



*“United In Pursuit Of Living And Helping Others”*

On May 2<sup>nd</sup> 2013, Ben Thomas gave a presentation at Stony Brook's Annual Neuroscience Conference. In attendance were 170 neurology specialists, doctors and nurses. Ben spoke not only as our co-founder but also as a stroke survivor. He gave a moving account of what it means to come to terms with this new life and the need for the medical profession to see itself through the eyes of stroke survivors. Only in this way can we evolve a seamless coordination between acute (hospital) care, rehab and other stroke support groups like Stroke Life Society.

***Here is what he shared:***

Welcome, my name is Ben Thomas. I am a very grateful stroke survivor with a good story to tell! First, I would like to express my appreciation for the opportunity to speak here today about my transformational journey. Hopefully, our experiences will enable you to briefly look at your own world through our eyes.

In the end, Hemingway once wrote, life humbles all of us. 14 years ago I was humbled by a hemorrhagic stroke at the height of my powers with a young family and a busy career in bank finance. Bewildered, scared and unable to fully comprehend what had happened, I felt so.... broken.... so lost. My mother gave me a stone with an embedded compass to help me find my way home and so after my hospitalization I plunged into a protracted rehabilitation regimen that ultimately included hundred's of physical and occupational therapies, Botox injections, biofeedback, trials with FES devices (Walk Aid, Bioness) for my dropped foot and numerous short leg braces including the "dreaded" symbolic cane.

*But in the end* I was left with several cognitive impairments and significant right sided deficits. Unable to accept my fate I soaked in depression while my anger and frustration mounted to find myself, always feeling that I was "outside looking in" as the world passed by me. I felt increasingly irrelevant and isolated despite the constancy of my family and a loving support system. Not even loved ones could truly relate to how I felt inside!

John Lennon once wrote "that life is what happens to you when you are making plans"

So now this was my life to live with its new "normalcy" and I had to redefine myself. Always a history buff I read everything I could get my hands on and tried to find anything that would make me laugh (fun is good!) and yet still I felt emotionally and physically trapped.

Seeking others who had walked in my shoes I joined a small stroke support group at LIJ (New Hyde Park) and quickly felt "connected" with the comfort of expressing my inner self openly to others who intuitively understood. Our insightful nurse stroke support leader ( Rose Gonzaga-Camfield) impressed upon us the overriding importance of the human spirit in treating the whole person with the simple but powerful advice to "always keep moving"..and never, never quit!

Maybe, Albert Camu was right when he said "that in the depth of my winter I began to realize that what lay within me was the invincible summer".

I slowly began to discover a serenity in sharing and a joyful purpose in helping others who had suffered the same fate. This transcendental spiritual shift pushed me beyond the drag of my

physical impairments to a level where even my cane didn't irritate me. In fact it became almost magical in its effect on others! People jumped out my way, doors opened, better restaurant tables, and I could cut through pedestrian traffic with ease (with a strategic tap or two). More importantly I began to realize how easy it could be to release the laughter trapped in others.

Several years ago while walking up a hill in New Hope (PA) I noticed an elderly woman with a blank expression coming down walking slowly with her ornate jewel encrusted wooden cane. As we passed each other I raised my cane (sword like) and said "en garde". She quickly raised hers and started dueling me but with the high ground advantage and after a few moments we both laughed and continued on own way but I learned a subtle lesson that would help me in the future.

In September, 2010 I co- founded with Darleen Schauder, the Stroke Life Society to be a grassroots community driven organization run by stroke survivors dedicated to providing unconditional support services to both survivors and co-survivors within a "safe haven " environment to humanize the face of stroke enabling all to laugh, share, make friends, help others and to eventually regain a spiritual footing in their own rebirth to live happy and productive lives once again able to view the world by "looking inside out".

We started our support meetings in a space provided by St. Bernard's church in Levittown in September, 2010 within a format that nurtured our relatable connection, encouraged expression through the sharing of fears, leaning on commonality, gaining realistic feedback and knowledge, always ending with a round of inspirational stones or story starters (prop).

Our support meetings remain a bedrock activity within Stroke Life that has grown considerably as our outreach programs have expanded.

- Response in the stroke community so encouraging. Next Wednesday will be our 170th meeting of the Stroke Life Society!
- We now have monthly meetings in 10 locations from Queens to Suffolk.
- 183 survivors (and co-survivors & angels) registered as members of which 115 belong to a member contact directory available to all.
- 276 people have attended our meetings since August, 2011 of which 35% were non-members (guest speakers, observers, etc). We average 12-19 people per meeting.
- Implemented a monthly guest speaker program in September, 2012 to provide an educational forum on stroke related topics (risks, aphasia, rehab, wellness strategies, etc) presented by specialists including medical experts. Proven very popular (25-30) attendees.
- Established a comprehensive, interactive website ( [www.strokelife.org](http://www.strokelife.org)) with informative segments including "Ask the Specialist" with answers to questions posted by neurologists and other specialists (up to 23), membership signup access, meeting schedules, upcoming/past events, member's stories. Our website has attracted high levels of national (Dr. Oz) /global interest (India, Ecuador), including a multitude of support inquires.
- All Members are kept in the loop of periodic updates (events, news, new members, etc) via email communication software.
- Implemented an online bi-monthly colorful happy newsletter especially for those unable to attend meetings featuring individual survivor spotlight stories, inspirational writings/quotes, educational/new updates.
- Implemented a number ongoing of very popular social and fundraising activities including fishing trips, comedy clubs, beach/park walks with member involvement.

- Established a Recycled Medical Equipment and Supplies Program that to date has received 489 pieces (wheelchairs, walkers, canes, scooters, etc) of which 331 pieces have been donated to those in need.
- Established working partnerships with several Hospitals (LIJ New Hyde Park, LIJ Plainview, Stony Brook Medical Center) to jointly setup/run stroke support group meetings.
- Stroke Life Society was incorporated in May, 2011, received its 501(c)3 status in February, 2012 and is registered with the New York State Charities Bureau.

In 2 1/2 years we had come a long way thanks to the unfettered generosity of those willing to help us (our angels) and the survivors and co-survivors whose fortitude, mutual advocacy, love of life and shared compassion underscored what Winston Churchill wrote so long ago "that success is not final, failure is not fatal but what matters is the courage to continue" and Eleanor Roosevelt's insightful quote "that you can only be inferior with your consent".

All of us learned so much from each other's experiences on so many different levels but I wanted to share with you the more important:

1. **HOPE** For if you have hope all else is possible. Whenever there is hope there is life! The presence of hope throughout the recovery process and beyond is crucial to ones physical, emotional and spiritual recovery. Especially after post stroke rehab, where depression, isolation, loss of self-esteem and friends is common. A patient's sense of hope needs to be encouraged with sensitivity for it will energize the recovery process and the ultimately the quality of life for survivors and co-survivors far beyond the lingering deficits of stroke

2. Recovery is not ratable but relative to the individual nor is it limited to a specific arbitrary timeframe. Just Imagine seeing what I have seen over the several years: those with aphasia speaking long after it was thought impossible (Angela, Cynthia), shaking hands with those with severe arm impairments and watching them haul in 25 lb bluefish (Sandy/ Lou), seeing the wheel chair confined walk and catch the "pool" fish (Denis), beach walking with those with great difficulty ambulating. They never give up nor should anyone else!

3. Stroke support groups should be more seamlessly integrated into patient discharge protocols to bridge the gap between acute treatment/post stroke rehab and "rehab" for living productive lives (support groups) (Stony Brook - Eileen Conlon - brochures, etc)

Unfettered hope powers the survivors to the limits of his or her recovery whenever that may occur lifting the spirit to begin living life anew.

In the end I have become a passionate advocate for stroke survivors regaining a renewed sense for living. I came to learn that my stroke was not the watershed event in my life but it was my recovery that unlocked the possibilities in my life well beyond my physical limits.

Abraham Lincoln once said that "people are as happy as they make up their minds to me"

I made up my mind to be happy! By refining my life's purpose I had found my "invincible summer" and having done so I was finally able to find my way home!

It is my hope that you have gained a greater sense of understanding regarding the emotional struggles confronted by stroke survivors in finding a renewed sense of purpose and what can be done to help them!

For as one survivor once wrote: *"there is no hiding in the darkness. No anger and no pain. The outside may be different but inside I am the same"*.

Best illustrated by a touching anonymous poem:

### **Cranky Old Man**

What do you see nurses? . . . . .What do you see?  
What are you thinking . . . when you're looking at me?  
A cranky old man, . . . . .not very wise,  
Uncertain of habit . . . . . with faraway eyes?  
Who dribbles his food . . . . . and makes no reply.  
When you say in a loud voice . . 'I do wish you'd try!'  
Who seems not to notice . . .the things that you do.  
And forever is losing . . . . . A sock or shoe?  
Who, resisting or not . . . . . lets you do as you will,  
With bathing and feeding . . . .The long day to fill?  
Is that what you're thinking?. Is that what you see?  
Then open your eyes, nurse .you're not looking at me.  
I'll tell you who I am . . . . . As I sit here so still,  
As I do at your bidding, . . . . . as I eat at your will.  
I'm a small child of Ten . .with a father and mother,  
Brothers and sisters . . . . . who love one another  
A young boy of Sixteen . . . . . with wings on his feet  
Dreaming that soon now . . . . . a lover he'll meet.  
A groom soon at Twenty . . . . .my heart gives a leap.  
Remembering, the vows . . . .that I promised to keep.  
At Twenty-Five, now . . . . .I have young of my own.  
Who need me to guide . . . . And a secure happy home.  
A man of Thirty . . . . . My young now grown fast,  
Bound to each other . . . . With ties that should last.  
At Forty, my young sons . . .have grown and are gone,  
But my woman is beside me . . to see I don't mourn.  
At Fifty, once more, . . .Babies play 'round my knee,  
Again, we know children . . . . My loved one and me.  
Dark days are upon me . . . . My wife is now dead.  
I look at the future . . . . . I shudder with dread.  
For my young are all rearing . . . . young of their own.  
And I think of the years . . . . And the love that I've known.  
I'm now an old man . . . . . and nature is cruel.  
It's jest to make old age . . . . . look like a fool.  
The body, it crumbles . . . . . grace and vigour, depart.  
There is now a stone . . . . where I once had a heart.  
But inside this old carcass . A young man still dwells,  
And now and again . . . . . my battered heart swells  
I remember the joys . . . . . I remember the pain.  
And I'm loving and living . . . . . life over again.  
I think of the years, all too few . . . . gone too fast.  
And accept the stark fact . . . . that nothing can last.  
So open your eyes, people . . . . . open and see.  
Not a cranky old man .  
Look closer . . . . . see . . . . . ME!!

SLS members standup (introduce)

At this point we would love to entertain questions about our program or even recommendations or ideas to advance our cause!

Thank you!