The Swallows®

Head & Neck Cancer Support Group

Registered Charity Number: 1149794

The Queen's Award for Voluntary Service

The MBE for volunteer groups

Patient & Caregiver Support

HEAD & NECK, LARYNGECTOMY, PATIENT AND CAREGIVER SUPPORT

INFORMATION BOOKLET

The Swallows®

Head & Neck Cancer Support Group

Registered Charity Number: 1149794

The Queen's Award for Voluntary Service

SUPPORT FOR ALL AFFECTED BY

HEAD & NECK CANCER

YOU ARE NOT ALONE

PLEASE JOIN US AT OUR MONTHLY MEETINGS

PATIENTS, CAREGIVERS AND FAMILY MEMBERS ALL WELCOME

MEET LIKE-MINDED PEOPLE AT OUR MONTHLY MEETINGS ACROSS THE UK

To find your local support group visit our website or call **01253 428 940**

24/7

OUR 24/7 PATIENT & CAREGIVER SUPPORT LINE SERVICE IS ANSWERED BY A REAL PERSON

(+44) 07504 725 059

TEXT (LARYNGECTOMY ONLY): (+44) 07830 929400

www.theswallows.org.uk

FUNDRAISING IS VITAL TO OUR CHARITY. OPEN YOUR PHONE CAMERA AND SCAN THE QR CODE TO DONATE.

theswallowscancersupport @swallowsgroup

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WWW.THESWALLOWS.ORG.UK

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Head & Neck Cancer Support Group
Registered Charity Number: 1149794

The Queen's Award for Voluntary Service

WHO ARE THE SWALLOWS HEAD & NECK CHARITY?

We are a UK-based, patient-led charity dedicated to supporting those affected by head and neck cancers - including patients, survivors, caregivers and their families.

Founded in 2012 by Chris Curtis, a survivor of throat cancer, the charity was born out of lived experience, compassion and the need for meaningful, practical support during and beyond treatment. Named after the simple yet vital act of swallowing (with which many head and neck cancer patients struggle) The Swallows symbolise resilience, survival and community.

OUR MISSION:

To ensure that no one faces head and neck cancer alone by providing emotional support, practical help, peer connection and access to trusted information.

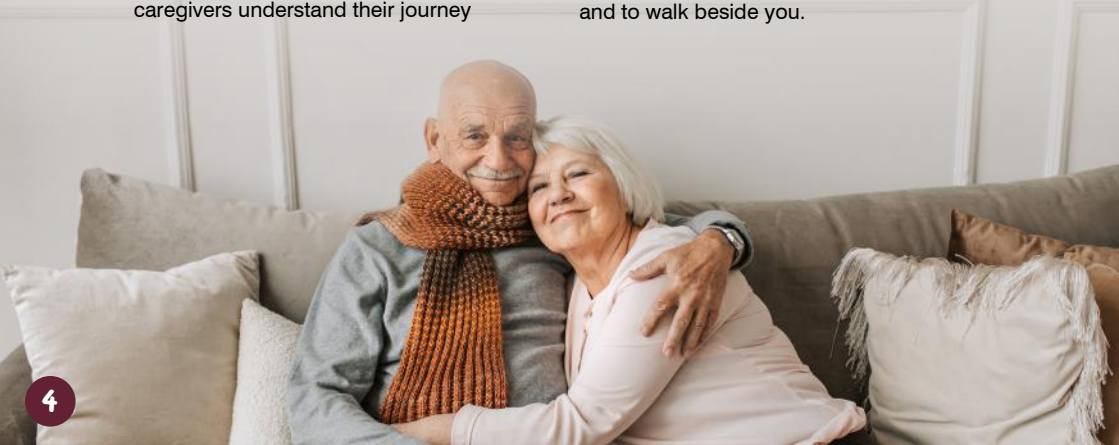
WHAT WE DO:

- Peer Support Groups
- Virtual and in-person support groups across the UK, led by people with lived experience
- 24/7 Support Line & Text Service - a listening ear at any hour:
  - Call: 07504 725 059
  - Text (Laryngectomy only): 07830 929 400
- WhatsApp Head & Neck and Laryngectomy Support Groups - private peer groups offering daily support and community connection
- Patient & Caregiver Support Boxes - thoughtfully curated packs filled with comfort items, helpful information and essentials
- Educational Resources - guides, videos and printed materials to help patients and caregivers understand their journey
- Caregiver Support - practical and emotional support for those who care for others
- International Head & Neck Cancer Conference - an annual event bringing together patients, professionals and researchers to share insights, support and innovation

OUR GOVERNANCE

The Swallows are governed by a committed Board of Trustees. We are supported by Charity Patrons, Advocates and a network of volunteers and professionals with lived experience.

Whether you're newly diagnosed, in recovery or supporting someone through their journey, The Swallows Charity is here to listen, to guide and to walk beside you.



WELCOME

TO ALL HEAD & NECK CANCER AND LARYNGECTOMY PATIENTS AND CAREGIVERS

When I was diagnosed with base-of-the-tongue cancer in 2011, nothing could have prepared me for the reality that followed. The treatment (radiotherapy, chemotherapy and two neck dissections) left me physically transformed and mentally exhausted. I lost over 12 stone in weight, struggled to swallow and, at times, struggled to find a reason to keep going. Like so many others I was overwhelmed - not just by cancer, but by the silence and isolation that surrounded it.

That's why we have created this book - not just as a guide, but as a lifeline.

Whether you're a patient recently diagnosed, someone navigating life after a laryngectomy or a caregiver trying to make sense of how best to support a loved one, this resource is for you. It brings together practical information, shared experiences and emotional support in one place, written by people who truly understand what it means to walk this path.

Through The Swallows, we have helped thousands of patients and caregivers find connection, hope and strength. Our 24/7 Support Line and Text Service, peer-led groups (online and virtual), patient boxes and educational materials all stem from the same belief: No one should face this alone.

This book is more than facts and advice. It's built on lived experience, the wisdom of survivors and the unwavering compassion of those who care. Inside, you'll find answers to difficult questions, stories of resilience and ways to connect with our nationwide support services, including our 'Head & Neck, Laryngectomy' WhatsApp group, 24/7 Support Line and 24/7 Text Service.

Above all, I hope this book reminds you that you are not alone.

There is life after diagnosis, there is support at every stage and there is a community ready to walk with you.

With strength, solidarity, and hope,
Chris

Chris Curtis
CEO & Founder, The Swallows
Head & Neck Cancer Charity
chris@theswallows.org.uk

'LAUGHTER IS THE BEST MEDICINE'

USEFUL INFORMATION FOR NEWLY DIAGNOSED HEAD AND NECK CANCER PATIENTS

Being told that you have head and neck cancer is overwhelming. You may be feeling frightened, uncertain and full of questions. Please know you are not alone. The Swallows Head & Neck Cancer Charity is here to walk this journey with you, every step of the way.

WHAT IS HEAD AND NECK CANCER?

Head and neck cancer includes a range of cancers that begin in the mouth, throat, voice box (larynx), nasal passages or salivary glands. It can affect speaking, swallowing, breathing, hearing and appearance but with the right treatment and support many people recover and live fulfilling lives.

WHAT IS HPV?

HPV (Human Papillomavirus) is a common virus that can infect the mouth and throat and is now known to be a leading cause of certain types of head and neck cancers, particularly those in the oropharynx (tonsils, base of tongue, and throat).

- HPV-related head and neck cancers often affect younger people, including those with no history of smoking or drinking
- These cancers often respond well to treatment and may carry a better prognosis
- HPV can be passed through intimate skin-to-skin contact, including oral sex

The HPV vaccine is now offered to both boys and girls in schools to help prevent HPV-related cancers in the future. If you've been diagnosed with HPV-related cancer, it's important to know you did nothing wrong. This is a virus that most people will encounter at some point in their lives.

WHY IS IT HARD TO TALK ABOUT THIS?

Head and neck cancer can impact parts of the body associated with identity and communication. That can make it difficult to speak openly about what you're experiencing.

You may feel:

- Embarrassed or self-conscious
- Afraid of changes in how you'll look or sound
- Unsure how to talk to family or friends

These feelings are normal and talking about them can be the first step toward feeling in control again.

WHO CAN I TALK TO?

You don't need to face this alone. The Swallows offers a wide range of support options from people who understand, many of whom have lived through head and neck cancer themselves.

- Trained support volunteers
- Survivors and caregivers
- Peer support groups (face to face & virtual)

We're here to listen, whether you want to ask questions, share feelings or just talk.

WWW.THESWALLOWS.ORG.UK

IS THERE A HELPLINE IF I'M STRUGGLING?

Yes. We offer a 24/7 Support Line and Text Service that's free, confidential and available any time of day or night:

- CALL: 07504 725 059
- TEXT (LARYNGECTOMY ONLY): 07830 929 400

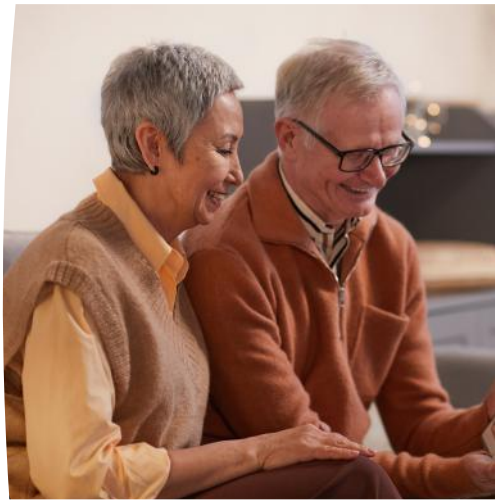
Whether you need emotional support, practical advice or just a friendly voice - help is only a message away (we cannot offer medical advice, please refer to your medical team for this).

CAN I MEET OTHERS WHO ARE GOING THROUGH THIS JOURNEY?

Absolutely. Meeting others who truly understand what you're going through can be incredibly reassuring and empowering. We offer:

- Virtual and In-Person Peer Support Groups
- WhatsApp Peer Support Groups, including our Head & Neck Support Group
- Events, Meetups, and Awareness Days

For details, visit **www.theswallows.org.uk** or email us at: **info@theswallows.org.uk**



YOUR LOCAL MONTHLY MEETING INFORMATION:

WHAT PRACTICAL SUPPORT CAN I GET?

We provide Support Boxes filled with helpful and comforting items tailored to head and neck cancer patients. These include:

- Dry mouth and skin care products
- Useful information leaflets
- Emotional wellbeing tools
- Items for comfort and recovery

Ask your nurse or support team to request one, or contact us directly on info@theswallows.org.uk

HOW CAN I LEARN MORE?

We offer a range of educational resources to help you feel informed and empowered. Visit our website or contact us to access these free resources.

REMEMBER: YOU ARE NOT ALONE

You didn't choose this journey but we chose to walk it with you. At The Swallows, we offer real talk, real support and real people who understand. Whether you're newly diagnosed, well into your treatment or a survivor we're here whenever you need us.

- SUPPORT LINE: 07504 725 059
- TEXT SUPPORT (LARYNGECTOMY ONLY): 07830 929 400
- EMAIL: INFO@THESWALLOWS.ORG.UK
- WEBSITE: WWW.THESWALLOWS.ORG.UK

OUR 24/7 PATIENT & CAREGIVER SUPPORT LINE SERVICE IS ANSWERED BY A REAL PERSON

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PAUL'S JOURNEY THROUGH HEAD AND NECK CANCER

My name is Paul, and in 2019 I was diagnosed with stage 4 tonsil cancer. I was a fit and active man, regularly at the gym and loving life. Hearing the words "you have cancer" was an unbelievable shock.

I underwent intense radiotherapy and chemotherapy, followed by a neck dissection. The treatment saved my life but it took a huge toll. I lost a lot weight, couldn't eat or speak properly, and spent months in and out of hospital.

I became isolated and overwhelmed. At my lowest point, I felt completely lost. What made the difference was finding the right support. A friend connected me with The Swallows Head & Neck Cancer Charity and, for the first time, I called the 24/7 Support Line at 3am and spoke to someone who I now know as Chris, and he truly understood. He had walked the same road, and his encouragement gave me hope.

Recovery wasn't easy, but I slowly rebuilt my strength. I began to train again. Small steps at first. Over time, I got back to the gym. It marked my return to life.

With the right support, you can come through it stronger. The Swallows gave me a lifeline when I needed it most. If you're struggling, please reach out.

There is always someone who will listen.

Paul, Head & Neck Cancer Survivor

USEFUL INFORMATION FOR NEWLY DIAGNOSED LARYNGECTOMY PATIENTS

SUPPORT FOR LIFE AFTER LARYNGECTOMY

Hope. Help. Healing Together.

Being diagnosed with head and neck cancer requiring a laryngectomy is life-changing. It's natural to feel overwhelmed but you are not alone. The Swallows Head & Neck Cancer Charity is here to support you through every stage of your journey.

UNDERSTANDING A LARYNGECTOMY

A laryngectomy is a surgical procedure to remove the larynx (voice box). After surgery, you will breathe through a permanent opening in your neck called a stoma. Speaking, swallowing and daily life will change but with time, support and training many people go on to live full, active lives.

The Swallows are here to support you every step of the way. You are not alone.

COMMUNICATION OPTIONS AFTER SURGERY

Losing your natural voice can be emotional. However, there are several ways you can learn to speak again:

- Text or written communication in early stages or as needed
- Electrolarynx: A handheld device that produces vibrations for speech
- Oesophageal speech: Learning to speak by swallowing air
- Voice prosthesis (TEP): A valve placed between the trachea and oesophagus to allow speech using air from the lungs

A speech and language therapist (SLT) will work with you to find the best method for your needs.

DAILY CARE AFTER SURGERY

You will learn how to care for your stoma, keep it clean and humidify the air you breathe. This is essential to prevent infection and keep your airway healthy.

Your healthcare team will support you with:

- Stoma cleaning routines
- Use of filters and heat moisture exchangers (HMEs)
- Nutrition and swallowing support
- Neck and shoulder rehabilitation

PATIENT SUPPORT BOXES

All newly diagnosed patients can request a Swallows Patient Support Box. These contain helpful items and comfort essentials chosen by survivors, including:

- Oral care items
- Information resources
- Emotional wellbeing tools
- Small gifts to lift your spirits

To request one, speak to your nurse or contact us directly by emailing:
info@theswallows.org.uk

CONNECT WITH US

The Swallows Head & Neck Cancer Charity is here for you. We support patients and caregivers every step of the way: before, during and after treatment. We can offer:

- Face-to-face and virtual support groups
- WhatsApp Group – Laryngectomy Support

Email us: info@theswallows.org.uk

FROM DIAGNOSIS TO TRIATHLON CHAMPION

I never thought I'd speak in public again. I was diagnosed with throat cancer in 2020 and underwent a total laryngectomy. At first, I felt frightened, isolated and unsure how I'd communicate or even live again. But then I found The Swallows.

Through their WhatsApp Support Group, 24/7 Text Line and practical help (including a support box and personalised recovery advice) I rebuilt my strength. They helped me learn to speak again with an electrolarynx, but more importantly they helped me believe in myself again.

Since then, I've not only spoken at events and supported others going through laryngectomy, but I've competed in multiple triathlons including open water swims, long-distance bike rides and running races - all post-surgery. Each finish line is a message to others: life after laryngectomy can be powerful, active and full of purpose.

I now mentor new patients and survivors and represent The Swallows with pride. I'm proof that this isn't the end, it's just the beginning of a different kind of strength.

Richard Andrews, Laryngectomy Survivor, Triathlete & Swallows Advocate

Final Note:
Whether you've just had surgery, are years post treatment or are caring for someone through recovery, we're here for you. No one should face laryngectomy alone.

HOW WE HELP:

Peer Support Groups: Virtual and in-person groups led by people with lived experience.

24/7 Support Line & Text Service: Help, advice or just a listening ear. Text us any time: 07830 929 400

WhatsApp

Laryngectomy Support Group: Daily peer connection, real talk, shared strength.

Support Boxes: Thoughtfully curated packs of essentials and comfort items.

Emergency Car Window Stickers: Vital for communicating in emergencies - always with you, just in case.

Caregiver Support: Because those who support others need support too.

Patient & Caregiver Education: Guides, videos and printable resources for every stage of the journey.

Annual Laryngectomy Focus Events: Part of our International Head & Neck Cancer Conference.

For Those Who Walk Beside You: Caring for someone after a laryngectomy can feel overwhelming. We're here to support family, friends and caregivers with:

- Caregiver support 24/7 (text or phone)
- Text 07830 929 400 (Laryngectomy only)
- WhatsApp community
- Educational resources

"As a caregiver, I found strength in the Swallows community. They helped me support my partner while caring for myself too."

USEFUL INFORMATION FOR NEWLY DIAGNOSED HEAD AND NECK CANCER CAREGIVERS

Caring for someone with head and neck cancer can feel overwhelming, especially at the beginning. You may be experiencing a mix of emotions: fear, confusion, exhaustion and love all at once. Here's some essential information and guidance to help you on this journey.

>> YOU ARE NOT ALONE

Thousands of caregivers support loved ones with head and neck cancer every year. Support is available for you, not just the patient. The Swallows Charity offers dedicated resources for caregivers, including peer support, 24/7 helplines and emotional check-ins.

>> LEARN ABOUT THE DIAGNOSIS

Understanding the type of cancer your loved one is facing (e.g. laryngeal, oropharyngeal, tongue, throat) and the treatment pathway (surgery, radiotherapy, chemotherapy) can help reduce uncertainty and empower you during appointments and care planning.

>> COMMUNICATION CHALLENGES

Many patients experience difficulty speaking, eating or swallowing - especially after surgery or during treatment. You may need to adapt to new ways of communicating (writing, apps, gestures) and support their speech therapy and nutritional needs.

>> ASK FOR A CARE PLAN

A Holistic Needs Assessment and Personalised Care Plan should be offered at the start of treatment. You can request this if it hasn't been provided. It helps clarify what to expect and how you'll be supported.

>> TAKE CARE OF YOURSELF

You cannot pour from an empty cup. Make time for sleep, food and emotional care. Join our support group, speak to your GP or talk to us at The Swallows.

>> CONNECT WITH OTHERS

Talking to fellow caregivers makes a world of difference. The Swallows offers virtual and in-person Caregiver Support Groups where you can share, listen and learn in a safe, understanding space.

>> KEY SUPPORT SERVICES

- 24/7 SUPPORT LINE: 07504 725 059
- TEXT SUPPORT (LARYNGECTOMY ONLY): 07830 929 400
- EMAIL SUPPORT: INFO@THESWALLOWS.ORG.UK
- WHATSAPP PEER GROUP: CAREGIVERS SUPPORT GROUP
- WEBSITE: WWW.THESWALLOWS.ORG.UK

YOU MATTER TOO!

Many caregivers feel overlooked. But we see you. You are doing an amazing job under incredibly tough circumstances. We are here every step of the way.

CAREGIVERS

I'M FINE — BUT I'M NOT...

BEHIND THE WORD "FINE" CAN HIDE A WORLD OF PAIN AND FEAR. YOU MAY FEEL:

- **Frustrated** by not being understood, by losing independence or by the slow pace of recovery
- **Isolated** from friends, family or work - feeling like no one gets what you're going through
- **Neglected,** sometimes unintentionally, in conversations, systems or even support services
- **Emotional** from the rollercoaster of diagnosis, treatment and everything in between

FOR THOSE WHO WALK THE LIFE OF A CAREGIVER

Caring for someone after a Head & Neck Cancer diagnosis can feel overwhelming. We're here to support family, friends, and caregivers with:

- Caregiver support 24/7 (text or phone)
- 1:1 phone support
- WhatsApp community
- Educational resources

"As a caregiver, I found strength in The Swallows community. They helped me support my wife while caring for myself too."

Andrew Hyde, caregiver to Jo (tongue cancer)

CAREGIVER STORY

SARAH'S JOURNEY BESIDE HER HUSBAND

My name is Sarah, and I became a caregiver overnight when my husband, Tom, was diagnosed with head and neck cancer. One day we were planning our retirement. The next, we were facing consultations, scans and the terrifying unknown.

Tom's diagnosis was devastating. Throat cancer after finding a small lump on his neck. He began treatment almost immediately: radiotherapy, chemotherapy and major surgery. I quickly realised this wasn't just his cancer, it was ours.

I became his advocate, nurse, nutritionist and emotional rock overnight. I managed his medication schedule, learned how to clean his feeding tube and monitored every sign of pain or exhaustion. I didn't sleep much.

I didn't eat properly. And I never really let anyone know how scared I was, I just said that I was FINE.

People asked how Tom was doing but rarely asked about me.

There were moments I felt invisible. Alone. Burnt out. Watching someone you love go through such suffering is heartbreaking. I put on a brave face, but inside I was crumbling.

Then I found The Swallows Head & Neck Cancer Charity and suddenly I wasn't alone any more. Their caregiver support group gave me a space to speak honestly, cry if I needed to and hear from others walking a similar path. They reminded me that it was okay to need help too.

Now, with Tom thankfully in remission, I want every caregiver to know: you matter too. Your strength, your love and your sacrifices are seen, and they're honoured.

If you're caring for someone with head and neck cancer, please know the charity is there for you.

Sarah, caregiver to Tom

PATIENT STORY

JOHN'S STORY

Life after laryngectomy:

Learning to live without a larynx

My cancer story began in February 2009 when I had a sore throat. Like most people I did nothing about it and at the time I didn't realise how severe it would turn out to be.

It wasn't until 4 months later that I had started to question whether this could be something far more serious so I finally went to see my doctor. He quickly referred me to the hospital where the specialist consultant diagnosed me with throat cancer.

My wife struggled to process the news, but for me it was no shock as I had a feeling that something wasn't right for a while. The first step in the treatment process was to try laser and radiotherapy. I had 15 rounds of radiotherapy and it wasn't until my final 15th session that I felt a severe pain due to the treatment. Unfortunately, neither of these treatments worked, so in January 2010 the decision was made to have a total laryngectomy and neck dissection.

The healing process was slow, both physically and mentally. It was difficult to recover and adjust to a life after my laryngectomy. There was a lot of swelling around the neck; it was extremely sore and painful but my wife was there with me every step of the way. It's easy to forget that partners suffer as well - my wife saw the toll each stage took on me especially after the surgery. It was especially difficult for her to see me in pain and with extensive neck swelling.

The hardest part for me was having to endure 3 months without talking due to extent of the swelling. Talking is such an important part of who I am and how I express myself that I found it extremely hard to be without my voice.

"After the surgery my wife became my caregiver until I was strong enough to start becoming more independent."

Once I had recovered from the surgery I worked with my Speech and Language Therapist (SLT) to try and gain my voice back - testing many different valves with no success. With nothing left to lose we attempted one final type of valve, and just like that I spoke! I remember jumping up and hugging my SLT. To be able to talk again was everything. I can't express how overjoyed I was to finally get my voice back. My wife was in tears, after so much time we could communicate easily with each other.

A lot has changed since having a laryngectomy. I have had to learn how to live without a larynx, which has meant many new changes to my day to day life from understanding the types of food I can eat to coming to terms with not being able to smell. I have had to acquire a clear routine around caring for my stoma and how to clean the valve. What other people take for granted, I can't. I have to be very careful about what I'm doing.

In the beginning, one of the biggest challenges was going out in public because people do stare. I learnt over time to not let this bother me and I've learnt to not let the situation dictate how I feel.

It can seem a daunting prospect to adjust to a new way of living but there is a lot of support out there from your assigned specialist nurses, dieticians and patient groups. My advice to others is that there is always someone to talk to. It is easy to become lonely or isolated, so get out there and find local support groups. Try to stay positive and try to take things one step at a time.

PATIENT STORY

NEIL'S STORY

OK guys, this is my journey into what I thought would be hell..

In 2015 I had food poisoning coming back from Portugal. A lump appeared on my neck shortly after, and maybe a week later it disappeared, then 2 weeks later it appeared on my neck again but the opposite side. I got this checked out 2 weeks later. Dr Patel referred me to ENT straight away and this is where the journey started. Biopsies, MRI scans, blood tests, CT scans, PET scans, more blood tests - it was endless but the torture on the way.

Then on the 13 January 2016 I had to go to Addenbrookes hospital to see my consultant, Mr Amen, where he told me that the biopsies came back unsuccessful. More scans followed and on the 16th January I was diagnosed with Head & Neck Cancer, stage 4. 'Gutted', was an understatement.

I had my surgery on the 9th February. Whilst waiting in J3 ward for my surgery I was very nervous - particularly as I have 3 children at home. Abigail then was 5, Samuel 7, and my eldest Katie 17. The surgery lasted for 7 hours, although I was out of hospital within 4 days! I had a lot of support, with wonderful friends visiting me, Peter Whitwell, Vete & Denise Klimczuk; the list was endless.

Afterwards I had to have a feeding PEG fitted as I'd struggle to eat and drink. Three weeks later I had my radiotherapy mask made, then on the 15th March my 1st radiotherapy session started. There were 30 in total. I was hospitalised in the middle of April as the chemotherapy didn't agree with me after five 5hr sessions. My mouth and throat were full of blisters and ulcers and my neck was black through burning of the radiotherapy. This wasn't treatment - this was torture, barbaric torture, but if it was going to mend me, let's get on with it...

Apart from my family there are just a few people that made me feel alive, in a sense of a word: Vete Klimczuk, Mick Burch, Tony Palmer, Wayne Savidge, Michael Lakey, Peter Whitwell, Terry Austin and too many more to mention. Then, there's also a massive thank you to my family. It's 2019 now, and although I'm 4 stone lighter, I feel wonderful.

Thank you for reading about how I beat cancer.

CAREGIVER STORY

HELEN'S STORY: SUPPORTING FROM AFAR

I worked as a Clinical Scientist in the NHS for 20 years, specialising in cancer genomics for much of this time. The laboratory I worked in processed thousands of tumour specimens every year from patients with a range of cancers, including head and neck cancers. I dealt with cancer referrals every day at work for over 10 years. What I had never dealt with was a close family member receiving a cancer diagnosis. All these years working within the cancer field did not prepare me for when my dad received his stage 3 tonsil cancer diagnosis.

Cancer: A scary word

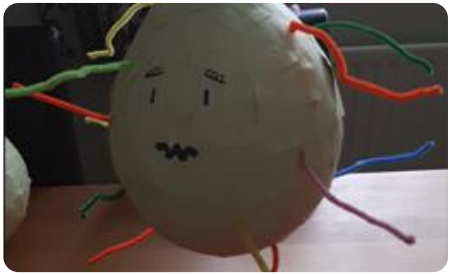
When my 72-year-old dad lost his voice in May 2024 he was given a course of antibiotics for laryngitis. Around 6 weeks later following an urgent referral to Ear, Nose and Throat (ENT), the true cause of his paralysed vocal cord was identified to be pressure from a tumour. Dad had stage 3 tonsil cancer. Well, in the words of Ed Sheeran/Jamie Lawson: "I wasn't expecting that".

Cancer can be a scary word, there's no getting away from that. It can conjure up images from the Cancer Research UK adverts of people with headscarves in hospital with tubes coming out of their nose. And, of course, the high incidence of cancer means that most people, including myself, know someone who has sadly passed away because of cancer.

My cancer-focussed employment history didn't mean I wasn't scared about what was ahead for my dad and it didn't lessen the sadness of knowing that my dad had cancer (you just want your family to be healthy don't you, and laryngitis would've been a much better diagnosis). But my scientific knowledge did give me hope and optimism. I know that there are hundreds of ongoing cancer clinical trials striving for more effective treatments to fight cancer. And I know from implementing new innovative cancer genomic tests in the laboratory, that these trials are bringing successes with them that are benefiting cancer patients now.

Cancer prognosis and cancer survival is improving. When my dad got his diagnosis, I held onto this fact.

And how did we deal with dad's diagnosis as a family? Humour was quite high on the list. We had a family holiday the week before dad started radiotherapy and my sister and I both had the same idea (some may say bizarre idea): to make a cancer cell pinata that we could get the kids to smash. We spent time on holiday literally beating cancer!



Radiotherapy: The daily regime

At the time of his diagnosis, my dad's cancer had spread to the lymph nodes on the left side of his neck. An operation wasn't feasible as the lymph nodes were close to the jugular vein so operating would have been too risky. Dad's radiotherapy started on August 12th, 2024. 5 days a week for 6 weeks.

I live 4 hours away from my dad. The distance made me feel pretty helpless. I'd not been there for the early hospital appointments that came prior to dad's diagnosis, but I travelled to see my dad as much as I could between the diagnosis and start of treatment within the constraints of having two kids under 10 years old and juggling home and work life. My husband was super supportive.

I knew that the distance would make it difficult for me to be as supportive to my dad as I would like as he went on his treatment journey. I was looking for a way to show my support to my dad. I decided to embark on a running challenge that mirrored dad's radiotherapy regime. The challenge was: running 5km 5 days a week from 12th August through until 20th September. I would run every day my dad had radiotherapy. It was a small gesture to recognise the daily commitment

required of my dad for the next 6 weeks. Radiotherapy is tough. Daily hospital visits, tiredness, side effects. Running every day was so little effort compared to what my dad was going through every day, and I was encouraged by a whole troop of friends who joined me on many runs to get me through the challenge. Don't get me wrong, prior to this running effort, I only did a short run each week, so it wasn't easy, but knowing my dad was going through a much bigger challenge was all the motivation I needed to get my butt out of bed/off the sofa to tread the rainy streets. My friends spurred me on to start a fundraising page. Through sponsorship from generous family and friends, we raised a total of £1,345 for the Swallows charity. I'm so proud of this achievement and know that the Charity will benefit enormously from this financial support.

The Swallows network provides immense support to head and neck cancer patients and their families. On a personal level, I am appreciative of the on-hand support and advice offered on the local Swallows WhatsApp group and grateful for the support pack that the Charity sent my dad – full of useful creams, lotions, and information leaflets to help my dad through his treatment.

Support: My amazing family

Thinking about support brings me onto my amazing family. My brother, my sister, and my mam were incredible throughout my dad's diagnosis and treatment. They were strong, dependable, loving, unwavering in their support of my dad. Anything that my dad needed: chauffeuring to each hospital appointment, prescription collections from the pharmacy, learning to use the stomach PEG – they nailed it.

As I say, I couldn't visit dad as much as I would have liked throughout his treatment, so I often sent him cards and treats in the post to make sure he knew I was thinking of him. In one of these cards, I wrote a poem for dad, which sums up some of my feelings at the time:

If cancer could be cured by the love
of those around,
I'd say stick your radiotherapy, the
cure for Dad is found.
But medicine can be marvellous, so
we'll do as the doctors say,
We'll trust in the process and hope
that dividends will pay.
We'll remain by your side and
support you through the course,
'Cos medicine plus love is surely the
strongest force.

Pride: Ringing the bell

With my legendary family by his side, my brother, my sister and my mam, my dad rang the bell to signal the completion of his radiotherapy on 20th September 2024. He'd done it. Surely one of the toughest challenges he has faced. I'm very proud of him. Was it tough – yes. But he got through it. He tackled every new challenge head-on: the claustrophobia of the radiotherapy mask, the use of the light therapy machine (photobiomodulation PBM), the use of the stomach feeding tube (percutaneous endoscopic gastrostomy PEG). He smashed it.

Cancer patients, I salute you. It can be a challenging journey. My dad is a superhero in my eyes, although thankfully without a tight lycra costume.

Future: Cheers to that

So, what does the future hold? Well, in terms of dad's cancer, it's a waiting game. A 12-week treatment-free wait until a scan to tell us how effective the radiotherapy has been. I'm not a religious person but am praying for some good news. On a personal level, I am looking forward to a family Christmas and maybe a cheeky beer with dad. Even if he is limited to 100ml of beer with a thickener in! Cheers to that.

In terms of what the future holds for cancer patients generally, I'm going to reiterate an earlier point: have hope and optimism. Treatments are advancing and prognosis of cancer patients is improving. I would love for cancer to be less of a scary word. And with this in mind, I am certainly more motivated than ever in my career to support the development of new cancer therapies and to maximise the number of patients across the world who can access and benefit from these treatments, so that more cancers can be beaten. **Cheers to that.**

JO'S STORY:

How I found The Swallows charity

"There's nothing to worry about".

The dentist smiled at me comfortingly. Just as she had six months previously. The sore patch on my tongue wasn't improving and a year seemed a long time to me, even with her reassurance, so I decided to get a second opinion. My GP took one look at it and referred me to the hospital immediately.

The resulting tests showed that it was cancer. After two smaller operations over a four year period, to try to deal with the problem with minimum impact, a further recurrence meant that I had to undergo the 'belt and braces' treatment. A ten hour operation involving a partial glossectomy (the removal of most of the left side of my tongue), a 'free flap' reconstruction using skin from my left arm, and

> I CAN HONESTLY SAY THAT LIFE IS MUCH RICHER SINCE HAVING CANCER.

a neck dissection. This was then followed by six weeks of chemotherapy and radiotherapy.

The treatment was gruelling. I had to have a RIG feeding tube, and managed to faint and fall over in hospital and break my ankle. This meant a further operation to pin it - and that I was in a wheelchair throughout the chemotherapy and radiotherapy. As if it wasn't hard enough already, the forty five minute journey to hospital by car each day became fraught with practical difficulty – my leg raised on the dashboard and my head over a bowl!

My wonderful husband, Andrew, and I managed well, although it was a very difficult time for us both. When the treatment finished and the side effects of radiotherapy were diminishing, we realised that the next challenge was to build a new normal.

I now had only half a tongue with limited movement, my salivary glands were damaged (so I had all of the complications of dry mouth), I had lost some teeth and food sometimes slipped down my throat where my tongue had been. Andrew had to develop his first aid skills and to be alert to problems at all times.

It was after treatment had finished that we were introduced to The Swallows. At first we attended the local group but that had to stop due to Covid. We found the national online meetings, which were introduced during lockdown, to be particularly useful. We were able to talk to people who, whilst living a long way away from us, had endured a very similar treatment path. Their advice on building a new normal was central to the progress which we have made. The Swallows online meeting also introduced me to the Aquax2 trial, which has boosted my saliva production, therefore giving me the confidence to try different foods and extend the range of my diet.

I am very proud of my new normal. My ability to eat continues to improve. I still notice small changes that mean a lot to me, but to others would seem insignificant, and we celebrate them when they occur. I can now lick an envelope, eat biscuits, a bag of crisps and an egg sandwich (though not all at the same time)! We manage to do most of the things which we had planned to do in retirement and life, whilst still having its ups and downs, is good.

My advice to anyone treading a similar path is simple. Find others who have trodden it before you. Take heart from their progress and use it to benchmark your own. Don't forget how you felt during treatment and notice the steady improvements as you make them. The Swallows will help you to achieve so much.

I can honestly say that life is much richer since having cancer. I am now six years out of treatment and making the most of every minute. Andrew and I are proud to now lead our local Swallows group. We have met some wonderful people through The Swallows and have made lasting and valuable friendships.

TO FIND YOUR LOCAL SWALLOWS GROUP VISIT: WWW.THESWALLOWS.ORG.UK OR EMAIL: INFO@THESWALLOWS.ORG.UK

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