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An Encounter & Coping Up with a Rare Condition

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As Anne Frank once said '' If I haven't any talent for writing books or newspaper articles, well, then I can always write for myself'', I thought of penning down a lot from my personal experience, hoping to help others suffering from *'Isaac's Syndrome, A Rare Neurological Condition'*.

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An Encounter & Coping Up with a Rare Condition

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Introduction

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I am not, just a bed number (a real life fight against cure):

If you had told me a couple of years back, I wouldn't be writing this note, instead planning into the future. A part of me is surprised, as was all healthy & hearty, not on any peculiar medication & no known allergies except periodic diarrhea since a couple of months. There was no history of alcohol or any other substance abuse & completely believed that *true healthcare reform always starts in one's kitchen.*

As a senior executive in the Investment Banking space based out of Mumbai, my professional experience journey speaks in itself.

One of the evenings in Feb'16 during my walking session, got trapped into a severe pain in the Lumbar region & continuous cramps in right leg. The pain could be described as some sharp object stabbed at the lumbar extending till the femoral region which started alleviating & aggravating.

Next morning was tough as the pain still persisted & was accompanied with enough stiffness which made movement toilsome. Anyhow gathering all my muscle, I presented myself to a conventional Orthopedic who after a thorough investigation put me on drugs.

The post pain realization of diarrhea slowly denting the body had factored in. All of a sudden things took an evil turn & seeing my Gastroenterologist again seemed a wise decision.

My Gastroenterologist, a well known figure in Mumbai was surprised to see my CPK levels and immediately asked me to consult a Neurologist & get back to my hometown as he realized that soon a gig's world's was transforming into serious profiling.

It was inconceivable how I was bought directly to be hospitalized from the airport with no guess that my encounter with time had just started. The essential first step in managing the situation began with a detailed medical evaluation. One after the other, investigations started & the doctors decided to put me on the Steroid therapy for next 5 days as they diagnosed Polymyositis.

Polymyositis?? (A condition marked by inflammation and degeneration of skeletal muscle throughout the body).

Initially I had no idea about these medical terms and was even completely out of energy to put my head. Everything was just happening so fast……Post being in the hospital for a week I was advised to take up my further investigations in Bombay Hospital under a team of experts.

In March'16, I got under the lights with general examination, pricked everywhere in both my hands. There was presence of stiffness and excess weakness with spontaneous gross fasciculation in both the arms.

I was diagnosed with *Isaac Syndrome* even called *Neuromyotonia.* Some of the other tests showed traces of *Membranous Glomerulonephritis.*

Neuromyotonia (NMT), also known as Isaacs Syndrome, is a diverse condition with muscular hyperactivity, patients may present with muscle cramps, stiffness, myotonia-like symptoms (slow relaxation), myokymia (quivering of a muscle), fasciculations (muscle twitching), fatigue & exercise intolerance.

Membranous Glomerulonephritis is a slowly progressive disease of the kidney. It leads to changes and inflammation of the structures inside the kidney that helps filter wastes and fluids. The inflammation may lead to problems with the functionality.

The team of doctors decided on IVIg therapy injected intravenous, which is the use of a mixture of antibodies to treat a number of health conditions. Considering the tests (EMG, Pet-CT, MRI Lumber Spine, Sonography, Kidney biopsy etc...) & treatment, my stay at the hospital was almost for a month. Each passing day was a nightmare but my belief of no situation being hopeless and every circumstance in life can change if dealt with patience went stronger.

And finally the day arrived……..I was discharged from the hospital in April'16 with some

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medicines & a suggestion to consult another neurologist in Lucknow, if need be with a recommendation that there is no such thing as a fair flight & all vulnerabilities must be exploited.

I couldn't lie to myself, & started to laugh on the ambulance not realizing that feeling better was just a temporary phenomenon. Soon my health proved a tragic experience wrapped in bonkers, making me crawl through broken glass & within 3 months timeframe I was on my way to Lucknow.

As it's always said that no medicine or doctor has a strike rate of 100%, I could experience it happening in my case. The medicines denied integrating with my system. Diarrhea which was on a break for a while again took its full swing. Pain, Sugar, BP & all the other symptoms returned & my hopes of recovery showed signs of a day dream with open eyes.

Unexpectedly I was getting weaker. The situation seemed to have stagnated where I slept for almost 14 hrs daily due to weakness & pain in-spite of being on heavy medications with pain killers, immunosuppressive agents, blood pressure, intestine related medicines & steroids. The daily intake of medicines went as high as 38 with enough food restrictions due to shooting sugar levels, fluctuating blood pressure & diarrhea. I was bedridden till things stabilized when Dr. Panagariya & his team took me under their supervision in Jaipur @ Aug'16.

In Nov'16, I was again admitted for IVIg therapy, in Jaipur hospital which I did not respond to & had to be stopped midway.

I was asked to go to Mumbai again, this time to see a different set of specialists to know a little better, the difference between stories & realities. The trip came across as Phishing in my own backyard due to the suggestions varying rational expectations.

I was given some medicines with immunosuppressants & ask to continue it for some good two months.

In March'17 as my health didn't show favorable improvement, I was asked to take weekly shots of ACTH injection (It may work directly on the brain in addition to stimulating the adrenal glands. It may also be used in treatment of various other childhood seizures when other treatments have failed).

Quantum of Solace was short-lived and soon I realized that these changes don't happen in a jiffy. As treatments have limitations, it was time to see my mainstream allopath doctor who made some changes in the medicines & asked me to wait patiently for results to unwind.

Pain killers which were on sabbatical became a daily phenomenon again. I was admitted to Medanta Medicity @ Gurgaon for Plasmaferisis in Dec'17. Though I was taking the procedure light, it proved me wrong, each passing day as the central line which was inserted around the pelvic region, created issues with its inlet & was a nightmare till the last day of completion.

Post discharge it took me good 20 days to get a bit normal as there was enough weakness & usual pain at the back & thigh area, all medications being like before. The journey continuous……. I am focusing on the journey, not the destination. Therefore if you can't go back to your mother's womb, you'd better learn to be uncomfortable & fight back. To do otherwise is to settle.

➢ *My Experience, the hard way (Important section)*

1) The holy trinity between the doctor, you & the treatment becomes a dangerous Bermuda triangle when there is communication gap.
2) *Adopting to new aspects of treatment can contribute to healing:* Yoga, Meditation, Walking, Calmness of mind & body, Being positive.
3) Make proper synopsis before consulting any doctor (he needs to know it all, from medicines to various treatments to other doctors consulted to medical tests).
4) Changes in lifestyle can work wonders (eating, sleeping, drinking habits etc..).
5) Eating right is very important.
6) *Keep involved:* For mind distraction.
7) The self-management plan should be reviewed from time to time to ensure the advice remains current
8) Right body postures can help reduce pain.
9) *Avoid & try reducing dosage of pain killers from the physical longevity prerogative:* Try SRP (systematic reduction plan).
10) People on steroids & suffering from high sugar levels should maintain a *strict diet chart.*
11) *Enough water in-take with medicines*: Swallowing medicines without enough water may prevent the medicine from acting properly and may even lead to undesired side effects in some cases. One example is the class of drugs known as non-steroidal anti-inflammatory agents
12) *Eat less Sugar, you are sweet enough already:* For me the following helped in controlling my sweetness:

i. Bitter Gourd juice.
ii. Indian Gooseberry juice.
iii. Jamun fruit grounded seed – one spoon empty stomach.

13) Gluten free food might relieve symptoms.
14) *Family, a nature's masterpiece:* One of my biggest strengths & support function in this tedious war field was my Family. I never realized when it became 'Our' journey from 'My' journey.
15) *Health cover*: One of the most important aspects of my treatment as it provided me with financial security to peace of mind to coverage of specific

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medication & ailments to cashless hospitalization benefits.

16) At times, being smart, is even to know when to play dumb. Whenever, I sensed the treatment could cost a bomb, I connected with genuine distributors candidly rather than being on retailer's disposal or hinged onto the hospitals to walk me through.
17) Everyone is unique, so from a macro perspective what proves a relief for one might be a cause of pain for the other.

➢ *Answers Re-invented Daily*

"*The treatments themselves do not cure the condition; they simply restore the body's self-healing ability.*" *Alternative Medicine ~ Leon Chaitow.*

➢ *Coping with Body pain, one of the major symptoms*

For pain management, I have a piece of raw garlic early morning, my homeopathic medicines, magnetic acupressure along with my mainstream medicines.

Garlic supposedly has a bouquet of medicinal qualities with scientific evidence on anti- inflammatory responses and its ability to boost our immune system. To complement alternate therapies, I even worked hard on *SRP (systematic reduction plan)* by regular monitoring and reducing my daily dosage of immunosuppressant, pain killer, insulin and medicines in consultation with my doctor (from 38 pills a day to 18 now)

➢ *Some simple but important changes*

As it's said '*a charging bull always looks at the red cape and not at the man with the sword*', I decided early to keep my eyes stagnant on this armed man therefore agreed to make small miscellaneous changes by keeping surroundings green, paying attention to body postures, inculcating a self motivating attitude, wearing surgical mask while exposed to a crowded place, taking up a sport as a therapy, wearing loose clothes and sticking to a positive attitude.

➢ *Lose clothe, Body Message, Music Therapy& Magnetic Acupressure*

Tight clothes can cause nerve compression and I realized that wearing loozies made me feel lighter and relaxed.

I was advised to have mild *body massage* often which was effective to reduce my stress levels, helped in pain management, eased stiffness and improved my flexibility.

Music Therapy (a math to convalesce), is an effective tool which helps bridge gaps between emotional, spiritual and mental needs. I initially, focused on a variety of music engagements and zeroed down on customizing some to my palate.

Acupressure, a science that stimulates and influences the acu points in the body to balance the accurate flow of energy integrating with individual organs rather than co-coordinating with the entire system to generate results. It helped me reduce high sugar levels and back pain, leveled my BP and capped excess flow of protein from urine.

I never cared whether a therapy derived from some ancient medical literature or a test tube instead the safety, durability and its effect. It is very individualistic in nature.

On that note would like to suggest that - Thinking of disease constantly will intensify it. Feel always 'I am healthily in body and mind'. As Charlie Chaplin once said ''to truly laugh, you must be able to take your pain, and play with it''. Easy said than done but making an initiative would help.

The fact, you read this right till the end makes me feel: HEARD.

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