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Life After Diagnosis of ALS/MND – Soremathy's Story

Rosemarie Johnson BA, MA(Econ)
Gdip (Banking), GDip (Social Anthropology)

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***Corresponding author:** Rosemarie Johnson, BA, MA(Econ), Gdip (Banking), GDip (Social Anthropology), New Zealand.

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Abstract:

This is the story of Soremathy, and according to the official record, she is 67 years old on 30th of May 2024. But she really is 69 years old at present according to the real date of birth. This is because in the remote villages in India, prior to 1960's, predominantly with Hindu population, no one officially recorded date of births and deaths as it was done with the Christian and Jewish populations. The Hindu families followed astrology, planetary positions to make up a horoscope paper that will point to a certain date and time of a child's date of birth, which never equates to the 'normal' calendar that we follow in our daily life. So, when the time comes for admission to school, the parents and the relatives would provide this random date of births for the children and get them admitted into school. This practice was abolished post 1960's.

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Introduction

This is the story of Soremathy, and according to the official record, she is 67 years old on 30th of May 2024. But she really is 69 years old at present according to the real date of birth. This is because in the remote villages in India, prior to 1960's, predominantly with Hindu population, no one officially recorded date of births and deaths as it was done with the Christian and Jewish populations. The Hindu families followed astrology, planetary positions to make up a horoscope paper that will point to a certain date and time of a child's date of birth, which never equates to the 'normal' calendar that we follow in our daily life. So, when the time comes for admission to school, the parents and the relatives would provide this random date of births for the children and get them admitted into school. This practice was abolished post 1960's.

Soremathy has been diagnosed with ALS/MND in January 2024. She has planned to write this paper from the perspective of an ALS/MND patient and provide the behavioral changes and patterns as she sees and experiences them while this condition takes hold. So being an author and as the patient, she disguised her real name to an imaginary name as set out in the first paragraph above – Soremathy (S O R E M A T H Y)

However, Soremathy is an ordinary person like anyone, working full-time thinking of not retiring until 70. The reason for this was to continue working, save up some money, enroll herself in a New Zealand / foreign University and do a PhD being a full-fledged research student in the field of Social Anthropology, which she loved all throughout. However, all these dreams came crumbling down and crushed Soremathy once she was diagnosed with this debilitating condition. Sorematy was very well aware of her condition, which has no cure but will take hold and consume her in the end.

Sorematy was finding it extremely hard to perform any task or to focus / concentrate on anything that she loved doing due to extreme tiredness and anxiety. Brushing the teeth, making a cup of tea, showering and dressing etc., became huge tasks. At the end of each of those tasks, she was feeling as though she spent hours working out in a gym. When she was noticing these unusual, unexplainable conditions, she approached her general Practice (GP) doctor. Incidentally she also had lower back pain and at times unable to walk easily. This was treated somewhat successfully by the GP who was also an Osteopath in conjunction with a acupuncturist. But the other conditions remained without properly addressing. She continued struggling with the conditions that interrupted heavily her day-to-day activities. Subsequently, Sorematy started noticing her right hand thumb movement was getting affected. She couldn't flick her thumb in combination with the pointing finger. This condition interfered with wearing her bra, buttoning her dress etc. She also started noticing she couldn't grip anything with her right hand and finding difficulty in showering.

While Sorematy felt that she's not being taken serious by her regular GP, she approached another GP at the same practice and explained her conditions – numbness, lack of grip on her right hand, anxiety etc. She also said to the new GP that she is suspecting something wrong with her. Could it be one of the nerve degeneration issues – Lupus? Parkinson's decease? Alzheimer's? or even motor Neuron Disease (MND)? The doctor was flabbergasted - "What are you talking about? You are stretching your imagination too far, it could just be some nerve pinching and hence you are feeing the numbness in your right hand thumb and forefinger. It can easily be fixed.

At the insistence of Sorematy, the GP sent her to a 'hand specialist' in the nearby practice, who is a trained orthopedic surgeon. From the initial tests, the surgeon quite easily concluded that Sorematy has a condition more serious than just a case of nerve pinching and numbness. He sent her to the nearby town to get 'nerve conduction' tests, which measures the neuron-conductivity in the limbs. Subsequently, the surgeon sent Sorematy to get an MRI scan and Ultra-sound tests on the neck to rule out something serious as MND. But the results clearly pointed to the probability of MND from the twitching of the muscles throughout her body.

Quite rightly, the surgeon recommended her to get a referral from her GP to see a neurologist to do further tests to confirm if she has neuro-degenerative condition. While she was awaiting the neurologist's appointment Sorematy researched and read quite a lot of articles from the Ministry of Health websites of New Zealand, India, US, UK and Australia. She understood the many root-causes of MND in relation to the toxicity caused by the protein TDP43, SOD1 to motor neurons generated by the brain and the spinal cord. This resulting in the motor neurons getting weak and don't reach the muscles. The unused muscles over a period of time become wasted resulting in continuous twitching of the muscles and painful muscle cramps. These are exactly the symptoms that Sorematy was experiencing for a long time.

Sorematy finally got her appointment with a neurologist on the 4th January 2024 at the city's hospital. The neurologist conducted extensive tests for about 45 minutes. At the end of it, the diagnosis was that Sorematy probably has the MND and referred her to get Electro Myography tests. This was done not very long after. The reports concluded that Sorematy does have the ALS/MND. Though this diagnosis came as a bolt from the blue for both herself and her husband, they knew that's what it's going to be – since they have been closely following the symptoms, deterioration that were occurring and related to the results of the tests!

Apart from the physical deterioration, this article explores the mental status, behavioral patterns, frustrations, and irritations from the condition that Sorematy suffers from. Since the diagnosis in January '24, within 4 months pretty much most mobility has stopped for Sorematy.

Sorematy was quite aware of preserving and respecting the dignity of the patient by the carers. Well into 4 months after the diagnosis, Sorematy's mobility was declining quite fast. She needed elevated chair, for sitting, a specific stool in the shower, elevated toilet seat along with a frame to support and they were all provided by the local auspice organisation with the intervention of her GP. The walking frame and a manual wheelchair followed this. Not long after that, the 'mobility solutions' came up with a custom-made motorized wheelchair that she could operate with her head movement as her hands and fingers lost their functions!

As Sorematy's condition started declining further, her husband couldn't cope with the caring needs of her as he had a full-time job with the flexibility of working from home most times. With the cooking, cleaning and caring of Sorematy all became a bit too much at this stage. So they approached the GP for the needs assessor from the health department to visit them and tailor the care options. Though initially, they advised to send three different people for an hour a day each for showering and caring for Sorematy, they found it wasn't going to be conducive from dignity point of view. So they opted for 'individualised funding' model. This was agreed to be the department, they went ahead, advertised for appropriate caregivers, interviewed a few and selected a qualified young nurse. She would care for her 8 hours a day and 5 days a week. Her husband will manage the rest. This worked out ok, for a while.

Around this time, there was a fundraising event organized by the NMD Association of NZ in town, which Sorematy promptly attended. She met 7 other similar patients with varying degrees and type of declining conditions. Some had lost the voice totally and a few others couldn't move upper limbs much like her. This visit gave her the real perspective of how this decease affects different people differently.

Sorematy watched several documentaries and professional / scientific lectures on MND on YouTube and these sittings gave her the whole lot of understanding as to how this condition fatally manifests in patients. One particular documentary titled 'The Australian Story' certainly attracted her attention which detailed the story of Dr. Jason Yerbury who was personally affected by so many of his loved ones dying of MND. Jason also died of this condition while he was researching on finding a cure for this disease. While Jason's condition resulted from his hereditary line, Soremathy's wasn't. From what she understood from he MND specialist Dr. Alison Charston, there could be several contributing factors that need to be lined up like a ducks in a row to get this triggered.

Though she could do a blood test to reveal if it's hereditary, that will then affect her children knowing that will be one of the factors. So Soremathy refrained from getting that test, understandably! Other contributing factors in her case could have been – her low immunity levels from constant falling sick since young age, hyper thyroid, several head injuries, flu infections and Covid immunization etc.

In July that year (2024), her condition further declined and needed extended care. They approached the needs assessor again and could secure further funding for one more carer who would come in the evening and look after her, attend to her needs until she goes to bed.

From the behavioural domain perspective, as an MND patient, Soremathy observed that her inhibitions are vanishing. She became even more realistic, practical and pragmatic in her approach to anything. Her cognitive behaviour had improved quite a bit by this time. She also noticed that when her husband came up with spontaneous jokes, she would laugh uncontrollably which her husband felt that was unusual. She then would follow that with crying episodes. While consulting this with the specialist, it was revealed that Soremathy abruptly stopped the anti-anxiety medication, which would lead to this condition. She resumed the medication and the condition gradually disappeared.

Another aspect is that Soremathy has got good photographic memory. She remembered important dates in many of her relatives' lives, birthdays, events and occasions. This ability seemed to have sharpened even further as she travelled with the MND journey!!
From the cognitive capability point of view, Soremathy has noticed that this ability has not diminished with the onset and progression of MND. Social communication, understanding humanity and comprehending others' behaviour pattern towards her remained intact.

By July 2024, that is 6 months into the diagnosis of the condition, Soremathy's mobility has been cut to 99%. She needed help with everything from moving from place to place, modifications to seating and sleeping arrangements and pretty much all aspects of day-to-day tasks. The thinking, comprehending and memory capabilities remained sharper as ever.

The fact that her condition was declining linearly, she opted for Assisted Dying (AD) and on her contacting the AD Secretariat, two doctors assessed her independently and approved her to go ahead with the process. Though she initially fixed the date to be 7th of Jan 2025, as the condition started worsening she kept bringing the dates forward – all the way up to 30th August 2024!! Just about in the beginning of August, Soremathy and her husband were tested positive for Covid, which through the spanner in their works! She was taken to the hospital for observation while her husband was recovering at home. When she returned home in the next day or so, she was weaker than ever and her movement was totally restricted. So, ironically when the doctor associated with the AD called, she had no hesitation in bringing the date forward to 16th of Aug '24!! She wouldn't want to go before 15th August, since that date is India's (her mother country) independence day and she wanted to salute the flag on that day. This shows her true Gandhian spirit and nationalism.

Soremathy is also a believer in organ donation, as she strongly believes being useful to others even after she passes away. She contacted the organ donation organisation and they readily agreed to do the necessary steps to proceed with her desire. All necessary scans and tests were carried out and found the vital organs are in good condition. Therefore when the AD is completed, a team of surgeons will carry out the collection of the organs for transplant. Soremathy's brain tissues will be taken for research purposes at University of Auckland. She is so keen and hopeful her brain cells may provide some clues about the MND and a possible cure in the future.

In conclusion, being an MND patient, Soremathy has found that she didn't get any negative thoughts; her cognitive abilities have become sharper than before. She wasn't afraid of the outcome of the disease even though she knew it would end her life. Many visitors have openly commented how she was alert, sharper than before, displayed photographic memory and more jovial than ever before. Very seldom she displayed any negative feelings because she had this debilitating, life-ending terminal disease. Soremathy was very happy and proud that she is donating her vital organs for transplants and research, which she thinks the charitable qualities coming to the fore!

With this, she bids goodbye to this earthly world, transitioning to the unknown!