



CALIF

Communities Actively Living Independent & Free

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YOU AND I IN THIS TOGETHER!

Here we will share our stories, our tools, our services as we journey with disability and/or aging together.

I think that every day, we encounter things that we either enjoy or suffer from, because when broken down to basics, life is simple: it is either good or bad. Yes, there are many different shades and hues and many degrees of goodness and evil but the final categories in the overall valuation of life and its aspects are only two—good or bad. I understand that this had its genesis in the Biblical and proverbial references to the Tree of the knowledge of good and evil. This tension between good and evil is particularly pronounced in our lives as people with disabilities but depending on our life experiences, the focus differs.

As people with disabilities struggling with all the obstacles, we know that society still expects us to attain the most possible optimal functioning of the whole body-mind and spirit connection. So we aim for possible maximum ambulation, hearing, seeing, balance, grace and beauty in form. For years we have struggled to cope (and still are) until we gained the gumption and wisdom to conclude that the world, too, had to adjust to us as members of the human family. In the process, we founded the Disability Rights Movement and we dared define life in our own terms—insisting on participation in the public mainstream with an accessible environment we had a say in designing. “Nothing about us, without us!” we keep repeating as we valiantly wage the struggle for respect and humanity. We have produced incredible legal gains in securing our civil rights in all fields of society, enshrined in the Americans with Disabilities Act of 1990 and many other laws that came before and after. We have transformed the practice of professions and have caused the incredible production of an infinite number of services, assistive technology, computer technology, and networks that ensure our thriving and survival. As we continually encounter the invisible obstacles of discrimination, we aim harder for clarity, understanding, empathy, emotional integration and relevance, among many other things. But between us and the rest of humanity, our common experience is still suffering and what to make of it.

When I was five years old, I was due for surgery because polio had created contractures in my knees which needed to be straightened. The doctor also wanted to fit me with braces. One day I was in the therapy room and saw

this little baby crying his heart out, screaming for his mother who was waiting at the end of the table on which the baby was crawling. As soon as he reached his Mom, the Mom ran to the opposite side so that the baby could crawl the other direction and catch her. I was so sad for the baby and angry at the Mom. I thought that she and the doctor were intentionally being cruel to the baby. I could not understand why the baby needed to suffer that. As for myself, I struggled with my burdens too. I wanted to jump and run and climb trees like my siblings but I could not. And I dreaded the nights because they were times of torture. I had to sleep with a head halter pulled down by weights and a similar contraption for each of my legs both on straps on a pulley system pulled down by weights. I wore myself out crying and complaining about why I had to sleep that way. My whys were many and I was angry. So I sought for answers in my limited little world. Complaining got me what I needed sometimes but for the most part, I was censured and taught to just bear with it. Since children are resilient, I learned to live with things but each suffering still left me with a longing for answers.

So I looked at my environment—mostly it was not hospitable to my mobility needs and I was often left to wait in one place wondering about the life outside those walls. The white walls of the hospital were boring but it was those dismal walls that developed my love for art. Beautiful art that graced the walls brought me hours of entertainment and tremendous joy. The walls came alive to create for me many different stories from childhood imaginings. I also loved watching people and observing them taught me about the different personalities and the varied ways they reacted to me as a disabled child. My favorite part about watching people is watching them work—household tasks fascinated me. Washing dishes, cooking, doing laundry by the water pump demystified the secrets of a well-kept and efficient home and prepared me for adult life even if my folks would not allow me to do the work. Everything was a productive distraction to the painful and nagging whys.

And then, there were my grandmother's beads—the Catholic Rosary. The Rosary is a Catholic meditation tool made up of beads—reflecting the 20 different major episodes of the life of Jesus Christ: the Joyful, the Luminous, the Sorrowful and the Glorious. I mention them here as a real tool for my Grandmother's immense recovery from PTSD. My maternal Grandmother Placida Espinosa had a difficult life—she was orphaned at eight years old and raised by her sister who came down with Leprosy. She married early while she was in college and her husband was accidentally shot leaving her two young sons. When she married my Grandfather, the war broke out and they had to flee to the barrios to escape from the Japanese. When peace came, my grandmother was deserted by her husband and she was left to raise five children. She had the loving support of her extended family and in-laws but she suffered from extreme PTSD. She could not leave the house at all, not even for

short trips around town for errands. In the morning when the sun was bright and wanted to bathe the living room with light, she kept the windows shut and dark and would lay in bed until 10 AM. In the dark, she would whisper her prayers hanging on to her Rosary, reciting the Hail Mary fervently and devotedly every single day. That faithful routine was her source of mental health and she lived through every happy and tragic event of her life, always with equanimity, with grace and humor and truly formidable strength. As a teenager, I would ask to be brought to see her to spend a couple of days just to seek solace from the world. She lived an austere life but her home was a palace of peace, kindness and prayerfulness—every simple thing took on some importance to her, nothing was ever random. I'm sure, just like her, you will find your own tool and strategy for wellness.

For my Mom, it was self-care and quick thinking. Raising seven of us children could have been overwhelming as she went through a lot of other suffering. She solicited the emotional support of family and friends—my Dad was not always around and most of the problem solving fell on Mom's shoulders. Mom had no time to mope but she zeroed in on what was most essential—that first she was well so she could take care of us. She was and still is, a very beautiful woman and she had class. She was well put together—complete with make up and proper clothing and was never looking disheveled and untidy. She always smelled good too. Mom was also very orderly—she made sure we had everything in place and despite our economic struggles, there was still plenty to share which she promptly gave away. So we never had the problem of hoarding. Mom was also an efficiency expert—she ranked things according to importance and impact and worked on achieving them methodically. She had us engaged running the household and made us accountable. And then, she did exercise. When one engages in physical activities, it does wonders for the body and soul. So, from my wheelchair, I do moderate exercise, too and body massages four times a week does me wonders.

I think that with the many pathways to recovery, we just have to know what fits us in terms also of our culture and our capabilities and our faith. But which pathway do we take?

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