



“It Could Be Worse”

Taking Charge of The Situation Before It Becomes A Situation

Raffaella, Age 5, was about to attend her first week in kindergarten. She was a lovely energetic, playful and animated child, the oldest of two siblings, dark hair and with deep green eyes. She was also the darkest complected of the brood. Something that worried her family as they had just moved into an established neighborhood of blue eyed, blond hair, fair complected well-dressed families. She reminded her father to place her name tag squarely above her left blazer pocket as she walked across the street into the school yard.

Raffaella, could not be any prouder to have been named after her paternal Grandmother. An unusual name to say the least, let alone an unusual spelling of traditional old-world Italian heritage. What was further unusual, unlike her younger brother, was that she had not given a middle name.

Her teacher struggled with pronouncing her first name and while the children laughed and chuckled the embarrassed teacher was astonished hearing how different-looking child requested the teacher pronounce her unusual name correctly. The child actually used the word “please”. As the day went on, whether being hailed by an adult or other children, she was quick to respectfully request that she be called by her full name rather than a shortened version of her name (Rae, Ella, Raffi). Her typical response, same as her request to her teacher:

**“Would you please be kind enough to know me as
Raffaella, (Rah-Fee-Ella) I know it’s unusual, but so am I.”**

During the first parent-teacher conference, her father chuckled at hearing her teacher recant the way she felt so at ease being corrected by a new little girl in her class. The teacher felt as though she was speaking to an adult and was so touched, she researched the name to find its origin: Hebrew: Raffaella as a girl's name is a variant of Raphaela (Hebrew), and the meaning of Raffaella is "God heals". The proud father left the conference hearing those words often in his memory. That same evening during dinner he asked Raffaella if she gets upset when the other children mess up the pronunciation of her name or call her a nickname....and her quick response was

“No Daddy, it could be worse, what if they could not remember me”

She went on further noting that most all the other children in the school were very pale skin, all with blond and red hair compared to her olive complexion and dark hair. Her father asked what did she feel about that....she was quick to respond.

“It’s easier to remember everyone when we are not the same”

As he felt it was a clever answer, he did not pursue her thoughts further. Raffaella had been raised by her “Mr. Mom” father and Grandmother, to whom she was named. Her earliest years was sitting in the grandmothers home-beauty shop chatting with mostly grey-haired, wheelchair



bound, ladies with walkers and oxygen machines coming for their weekly appointments. She quickly learned adult forms of communication. She loved most hearing stories about the lady's life stories, the home-land from her immigrant Grandparents or Bedtime stories about Angels who whispered in the ears of children as to why they were each special in their own way. Every evening the stories created by her father, were the last words she heard as she was lulled to sleep.

Raffaella's school years were not unusual, her intellectual capacities grew beyond expectations and with each new friend she was always quick to stand her ground proudly introducing herself formally and always so very interested in listening into others conversations. A curious-child to say the least. Her friendships were many and as those friends introduced her to another new friend, they would often say "This Is My Friend Raffaella, she does not have a nickname."

At Age Nine, Raffaella began to have physical muscular difficulties as it was obvious that her body was not growing in the typical leaps and bounds at that age, mostly attributed to her petite stature.that is... until she passed out while suffering a stroke in her father's arms and soon diagnosed with a very rare disease called "MELAS" (Mitochondrial encephalomyopathy, lactic acidosis and stroke-like episodes.

So rare a genetic disorder that only 9 people in the country were suffering with such a syndrome. Raffaella was hospitalized for quite some time, missing school, and eventually bed ridden at home. Her plight was set forth when it was explained that the reason, she had the stroke was that her body was now becoming that of a teenager requiring more energy and her genetic makeup did not have the ability to transform energy from the food she ate into energy needed by her cells. First her brain cells would starve for energy, hence strokes; Next her muscular system would fail and she would experience extreme fatigue, hence Lactic acidosis; eventually all body systems would suffer.

MELAS had left Raffaella with 30% of her brain calcified. She was told that there was no cure, and no medicine available and that she was in fact terminal.

She could not speak, hold a spoon to eat, nor hold herself up without assistance. Therapy began, she astonished the medical profession how quickly she was able to re-teach herself to speak, to hold a spoon, etc. When asked about her plight, she would always answer the medical professionals....

"It could be worse, what if I did not know how to fix myself."

The medical world offered the idea to create a drug on a trial basis to give her the opportunity to at least prolong her life as best she could. Her answer to their offer was

"Why Not, I don't mind being first!"

but insisted that she be allowed to get back to school,



School was now a very different experience than either Raffaela or her father could ever imagine. Her father would give her IV medicines in a van during lunch and then back into class. Now being in a wheelchair, and having difficulty to speak, etc....even though her classmates knew of her medical tribulations, Raffaela found her old friends starting to shy away from her and not asking her to join in with their conversations.

Her father offered her the thought that she knew how to speak to the ladies in the beauty parlour....so nothing has changed other than her role. The very next Monday at school, the teacher overheard Raffaela's conversation with two of her girlfriends. They asked her if she was sad and if she was in pain.

“You know, it’s a pain for others to help me, but it could be worse...what if you were in this chair and I was you....what if I could not ask for help.

First there was silence, then she continued to say:

Can I ask you guys for something? Would you let me be the best cheerleader of everything you are doing? When you think you can’t do something, look over at me and I will give you the wink, I will send you my energy, you can do it....I’ll show you how....don’t worry”

Raffaela had re-positioned herself not as the victim but as their secret weapon to success. Their lucky charm. And the girls did just that, before they would take a test, before they tried a basketball shot, before they tried their gymnastics,....they would look over at her. She would nod and wink. The children would hover around her as their own private “confidence” guru.

Months later, Raffaela suffered another stronger stroke, again losing her her abilities to speak, But this time around rehabbed herself faster while at a stay at Columbia Presbyterian Medical Center in New York City. This hospital trip presented Raffaela another moment to display her positive attitude towards her ongoing and eventually terminal situation.

As her father moved the wheelchair into the elevator on the 5th floor, he noticed Mr. Tom Cruise and Nicole Kidman coming down from another floor. He immediately said hello and motioned to his daughter, “Raffaela this couple is Tom Cruise and His Wife Nicole, do you know who they are?” Raffaela without hesitation reached out to shake their hands. Mr. Cruise was kind enough to introduce himself and his wife noting that they were in the hospital to see a nephew. Raffaela responded with:

It is very nice to meet you... You probably have heard of me, I am Raffaela, its OK if you don’t remember and don’t worry about your nephew, he will be just fine.

The couple had played their elevator star role part perfectly as our adult eyes met with surprise and thanks. Raffaela's father simply smiled and whispered “amazing and thank you” as the elevator door opened.

Now back home, having suffered more strokes Raffaela found that at times she would wake blind or not able to move off her bed. And as usual...her response to her father was ALWAYS

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“It Could Be Worse....what if you were not strong enough to pick me up or what if you could not tell me it was daylight”

The confidence with which Raffaella exhibited on a daily basis was astounding. She would offer nutrition advice to her fathers’ business associates

“ You Better Watch what you are eating gentleman...health first!”

She furthered her role as a confidant and confidence builder even to younger brother as he pursued his muscle building, athletics and music studies.

Year after Year, stroke by stroke she lost more and more physical and mental capacities, but never once complained of her plight. In fact, at age 14 she continued to take the 60 pills per day, which had to be manufactured by her Aunt Pharmacist as part of the experimental regime for MELAS. Yet even with taking so many medicines, that would be a painstaking effort by most, Raffaella would turn it into a game show...humorously speaking like the MC of a TV program,

“And now behind curtain number 3, DiCholorAcetate “

At Age 15, four young boys asked Raffaella to a school dance, OK...

“I promise, I will take it easy on all of you at the dance”.

She by her OWN ACCORD had become the guru of knowing positive thinking and spread the thought that being confident with loving actions can beat all odds. During her last hospital stay, she showed her father a story she has written for her girlfriends, labeled

“How to Go On Your First Date by Raffaella”

(Her premise was to have fun but demanding respect from the boy and never kiss on the first date...to see if he has guts to come back for a second date” It could not be said any better than by this old soul.

Raffaella Died a few days short of her 16h Birthday. On her death bed she whispered to her father...

“I see the Angels in the stories....are you going to be OK Dad”?

He answered:

“ of course my darling Raffaella...It could have been worse; I could have not known you....so it’s OK for you to go to your Angels”

The lights literally left her chest, hovered over her head for a moment, and then like a flash...flew towards the hospital window. Her father looked up to the family and of course....simply said:



“It Could Have Been Worse”

The Funeral procession, miles long eventually gave proof to those words as forever true, as over 1000 visitors signed the guest book, and each with their own little story as to how their lives and their confidence came from knowing Raffaella, and everyone of them pronounced the name of a terminally ill child perfectly.

Respectfully Submitted

Alfonso W. Nardi, AIA, NCARB