

“I have always been very driven and try to make the most of every opportunity that was given to me.”

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My favourite football team is Manchester United, and my favourite player is midfielder Juan Mata.

I was 10 years old when I was diagnosed with a rare congenital bone contracture known as Arthrogryphosis Congenital Multiplex which affects my wrist and feet. Football was my love and passion. I have such fond memories of the regular soccer games I had with my friends. I continued playing football after a surgery in 1973 to repair my feet that allowed me to walk with more stability.

My condition does not affect my mobility and I have never deemed myself as a disabled person. I've worked many jobs -in sales, operations, and credit control. I guess I have always been very driven and try to make the most of every opportunity that was given to me. Life was simple and I was just happy to live life on my own terms.

However, in my 30s, I was further plagued with another rare medical issue. I was diagnosed with Patent Ductus Arteriosus, which resulted in severe pulmonary hypertension over time, one of the main causes for my constant tiredness and breathlessness.

When I was diagnosed, I asked if there were other patients like me. I realised there was no such support group so I started one in 2004 known as Pulmonary Hypertension Support Group which serves to educate and reach out to patients with this rare terminal disease. Patients and family members meet quarterly for educational talks, workshops. The support group was subsequently registered as a non-profit organisation called Pulmonary Hypertension Singapore in December 2015.

I used to be a smoker and in 2006, I contracted Chronic Obstructive Pulmonary Disease (COPD), another degenerative disease. Again, I started

a support group with SGH Department of Respiratory and Critical Care Medicine. The COPD Support Singapore provides a platform for patients to interact and share their experience. I hope to integrate all the COPD support groups in Singapore into one national organisation one day.

I have stopped working because my pulmonary hypertension has worsened in recent years. To avoid lethargy, I make it a point to move around every day. I also go for regular pulmonary rehabilitation in SGH.

The typical life expectancy of a patient with pulmonary hypertension without treatment is to 2 to 5 years. With advanced therapy, it does improve functional outcomes and better quality of life for patients. I do not think about my diseases as I've done whatever I've set out to do. I will continue to live my life to the fullest and make a difference along the way, where possible.

“Amin has physical limitations yet he does not use his condition as an excuse to wallow in self-pity. He gives his all in his volunteer work as he believes it will benefit other patients and their caregivers.”

Dr Jessica Tan
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