and it's not good for me to make Thanksgiving dinner alone anymore. I am valuable just because I'm me, not just because of what I do. Now, are there any volunteers?"

Polio survivors know that physical over exertion and emotional stress are the first and second leading causes of PPS. If you continue to listen to the voices of the Vampires in your head and keep trying to Get Normal, your constant working, doing, taking care of others and rushing around will give you PPS and kill your spirit slowly - and in a socially acceptable way.

Getting Real: You Can't Fool All of the Polio Survivors All of the Time.

I wonder sometimes if polio survivors' real fear is not of dying, but of being alive and looking disabled. Polio survivors have been trying to fool people, including themselves, into believing that they are not disabled. Let me use myself as an example: I had polio at six and have always used a wheelchair since then. I have never been able to walk. At the age of twenty-eight, I saw myself by accident in a full-length mirror and was shocked to see myself in a wheelchair. When I enter the room, everybody else knows I'm in a wheelchair. How did I fool myself for twenty-two years? I Got Normal, of course.

Hugh Gallagher's book FDR's Splendid Deception describes the ultimate example of trying to fooling yourself and the entire world. President Franklin Delano Roosevelt was a polio paraplegic. He couldn't stand at all without braces to his hips. Not only he, but the entire country, went along with the deception that he wasn't disabled at all. If you want to know what it means for a polio survivors to fool himself, you should read this book; but, while you are reading it, remember you may also be reading about yourself.

In our first national survey, we asked the question "Did you consider yourself disabled when you first had polio?" Most respondents said "No." However, in the same survey, polio survivors were asked another question: "When you got PPS, did you feel you had a second disability?" Most people said "Yes." Apparently, polio survivors knew they were disabled by polio, they just weren't admitting it. The question is, are

polio survivors still unwilling to give up their pretense and activities; are they willing to do whatever it takes to keep up appearances in spite of PPS? Would they rather be in pain and continue to slowly lose function rather than Get Real with themselves?

It is difficult to Get Real after all that polio survivors have experienced during their lifetimes. It is not impossible, but it's very difficult. The voices of the Vampires have become the voices you hear everyday in your head, telling you what is good and what is bad about you. How many polio survivors are spending today planning for the future, living in the future? If your mind is busy fretting about the future you are missing today, you are missing this moment. And your life is literally slipping through your fingers while you plan later.

Getting Normal = PPS but Getting Real = SURVIVAL.

The original polio equation of Getting Normal = SURVIVAL is now actually causing PPS. Polio survivors must realize that today, Getting Normal = Progressive Disability from PPS. Your body is telling you to slow down, but your conditioning and fear keep telling you to run or the Vampires will get you.

Can polio survivors stop their PPS symptoms and become "true" polio survivors? Psychologist Al Siebert became very interested in what he calls the Survivor Personality when he

joined a group of paratroopers that had been trapped by Communist armies in Korea. Nine out of ten of the men in that unit had been killed. As Siebert got to know the survivors of the unit, he began to wonder what had allowed them to survive when most of their buddies had been killed. He found out it wasn't just luck or fate that had saved them, but that there was something specific about them that tipped the scales in their favor. He discovered that they had a complexity of character traits that looked to him like a union of opposites that shouldn't really appear in the same person. Then he realized it was because of those opposite character traits that they were able to survive. The opposite traits offered them an infinite group of inner possibilities that made them infinitely flexible. Whatever reaction was required in any given situation, they were able to provide it. Look at the list of traits in the survivor's "split personality:"

COLUMN A COLUMN B

Flexible Stubborn

Pessimistic Optimistic

Serious Easygoing

Excitable Calm

Involved Detached

Thorough Impulsive

Predictable Unpredictable

Cautious Trusting

Mature Childlike

Sensible Emotional

**Conforming Individualistic
Self critical Self confident
Hard working Playful**

If you compare these two lists, I would guess that the Type A polio survivor has more traits from Column A than Column B. Take a look at Column B because these are the traits that one needs to develop to become a true polio survivor. It is possible; you can do it. You have all of these traits inside of you; they are just underdeveloped. The more pairs of traits you possess, the more flexible you are, the more successful you will be in dealing with the physical and emotional trauma of PPS and the more likely it is that you can learn to give up being Type A and say "No!" to the Vampires.

Remember these words of an 85 year old man who learned he was dying:

"If I had my life to live over again, I'd try to make more mistakes next time. I wouldn't be so perfect. I'd relax more. I'd be sillier. In fact, I know very few things that I'd take so seriously. I'd take more trips. I'd go to more places I have never been to. I was one of those people who lived sensibly and sanely hour after hour and day after day. Now, I had my moments, and if I had it to do over again, I'd have more of those moments. Moment by moment by moment. If I had it to do all over again, I'd start barefoot earlier in the Spring and stay way later in the Fall. I'd watch more sunrises and I'd play with more children, if I had my life to live over again. But you see I don't."

And neither do polio survivors. Don't wait until you are 85 to start living. Be a true polio survivor starting now. How do you develop a survivor's split personality? Here is the golden rule for becoming a true polio survivor:

If you are not anxious and guilty, you are not a true polio survivor.

Sound crazy? Think about why it is true. If you start taking from Siebert's Column B and saying "No!" to the voices in your head and to the Vampires, what do you think is going to happen? First, you are going to start feeling better. You are going to feel less fatigue, less pain, less muscle weakness. Then you are going to become absolutely terrified. You will be slowing down, both in doing and thinking, so there will be time for fear to surface, fear that the Vampires will get you. You are going to begin to worry: "Will my friends and family still want me? Will I be ostracized again? Will the Vampires get me?"

Taking care of yourself for the first time in you life will make all the old feelings of guilt and worthlessness surface. (Will the Vampires get me?) If you ask others to pull their own weight, those awful feelings of helplessness and lack of control from when you originally had polio will return. (Will the Vampires get me?) Polio survivors worked so hard to be independent. They had all that physical therapy and endured all those operations and now somebody wants them

to walk less, to use a cane or a wheelchair? The doctors want them to look disabled again? (The Vampires will surely get me.)

Those decades of fear, of conditioning to Get Normal, make psychotherapy necessary if polio survivors are to have any chance to Get Real. The way to test whether a polio clinic is good is to find out whether it has a "shrink" who knows about what polio survivors have gone through and what PPS really means to them. Polio survivors all need some help, somebody to talk to and work with, to help them tolerate the anxiety, the guilt, the fear, the loss of control, and even fear of dying, that the changes in lifestyle and appearance needed to treat PPS are going to cause.

When you become frightened, know that fear is normal, and remember this quote from Grace Hansen: "So often our focus upon death and the possibility of dying, is an escape from our real fear: that of living our lives," living our lives with an obvious disability.

When Getting Real becomes tough, remember this prose poem written by Ruth Mihalenko after thinking about herself as a child with polio:

Where is that little girl?

She is sick, her family is concerned.

Where is that little girl?

She's been taken apart and put together again by the surgeons.

Like a fledgling about to leave the nest for the first time she is testing the waters of a normal life.

Can she catch up? Can she achieve? Can she excel?

Certainly, she must.

Lost time must be made up.

A lifetime of memories must be crammed into a shorter period.

Where is that little girl?

She is not one hundred per cent.

There is new weakness; there is new pain.

Fatigue sets in long before she is willing to deliver her body to rest or to sleep.

Where is that little girl?

She has been taken apart and put back together again by the surgeons. Braces put her back on her feet.

Just as she has been alone with the pain and weakness and fatigue, she is alone in her acceptance and determination.

Her muscles will never grow strong again, but she will be strong again.

She is strong.

Where is that little girl?

She is here and now.

Who is that little girl?

That little girl is me.

Life is a dynamic process filled with changes. Some are frighteningly unwelcome at first. But if you can learn to love yourself and tell the Vampires to go bite someone else, you will start to feel less anxiety and guilt, and become a true

polio survivor. I recently received a letter that said in part: Beginning March ninth of this year, I have made some dramatic changes. Since I have begun this alteration of behavior, I have been feeling better. My cohorts and friends and family members have been very supportive. They have said, 'It's about time!' Funny thing is, I had always expected something horrible to happen when I started taking care of myself. But, it hasn't. I feel reborn.

I wish each of you your own personal rebirth.

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