

Patient voice

Together we are stronger: COVID-19 for those of us with pre-existing conditions

My name is Stefano Pavanello, I live in Northern Italy and my symptoms first started at 6 years-old, I had a continuous cough that no doctor could find the cause of. Only after 3 months at the University Hospital of Bologna did I receive my diagnosis: cystic fibrosis. It was 1973 and the prognosis was very poor at that time. I have always been a dreamer and I immediately started to wait for the day when a lung transplant would become a reality. My dream came true; after 15 years of 24 h oxygen therapy, I received a double lung transplant in April 2012, at the thoracic surgery department of Padua University Hospital.

This is a story about my personal experience as a patient and patient representative during the first year of COVID-19.

It is a very hot afternoon of a typical Italian summer and I am packing my bags for my first beach trip of 2020. One of these bags is completely full of drugs and every kind of mask, from the most protective, to the slightly more fashionable one. This is going to be my "COVID-19 adapted Tuscany Summer Tour!".

I will take the opportunity to visit two dear friends who, surely more than me, are experiencing the COVID-19 anxiety syndrome.

Anna, who will be my host for during my trip, has been on the list for a transplant for a year now and the 3 months of almost complete cessation of transplant activity has been difficult on both her physical condition and her confidence that everything will be okay.

Carla lived a totally different experience; instead, she was one of the just two or three people who



Stefano Pavanello.

had a lung transplant during the lockdown in Italy. Everything went well, but experiencing the delicate months of the first post-transplant phase with the fear of being infected by COVID-19 is not easy at all and has made recovery even more taxing for Carla.

I will try, as a good friend and as a good patient representative, to help them with some laughter and some good advice; all the while knowing that they are only words and that Anna and Carla will have to find the strength to face all the difficulties inside of themselves.

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Stefano Pavanello shares his experiences of navigating through the pandemic as a recipient of a lung transplant, and of supporting others as a patient representative. #TogetherWeAreStronger #UnitiCeLaFaremo <https://bit.ly/2HVCeop>



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Preparing for my holidays, I think back to February when COVID-19 seemed to be a very distant thing, destined to remain “someone else’s problem”. After the 21 February, the nightmare became part of our lives and within 10 days Italy was literally paralysed.

Italy remained in total quarantine for 3 months, but to me it seemed something like an eternity because I had had a transplant, I am immunosuppressed: one of the “risk categories”. But what does it mean exactly being in a risk category?

I do not recommend it to anyone. You feel something like a “series B citizen”: every time you see the news on TV and the numbers of this tragedy are announced one by one you can hear “today we had 4821 new infections, 943 healed people and, unfortunately, we had 793 new deceased (on 21 March 2020). We want to reassure citizens that those who have died are elderly or at-risk people, with one or more concomitant diseases”.

Well, someone will be surely reassured by this, but not me. And definitely not our elderly and all people with lung diseases. For this reason, at the beginning of this situation most people took the question lightly, but when the numbers started to increase, fear became part of our lives. The laws of our government started to become stricter and stricter, trying to contain the number of infections, but it was not easy because today’s death toll refers to infections that occurred 2 weeks ago, so every decision is taken from a place of unknowing.

The most dramatic situation was being experienced in Lombardy, the region where Milan sits. Still, nobody can say why. Our newspapers, TV news and social networks were invaded by opinions

and declarations of everyone, from scientists to politicians to journalists. Not to mention all the false news that made people even more confused.

There will be images that will never be erased from our minds, such as those of the very long column of military trucks that carried the corpses of dozens of people for whom there was no longer space in the cemeteries of Bergamo. Whatever happens, we will not be same people after this experience.

As a patient representative, I decided to be strong and to emit strength, confidence, and hope to all our members, friends, and their families. From when I woke up in the early morning, to midnight when I usually went to bed, it was a continuous interaction with them using every kind of system that technology could offer.

The best moment was a conference call that I organised that involved even people who were completely reluctant to use technology. I taught them one by one how to use the system to connect. It was a success, people living all over Italy could meet and talk to each other and to our doctors, we shared experiences and fears but, above all, we realised that together we are stronger.

Nobody can see into the future, and I do not think it is unlikely that this autumn we could face the problem again. We will have a little more experience, but the fear among patients, the elderly and our families will remain the same.

What I can suggest is to follow all the instructions given by the healthcare and political entities, be strong and confident in the future. Stay with your loved ones, rediscover the true values of life such as friendship, love for nature and the little things in life.

Affiliations

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