Humanities

Two for one:

# A patient testimonial and clinician's perspective

**Ravi Sankaran**[1]

## Part 1 – From Stillness to Strength: My Journey Back to Life!

*By Patient name– Anonymous*

It all started on June 5, 2024, a beautiful sunny day and my daughter's first day of school. When I held her little hand and walked her to school with happiness and pride, I had no idea that the very next day, my life would change completely.

The following morning, I woke up with a severe headache, double vision, and an inability to swallow food. I could sense that something was terribly wrong.

I was rushed to Amrita Hospital, where I was admitted under the Neurology department- Dr. [redacted]. It was a Thursday. Within just two to three days, my condition worsened drastically. On that Sunday, even though doctors usually take a break, Dr. [redacted] came to see me - perhaps he knew something was not right. He had warned us that we needed to be careful about any infection but at the time, none of us realized how critical that warning was. On the night of June 9, at around 2 a.m., everything changed. I said I needed to get up—but I couldn't. My body refused to respond. I couldn't move at all. I was immediately shifted to the ICU. After that, everything is a big void for me.

I don't remember what really happened—only fragments of strange dreams, some connected, some completely random. It felt like I was trapped between reality and an endless nightmare. I have a faint memory that one day when I opened my eyes, I saw my mother. I couldn't understand what she said. At first, I thought it was a dream—but the dream never ended. Nurses came and went. Doctors appeared occasionally. Sometimes I saw my father, sometimes my mother, sometimes my husband. But I had no idea what was happening to me.

After few days, I remember my mother telling me that I had developed an infection in my brain. She kept reassuring me that my daughter was fine, going to school, and being cared for by my in-laws. It was at this moment that I realized that I had a child but even that didn't fully sink in. It was as if I had lost a part of myself. My father would come, touch me, and pray. Watching him in that state somehow made me think that this was it, I am going to die. It also made me realise how severe my condition was.

Slowly I regained my consciousness, but I was completely immobile. My life was sustained through a feeding tube inserted through my nose, a urinary catheter and a tracheostomy tube in my neck to help me breathe. I couldn't move my body, couldn't even turn my head. I could only move my eyes and hear. Nothing else. Every five to six hours, the nurses would turn me. The pain that I had to endure then was unbearable but I couldn't cry or speak. I couldn't even shift slightly on my own to try and ease that pain.

For two long months, I lay there, unable to move, yet fully aware. Finally, on August 7, 2024, I was shifted from the ICU to a room. Slowly, my left side began to respond—tiny movements in my hand and leg. Later, the right side began to move too, though it remained more affected. Physiotherapy became my path forward.

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Every day, therapists worked with me, helping my muscles regain strength. One day, they made me sit up. But my head had no control—it swayed like that of a newborn baby. Slowly, with time and effort, I learned to hold it steady. From being carried on a stretcher, I progressed to sitting in a wheelchair. Every small step felt like a victory. On October 7, 2024, I was discharged. But to continue with my rehabilitation via the hospital guest house. Every morning, it was the same routine, heading to physiotherapy—pushing through one to one-and-a-half hours of exercises before going back to rest.

Eating was truly a struggle. Because of the tubes in my throat and nose, I couldn't swallow. So, the nasal tube was replaced with a feeding tube directly into my stomach. Then came a moment I will never forget—I began to swallow again. At first, just the tiniest amounts. But it was my ray of hope. After six long months, with the approval of all my doctors, we finally returned home on December 22, 2024.

That's where I began learning to live again. I slowly started eating normally. I moved from a wheelchair to a walker. Step by step, I regained my independence. A huge part of my recovery was thanks to my therapists. Even after long workdays, they would come to my home and continue my therapy. Their dedication helped me rebuild my life.

The hospital visits continued. In May 2025, I had to return to the hospital due to stomach pain and fever. There was an infection around the feeding tube, but since I was able to eat through my mouth, I was prescribed some antibiotics and the tube was removed. In July, I was admitted again to remove the tracheostomy tube. Though it was removed, the opening in my neck didn't close and required a surgery in October. By then, the urinary catheter had already been removed. And finally, by October 2025, I was free from all the tubes and medical attachments that had once defined my existence. Even today, I am not fully back to who I was. My right side is still weak. I cannot walk independently with complete confidence. My balance is not fully restored.

But I am still here, walking slowly towards full recovery. From a point where I could only move my eyes - to standing and taking steps again—this journey has been painful, slow, and incredibly challenging. Through it all, my strength came from my family—my father, my mother, my husband, and my brother. And above all, my little daughter, who waited for me without even fully understanding what was happening. I have not yet recovered completely, but I am sure I will. I will not be defeated. Every step I take today is a victory. I am Grit and will power crystallized. This was an episode of fight, all the way with prayers of all dear and impeccable care by Hospital and grace of God. And this… is my story of coming back to life.

## Part 2 – Being the Unmentioned Part of Someone's Story: Physiatrist's Perspective

*By Dr Ravi Sankaran*

One day I opened my work email and found this forward from Admin in my mailbox. It detailed the above patient testimonial. My first interest was to share this with the Physiatry community, so I contacted the person who initially had sent this on the patient's behalf. Permission to share was granted. To protect patient privacy, I had to redact some details. Reading this raised a question for me: Was PMR involved in this case? Certainly, much of what is described falls within our purview and has been our position since 2009 in Amrita. The only named individuals per the narrative are the neurologist and a single therapist. On receiving the MRD number everything fell into place. What follows are the missing details.

31 y/o female with hypothyroid for 3 years

12-16/3/2024: Nephrology admission: Primary glomerular disease s/p biopsy

6/6/2024- 22/8/24: Neurology admission: Listerial Rhombencephalitis Klebsiella & Acinetobacter pneumonia, SLE with Lupus nephritis

22/8/24-17/10/24: Physiatry admission: Impaired ADLs secondary to Infective Encephalopathy resulting in quadriparesis, dysphagia on Ryle's tube, respiratory insufficiency on tracheostomy tube, urinary incontinence on IDC, SLE with Lupus nephritis Hypothyroidism, Brainstem and upper cervical cord demyelination, Critical Illness Neuropathy w/ phrenic nerve demyelination

With the snapshot you can see how major organ dysfunction and secondary infection eventually warranted Acute Inpatient Rehabilitation. The biopsy led to the SLE diagnosis and mycophenolate being prescribed. The nephritis on immunosuppression led to the secondary infection of her brain, which was promptly treated. Once antibiotics were nearly over rehabilitation became central to her care. What we received was a semiconscious quadriplegic patient on continuous BiPAP who desaturated with position shifting daily. Weaning her off, getting her stable enough for therapy, swallowing, decannulation, etc became the responsibility of PMR. Accustomed to such work, she was taken up as routine care. She went home walking, talking and doing her ADLs independently in about three months. From there we never saw her again. She has ongoing rehabilitation needs home therapy has not solved and still visits the hospital. Just not PMR.

## Why did she not mention Physiatry?

People remember experiences that make their story, not the whole thing. Memory tends to align with emotionally salient and visible phases of care. From a systems perspective, recovery is often understood in fragments, with different phases attributed to different visible contributors. In that way sleepless nights handling her emergencies and weaning her off supports may go unrecognized.

While many therapists were involved in care from ICU when unconscious to ward to home, only one is mentioned. This therapist does deserve credit for the work of getting the patient from sit to stand to walk. As therapists are closely involved in visible functional milestones like walking, they are more readily associated with recovery. They are then valued more than those involved earlier in care, when the patient is capable. Stepping back from this individual case, it reflects a broader pattern. Rehabilitation medicine is structurally under-recognized because our most critical contributions occur when patients are least able to perceive them.

This testimonial highlights a recurring pattern in rehabilitation medicine: the most critical interventions often occur when patients are critically ill, sedated, or cognitively impaired. As a result, these phases are rarely encoded into patient memory or narrative.

By the time recovery becomes visible—sitting, standing, walking—the contributors most directly associated with those milestones are remembered. Earlier work—ventilator weaning, secretion management, dysphagia care, early mobilization—remains largely invisible despite being foundational.

This is not a failure of the patient's perspective, but a limitation of how recovery is experienced and remembered.

The question, then, is not why patients fail to acknowledge physiatry—but how we can better make our role visible, understandable, and narratable within the patient journey.

## A set of steps to a solution

**1. Narrative ownership**: Patients tell stories using: Names/ Roles/ Moments. If "Physiatry" is not explicitly introduced, it won't exist in their story.

**2. Milestone labelling**: PMR work is often invisible because it's continuous. The solution is to convert it into named milestones e.g. "Today we got you off BiPAP"/ "Today you swallowed safely"/ "Today you no longer need the trach". Patients remember moments, not processes.

**3. Discharge narrative shaping**: Before discharge, patients should leave with a coherent story: "You came in unable to move or breathe independently. The rehab team helped you regain breathing, swallowing, and mobility step by step." If you don't give them this story, someone else will.

**4. Written summary for patients**: A simple one-page summary/ "Your recovery journey". Patients often use this when writing testimonials later.

**5. Institutional branding problem**: The term 'physiatry' itself is often not understood by patients, limiting recognition of the specialty.

**6. Accept the asymmetry**: People credit those who help them when they are conscious and emotional e.g. ICU = survival (blurred memory), Rehab = relationship + visible progress. You can mitigate this, not eliminate it.

If rehabilitation medicine is to be fully understood, it must not only deliver outcomes—but also ensure those outcomes are visible within the patient's story.