

# A PATIENT'S JOURNEY THROUGH LUNG CANCER: JUST HEAR ME OUT

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*"I told you I was ill"* was recently voted Britain's favourite epitaph for a tombstone. I definitely plan for that to be on mine-but not yet, definitely not yet! My name is Tom Simpson and the beginning of my story is unoriginal, even boring for oncologists to read because it is heard so often. Unfortunately, it must be repeated until it is no longer the norm. I hope you continue to read my story beyond the diagnosis because that was only the beginning.

For over a year I had been suffering from a few irritating aches and pains resulting in a sore back and gurgling sounds in my lung. This led to various examinations bringing various diagnoses from various family doctors, ranging from pneumonia and psychosomatic pain to asthma. Well, referring to my opening line above, I knew something serious was wrong. Even a week before things changed I shared concerns with my wife (figure 1) that "they" just weren't listening to me.

## DIAGNOSIS

A week later, in August 2014, I found I was unable to talk properly and was starting to struggle to catch my breath and talk for more than a few seconds. I was actually laughing with my patients (I am an optician) because I was trying not to sound like a walrus. I phoned my family doctor to be told it sounded like an asthma attack and to take ten puffs. No change. Another ten, still no

change! I should point out here that I had been diagnosed as asthmatic only a week before. I was offered the choice of coming into the doctors' surgery or going to Accident and Emergency should it get worse. Thank goodness I chose the hospital option because, within half an hour of arrival and a simple tap on my back, I was told I had a significant build-up of fluid in the lung and needed to be admitted. At this stage I was not laughing but felt at least something was being done. I had no idea of what was to come. Within a day the fluid was drained off and a biopsy was performed, but my lungs began to refill. At this point I was made aware that the biopsy and the fluid they removed contained cancer cells. Now, I won't deny it, I was getting a little worried.

A full computed tomography (CT) scan was done which found a "hot spot" in a rib and, from the initial biopsy results and the fact that the fluid contained cancer cells, I was diagnosed as having nonsmall cell lung cancer (NSCLC), a stage IV adenocarcinoma. I asked my surgeon what the prognosis was. He told me less than 12 months and that I should get my affairs in order, become more reckless, but stay off the morphine for as long as possible. He was lovely and seemed genuinely troubled to be delivering this news. I realise everybody reacts differently but I was surprisingly calm. I knew something was wrong, it was a bit rubbish that it was this bad but, like many others, I became obsessed with preparing the means to protect my family (figure 2). I was in "fixing mode".



FIGURE 1. My wife, Jan, and I.

## BEATING THOSE DAMN STATISTICS

Now, obviously, I am writing this in spring 2017, so not everything I was told then was accurate. With testing it turned out I had exon 19 deletion (my favourite), which means I am able to benefit from a biological therapy where the regimen is one tablet each morning. I have avoided damaging chemotherapy and radiotherapy, which the vast majority of late stage lung cancer patients face as a first line. Afatinib is literally a miracle drug for me because I've gone from being in constant pain in my back and side to someone able to walk 10 km a day, climb stairs and ultimately return to work. My surgical treatment was not removal but talc inserted in the pleura. This pleurodesis stops the fluid building up again. From taking painkillers on a regular basis I needed no pain



FIGURE 2. My children, Camille and Blake.

medication for an 18-month period—that is amazing! My condition is not cured—it is currently being maintained. This is combined with a positive “non-prognosis” from my oncologist who avoids giving specific timeframes. She prefers comments such as “I’ve had patients on this drug for years”. The median timescale for Afatinib is only 11 months and, as I write, it is still working for me 30 months later. I am obviously grateful that this medication has kept me alive but it comes with a dark cloud that can hover overhead: that one day it will stop working due to that lovely mutation T790M. However, there are now other drugs that may help me again, so even that dark cloud is hovering a little less.

## THE BIT FOR YOU TO REMEMBER

It’s amazing how, a few years ago, my diagnosis would have been considered terminal. Now, due to modern drug therapy, it is getting close to being considered a condition which can be maintained for a reasonable time. This simple change of perception brings a change in the psychology of patients. In fact some patients feel that it’s offensive to be referred to as terminally ill. Trust me, there are plenty of militant cancer patients out there who will correct you online. So, the goalposts are moving all of the time. It’s something that oncologists are aware of but maybe not all medical professionals are as well educated, relying instead on their experience. This is understandable but flawed and outdated.

Stage IV lung cancer is often diagnosed late because symptoms are regularly missed at an earlier stage. **This must change!** Family doctors must be more aware that some symptoms can indicate more serious conditions.

Smoking is the usual risk factor for lung cancer but if your patient doesn’t smoke don’t assume that lung cancer is unlikely. A significant number of newly diagnosed patients haven’t smoked. Also, medical staff must keep up to date with new treatments which might give hope to patients who are given a “terminal illness” diagnosis. Hope is the one thing

we can hold on to—there is no coming back from someone telling you “it’s terminal”. Some patients will give up, although I realise others will stick two fingers up at that and fight.

## PAY IT FORWARD

So, what have these extra years given me? Obviously more time with my family and the opportunity to continue working. Surprising even myself I have taken my illness on board and chosen to become a more active patient representative. This has been such a positive, confidence-building experience that I truly believe it has boosted my overall well-being. I began to volunteer with the European Lung Foundation (ELF) in my first year after diagnosis, where I met other lung cancer patients. Some of them had been diagnosed as stage IV many years prior even to some of the new genetic treatments which are now available. It was the first time I really understood the term “cancer survivor”, those individuals who survive longer than 5 years.

As I became more confident in my ability to contribute to meetings, I started to volunteer as a patient representative at the European Medicines Agency. This has provided me with an insight into how new cancer drugs for my condition gain approval and how vulnerable patients are protected from taking the first option provided, often because they might feel they have no alternatives. My participation in these bodies has been made possible because of the new rules that require patient representation. Going to European Cancer Organisation (ECCO) conferences has also made me realise how oncologists struggle with the financial aspects of oncology care when working in national health services. It is so important to get as many of your lung cancer patients involved at this higher level as possible. For me it has been such a rewarding and positive experience but I would not have considered stepping up if it had not been for a supportive oncologist and specialist nurse. I haven’t stopped there—over the last year I have contributed to the Scottish Medicines



FIGURE 3. Speaking on behalf of Lung Cancer Europe (LuCE) at the European Parliament (November 2016).

Consortium's decision-making process over the sanctioning of the drug which will hopefully become my next-line treatment, while also going to Brussels to speak to the European Parliament (figure 3) about raising awareness of lung cancer. I believe I am part of a new breed of patient who is more acutely aware of their role in the formation of treatment plans across Europe.

## CONCLUSION

Please encourage your patients to get involved if they can. Many of them might think they only have months to live and they, like me, might gain years.

So what's next? I hope to continue contributing as a patient representative but my primary aim this year is to make a short documentary-style film about my experiences since diagnosis. This might help patients and their carers understand that many of the things that have happened to them have happened to others. I would hope to do this in a positive way.

Obviously nobody chooses lung cancer, it definitely chooses you. However, for me, with the help of these new medications, I have been given a second chance to make a difference; a second chance to help others deal with their diagnoses. I hope this article gives you, as medical practitioners, an example of someone who has taken what is your daily work and turned it into something positive.

Thank you for getting to the end of the article, but remember, I did tell you I was ill.

## CONFLICT OF INTEREST

None declared.

## RECOMMENDED READING

European Lung Foundation. Lung cancer factsheet. [www.europeanlung.org/assets/files/en/publications/lung-cancer-factsheet\\_web.pdf](http://www.europeanlung.org/assets/files/en/publications/lung-cancer-factsheet_web.pdf) Date last updated: October 2016. Date last accessed: May 12, 2017.

Lung Cancer Europe (LuCE). LuCE report on lung cancer: challenges in lung cancer in Europe. [www.lungcancereurope.eu/wp-content/uploads/2016/11/LuCE-Report-final.pdf](http://www.lungcancereurope.eu/wp-content/uploads/2016/11/LuCE-Report-final.pdf) Date last updated: November 2016. Date last accessed: May 12, 2017.