



Let's Sleep With Our Nightmares and Follow Our Dreams Sunny Roller, M.A.

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This presentation is dedicated to my Dad who passed away 2 days ago.

Good Morning. I'd like to begin by introducing you to the man who has been my partner in the post-polio experience for the past 12 years. Dr. Fred Maynard is my physician. He is the one who had to give me the desolate news in 1984 that I had post-polio syndrome and that there was no cure. Five years ago he faithfully saw me through the onslaught of a broken leg and 9 months of careful rehabilitation. He also dragged me through the transition from walking full time to using a wheelchair more often. But even more important, he taught me over the years that health means balance in my daily life and that my own creativity and flexibility were the two qualities that would help me achieve balance and wellness. His openness to new ideas - especially my ideas, along with his ingenuity and his compassion as my partner in wellness have made him the most influential person in my post-polio healing and growing process. I have asked Dr. Maynard to take part in my presentation this morning because as my physician-partner, his contribution to what I want to share with you is natural, essential and pertinent.

The title of our presentation today is "Let's Sleep With Our Nightmares and Follow Our Dreams." Living with polio for 40, 50, or 60 plus years has filled each of our lives with a generous supply of both nightmares and dreams. I believe that from time to time it is important for us to reflect on our very private nightmares and dreams, if we are to live an abundant and healthful life in the years ahead. As we take time consider this dual challenge today, thinking about following our dreams or being led by our hopes is one thing. We've been doing that successfully for years, but sleeping with an array of nightmares - now that is quite another thing! How could I suggest such a thing? Well, let's stop and contemplate. Maybe I shouldn't ask, but have you ever slept with a nightmare? Well, I'll tell you a secret, I've slept with a few horrible nightmares during the course of my adult life and I highly recommend it. It can be liberating, rejuvenating and VERY good for your mental health!

In order for you to more clearly understand what I'm trying to say, I'd like to share a children's story with

you. You probably know it. It's called *There's a Nightmare in my Closet* by Mercer Mayer... (*LincsPPN Note. Sonny then showed slides of the different pages*)

"There used to be a nightmare in my closet.
Before going to sleep,
I always closed the closet door.
I was even afraid to turn around and look.
When I was safe in bed, I'd peek...
sometimes.
One night I decided to get rid of my nightmare once and for all.
As soon as the room was dark, I heard him creeping toward me.
Quickly I turned on the light and caught him sitting at the foot of my bed.
"Go away, Nightmare, or I'll shoot you." I said.
I shot him anyway.

My nightmare began to cry.
I was mad ...
but not too mad.
"Nightmare, be quiet or you'll wake mommy and daddy," I said.
He wouldn't stop crying so I took him by the hand
and tucked him in bed
and closed the closet door.
I suppose there's another nightmare in my closet,
but my bed's not big enough for three."

The late effects of polio started for me about 15 years ago. It was at that time that the monster that I called polio came out of my heart's closet and scared me half to death. All my life I had been running away from the nightmare. I was living in spite of my polio, not with my polio. As I was growing up with my nightmare monster called polio, my mom would tell me I was a normal girl who just walked a little slower than everyone else. She also told me that a wheelchair was not acceptable in our house. A wheelchair would make me feel sick and I was not sick. I remember as a 4-year old the unique stench of hot wet wool in the hospital those Sister Kenny hot packs. I remember the fear and pain when a nurses aid accidentally scalded my leg with one of those hot packs and I had to lie limp and take it because I couldn't jump away. I was completely helpless as [a] paralysed little girl under her outreached arms. I remember being accidentally dropped off a stretcher into a huge tank of water by the therapists and almost drowning at the age of five. I didn't want to swim again until I was in high school. I remember complex orthopedic surgeries when I was 7 ... when I was 11, 12, 13 and 14. Bedpan after bedpan after bedpan - cold, white enamel. Black cat gut stitches in my leg skin. Ether that made me vomit over and over. Mom and dad walking away leaving me to lie there in the bed sheets by the window week after week after week. They bought their first car so they could come and see me across the city. But I couldn't go home with them. They just left me there every time. I remember being trapped in the prison of those old inner city hospital buildings. And I had to take it. Rooms with white walls ... metal frame beds with side rails that were arbitrarily clanked up around me ... windows that looked out onto brown brick walls. I remember the hospital sound of long lonely boat whistles on the Detroit River as I lie awake gazing from my bed through the screen window into the dingy inner city night. I remember a little girl in the bed next to me who had been burned from head to toe. She was in agony. She screamed in such pain. A little boy had set her on fire as she was swinging at the playground. I never saw her face. I remember the creamy complected teenage girl with long shiny black hair who was forced to lie in the bed next to me stuffed into a hot, unmoveable, itching full body plaster cast all summer long.

In a book by Tony Gould, the voices of other children and adults with polio herald their old monsters:

Jean remembers her experience as an 11 year old girl: "I was put in a bed on the second floor. A nurse came in and gave me a plate with spaghetti on it, and I was totally paralysed, except I could move my right hand and my left foot. And I could breathe all right. She said, 'We're not going to coddle you here. You'll have to eat your dinner. And I couldn't reach it. There was no way I could even get one strand of that spaghetti. I'll always remember that. And she came in and took it away.

As she grew into womanhood Jean describes another nightmare: "In this kind of culture - in most cultures - men like perfect women; they like their arms and legs to match. And that was quite a shock to me, because I still thought of myself as quite a catch! And yet I came out into a culture which gave me much more resistance. Right away, you knew where you stood with men and it was just devastating. I mean; it was terrible. And nobody ever talked to me about it, nobody ever said, 'this is what you should expect.'

Lennie who got polio in 1944 mentions the hot pool therapy he enjoyed but the salt tablets he had to take: "Even today, more than four decades later, I still shiver at the mere thought of those salt tablets. Sometimes the hospital orderly would literally have to pry my mouth open to force me to swallow them. I dreaded the nausea that the taste of salt inspired in me." He goes on to describe getting his first pair of double long-leg braces with a pelvic band: "At first, all I could feel, as I stood hanging like dead meat on the shoulders of John the Barber and Charley the Bracemaker, was a sudden surge of new consciousness, frozen for a moment, in a dark corner of my terror. The legs are dead, it whimpered, boring into some quiet alley of my twelve-year -old mind." In many ways, we were American children who suffered atrocities like concentration camp victims in the 1940s and 1950s.

That was during the first half of our lives. I recovered, went to college, taught high school English for 10 years and began to work on my Masters degree. Then, As a woman with the late effects of polio 30 years later in the mid - 1980s, with new pain, weakness and fatigue. I was reluctantly forced to return to a hospital building to see Dr. Maynard. I had to smell the old smells, witness the therapists and nurses and watch the sick people who were lined up in the hallways in wheelchairs waiting for their next treatment. I was compelled to face those old fears and nightmares of childhood. It was totally horrifying. I was told to use a wheelchair. God no! I was told swimming was the best exercise for me. How ironic! I was told that I had some fine skills to offer to other polio survivors, but I would have to come to the hospital building to work everyday and interact with the nurses aids and therapists. I had to return to my old prison. The thought was repulsive. But my whispering intuition told me I needed to do this ... that it was time to reframe my old memories from the vantage point of a reasonable adult. Old nightmares needed to be yanked out of the closet and intimately embraced. And as many of us continue to experience the late effects of polio there are a variety of new fears breeding ... I sometimes worry what will happen to me in five years? Ten years? Will I have to use a wheelchair full time? Will my right hand go dead from carpal tunnel syndrome? Will I develop sleep apnea? What horrible thoughts. But acknowledging these nightmares is my own calling to wholeness. It's me embracing all that I am and claiming it. I'm not running away anymore. Our fears are real parts of us that grow when we ignore them too much. I remember Dr. Maynard saying that it is important to acknowledge the fears and nightmares, but not get stuck in them! So I need to take time to pay attention to the monsters in my closet. Sometimes in my mind I take one nightmare out separately or in little pieces and set it beside me and I sit very still with it and I observe the creature in detail and see what it looks like, sounds like, even smells like.

I say to the nightmare, "Who are you?
Get closer and show your face!

Let me see where you came from! What gives you life? What's your name?

I think I'll call you Sherman!

What are you doing?

Are you a real fear or are you FEAR - false evidence appearing real?

Now that we're out of the closet and the room is bigger

I see you more clearly in the light.

Look! You're getting smaller

because you are simply a minor part of my whole life and I see that.

I can live with you!

You can't kill me! Sherman, you're like a tiny bug on the wall.

You can't destroy my happiness!

You're just another part of my life's tapestry and I can live with you.

When I really took a look like that at some of my nightmares I even saw for the first time many of their positive qualities and characteristics that I hadn't noticed as a child. Making friends with our past and current fears can help free us to pursue our dreams for the future. I remember 10 years ago, when I was going to my first GINI conference. I was petrified because I had never been with a large group of people with disabilities. I had spent my time running away from such encounters. As a teenager and young adult I would literally cross the street to avoid a person who used a wheelchair because I didn't want to be associated with the group in our culture called handicapped. I practically threw a friend out of my apartment one day when she suggested that I might want a job working with people with disabilities. But on a warm weekend in May in St. Louis, Missouri, I made myself leap braces and crutches first into that horrifying situation - a hotel full of polio survivors. After 2 days with hundreds of people who were like me in many ways and unlike me sometimes, I was calmer and saw things in a completely new light. Embracing this embarrassing fear offered me a huge freedom. I don't race to avoid myself and people like me. I have a choice to join in if I choose. And love it, if I choose! It's part of that coming to wholeness.

If we aren't wasting our time being haunted or scared by old nightmares, we can move on to the good stuff in life. We can put the negative behind us or at least next to us and we can say "we've been there, done that and now we're movin' on", at least for the time being. What are some of your fears? I bet we all have a few left in there. The nightmare of a doctor's examining table ... the threat of being abandoned ... having to wear a brace? What scares you? I'd like to invite you to use this conference as an opportunity to talk about and confront a nightmare or two. **Do what scares you!** Learn to manage those pesky nightmares! It can be done. It has been done! As Daniel C. Steere has said, "Life is very manageable. It is intended to be. Life is exciting and positive and rewarding. Life is the most marvellous tool God has created for you. Everything on earth has been put here at our disposal. God intends for you to use life. He wants you to take advantage of all the things he has put here, and to use them as resources and opportunities.

We have a wonderful array of resource speakers here who will give us new insights from their learned perspectives. Dr. Leslie will share information on fatigue and post-polio, Roberta Todd will discuss adaptations and innovations for easier living, Dr. Alba wants to share her expertise on breathing and sleeping well with you. That's just to name a few! We have an opportunity to discover the most recent knowledge in the post-polio field and then think about how to apply it. Dr. Maynard will discuss his paradigm called the life-course perspective¹ in his presentation tomorrow. His very relevant frame of reference shows us that we have always been adapters with our polio disabilities and we continue along that path even now as we grow older with polio's effects. Life is a never-ending series of adjustments and our highest priority must be to be flexible and adaptive. Adapting is one of the things we do best!

This month I turned 50 years old. This birthday for me has been a reflective one. I have grieved over past

omissions and felt pride in many of my achievements. I thought about life before polio, after polio in my childhood and teenage years, and life with the late effects as I mature. I reflected on being part of the polio survivor population in America. I reflected on how some so-called scholars have referred to us as medical dinosaurs. I'm concerned about how so many physicians and therapists are inadequately applying the post-polio information that now exists in the literature. Because they can't seem to apply it, many polio survivors are still saying that they cannot find physicians that really know how to help. We still feel abandoned and isolated especially in many doctor's offices. I thought about the important legacy we will leave behind us that will forward all civilized societies - we started the disability rights movement opening doorways for moving and living more freely in the world, we are participating in medical research that will help generations to come, as polio patients we have been the catalysts for huge developments in the field of medical rehabilitation. We have provided many success stories for our parents, employers, physicians, teachers and clergy to tell.

I know that as I commence into the next 50 years of my life, it is my personal vision for the future that will direct me. What dreams do I want to work toward and follow now? What dreams are leading you along your way? I want to flourish in the years ahead! I want to feel economically comfortable and to be very mobile - no matter what that looks like. I want to contribute to my society and make a positive difference in the world. I want to love and help people. I want to be physically and emotionally close to bright, loving people. I want my friends to want to be close to me. I want to do the things I choose. I want to do the things that scare me and feel more free than ever. I want to be pain-free and to stay clever and creative enough to figure out how to get things done during the day - successfully. I hope to stay connected to a large number of resources - people and things. It was great to travel to India, Europe and New Zealand to teach about polio. I want to always feel that life is an adventure and that there is more excitement just around the corner. It was a proud moment when I quit smoking 8 years ago. I want to know more about what wellness is and how to incorporate it into my life. We are developing a program at the University of Michigan called "Wellness for Women with Polio: A Holistic Program Model." It is a research study to investigate what will help polio survivors optimize our health as we grow older with our disability. I want to live in a constant state of wellness. I want the personal power to grapple with difficulties and fears and know that I will come out a winner. But most of all I want to stay optimistic. I want enthusiasm and hope to be my minute-by-minute companions.

How about you? What are your dreams for the future? Have you any new ones? To accomplish and important task? To be a great grandmother? To travel to Alaska or South America? Have you written them down?

We're not done yet. We're never done. Each of our personal stories continue. How we play our story out is our choice and our responsibility. I say bring on the next monster! We know struggle and we know victory. We have created new knowledge about polio's late effects, when there was none 15 years ago, and merged it with established medical facts. Professionals have now heard of post-polio syndrome. Look around. We have created networks of caring friends and helping professionals. We have individually developed new adaptive skills and techniques in the past and know how to do that. We draw from the wisdom our past generously offers. We also leave behind the outdated and the useless. There is hope and there is help. We are smarter and wiser now than ever before. Remember that last line in our Mercer Mayer story?

"I suppose there's another nightmare in my closet,

but my bed's not big enough for three."

Look what Mercer Mayer shows us at the end of his story

"There is always another nightmare to befriend, another fear to diminish."

I believe that we actually have the power to turn our monsters into genies and to help others based on our important polio experiences. Good things are waiting for us behind the next door.

Let's sleep with our nightmares and follow our dreams.

¹ *The complete text Dr. Maynard's article "[Managing the Late Effects of Polio from a Life-Course Perspective](#)", Ann NY Acad Sci 1995, can be found in our [Lincolnshire Post-Polio Library](#).*

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