

From: John Martinelli **Sent:** Thursday, August 25, 2005 11:04AM
Subject: TESTIMONY MEDICAID COMMISSION

FIGHT THE GOOD FIGHT

Next month I'll be 64 years old, 29 of those years have been as a Quadriplegic, it's a lifestyle, a mindset, like being born again, you can't explain it, you have to experience it.

No one can prepare you for this world of readjustments, so I'm not going to try, but if you walk away a little wiser, grateful, enlightened, Or not, if you are able to walk away your doing better than many.

This will be in steps, plateau's, stages, because it can not be understood or masticated in one sitting. It happened on October 9, 1976 in Lenox, Massachusetts. An unexpected storm, a gust of wind, a 40 foot Oak tree, yes, a 40 foot Oak tree sitting on this acre of land for 100 years, ordained

From the foundation of the world to fall on the Ford Falcon Station Wagon we were riding in. We had

Just pulled off the campus grounds, when the wind increased, then pain is what I remember mostly, a

Red tail light, Voices, grinding noises. I woke up sometime later at the Berkshire Medical Center, in

Pittsfield, Massachusetts. I opened my eyes to a pair of white shoes, my chin seated in a canvas sling

of a Stryker Frame. One friend died, one broken spinal cord, yet 6 yo Joey and his parents were ok, but

lets skip to my first awakening.....

I was told by my Mass Rehab Counselor (Massachusetts Rehabilitation Commission) that if I purchased

A new van, less than two years old, that they would do all the necessary adaptations needed so that I

Could drive from my wheelchair. I was still in the hospital so my wife went out to the local dealership and

Purchased a new 1976 Dodge Tradesmen 100 cargo van. \$5,200, but it was worth the investment to be

Able to drive. The bids went out, Target Industries, in Springfield, Massachusetts made plans to pick

The van up to start the modifications. It's never that easy is it? When you're in the front lines there's no

Book of rules, because in most cases you're writing the book and the rules as you go along. My Rehab

Counselor tells me that the modifications could not be made to my van because my wife purchased a

Cargo van with a standard transmission, and I couldn't kick in a clutch anymore. No one told us and we

didn't bother to ask. My wife did as I asked and purchased the least expensive van, not realizing that I

Couldn't drive a standard transmission anymore, I was a quadriplegic, like having Leprosy, or being an

Alcoholic at a 'AA' meeting, I'm John Martinelli, I'm a quadriplegic and that's the way it is or was. My

Wife returned the van but it was a used van now, it had a 150 miles on it, it had been registered and

Insured, and the trade in value was \$800.00 less than the purchase price. A new van with an automatic

transmission was another \$600.00. I was \$6,600 in debt and never left the hospital yet. This was my first

Milestone, I couldn't kick in a clutch, and the blue book for a used van with a 150 miles trade in value

was \$4,400, take it or leave it.

Shortly after my discharge from BMC I was admitted to the West Roxbury V/A Hospital Spinal Cord Unit

Because of chronic bladder infections. My time at home with my wife and family after being discharged

From Berkshire Medical Center was a disaster. My anger was vented at my wife and loved ones, so it was

The best. On a visit my daughter Lisa (6 yo) sat in my lap looked up and said, "daddy, I thank Jesus for you,

just because your paralyzed, I still love you." Lesson two, the love of a child is a wonderful thing.
A year of

recuperation I was admitted to Brockton V/A. My marriage ended in divorce, but was told that
over 60% of

previous relation-ships fail after such injuries. I spent the next 4 years in the Brockton V/A Spinal
Cord Unit.

During those years I did learn to drive my van from my wheelchair and I earned an Associates
Degree from

Massasoit Community College. About this time I learned my third lesson about life in the fast lane
of the disabled.

I had big plans, I was going to depart the life in the gilded cage of institutionalization and move
into the community

of independent living and I was going to help my friends get out into their own apartments also.
When I Told my

friends about my plans of deliverance they told me to mind my own Frigging business, just
because I wanted to live in

the community didn't mean that they did. They were very happy where they were. After that I
worried about John and

those who had similar goals. Shortly after I moved in with Carole and her son. We lived together
for several years, my wife to be

still was Director of Nursing at a local nursing home, I was working as a Independence Living
Counselor for a I/L Center. I was

assisting people with disabilities to move into the community, but there were many pitfalls and
short coming that I was not aware of,

And looking back to my years in Veteran's SCI Unit I could see why many choice the way they
did. Poor wages, unskilled or few workers.

Cost of living, no coverage or no one shows up because of weather, holidays, week ends or
illness. Lack of housing, medical setbacks,

lack of transportation, inaccessibility, but the forth lesson, by the government who claimed to want
to help, was hurtful, I didn't see it coming. A snake warns you, whether a bright Coral snake, or a
Rattlesnake makes you aware of danger, but not the Government of the United States of
America. They are lower than a snake, they are Assassins, Terrorist, Yes, Terrorist, they live with
you, work with you, eat with you. You trust them and all the time they hover like Vultures waiting
to eat your flesh, but Vultures wait till your dead, the IRS eats your flesh while your

still alive, they like the warm blood, the pleading, the begging. User Friendly. Ha.

Did you know that Social Security Income Disability Checks are Taxable Income ?

I remarried in June, of 1989 sometime in November of 1992 we received notice from IRS that back taxes for '89,'90,'91, + Penalties and Interests for those years. I explained That we filed jointly and paid all taxes. They explained that since I remarried my SSDI Check assets where taxable for those years. I asked could they "Forgive" the Penalties And Interests for those years and I would pay the out standing balance ? The answer Was "No" Could they "Forgive" the Penalties and Interests while I was paying them The \$200.00 monthly fees that we agreed upon ? Again "No" was their reply. They Froze my daughter's checking account and Took all my daughter's college money Because my daughter had me as next of kin. The IRS never told her so when her College check bounced she called to tell me. After awhile the monies were refunded To my daughter, With the help of Senator John Chaffee and his aide Don Senate. I worked, they took away my Medicaid. I had to pay \$10,000 Out-Of-Pocket because I Became ill shortly after they discontinued Medicaid Services and only had Medicare Part A.....Hospitalization.

The years in the Veterans Hospital I didn't need my Medicare Part B so I discontinued The service. Years later when I needed to continue the Part B services the Punishment For having discontinued the services was calibrated times the months absent into the Part B monthly fees = My new Medicare Part B Fees are \$210.00 a month. That is a fixed Fee forever. Ordinarily my Medicare Part B fees would have been \$76.00 a month.

I became very depressed and was admitted to an Observation Unit at Brockton. It was a Locked ward and whenever we left the unit it was in small groups with male orderlies.

Haldol, the 'Liquid Nightstick' the drug that got your attention, was used when all else failed.

I was regulated with a anti-depression medication after several months I was discharged. I worked

As a consultant regarding public transportation. Contracted out for Bids to develop of Transportation

Booklet, I thought it would be easy money, but it was very stressful work. I was pleased with the results.

The Department of Human Services would call me in monthly to audit my income and Out-Of-Pocket

Work Related Expenses and my Out-Of-Pocket Medical Deductions. What I believed were legitimate

Deductions my young DHS Counselor didn't. It became a battle over every expense, It was costing me

Losses of \$500.00 a month to try to work. My emotional and physical health were effected to the point that

Terminating all Gainful Employment was my only option. I sit and watch 80 year old Bob Barker and the

Price is Right, and me at 64 years old I'm retired.

Sincerely;

John Martinelli