

A patient's initiative towards lung & mental health literacy to bridge the gaps between bedside-to-bench-to-bedside

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Abstract

Lung diseases are the leading cause of deaths in India (22.05%) as well as globally according to Global Burden of Disease (June 2021). Ironically, many of them go undiagnosed and the diagnosed ones are waiting for relief for decades. The ultimate aim of all medical advancements is to provide best solutions to improve the patient's quality of life. Power of collaboration between medical fraternity, patients and caregivers enriches the entire spectrum of the medicine Bedside-to-Bench-to-Bedside. There is a huge difference in knowing and living with the pulmonary & respiratory disorders. An insightful relationship between the medical fraternity & patients can bridge this knowledge gap fruitfully. Both these groups speak & understand different languages, medical & layman language. In this light, proactive initiatives must be encouraged & empowered by both sides to leverage the value of real-life experiences. This can save enormous amounts of money, effort and pain put in by medical professionals & patients. Also, this would fast-track the research & development of more effective treatments, drugs & equipment for the breathing & lung patients. Promoting awareness, encouragement, education & empowerment to the patients facilitates better health results and patient retention. With the support of treating doctors, there can be a rise in the patient advocates. With the power of proper mentoring, real-life experiences and digital technology, patient advocates can do wonders in multiple dimensions. Unresolved and unaddressed pain manifests into another dis-ease. This chain reaction leads to increased health care burden on the global population. The Breathing warrior movement is one such initiative. We are on a mission to empower 10 million people with Long-term Breathing Problems & their caregivers to Improve their Quality of Life without Losing Hope & Feeling Depressed, Dependent on others through a step-by-step BW action plan. We encourage the medical fraternity to accept patient advocates like us as part of your team in this shared mission and support such initiatives.

Biography

Madhu Vyas is a 65-years-old Indian lady diagnosed with Rheumatoid Arthritis related Interstitial Lung Disorder. She has been on non-stop long-term oxygen therapy & social isolation for the past few years. In the darkest phase of her disease, she lost her primary caregiver-husband in December 2018. Struggling with grief & depression along with the worst symptoms of her disease, she decided to take charge of her life. She decided to be a "solution/asset" to her children, instead of their "problem/liability". With consistent efforts & positivity her health improved. This lady with an oxygen tube, founded the Breathing Warrior Movement out of compassion & empathy. She along with her daughter Swati Vyas, PhD has been working to educate, empower, & support people regarding lung & mental health in native language & English, extensively through virtual & digital ways. Also, she has been interviewed several times. She recently shared the patient's perspective in a two-day virtual event organized by AIIMS, Rishikesh & Indian Association of Respiratory Care. She is also an upcoming author on this subject.

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