

3 to 5 years to Live: The truth behind the statistic

DISCLAIMER: Please note I am not a medical professional. I spent 8 years as caregiver for my mom (2 years pre- and 6 years post diagnosis of IPF), until her passing in 2009. I have since been a PF Advocate for Patients & Families, as well as Founder and Support Group Leader of the Breathe Support Network of Groups. Information provided is from personal experience, combined with years of learning through interaction with patients, other caregivers, & healthcare professionals in the field of PF/IPF.

Pulmonary fibrosis is often a progressive and 100% fatal disease, however the 3-5 year life expectancy is outdated and does not hold true for many with PF.

Those statistics came from the United States Medicare database many MANY years ago. (Before my mom was diagnosed in 2003.) This means that most of those people were of retirement age and older AND it was at a time when it took even longer to diagnose AND we had NO treatments, at all.

The only people in that statistic who were not of retirement age were those who had managed to get approved for disability because they would be the only younger people who were on Medicare. This means that many who were younger and living with PF were not part of the statistic.

Additionally, that 3-5 year life expectancy is for IPF (or originally was anyway) and was NOT for the other 200+ forms of PF. Over the years, now that statistic has become as interchangeable in the PF community as the name Kleenex is for tissues one would use to blow their nose.

It is very important to note that over the years, not only is PF in general being diagnosed sooner (though we have a long way to go on that front), but we have more treatments now. No cure of course, but we do have Esbriet and OFEV to help slow the progression, thus giving many people longer to live. We also have more people getting lung transplants, thus extending life in that way as well. We have more knowledge on things like better dietary habits, exercise, pulmonary rehab, supplemental oxygen use, general health, etc. and have ways to help people live an overall healthier life so that they can hopefully live longer with PF.

We now have better knowledge on the other 200+ forms of PF and how to better manage them and experts are learning more every day about better diagnosis and treatment. Someone originally diagnosed with IPF might later present with an autoimmune disease, causing a change in their diagnosis to autoimmune induced PF. (It happens at times that PF presents itself before the disease process that caused the PF in the first place.) Someone with autoimmune PF may be managed better for their autoimmune disease so their PF doesn't progress as quickly, and they may live longer.

MANY with PF - including with IPF - live a LOT longer than than 3-5 years. My own mom, diagnosed in 2003, confirmed by biopsy by one of the world's leading PF experts, was end stage at diagnosis. She was told she had "2 years, at best" to live. Because of her amazing attitude, better healthcare in general, and our being diligent about tackling all new problems right away, we were blessed with 6 wonderful years before she passed away.

There was absolutely no doubt that she had IPF. Her doc, that leading expert, even had a patient he had diagnosed about 20 years prior with IPF, and had that diagnosis verified many times over the years by other world renowned PF experts, lived for all those years with IPF. The patient passed away just shy of

our face-to-face support groups 25th anniversary celebration, at which he was going to be the guest of honor.

So yes, those with PF can live a very long time. We have a lot in the PF community who have been living with PF, even IPF, for 5,10, 15, and even 20 or more years. I have had many friends over the years who have lived with it a very long time.

I tell people to not get caught up in that 3-5 year number. I do warn them to never underestimate the disease. PF is elusive. It can sneak up and take someone who is early stage - not even needing supplemental oxygen - in a very quick manner. But many live a long time with it. Live each day. Cherish every moment. Truly focus on how to #LIVEwithPF.

Prepared by:

Taleena Koch
Pulmonary Fibrosis Advocate for Patients & Families
Breathe Support Network
breathewithpf@gmail.com
www.BreatheSupport.org

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