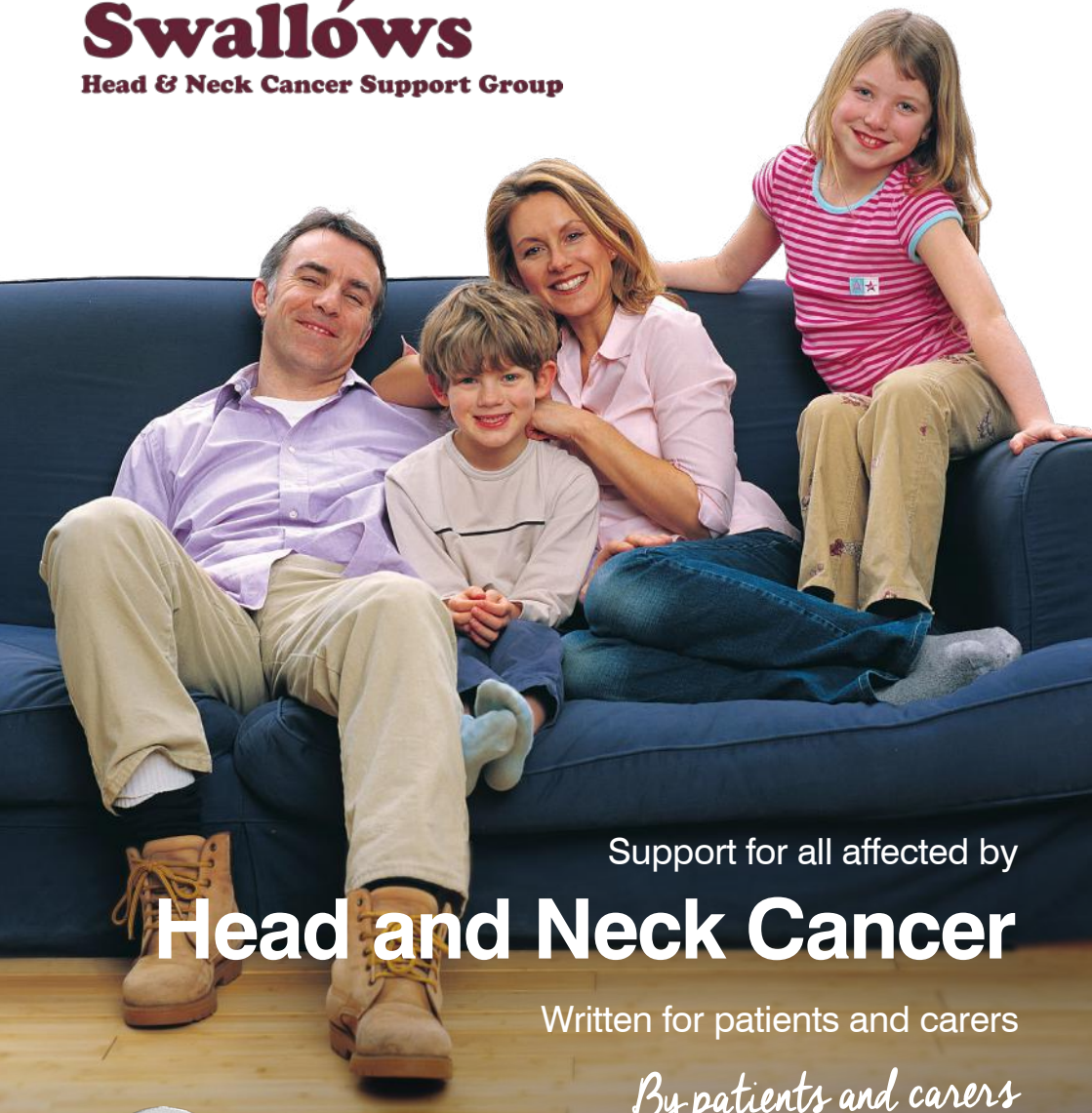
The Swallows

Head & Neck Cancer Support Group

UK 2nd Edition



Support for all affected by

Head and Neck Cancer

Written for patients and carers

By patients and carers

The Queen's Award for Voluntary Service

The MBE for volunteer groups

Head and Neck Cancer

Support

Visit our new website

New look...same great content

Events

Meetings

Latest News

Support

Stories

- Mobile & tablet friendly
- Keep up to date with our latest news
- Find dates for your diary
- All the info about our events and meetings

Visit us at **theswallows.org.uk**

Our monthly meetings

Don't go it alone

Our monthly meeting is for past and present patients, carers and anyone else who is affected by Head & Neck Cancer. They are held every second Wednesday of every month from 7pm. Our aim is to give all those affected with Head & Neck Cancer the chance to meet like-minded people, chat about concerns or best practice in the dealing of this cancer. You can listen to others who have been through the journey or just find some comfort in knowing that you're not alone.

We would encourage Carers to attend these meetings as we believe they also have their own concerns and need to know how best to deal with the changes being placed on them. So, by meeting other Carers we hope to be able to offer them support and encouragement.

We sometimes have a speaker at the meetings, these can range from Dietitians, Therapy & Mindfulness to local businesses offering benefits to their services. Why not come along to our next meeting and see what we're all about, we don't pressure you to return, we have a policy that we are there if you need us, wherever you need us!

'At a particularly low ebb and with no idea what I should do next I contacted Chris at Swallows who kindly came the same day to offer support and advice and then introduced me to the monthly meeting. Knowledge does make a difference. Knowing some of the things that are likely to happen, that other people have had similar experiences."

Shirley Patient

To find your nearest meeting and venue call:

01253 428 940

Visit us at **theswallows.org.uk**

Email info@theswallows.org.uk

We meet every second Wednesday of the month starting at 7pm

Chairman's Welcome

Welcome to the second edition of the UK Head and Neck Cancer Patient & Carers Book. Last year we launched the very first book in the UK and Australia and who would have thought that within a year we would be writing the second edition for both countries.

The book has been put together by patients and carers who have all been where you are now. We hope the content will help you and take away some of the fear of the unknown!

YOUR CANCER JOURNEY

Cancer is a long and hard journey, but you don't have to walk the road alone. You will meet many good people who are there to help and guide you on the road. They will find you when you are least expecting it.

Head & Neck Cancer patients have unique problems such as Dry Mouth, Swallowing, Eating and many other issues. It is therefore so important that worldwide we come together as 'one voice' and share our experiences to help others.

It is my dream to have a worldwide patient ambassador programme that allows patients and carers to talk, support and signpost other like-minded people to the services, medicines and treatments that are available.

The Swallows Head & Neck Cancer Support Charity now reaches out across the globe via the website and Social Media sites. In total we now engage with more than 5,000 patients, carers, health professionals and many other like-minded people.

We are all very proud of this book and hope you enjoy it as much as we have enjoyed putting it together. Feel free to contact me directly if you would like to see anything else or add your story in the next print run.

JustGiving™
justgiving.com/theswallows

theswallowscancersupport

@swallowsgroup

Chris Curtis

Chairman, World H&N Cancer Advocate
chris@theswallows.org.uk | +44 (0)7779 169 833

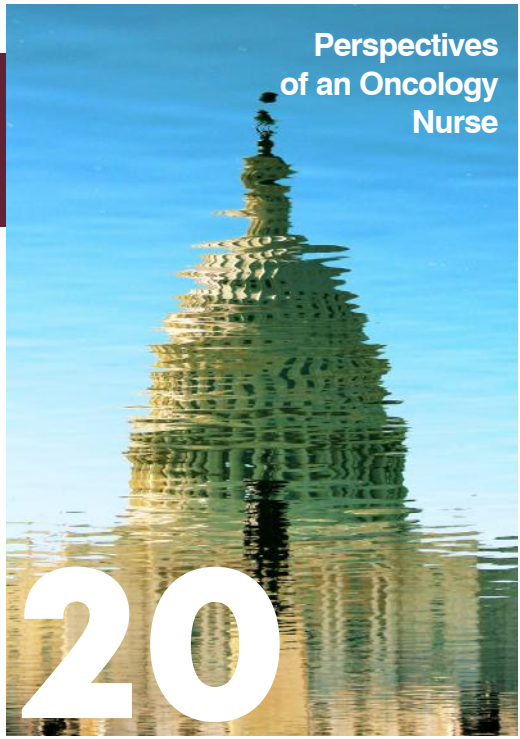
Contents

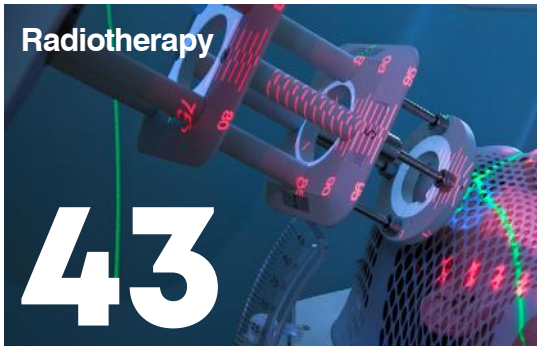
Written for patients and carers

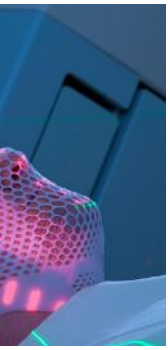
By patients and carers

For more patient and health professional stories visit our new website at:

theswallows.org.uk/support/patient-stories







Copies are available and ready for distribution. To order please contact The Swallows by emailing info@theswallows.org.uk quoting UK/PB/2018.

The Swallows
Head & Neck Cancer Support Group

The Queen's Award for Voluntary Service

Established 2011

Who are we?

We chose the name 'The Swallows' because many Head and Neck Cancer patients have problems with swallowing during and following treatment.

As a patient and carer group for those affected by Head and Neck Cancer we are based in Blackpool, but are now reaching out to all corners of the UK.

We offer fantastic support 24/7 and will signpost if that's what you need. The charity is run by patients, carers, family and friends, so everyone understands the problems when you are diagnosed.

Visit **theswallows.org.uk** for more information.

How did it start?

In 2010 the support group started as a small group of patients meeting to discuss how they were dealing with any issues and to share stories. A lovely lady called Wendy Hepworth (patient) led the group with the help of Jo Ashton, CNS.

In early 2011, with the help and vision of Chris Curtis, the group achieved full charity status. The charity will be forever grateful for the initial foresight and work Wendy and Jo put in during 2010 to get the support group going.

It is important to say that whilst the charity now helps with awareness, signposting, campaigns and fundraising, it will never lose the reason it all started in 2010 - ***'Supporting patients both locally and nationally.'***

What we do

Help each other and anyone else who is affected, directly or indirectly, by this type of cancer.

Offer one to one or group support. Be available to Clinics to help patients and carers

Advise on locating reliable literature, information and local resources.

Signpost links to other groups in different areas and recommend trusted websites for people at home.

Raise funds for items to help both patients and carers 24/7 help line answered by patients and carers, offering a like minded person to talk to.

Fundraising

We are here for everyone affected by cancer; every step of the way. But we can't do it without your help. Our volunteers are invaluable and make a real difference through their fundraising and support.
Find out more details on page 55.

Monthly Meeting

Our patient and carers meeting is held every second Wednesday of the month, starting at 7pm. It is an opportunity to meet other like-minded people and share experiences.
More details on page 3.

Our charity shop

68-70 Waterloo Road, South Shore, Blackpool FY4 1AB

Charity shop history
A largely British institution, charity shops are retail outlets selling mainly second-hand donated goods to raise funds for their parent charities. Every year charity shops raise around £300m for a range of causes in the UK. They also function as a way of raising awareness of the parent charity.

The Swallows Charity Shop
We are proud to say we have our very own charity shop on Waterloo Road, South Shore, Blackpool - and has a reputation for selling quality items at affordable prices. Volunteers enjoy working in the shop and see the opportunity as a social gathering, and at the same time help generate valuable funds for the charity.

We look forward to welcoming you anytime - you might find a bargain or two!

For more information call:
01253 428 940

We are always in need of the following:

Clothing | Furniture | Bric-a-brac | Household | Toys

12 year old Oscar's Story

Oscar hadn't been ill at all although he had a lump on the side of his neck. We got it checked out just before Christmas 2013 and a referral to see a paediatrician in the New Year was sent. We enjoyed Christmas even though Oscar did seem a little quieter he still managed to take part in his passion of stunt scootering....

On the day he was due back in school he was tearful, lethargic & just not himself. Richard & I managed to get him in at the doctor's surgery. She requested bloods for the following morning, results arrived back the following day & we were sent down to the hospital in Halifax for a chest x-ray & to be examined. An appointment for a neck scan the following morning if a senior radiologist was available was planned. After the scan we met the paediatrician, who informed us that he needed to be seen in Leeds as he would need a biopsy on the lump. We had our first appointment at Leeds General Infirmary on 17th January, meeting the surgeon. The biopsy was carried out the following Friday. All of our hopes were pinned on it being a nasty infection. After receiving a phone call from the surgeon I knew deep down the news wasn't going to be good. He told me that it wasn't an infection & Oscar needed to have an MRI that Friday.

Friday arrived I went to the appointment in old clothes as I knew I would probably never want to wear them again... !! Oscar had his MRI as planned

We then met the doctor who broke the news that our most amazing full of life boy had a rare form of cancer called Nasopharyngeal Carcinoma. Richard & I were numb but we heard every word we were told. The treatment was going to be hard but the tumour responds well to treatment, three 21 day cycles of Cisplatin & 5FU, 33 radiotherapy sessions with a small chemo to begin & end followed by immunotherapy for 6 months. Arrangements were then made to operate and insert Oscar's porta cath & feeding tube. We also met Oscars Macmillan nurse who quietly spoke with Oscar about his diagnosis. He also told us not to Google, but gave us some trusted websites to look at.
Three weeks later chemo began, but before this Oscar needed a bone scan to see if it had spread to his bones. Luckily it hadn't.

Pre chemo heart scan, kidney function test, hearing test to monitor & to see the dentist, then a final biopsy to determine which of the three types of NPC Oscar had.

During the first 21 day cycle we spent 7 days in hospital due to Oscar's sickness following the chemo. They needed to get the best combination of anti-sickness drugs to suit him & also to see how he reacted to the drugs. We went home with our sick boy, a huge bag of drugs, sick bowls galore.

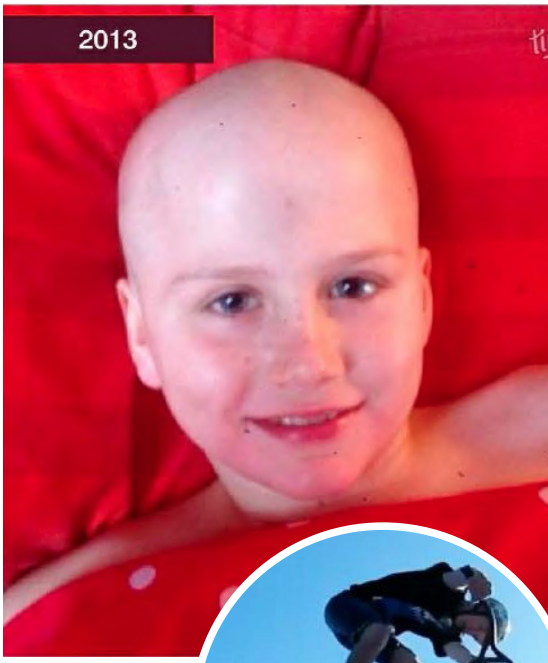
We were ready to fight this enormous battle ahead. Oscar needed to be hospitalised on day 15 of the 1st cycle due to an infection in his mouth. IV antibiotics through his port soon did the trick. We as a family were finding our feet & in my opinion we did pretty well.

2nd & 3rd cycles of chemo came & went. Our routine was better. We were even allowed home after the hydration & Cisplatin had been given to Oscar, the 5FU could be infused whilst Oscar was at home. The pump was then disconnected by a member of the Halifax Community Team who also performed regular blood tests whilst Oscar was at home. I had Oscar's head shaved just after the 2nd cycle as he didn't want to watch it fall out & also he could control when it went. We as a family decided early on that we would learn about each part of Oscar's treatment as it was happening instead of saturating our brains with too much information at the same time.

Preparations soon began for Oscar's radiotherapy. We met his radiotherapy Consultant & arrangements were made to see the machine, meet the incredible staff & for Oscar to have his mask made. Oscar had 33 sessions in the machine, each one getting tougher as he became more unwell. Oscar's skin burnt in three places on his neck but miraculously healed before the 33 sessions were done.

Every morning Monday to Friday we travelled from Eckersley House in the grounds of the LGI to St James's Hospital & each morning Oscar listened to the same CD so he would be able to gauge his time in the machine. One of the songs I found quite odd was 'Happy' by Pharrell Williams. Happy we weren't, but we were just getting on with it. During radiotherapy we stayed at Eckersley House which is a short distance to the LGI, as Oscar would become too unwell to travel the distance on a daily basis.

Oscar was prescribed a drug called Nabilone which is artificial cannabis. He soon became known as the Space Cadet as he was so relaxed during his radio. Radiotherapy was tough but he received A1, gold standard treatment & care. 2 weeks into radio Oscar required morphine which quickly needed to be doubled. The only thing with that was it affected his blood pressure so we had a short weekend break on the children's ward. By June 20th all Oscar's nasty treatments were over & he had a couple of weeks break before the immuno started. Oscar's bloods were so healthy after the 1st week he could start early, 3 injections weekly for 6 months initially. The immuno (interferon) was kick starting his own immune system, hunting out any nasty cells that might still be lurking.



Oscar is now almost 2yrs out of treatment. Last scan was a good result. He is now having MRIs twice a year & checked regularly at ENT in Huddersfield & by the paediatrician. His treatment was incredible & we will always be grateful to all the people involved on his journey. Life is different & we will never take anything for granted. We still have our boy.

Charlotte Crowther

Oscar's Mother

Complete Connected Care

Lowell General Hospital

Arthur M. Lauretano

MD, MS, FACS, Chief Medical Officer, Circle Health
Medical Director - Multidisciplinary Head and Neck Cancer Center, Lowell General Hospital

The promise of Complete Connected Care at Lowell General Hospital manifests itself in our Multidisciplinary Head and Neck Cancer Centre. Our commitment to providing comprehensive and coordinated care finds its origins in Sir William Osler's statement, "The good physician treats the disease; the great physician treats the patient who has the disease." All of our providers and staff embrace this concept, enabling us to provide each of our head and neck cancer patients with the medical care they require and the compassionate support they deserve.

Head and neck cancer is a complicated disease. It affects functions that are essential to every aspect of our lives. It can, and in fact often does, alter the appearance of the patient. Not only does the cancer lead to such life-changing results, but also, and perhaps more often, the treatment itself causes such effects. Radiation therapy may yield scarring that can affect swallowing and speech as well as neck flexibility and mouth opening. Surgery can involve removal of essential parts of the head and neck, including the voice box, parts of the tongue, sections of the throat, and muscles in the neck. Reconstructive procedures that take skin and muscle from other parts of the body may cause weakness and numbness in those areas as well. Some patients will require permanent tracheostomies, feeding tubes, and prostheses to restore function. All of this occurs against a background of a disease that nevertheless can recur, requiring additional treatment or a decision to enter hospice.

The patient who arrives at our centre, along with their families and friends, meets a team of friendly and enthusiastic staff. We have developed a large team consisting of nurses, social workers, speech and swallowing therapists, nutritionists, radiation oncologists, medical oncologists, and the head and neck surgeon. We always meet with the patient and their caregivers as a team. For follow up patients, those who are undergoing treatment or have completed treatment, we address their disease state, looking for remission or recurrence as well as side effects of the treatment. For new patients, we assess the extent of the disease, formulating a plan to treat the cancer and manage the anticipated side effects of the treatment.

People are often described as having five areas of composition – physical, psychological, emotional, social, and spiritual. After greeting our patients, the first questions we always ask are, "How are you feeling? How are you doing?" Sometimes the answer is specific to the cancer and its treatment, but other times we find out that the patient is having financial struggles, transportation problems, or relationship issues. Patients can feel very isolated because of physical appearance, trouble eating, speech issues, and mobility. We realize that carers also have a lot of stress – the isolation the patient feels can leave the caregiver feeling isolated. Both endure significant psychological burdens. It is the goal of our team to make sure we have the right disciplines present at each visit to address these issues.

The care we provide in this multidisciplinary approach is for life as cancer treatment can cause progressive changes, even years after treatment. We continue to monitor for cancer recurrence. In the case of recurrence, we can design a new treatment plan. Additionally, we understand that in some cases, the best plan is not an attempt to cure the cancer, but instead to initiate palliative care. In such cases, we may decide on less aggressive treatment that keeps the cancer in check while minimizing side effects. In other cases, the patient, caregivers, and our team decide that the best treatment is no treatment at all. In such situations, we still see the patient on a regular basis, making sure they are comfortable, nourished, and psychologically supported. We also make sure their caregivers are themselves being cared for.

This comprehensive cancer care can only be delivered through a multidisciplinary approach. This approach is best provided by a team assembled in one setting, such that the patient and caregivers receive full care at every visit. We can expedite treatment, avoid fragmented care, and provide a consensus based patient-specific plan.

Most importantly, the patient and caregivers know that they have a whole team united to support them during their cancer journey. In short, a team dedicated to deliver on our promise of Complete Connected Care.

circlehealth
Complete connected care™

Lowell General Hospital · circle home · Our Community of Physicians

Colin's Story

My journey started in July 2017 when a routine visit to my dentist showed a growth in the soft palate at the back of my mouth. I had dismissed this as an ulcer, but thanks to the tenacity of my dentist this was photographed, and within a week I was in the hands of Blackpool Victoria Hospital.

Professor Crean arranged for a CT scan, an MRI, an Ultra Sound scan and a Biopsy. Within a fortnight the results were in and I was diagnosed with grade 2-3 squamous cell carcinoma in the soft palate of the mouth. Naturally I was devastated and couldn't see beyond my next appointment, of which there were many to come.

A cousin of mine, who had had throat cancer 4-5 years previously suggested I contact Chris at the Swallows as they had both had similar journeys and Chris now was involved with the charity.

I rang Chris and within hours he met me within the local Solaris centre. Over a coffee he was able to answer many questions that a very frightened, newly diagnosed "little boy" had. Anything he couldn't tell me he was able to signpost me to get the information.

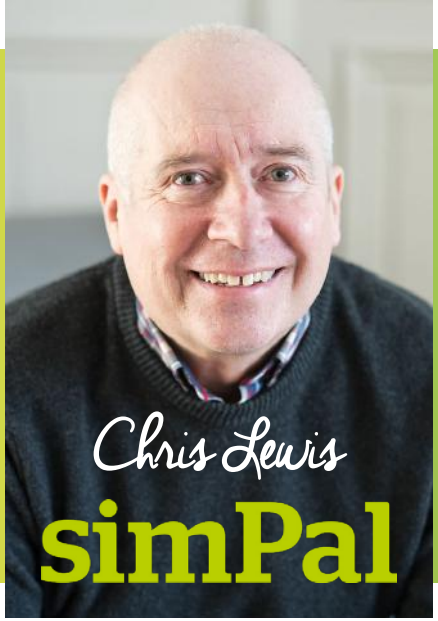
I had to have all my teeth out to prepare me for the 6 weeks of Radiotherapy and once a week I also had Chemotherapy which my rock (my wife) arranged time off work to attend with me. This treatment was administered at the Rosemere centre in Preston.

I was very lucky as I was able to continue to drive myself there and back everyday for my treatment. I didn't have a feeding tube in my stomach, nor a rescue tube through my nose into my stomach. I never lost my ability to taste or swallow and I didn't lose any skin on my neck through continuous burning from the radiotherapy. Nor did I have any painkillers throughout.

Apart from stinging ulcers on my tongue post treatment and a bout of sepsis which needed a course of antibiotics, hydration necessitating a day in hospital, and being a serious claustrophobia sufferer, (which I had to find a way through) not good when you are bolted down for radiotherapy in a mask everyday, nor for MRI scans. Thanks to all my family and friends and professional help, including continued support from the Swallows, I am now out the other side and back to work full time. Soon to be provided with a full set of dentures by the NHS.

We have booked a couple of cruises to help us both (my wife and me) to look forward to. With the help of my new friends at The Swallows, I am determined to turn this positive into a negative. As you can see by my picture, I'm looking forwards - not back!

Now in April 2018, I am a head & neck cancer survivor



Most of us have ups and downs in our life, but my own in recent times, feel somewhat extreme! In the last 10 years I have gone from being one of the best business people in the clothing business, to nearly dying, and struggling for many years to hang onto my life. Now I am one of the most influential cancer patients in the world, speaking and writing internationally about my experiences.

I was a self-employed business consultant with all in the world looking rosy, until in 2007 when I was diagnosed with stage 4 Mantle Cell Lymphoma, an incurable blood cancer. My prognosis was poor, being given 6 months to live. Aggressive chemotherapy was followed by a stem-cell transplant from an unrelated donor, organised by the Anthony Nolan charity.

For a man aged 51 this was a lot of treatment and there were tough times. My immune system was weak and I was constantly being brought down with viruses and infections. My own body started to reject the cells that were trying to save me (GVHD) and I nearly died on several occasions as my body started an 'internal civil war.'

Despite such a poor prognosis and very irregular health, the years went by. I can't say I saw that period as living, more just staying alive. But my mind was full of new ideas! I knew that I was never going to be fit enough to return to my old work, but needed something to keep my mind active.

My own experience was showing me, how poor the cancer support system in this country really is, and I wanted to do something about that. So I did some charity volunteering to find out more. The corporate side of things was not for me, so I decided to work on my own.

Firstly doing some guest speaker slots, then as things got busier my friends pointed me towards creating a website and learning about social-media. My work won some awards and I was featured on the TV, and things took off from there.

The invitations to speak started to flow, and after time I was speaking in Parliament and national health conferences about cancer support issues. All this is done whilst still being a patient. I have done many interviews and videos and now I speak at international conferences, where the audiences range from patients to very senior Healthcare Professionals.

My website is now an official resource for many organisations across the world, and my very rare case is seen as a beacon to other patients. In between my practical work I have been invited to write a book about my experiences.

After 10 years I am still alive and meeting incredible people. I have started my own unique charity **(www.yoursimpal.com)** being the only one of its type in the world. We give phones and sim cards, free of charge to anyone in the U.K affected by cancer.

By looking at how my own life has altered so dramatically, you can understand that when people say that their cancer diagnosis was life changing, they are not exaggerating!

If you would like to read more about my story you can visit www.chris-cancercommunity.com

simPal

CONNECTING PEOPLE THRU CANCER

We are the only cancer charity in the UK offering free pre-paid sim cards for people living with cancer

simPal is the only charity in the world providing this unique service. Support provided by simPal is completely free and non-means-tested. Our aim is to keep those living with cancer connected during their most challenging times.

£10 keeps somebody living with cancer connected for 30 days.

£40 provides a basic handset and 60 days service to somebody living with cancer.

£60 keeps a family living with cancer connected for 6 months.

JustTextGiving by vodafone

simPal

Help us keep people living with cancer connected.

Text **simp18** to 70070

- Donate as little or as much as you can -

£1 £5 £10

"simPal allows my daughter to watch Peppa Pig on her tablet without me worrying about how much of my credit she is using."

Sajjad Iqbal, MD.

My Story of Hope, Determination and Survival

I am a physician, a pediatrician, and a cancer survivor. Given only a 30% chance of surviving for 2 years, at initial diagnosis, I have now lived for 16 years and counting.

It all started with a sudden but partial paralysis of the left side of my face. My doctor thought it was Bell's palsy, a common condition that goes away in a few weeks. Contrary to that, my facial paralysis got worse with time. As a physician, I knew I did not have Bell's palsy. Unfortunately, multiple experts at various medical centers insisted it was just that. I was even subjected to an unnecessary operation for Bell's palsy. Of course, it did nothing and my paralysis progressed.

Ultimately, I took it upon myself to solve this diagnostic puzzle. Using my basic medical knowledge and simple logic and reasoning, I concluded that the only diagnosis that fit perfectly was: parotid cancer. Unfortunately, the experts refused to accept my diagnosis, which caused further frustration & delay.

Finally, a detailed MRI of the parotid gland confirmed the diagnosis of cancer. In February 2002, I underwent an extensive & radical surgery on the left side of my face and upper neck followed by a reconstruction utilizing the muscles, tendons, nerves and arteries taken from other parts of my body.

The pathology report revealed that I had an extremely rare and highly malignant type called Salivary Duct Carcinoma that killed 70% of patients within 2 years. No patient had ever survived for 5 years, I was told. My prognosis was bleak.

I needed to summon every ounce of positive thinking, unshakeable optimism, and all the good karma I was due. I decided not to focus on the poor prognosis but on the slim chance that I CAN beat the odds. If only 30% of patients survive, then I shall be among those 30%.

'If no one has ever survived for 5 years, then I shall be the first one. After all, I thought - somebody has to be the first.'

With interminable hope and unwavering determination, I set out to fight my mortal enemy. I decided to learn everything I could about my cancer, did my own comprehensive literature search, and visited several experts across the United States.

Besides the surgery I had already undergone, and the radiation I was receiving at that time, medical science offered little to improve the survival odds. I pushed for much more aggressive chemo-radiation therapy to reduce the chance of recurrence.

That strategy seemed to work. The two-year mark came and went and I was still alive and cancer-free. Had I completely rid myself of cancer? Not really!

Exactly 4 years after initial surgery, the cancer returned—this time in both lungs. The prognosis was grim and the treatment options virtually nil, yet my relentless quest for answers persisted.

Finally, I saw a small ray of light among the darkest clouds. The biopsy revealed that my cancer was positive for HER2 receptors, a feature found in some types of breast cancer. Luckily, a new drug, Herceptin, had just come to market, that targeted HER2 and improved survival in those types of breast cancers. Could Herceptin work for me?

Herceptin was the logical drug choice, indeed my only hope. However, finding a doctor to prescribe and administer it was next to impossible. The FDA had not approved its use in the parotid cancers so using it would be considered an unapproved "off-label use"—a term that makes most doctors nervous. In addition, a recent study involving 14 patients with parotid cancer had failed to show any benefit of Herceptin therapy. Every oncologist I consulted referred to that small study to reject my logic that Herceptin should work for me. So, I decided to go and visit the author of that study. He was most generous with his time and open to my analysis. At the end of the visit, he agreed that it made sense for me to try Herceptin and even wrote me a note to that effect.

Three months into the Herceptin treatment, the cancer nodules in my lungs had stopped growing. So, now I had a stable disease, not progressing but not improving either.

Still, it allowed me some precious time to plan my next move when, inevitably, cancer would break through Herceptin treatment.

That moment came about 22 months later with sudden emergence of several new cancer spots scattered over both lungs. Luckily, my CT scan showed that all those nodules were rather superficial and could be excised by a surgeon. But, such a major surgery on both lungs was a highly risky undertaking with the possibility of serious life threatening complications and a long and difficult recovery. In addition, there was a high degree of probability that new cancer nodules would sprout up within a few months post-operatively.

My solution was that the surgery should be done via multiple endoscopy procedures (Video Assisted Thoracic Surgery). The surgery would be far less invasive with only 2 weeks of recuperation. Best of all, we could repeat the procedure if, as expected, new cancer spots appeared later.

After a long battle with multiple chest surgeons who were adamant that it couldn't be done in the manner I wanted, I finally found a surgeon—with an extensive experience in this technique—who performed the VATS surgery. It was a huge success. My recovery was relatively smooth and the cancer has never returned in the lungs.

I won another battle but the war was far from over. Three years after the lung surgery, the wily cancer returned to attack my bones. I developed metastases in my spine and multiple other bones. Once again, I had hit a dead end. There was no standard treatment and I could not enter a clinical trial. Once again, I charted my own path.

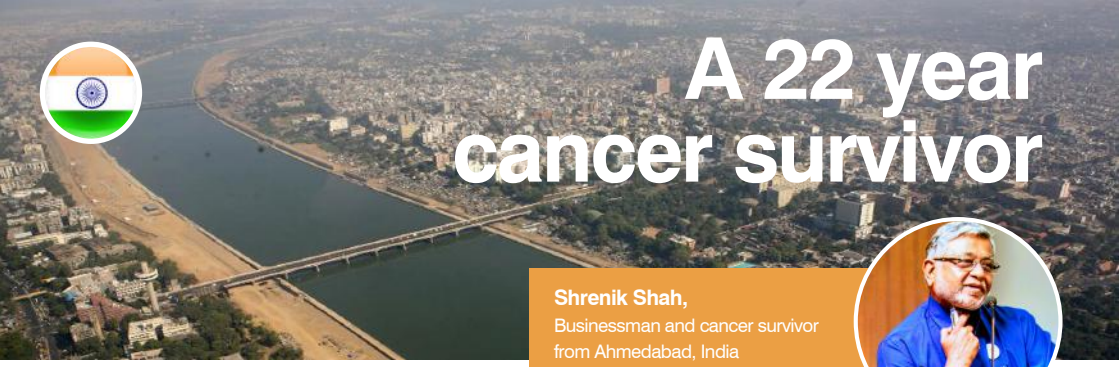
An extensive review of the medical literature from the world over revealed 3 case reports of patients who had metastatic cancers somewhat similar to mine, successfully treated with Herceptin-based chemotherapy combinations. I presented this limited data to my oncologist. Together, we carefully analyzed the information and formulated a treatment plan.

This regimen, just like all others, could not destroy my cancer, but it stopped the progression and converted it into "stable disease," a status quo. It has been 5 years since and I am still alive, still on chemotherapy and still have metastatic bone cancer but under control. We monitor it closely and tweak the drug combinations at the earliest signs of activity. I remain pain-free and feel quite well overall.

It has been 16 long but lucky years since that initial prognosis when I was given less than two years to live. I am the longest known survivor of salivary duct carcinoma. I consider myself among the luckiest in the world. But, as they say, "luck is the residue of design." It has been my eternal optimism, interminable hope, invincible determination and the support of my loving family that have carried me through this incredible journey. And, of course, being a physician was most fortunate.

The fight must go on.

I appreciate the opportunity to share this brief summary of my very long journey. To learn full details of this amazing story, please read my book, Swimming Upstream, which is available at Amazon.com.



A 22 year cancer survivor

Shrenik Shah,
Businessman and cancer survivor
from Ahmedabad, India

I am a cancer Survivor in my 22 year as Laryngectomee (vocal folds removed because of Cancer T IV A, using an Electro Larynx as alternative method of speaking since 1997. The sound quality is like robot with much clear audibility compared to a TEP valve. I have been a businessman in international marketing for more than 3 decades, exporting dyestuffs (synthetic colouring products) for various dyeing applications, and have visited over 35 countries as part of my motivational cancer speaking.

While leading "Moxie" Life 2.0 after cancer for more than 2 decades, I am on a mission with passion to extend my hands of hope to hold, heal, protect & comfort cancer patients across the globe by sharing my fight & experience in lucid language to turn them from Survivors to Winners. I am listing some of my previous activities & recommendations received from cancer field:

- Cancer Aid, the No.1 digital app in USA, UK & Australia with presence in 53 countries on April 23rd 2018 announced me as Hero MVP Champion & Ambassador
- On July 27th #WHNCDay2018 I was invited by GCRI as 1st time in 50 years to speak as Cancer Winner
- On #WHNCDay2018, I launched, "Dedicated To The Win To WILL" Facebook page for motivating Cancer community
- Addlife Foundation invited me as their Hope ambassador for FB live presentation in July'18
- Did presentation in industrial unit with 1000+ workforce to fight cancer & quitting tobbaco & smoking as well as pictures of my various meetings, presentation
- "Alternative Method of Speaking" for Google Voice project team on January 17th 2018 to be helpful to many unknown faces lost their vocal folds for because of cancer
- I am privileged to connect digitally with 12k+ cancer patients, care givers through various cancer support groups for sharing experience & solutions
- On July 1st 2017 I received an award for my work from Chief Minister of Gujarat during book for Cancer patients "Tame Ekla Nathi" (You are not alone) by Ahmedabad Cancer Foundation & addressed 500+ people
- On May 1st 2017 I had the great privilege to meet Dr. Jatin P. Shah, Chairman of IFHONS & Pioneer & widely admired Head & Neck Cancer Surgeon @MSKCC, NY
- On March 29th 2017, I was honoured to meet & interact with Prof. Martin Birchall, Briton of the Year 2008
- In March 2017, The Swallows Charity, did our filming in Central London to showcase "Pretty Life After Cancer"
- On February 14th 2017, Atos Medical, Sweden visited me in London & took my interview
- I am grateful to following cancer groups for featuring my cancer winning journey:
  Ahmedbad Cancer Foundation, Cancer Aid Australia, From UK by: The Swallows Charity, in their UK and Austalian edition. N.A.L.C,BLA, The Plymouth Head & Neck Cancer support group. Head & Neck Cancer support group New Zeland & several other support groups.
- Life after cancer gifted me timeless bonding with many National & International Surgical, Medical & Radiation Oncoligists & in turn they helped for treating many cancer patients. A huge thanks to my Cancer Surgeon Dr. Kaustubh Patel, MS, MCh & President of FHNOS, India who saved my life in September 1997.
- Last but never the least, I am lucky to enjoy inspirational acquaintances with Chris Curtis, Dr. Thomas Moors, Alan Wells, Malcomm Bob, Geoffery Read, Chris Lewis, Tony Smith, Jim Lauder, P J Jordan & many others.

Following are quick links to my online social media presence:
Website: www.shrenikshah2110.com
www.facebook.com/shrenik.shah.355
www.linkedin.com/in/shrenik-shah-ba3b329/

Early Oral Examinations are so important

1 for 3

Mouth Cancer can occur in any part of the mouth, tongue, lips, and adjacent areas like the throat, salivary glands, pharynx, larynx, sinus, and other sites in the head and neck area. Mouth cancers have a higher proportion of deaths per number of cases than breast cancer, cervical cancer or skin melanoma. 1 person dies every 3 hours from mouth cancer and the mortality rate is just over 50% because of late detection.

How to avoid mouth cancer

About half of all cancers can be prevented through healthy living and sensible lifestyle choices:

- Avoid tobacco use.
- Avoid or limit alcohol use.
- Eat healthy food, in moderation, and maintain a healthy weight.
- Exercise moderately most days.

What to do now

- Talk to your Doctor
- Talk to your Dentist
- Talk to your Nurse

Look for an Oral Examination event in your area or ask your dentist to check next time you are there.

REMEMBER
25% of cases have NO associated high risk factors!

Early diagnosis can save your life

Sore tongue, non-healing mouth ulcers and/or red or white patches in the mouth	**Pain in the throat**	**Persistent hoarseness**
Painful and/or difficulty swallowing	**Lump in the neck**	**Blocked nose on one side and/or bloody discharge from the nose**

WEEK 1 | **WEEK 2** | **WEEK 3**

ASK YOUR DENTIST ABOUT 'ORAL SCREENING'

SEEK MEDICAL ADVICE

CALL YOUR GP TODAY

Perspectives of an Oncology Nurse

Claire Burke, RN, CRNI, OCN
Oncology Nurse Educator
Washington, D.C., USA

The practice of nursing has changed significantly over the past thirty years. As healthcare costs skyrocketed, a new era of medicine has evolved. As a result, transformative changes have entirely redefined healthcare throughout the world.

I entered the field of oncology fifteen years into my nursing career, in the 1990's. I had just given birth to my son and did not want to go back to my full-time job as a staff educator for a home health agency. The thought of taking my baby to daycare every day was inconceivable. My good friend offered me a part-time position as a chemo nurse at her oncology practice. "I don't know anything about chemo," I said to her. She told me I had excellent communication and IV skills, and she would teach me about the drug regimens. I had taken care of homebound patients with cancer, so I accepted the job.

I jumped right in and immediately loved my work. My daily activities included patient and caregiver education, emotional support, administration of chemotherapy, advocacy and patient management throughout the oncology journey. My patients had all types of cancers, and were from multiple ethnic backgrounds, ages, educational and income levels. Many came to the clinic with devoted family members, some did not have any carers, and a few did not want anyone to know they had cancer. I functioned as a nurse, sister, mother, therapist, social worker, pharmacist, and financial counselor. I cried with my patients and shared their joy at the good news. I respected their varying moods, grief, and anger. I learned to listen well. I looked them in the eyes and never "saw" any disfigurements. I gave them hope, and when hope faded, I gave them my ears and listened to their feelings about death. I fell in love with most of them. People said to me, "Isn't caring for cancer patients sad and depressing?" I said "No" emphatically. I left work every day and never felt depressed or burned out. My husband regularly heard my stories about all the interesting people receiving chemo. I wished I had known them before cancer.

In the 1990's, having cancer was still associated with dying. However, the emergence of new drugs was beginning to change the cancer experience. Over the years, I have witnessed a dizzying array of changes. Scientific discoveries are narrowing down the causes of cancer, which has led to improved treatments and survival. Caring for patients has evolved beyond the body and mind, to include the spirit. Technology in healthcare, previously associated with improvements in machines, now has an entirely new meaning. The internet has allowed people to access information at any time, and without leaving home. Cell phones and email have facilitated global communication. Electronic health records have improved patient safety and outcomes. Patient advocacy, previously done by nurses on behalf of patients, has evolved to where patients and caregivers are advocating for themselves and others. Cancer patients have more choices and are increasingly involved in decision-making. All of these changes have significantly impacted cancer care.

Some things remain unchanged. Oncology nurses continue their dedication to the field of oncology. What is it that keeps nurses in Oncology? I can assure you that it has nothing to do with our organizations, managers, hours or pay. Nurse's satisfaction comes from what we get back from our patients. There is a special bond that develops between nurses, patients, and caregivers. It is an intimate relationship that is outside of the usual marital bond. For me, it was my lifeblood.

My patients showed me that a cancer diagnosis was not the end of the world. I learned that hope goes beyond being able to cure cancer, and is often manifested in the achievement of shorter-term goals, such as getting through 4 cycles of chemo without missing work or being able to be present as a parent for as little as 30 minutes a day. I discovered that my despair at not having "visible" skills such as excelling at sports, music or art, was all for nothing. I am skilled at the art of nursing, and it was my patients and their families who taught me that. Of course, I experienced sadness at times, but the gratitude my patients expressed to me for doing what I would consider small things, enabled me to see the bigger picture.

Dedicated oncology nurses have an essential role in helping people through the cancer journey. I am forever grateful that I am one of them.

Let me introduce myself my name is Mouth Cancer, I'm not as well-known as my other brothers and sisters in our family but I'm no less dangerous. Sometimes I will call on you without notice but in some cases I will give you an idea that I'm going to visit.

The legacy of my visit will often linger with you and your family for years to come, even though some very clever and caring professionals will try to help you move on and try to forget me I can be rather stubborn!

Although not invited I'm the guest at every meal you ever take, I'll dictate what you eat and whether you will enjoy it, I'll decide if you go out for that special meal, or that night out with the "girls". Just a dry mouth? One of things I leave you with after I've been, red wine may be problem from now on!

My visit also touches your family and friends too, although they don't want to, they may look at you differently after I have gone, but my shadow will always remain if you let it.

I'm the third party in your marriage or relationship, whenever you kiss your partner it will be me you think of not them.

And finally if you let me I will dictate if you smile or not, because when you do smile you will always be thinking of me and whether people can still see me or where I visited.

Of course those clever people I mentioned will try and stop my visit if you let them and they will also help you erase my memory but only if you visit them before I visit you!

Emma Riley

Healthcare Services Director
Chair Society of British Dental Nurses

Geoff's Story

In The Beginning

I was coming to the end of my 15-year engagement with British Aerospace in the Kingdom of Saudi Arabia when I started getting a husky voice and was hospitalised for a few days due to flaking out a couple of times. After returning to the UK upon retirement I became a little bored and went to Baghdad, Iraq for a year or so to help to set up a Private Security Company. Again, I suffered similar voice problems and my voice would come and go. And again, I flaked out a couple of times, once on my flight home to UK. I put all this down to the dusty conditions of the desert. Once back in the UK I saw my local General Practitioner who immediately referred me to a consultant at my local hospital.

The Diagnosis

The Consultant took a telescopic look down my throat which was piped via my nose, and then said, "You know what this is don't you?" I immediately knew and replied "Yes, I think so." After various scans, x-rays and being prodded and poked, I was informed that the cancer on my larynx was T-4 which meant it was very aggressive, was already eating my larynx, and was now looking for somewhere else to go. We then discussed the options.

The Operation

I was given a total laryngectomy in January 2009 and they also removed the lymph nodes in my neck and part of my thyroid. This all went well, and I healed surprisingly quickly. And was soon eating and drinking, and talking again with confidence.

The Side-Effects

After that operation I was to endure 37 consecutive days of radio-therapy and weekly sessions of chemotherapy. This went well although towards the end I started to get nauseous and my neck was quite badly burned. I was re-admitted to hospital due to dehydration, but was soon up and about and settling back into my normal daily routine.

After a few months I started to suffer frequent problems with my the speech valve in my throat and had to have it changed frequently because it would leak, causing me to splutter and choke when eating or drinking. The effects of the radiotherapy had badly scarred the tissue inside my throat. I was in and out of hospital until 2014, when I was eventually unable to eat or drink by mouth, or talk at all for eight months. Now, over eight years since my laryngectomy, the hair on my chest has still not grown back and under hot sun my neck starts to cook again from the radiotherapy effects. Prior to radiotherapy I was fitted with a PEG (tube) to enable me to take food and liquid directly into my stomach. I still have the same PEG fitted all these years later!

The Major Pectoral Muscle Flap

Eventually, in 2014 my consultant in Devon, referred me to a consultant surgeon in the Northeast of England where I underwent a Major Pectoral Muscle Flap. This entailed taking muscle tissue from my left chest / breast and flapping it into my neck. I no longer have a left man-boob and had eighty metal clips stapled in my chest during the operation, but since removed. This all went remarkably well, and I was up and running again reasonably quickly. I was again able to eat, drink and talk. I can eat and drink now, albeit slowly, and the food must be soft and small. But…Then in 2016 I was once again unable to talk at all.

Speechless

Another operation was necessary to realign my speech valve as it had "migrated" and wasn't sitting in my throat correctly. This was preventing me from using what voice I had left. However, my consultant who seemed somewhat hesitant said to me "That sometimes when we try to put things right, we can make matters worse." That didn't instil me with a great deal of confidence, but I was completely in their hands. I was also given the choice between eating and drinking, or talking, for the rest of my life. There was a chance I might not be able to do both.

A Brand New Speech Valve

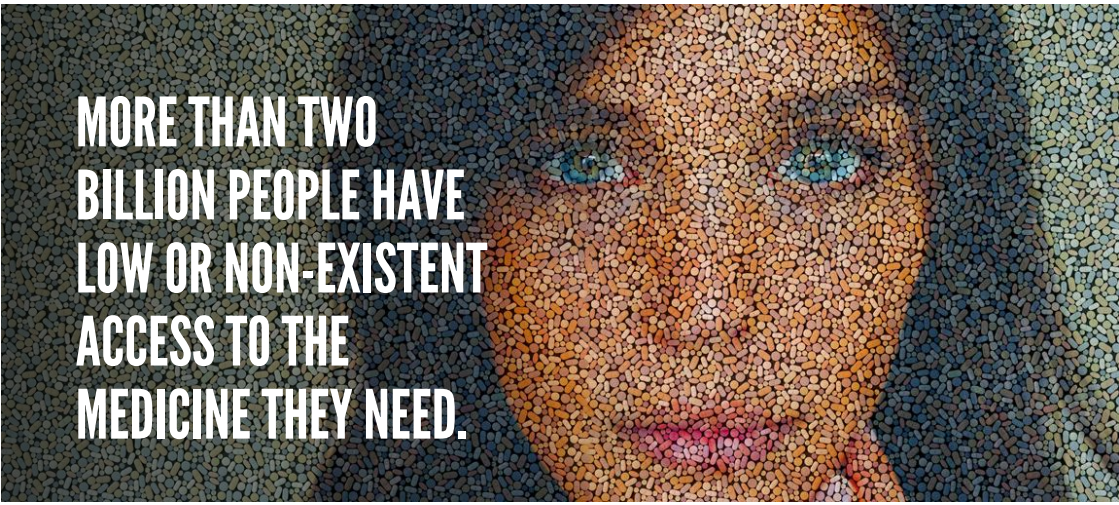
However, in March 2016 they removed my speech valve and then let the fissure close over completely. In November 2016 they checked me over and said they would try to fix a new speech valve before Christmas. I was elated. But then Christmas came and not a word. Easter of 2017 came and still no word.
Eventually I was admitted in May and they punctured a new hole inside my throat in readiness to receive a new speech valve. Although this procedure was performed under a general anaesthetic I was discharged that same day which was a Monday. On the Friday, the Speech & Language Therapist fitted me with a new speech valve and this allowed me to eat, drink and to utter a few words.

Thanks

Without a doubt, I owe my life to the GP who first spotted a problem and immediately referred me to a consultant. That in itself saved my life. And of course, I will be eternally grateful to all the surgeons, clinicians, therapists, and hospital workers who have been there for me for these past few years. And special thanks to the nurses and other hospital staff of Lynher Ward at Derriford Hospital.

CLINIGEN

Access to Medicines



Population growth, an increasingly elderly population, growing incidences of chronic diseases, rare or orphan medicines, increasing patient knowledge, and concerns around counterfeit medicines are all driving increasing demand for quality medicines which are not available at the 'point of care'.

Every year, thousands of patients and care givers across the globe face the dire situation of discovering that the medicine they need is unavailable to them. It could be that it is still in development, a discontinued line, or simply unavailable in the country they reside in. In these difficult times, patient advocacy groups can play a critical role as a trusted resource for their patients, providing timely and accurate information about the process for accessing unlicensed medicines, and explaining the roles of all the different stakeholders involved.

Clinigen is a global leader in providing access to medicines to support the care of patients and to help the clinician get access to the right treatment at the right time. Shortages and delays can be life-threatening; therefore, ensuring that the physicians are offered the best, most effective treatment can help to save lives. For good clinical reasons, the use of unlicensed medicines is essential and access to medicines throughout the product lifecycle ensures physicians have the broadest range of treatment options available.

Clinigen provides access to medicines around the world with ethical, compliant and timely access to the treatments that are unlicensed or unavailable at the point of care. We provide access to our own and other pharmaceutical companies' products, whether to service unmet medical needs or for use in clinical trials. This includes providing access to medicines that have received regulatory approval, that may not be available in a specific patient's own country ('unlicensed' medicines). Ethical unlicensed access helps protect patients from the growing threat of counterfeit medicines distributed online. Whether a medicine is unlicensed in a given country, not yet commercially available, is experiencing a supply disruption, or is discontinued, we can help!

Clinigen are the global leader in access to medicines, with extensive experience, presence and expertise allowing clinicians access to a portfolio of 23,000 medicines across 130 countries, 24/7 via a network of 650 experts in 13 locations worldwide. At Clinigen we get medicines, we ensure that the right medicine reaches the right patient at the right time!

For further information on access to medicines visit our website at **www.clinigengroup.com**

TOUGH LOVE

Robert's Story

At age 52, I was diagnosed by Duke Surgical Oncologist Ramon Esclamdo MD with advanced stage human papilloma virus (HPV) and associated squamous cell carcinoma of the oropharynx.

My story begins. My first sign of getting sick was at work. I was parking a car. While walking back to the dealership I started walking side ways to my left - which is the side of my cancer. I shook it off and talked myself out of being worried. I began to have a sore throat and had been coughing up blood at the same time. One day in the bathroom at work I said to myself "Will I ever feel better again?". That kept on for a while then my left ear started to go deaf when I would go to bed, I could feel a mass going over my eardrum, then it went blank. After that I was pretty much deaf in my left ear. I knew it was time to go the doctor. The doctor claimed he looked down my throat and ears and saw nothing and said it was allergies and I needed to get the allergy spray. I did, and nothing happened.

By then I could feel something hard on the left side of my tongue. Luckily, I had made an appointment with my primary doctor for a complete physical, although I was told that I am, "One healthy man and will live for a long time, with a few bad allergies." A few weeks passed, and I was feeling worse, so I asked my wife to shine a flashlight down my throat. I knew it was bad. She almost passed out. My tonsil was hanging inward in my throat with open sores. We googled throat and mouth cancer that night and I was scared and knew I was going to die. I called the local ENT and made an appointment. He looked down my throat and ordered biopsy ASAP. The ENT doctor told me I had cancer, but it was 'good cancer', and I will be fine.

We wanted a second opinion and made an appointment at the Duke Cancer Institute. After a further test I was told it was advanced stage HPV associated squamous cell carcinoma of the oropharynx. This is not, 'good cancer.' This is bad, really bad cancer. Every local doctor I met with had no clue at all. They let me down. If I would have listened to them I would have been dead a few years now. More tests were performed; I met with my oncologist to come up with a plan to treat my cancer. I had two choices - either surgery or radiation with chemotherapy. We decided on 7 weeks of intensive radiotherapy and (35 treatments) concurrent chemotherapy (10 treatments) administered on the first and fifth week.

It started off well the first week, with no symptoms. The second week I started feeling 'it'. I began to lose my appetite and my throat was beginning to hurt. By the third week, the vomiting felt like hot bile raking over open sores. That went on four more weeks. During that time I was admitted to the hospital for many issues, such as failure to thrive, malnutrition, constipation, abdominal pain, orthostatic hypotension, neutropenia and mucositis. I was at the point I was asked a few times if I wanted to talk to a preacher and I did. Not being sure what God thought of me, from what I know now God thinks a lot about me.

Recovery was not easy. I lost 50 pounds. My weight was down to a mere 137 pounds. The first month at home I had bad panic attacks, would not eat and had open sores on my tongue that were getting worse. It was bad. I went back to meet with my doctor at Duke and he told me to get over the panic attacks, which I did. He said "Robert, I did my job. The cancer is gone. If you want to die, die. You need to eat."

'Tough love!'

A few weeks later, I had a feeding tube. It was terrible, and I hated it. I had to spend every day feeding chocolate drinks into the tube, which fed through my nose and into my stomach, until I threw it up one afternoon and had to go to the local doctor to cut it out.

I ended up going to work in December which was way too early. I was taking 6 oxycodone a day - two for breakfast, two for lunch and two for dinner, while numbing my mouth to attempt to eat. I remembered crying on the way back to work during lunch because my mouth hurt so bad. During that time the sore on my tongue had gotten infected, I was not eating at all and was losing more weight. My doctor at Duke sent me back to Durham for Hyperbaric Chamber Treatments to cure my tongue. So it began again, 60 dives, twice a day for 30 days, two hours per dive at a pressure equivalent of being under 33 feet of sea water. I had to put a plastic bubble on my head during the dive and sit with other people with plastic bubbles on their head. People with no legs, no arms etc. The treatments did work, and I have been getting better daily.

I am cancer free, gained my weight back, gone back to work, and attend Church regularly. I will have dry mouth, chemo brain, tinnitus, and a few other long-term issues to deal with. I would not have made it without God, Duke Cancer Institute, The Caring House, Family and Friends.

Carers are the unseen heroes

This is what my senior colleague said to me when I was starting out as a doctor. It's a lesson that I've been reminded of on many an occasion over the years, and a lesson I share with those I teach and work with.

It's also something I regularly say to carers, who invariably raise their eyebrows at me and respond by saying they, "Couldn't be so selfish". To which I counter, "It's not selfish, it's self-caring".

The reality is that when someone is diagnosed with a long-term health condition, like cancer, those around them - particularly those living within the same home - inevitably become a carer to some degree. Whether or not it's through the needs of their loved one or their own desire to help, it happens. Of course it's a good thing It helps the individual with the health condition obviously, but it can also benefit the carer. In addition to feeling reassured that they are 'fulfilling their duty' it means they can also be involved in the appointments, treatments, and so on, that the person they are a carer for has, and so they don't feel excluded.

The truth is, however, the caring role is usually an additional, and sometimes all consuming role added lo existing roles of partner, parent, or friend, for example. It can mean time previously spent on yourself is now taken up with caring. It is often the cause of physical problems - many carers suffer back injuries, for example - and can be mentally draining too. This is compounded by the resentment that all too often creeps in as the carer finds themselves with less and less 'me time', making stress, anxiety and depression far more likely for them too.

If this is sounding familiar then it's time to take some positive action. Seek some help and advice from your doctor, nurse, or other healthcare professional. Carers' organisations - such as Carers UK - are an excellent source of advice, help, and resources. There's no shame in asking for help -we all need help sometime. Asking for help is a sign of strength, not of weakness. If you think it can't, or won't, happen to you then please think again. In healthcare the phrase 'prevention is better than cure' sums it up nicely. So seek the help and advice before you find you actually need it- be prepared.

You might be forgiven for thinking that being a carer is all doom and gloom. It's not, of course. It's a rewarding, valued, and needed role - in the UK you'll often hear the millions of carers described and lauded as the unsung (and unpaid) heroes of-the NHS. The key-to being an effective, and healthy, carer is to look out for your own needs too, and not to feel guilty about spending time on yourself. Do the things you want to do, not just the things you need to do that may be cluttering up your 'to do' list. Each of us has our own ways of relaxing, re-focusing and re-energising, whether this be with relaxation exercises, listening to music, or simply enjoying a cup of tea whilst gazing into the distance. The important thing is to make use of these and to make them part of your daily routine.

It's probably taken you a few minutes to read this - so for those of you who might have thought you don't have time to spend on yourself, you've just shown that you do. In doing so you've not only helped yourself, but you'll be helping the person you care for, because just as my colleague said to me, and I'm now saying to you: "If you don't look after yourself, you can't possibly expect to look after others well".

Fund raising

£100 to us is like winning the Lottery, so please remember...

Every penny counts!

Our volunteers have completed a number of different events, from bag packs to 28km swims in the Lake District! We are truly thankful to all the volunteers who have taken part in an event to help valuable funds for the charity.

Some ideas:

- Run a marathon
- Sponsored walk
- Sky Dive
- Dress as you like day
- Bike Ride
- Shave your head
- Bake off!
- Come dine with me

We will gladly help and provide materials such as t-shirts, sponsorship forms and letters of authority.

To get involved email **fundraising@theswallows.org.uk**

The best events are those when you have fun while fundraising. So just think what you would enjoy doing, then get sponsored for doing it!

JustGiving™

justgiving.com/theswallows

Support Services for patients with Head & Neck Cancer

NHS
Lancashire Teaching Hospitals
NHS Foundation Trust

"I'm sorry to say that the biopsy shows that you have cancer..."

No matter how much the diagnosis of cancer may have been suspected, the sheer enormity of the statement above often results in a range of gut-wrenching emotion and anxiety. The rest of the conversation often blurs into a nightmare of thoughts and fears. "What am I going to tell my wife/husband/partner/children, why me, how did this happen, when etc" all fill your mind as you try to rationalize what you are hearing. The Medical and Nursing team provide details of the cancer and treatment, but your mind hasn't yet moved on.

"Will I live?"

Once the realization hits home there is often a feeling of isolation despite the individual support of family and friends. Some people are fortunate to have lots of support but this is not available to everyone. However, no matter the age, social status or background, the basic support needs are often very similar.

The diagnosis, subsequent treatment and consequences of therapies take their toll. The need for support is there at all stages of the process. Some require this short term, during specific stages of this journey, whereas others require a much more prolonged service.

Whilst most people are aware of the support available from the conventional sources such as GP's, Hospital specialists (Surgeons and Oncologists) and Specialist Nurses, there are many other sources available. People often turn to Google as the first port of call. Whilst the Internet is a useful resource, it is not sensitive to the requirements of individuals. However, it means generic information can be readily available within a few minutes. Some people prefer the factual and often non-attachment of this approach but others prefer a personal and empathetic approach.

The provision of support services varies depending on regional and geographic availability. However, all regions have access to one or more of the services of the larger charitable services for cancer e.g. Macmillan or Marie Curie. These provide access to general information as well as patient -specific support. Many regions are further supported by Hospices, which add to the provision of services, which may include support of people who have cancer and also their families/ carers. These services are run by a combination of health-care professionals ably supported by funded counsellors and volunteers. Formal support in the form of Psychology, and in some instances the expertise of Psychiatrists can be helpful, as anxiety and depression are much more common than in the general population.

Many localities have independent patient and carer organized support services and self help groups, such as The Swallows, Laryngectomy groups, Mouth Cancer Foundation and Saving Faces. These provide an invaluable service. The exact nature varies, depending on the constitution of the group, but would typically provide a range of services including advice, support, buddying and telephone services for crisis care.

Whilst support is available, individual requirements vary with respect to the amount and timing of it. There is ultimately no single answer to what is right for every individual. There is also a significant variation in how people take up this support, with a gender variation in acceptance. In addition, some view this as a personal failure; a view that has to be acknowledged, but counteracted with a supportive, balanced view given.

Mr S Akhtar
Oral and Maxillofacial Consultant Surgeon,
Royal Preston Hospital

Andrews's Story

I am just an ordinary 56-year-old English guy who was diagnosed with throat cancer out of the blue in November 2016. Having gone through the last 18 months, what I want to share with this story is simply this:

"Keep battling and stay positive - the power of the human mind and the strength of those around you will make your journey easier, whatever the outcome"

I'll start at the end. It's just over 12 months since my treatment for HPV 16+ Oropharyngeal Squamous Cell Carcinoma of an Unknown Primary ended, and I am happy to report that I am entirely cancer free at this time. The most amazing thing is that I am an even more positive and healthy person than I was before the Big C landed – with a few little kinks! The journey to get to where I am now has been far from easy though.

I had little or no experience of cancer except for my mother dying of an untreated melanoma in 2015. I had certainly never heard of Squamous or throat cancer and had absolutely zero idea of how it was treated and what that treatment would do to me.

It's the knock on effects of the treatment that the awesome folk at the NHS don't really want to expose to you and for very good reason. Of course, everyone wants to be cured, I am pretty sure the survival percentages would drop dramatically if every throat cancer patient could really understand what 6 weeks of daily radiotherapy of the neck does to you.

I remember distinctly the moment that my quiet, unassuming but amazing ENT surgeon told me that I had a cancer of unknown origin somewhere in my mouth or neck. I was already 95% certain he was going to tell me the worst, so I was not surprised at all. I was with my wife of 30 years and on being told, my first words were:

"I don't care what you do to me even if it means being dipped in a vat of acid, let's get this thing sorted!"

A tiny smile flitted across his face but all he said was that he would give me a Radical Right Neck Dissection to remove the tumour and then I would have 6 weeks of chemo and radiation therapy. How little did I know…

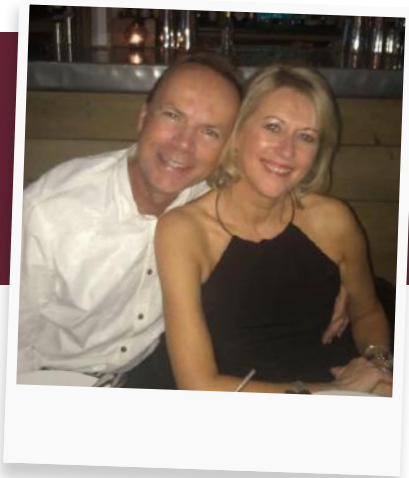
I had a PEG (tummy feed tube) fitted which was not a pleasant experience, boy was I glad of it after four weeks of radiation.

I had an Unknown Primary cancer, meaning no-one knew where its exact origin was, I had to have "shotgun" radiation treatment for my entire neck area. This caused more trauma to the throat than if say they targeted just your tonsils. And by week four my taste was going, saliva was turning to a shitty

goo and eating was almost impossible. The PEG and the thick chocolate protein drinks I pumped in, definitely saved me from losing a ridiculous amount of body fat. As it was, over the next three months, I dropped from 13.5 Stone (86 KG) down to 11.5 (73 KGs) and at 6' 1" I did look a bit skeletal! My brother freaked when he first came to see me at home!

Ironically, my lowest point came a couple of days after ending the six weeks of chemorad. It was Sunday and I just could not keep anything down. I spent most of the next two days wrapped round our bathroom toilet and, in some distress, my wife drove me back to the brilliant Northampton General Oncology Center on the Tuesday morning. As ever, the hospital staff were fantastic, and I was admitted and kept on a drip for four days while they stabilised me.

I got home, on a lot of oral morphine as I continued the battle with mouth ulcers. I don't really remember a lot about the next two weeks my incredible wife and two grown up children will tell you that I was not in a good way at all.



It was the beginning of June, four weeks later, that there was a little improvement. I decided, with some heavy persuasion from my daughter, that I should still aim to go to Glastonbury on the 21st June. I used this a target to force my self to eat and exercise to build my strength up as much as possible. It worked, as I did get to the festival, although I could not do a lot as I got very tired, I am really happy that I made all that effort. Being at home while wife and daughter went would have been a nightmare! We were in a motorhome and not a tent in case you were wondering!

From that point on it was a slow but steady progression back to decent health. The thing is, as part of the positives I take from this experience, I am a healthier person than I was before. I eat less meat, more vegetables, less booze, no fags and bang on my target BMI at 12 stone. Not that they were unclean before but now I have incredibly clean teeth as I jet wash and brush them three times a day after every meal.

Always been a very positive person, now my perspective is even more holistic in nature – all those little daily annoyances that used to upset me mean nothing anymore. Live for today and enjoy every tiny thing that you can. Its really true that having a life threatening illness can change you, but don't let it be for the worse when you can really turn into a massive positive for yourself and those around you.

I will leave you with these final words:

**"Thinking about the past can cause depression,
Thinking about the future can cause anxiety,
Live in the now and just be happy."**

Listen to your health professionals and learn as much as you can about your disease and how to beat it. Fear is nothing but ignorance.

Thank you to my wife, children, extended family and wonderful friends for their loving and extraordinary support and faith in me, I could not have made it through without you.

Coping with the fear of cancer returning

This is the most prevalent concern for most patients. Others include feeling stressed, depressed or anxious, experiencing anger, feeling alone or changes in relationships. Here are a few tips to support you:

Be informed about your health:
It is useful to have information on how often you will meet with your doctor, what follow-up tests you can expect, symptoms you should look out for and who you can contact should you experience any of these. Learning about your type of cancer, recognising what you can do for your health now, and finding out about other services available to you can give you a greater sense of being in control.

Pay attention to the positive:
Even when things get really tough, trying to stay hopeful, rather than only thinking of the worst, can help, focussing your strength on your wellbeing and doing what you can in the present to stay healthy.

Look at the things you can control:
Some people say that having structure in their lives is a comfort, being involved in your health care, keeping your appointments, and making changes in your lifestyle are among the things you can control. Even setting a daily routine can give you a sense of control.

Don't take the blame:
Some people blame themselves for feeling they did/did not do something concerning their health. It is important to be aware that cancer can happen to anyone.

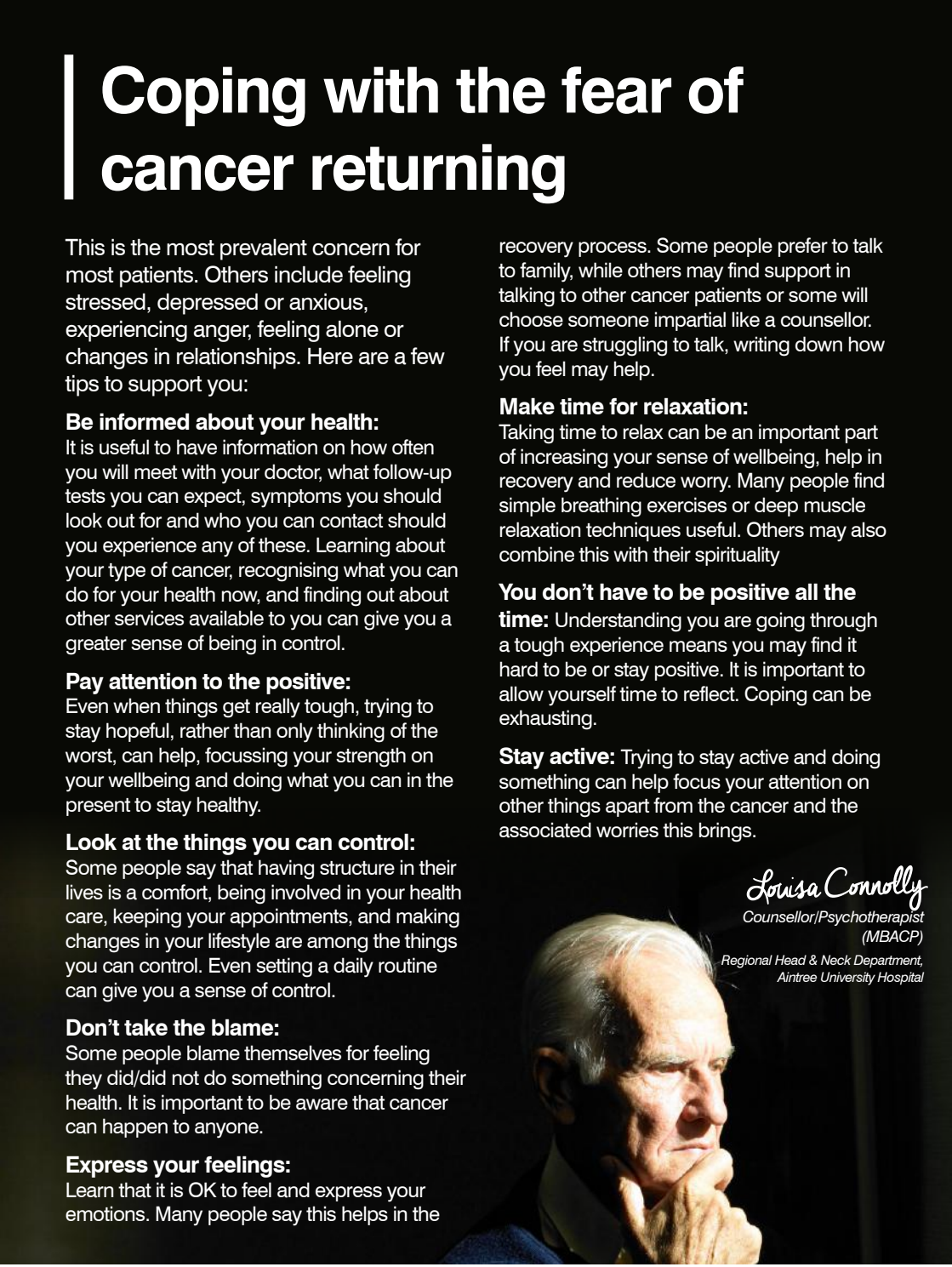
Express your feelings:
Learn that it is OK to feel and express your emotions. Many people say this helps in the recovery process. Some people prefer to talk to family, while others may find support in talking to other cancer patients or some will choose someone impartial like a counsellor. If you are struggling to talk, writing down how you feel may help.

Make time for relaxation:
Taking time to relax can be an important part of increasing your sense of wellbeing, help in recovery and reduce worry. Many people find simple breathing exercises or deep muscle relaxation techniques useful. Others may also combine this with their spirituality

You don't have to be positive all the time: Understanding you are going through a tough experience means you may find it hard to be or stay positive. It is important to allow yourself time to reflect. Coping can be exhausting.

Stay active: Trying to stay active and doing something can help focus your attention on other things apart from the cancer and the associated worries this brings.

Louisa Connolly
Counsellor/Psychotherapist (MBACP)
Regional Head & Neck Department, Aintree University Hospital



David's Story

My cancer story started in December 2013. I worked as a welder all my working life but started feeling tired, struggling with a sore throat and kept losing my voice. I had just had my 52nd birthday and got the news that shocked me and changed my life forever. After several visits to my GP and always being told that I had a chest infection, I was finally referred to the hospital.

I was diagnosed with stage four throat cancer and told that I needed a laryngectomy. I was stunned! The following day I was back at the hospital having my pre-op and two days later was admitted to North Manchester general hospital to have a total laryngectomy operation. Because of a couple of complications I was in hospital for around four weeks and not the usual 10 days and spent Christmas and the New Year in hospital. I left hospital in January 2014 still unable to talk. I was supposed to have a speaking valve fitted at the time of the operation but due to complications it wasn't possible and it would be two years before I would eventually be able to talk again.

I was given about 4 weeks to recover from the operation before I started my chemotherapy and radiotherapy course at the Christie hospital in Manchester. I had 2 sessions of chemotherapy and 30 sessions of radiotherapy. I wasn't prepared for what to expect and found it a real low point.

Things didn't go totally smoothly but I started on the long road to recovery and I was off work for 13 months. I had problems along the way with eating and drinking and lost over 6 stone in weight. (I was very overweight so this was a massive plus point although it cost me a fortune having to buy a new wardrobe!) I had a new speaking valve fitted but it didn't work and I ended up with a bad infection and another feeding tube in for another 3 months until it cleared up. Going back to work was always going to be difficult, but I was given enormous help and encouragement from my speech therapist, Janice. She arranged a back to work government grant to get equipment modified so that it would be safe for me to try and return to welding.

Eventually, after 13 months I did return to work. Although we were trying to get a grant to get the equipment modified these things take time to sort out. My employers, knowing that I felt well enough to try and return to work found me a part time job in the office. Even though I was only doing 4 hours a day and getting home absolutely shattered I still felt I was winning my battle. After eventually having a speaking valve fitted and having massive problems with it and still being unable to talk, it was decided to have it removed and let it heal up. So again, I was unable to eat or drink for 3 months until the hole had healed up.

I was referred to the gym by the doctors on an exercise referral scheme to try and get stronger. I had never done any exercise before or been in a gym but I thoroughly enjoyed it. I was just doing light exercise going just a couple of times a week but felt so much better. The staff at the gym at Royton Leisure Centre that I go to were very helpful and supportive to me and nominated me for the changing lifestyle award at the Oldham Sports Awards. A big posh do at the Queen Elizabeth Hall in Oldham. I invited Janice and her assistant and my Macmillan nurse along to support me and unbelievably I won! I was then put forward to the Greater Manchester sports Awards representing Oldham - a huge event at Old Trafford which I also won! I even managed a few words on stage in front of hundreds of people thanking everyone for my award. A massive step for me.

Its 4 years now since my laryngectomy but I can now talk. I had a second valve fitted but still I was finding it very hard to talk. Janice sent me down to London to see a specialist and they injected my throat with botox to try and relax the muscle in my throat. I have had 4 treatments up to now and it's not perfect but it's getting there. I am now back welding working 30 hours a week doing the smaller jobs that will fit on a special bench that I have that sucks all the welding fumes away. I also wear a head shield that blows air in so that I breathe fresh air.

I'm also heavily involved in our local laryngectomy support group, the Oldham Quiet Ones. I go to all the meetings and have found it very supportive and helpful and I have now been asked to be the chairman of the group. I help out with all the fundraising, the website and we've now started a Facebook page with lots of info. I've had terrific help and support all through my journey from my speech therapist. Now added to this great support is the new specialist nurse, Izzy, who's been provided by Countrywide Supplies. It's a personal service that's tailored to each individual patient.

So that's my story - I've had loads of setbacks and it has been far from straight forward or easy. But I feel that I have come through having cancer a stronger person and the positives outweigh the negatives and even though I'm not great at talking, and I'm not that great at breathing. I'm still here and I wouldn't change a thing. Any advice for others would be, stay strong, stay positive and keep smiling. Having a laryngectomy is life changing, but it's definitely NOT life ending.

A commitment to quality of life

Undergoing a total laryngectomy can be a difficult, invasive and life-changing experience. But it is quite possible to live a good life again. Atos Medical has – for three decades – developed, refined and manufactured quality products for people with a laryngectomy.

Our engineers focus on one single thing: What can we do better? It is precisely this ethos that has driven Atos Medical forward for over 30 years and lead to several innovations. The development of products takes place in close cooperation with end users themselves, the people who actually use the products in their day-to-day lives.

"As long as there is a gap between users' wishes, and what is actually on the market today, we will continue to fight to improve their quality of life. Innovations are the backbone of our existence. That is why we work very closely with our users in everything we do," says Mikael Melefors, Vice President Design and Development.

User feedback leads to smarter products

Atos Medical seeks constant feedback from users and patient associations. We carry out studies on the reality of users, and hold focus groups to help identify problems and frustrations. Also clinicians, such as doctors and speech therapists, are a major and important source of new knowledge and smarter products. One of the results of our commitment to develop products that make a difference is Provox Luna, users and clinicians across the world have been involved in the creation of this product.

Provox Luna is a unique night-time solution that helps people who have had a laryngectomy sleep more comfortably, care for the skin around the stoma, and get superior lung humidification. Due the high quality design and innovation of Provox Luna it won the prestigious Red Dot Product Design 2018 Award.

There has been an overwhelming response to Provox Luna from users across the globe. "I received Luna yesterday and I slept right through the night without

coughing." "I thought it would be good, I just didn't realise it would be this good!"

The Red Dot Award is an international distinction for high quality design and innovation and this isn't the first time that Atos Medical received this important recognition. Atos Medical first won this award back in 2016 for the Provox Coming Home Kit. The Provox Coming Home Kit is an intuitive tool, which facilitates returning home from hospital for patients after their laryngectomy. The tool includes a durable carrying case with selected products and information in several languages. The Provox Coming Home Kit is the result of cooperation with leading institutions, doctors, nurses and patients from all over the world.

Long-standing commitment to users

No new product reaches users without having gone through a wide range of clinical tests. Atos Medical products have featured in more than 150 publications, have been reviewed by experts, and the company supports hundreds of forums and training programs every year.

Different products for different needs

- **Active:** Provox XtraFlow helps you breathe more easily. Use it during the day when you are physically active.
- **Relax:** Provox XtraMoist makes the air more moist. Use it during the day when you are taking it easy.
- **Protect:** Provox Micron is an HME with an effective filter against bacteria and viruses.
- **Sleep:** Provox Luna is soft and smooth for night-time comfort. Low breathing resistance for easy breathing at night.

A celebrity survivor

Bryan Robson has revealed he has beaten throat cancer. The former Manchester United & England captain was diagnosed in 2012 after doctors discovered a tumour.

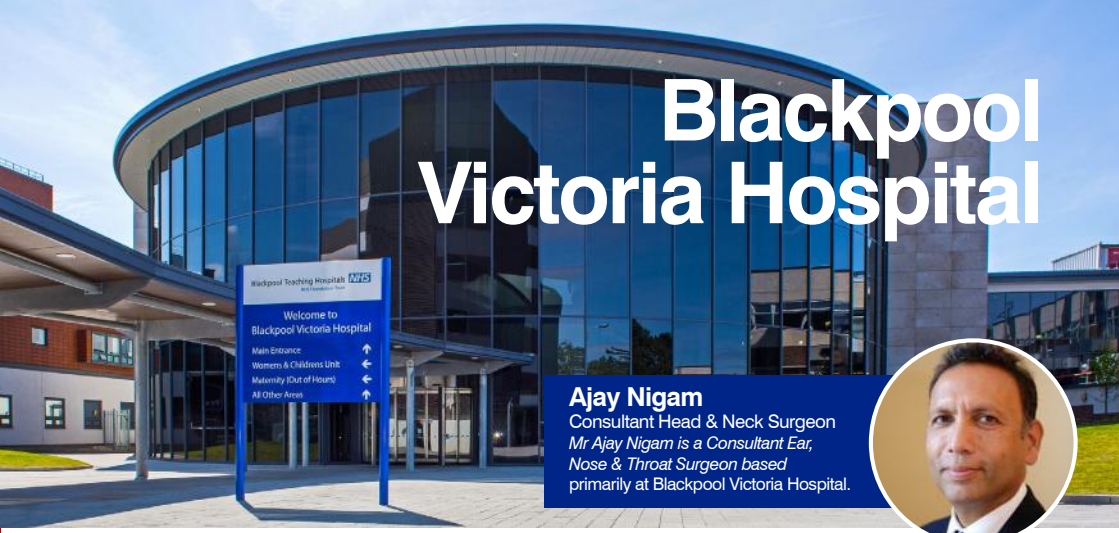
But after having it successfully removed and a course of radiotherapy, Bryan was given the all clear in a letter from his specialist.

Bryan Robson, known as Captain Marvel by fans, said, "It was great news. Things are going so well for me and I received lots of messages and had great support from fans throughout the world, especially West Brom, Middlesbrough, Thailand and obviously Manchester United.

Bryan is happy to support the Swallows Patient Book and the work we do in helping those in need. He wishes everyone the very best for their personal cancer journey.

Bryan Robson

No7, former England & Manchester Utd



Blackpool Victoria Hospital

Ajay Nigam
Consultant Head & Neck Surgeon
Mr Ajay Nigam is a Consultant Ear, Nose & Throat Surgeon based primarily at Blackpool Victoria Hospital.

Blackpool Victoria Hospital is a large acute hospital that treats more than 80,000 day-case and inpatients and more than 200,000 outpatients from across Blackpool, Fylde and Wyre every year.

The ENT/MAX-FAX department of the hospital is a fully functioning local diagnostic centre which sees around 100 newly diagnosed Head and Neck cancer patients every year. As the incidence of cancer continues to rise, it is expected that the NHS will continue to provide efficient, timely, best care to its patients, which our department is passionate to help achieve.

The Head & Neck Cancer Team meets on a weekly basis with our colleagues across the cancer network to discuss and formulate individual treatment plans for our patients. Surgery and Chemo radiotherapy treatment is provided at the Royal Preston Hospital, but for diagnostic services and follow up, this care remains local.

The Head & Neck Cancer Nurse Specialist holds a weekly pre and post treatment clinic alongside the Head & Neck Specialist Dietitian & Head & Neck Specialist Speech & Language Therapist. This collaborative way of working allows a one stop clinic setting for each patient to be seen before and after their treatment which facilitates a multi-disciplinary approach to formulating a management plan for coping with the expected side effects of their treatment. The local support team have excellent working relationships and each specialists advice does indeed compliment the work of their colleagues, for example assessment of current pain levels and appropriate pain relief advice by the clinical nurse specialist which allows the patient to carry out specific swallowing exercises encouraged by the speech therapist, therefore helping the patient with their swallow which enables them to manage the specific dietary intake whilst being guided along with nutritional advice by the specialist dietitian.

We at Blackpool Teaching Hospital are fortunate to have the ongoing support of one of our local cancer support groups, The Swallows. They are a group of like-minded individuals who strive to support Head & Neck Cancer patients throughout their diagnosis, treatment phase and into the individual's recovery. The group was formed by Head & Neck Cancer patients and their purpose is to provide help, support and information to their members. They are a very active group who work together tirelessly to help raise awareness about early detection of head and neck cancer and the importance of follow up and survivorship.

The group regularly hold fundraising event such as family fun days, sponsored runs and celebration balls in their quest of building up funds to help promote their good work and support for all Head and Neck cancer patients, not just the local ones.

The Swallows joined forces with Blackpool Victoria Hospitals designated charity, Blue Skies. They worked together to raise a large sum of money to purchase a state of the art Ultra Sound Scanner for the ENT department that is used to help detect neck tumours, thus enabling patients to access treatment quicker. This piece of equipment is invaluable to our department and we are extremely grateful to the Swallows and Blue Skies for this donation.

We look forward as a department in continuing to refer our patients on to the Swallows for continued help and support and look forward to hearing about the benefits our patients report back to the department of the support from this group.

"Metastatic Squamous Cell Carcinoma with an Occult Primary..."

Eight words that changed my life forever...

These words gave me the opportunity to see the beauty and love of members of my family, feel the genuine concern of my friends and the friendship of people I had never met before.

I was admired by colleagues at work for the way I conducted myself during treatment and I was given the opportunity to reconsider my life so far and how I wanted to live it in the future.

I was able to work on the relationship between "do-ing" and " be-ing" and between "ego" and "spirit". I was able to appreciate that you can't worry about the "what ifs". The most important time is the present and it takes a lot of courage to "let go" and know that everything is going to be OK. Those words helped me realise that "I am the master of my fate" and what you think about is what you get. So change the way you think and what you think about will change.

I realised you only get a certain amount of energy a day. How you use it is up to you. By the end of the treatment I had lost 26 kilos in 6 weeks, lost my muscle mass and was extremely tired every day. My throat was sore and I couldn't swallow solid food. My skin was peeling from the radiation and chemo had drained all my energy. At times I could hardly walk from the bed to the front door.

I was very sick and it was very frustrating. I couldn't just sit around and feel sorry for myself. I had to do something I decided each morning to go for a walk. At first it was just from the bedroom to the kitchen, then the front of the house to the back ...and twice around the lounge. Then the front of the house to the street...then down the road...then around the block. After a couple of weeks I was walking for 15 minutes a day at a very easy pace and getting stronger every day. Then I discovered the hill at the end of Kays Rd.

It was a monster of a hill. After walking on fairly flat roads I though it would test myself and see how far up the hill I could get. I had only walked 10 metres before my legs were burning; I was out of breath,exhausted and felt very sick. After I recovered I had to walk 5 kilometres home.

When I got there I decided that was such a dumb idea. I was still very sick and what was I thinking walking up a hill like that. I shouldn't be walking. So I stopped I wanted to remain well and sitting around feeling sorry for myself wasn't doing me any good. So, I started walking again. I walked past the hill, looked up it and continued on..."You must have had rocks in your head to even think about walking up that hill."

Next day I walked to the bottom of the hill and thought I am not going to let this beat me. I will get to the top of this hill. The cancer has gone. I am healthy it's just that the body needs to know that. When I get to the top of the hill my body, my mind and my spirit will all know I'm OK. Each day for the next couple of weeks I walked up the hill. Some days I only got 10 metres before having to stop. Some days I got 50 metres only to get 20 metres the next time. My lungs burnt, my legs turned to jelly but I was determined to get to the top.

2 months later I reached the top of the hill at the end of Kays Rd without stopping. That was the day I realised "it really does get better". I was able to look back down the hill and see all the places where I had stopped because I couldn't go any further. I realised you just need to take one step at a time and not get too far ahead of the game. The hill at the end of Kays Rd is something we all got through at some stage in our lives.

Some of us never take the first step because it looks too hard or we are worried what will happen. Some only go so far and then they give up. It's those that make it to the top that get the benefit of the view and the lessons learnt on the journey.

Head & Neck Cancer Support Australia

"Our biggest fear is not that we are inadequate, our biggest fear is that we are powerful beyond all measure." *Marianne Williamson*

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 care giver 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.

My sore throat

My sore throat just wasn't getting better...I'm glad I went to see my Doctor!

We all worry about our health at times. If you have a symptom that's been bothering you, it's best to visit your GP as early as possible to get it checked out.

Although it's not common, cancer can occur in a number of areas in the head and neck, including mouth, throat, nose or salivary gland.

Here are some of the most common symptoms of head and neck cancers. All these symptoms may also be caused by conditions other than cancer.

- An ulcer that doesn't heal within a few weeks
- Difficulty in swallowing, or pain when chewing or swallowing
- A hoarse voice or trouble speaking
- Persistent noisy breathing
- A constant sore throat
- Earache affecting one side
- A swelling or lump in the mouth or neck
- A numb feeling in the mouth or on the lips
- A unexplained loose tooth
- A persistent blocked nose
- Recurrent nosebleeds
- Ringing in the ear or difficulty hearing

Remember, the earlier cancer is found the more likely it is that treatment will be successful.

Living with Cancer after treatment

Living with Cancer after your treatment and being told, 'The treatment has been a great success,' should be the best news you get, but sometimes it can actually be the most frightening part of the journey. For the last months since being diagnosed you have been going to chemotherapy, radiotherapy and lots of hospital appointment. You may have needed surgery and lots of recovery time. Now, there is nothing apart from the six-monthly appointment!

Questions that may come to mind:

What do I do? Need to get back to work? Am I ready? Need to get back to normality! Who will help me do this? And the big one -

"Will it come back?"

The uncertainty is the hardest part of your journey.

You're likely to feel relieved that your treatment is finished, and keen to get back to the life you had before cancer. You may also be thinking about how you can make the most of your health, or about positive changes you can make to the way you live. The end of treatment may present you with changes and new challenges.

You may hear the term 'Cancer Survivor', or perhaps see it written in some information. The term 'survivor' includes anyone who is living with or after cancer. There may still be some physical problems, such as the side effects of treatment, or emotional and practical problems.

You now have the chance to look at how you want to live in the future. You may want to do things you've often thought about but never done, perhaps visit places you've always dreamed about, or enrich personal relationships. This can be exciting, but we understand that you may not feel quite so confident.

Uncertainty is so frightening, but you need to teach your mind to remain positive and think about the good things that are in front of you. At The Swallows we hold regular monthly meetings to help with these questions, and you can talk to like minded people who have been there and worn the t-shirt. Please call or come to a meeting, we are always here.

24/7 Patient and Carer support and text service:

07504 725 059

Visit us at **theswallows.org.uk**

What other services you may need to access

Head and neck cancer may lead to various difficulties and the following services aim to support you with the rest of the multi-disciplinary team from diagnosis through treatment and at follow up in to survivorship.

The Role of the Dietitian in Cancer Care

Food and eating are an enjoyable and social part of everyday life. Nutrition is the process of nourishing or being nourished and is essential for living. Cancer and its treatment can affect your appetite or ability to eat your usual meals.

Assess your nutritional needs and gain an understanding of your lifestyle, food preferences and eating pattern.

Use the knowledge of nutrition, health, disease, cancer and its treatment to provide practical advice that will help you to eat and maintain your quality of life.
Support you in making informed choices regarding healthy lifestyles.

The Role of the Physiotherapist in Cancer Care

Physiotherapy is an autonomous profession concerned with the care, management and rehabilitation of patients. These principles apply to the management of patients with cancer through all care and rehabilitation programmes from diagnosis to the end of life.

Physiotherapists conduct ongoing assessment of the needs of this patient group and their carers, in order to apply skilled interventions, which are vital for patients' independence, functional capacity and quality of life. The role of the physiotherapist, as an essential member of the multi-disciplinary team is key to the successful rehabilitation and management of patients with cancer and palliative care needs. The absence of physiotherapy intervention would be detrimental to patient care and the ability of the patient's family to cope with the effects of the disease or its treatment on their functional capacity and quality of life.

The Role of the Speech & Language Therapist in Cancer Care

If your treatment involves having radiotherapy and or chemotherapy and it is felt at the *MDT meeting that this would affect your speech and or swallowing, you will be contacted by the speech and language therapist and if appropriate, offered an appointment prior to starting treatment. This may be a joint appointment with the dietician.

Normally at your appointment you can ask questions regarding your speech and swallowing and the therapist will assess your progress, advise and support you and practice any exercises with you that are needed to maximise your recovery. This may include lip, tongue, palate, jaw and or voice exercises and strategies to help you swallow and communicate more easily. Some exercises are to prevent future difficulties occurring e.g to keep the jaw and tongue moving freely and to keep your voice working efficiently.

Your speech therapist will normally follow you up after you have finished your treatment this may be a phone review or an appointment in the speech therapy department.

A group of health professionals with expert knowledge in your type of cancer will manage your treatment. This is called a multidisciplinary team (MDT).

Simon Tucker

My name is Simon and I'm a salesman.

Originally I trained at Rolls-Royce, as an aircraft engineer, (Don't worry, nothing I worked on is still flying!) however, life on the factory floor was not for me and I followed my Dad in to sales. A company car, the freedom of the road and an expense account added to the attraction.

For the first 18 months I tried to sell toothbrushes to dental practices for Wisdom - No easy task, especially for a rookie with no sales experience or training. However, with a lot of determination I had some success. Enough for the competition - Oral-B - to decide to poach me, so off I went. (Better car and more money too!)

The big change for me at Oral-B was some basic sales training. Albeit only two days in their offices with the senior sales manager, but it helped, a bit.

My real 'light bulb' moment came when I joined KaVo Dental. They had an in-house training program that consisted of an initial two-day basic selling skills course, followed by regular days out on the road with a sales manager to give feedback and coaching. This ensured I developed the skills they gave me in the classroom. A sort of on-the-job CPD, if you like. They also enhanced my skills, year in-year out, by adding other courses - Advanced selling skills, Negotiation skills, Presentation skills, etc, etc.

From then on, my sales career took off! Soon promoted to sales manager, then sales director and eventually sent to America to run the KaVo America sales team for 3 years. It was that training - and I have to thank Nick Gartside of PGP, for the courses that made my career.

Since those days I have run Kerr UK as Managing Director, Kerr Europe as European Sales Director and been Director of Equipment Sales for Henry Schein. Recently, myself and 2 colleagues built Medenta Finance from £0 to £24million per year in Patient Finance sales, not just because we had a good product but because we were able to train our clients - Dental Teams - in how to 'sell' treatment plans.

In essence, I have spent over 30 years selling to dental practices. I have trained many sales people and dental teams. I have been in to hundreds of dental practices, all over the world. I understand what goes on in a practice and I understand the difficulties in going from only having to think clinically, under the NHS, to trying to become a service provider and asking for money from patients - It's hard, but it can be done.

You just need to become comfortable with conversation. ***Simple.***

Effective Communication Skills for the Healthcare Team

"It's just a conversation..."

A Synopsis

Effective communication skills create:

- Better patient experience
- Increased treatment acceptance
- Less stress
- Happy team

In most cases, patients who come in for a health screening are hoping to hear that everything is fine and no treatment is needed. However, for those needing some kind of treatment having the time and the skills to communicate options fully is often daunting for many of you and your colleagues alike.

When it comes to offering more complex treatment options, many clinicians have a tendency to offer as much detail as possible - in writing - to ensure they have covered all the options. This can often lead to confusion on the patient's part and frequently results in a reluctance to comply with recommendations.

Objectives

- Enable every delegate to find their own conversation style
- To develop a bespoke process that fits the delegate and their practice environment
- To create an ethos that allows for continual self improvement & development

Outcomes

- Recognise their own strengths & weaknesses as communicators
- Know what their part is and when to share information
- Focus on what is important to the patient
- Discuss options with every patient
- Deliver a fab patient experience

Your rights at work when you are affected by cancer

* The following resources are included in The Essential Work and Cancer Toolkit, a pack for employers that can be ordered from www.macmillan.org.uk/worktoolkit.

For Employees:

- Work and cancer: a guide for people living with cancer
- Work it out: essential questions to ask about work and cancer
- Work it out for carers: essential questions for carers to ask about work and cancer
- Working while caring for someone with cancer
- Self-employment & cancer: living with cancer when you're self-employed or running a business
- Your rights at work when you're affected by cancer

For Employers:

- Managing cancer in the workplace: an employer's guide to supporting staff affected by cancer
- Top 10 tips for Line Managers
- Cancer in the workplace (a DVD to help employers manage people affected by cancer at work)*

**You can order any of the resources online from www.be.macmillan.org.uk/work.*

Your rights at work:

If you have cancer and are in paid employment, your employer should try to help and support you. Where reasonable, they should make changes to let you do your job during and after your cancer treatment.

Legislation protects you from being treated unfairly at work because of cancer. If you live in England, Scotland or Wales, the Equality Act 2010 protects you.

The Disability Discrimination Act 1995 and its extension, the Disability Discrimination Order of 2006, protect you if you live in Northern Ireland.

This legislation doesn't just protect employees. It also protects job applicants and people who are self-employed.

What is discrimination?

Discrimination can include:

- An employer not making reasonable changes to allow you to do the job (e.g. to cope with fatigue)
- An employer giving you a warning for having time off sick, but not taking your cancer diagnosis into account.
- An employer suggesting that it would be better if you retired or stopped working.
- Being dismissed for a reason related to cancer.
- Being demoted to a lower-paid or less demanding job for a reason related to your cancer.
- Being passed over for promotion in favour of someone with less experience or ability to do the job because of a reason related to your cancer (for example if you've used more sick leave than your colleagues).
- Not being given a job because of cancer.
- Not being allowed time off for medical appointments.
- Having an unfavourable appraisal or performance review (for example, if you've had a lot of sick leave or tiredness and haven't met targets or objectives as a result of this).
- An employer making it difficult for you to get any sick pay you're entitled to.
- Being harassed – this is when an employer or colleague bullies, intimidates, insults you or makes you feel uncomfortable so you feel you can't stay in your job (e.g. being teased about hair loss, or being laughed at or whispered about by colleagues.

Almost four in ten people (37%) who return to work after cancer say they experience discrimination from their employer or colleagues.

Macmillan Cancer Support / YouGov online survey 2012.

How am I protected?

Under the Equality Act 2010 and the Disability Discrimination Act 1995 (DDA), it's unlawful for an employer to treat you less favourably (discriminate against you) because of your disability. If you have cancer, you are legally classed as disabled.

Even if you've had cancer in the past, it has been successfully treated and you are now in remission, you will still be covered by this legislation. This means your employer must not treat you less favourably for any reason related to your past cancer.

Which areas of employment are covered by this legislation?

The Equality Act and the DDA cover all areas of employment (even when you no longer work for your employer).

These include:

- The recruitment process
- Your terms, conditions and benefits.
- Opportunities for promotion and training.

They also cover you if you are treated less favourably than other workers because of your cancer. This includes harassment and victimisation. Your employer also has to make reasonable adjustments to make it easier for you to work.

What are reasonable adjustments?

Both the Equality Act and the DDA require your employer to make reasonable adjustments to your workplace and their working practices. They are required to do this when the workplace or their working practices mean you are at a substantial disadvantage because of your cancer, compared to those who don't have cancer.

There is no fixed description of what a reasonable adjustment is. But it will depend on things such as:

- How much the adjustment costs
- How much the adjustment will benefit you
- How practical it is to make the adjustment
- Whether making the adjustment will affect your employer's business, service or financial situation.

Your employer does not have to make a reasonable adjustment unless it knows (or should reasonably know) that you have cancer.

For more information visit www.macmillan.org.uk/information-and-suuport/organising/work-and-cancer/information-for-employees/your-rights.html

This information is not a substitute for legal advice. If you need legal advice, please contact a solicitor. While we do everything we can to provide the highest quality information, the Swallows & Macmillan will not accept any liability for the use, or inability to use any information provided in this editorial.

Protection during and after Radiotherapy

Aspen Medical
A Hill-Rom Company

PolyMem Dressings for patients/clients/people with radiotherapy induced skin reactions

A patient's perspective of the problems associated with radiotherapy skin reactions, taken from patient's experiences in clinical trials.

1. Pain/ hotness/ burning particularly during dressing changes

PolyMem uses glycerin to soothe traumatised tissues, reducing wound pain and providing comfort at the wound site. It prevents the dressing from adhering to the wound bed.

2. Weeping skin

The starch copolymer in PolyMem absorbs and binds the water molecules from the wound fluid, allowing the natural growth factors and nutrients to concentrate in the wound bed.

3. Peeling skin

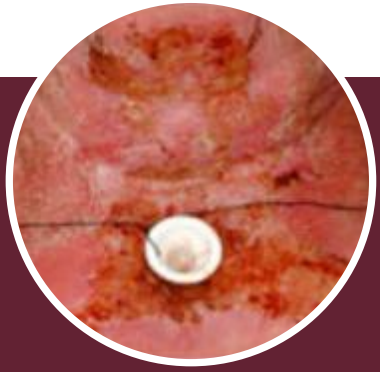
The dressing contains a mild, non-toxic wound cleansing agent that is activated by moisture and gradually released into the wound bed. This helps remove debris and loosens dead tissue, all the while keeping the wound bed clean throughout healing. It reduces the need to cleanse the wound between dressing changes.

4. The skin dries and hurts

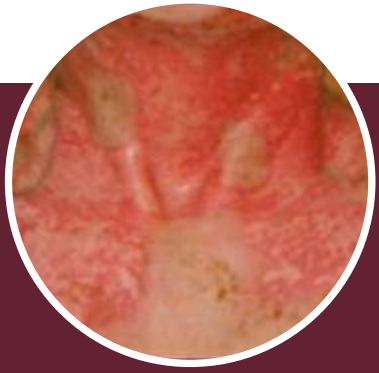
If PolyMem is to be used on dry skin it is helpful to lightly moisten the affected skin with either tap water or normal saline 0.9% solution before applying the dressing. This will ensure that the active ingredients in the dressing are released.

In clinical trials it has been identified that PolyMem is:

- An easy to use product
- Suitable for patients to use if self-caring for their wound
- Minimises trauma during dressing change
- "Soothing and cool" on radiotherapy skin reactions
- Reduces frequency of dressing change
- Comfortable for patients to have in contact with their fragile, vulnerable tissue
- Conforms to difficult to dress areas



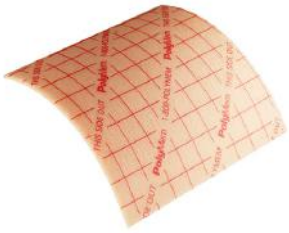
Dry, itchy and sore



Weeping and peeling skin

Collar that can be made with PolyMem roll and tapes

Neck Collar



PolyMem Non Adhesive Flat Dressing

PolyMem Non Adhesive Roll (can be cut to fit)

Radiotherapy treatment FAQs

We are often asked, 'What are the side effects of radiotherapy?' or 'What happens when I have radiotherapy?' These are some common questions that people ask.

- What side effects might I have with this radiotherapy treatment?
- What kind of diet will help?
- Can I see a dietician before I start treatment?
- What if I don't feel like eating?
- Will the treatment have any effect on my teeth?
- How can I care for my teeth?
- What does dry mouth mean?
- Will my dry mouth last?
- Will the treatment affect my jaw now or in the future?
- What can I do to keep my mouth moist?
- Will my hair fall out and in which areas?
- Do you expect the hair to grow back after the treatment ends?
- Will my voice change?
- Will my taste buds be affected?
- What is a planning meeting and what happens?
- Can I see a mask?
- Is it possible to talk to another patient who has been through the treatment?
- What happens if I miss any treatment dates because I feel ill?

Possible side effects of Radiotherapy

- Soreness (or even open sores) in the mouth or throat
- Dry mouth
- Trouble swallowing
- Changes in taste
- Nausea
- Earaches
- Tooth decay
- Swelling in the gums, throat or neck
- Hair loss
- Changes in skin texture
- Jaw stiffness

The Swallows

Head & Neck Cancer Support Group

Registered Charity Number : 1149794

The Queen's Award for Voluntary Service

You are not alone

Please join us at our monthly meetings

24/7 Patient and Carer support line service:

07504 725 059

theswallowscancersupport @swallowsgroup JustGiving™

Dry Mouth? Relieve it!

Don't ignore it.

A.S SALIVA ORTHANA

Dry Mouth (Xerostomia), is a common side-effect of necessary treatment for cancer of the head and neck. This distressing and debilitating condition can have a profound impact on a person's quality of life. Symptoms should not be ignored, as doing so can lead to additional complications including:

- Oral infections
- Halitosis
- Eating and swallowing problems
- Speaking difficulties
- Tooth decay
- Sleeping issues

Keeping hydrated is very important, but this alone is often not enough. Therefore, to help relieve Dry Mouth symptoms, clinicians often prescribe a saliva substitute. Due to its long history in clinically proven Dry Mouth relief, they often choose A.S Saliva Orthana to get the best results for their patients.

Available in 50ml oral pump spray, 500ml refill and lozenges, see our website for more details.

The A.S Saliva Orthana Range

Dry Mouth relief

- **Clinically proven**
- **Easy to use & long-lasting**
- **Pump action spray, no propellent**
- **Creates a protective oral coating**
- **Mild flavoured and pH neutral**
- **Based on natural mucin**
- **On prescription**

Unlike most other Dry Mouth products, that are chemically based, A.S Saliva Orthana is formulated from natural mucin - an important component of normal saliva. All our products can offer long-lasting relief and are mild flavoured. They are also pH neutral, this is important, as any increase in acidity levels can result in additional mouth soreness and accelerated tooth decay.

For more information on Dry Mouth and our range visit our website. Follow us in Twitter and Facebook @DryMouth_Relief

T: 01264 332172 - E. info@ccmed.co.uk - www.ccmed.co.uk

CCMed

Lucy Burscough

National Portrait Gallery exhibited and Royal Society of Public Health award winning portrait painter.

For more than a decade she has led numerous 'arts for health' engagement projects collaborating with renowned galleries, hospitals and charitable organisations. Lucy creates her paintings in public spaces providing opportunities for conversation and relaxation as viewers watch her at work. Lucy is currently artist in residence at Maggie's Manchester, a charitable organisation that offers psychological, social and practical support to people who have had a cancer diagnosis, their family and friends.

There, she is working on an Arts Council England National Lottery funded project called Facing Out, painting portraits of people who have experienced facial cancers. She has spoken to us about her art practice and how she came to be interested in working with people who have visible scarring and disfigurement due to cancer.

"I have always wanted to spend my life painting people. They inspire me to put paint to canvas. I am interested in them as individuals, in their families, backgrounds, histories and experiences which shape the character who sits for me. I love looking at faces, spending time to deeply scrutinise, becoming aware of their anatomy and conscious of the blood behind the skin affecting its abundant range of colours and tones. However, with that delightful physicality comes the possibility of physical disruption, of illness and disease.

In recent years I have developed an interest in the delivery of art activities as a means to promote good mental health, particularly amongst people whose wellbeing is at risk due to physical illness. As often happens, I ended up working in this field through a circuitous route, with luck playing a significant role.

It started with a dog walk. We had just got a puppy, a lovely blue grey whippet called Boo. Our walks often included a stop at a pub on the banks of the Mersey, and one Saturday afternoon we sat with another couple who also had a puppy, a scrappy little terrier called Grizzle. As we ate our lunch, the dogs made friends and so did we. I chatted to the woman, who was called Wendy. She would become one of my best friends and change my life!

As we talked, it became clear that we had a lot in common, not least a love of art. She worked at The Whitworth Art Gallery, was about to take on a newly created role as Arts for Health Coordinator. She was looking for sympathetic and skilled artists to work with. I had trained as a teacher and could deliver workshops, had lots of making skills from my current job (I made props for Postman Pat) and was really interested in how engaging with art could be harnessed to become a transformative act. Fate had brought us together! We met in 2007 and have worked together ever since. I was definitely in the right pub at the right time!

In the early days, the projects that Wendy and I put together were inspired by The Whitworth's collection. They were often delivered in hospitals and were aimed at a wide range of people, from children with mental health difficulties to elderly stroke or dementia patients. The projects offered opportunities for people to improve their wellbeing, to bolster their sense of self and to make new friends creating art in social situations.

As time went on I began to develop and find funding for my own arts for health projects, which were built around my portraiture practice. Each had a specific theme, telling stories of patient experiences and of medical

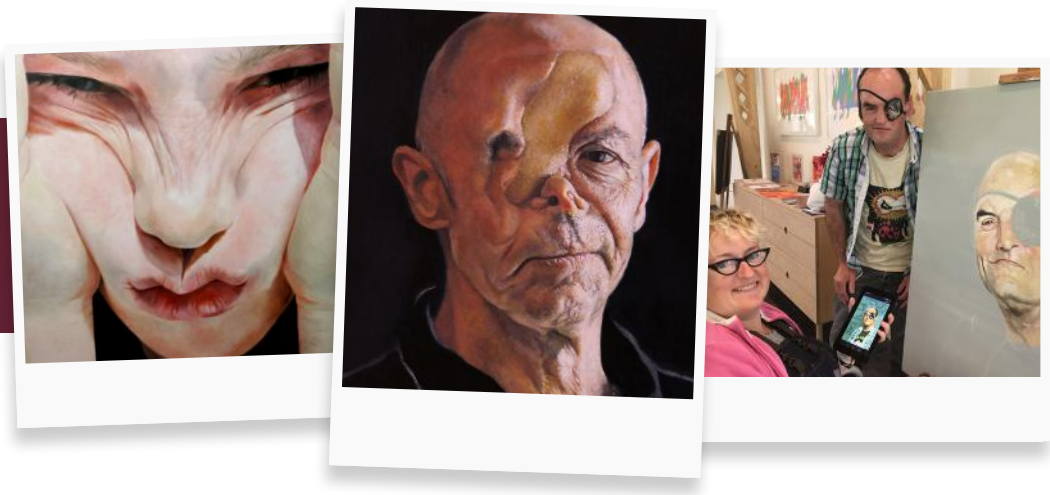
advancements. Painting became performance as the production took place in the waiting areas or wards of hospitals. The stories behind the paintings inspired interesting and lively conversations with patients, visitors and staff, and just this, being available to take time to have a friendly chat in an otherwise busy clinical environment, became recognised as a really important element of the 'arts for health' nature of the work.

While I was painting in the atrium of the Manchester Royal Eye Hospital, I met the man who inspired the Facing Out project. He had an eye patch and had some scarring around his face and he was hilarious. His opening line was, "I've just had my eye removed, will I still be able to watch 3D films?". We had a great chat, I found out that his name was Bern, and we became Facebook friends. Over the next eighteen months, I followed him as he had a saline bag implanted in his forehead which was gradually extended to create enough skin to make a pedicle flap. This was eventually used to cover his eye socket. Bern also lost a lot of bone from this cheek, upper pallet and jaw, his speech and eating and drinking were affected. Through a punishing schedule of radiotherapy, Bern showed a brave face online, his feelings about the process expressed through the often darkly humorous poetry that he shared. His story was fascinating, and it gave an insight into the stores of resilience that people battling cancers are called to draw upon, often again and again and again.

Since my earliest portraits and throughout my career I have often tried to explore what we think of as 'beauty' by painting my subjects in what might be considered unflattering poses: with the flesh squashed and distorted or under paint or mud masks. By doing so, I hoped to raise questions in the mind of the viewer, and indeed in the subject of the painting, about the nature of what we find beautiful about ourselves and others. In meeting Bern, a man whose beautiful warmth and humour shone through, despite the disfigurement that his face had endured, I found a way to bring together this aspect of my practice with the arts for health elements. Bern became the first 'Facing Out' portraiture subject.

Portrait painters talk a lot about 'the gaze'. This might be the gaze of the artist upon the sitter, the gaze of the subject towards the viewer or the gaze of the viewer upon the portrait's subject. I am interested in the gaze as it is altered by acquired facial disfigurement: how strangers may stare at an unusual face and the loss of social anonymity that accompanies that act. I wonder if that dynamic is disrupted when a disfigured person becomes a portraiture subject and invites strangers to openly spend time looking at their face and appreciate the beauty and the personality therein. I think that sitting for such a portrait is a powerful and thought-provoking act, one of both welcome and defiance. I hope that the paintings will inspire the viewer to consider the particular challenges encountered by people who are disfigured when they face out towards the world."

Facing Out will be exhibited at The Whitworth Art Gallery Manchester in early 2019. The Whitworth will be offering activities of special interest to people with head and neck cancers as part of a programme of events accompanying the exhibition. You can sign up to be invited to the exhibition opening, receive blog posts via email or read more about the project at **www.LucysArt.co.uk.**



Rachel McGowan

Nurse Manager at Countrywide Supplies

Countrywide Supplies

- **Leads the Countrywide Supplies nursing service and responsible for Clinical Governance**
- **Has extended training in Laryngectomy and Tracheostomy care including emergency airway management for neck breathing individuals and is a registered member of British Association of Head & Neck Oncology Nurses (BAHNON)**
- **Career includes caring for patients with long term respiratory problems including rehabilitation and where necessary, palliative care**

Having a laryngectomy means adjusting to life after surgery. Following a total laryngectomy, the body needs to adjust to a new way of breathing. One of the biggest changes is that you no longer breathe through your nose which impacts the quality of the air that reaches your lungs.

As a nurse who cares for people living with a laryngectomy or tracheostomy, I understand that when you come home from hospital, taking care of your stoma can seem daunting. You are not alone; there are more than 100,000 people worldwide who have had a total laryngectomy. However, after a while, you may find a new way to enjoy life as you did before including talking, travelling, eating and being physically active.

There is a lot of information available to you which can help your transition from hospital to home and help you return to living a comfortable and enjoyable life. This information can be provided via your clinician, local support group or online resources.

There are also many products specifically designed for you in different situations, depending on the time of day or the activity. These products can help reduce

coughing, improve quality of breathing and assist with staying active. Please always talk to your clinician to discuss what is suitable for you.

As your stoma opening leads directly to your lungs, it is extremely important to keep it protected. Many laryngectomees find that using a Heat and Moisture Exchanger (HME) all day and all night will help to provide the lungs with the heat and moisture it needs. This is because the HME can lead to less mucous production, and reduce coughing and irritation in your airway.

Here are some key benefits of using a HME:

Health of your airways

Wearing a HME 24 hours a day can help to reduce coughing and mucous production. It can also help to reduce the need to clean or touch your stoma as often.

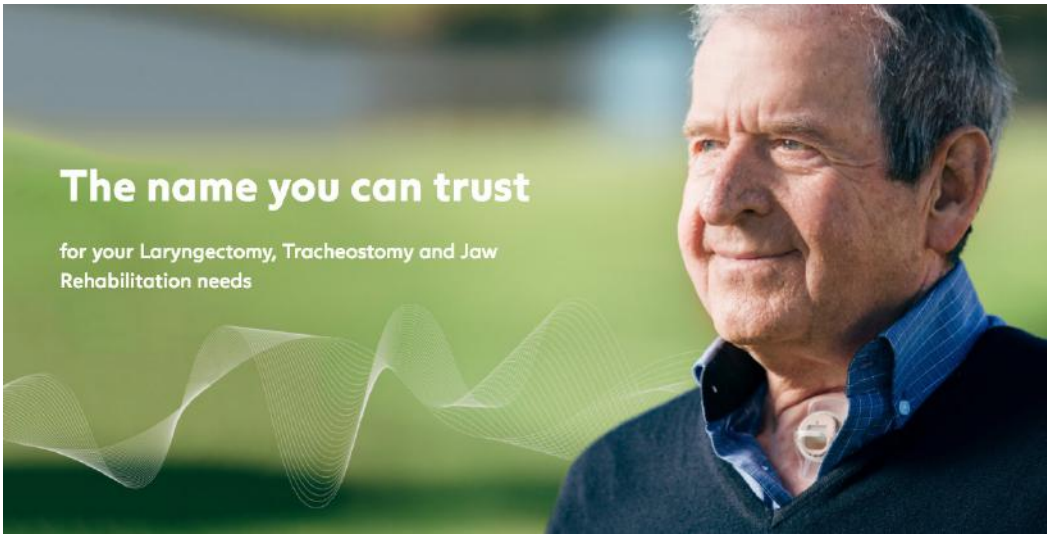
Voice

Those who have a voice prosthesis and use a HME can experience better volume and clarity of their voice.

Quality of Life

Research has shown that people with a laryngectomy who use a HME continuously, report better quality sleep and less fatigue.

I pride myself on leading a dedicated and passionate team of nurses that help to empower those living with a laryngectomy or tracheostomy to achieve their maximum potential and independence.



If you would like additional information or support please contact a member of the countrywide team on 0800 783 1659 or email nurses@countrywidesupplies.co.uk.

Rachel McGowan

Rachel McGowan
Countrywide Supplies Nurse Manager

Your Dentist

How can they help you?

Dr Hitesh Panchal
BchD, MFGDP(UK), DPDS(Bristol),
Rest Dip Dent RCS Eng
Principal dentist at Dental at MediaCityUK
www.dentalatmediacityuk.co.uk

We are seeing a huge rise in mouth cancer cases each year - almost 6,500 more cases are seen each year. Regular check-ups by a dentist, which include examination of the oral mucosa is becoming increasingly important. It allows early detection of oral cancer or potentially malignant lesions, which can greatly increase success rates for treatment. Early detection of the disease can transform survival rates to as high as 90%.

Risk factors:

Early detection is particularly important for those who fit into the high risk categories:

- Over 40 - however this age is dropping
- Smokers
- Chewing tobacco, gutkha/pann
- Heavy alcohol consumption
- High fat diets
- History of a human papilloma virus (HPV)

Signs & Symptoms:

It is advisable you visit your dentist or hygienist once every 6 months, or earlier if you have any of the symptoms listed below which have lasted longer than 3 weeks:

- Ulcer or sore
- Persistent pain in mouth
- Red or white patches in the mouth
- Hoarse/croaky voice
- Lump in the mouth
- Lump in the neck
- Numbness of mouth or tongue
- Difficulty swallowing
- Unexplained earache
- Unexplained tooth mobility

What will your dentist do?

During your routine dental examination, or if you have attended with any one of the listed symptoms, the dentist will carry out an oral cancer screening of your mouth. This will be done as follows:

'45 seconds to save a life'

Head: The face and neck will be checked for any lumps, bumps or swellings that are only to one side
Neck: Checked for any tenderness or lumps along the sides and front of the neck
Lips: Checked for any sores, changes in colour/texture and for any lumps or bumps
Cheek: Checked for any red, white, dark patches, lumps or bumps
Roof of the mouth: Will be felt for any lumps/bumps or changes in colour/texture
Tongue: The top and side surfaces of the tongue are checked for any sores or changes in colour -along with the under surface of your tongue.
Floor of the mouth: Changes in colour, swellings or lumps are checked for.

All of the above can be carried out as regular self-examination with the aid of a small mirror.

What will happen next?
If during your examination something suspicious is spotted, your dentist will refer you to your local oral cancer department for further investigation. From there you will receive a definitive diagnosis and further treatment if required.

What to do pre, during or post oral cancer treatment?

Pre-treatment:

Depending on what treatment you are having it is very important that the oral status of your mouth is as healthy as possible. It is recommended that teeth with a poor border- line prognosis are extracted. This is to avoid any potential disturbances during cancer treatment. It will also be recommended that any pre-existing conditions such as gum disease or failing restorations are treated. The dentist will also recommend several preventative measures such as high fluoride mouthwashes and toothpastes to use during your treatment.

During treatment:

It is important your dentist sees you urgently if you have any dental problems during your oral cancer treatment. The most common dental side effects from oral cancer treatments are as follows:

- Tooth decay
- Altered taste
- Inflamed and sore gums
- Xerostomia (dry mouth)
- Burning mouth
- Difficulty chewing

Your dentist may wish to apply a fluoride varnish on your teeth from time to time to strengthen them to prevent tooth decay. They may also consider placing soft linings on dentures to make them more comfortable to wear. Artificial saliva can be prescribed to increase the lubrication of your mouth if needed.

Post treatment

Patients who have received radiation therapy for oral cancer are at lifelong risk for oral diseases. Dental decay and periodontal disease being the most common of these. You are also at risk of developing osteoradio-necrosis and tumour recurrence. For these reasons it is very important that you regularly visit either your hospital dentist, your general dental practitioner or a combination of both.

If oral rehabilitation is needed, the hospital dentist normally carries this out. Your normal dentist can carry out your regular dental check-ups. If you have a NHS dentist this treatment will be done free of charge if you have undergone cancer treatment.

Early detection of mouth cancer can transform survival rates to as high as 90%

Support Groups

Self help and support groups bring like-minded people together to offer mutual support and encourage people to talk.

Being part of a group gives you the opportunity to talk openly with other people affected by cancer in a supportive and understanding environment.

To find your local Swallows Support group, call 07779 169 833 or visit theswallows.org.uk

What do they do?

- Help each other and anyone else who is affected, directly or indirectly by cancer.
- Offer one2one or group support.
- Be available in clinics or GP surgeries to help patients and carers.
- Advise on locating reliable literature, information and locally available resources.
- Signpost links to other groups in different areas and recommend trusted websites for people at home.
- Raise funds for items to help patients, carers and hospitals.

"Just a note to say that I enjoyed the meeting last night. It is always good to know that you are not alone in your experience. Everyone was so welcoming and I look forward to the next meeting." **(Sylvia, Patient)**

24/7 Patient and Carer support line and text service:

07504 725 059

Answered by patients and carers

Support Group Locations

Visit theswallows.org.uk to find your local support group or call 01253 428 940

The Swallows
Head & Neck Cancer Support Charity
Office Number: 01253 428 940
Information: 07779 169 833
24/7 Support Line: 07504 725 059
Email: info@theswallows.org.uk
Web: www.theswallows.org.uk
The Michael Stenhouse Centre, 68-70 Waterloo Road, South Shore, Blackpool, FY4 1AB
Patient and carer meetings every 2nd Wednesday of the month.

TRACTion Cancer Support
Covering all of Scotland
Office: Call 07711 001 502
Website: www.tractioncancersupport.org
Email: info@tractioncancersupport.org
Address: Flat G/3, 1 Craigend Gardens, Lomond Drive, Glasgow, G77 6FL
For patients with head and neck (Thyroid, Larynx and Pharynx), Oesophageal and Gastric Cancers.

Oral Health Foundation
Contact Name: The Information Team
Office: 01788 539792
Website: www.dentalhealth.org
Email: mail@dentalhealth.org
Address: Oral Health Foundation, Smile House, 2 East Union Street, Rugby, Warwickshire, CV22 6AJ
We are an independent charity passionate and dedicated to delivering better oral health for all.

HaNC - Head and Neck Cancer Support and Research
Contact Name: Mike McGovern
Mobile: 07982 408 171
Website: www.hanc.org.uk
Email: mikemcgovern54@aol.com
Address: MFU Directorate, 1st Floor, Aintree Lodge, Aintree University Hospital, Lower Lane, Liverpool, L9 7 AL
Meetings: Contact Mike McGovern

Ipswich H&N Cancer Support Group
Contact: Dave Wilkins or Pat Whitman
Office Number: 01473 636 701
Mobile: 07494 747724 or 07867 996700
Website: theipswichheadandneckcsg.org.uk
Email: ipsheadandneckcsg@yahoo.co.uk
Address: Head Office: 64 Broadlands Way, Rushmere St Andrews, Ipswich, IP4 5SU
Meetings: Contact Dave or Pat

The Head and Neck Cancer Hub (NCIN)
Office Number: 01865 334700
Website: www.ncin.org.uk | Email: enquiries@ociu.nhs.uk
Address: 150 Chancellor Court, Oxford Business Park South, Oxford OX4 2GX
The NCIN coordinates and develops analysis and intelligence to drive improvements in prevention, standards of cancer care and clinical outcomes for cancer patients.

The Plymouth Regional Head & Neck Cancer Support Group
Contact Name: Geoffery Read
Office Number: 01752 563 800
Mobile: 07734 517 682 (text only)
Email: Secretary.PlymouthHNC@gmail.com
Head Office: 80 Warleigh Avenue, Plymouth, PL2 1NP
Meetings: Contact Geoff for details. Usually the first Monday of each month.

About Face Support Group
Contact Name: Jane Boyle | Office Number: 01202 677 340
Website: www.about-face.info | Email: contact@about-face.info
Address: The About Face Centre, 111 Longfleet Road Poole, Dorset, BH15 2HP
Drop In Meetings: Tues & Thurs 10am to 4pm
Centre Open: Mon - Fri 9:30am to 5:30pm

Suzanne's Story

I was first diagnosed with a head & neck cancer in April 2010 - a SCC in my right tonsil - which, because of late diagnosis, was large and had spread into my lymph nodes.

"In an instant, at the age of 47, my life was turned upside down when that diagnosis was made. "

I had no choice but to undergo severe treatment- concurrent chemo radiotherapy - a double whammy - and then neck dissection surgery.

Late diagnosis at GP level is the biggest betrayal – this is where so much more emphasis and resources should be placed. Many of us would never have to go through such a bad ordeal if the NHS could regard it as one of the most important aspects in the fight against cancer.

In the months before, I had no obvious symptoms other than a persistent sore throat and periodic earache for which the GP prescribed anti-biotics. It wasn't until Nick and I came back from a holiday in India in early April 2010, that I was aware of a hard lump in the side of my neck.

My treatment at the Royal Surrey County Hospital in Guildford eventually started after delay in the radiotherapy planning process. I also had to have a stomach 'PEG' feeding tube inserted to administer liquid feed as well as medication – too large a size since I am small, so it left me with internal scarring. At my insistence I had the PEG removed as soon as possible after finishing treatment which helped recovery of my swallow.

The treatment spanned seven months, with weeks of concurrent chemotherapy and radiotherapy. The acute effects of it are immense and scary but by weeks 5–7, one is just going through the motions as I felt too toxic and exhausted to feel anything anymore on an emotional level. But I sure did feel physical effects, and even with oral morphine and fentanyl patches I was still waking up with break through pain, with the inside of my mouth and throat disintegrating and skin peeling off.

Just when I was starting to recover from some of the worst effects of this treatment, , I had to have neck dissection surgery. This entailed peeling back flesh from my neck and scraping away fat and lymph nodes to remove the remaining malignant tissue. It left me with some permanent problems such as reduced right shoulder movement, neck pain and stiffness.

A few words on what I learnt from this first horrible experience. Good, reliable information and trust in your team is paramount. I had a lot of time for the RT team – a life saver for me and I liked their down to earth approach, and honesty. Likewise, I had full trust in my head & neck surgeon, who was honest and straightforward, and very self-assured, which gave me confidence and helped when I had to make decisions. It is important to do some research oneself which can be challenging. For example, I researched best medication to use on protecting my mouth and got recommendations from my online support group. My GP and pharmacist sourced these for me from Belgium.

My recovery continued well in 2011 but I realised that at 48, I was having to adapt to living in a different body and one that would never feel or look the same again. In that I am not alone. Had I not "gone with the medicine", I would not be living at all and would also have to live with the anxiety that the cancer might recur.

In mid-2016, my excellent head & neck surgeon discharged me from check-ups on the basis that if anything were to develop, it wouldn't necessarily coincide with an

appointment. She said that if I felt that there was any cause for concern, I should visit my GP and get referred immediately back to her for investigation.

Little did I know that, months later, this advice would have such significance.

Second time around

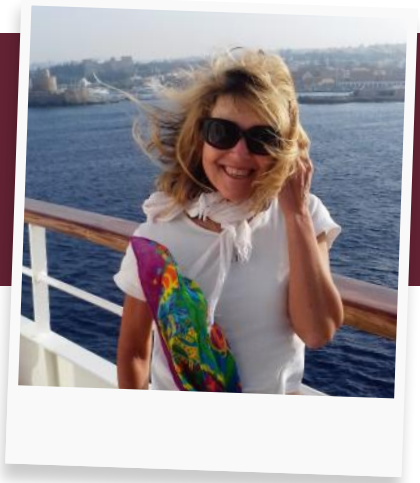
Towards the end of 2016, I started to feel there was something seriously wrong because I was exhausted, losing a lot of weight, despite a good appetite, and had periodic dizzy spells.

At the beginning of February 2017, I went to my GP and explained my symptoms, but it was not until June 2017, with delays and mishaps along the way, that a diagnosis was made. After months of uncertainty, my worst fears were confirmed. I had cancer again.

This time it was a rare cancer for Europeans - in an inaccessible area in the naso-pharyngeal space which had spread up towards the base of my skull, encircling the carotid artery that delivers blood to the brain. In view of the difficult location of the tumour, in July I was referred to a surgeon at Guy's Hospital in London. Following biopsy, the cancer was confirmed as an SCC HPV 16+ again.

Following further tests, I was told that no surgical solution was possible because of the spread and position. My condition was terminal, and they could provide only palliative chemo to slow the tumour's development. It was shockingly, hideous news. I asked if I could seek treatments abroad but was told I didn't have time.

I remember vividly coming out of Guy's on a beautiful July evening just days before my birthday, completely shell-shocked. The world around seemed to be going on as normal with people enjoying themselves, but my world was shattered, with the thought that I may not see another birthday.



I wasn't prepared to give up. Instead, after meeting with Prof Nutting at the Royal Marsden in London, I opted for another course of RT plus chemo, even though I was warned of the high risk after-effects from irradiating parts of my mouth previously treated in 2010, and a possible 30% chance of cure.

The thought of going through all that again was terrifying and daunting. I also felt anger that yet again, a late diagnosis had adversely affected my prognosis. On 8 August, I started daily treatment at the Royal Marsden, Chelsea. I experienced severe oral side effects almost immediately and as a result, my husband and I decided we must live in London most of the time until the end of September, as daily travelling from the Surrey/Hants border would be very tiring.

Getting through this was physically and emotionally exhausting, far worse than in 2010, since the pain was extreme, and it was combined with anxiety about how successful the treatment would be. It was so bad that I decided to join Dignitas in case everything went horribly wrong and I would be faced with the prospect of a slow, painful death. However, I managed to complete treatment on 15 September and the good news was that just before Christmas 2017, I was told that the results of scans showed no sign of the tumour.

In the following months post-treatment, I have endured extreme pain from a non-healing ulcer in the bottom of my mouth caused by soft tissue necrosis, difficulty eating and swallowing, and mouth blisters that formed, subsided and re-formed on a daily cycle. As a result, the Marsden referred me to an excellent oral specialist at UCLH Eastman in London, who is keeping a close eye on the very slow healing process and other issues.

Once again, my life has been turned upside down and horrible uncertainty about the future re-introduced. Although the blistering has stopped, my mouth remains very sore and fragile, the area of soft tissue necrosis being a major concern and source of pain. I did not, however, realise that the damage in my mouth could be so great and healing so impaired, that even diagnostic biopsy would be impossible. This leaves me in a very insecure situation and after 12 months of full on tests, scans, surgery, and of course repeat treatments, I am left with such an intolerable level of constant physical effects, and high level of pain.

"The effects of chronic sleep deprivation upon recovery are often underestimated. In my experience, some of the best advice for all permanent effects of both surgery and RT have come from the people I have met through the online support, and other emotional support from some great groups."

I too can relate to comments from other head & neck patients about not being treated at all holistically. It would have helped to have had early access to very regular massage for the tissue damage, as I now have severe muscular atrophy on my RHS, and consequential pain, weakness and problems with the chronic imbalances that these initiate. Furthermore, early on I should have been prescribed a 'Therabite' mouth exerciser to reduce the impact of fibrosis on jaw movement.

The emotional strain and anxiety continues but despite all I have been through, we are trying to make the best of things and get breaks away, hospital appointments permitting!

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We support laryngectomy and tracheostomy patients right after surgery and continue to offer support through our Nursing Service and Customer Care Team. The first step on any new journey can be challenging, but we will do our very best to help you feel confident on your journey and continue on the right path.

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"I pride myself on leading a dedicated and passionate team of nurses. As a team, we provide care for a niche group of individuals with a very specific set of needs. Our objective is to empower them to achieve their maximum potential and independence"
- Rachel McGowan, Nurse Manager

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The objective of our nurses is to improve the quality of life and independence of those living with a laryngectomy or tracheostomy. This is achieved through advice and support on appropriate product use and by working collaboratively with your hospital team or GP.

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Currently our Nursing Service is only available in selected areas of the UK. Please contact us to find out if our service operates in your area.

"I am proud to be a part of the Countrywide Nursing Service and it is personally rewarding to see the difference we can make to peoples lives"
- Daniela Esteves, Head & Neck Nurse

If you would like to learn more or find out if our Nursing Service operates in your area, please call 0800 783 1659 or email nurses@countrywidesupplies.co.uk

Countrywide Supplies

Jocelyn Harding
Dental Hygienist
Mouth Care for Cancer Patients

How to help your mouth

Your journey as a head and neck cancer patient will be full of many things to consider, so this is a helpful piece on the importance of your oral care.

There are three dental conditions which you may be affected by during your chemotherapy and/or radiotherapy treatment: decay (holes in your teeth), gum disease or dry mouth (xerostomia). You may be aware of one, two or all three of these conditions; this piece will give you some preventative advice and suggestions to help. On completion of treatment ,your specialist will let you know when you are able to move to the care of your general dentist and their team. Always attend regular checks with your dental team and they will give you current advice.

Decay

Decay occurs when sugars are consumed, eaten or drunk, on more than 4 occasions throughout the day. Sugars can either be natural sugars or added sugars. The bacteria use the sugars by converting them to acid which then dissolves the enamel (hard outer shell of a tooth) or root (softer root surface). If you are able to give your mouth a rest, ideally 30 to 45 minutes after eating and drinking, then the saliva (spit) in your mouth is able to rebalance (stabilise the acids) remineralise and harden the enamel. So, for most people 3 mealtimes and maybe a snack mid-morning could be a usual routine; if the sugars are consumed on these 4 occasions, then your risk of decay is kept low. Choose other snacks and drinks that are sugar free to have variety, not harm your teeth and keep you low risk of decay.

Xylitol is a natural sugar alternative suggestion available in both granulated form or in mints and chewing gum. This is a clever option as the bacteria aren't able to use this type of sugar to create acid and then cause decay. Sweeten your drinks with xylitol without damaging your teeth.

Gum Disease

Gingivitis is a gum disease that affects 99% of the population. Gums can become inflamed, red, swollen and bleed due to the bacteria being left around the teeth and gums for longer than the body is happy with. Ideally the bacteria need to be removed every day, brushing 2 x day for 2 minutes and using interdental aids is ideal. If your mouth isn't cleaned effectively gingivitis may then possibly progress to become another gum disease called periodontal disease which affects 10% of the population. Bacteria can work their way further below the gum margin and effect the bone support around your teeth. Your dental team will guide you with the correct technique of how to use your tooth brush and what interdental aids would work best for cleaning between your teeth.

Dry Mouth (Xerostomia)

Dry mouth and ulcers can unfortunately be a common side effect of chemotherapy and radiotherapy and can affect your chewing, speech and swallowing. Saliva is protective and also contains enzymes which help to balance the mouth and breakdown of fats; this is the start of your digestion. There are many suggestions to help the mouth with lubrication, some are available on prescription or over the counter. Always check with your team which would be appropriate to use.

1. Fluoride toothpaste:

Public Health England (PHE) recommend using high fluoride toothpastes. Duraphat 5000 toothpaste, for patients over 16 and Duraphat 2800 toothpaste for patients over 10 years old. These are prescription high fluoride toothpastes which only require a pea size amount on the toothbrush used twice per day. With a lack of saliva, you are categorised as higher risk for decay especially if any root surfaces are exposed.

2. Fluoride varnish treatment:

For high risk patients Public Health England (PHE) recommend a high fluoride varnish to be applied professionally to your teeth and any exposed root surfaces at at least six-monthly intervals.

3. Toothbrush:

You may or may not be able to manage toothbrushing. An electric toothbrush is ideal but your mouth at times may be too tender. There are soft versions of manual toothbrushes which may be easier to use whilst your mouth is tender.

4. Interdental cleaning (cleaning between teeth):

Controlling bacteria in these inaccessible areas is difficult but should be attempted. Your dental team will advise you of the easiest option.

5. Mouth rinses:

PHE recommend a fluoride alcohol free mouthwash (0.05%) to be used at a different time to brushing.

6. Dry mouth products:

There are many companies who have developed a range of products to help with dry mouth. You may need to try a few until you find something which helps you best.

7. Chewing gum and sweets:

Saliva production can be stimulated when chewing gum so encouraging the use of sugar free gum and ideally versions that contain xylitol can help with lubricating and reducing decay.

For some head and neck cancer patients (HNC) the problem of osteoradionecrosis (ORN) cannot be avoided. Regular dental visits are recommended for checking oral health and helping to prevent infections and decay. If you have any worries, we are always here to help.

Jocelyn Harding

RDH CEB Dip DH (RADC)

The Role of the Histopathologist in the diagnosis and management of Head and Cancer

Blackpool Teaching Hospitals NHS
NHS Foundation Trust

The Histopathologist is an important member of the multidisciplinary team, which also includes surgeons, radiologists, oncologists and nurses involved in the management of a patient with cancer.

One of the prime duties of the Histopathologist is to make an accurate tissue diagnosis from the biopsy submitted by the surgeon. Many inflammatory and other conditions that mimic cancer have to be recognised. On the other hand, pre-cancerous changes should not be missed as, if not promptly dealt with, they may progress to full blown cancer. Benign tumours need to be identified to avoid unnecessary treatment. Changes brought about by the Human Papilloma Virus (HPV) have to be recognised and reported, as infection with some strains of the virus has the potential to lead to cancer. As a variety of different cancers can occur in the Head and Neck region, the Histopathologist has to inform the surgeon and the oncologist of the precise type of the tumour. This is important as the management of each type of cancer varies. When dealing with excision biopsies, the Histopathologist has to assess the completeness of removal of the tumour, as any tumour left behind can potentially recur and grow.

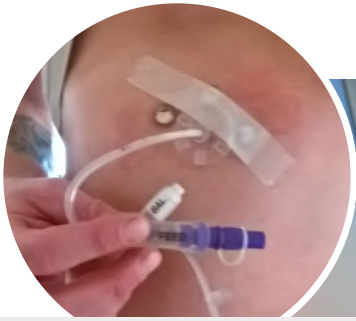
The Histopathologist also provides a comprehensive and detailed report about the cancer once it has been removed. With naked eye examination, the Histopathologist describes the precise location of the tumour in relation to the surrounding landmark structures/tissues. Measurement of the size of the tumour is important and may have a bearing on the subsequent behaviour of the cancer.

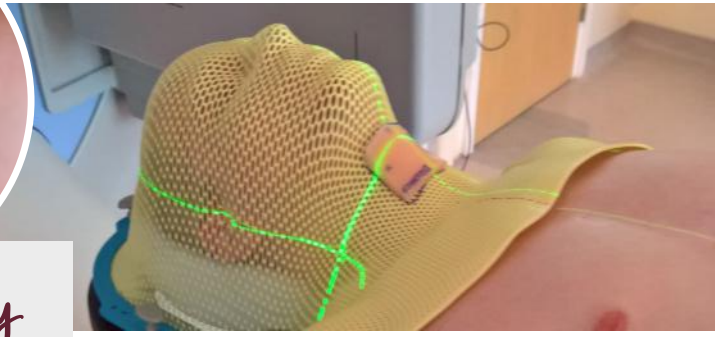
Examination of tissue sections under the microscope enables the Histopathologist to provide other important information. This includes the type and extent of the cancer, its grade or degree of aggressiveness - high or low, involvement of surrounding blood vessels and lymph nodes and completeness of excision.

The Histopathologist might use an array of special techniques to provide additional information about the cancer. Armed with all this information the Histopathologist is then able to comment on the extent on the tumour as seen under the microscope. A cancer that is still localised (Stage 1) signifies a better prognosis than that of one that has spread to the surrounding tissues and lymph-nodes (Stage 2 & 3).

The surgeon and the oncologist use the Histopathologist report in planning subsequence treatment. The pathologist actively participates in the multidisciplinary meetings when every patient is individually discussed to agree upon the treatment plan.

Dr K Vasudev
Consultant Pathologist Retired
BLACKPOOL VICTORIA HOSPITAL





Floyd's Story

My name is Floyd. I am 40 years old and on the 20th December 2017 I found out that I had stage 2 laryngeal cancer. It was the most devastating news I could ever wish to have, especially only 5 days before Christmas. That year I had my 2 children Caitlyn 16 and Scarlett 11 who were too young to have to be told their dad had cancer.

The week over Christmas was so difficult trying to come to terms with having cancer, I lost weight through the stress when I was told to put weight on for treatment. A few days before the new year I had to come to terms with telling my children that their dad had cancer, it was so hard to destroy their life in that one moment but I did it. It was the hardest thing I have ever done and they took it pretty well, there was lots of tears from all three of us and I made a huge promise that I couldn't break that I would beat this cancer.

In the January I had an operation for a (RIG) feeding tube in my stomach so I could feed myself if needed throughout cancer treatment. I was awake for this operation and it wasn't very pleasant!

Early February I had another operation for 4 wisdom teeth to be removed, luckily I was put to sleep for this one! 2 weeks after having my teeth out I had a mask made which was moulded to my face and shoulders ready for radiotherapy. This wasn't a nice experience as you are bolted to a table with the mask and are unable to move at all.

End of February - it was time for my battle to beat this cancer. I'd gained 15kg in weight since the end of December and the wait felt like a lifetime to get to this stage but I was ready for the fight. 30 sessions of radiotherapy 5 days a week and 6 sessions of chemotherapy once a week at Musgrove Park Hospital in Taunton. I also decided to attend a laser trial of 3 sessions per week to help prevent any mouth ulcers and pain. There was a 50/50 chance I was going to receive the real laser treatment.

I remember the first radiotherapy session. I was pretty nervous knowing I had to wear the mask again. I laid on the table and they put the mask on and started locking it down to the table which pressed down so hard they had to remove it, I'd put on so much weight since the mask was made it wouldn't fit! Luckily they could remove 2 plates from behind my head which didn't make much difference but at least I could breathe!

It took me a good week to get used to wearing the mask but it was only for 15-20 minutes a day. As the weeks passed it was easy to fall asleep wearing the mask! 3 weeks in I started to feel pretty sore in my throat. My food was tasting like cardboard and on the 4th week there was too much pain to carry on eating so I started to use my feeding tube for food, water and medication.

My first chemotherapy treatment was easier than radiotherapy as I had a nice comfy chair to sit in! I had no problem with needles, I had a cannular in my hand to deliver the chemotherapy. After the second week of chemotherapy I started to feel pretty ill which got worse as the weeks went on. After all my treatment I'd lost about 10kg but luckily the treatment worked and the cancer had gone and now I'm in remission.

Throughout my treatment one of my main worries was my financial situation as I was close to using up my 12 weeks sick pay from my job. I didn't know what I was going to do when that stopped I was going to lose everything when what I should of been doing is going through a stress free recovery.

I was passed to a charity called The Swallows Head And Neck Cancer Support Group who were great and very helpful. not only could I ring them for any support or even just a moan, they offered me a grant to help pay my bills for 3 months which totally changed everything.

The weight off my shoulders was immense knowing I could recover knowing my bills were going to be paid. I can't thank The Swallows enough for their help in my time of need.

Bob's *Memorable Quotes*

Throughout the past 20 months, there have been many memorable moments - for good and bad reasons - here are some of the ones that best sum up my journey through having a "Head and Neck Cancer".

"Okay, I think you have got a cancer on your tonsils which has spread to a lymph node in your neck. I am not God, but I don't think it is going to kill you, but we need to deal with it."

That was how my head and neck cancer journey started. The Consultant was very efficient but also very quick to reassure me. I appreciated honesty like that and it served to get me past the "C" word 'panic' very quickly and straight into "getting on with it" mode.

Things moved very quickly thereafter. Operation 1 - 20th December 2016, in I went for my operation. Five hours later, tonsils and lymph node removed by laser surgery. Operation 2 - 4th January 2017, as not all of the potentially affected area had been successfully removed. February to the end of March, 30 sessions of radiotherapy at Clatterbridge. Thankfully no chemo required. The Consultant was right but there were times in that period when I thought the treatment was going to kill me.

"You need to eat more."

The treatment made it is almost impossible to eat. Firstly, my mouth was dry, sore, and 'on fire'. Secondly, I could not open my mouth properly. Thirdly, because my taste buds and saliva glands had been affected, food tasted very different, even horrible, and I could not swallow without drinking water, as my mouth was so dry. The weirdest thing for me was the change in texture of food. Having stocked up on items like Rice Pudding, I found that a spoonful of it felt like my mouth was full of gravel. There were so many things that I just could not eat. I just kept trying different things until I found something nutritious that I was able to eat. *One heck of a diet.*

"Walkies, Alfie."

As it was so near to Christmas, we needed to take back our Boxer dog, Alfie, from the lady who had kindly looked after him for a few days. Never in my life had I felt less like going outside, never mind going for a walk in the middle of Winter, but having to take him out for a walk three times a day proved to be a God-send.

Not only did I get some exercise but I also met fellow dog-walkers who wanted to know what I had been going through. Being able to talk about it helped me too. People were very kind, offering to look after Alfie if I did not feel up to the task, so it was very reassuring to know that not only did I have my family behind me, but also a good number of very supportive acquaintances.

"You do know it is going to get worse, don't you?"

I had just completed my first week of radiotherapy and I was booked to see a Doctor. He asked how I was feeling and as I was feeling pretty good, that is what I told him. The look on his face was quite sobering when he uttered the above sentence, and sadly, he was right. By the end of the second week, the pain from the radiation started to affect my mouth and it continued throughout the treatment and beyond.

"75.6 kilos"

I dropped from 75 kgs to 65 during my treatment. Eight months after the first operation, I joined a gym and asked for a programme to help put weight back on. At my follow up appointment in Spring 2018, the Nurse weighed me and told me the reading. This showed me that I had achieved the target I had set myself, to get back fit and to put back all the weight I had lost. In May 2018, I stripped off my t-shirt and jumped into a Pool with my grand children, unashamed!

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Something to say?

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www.christie.nhs.uk

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