

# INSPIRE

THE LUNG CANCER MAGAZINE

## Cathy Brokenshire

"It's that ripple effect of getting people talking about lung cancer and breaking down the stigma"

### CHANCE TIMINGS & SILVER LININGS

Could the pandemic have some positive outcomes?

### When Harry met Screening

Targeted lung health checks save 600 lives

ROY CASTLE  
LUNG CANCER  
FOUNDATION



**IT'S HARD TO PUT INTO WORDS HOW I AM FEELING RIGHT NOW.**

**Ecstatic. Overwhelmed. Jubilant. This year we have taken the biggest step towards achieving one of our primary objectives – a national lung cancer screening programme.**

On 11<sup>th</sup> March, the National Screening Committee launched its public consultation on lung cancer screening (page 8), giving us all the chance to have our say on what such a programme could do.

This is something for which we have been campaigning for since the charity started, and while there is still work to do, the fact that this dream could soon become a reality is just wonderful.

We know screening for lung cancer works. We're seeing it in action with the Targeted Lung Health Checks, saving the lives of people like Harry (page 16). A national programme would mean even more people getting the chance of having their lung cancer caught at the earliest opportunity.

As significant as a screening programme would be, this is by no means the end of our work on early detection. A lung cancer screening programme would be no different to the existing programmes for breast, bowel and cervical cancers. There will be many people who won't be eligible for screening, and I know that is frustrating to a lot of you.

We remain committed to improve the early detection of lung cancer for everyone. On page 14 you can meet the newest member of our research grants committee, Cameron Millar, who is living with ALK+ lung cancer. We share his desire to see more research into genetic mutations, while on page 28, you can see the positive impact we're having with our symptom-based awareness campaigns, highlighting how anyone can be affected by this disease.

'Exciting' is a strange word to use in the context of lung cancer, but there is now a real momentum and I am truly hopeful that this time next year, I will be talking about the implementation of a national lung cancer screening programme.

*Paula x*  
Paula Chadwick  
Charity CEO

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# CHANCE TIMINGS SILVER LININGS

Figures from the National Lung Cancer Audit have given the first significant insight into the impact of Covid on lung cancer.

Surgery is down, emergency presentation is up, both pointing to later diagnosis.

However, with so much focus now on lung cancer care and ensuring its recovery, can something positive come out of the pandemic?



Richard Tunngley smiles as he sips his coffee. He's travelled down from his home in Knottingley, West Yorkshire to our head office in Liverpool to share his experience of being diagnosed with lung cancer during the pandemic.

From his demeanour you can be forgiven for assuming his story is a happy one. The reality is very different; the pandemic clearly played a part in delaying his diagnosis.

After contracting Covid in March 2020, Richard was left with an aggressive cough. He had several telephone consultations with his GP, but the pandemic meant he couldn't get a face-to-face appointment until August, when he saw a nurse. Following three x-rays and a subsequent CT scan, Richard was eventually diagnosed with stage 4 lung cancer, just before Christmas.

"I'm not angry about the time that it took to get the diagnosis. Obviously, the whole world was going through an unprecedented situation with the pandemic and people were trying their very best to control the situation. It's just a fact of life that at that moment, when I probably needed to see a GP, it just wasn't possible.

While my cancer is not curable, it is treatable, and I am so grateful for that. The targeted treatment I am on allows me to lead a normal life. I'm suffering very minimal side effects, and I'm doing all the things that I've done prior to my diagnosis.

I am a very positive type of person. I always try and see the best in things, so for me now every day is an extra day and life continues; there's laughter, there's tears, there's arguments, there's celebrations. It's normal."

### Dealing with the unknown

Sadly, Richard's story is not uncommon, even without a global pandemic. The nature of lung cancer and its often vague symptoms mean that many people yo-yo back and forth to their GP before being referred.

In many ways, Covid remains an unknown entity and healthcare professionals are left unsure of its potential long-term effects. So, when Bettina contacted her GP, having had Covid, and was starting to get short of breath, immediate action was taken.

"I first contracted Covid near the beginning of November and was still testing positive towards the end of December," she says. "I then woke up one morning and found myself quite breathless. My son, who is a GP, said I should contact my doctor. I did, and she referred me straightaway to the hospital.

I was diagnosed with pneumonia and given antibiotics. I was then asked to return for a second chest x-ray a few days later. It was after the second x-ray that I was then sent for a CT scan and referred to a lung specialist.

After a series of tests, I had an appointment to see a consultant. Lung cancer was not on my mind; I had presumed this was all Covid-related and so I didn't take anyone with me. So, the diagnosis came as a complete shock."

Bettina has since had surgery, undergone chemotherapy, and is now on a targeted therapy. This was recently approved for patients with early-stage EGFR+ lung cancer, after studies showed it halved the risk of recurrence.

"It was an aggressive treatment plan," recalls Bettina. "I really struggled with the chemotherapy. I wanted to quit after two rounds, and the targeted therapy, though milder, is not without side effects.

"But it has been worth it, especially as my first grandchild was born at the end of last year. She's a joy. I'm now back out walking my dogs. We walk two miles every day. Life is good - and I have Covid to thank for that."

Timing was on Bettina's side. Having just witnessed the devastating effects of Covid on the world over the past year and with very little then known about long Covid, investigation into her symptoms was swift.

### Fighting with foresight

However, there is now concern that the presumption of long Covid could mask potential lung cancer symptoms and delay diagnosis. It's a worry that is shared by Bettina's eldest son, Dr Chris George, a general practitioner in Cambridgeshire.

He says, "I don't think Mum would have been referred as quickly had she not had Covid. In fact, I'd go as far as saying Covid probably saved her life.

However, I know Mum's case is rare, and that in general Covid has led to fewer people being diagnosed. They have followed government messaging, and often experienced difficulty getting appointments. It is absolutely vital now that we do not see similar delays because of long Covid and the crossover of symptoms.

Mum's diagnosis has had a huge impact on my awareness of lung cancer. I have learnt so much more about the symptoms and broad range in which people can present. I am proud to be working with, and supporting, Roy Castle Lung Cancer Foundation in improving awareness among the general public, and GPs like myself."



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Chris's desire to avoid history repeating is one he shares with Richard.

"My advice to anyone experiencing the symptoms that I had would be to really consider going to see a GP," Richard adds.

I'm a typical male. I wouldn't normally go to bother a doctor. I don't usually see a GP, but if a cough isn't going away, then there's a reason for that. You need to go and get checked out if you have those symptoms. It's really important.

I don't want people to have to go through what I've done. It's not just the individual, but their families too. It affects the family so much, and if I can help someone to get an early diagnosis, have treatment and have a successful outcome then I'll have achieved something."

**If you have any concerns about symptoms, or are struggling to speak to your doctor, please contact our Ask the Nurse team by phone or email:**

**0800 358 7200**

**[lungcancerhelp@roycastle.org](mailto:lungcancerhelp@roycastle.org)**

**I think Mum would have referred as quickly had she had Covid.**

**As far as saying Covid probably saved her life.**

# Road to R

Where do you see yourself in five years? It's one of those standard interview questions asked when possibilities seem endless.

However, the same question to someone with lung cancer holds far greater weight.

Traditionally seen as a benchmark when the chance of recurrence is no longer likely, the five-year milestone remains a point that sadly too few people reach.

Things were starting to change. Pre-pandemic, real progress was being made in raising five-year survival rates, and hopes were high of achieving a 25% five-year survival rate by 2025.

We now find ourselves facing the possibility of a drop of up to 5.3% in five-year survival in England - from 17.6% to around 12.3%.

Familiar with adversity, our charity is among those agencies rallying together to ensure the progress made prior to the pandemic is not lost.

"We are starting to see the true extent of the impact of Covid on lung cancer, and it is devastating," declares our chief executive, Paula Chadwick.

"A significant drop in surgery and increase in emergency presentation both point to later diagnosis. This is reflected in the many conversations we are having with patients whose diagnoses were delayed because of the pandemic.



## Give Way to Optimism

"I don't think I realised how much my life had been subconsciously on hold until I heard those words," recalls Mande Lucas, who received her five-year 'all clear' this January.

"I was absolutely convinced that I wouldn't get to this point. Statistically, being diagnosed at stage 3, I had around a 15% chance of surviving for five years. But I guess that just proves that statistics should

be taken with a pinch of salt! That said, at the time, it is often easier to think, or fear, the worst.

For me, that has never really changed. I suffer from terrible scanxiety, and especially at my five-year scan. It felt like there was even more riding on it. By the time that day finally arrived, my fear was through the roof. It was the longest week of my life.

# Recovery

Sadly, we cannot change this. We will, and we are, supporting those living with this shattering reality. We must also take every possible step to minimise the number of lives being lost.

Awareness campaigns like our own Spot the Difference are vital to improving awareness. Targeted Lung Health Checks and lung cancer screening can also play significant roles in the recovery of lung cancer, earlier diagnosis and improved survival.

To do this however, we will need to address the growing workforce shortages within the NHS. For that to happen, the Government needs to step up.

I don't just mean by setting targets. It must invest in the cancer workforce.

Then we can really start to recover, rebuild and restore the hope that long term survival for lung cancer is possible."



TARGETED  
LUNG HEALTH  
CHECKS AHEAD



ROY CASTLE  
LUNG CANCER  
FOUNDATION

Now it's all about looking after myself, planning my retirement, and my work with Roy Castle Lung Cancer Foundation to help others reach this milestone.

I fully intend to live my life, not sweat the small stuff and celebrate every birthday like it's my 21<sup>st</sup>. because old age is a privilege not afforded to everyone and it's something I'll never take for granted."



a lot more

# Conver

an

**Cathy Brokenshire lost her husband, James, to lung cancer in late 2021. Now, as time starts to heal the most painful of wounds, Cathy is taking up James's mantle and joined us in our campaign for lung cancer screening.**

"James had a moral compass," she says. "He always wanted to do good and help people. That's why he went into politics.

When he was diagnosed with lung cancer, this became another thing he wanted to try to make better. Now, that's what I'm trying to do. If I can help prevent one other family having to go through what I've been through, it's a win."

Cathy's support started immediately after James's death on 7<sup>th</sup> October when she set up a Lasting Tribute page, asking those who knew James to donate. The Tribute currently stands at over £86,000 and is full of wonderful memories of a man who transcended political allegiances.

James was never one to court publicity while Cathy did everything she could to avoid it completely. However, after experiencing the devastating consequences of this disease and recognising the impact of the pandemic on lung cancer, she bravely stepped out of her comfort zone and shared her story.

## **The media took notice**

On a blustery January day on platform 7 at Cannon Street Station in London, a simple ceremony was held to mark the naming of a train in honour of James. It also marked the start of a media frenzy, with Channel 4 News, Good Morning Britain, BBC Breakfast and many other media outlets scrambling to give airtime to Cathy and her important message.

Joined on the BBC Breakfast sofa by patient advocate and charity trustee, Mande Lucas, Cathy



# sation d even more Action

publicly called for a national screening programme for lung cancer, just as her husband had done in parliament back in 2018.

“Our stories are very different,” notes Cathy. “Mandee is five years all clear, whereas I sadly lost James. But, hopefully, we can team up and create something. We’re calling for national screening. That’s the end goal, but it’s also about raising awareness along the way. It’s that ripple effect, of getting people talking about it and breaking down the stigma attached to lung cancer.”

Sadly, James can’t continue that fight but I’m here and I’m willing, ready and able to do that. We want a lot more Mandees and far fewer Jameses.”

## Immediate impact

On the day of the BBC Breakfast interview, enquiries to our helpline rocketed by 540%. Our amazing nurses were answering questions about symptoms from worried viewers, and providing support to those already living with lung cancer who had been made aware of the help we offer.

“We’re calling for national screening. That’s the end goal but it’s also about raising awareness along the way. It’s that ripple effect of getting people talking about lung cancer.”



News



**“Just found your site after watching BBC Breakfast today. I have downloaded your booklets and will read them later today. I would like to thank you for this information.”**

**There was also a 284% increase in visits to our Signs and Symptoms webpage, as viewers took on board Cathy and Mandeel's advice and sought to remedy any gaps in their knowledge about potential symptoms.**



## Turning words into action

The National Screening Committee has now launched its public consultation on lung cancer screening. This allows professionals, organisations, and the general public to share their thoughts on lung cancer and a screening programme. All responses will then form part of a review before a decision is made.

“This is incredible news and takes us a significant step forward in achieving a national screening programme for lung cancer,” adds Cathy. “I wish James was here to

see the progress we've made but I know he'd be so proud.

It's quite overwhelming to think that soon screening for lung cancer could be a reality, helping more people to live though lung cancer than die of it. That was James's wish and I hope it's about to come true.”

Roy Castle Lung Cancer Foundation is urging everyone affected by lung cancer to make their voices heard and submit comments to the consultation before it closes on 8<sup>th</sup> June 2022. For more information visit:

**[roycastle.org/screening](https://roycastle.org/screening)**



# NO Brave Faces Required

We know it can be difficult to talk about lung cancer with your loved ones.

Our online and phone support sessions connect you to others who truly understand what it's like to live with lung cancer so you can take your brave face off for an hour.

We currently have places available for our online support sessions:

- Managing During Treatment
  - Living with Lung Cancer
  - Genetic Mutation Driven Lung Cancer Support
  - Support for Carers

[roycastle.org/lungcancerconnect](http://roycastle.org/lungcancerconnect)

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# Life on a watch & wait regime

Kerrie Mitchell's Story

**"I really wish they would use a different name for palliative care."**

I remember when my oncologist told the nurse to refer me to the hospice for palliative care. I thought 'What the hell?! I'm being sent off to die.'

My whole world just came crashing down at that point. I wasn't ready for this. *I didn't want to die.* There was still too much to do. It didn't make any sense.

I now know that palliative care is very different to end of life care.



### Treatment trauma

I had been on a treatment regime of immunotherapy, pembrolizumab and carboplatin along with pemetrexed chemotherapy for three cycles over three-week intervals. This was followed by maintenance of pembrolizumab with pemetrexed every three weeks for up to two years.

After eight rounds of treatment, I had to stop. My immune system had gone into overdrive and caused ulcerated colitis, an inflammatory bowel disease. The colitis took around a year to subside, even with a very high dose of steroids and two infusions of infliximab. I was then told I couldn't resume my lung cancer treatment as it was far too dangerous.

I felt like the ground had been taken away from me again. The treatment had reduced my tumour by about 85% so the fact that I could no longer have it was terrifying. It felt like a death sentence all over again, thinking my cancer was growing and nobody was doing anything.

My oncologist assured me that she has other patients who also had to stop treatment and remained stable a couple of years down the line. Despite this, I still expected the worst, so when my first follow up scan came back stable, I was relieved, but it didn't stop that nagging feeling.

Another three months passed.  
Then another and the scans

were still ok. I was starting to feel a bit calmer, but certainly not complacent. I think that fear, that scanxiety, never goes away. I've learnt that you have to trust your medical team and stay hopeful.

### On the plus side...

There are some benefits of being on a watch and wait regime. My body is not being pumped full of chemicals. I see other people on treatment and they're having a really hard time. Their bodies are going through so much. I just count myself lucky that my cancer is ok for now. It's not better, but it's not worse either. It's ok.

It's not been easy, and I know there are lots of people who will be in the same situation as me. The best advice I can give is to keep talking. Get a counsellor. Ring Roy Castle Lung Cancer Foundation's support team.

Lung cancer is terrifying and it's traumatic but you don't have to go through it alone.

I also found some hope in reading the stories of other people who have had their treatment stopped, so I hope my experience has helped someone too.

I feel I've come to terms with the situation now and things feel normal again – well, as much as they can when you've got lung cancer. I've continued to work ever since my diagnosis, and now I'm fully up to date with my Covid jabs, I'm enjoying planning things again. I am so appreciative of everything I get to do and there's an element of freedom in not being tied to a treatment regime and I am loving discovering the world, one holiday at a time!"

# Dreams, dedication and... DISNEY?

Turning research concepts into reality.

"If you can dream it, you can do it."  
Walt Disney

Few people have ever made more dreams come true than the creator of Disneyland, so he clearly knew what he was talking about.

Our charity also began with a dream, one shared by two men – our founder, Prof Ray Donnelly and the late, great, entertainer, Roy Castle himself.



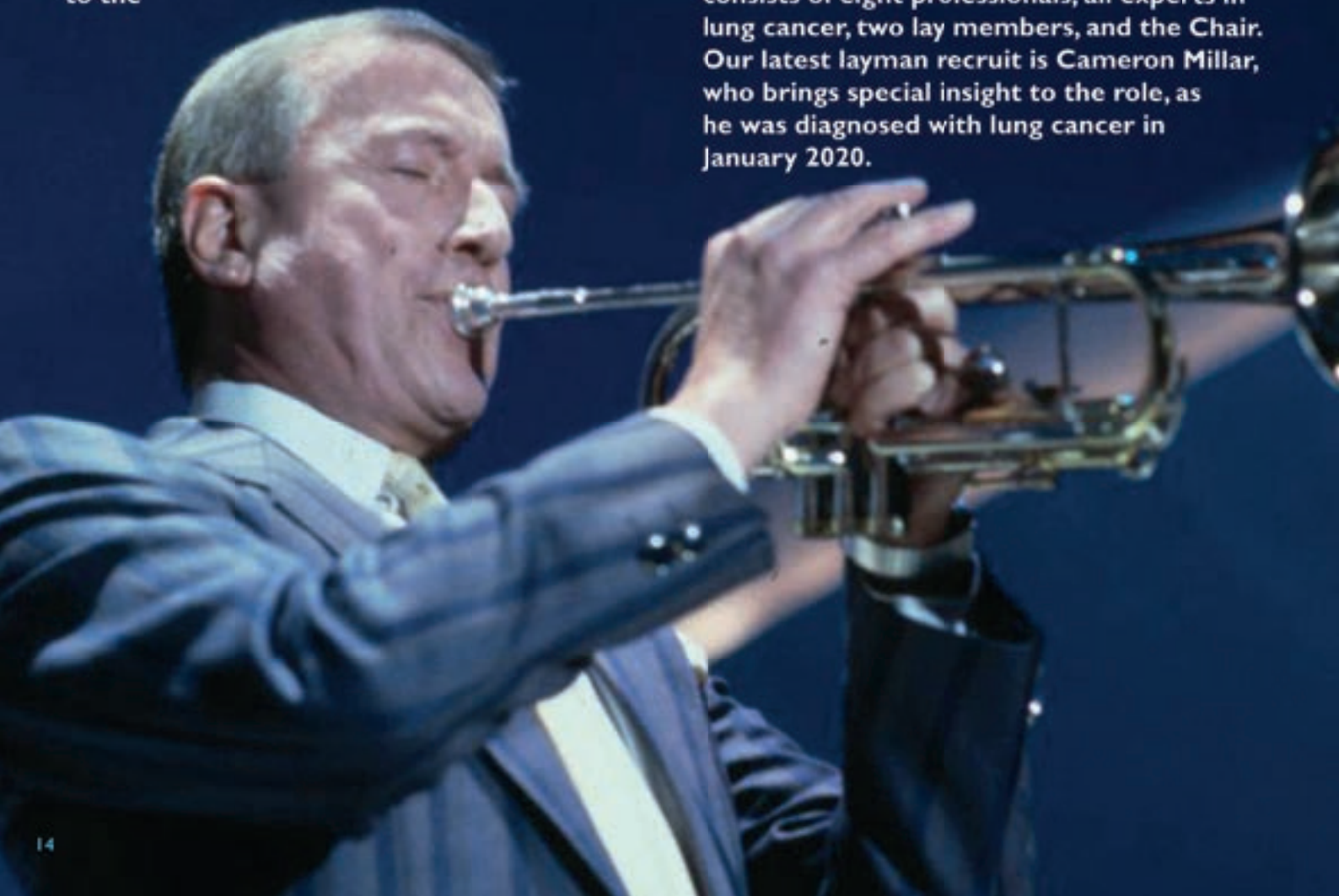
They both recognised that research was the key to tackling lung cancer, saving lives and improving outcomes. They dreamt of building the world's first centre dedicated specifically to lung cancer research, and thanks to the

astonishing generosity of so many people, they made that dream a reality.

The Roy Castle Research Centre building was completed in 1997, but quickly outgrew its original site. Nowadays, lung cancer research is carried out in laboratories, institutes and universities right across the globe.

This year marks what would have been Roy Castle's 90<sup>th</sup> birthday, but his legacy lives on. Nowhere is it more evident than in the many research projects we fund. From day one, our priorities have been early detection and improving the patient experience.

The task of deciding which applications to support lies with the people who make up our Research Grants Committee. This consists of eight professionals, all experts in lung cancer, two lay members, and the Chair. Our latest layman recruit is Cameron Millar, who brings special insight to the role, as he was diagnosed with lung cancer in January 2020.



"That was a complete shock", he admits. "But then I was then diagnosed as ALK+, so I can have targeted therapy.

"All of a sudden, my life was extended by years. I feel incredibly grateful for modern medicine.

"I'm really excited to be on the Research Grants Committee. Roy Castle Lung Cancer Foundation has the brand, it has the name, it's well-known, so I want to be involved.

"These days we're seeing a big percentage of people with lung cancer whose disease is not linked to smoking. We're looking at, what, 28% or so? And it could even be higher than that, because not every patient is getting the genomic testing when they're diagnosed because they don't fit the profile. That needs to change.

"More and more genetic mutations or re-arrangements are being identified as potential targets for therapies. We've seen during the pandemic just how quickly the scientific community can swing into action when they work in a coordinated way. We need to see more of that in the field of lung cancer."

Cameron brings extensive knowledge of working with others to represent the best interest of patients within medical structures. "I'm on the board of the NCRI, I'm a Patient



Trustee, so I represent cancer patients right across the UK. I put on my patient hat and listen to what's going on and think, yes, this is interesting.

"It takes an army of patient advocates to make an impact.

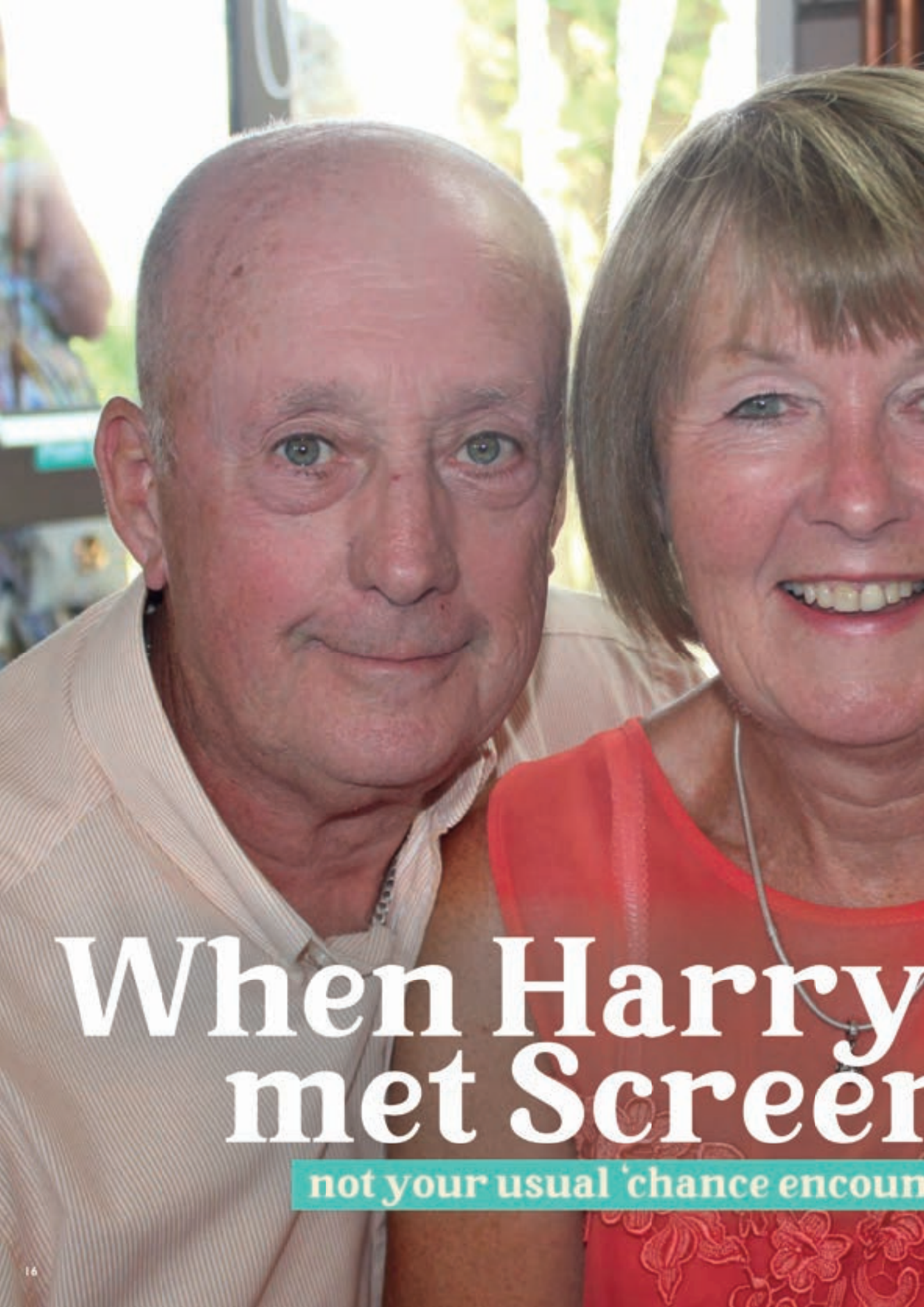
There are a lot of patients, and people who care for them, all keen to do something, but they just don't know which way to go, they don't know how to do it, so we have to coordinate and work together."

Cameron is right - the challenge is clear. We are proud that, even throughout the difficult days of the pandemic, we continued to fund research projects at universities and institutions across the UK. Several are now nearing conclusion.

Often this will result in publication of findings in a prestigious scientific journal, allowing the work to be accessed, evaluated, and shared by scientists worldwide.

Research is all about adding to our store of knowledge, piece by piece, building on the data and learnings shared by others. With people like Cameron aboard, there will be no shortage of dedication in assessing applications for our research funding to help make dreams come true.

***"This year marks what would have been Roy Castle's 90<sup>th</sup> birthday, but his legacy lives on."***



# When Harry met Screen

not your usual 'chance encounter





ning  
ter' cliché

## **“I thought I was pretty fit.**

**Then they confirmed I had a nodule in my right lung. They also found calcification of the heart, a problem with the parotid gland in my neck and mild emphysema. At that point, I thought Oh! Perhaps I'm not as fit as I thought!”**

**Harry chuckles as he recalls the results from his latest lung health check. Because he is able to laugh at it now.**

**After seeing an advert for his local targeted lung health check in Stoke, Harry went on to be diagnosed with early-stage lung cancer. He has since had surgery to remove the tumour and is recovering well.**

**Had he not gone for that appointment, it would have been no laughing matter.**

**“I can't believe how well the operation went, and how well I felt. I was a bit concerned about how much pain I would be in after having such a big operation, but I needn't have worried. I had no pain at all, and now I'm back to my old self. There's nothing that I can't do.**

**Absolutely nothing.**

**I honestly don't know what would have happened had I have not gone for the check-up. I don't think I would have gone to my doctor with the cough or the breathlessness because I just presumed it was one of those things. I probably would have carried on in the same vein and things would have got worse. Instead, I can look forward to growing old.”**

**While many of us joke about getting older, the truth is we take it for granted. Sadly, for many with lung cancer, it won't happen. However, with the relaunch and expansion of targeted lung health checks in England, the tide is starting to turn.**

**After being forced to pause during the peak of the pandemic, Targeted Lung Health Checks in England are now getting back on track, with 77% of cancers diagnosed at stages 1 or 2.**

**A further 27 programmes are set to launch this year, making 50 in total, with approximately 20% of England now having access to a check. The key now is ensuring that those who are invited actually attend.**

## But I feel fine...

Harry attended his appointment without any apprehension. He thought he was fit and healthy and so never expected to be diagnosed with lung cancer.

And he is not alone. Jo Shoba attended a similar programme in Liverpool. She too had no symptoms but went on to receive a diagnosis. This is what makes these programmes so vital.

With a disease as serious as lung cancer, it is hard to believe that the symptoms don't match up, that there is not a clear and obvious sign that danger is afoot.

This is the nature of the disease; symptoms often don't get our full attention until it is too late, or in some cases, they are not there at all. Lung health checks allow us to get ahead of lung cancer and stop it in its tracks, and this is the message we are trying to make clear as we support programmes across the country.

Using social media, outdoor advertising and community engagement events, we are working hard ensure everyone who is invited for a lung health check makes an appointment - even if they feel fine. Just as people would go for a mammogram or cervical screening or send off their bowel cancer home test kit - it's a matter of course, rather than because something isn't right. And it's working.

The relaunch of the Liverpool programme in the northern part of the city saw a 52% uptake rate. Prior to our involvement, uptake had averaged around 40%.

It's a similar success story in Mansfield and Ashfield, with almost three quarters (72%) of people opting in.

As part of our activity here, we interviewed a lady called Terri.

Although she wasn't diagnosed through the lung health check, her lung cancer was caught early, and she was keen to share her experience:

"I've been able to enjoy six more years of my son's birthdays, sharing times with him. He's left home now but we still go to music festivals together. We go to gigs, and we're creating lots of memories, whereas, if I hadn't gone to the doctors, I might not have been here to share these memories."

"I think early detection is why I'm urging anyone for a lung health check."

You've got nothing to lose and everything to gain. I'm proof that with early diagnosis you can go on to live a long and happy life."



The National Screening Consultation on a national scale.

From 11<sup>th</sup> March until the 8<sup>th</sup> June, we will be conducting a consultation on lung cancer from professional staff, patients and family members.

All responses will then form part of a consultation which, if implemented, a lung cancer screening programme.

For more information and to sign up, visit

[roycastle.co.uk](http://roycastle.co.uk)

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Committee has now launched its public  
lung cancer screening programme.

une, the NSC is currently accepting public comments  
nals, organisations and members of the public, including  
who have experienced the disease.

part of a review before a decision is made. If  
screening programme would cover the whole of the UK.

share your experiences, visit:

[nsc.org.uk/screening](https://www.nsc.org.uk/screening)

Wales hopes to launch  
its Targeted Lung  
Health Check  
programme later this  
year, while work is  
underway to see how  
programmes could  
operate in Scotland  
and Northern Ireland.



For more information  
about Targeted Lung  
Health Checks  
and lung cancer  
screening,  
please visit:

[roycastle.org/tlhc](https://www.roycastle.org/tlhc)



# **T**hinking nothing of it *means everything*

Carolyn Sotelo, or 'Pip' as everyone knew her, was not one for the limelight.

But after leaving a gift in her will, her partner Mike, wanted to show that even in death, Pip's legacy of kindness lives on.

**"Pip had always been generous. She had always given to charity throughout her life and she knew she wanted to do the same when she died. If we ever had a fight, she would laugh and say 'Well, that's less for you and more for the charities!'"**

**Pip chose to remember many different charities in her will. There was a real eclectic mix – from cancer charities to animal ones. Given her diagnosis, Roy Castle Lung Cancer Foundation was an obvious choice and major benefactor.**

**Pip was diagnosed with lung cancer in 2019, a day before my 70<sup>th</sup> birthday. It came completely out of the blue. She had had absolutely no symptoms. We were at the bus stop on our way to get supplies for my birthday party when she began to feel unwell. We went home and she had a seizure.**

**Scans revealed a brain tumour which was operable. However, we soon learnt that the brain tumour was a secondary cancer and the primary tumour was in her lung. We knew then that palliative care was our only option and she started on chemotherapy and immunotherapy, of which she had 29 cycles.**

**Upon learning this, Pip was adamant that she wanted to support charities in her will, and particularly smaller, more specific charities like Roy Castle Lung Cancer Foundation. Pip had been a heavy smoker, although quitting over ten years ago, but she knew many people get lung cancer despite never smoking. She wanted to help the charity find out more about the other causes of the disease.**

**Pip gave selflessly, she would probably hate the fact that I am sharing this with everyone. She didn't like the limelight but I am just so proud of her and I want her endless generosity to be remembered. It gives me great comfort to know her legacy could help save the life of someone else."**

**“It’s too late for me, but it’s not too late for my children and my children’s children.”**

**This year would have marked Roy Castle’s 90<sup>th</sup> birthday.**

**Though taken too soon, Roy left a vast legacy.**

**It’s why we’re here.**

**You too can change the landscape of lung cancer for generations to come by leaving us a gift in your Will.**

**Learn more here:**

**[roycastle.org/leavealegacy](http://roycastle.org/leavealegacy)**





# Take to the SKIES

Samantha Cullen has seen both sides of lung cancer. In 2011, her gran Sylvia was diagnosed and had surgery. Eleven years on she remains cancer-free. Sadly though, in that time Samantha has lost her Papa in 2015 and then her other gran, Chris, just last year. After two previous failed attempts, Samantha took to the skies to honour of all three grandparents.

"I have always wanted to do a sky dive since I was young, but never really had a cause," she says. "But since lung cancer has had such an impact on my family, it felt like the right time to finally take the leap.

My sky dive was rescheduled twice, with the weather thwarting the first two tries. Finally, third time lucky, and I couldn't have asked for a better day! The sun was shining, and I was bursting with excitement.

When the doors opened, it was very loud. Then everything happened so fast. I thought they'd count down from three but no, we were out on two!

Those first few seconds out of the plane were amazing. Words cannot even describe it. It's just the most blissful feeling in the world.

The freefall is over so quickly before you're yanked by the parachute, but then you get to take in the sights like never before.

Because it was such a lovely day, I had the most beautiful views of Scotland. I was even able to fly the parachute. We did spins all the way down! It was one of the best things I have ever done and want to do it again already, especially if it means we can raise more money for the foundation.

It's such an important charity. The research it funds, the support it offers, all the awareness it raises - I'm so glad we've been able to help in some way. Awareness is so important - now more than ever. It can be the difference between an early and curable diagnosis or a late and incurable one.

My gran Sylvia was diagnosed early, and she's still here. She was still smoking at the time but the moment she was diagnosed, she quit. She said, 'I wanted to live to see my granddaughter get married, so the fags are gone.' I recently got engaged, so it looks like she will get her wish!

Sadly, my Papa and other gran Chris weren't as lucky. Papa Cullen, or Jokey as he was known, passed away from lung cancer seven years ago. He loved to go to his local bowling club. It was his favourite pastime. I

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think it's likely his lung cancer was caused by the passive smoking from his clubbing days - just like Roy Castle himself.

My gran had many symptoms. She was always out of breath - stairs were a real struggle for her. She also had a continuous cough and a raspy voice. Despite all this and our family history, she was sent home with nothing diagnosed and only a few water tablets. If it hadn't been for my dad's persistence and taking her to the hospital, who knows when, or if, she'd have been diagnosed.

I just want people to know what the symptoms are and that if they have any of them they should go and get checked. Coughs are now so quickly put down to Covid, or simple chest infections.

But they can be so much more than that. We found that out the hard way."

**You too can take to the skies to  
raise money like Samantha.**

**Join us for our Skydive Day  
2<sup>nd</sup> July:**

**[www.roycastle.org/skydiveday](http://www.roycastle.org/skydiveday)**



# Biopic

Picture the scene... 28-year-old woman given just weeks to live. Then the phone rings with a life-saving solution. Two years later, the woman is fit, well and has no evidence of disease.

It sounds like the plot of a movie, but this is not make-believe. This is Becca Smith's story, made possible by a biopsy and a wealth of new treatments:

"It was my mum who answered the phone. I was bed-bound and on oxygen at this point. My friends had even started to come and say their goodbyes.

The lady on the phone was jumping for joy. She explained they had found this ALK+ mutation from my biopsy. We didn't really understand what that meant at the time but knew it must be good news and there was a different energy in the house after that phone call."

People diagnosed with non-small cell lung cancer now have their tumours routinely biopsied for genetic mutations. Depending on the location of the cancer, this may be a bronchoscopy, thoracoscopy, mediastinoscopy or CT guided biopsy. A small sample of cells is taken and tested. The results can then shape your treatment path.

In Becca's case, her biopsy identified the anaplastic lymphoma kinase positive (ALK+) mutation and she immediately started on a targeted therapy. Two years on, and with an upcoming 30<sup>th</sup> birthday celebration in Italy, Becca is not only surviving, she's thriving.

"What started out as a nightmare, now feels more manageable. Liveable. My latest scans have shown no evidence of disease (NED) and whilst I know the cancer has not gone, the medication is doing its job and I believe my holistic approach to life is also playing its part.

I tell myself that my lung cancer is like a chronic illness. There are people that live with MS. There are people that live with this. I take tablets every day, but my life continues."





# c of a Biopsy

“My experience shows just how important it is to have your tumour re-biopsied.

When I was first diagnosed I had no genetic mutations. Now I do, and a new lifeline to boot.”



## ***Not a one-time thing***

Biopsies should not just be part of the initial diagnosis.

“As a cancer grows, it adapts to its surroundings, evolves and spreads,” explains Dr Mike Davies, Roy Castle Lung Cancer Foundation Senior Research Fellow at the University of Liverpool. “This means when we treat cancers with drugs or radiotherapy, it can develop so that the therapy stops working and the tumour starts to re-grow.

When this happens, it’s important to rebiopsy the tumour to try to determine how the cancer has evolved and look for new mutations. Results from the rebiopsy may give the opportunity for a more effective therapy, one that might not have been suitable originally, or not been available at that time.”

Nicky Peel was on a clinical trial, having exhausted all available treatments for her lung cancer and subsequent bone metastases. It was a gruelling regime of intravenous immunotherapy with concurrent chemotherapy tablets.

However, a new biopsy showed she now has the KRAS G12c mutation. At the same time, the first targeted therapy for this type of lung cancer was undergoing approval. Nicky’s consultant confirmed she qualified for the new treatment. The tumour has now shrunk by a third.

If you have any questions about biopsies, lung cancer tests or genetic mutations, contact our Ask the Nurse helpline on: 0800 358 7200 or email: [lungcancerhelp@roycastle.org](mailto:lungcancerhelp@roycastle.org)

# Remembering Katie Willcox

Losing a child at any age is every parent's worst nightmare. Sadly, for Lorna Leaver this nightmare became a reality when her daughter Katie died of lung cancer earlier this year. Still faced with a wave of emotions, Lorna shares Katie's story with Inspire to try and help others spot the signs sooner than they could.



I want something positive to come out of Katie's death. Because that's the kind of person she was.

Katie was determined and she was caring, so I want someone to benefit from our hindsight. Looking back now, I can see there were signs. We just didn't know what they were all pointing to – but why would we?

Katie was a 42-year-old woman. She loved her job as a Forest School Manager in a day nursery. She worked hard and had a wonderful social life. She was in the prime of her life and lung cancer wasn't even a passing thought.

The first 'sign' came in August 2021. I remember she mentioned she had backache. Later, she said that she was feeling extra tired and was sometimes breathless when going upstairs.

We now know these are all symptoms of lung cancer. At the time, we went for what seemed the more logical explanation - her bad back was due to her mattress, so she bought a new one, and the fatigue and breathlessness were aftereffects of Covid which she'd had the previous summer.

The next 'sign' came a few months later. Katie had a cough and a cold which she couldn't shift. She had several telephone conversations with various GPs, resulting in three courses of antibiotics and two courses of steroids. She then insisted on an x-ray, which showed a shadow. Even then lung cancer wasn't considered.

Then on 15<sup>th</sup> November, she arrived at work and was very short of breath. She took herself to the local Outpatients Department and was sent by ambulance straight to the Emergency Department of another local hospital where she was admitted and put on intravenous antibiotics.

She was released three days later, and felt much better. However, it was during the follow up investigations – various scans and a bronchoscopy and the referral to the lung nurses – that we realised it was something serious.

Katie was diagnosed with stage 4 lung cancer. It was inoperable and aggressive, and she deteriorated quickly. An infection delayed her treatment. She did manage one cycle of chemo and immunotherapy at the start of January but

suffered more complications so couldn't continue. We lost her by the end of the month.

In the short time since her death, I have gone through so many emotions – anger and sadness being top of the list.



*I can see there were signs.  
We just didn't know what  
they were all pointing to –  
but why would we?*

Then, just a few weeks after Katie died, I saw Cathy Brokenshire, the wife of the late MP James Brokenshire, calling for early detection and screening.

Katie had read one of the foundation's booklets which she found helpful, so we were aware of the charity and decided we wanted to try and help.

And this brings me back to where I started, wanting to highlight Katie's experience to try and prevent someone like her going through something as awful as we did.

Early diagnosis can make a world of difference but there are still some real hurdles preventing people like Katie from being diagnosed sooner.

The belief that lung cancer only happens to older people who were heavy smokers is totally untrue, but it took Katie's diagnosis for me to know this. I want people to know lung cancer can happen to anyone before it tears their family apart, because that knowledge can make all the difference.

There are many different symptoms of lung cancer, and many different causes. But one thing remains the same... the sooner lung cancer is diagnosed, the easier it is to treat.

This was the focus of our latest awareness campaign, **SPOT THE DIFFERENCE**, helping people spot any differences in their health – no matter how subtle - and encouraging them to take immediate action.

Working for the NHS, Tracy always tells her patients to give her the full story of their illness. So, when she had a second chest infection in the space of just a few months, she made sure she told her GP about both:

"Something just sort of clicked with him. He asked if I was normally fit and healthy which I am.

Like everyone, I have the odd cough and cold, but I usually shake them off quite quickly, so this was unusual for me. That was when my GP said he would like to send me for an x-ray."

This immediate action made all the difference. Tracy was diagnosed with early-stage lung cancer. A month after surgery, she went on holiday to Fuerteventura.

"I came out of hospital on the 21<sup>st</sup> May and was due to go on holiday on the 26<sup>th</sup> June. I spoke to my consultant, and he was confident I would be ok to go, so a month after having part of my lung removed, I went on holiday!

I obviously took things easy, but it was just wonderful. I then went back



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to work in October, and now life is totally back to normal.

I am just so grateful that the GP spotted that these chest infections were unusual for me and sent me for that x-ray. But I'm also relieved that I made sure I told him the full picture. If I hadn't mentioned the previous chest infection, if I had just dismissed it or thought it wasn't relevant, then things might have been very different."

### NOT ALWAYS SO SIMPLE

Sadly, Tracy's case is not all that typical. Often vague in nature, lung cancer symptoms are easily dismissed as something else – by both the patient and healthcare professionals, and even more so since Covid.

Nick was seeing his doctor for nearly two years with several symptoms, including a persistent cough.

Under the guidance from the National Institute of Health and Care Excellence (NICE), he should have been referred for an urgent chest x-ray. Instead, his lung cancer went undetected until he eventually coughed up blood:

"I constantly mentioned my cough to my doctor, but I was repeatedly told that I didn't need to worry because it was just 'a smoker's cough'. So even when the cough got worse, I wasn't that concerned. I was still smoking, so it made sense.

However, while I was working away, I coughed up some blood.

That's when I did start to worry. I went to A&E, and this was the



Catherine Groat Called the doc about this today. Going to see him tomorrow. 😊😊 thank you

Like · Reply · Message · 5d



SPOT THE DIFFERENCE



the start of my diagnosis.”

Fortunately, Nick was still diagnosed early enough for curative-intent treatment, undergoing both surgery and chemotherapy. He has even been able to return to scuba diving. However, it could have been a very different story:

“Looking back on my diagnosis, I can see that there were many missed opportunities. I think one of the reasons I wasn’t sent for an x-ray earlier was because of how fit I was. As a scuba diver, my lung capacity is good, so I wasn’t having any shortness of breath. I wasn’t tired and I wasn’t losing weight, I think it was put down to just being a ‘smoker’s cough.’

I don’t lay any blame. I accept that a GP can’t be expected to know every symptom for every illness. But I do wish I had been referred sooner than I was, and I just hope that campaigns like Spot the Difference can educate GPs and help them to recognise sooner the need to refer a person to somebody more specialised, or to at least send them for an x-ray.”

Nick’s story was featured in the campaign’s primary care toolkit and distributed to GPs across the country. Dr Afsana Bhuiya, GP Cancer Lead for the North Central London Cancer Alliance, described the toolkit as ‘really helpful’.

Charlotte Beames from C the Signs, a digital tool to help GPs identify patients at risk of cancer at the earliest and most curable stage of the disease, also found it ‘a fantastic resource’.

### THE DOCTOR WILL SEE YOU NOW?

However, there remained another consequence of the pandemic; the ability to see a doctor face-to-face became a real challenge. So, upon hearing the advice to contact their GP if they were experiencing symptoms, many scoffed at the prospect.



"I think the first thing is to be persistent," advises Carol Stonham, primary care nurse and executive chair of the Primary Care respiratory society.

"It's very easy to request an appointment and be brushed off and feel that's the end of it. It absolutely must not be the end of it. It's up to you, as the patient, to make sure the person you are talking to realises what the problems are, that they are persistent and ongoing and should not be brushed off.

"Saying the words 'I think I might have cancer' are really hard, but if that's what you think is happening, it's really important that you tell someone that's what your fear is. Then you'll be taken more seriously."

When it comes to lung cancer, there are so many different experiences, from the symptoms, to the speed of diagnosis, treatment received and especially outcomes.

Tracy's story was as straightforward as they come. Nick's was far from perfect. But thankfully, they both had a similar happy ending.

It's our hope that campaigns like Spot the Difference, which help raise awareness and validate even the most subtle of symptoms, will continue to make a difference, so more people can have positive outcomes like Nick and Tracy.

The key is persistence. If your symptoms are persistent, you need to be too. Insist on seeing a doctor. Be polite but be persistent, and when you do have an appointment, be prepared. Make notes of all your symptoms and concerns before your appointment so you can give the doctor the full picture.

Chase up appointments and test results. Don't just wait for them to call.

If you have had a course of antibiotics and they haven't worked, don't just accept another round. Explain that they haven't helped and ask if there is anything else you can try or if it needs to be investigated further. This can make all the difference.

**YOU CAN  
BE THE  
DIFFERENCE**

# Cor,

## they narf pack a punch!

When Katie Talbot lost her dad John last year, she wanted to do something to honour him, pay tribute and support a charity that helps raise awareness of lung cancer.

So, following in her dad's footsteps, she headed to the kitchen to master John's signature pickled onion recipe...



*Onions weren't on the day's menu (fortunately...)*



*I remember watching...*

"Dad found cooking a bit later in life and developed a real love for it. He came up with his pickled onion recipe all by himself. He really enjoyed making it and it soon became a Christmas tradition.

Mum would get all the supplies and then he'd commandeer the kitchen for the weekend. The radio would be retuned to Absolute 80s.

He'd have a few cans of his favourite beer, and off he went, with the grandchildren running round his feet. Everything was just as he liked it.

He loved hearing about, or watching, people taste them, and enjoy the 'crunch' and the heat. I remember one year he took great pleasure in watching one particular batch 'blow my head off'!

My husband Lew also got in on the action, and made a couple of jars. Dad and Lew were great friends. They shared a love of Manchester United, 80s music, beer and cooking.





*Remember one year he took great pleasure in one particular batch 'blow my head off'!*

When Dad died, it was Lew's idea to make Dad's pickled onions and sell them to honour Dad and raise money for Roy Castle Lung Cancer Foundation.

I think we made about 30 jars, but we could easily have sold more than 50. They were in great demand from family and Dad's friends. Lew has even been asked by some pub chains for a large batch!

I chose to support Roy Castle Lung Cancer Foundation to help other people, especially men, get diagnosed earlier. My dear dad was such a proud, hard-working, working-class man who never put himself or his health first.

Even though he was so smart, he couldn't see that his symptoms were severe enough to have them looked at. He hated fuss and thought he was 'alright'. But, by the time he was diagnosed, it had already spread to his brain.

I do believe, though, we were given extra precious weeks with dad. He had a massive brain seizure in early June, and we were called to hospital in the middle of the night as they thought we were losing him. He went into a coma.

We spent the next 16 hours around his bedside, kissing him, hugging him, and playing his favourite music. Then, he slowly started to tap his fingers to Fleetwood Mac's The Chain. From there he regained full consciousness. We got him home, to wrap him in the love of our family and hold him tight until the end.

This is why it was so important to find a charity that is working on this specific issue. Men deserve to put themselves first, and sometimes they need that extra push to do that, which Roy Castle Lung Cancer Foundation is working hard to do. I'm really proud we've been able to help in a way that is special and personal to us too."



**WOMAC** 

WOMEN ON THE MOVE AGAINST CANCER

**When women get together, they are unstoppable, so we are delighted to be this year's charity partner of Women on the Move Against Cancer (WOMAC).**

Established in 1979, WOMAC is a group of female volunteers working in the automotive industry with the aim to improve the quality of life for people living with cancer.

"It is never easy to select our annual charities," explains Georgia Fox, Chair of WOMAC, "but after seeing the facilities available and hearing the support Roy Castle Lung Cancer Foundation provides, as well as our other charity partner, Maggie's, it's clear to see what a difference WOMAC's fundraising will make to patients and their families."

Upon announcing the partnership, WOMAC surprised us with an initial donation of £1,000 to kickstart our partnership and setting a £7,500 fundraising target, something Georgia is determined to reach:

"I can't wait to provide more to these worthy causes. The figures around cancer, and lung cancer specifically, are terrifying and now with the added burden of the rising cost of living, the work Roy Castle Lung Cancer Foundation does is simply vital.

We want to do everything we can to make the worst of times that little bit more bearable."

# Sisters are doing it for Each Other

When it comes to corporate partnerships, we think the clue is in the name. It is a partnership. We are eternally grateful for the donations we receive from our corporate supporters, but it is not just about receiving.

By working together, not only can we raise money to help everyone affected by lung cancer, we can also help increase awareness of the disease and its symptoms within their businesses, helping employees to reduce their risk and improve their health.

Contact us for information about how we can partner with you:

**[corporate@roycastle.org](mailto:corporate@roycastle.org)**

# I couldn't have done it without you...

No one should go through lung cancer alone.

Use your experiences to help someone who has been diagnosed with lung cancer.

Join our peer support network and make someone's experience of lung cancer just that little bit easier.

[roycastle.org/helpothers](https://roycastle.org/helpothers)

# INSPIRE

THE LUNG CANCER MAGAZINE



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**Head Office:**

Cotton Exchange Building,  
Old Hall Street,  
Liverpool,  
L3 9LQ



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