

## Patient voice

# Lung cancer: keep your mind open – it's not always the usual suspects!

Some years ago, I entered a completely unfamiliar world. This was a landscape that clinicians deal with every day but for the individual suspected of having lung cancer, it can appear hostile and scary, often misrepresented by outdated imagery, information and television portrayal. Lung cancer is not awash with celebrities admitting to having it or grand fundraising campaigns like other conditions. Despite many changes in the treatment landscape, it's still generally much more stigmatised than other cancers.

How can someone navigate this unfamiliar area? A lot depends on whose perspective is considered and whether it's recognised that the factors that matter to patients may be completely different from those of clinicians or healthcare professionals. We can only learn of such differences by working together as collaborators and partners in research to improve awareness, treatments and understanding.

I've been involved in lung cancer research advocacy since 2014 and have learned so much.

I urge everyone working in this area to consider a favourite quote:

Minds are like parachutes. They only function when they are open.

SIR JAMES DEWAR, scientist (1877–1925)

## My experience

How did it start? In October 2010, I experienced unusual symptoms that, after a few days of self-medication, showed no improvement. I went to my local Accident and Emergency department late one Friday night, instinctively feeling something was seriously wrong.

Nebuliser, steroids and antibiotics, and a chest X-ray were administered whilst awaiting a doctor. The next morning, the doctor told me I was “well enough to go home”. I requested the chest X-ray results before leaving. She told me it showed an “anomaly – a lesion on the left lung”. I was readmitted by ambulance the next day, staying for 6 days, misdiagnosed as having “uncontrolled asthma”. Despite having had childhood/early adult atopic asthma, which I had not experienced in several years, this felt completely different.

A couple of months later, I had a computed tomography and positron emission tomography scan then saw a surgeon who advised he had to urgently remove “half the left lung with the large mass”. In January 2011, this mass was diagnosed as a 7-cm mucinous adenocarcinoma – non-small cell lung cancer. Having been reassured the “lesion” may be scarring and having never smoked, the diagnosis was a real shock, as several clinicians had suggested it was unlikely to be “sinister”.

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A few months after my surgery, a friend died in hospital within days of his unexpected widespread lung cancer diagnosis. He had suffered a bad shoulder for months; no imaging had been done. When I researched online, his experience was not rare. I was shocked to learn lung cancer is the most common cause of cancer death in UK and globally, yet at the time, received <5% of all cancer research investment. The long-held belief that it is a self-inflicted lifestyle condition continues to stigmatise it.

Anyone can develop lung cancer and although smoking has been known for decades as its major contributor, other factors remain largely unknown. I became determined to learn more and improve awareness. An article by UK political journalist Robert Peston about his never-smoker wife dying from lung cancer attracted my interest in 2013. I read about others too.

I started fundraising for UK charity the Roy Castle Lung Cancer Foundation, attending their Birmingham conference in October 2012. There I met a never-smoker nurse, a patient advocate with stage IV lung cancer ineligible for curative treatment. She encouraged my involvement in research and advocacy. A year later, I was appointed to the National Cancer Research Institute (NCRI) Clinical Studies Group. We reconnected at the British Thoracic Oncology Group (BTOG)'s annual meeting when she presented and I was a delegate. I still hear her voice when I'm wondering how I came to be at the table in high-level clinical discussions – she said, “this happened to you and you're in the NHS, you could do so much more to influence things”.

The research world was alien to me. Despite involvement with the National Health Service (NHS) in governance, scrutiny and oversight since 2006, I was not well versed in complex science, statistics, contributing patient perspective to study designs, patient literature, ethics/consent issues or data sharing. What a steep learning curve to understand and contribute to such discussions!

I applied to join a lung cancer patient advisory group (PAG) that the European Lung Foundation (ELF) was developing. Their willingness to include the patient/carer perspective in study design and implementation, and myth-busting on its dedicated lung cancer website, was evident.

I bring lived experience of a “deprived” area where patients are not treated at specialist cancer centres but must attend far-flung sites for tests and treatments, adding to delays, anxiety and confusion. Their voices are rarely heard, so I raise patient

perspectives wherever possible. Contributing feels useful and a way of giving back. Patient/public involvement is valued by many cancer organisations and many research funders insist on it.

I'd like to think the nurse and others who encouraged my involvement would appreciate what I do – now part of BTOG's steering committee and ELF's PAG to raise awareness of lung cancer and treatments to public and professionals, and offer patient perspectives to include in their valuable work.

My motivation is to advocate for those no longer with us and those less able to articulate their perspectives, and on behalf of those treated in smaller or less well-connected hospitals (*i.e.* “not the usual suspects” compared to large specialist or tertiary centres). It's important that scientists, researchers and clinicians consider not “what is the matter?” but “what matters?” to patients.

In 2017, I was invited to join the NHS England Clinical Expert Group and Screening Advisory Group. This considerably increased my knowledge of the complexity of potential screening programmes.

I often hear that the average lung cancer patient is in their “late 70s with a long history of smoking”. The patients I've met seldom fit these criteria, although this may be due to the nature of patients who are inclined to participate in advisory groups. Focusing on smoking as the only risk perpetuates the idea that only smokers can develop lung cancer. This general message has to change – anyone can develop lung cancer!

England includes former smokers and current smokers in its lung health check pilots aimed at detecting lung cancer earlier but we also need to recognise the contribution of air quality, industrial exposure and other carcinogens. There is still much to research and learn!

Lung screening is one of a number of approaches needed in the fight to improve lung cancer outcomes. I understand that I am not a typical high-risk lung cancer patient and would never fit the screening criteria, but in this issue of *Breathe*, which focusses on screening, it is important to remember that not all patients fit the expected profile of a lung cancer patient, *i.e.* not the usual suspects!

Janette Rawlinson is a current member of the European Lung Foundation Lung Cancer Patient Advisory Group, a consumer member of the NCRI lung cancer advanced disease subgroup and a steering committee member of the British Thoracic Oncology Group.

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