

## **HIGH FLOW OXYGEN THERAPY (HFOT): The reality of life sustaining treatment**

***DISCLAIMER: Please note I am not a medical professional. I spent 6 years as caregiver for my mom, until her passing in 2009. I have since been a PF Advocate for Patients & Families, as well as moderator & owner of the Breathe Support Network of Groups. Information provided is from personal experience, combined with years of learning through interaction with patients, other caregivers, & medical professionals in the field of PF/IPF.***

***I am also NOT telling anyone what decisions they should make when it comes to HFOT during their journey. I am simply writing this so others know what this can entail for a patient and know the questions to ask their medical professionals. Additionally, Donna has given me permission to tell her father's story.***

On September 7, 2018 family and friends said goodbye to Lee Pappas. Lee was a member of our PF support group. I didn't get to know him well, but I did get to know his daughter, Donna Opdyke. Donna was her father's primary caregiver as he lived with IPF.

During the last few months of his life, Lee was in and out of the hospital with pneumonia and pulmonary embolisms (blood clots in his lungs). The last couple of months were the most difficult, having spent all of it in the hospital or in a skilled nursing home on High-Flow Oxygen Therapy (HFOT). What is HFOT?

For many years, patients with PF/IPF have been using what is called "high-flow oxygen". This is basically a higher liter flow of supplemental oxygen, requiring a bit larger tubing. This is not the same as HFOT. (Side Note... I do wish these treatments had different names so as to not confuse patients and loved ones.)

HFOT is what is now being used in many hospitals in place of the traditional ventilator, or vent.

When a vent is used, a tube is put into the patient's airway and a machine helps them breathe. You may have heard of patients being "weaned off the vent" by lowering how much assistance the machine gives them. They may progress from being 100% assisted to being only 75% or 50% assisted and further down, until they are breathing on their own, without the assistance of the vent.

What has been found is that HFOT works quite well for many in place of the vent.

From the following link:

<https://www.resmed.com/ap/en/healthcare-professional/diagnosis-and-treatment/respiratory-care/treatments/hfot.html>

HFOT basically offers the same life-sustaining and life-saving advantages of a vent, without the invasiveness or possible damage to the airway. It is also found to be easier to wean patients from HFOT than it is with a traditional vent. This is great for patients who are in a situation where they can be weaned and sustain life without the necessary high liter-flow of supplemental oxygen.

Here's the potential problem...

HFOT is now being used for patients who are at end of life with diseases like PF/IPF. This is what was used to help Lee during his last months of life.

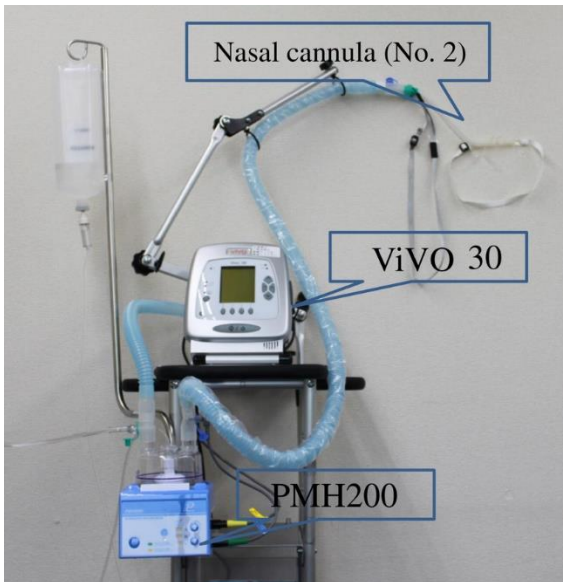
Originally it was used because no one really understood he was truly in the end stages of his IPF. He seemed to have pneumonia and pulmonary emboli. The goal at the time was to get him treated for these conditions, giving him the oxygen that he needed, wean him down, and release him to go home; hopefully to stabilize and have more time. This is a great reason to try HFOT.

Coincidentally, HFOT was used on my sister this past summer. She has very advanced COPD and was in the hospital for an acute exacerbation. She was on 20 lpm of HFOT, at a mix rate that the doctor said equated to approximately 50 lpm of regular supplemental oxygen. She was successfully able to wean off and go home on regular oxygen.

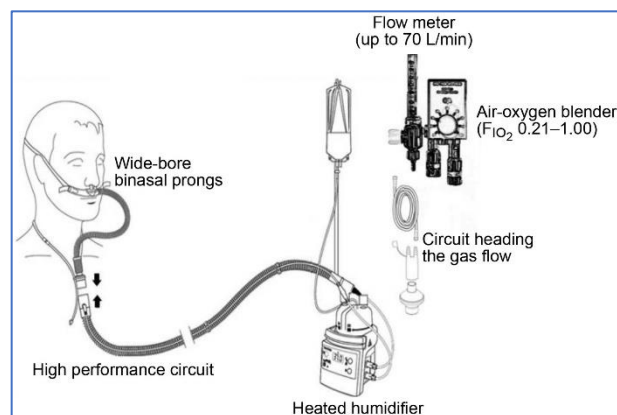
During my sister's stay in the hospital and, I believe, during Lee's multiple hospital stays, at no time was it mentioned that HFOT is "life-sustaining or life-saving treatment, much like a vent". It was simply provided that it was a higher flow rate of supplemental oxygen. However, this is actually not the case with this therapy. This therapy is now taking the place of a vent in many cases. This is something that needs to be considered when looking at "what does a patient want in the way of life-saving treatment"?

It is important for patients and loved ones alike to know, this is not typical supplemental oxygen. This is a type of treatment that a patient may never be able to wean from. In Lee's case, he was getting such a high liter flow of HFOT (up to 60 lpm) that it would take a "tanker full of oxygen" for him to live outside the hospital at this flow rate. In other words, 60 lpm of HFOT is not something that can be matched with regular supplemental oxygen provided at home.

## How do you know that HFOT is what is being provided?



Here are some photos of the equipment you would see. It is important you know this is not just regular oxygen. It is important you speak with the medical professionals about what this therapy means for you or your loved one. It is important the patient understands what the plan is going forward with this therapy. If the patient has a DNR, they may wish to speak with the doctor about how much life-sustaining treatment is being provided and what their chances are being weaned from this therapy. They may find this is not what they want.



Lee and Donna eventually learned, after many attempts to wean him from HFOT, that he was not able to sustain life without it. Decisions were made to remove this form of life support. This was a terribly difficult decision to make because HFOT is not as ominous in appearance as a ventilator. Lee was alert, able to speak, able to watch TV and engage with his medical professionals and his loved ones. He didn't seem as "sick" as someone who is on a vent. While being a great advancement in medical science, it is a deceptive form of life support and one that medical professionals are not addressing with patients and loved ones.

Lee Pappas lost his battle to IPF on August 31, 2018. May he forever rest in paradise, free from tubes and tanks and breathing freely.

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#LIVEwithIPF

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