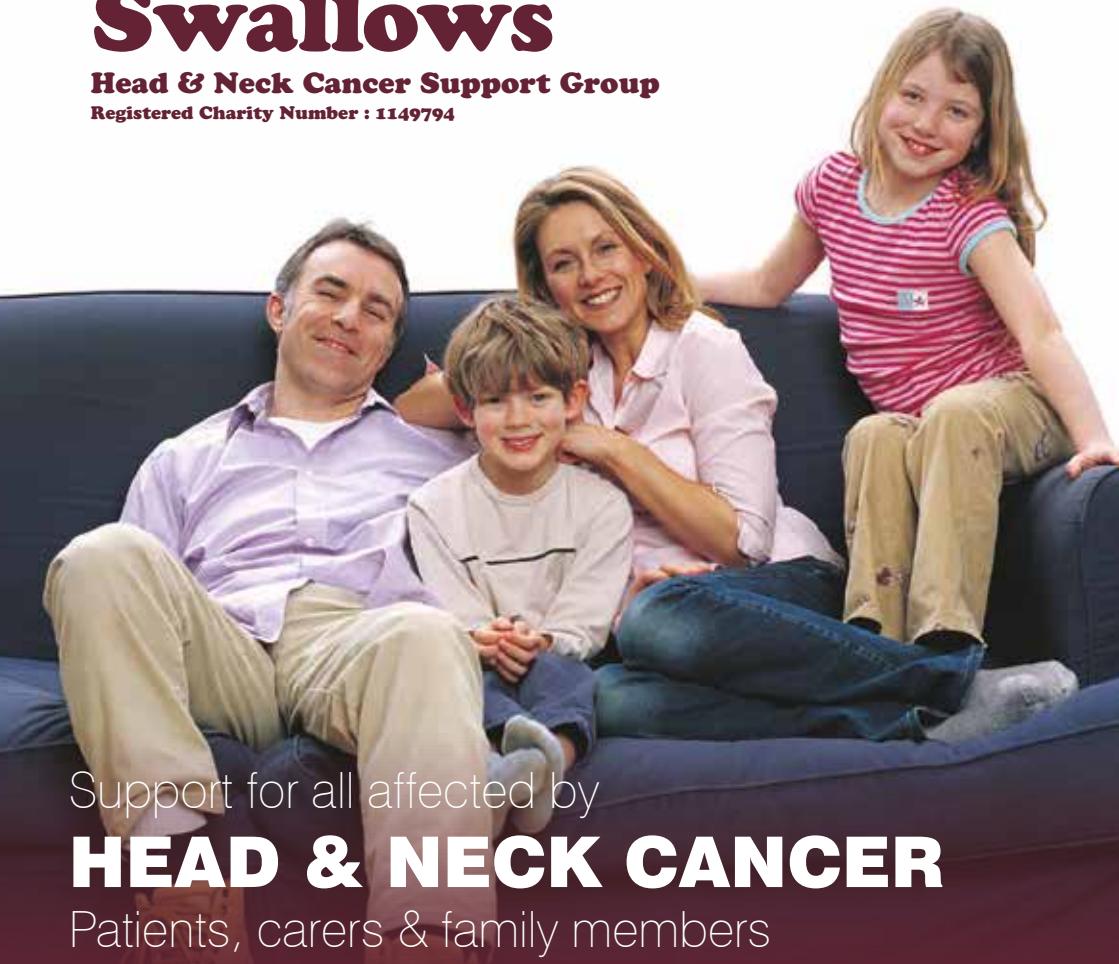


# The Swallows

**Head & Neck Cancer Support Group**

Registered Charity Number : 1149794



Support for all affected by

## **HEAD & NECK CANCER**

Patients, carers & family members



**Head & Neck  
Cancer Support**  
Australia

Head and Neck Cancer  
**Support**



## Chairman's Statement

Head & Neck Cancer patients have unique problems such as Dry Mouth, Swallowing, Eating and many other issues, it is so important 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 likeminded people to services, medicines and treatments that are available.

Following on from our successful launch of the Patients book here in the UK I am so pleased that with the help of Marty and Julie we have managed to produce the Australian edition. We all hope you enjoy reading the many stories in the book.

Talking to both Marty and Julie over the year has been a great honour and we have shared many an idea and with these two at the helm of Head & Neck Patient Ambassador in Australia H&N cancer will change for the better.

**Chris Curtis**  
World H&N Cancer Ambassador/Chairman

**24/7 Support line:**

**+44 7504 725 059**

For more information call:

**+44 7779 169 833**

**[www.thewallows.org.uk](http://www.thewallows.org.uk)**

**f** [www.facebook.com/thewallowscancersupport](https://www.facebook.com/thewallowscancersupport)

**t** @swallowsgroup



*“ It was a life-changing experience for me to connect via social media with Chris Curtis from The Swallows in the UK. We shared our experiences of head and neck cancer and discovered a mutual passion for improving the support for patients and families affected by this tough illness. Chris is a catalyst for action and collaboration across the world. Soon he had connected me to another survivor, Marty Doyle from Head & Neck Cancer Support Australia in Brisbane. All the way from the Blackpool, Chris has encouraged, guided and supported us to produce this Australian version of a similar book in the UK. The primary purpose of this book is to give encouragement and hope to people with a diagnosis of head and neck cancer and their families and carers. It will also be useful for professional development in multidisciplinary teams. It contains articles by doctors, nurses and allied health professionals. We want to raise the profile of head and neck cancers because we need funding for research to improve our treatment, survival and quality of life. However, the most important part of this book is the patient stories. Our voices are rarely heard. We hope sensitive health professionals will use these stories to improve services and support. Thank you so much to Chris Curtis and The Swallows for this significant contribution to patients and their families in Australia. ”*

**Julie McCrossin**  
Head and Neck cancer Survivor.

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# The Swallows

**Head & Neck Cancer Support Group**

Registered Charity Number : 1149794

## Who are the Swallows?

We chose the name 'The Swallows' because many head and neck cancer patients have problems with swallowing, during and following treatment.

We are the patient and carers Head and Neck Cancer Support Group Charity based in the UK but now reach out to all other parts of the globe.

We offer our Patient/Carer support line 24/7 and will signpost if that's what people want. The Charity is run by patients, carers, family and friends, so everyone understands the problems when you are diagnosed with Head & Neck Cancer.

### How did it all start?

In 2010 a small group of patients started to meet 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, Clinical Nurse Specialist in the Blackpool ENT department.

Then early in 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 group started.

It is important to say that while the charity now helps with Awareness, Signposting, Campaigns, Research and Fundraising it will never lose the reason it all started in 2010 and that is "Supporting patients and carers locally, nationally and now throughout the globe."

Our patient and carers meeting is held every



## Head and Neck Cancer Support

second Wednesday of the month. It is an opportunity to meet other like-minded people and share experiences.

### What do we do?

- Help each other and anyone else who is affected, directly or indirectly, by Head & Neck Cancer
- One to one or group support
- Be available in Clinics 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 both patients and carers
- 24/7 help line answered by patients and carers, offering a like-minded person to talk to

### QUEEN'S TOP HONOUR FOR THE SWALLOWS HEAD & NECK CANCER CHARITY

The Swallows Head and Neck Cancer Support Group are proud to announce that they were awarded "The Queen's Award for Voluntary Service (MBE)", the highest honour for Voluntary Groups.

This award is a tribute to a great team of past and present volunteers, trustees and patrons who have given support to those affected by head and neck cancer here in Blackpool, the Fylde and across the UK.

Chris Curtis, Chairman

The Swallows Head & Neck Support Group Charity

# Head and Neck Cancer Support Australia

## - Patron Statement Marty Doyle

Following my treatment of SCC with an Unknown Primary in 2004, I looked around for support from others who had been through Head and Neck Cancer Treatment and found none in Brisbane. I brought this to the attention of a friend at Cancer Council Queensland and they jokingly said "Why don't you start your own Support Group". So I did.

Over the last 13 years myself and a core group of fellow survivors have developed awareness of Head and Neck Cancer and held Support Group Meetings monthly so that anyone who has just been diagnosed, is going through treatment or is dealing with the many side effects of the treatment can join in a conversation about their experiences in a positive safe environment. We also invite, regularly, Medical Specialists and Allied Professionals to be part of the meetings, so we can all learn from each other.

Over the years I have reached out to other areas of this vast country to see if we could all support each other, exchange experiences and have a common message and we have slowly built a strong and caring network.

In late 2014 I started to think why don't we set up an awareness day in Brisbane? I thought why not July (It's fairly quiet in Australia from a Health Awareness perspective).

Then quite literally the next day, I received an email from the International Federation of Head and Neck Oncologic Societies making July 27th World Head and Neck Cancer Awareness Day.

We kicked off our first Awareness Day in Brisbane on 27th July 2015 with posters and signage at the Royal Brisbane and Women's

Hospital and Princess Alexandra Hospital. Princess Alexandra Hospital also held free Oral Examinations.

The Support Group along with Cancer Council Queensland also ran the first Head and Neck Cancer Forum which was attended by medical specialists, allied professionals, patients, carers and family to discuss experiences and the latest support available.

Since then I have set up Head and Neck Cancer Support Australia to join together all support groups across the country. Last year we had events in Brisbane and Adelaide and this year there will also be events in Sydney and the regional areas.

I connected with Chris and the Swallows on Facebook some years ago. We kept in touch and last year Chris invited me to submit my story for the UK version of this book. Earlier this year Chris suggested we do one in Australia and I jumped at the chance. I started to compile the stories then he introduced me to Julie in Sydney and we have all worked closely together to bring you this Australian Edition of the Head and Neck Cancer Patient, Carers and Family Book.

This book will bring together the Head and Neck Cancer Community in Australia and New Zealand; the Medical Profession, Patients, Carers and Family members so we can all understand how to support each other, exchange experiences and develop a common message.





## Foreword

### - A/Prof Martin Batstone

Head and Neck Cancer is not the most common cancer in Australia and it certainly doesn't have the highest public profile. It is however a disease that can be very visible and will make profound changes to the lives of those it affects, both patients and carers.

Treatment can be prolonged and difficult forcing people to find coping strategies they never knew they had. After treatment comes survivorship and adapting to physical changes which can impact on the most basic functions and pleasures of life such as speaking, eating and swallowing.

As a clinician, I have spent my working career trying to improve the diagnosis, treatment and rehabilitation of Head and Neck Cancer patients and despite trying to help hundreds of people, like many others working in this area, I still don't understand fully how profound those changes can be, or how they cope.

The best explanation of the treatment course comes from people who have lived that experience. Both as patients and as carers. Their stories will help others

travelling the path of diagnosis, treatment, and survivorship in a way that no one else can. I know this book will help two groups. Those who have written it, to put down in words and pictures what they have been through. Perhaps more importantly those on the first steps of that path who need someone who has walked it to show the way.

#### A/Prof Martin D Batstone

MBBS, BDSc, MPhil(Surg),FRACDS(OMS),  
FRCS(OMFS)

President, Australian and New Zealand Head and Neck Cancer Society

Director, Oral and Maxillofacial Surgery Unit, RBWH



**Head & Neck  
Cancer Support**  
Australia



## We are all in this together

Head and Neck Cancer is somewhat of an orphan in the Australian landscape, representing 4% of all cancers. From a national point of view it is not prominent on the agenda, and few people are aware that we can develop cancers in the mouth or throat. However, for the people who develop these cancers, for their loved ones and for the multidisciplinary teams that care for them, the impact of the diagnosis and treatment on both patients and their treatment team is high and greatly underappreciated by anyone other than those involved. It has an impact on body and soul and it takes a herculean effort from all involved to manage treatment as well as possible.

Many Head and Neck Cancers present at a relatively late stage and people affected often require combinations of surgery, radiation treatment and chemotherapy. It is essential that people with these cancers are seen and managed by an experienced Head and Neck Multidisciplinary Team. The specialised skills required means that there are only a few such teams in our state. When patients don't live close to treatment, the need to travel for care adds an additional burden, however, having access to these teams, which include dedicated Radiologists, Pathologists and PET Physicians, as well as Surgeons, Radiation and Medical Oncologists, and Allied Health and Palliative Care specialists, can make a marked difference to treatment and outcomes.

For those who develop these cancers, it is often a long and difficult road; it is complex with many appointments with multiple team members. Despite wrapping as much care around people as possible, it is still a lonely and difficult place to be. We need to better understand the effect of treatment on one's soul and long term wellbeing, allowing for us to provide better holistic care all round.

The earlier we detect these cancers the greater the chance for cure. Early detection can also minimise the impact of treatment.

Prevention and early detection must be at the heart of both meaningful research and public campaigns, even though the public message may be complex. Research into choosing treatment wisely, and furthering our understanding of which patients will benefit most from which treatment combinations is integral. We have some of Australia's finest research institutions on our doorstep and our Head and Neck research teams need support.

Today, nearly 70% of Head and Neck Cancers are cured. Many of our patients go on to live full and highly rewarding lives with no ill effects from their treatment. However, for others, this can be a major burden to bear. Our Head and Neck Support Groups remind us every day, that no matter how difficult and complicated treatment might seem, there is a bright light at the end of the tunnel.

Our patients are an amazing and constant source of inspiration and drive us to do better in every respect. They keep us going!

The term "we are all in this together" never ever seemed more appropriate.

### Adj Prof Liz Kenny AO

MB BS; FRANZCR; FACP; FBIR; FRCR; FCIRSE  
Radiation Oncologist  
Royal Brisbane and Women's Head and Neck  
Cancer Clinic

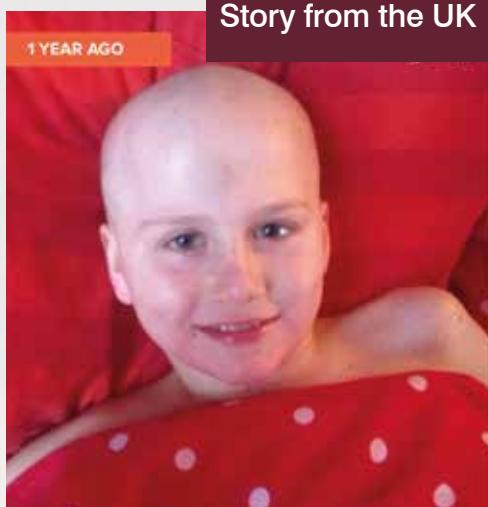


## 12 year old Oscar's Story - Charlotte Crowther, Mother of Oscar

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....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



Story from the UK

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 on 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. We stayed at Eckersley House which is within excellent distance to the LGI during Radio 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.

# Resilience

## - Rene Kloeti

Resilience through exercise and a positive mental attitude despite the odds.

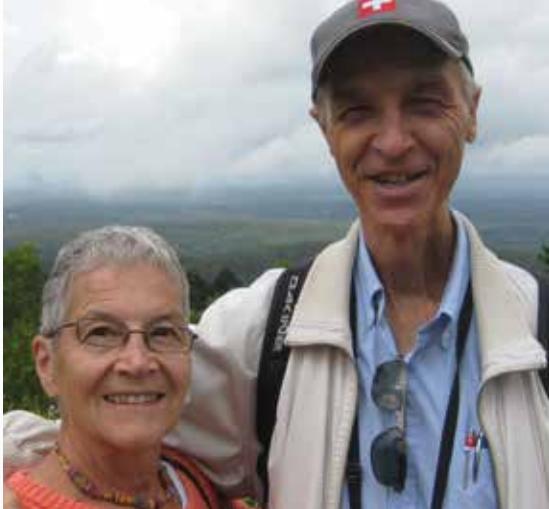
My wife and I never would have thought that one of us would ever fall ill. But it happened to me and at the most inopportune moment and place! We were just at the start of a two-year, re-experience of our back-packing days from the '70s. The place was Panama, Central America, and it was early in 2008, after having been on the road for only three months. I had just turned 61.

After overcoming the initial shock of a cancer diagnosis, tears followed but we accepted the reality and returned to Brisbane as quickly as we could. With the support of friends and family, I was able to see an ENT on the day of our return home. The cancer was not only in my neck but also in my mouth at the back of the tongue and the tonsil area, caused by a Human Papilloma Virus.

What followed was an excruciating treatment of 35 chemo/radiation sessions, after the prior removal of seven teeth and the insertion of a PEG feeding tube into my stomach. That was the common practice in those days. A year later, cancer was found to have remained in my neck resulting in 50 lymph nodes being removed from the left side of my neck, along with my internal and external jugular.

"No problem, you still have the main jugular, so you will be OK", said the ENT assistant. Having been a swimmer since my 20's, always a non-smoker and moderate consumer of alcohol, my main goal was to head back to the pool as soon as permissible by the doctors. Ignoring the shoulder pain from the neck dissection, I was delighted to still be able to swim freestyle, somewhat clumsy but with steady improvements.

The initial treatment in 2008 has left me with permanent swallowing difficulties through lack of saliva and a non-functioning epiglottis, resulting in an aspiration risk. Being a positive thinker and



doer, I just got on with life and have focussed on my new situation, what I can eat rather than what I cannot. The daily morning swims followed by coffee with my mates have kept me positive about the future. I am lucky to have a wonderful wife and son, as well as close friends who have stood by me throughout all these years.

We have spent some fantastic years travelling, whilst undergoing regular follow-up health checks by both my ENT and my original radiologist. Early in 2014, after being given an all clear and being declared a survivor of my original oropharyngeal cancer, our lives were again rudely interrupted! In May in Switzerland, after I had developed a cough, my wife talked me into consulting a local GP. A resulting x-ray and CT scan revealed a massive 11cm secondary tumour on my left lung! Chemo treatment was offered but we chose to once again return to Brisbane. It turned out to be inoperable due to its size and location, but 25 radiation treatments targeted just to the left lung shrank the tumour down considerably. I refused follow-up chemo and accepted the finality of this stage IV tumour.

Mid-2015 I commenced an immunotherapy clinical trial which has kept my lung cancer stable, allows me to maintain a good quality of life, daily swims and lately adding to this exercise routine by joining a gym. The H&N Cancer Support Group led by Marty has been a rock in my continued cancer fight. My life has been extended and however long it may last, I am eternally grateful.



## A Mother of 4 - Susannah Gallagher

After a difficult pregnancy, my fourth child was born in April 2014 and had to be hospitalised for over a month. During this time I developed an ulcer on the left side of my tongue that didn't go away. I checked with two pharmacists and family but all dismissed this as a result of the trauma of the past months. Whilst I had no other symptoms and did not feel unwell, after six weeks I visited my dentist to check if this was indeed nothing to worry about. The minute I saw her face as she looked in my mouth I knew that things were not right.

She referred me to an Oral Surgeon who recommended a biopsy. I cried the whole way through the biopsy despite everyone assuring me that it would be all fine. Somehow I just knew that it was not fine. I was told that the likelihood of the ulcer being mouth cancer was minute, as I was a 39 year old, non-smoking, very healthy female. However she recommended that we rule this out as the possible cause.

Less than 48 hours later, a day that will be etched in my mind forever, my husband Justin came with me to the appointment, even though he was not worried at all. The news was hard to process. I remember feeling almost out of my body. How could a healthy mother of four beautiful children under five and a half have cancer. Mouth cancer is an old male smokers' disease, isn't it? I remember asking if I was going to die. I rang mum on the way home and all I remember is that she answered 'its all fine isn't it' and I said 'no mum it's the worst possible result'.

The reactions of my family and friends were mixed. Some listened, some grieved with me, some

wanted to help but all were in shock. My dad broke down in the supermarket when a friend he hadn't seen for years asked how the family was. I went from being positive, to crying hysterically, to despair all at the same time. I remember sitting on my children's bed in the middle of the night crying that they would never know how much I loved them.

The following week I saw Dr Veivers, my ENT & Head and Neck surgeon. He recommended a PET scan and that I attend a multidisciplinary committee at the Northern Sydney Cancer Centre the following week. That following week was the longest of my life as I struggled to accept the reality of my situation. I tried to be positive and hopeful but this was not always possible. I had a PET scan followed by a meeting with some 25 experienced professionals in their fields to determine the best treatment option. Finally my doctor delivered the good news that my cancer was isolated and that surgery provided the best possible outcome for survival.

Two days later I had a left partial glossectomy and neck dissection. A 1x1x1.5cm, stage one tumour was removed from my tongue, and tested positive as an HPV cancer. I spent the night in Intensive Care and the following week in hospital. My results came back, whilst all the nodes were clear, one of the sides of the tumour did not have the clear margins that they like to get to ensure that the tumour has been removed. The despair I felt that I would need to go through another operation was extreme. Yes I was lucky that cancer had not spread and my chances of survival were high, but the thought of another operation was devastating. Two weeks later more of my tongue was removed and this time the margins were all clear.

Months of soup, pureed food, intensive speech lessons, yoga, meditation and research followed, mixed in with being a mum to my children who had no idea I was sick. The dietitians, speech therapist and cancer support groups became my new friends and, with my family and friends, their positive energy and support is something that I will never forget. We took a holiday and life returned to our "new normal". I found that I was continually checking my mouth and neck for changes and this lead me to see a counsellor to help me with recurrence anxiety.

Next month will mark three years cancer-free. I have a slight change in my speech but nothing that a stranger would notice. I still tear up when I talk of my journey and perhaps that will always be the case but it no longer consumes me 24 hours a day. Today I stand here with a scar across my neck, but one that I am strangely proud of as it shows what I went through to be here today.

# Mindfulness and Cancer

## - Sylvia Burns

**Has this ever happened to you...** You come out of a conversation frustrated that you failed to speak up, then spend the rest of the day in your head, going over what you wished you had said and how things should have worked out. You continue to carry the stress of those mental arguments, distracted and lost in a fog of your own creation.

**This is the opposite of being mindful.** We all spend much of our lives unconsciously absorbed in a future that hasn't happened yet or in a past that has already gone. In the process, we can be caught up in automatic thinking and ways of reacting much of the day out of touch with the present moment, which is the only time we really have in which to live or act. We can easily miss out on the opportunities the present moment is constantly offering us to be alive, here, now.

We can be "miles away" while playing with our children, lost in thought when we are with friends, missing tender moments with our lover, oblivious to the beauty of a sunny day or details of the place where we are: in short, missing out on life.

**Being mindful** gives us an opportunity to choose what we pay attention to, to free ourselves from automatic thinking and being caught up in the doing of the mind. Mindfulness Meditation is about learning to be aware, to experience life fully as it unfolds—moment by moment, without judgement.

One popular misconception about meditation is that it is a way to make your mind blank so you can escape from what you are feeling. However, in the mindfulness program we run at Cancer Council Queensland, we help people to understand that **meditation is an invitation to wake up**, to experience the fullness of your life, with all its ups and downs.



### Mind Full, or Mindful?

The Living Mindfully program teaches Mindfulness Based Cognitive Therapy (MBCT), a blend of mindfulness meditation and cognitive therapy. Over 8 weeks, participants meet either in face to face groups or by telephone, for weekly 2 hour sessions and are asked to commit to regular daily home based mindfulness practice.

Both in session and at home, participants are invited to spend time with themselves in meditation. As best they can to observe their thoughts, feelings and bodily sensations, bringing openness, curiosity and non-judgement to their moment to moment experience.

With the support and guidance of their trained group facilitator, participants learn to bring their insights and understanding to both the pleasant and unpleasant events of everyday life, including their cancer related challenges.

**Being mindful** is not about running away, or changing what is present. Rather it is about getting to know how your mind works and giving you greater choice about how you will respond to what life brings, moment by moment.

This can be particularly helpful when facing the challenges that come with the diagnosis, treatment and body changes you might experience from head and neck cancer.





Mindfulness is a growth industry and it has become a popular pursuit. A growing body of evidence shows that practicing mindfulness has many benefits – in sport, business, education and in health and wellness. With popularity comes misconception.

**Mindfulness meditation** is not intended as a blissful experience. Like exercise, it can be uncomfortable. In fact, mindfulness is about learning to recognise, allow and be with all of our experiences, whether pleasant, unpleasant or neutral, so that we can begin to exercise choice and responsiveness in our lives.

**Mindfulness is not a panacea** for all things in life. It is not the only way to reduce stress or increase wellbeing, nor is it right for everyone. In our program we encourage people to let go of their expectations and approach mindfulness as an experiment, emphasising that what you take away will depend on how much you put into the program.

Many people who have participated in our mindfulness program say that they are better able to be present in their lives. They report feeling less anxious and worried, more accepting of the difficulties in their life and able to better manage their thinking.

You can learn more about Cancer Council Queensland's mindfulness programs on their website: [www.cancerqld.org.au](http://www.cancerqld.org.au) or by calling 13 11 20.

Sylvia Burns  
Cancer Support Senior Specialist  
Cancer Council Queensland

# I'm Still Going Fishing

## - Des McGrady

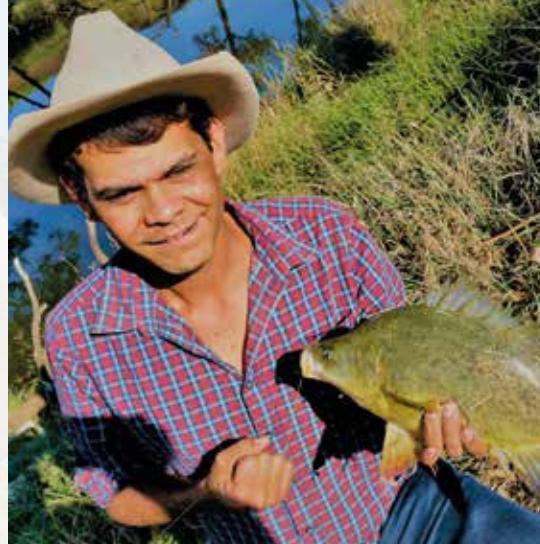
Hi, my name is Des. I'm 31 years old, I was diagnosed with Nasopharyngeal Carcinoma Cancer stage 4 in March 2016. Nasopharyngeal cancer is a rare type of Head and Neck Cancer. It starts in the upper part of your throat, behind the nose. Nasopharyngeal Carcinoma is difficult to detect early. That's probably because the nasopharynx isn't easy to examine and symptoms of nasopharyngeal carcinoma mimic those of other, more-common conditions.

I can remember exactly when I first started to feel unwell. It was while holidaying in Katherine October 2014. After coming home, I had to take time out from work to visit the doctors. I work In Alice Springs helping Indigenous children – 90% of these children are in foster homes and I help these children in every way I possibly can.

I ended up on medication for sinus. I had been dealing with sinus infection since Katherine and my health was declining. I could barely breath through my nose, my sleep was disrupted and I could no longer smell. I also had persistent sinus headaches. This continued for a while and then at the beginning of January 2016 things started getting worse.

Following a CT scan it was suggested that I have a Sphenoidotomy done. This was postponed due to me running a fever. Perhaps this was just as well, because I was living in Alice Springs with no immediate family support. I could not understand what was happening to my body, so I decided to fly back home to Brisbane, a distance of nearly 2000km, to see an ENT specialist at the Princess Alexandra (PA) Hospital.

I flew home on a Tuesday and I was diagnosed with cancer by the Friday. The doctors explained I needed 36 treatments of radiation, and within these treatments there will be 3 rounds of chemotherapy (Cisplatin). I guess from day one I was ready to fight this scum bag named cancer, it took 4 weeks of



treatment before I even started to go downhill with the side effects of the radiation and chemo. In week 6 of treatment, I was struck down with chickenpox I battled through by telling myself "I'm still going fishing and camping with my family at Christmas". By Christmas, I was sitting on a river bank fishing and camping with my family.

What did I learn from all of this? Well you've got to be on top of it, and if you don't get the diagnosis that you feel comfortable with, and if the symptoms persist and are not going away go back and fight. Ask for another assessment.

If I could pass on one piece of advice to other patients, it would be to remain positive. There will be days when it seems too hard.

I have good and bad days and some days I have really struggled with my emotions. But then on other days I am filled with happiness and laughter.

I have discovered just how strong I am and how much determination I have.

Each day is a gift I am truly grateful for. I am resilient.

Oh, and I'm still going fishing.

# Oral and Maxillofacial Surgeons outlook on patients with tumours of the Head and Neck

Oral and Maxillofacial Surgeons understand a Head and Neck Cancer patient's journey very well because we often see them from the very first investigative procedure and onward from there. We are likely to be part of the ongoing care and can follow up for many years.

For example, many oral lesions are first spotted by general dentists who will refer the patient to an Oral and Maxillofacial Surgeon (OMFS), as we are dentally trained. During our surgical training, we are exposed to the management of most head and neck tumours. This helps when we have to inform the patient and their families of what to expect.

A Maxillofacial Surgeon is usually part of a multidisciplinary clinic and a timely referral to one of these clinics is an efficient path to expeditious treatment.

Whilst we have a very good understanding of all of the different treatments that can be used for Head and Neck Cancer we only undertake the surgical one initially. This is because we are experts in the mouth/oral region and have a clear idea of how best to minimize patients' longer term issues with function.

All of us are aware of the emotional impact of an oral operation but we are specifically keen on restoring functions such as chewing, smiling and even pulling faces!

Radiotherapy and chemotherapy affect the mouth as well as the surrounding muscles and skin. Specifically, it affects the salivary glands, jaw bone and teeth.

Reconstruction after surgery, has developed enormously in the last decade as has management of the side effects of radiotherapy. With both medical and dental training, OMFS are in the optimum position to liaise with dental practitioners, oncologists and others to maintain the best care of Head and Neck Cancer patients, for life.

One of my roles is to educate patients about supplemental treatments that may make life easier following treatment of head and neck cancer; for example hyperbaric oxygen, very specific mouthwashes and tissue enhancing medications.

Maxillofacial Surgeons can suggest reconstructive options for the mouth, face and jaws including titanium teeth implants if required.

One of my greatest pleasures in caring for patients is in long-term management. Sometimes teeth need removal for any of the usual reasons, but after chemo and radiotherapy there can be issues of healing. It is very satisfying to be able to reassure patients that this is possible without dire consequences, to undertake the surgery, to monitor the supportive treatments which may include special medications, hyperbaric oxygen therapy and plenty of reassurance. There are reconstructive options for replacing teeth even in irradiated tissues which sometimes surprises people.

Before Brisbane had hyperbaric oxygen chambers (it now has two), I had to send patients to Townsville.

Our special relationship with dentists, specialist prosthodontists and prosthetists, gives many patients options for quality of life improvement after treatment.

Although the experience of a malignancy of the head, neck mouth and jaws is inevitably a daunting one at the outset, there are many options available for reducing the difficulties, and progress is being made all the time.

In my time as a specialist OMFS, not only has the life expectancy of patients with this diagnosis improved, but due to improving treatments and reconstructive options, so has the quality of life.

Dr Caroline Acton OStJ

Oral and Maxillofacial Surgeon

BDS, FDSRCS (Eng), MDSc (Oral Surg), FRACDS(OMS) - Royal Brisbane and Women's Hospital and Caroline Acton Oral Surgery Pty Ltd.:CAOS cheacton@powerup.com.au

# We're Here To Help You

## - Cancer Council

A cancer diagnosis can be stressful and you may face a range of emotional, physical and practical challenges. The Cancer Council offers a range of free information resources, as well as many services to support you and your family.

Each year about 4400 Australians are diagnosed with a Head and Neck Cancer. Cancer Council's Understanding Head and Neck Cancers booklet explains how these cancers develop, how they are diagnosed and how they are treated.

The booklet covers five types of head and neck cancers – oral (mouth) cancer, pharyngeal (throat) cancer, laryngeal (voice box) cancer, salivary gland cancer, and nasal or paranasal sinus cancer.

### **It also includes information on:**

- symptoms for each of the five cancers
- the tests you may have to diagnose a head and neck cancer
- the health professionals you will see
- treatment options by type of head and neck cancer, including surgery, radiotherapy, chemotherapy, targeted therapy and immunotherapy
- side effects of treatment – what they are and how to manage them
- coping with changes in your eating, breathing and speech, and managing pain
- how allied health professionals, such as speech pathologists, nutritionists and psychologists, can help you adapt to long-term effects of treatment.

You may also find it helpful to read other booklets in Cancer Council's Understanding Cancer series, such as Understanding Radiotherapy, Emotions and Cancer, Nutrition and Cancer, and Caring for Someone with Cancer. These booklets are available to download as PDFs or as eBooks, or we can post copies to you. We also offer online fact



sheets about Mouth Health and Cancer Treatment and Understanding Taste and Smell Changes.

Visit [cancercouncil.com.au/publications/](http://cancercouncil.com.au/publications/) to download these publications or to see a list of other booklets and information resources. You can also call Cancer Council 13 11 20 Information and Support Service to order free copies of relevant booklets.

### **Other services for people affected by Head and Neck Cancers**

Cancer Council offers a range of practical and emotional support services to help you and your family. You may be interested in:

- **Cancer Council 13 11 20 Information and Support Service** – phone 13 11 20 to talk with a health professional for information about head and neck cancers, treatment, support services and support groups available in your area.
- **Cancer Connect peer support** – get one-on-one telephone support from a trained volunteer who has had a similar experience to you. You might also like to visit one of the Head and Neck Cancer Support Groups around the country.
- **Cancer Council Online Community** – connect, support and share your cancer experiences through online discussion forums, support groups and blogs at [cancercouncil.com.au/OC](http://cancercouncil.com.au/OC).
- **Legal, financial and workplace referral services** – we can connect you with a lawyer, financial planner, accountant or HR/recruitment professional; free for eligible

clients.

- **Financial counselling and emergency financial assistance** – we can provide assistance and information to help you resolve your financial problems; free for eligible clients.
- **Transport to treatment** – we can help you find local patient transport services to get you to and from medical appointments.
- **Accommodation** – we can help you and your carers find low cost and reduced rate accommodation near your treatment centre.
- **Home help** – get help with household tasks from trained volunteers.
- **Cancer Council Information Services** – if there is one at your treatment centre, drop in to speak to one of our trained volunteers or to pick up booklets.
- **Support after treatment** – get information about the emotional and practical aspects of living well after cancer through our workshops, webinars, mentoring programs, and an exercise and nutrition program.

Not all services are available in all areas. To find out about Cancer Council services and programs available in your area call **13 11 20**, or visit the Cancer Council website in your state.





## A Winning Battle - John Welsh

To win my battle with Head and Neck Cancer, I was fortunate to have the love and support from my family and friends and a fantastic group of oncology nurses and doctors and a truly great surgeon at the Royal Brisbane and Women's Hospital (RBWH).

My dentist monitored a white spot on my tongue which a biopsy showed was not cancer. However, 2 years later, it turned into cancer and was removed with surgery and a clear margin was achieved.

Six months later at my monthly check up with the surgeon he noticed a lump in the left side of my neck. The cancer had found its way into the neck and a week later I had a neck dissection. Then started to treatment, 33 doses of radiation as well as chemotherapy. Unfortunately, the cancer was also wrapped around my spinal accessory nerve and this nerve had to be sacrificed and removed causing my shoulder to droop.

It was during this treatment I never realised how sick and weak my body could get. I struggled so hard to try and eat food and went from 82kg to 66kg. But within 2 years I returned to 82kg . It was great being able to eat all those fattening foods.

Unfortunately I had a rare reaction to the radiation and consequently I now have bad neck fibrosis for which I have had 50 treatments in a hyperbaric oxygen chamber to try and soften the fibrosis. But

so far this has been unsuccessful. Just recently my surgeon operated to try and loosen the radiation bands in my neck but this did not help either.

I also discovered the Head and Neck Survivor Support Group in Brisbane and, when I can, I attend the monthly meetings. I have found this group of fellow "neckies" to be very supportive and helpful. The support group is professionally run and it has supplied me with an enormous wealth of helpful and timely information. I would suggest that it would be well worth attending for any new cancer patient, if you are going through treatment or if you have finished treatment for some time. It's great to talk with people who are going through the same treatment, or have gone through the treatment in the past.

It is now three years since I was diagnosed and even though I am on medication (Lyrica, Morphine Patches, Targin, Endone and Cymbalta) to control the nerve pain, I am still fairly positive.

Yes my life changed the day I was operated on and now I have limited neck movement and struggle to do daily chores. I am also unable to play golf, go body surfing and do a lot of the physical things I once enjoyed. However, I am truly grateful to be alive and treasure each and every day.

I believe you must remain positive to enjoy your family and friends, because they are only human and they can only tolerate so much negativity. I know I am in a much better place than I was three years ago thanks to the long chain of command involved.



## A Carers Story - Rhona and Ken Collinson

Have you ever been asked to do something you didn't want to do and you thought of the best excuse ever to get yourself out of that job? Or you couldn't think of an excuse quickly enough, then ended up doing the job anyway? A cancer diagnosis for one person immediately creates an opening for another person – the carer. You didn't ask for the job, but you got it anyway. The patient didn't ask for the diagnosis, but they got it anyway. So, you just get on with it.

We were directed to the Princess Alexandra Hospital Brisbane for Ken's treatment. Most Head and Neck cancers these days are dealt with by a multi-disciplinary team, which includes doctors, oncologists, radiation therapists, dentists, dieticians, speech therapists, physiotherapists, social workers, researchers, care nurses and even Uni students who are learning the ropes. For about three hours at our initial interview, Ken and I and our daughter tried to absorb all that we were being told. The thing that amazed us most was that not one of those people used the word "cancer". They all talked about treating Ken, not the disease, and this gave us great confidence.

The chemotherapy and radiation regime is common to most cancer treatments. Ken handled the

chemotherapy well, but the 35 days of radiation were difficult. The radiation kills the salivary glands, so a dry mouth is a legacy of the treatment. The radiation also causes burning and swelling in the throat, so eating is increasingly difficult. This caused rapid weight loss and while Ken had excess weight to lose, the dieticians became increasingly frantic. They suggested he should be having at least 12 tablespoons of Sustagen a day mixed into his food. Can you imagine how difficult it is to disguise four tablespoons of Sustagen in one tablespoon of scrambled egg which was all he could manage at a sitting. That old favourite, junket, became a staple food, but it doesn't take kindly to having Sustagen mixed in it either.

With 10 radiation treatments to go, Ken could swallow neither food nor water and was admitted to PA where he had a tube through his nose for liquid food to be administered. One of my tasks was to learn how to manage the tube and administer the six daily poppers of Hospital strength Sustagen that became Ken's food for the next six weeks. I have never considered nursing skills as one of my strengths but again, as a carer, you can adapt to many things.

Throughout this time, I kept a daily journal which I used to write while Ken was having his daily dose of radiation. It helped me focus on what was happening, to record the difficulties and focus on the blessings we received. We learnt that some of the best most caring people in the world work in Queensland's public hospitals. We learnt that there is such a thing as thickened water. We learnt that yoghurt and avocado are life-saving foods. We learnt that the support we received from friends and family is priceless. And we learnt that time takes on a new meaning.

Four years down the track, Ken deals with the "new normal". That includes no longer being able to eat things like steak or rice or cake, losing the taste for chocolate and wine, and having to have a rest most afternoons. It means having a high maintenance dental routine because of the damage done to the teeth and the jawbones by radiation. It also means being 60 kilograms lighter, no longer being a Type 2 Diabetic and no longer having high blood pressure.



# Wesley Centre for Hyperbaric Medicine Study

## - Dr Ohnmar Aung

Dr Ohnmar Aung, MB, BS, FANZCA, is the Principal Investigator for the Wesley Centre for Hyperbaric Medicine. If you would like to be involved in this study or need more information: Please call: 07 3371 6033 or email: [reception@wesleyhyperbaric.com.au](mailto:reception@wesleyhyperbaric.com.au)

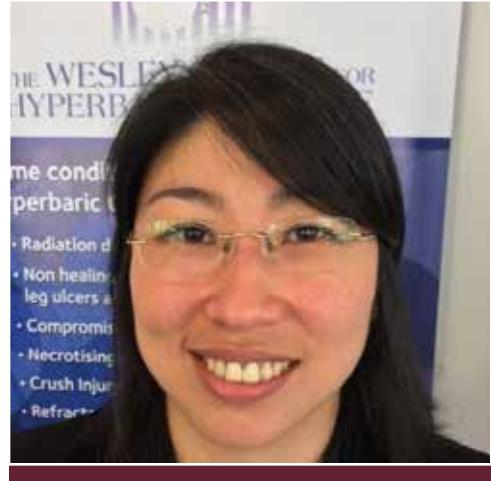
### Xerostomia (Dry Mouth)

In March 2016 Dr. Aung joined the Wesley Centre for Hyperbaric Medicine (WCHM) Brisbane as a hyperbaric physician. Shortly after joining, she set up a research program to study Xerostomia.

During the year of her provisional fellowship in 2014, Dr Aung started her career in Hyperbaric and Diving Medicine at the Royal Brisbane and Women's Hospital. This sparked her interest in Hyperbaric Medicine so she decided to further her career as a Hyperbaric Physician at Wesley Center for Hyperbaric Medicine.

Dr Aung has a keen interest in research. Her current research study about Xerostomia is designed for people who have received head and neck radiation and are suffering from dry mouth due to the result of the radiation. She is keen to recruit as many people into the study as possible. The result of the study would help with the future management of Xerostomia due to head and neck radiation.

The Wesley Centre for Hyperbaric Medicine is one of the most advanced hyperbaric oxygen medical treatment units in Australia, and in the world.



We are a Licensed Day Hospital and Australia's first and largest, private and fully comprehensive hyperbaric facility. Each year we perform over 3,500 hyperbaric treatments for patients from all over Queensland and Northern NSW for a range of medical conditions as well as conducting advanced hyperbaric medical research.

At the WCHM we treat 14 approved medical conditions. These conditions are either covered by Medicare or one or more of the major health funds. The most commonly treated conditions are those relating to chronic wounds and to damage caused by radiotherapy.

The benefits of Hyperbaric Oxygen Therapy (HBOT) in treating the approved conditions have revealed scientifically proven results.

Osteoradionecrosis (ORN) is a condition where dead bone develops at the site of high dose irradiation, with poor healing of the flesh too. It occurs mainly in the lower jaw. It follows high dose irradiation.

Xerostomia is the most common complication in patients who have had radiation to the head and neck area for the treatment of cancer. Salivary flow may continue to decline for up to several months after radiotherapy. Thereafter, some recovery is possible up to 12 to 18 months after radiotherapy depending on the radiation dose received by the salivary glands and the volume of salivary gland included in

the irradiation fields. However, generally, xerostomia develops into an irreversible, life-long problem.

Are you willing to participate in a study to improve the salivary flow for treatment of Dry Mouth? With the reduced saliva flow, it causes accumulation of dental plaque and increased retention of food particles between teeth, promoting recurrent dental caries. Post radiation, the saliva pH and buffer capacity is lowered, promoting growth of fungus, *Candida albicans*, as well as accelerated tooth wear, dental erosion and infection. A saliva test is an excellent way of being able to identify patients with this particular problem, and it provides the framework around which your management can be based.

**Step 1:** Saliva test is at the beginning of your treatment

**Step 2:** Saliva test after the 30 treatment course of Hyperbaric Oxygen Therapy (HBOT)

**Step 3:** Saliva test at six weeks after the end of treatment of HBOT. In addition to the treatment of Xerostomia, HBOT is also useful in the management of osteoradionecrosis of the jaw, both for the prevention as well as the treatment of the condition. The treatment regime is the same as that of Xerostomia and the duration is determined by Marx protocol.



# Physiotherapy

## - Sarah Ogdon

Sarah Ogden, Princess Alexandra Hospital Brisbane  
Physiotherapy Cancer Services

### The diagnosis

Receiving the news that you have cancer can often be very upsetting. The effects of the cancer and the cancer treatments can impact on you in a number of ways, physically, emotionally and spiritually.

Physiotherapists, along with other medical staff work together to minimise these effects and help you throughout your treatment and recovery.

If you have surgery there will be a Physiotherapist based on your ward. Depending on what operation you have they may see you during your stay. Initially they may be involved in helping you get back on your feet, teaching you breathing exercises to ensure your lungs are working well. They may even show you shoulder and neck exercises to reduce muscle and/or joint stiffness. If you haven't seen a Physiotherapist and you wish to, just ask your nurse and they can organise this for you.

Physiotherapists, however, are not just found on the ward, we can also be involved in all stages of your cancer journey. We can help you with a number of issues you may have as result of your cancer, surgery or treatment. These could be a loss of strength and movement, flexibility, lymphoedema (a type of swelling), scar management, difficulty walking and fatigue.

When undergoing cancer treatments such as chemotherapy and radiation many people experience cancer related fatigue, which is a tiredness that doesn't seem to go away even if you rest. This can then affect your normal day to day activities. Often the more fatigued you feel, the less you want to do....and the less you do, the more fatigued you feel.

One thing that can help with this fatigue is exercise. We all know that exercise is good for us. It can help us to sleep, improve our mood, improve our fitness, increase flexibility, muscle and bone strength. It can help us to maintain a healthy weight as well as provide us a sense of wellbeing.

Recently there has been a lot of research carried out looking into the benefits of exercise in people suffering from cancer related fatigue. This research has found that carrying out exercise during and after your cancer treatment can reduce the fatigue you



feel. If you are less fatigued you are more likely to be able to return to your usual activities quicker.

As Physiotherapists, we encourage you to participate in exercise regularly. It is important to choose an activity that you enjoy. Doing exercise doesn't necessarily mean going to a gym, start running or get on a bike. One simple way you can introduce some exercise into your everyday life is by walking. You could meet a friend for a walk, take the stairs instead of getting the lift, or getting off the bus one stop earlier and walking the rest of the way. It is very important to remember that everyone's fitness levels are different, so we want you to find an exercise that is appropriate and manageable for you. Your Physiotherapist can help you devise a suitable individualised exercise programme that will work best for you.

Physiotherapists will be available for you during your treatment and we are always happy to see you and help assist you in any way we can.

*“Exercise during and after your cancer treatment can reduce the fatigue you feel.”*

## The Neckies

- Tony Ng

*"I cannot express how lonely I would have been in my struggle to face my deepest fear of my mortality without the support of my fellow "Neckies"*



In August 2010, the diagnosis of oral cancer in my lower left jaw (SCC of left mandible) came as a complete shock to me. It was picked up by the dental specialist who was attending to the extraction of my troublesome wisdom tooth. Scans established that the T4 cancer had infiltrated the bone structure of the jaw and all the lymph nodes down the left side of my neck. It was difficult to understand and accept the enormity of this life threatening discovery.

After being assessed by the medical professionals at the Head and Neck Cancer Multidisciplinary Clinic at the Royal Brisbane and Women's Hospital, urgent surgery was scheduled for the removal of the cancer. A fibular flap was harvested from my left leg and reconfigured to replace the dissected jaw. A month after the surgery, I embarked on six weeks of radiation treatment to remove any minute traces of the cancer. To ensure that the radiation beams are targeted accurately into the designated zones, I had to wear a specially fitted plastic mask which immobilised my head during each radiation treatment. It was a painful experience made bearable through a pain management program and prescription of opioids.

Upon completion of the treatment, I experienced drug withdrawal symptoms and panic attacks and was treated by the psychologist/psychiatrist for depression and anxiety. Later I also underwent four weeks of hyperbaric treatment for osteoradionecrosis (the wound in the radiated area of the jaw was not healing).

All I wished for during all these arduous treatments and countless appointments with various medical and allied health practitioners was the end of the journey and a return to work and normal living.

The difficult journey was made lighter through my chance discovery of the Head and Neck Support Group in Brisbane. It was refreshing and reassuring to meet with the friendly group and to listen to the stories of people who have undergone a similar experience to me (some worse) and have come through the other side. I cannot express how lonely I would have been in my struggle to face my deepest fear of my mortality without the support of my fellow "Neckies", as we call ourselves. So, thanks Marty and everyone at the Support Group.

# Smell the Coffee

## - Angelina Tati

As I embark on recalling my journey, I would first like to praise the health care professionals and their administrative staff through whose expertise I have made it this far. You are all so very special to me and the very reason I am physically and medically able to write this story.

I was diagnosed in 2010 with Adenoid Cystic Carcinoma (ACC). The shock of this news hit me like a bolt of lightning, which made me crumble to my very core. Overtaken by fear, I was a mess, not even knowing what this terminology meant. I caught the words "aggressive", slow growing, "cancer" with "no cure" and my mind abandoned me.

First I thought how is this going to affect me especially my physical and mental being. Then came the dread of what this would do to my family and friends. How, what I was about to go through would distress them. Or my worse thought, imagine their lives without me in it, was something much too painful to bear. It was an intolerable thought for any of us. I have been asked, "are you sure you want to put yourself though this?" "Have you got informed advice on the procedure?" "What will your quality of life be afterwards?" My reply was, "I'm doing this for my family".

Since that fateful diagnosis, I have had 16 surgeries related to this condition, with some procedures far more lengthy than others, but each of these just as serious and painful. I also ended up having a peg feeding tube inserted into my stomach to enable me to get enough strength for my next surgery. Throughout the early stages, my weight fluctuated from 87kg to 48kg as a result of not being able to eat, barely only drinking. I have had skin and bone grafted from my body to create spare parts for those that have been removed from my head and face.



At many stages of this journey my mind could quite easily have convinced me to "just give up". However, the faces of my family gave me the strength to fight just that little bit harder. I recall one procedure where just before going into theatre I said goodbye to my sister. Her beautiful smile was her brave way of reassuring me that everything would turn out well. As she turned from me, I caught her reflection in a mirror and saw the smile disappear, her face awash with tears.

The strength derived from the support of my sisters, their families, my immediate family and friends, is inexplicable. They continue to support me, encourage me, pray for me and love me. It gave me and continues to give me the will to live and to fight, rather than just give up after all the great work that has been done. I believe no matter what your beliefs are, faith in your God is an integral part of healing, at least in my case. I draw strength knowing I have such a strong support system.

For me this journey started in 2010 and continues to date with ups and downs, good and bad days. Days where I can't even get my head off the pillow due to pain, or just exhaustion. On those days I say to myself, "you're alive, so just get up and smell the coffee"!!!

My advice is to be strong, stay positive, surround yourself with love and take one step and day at a time.

# It even happens in the Bush

- Vicki Provost

One morning when I was at work in a local aged care facility in Taree, NSW, working as a nursing assistant, one of the residents gave me a hug good morning and squeezed me around my face. It really hurt and I realised a lump I had noticed just in front of my right ear was not only getting bigger but was painful. Over the previous six years it had increased from the size of a pea to a small marble. I had returned to my GP numerous times over the years, who sent me for ultrasounds and a CT scan. Nothing came out of these tests, other than it being a cyst.

One day I woke up and the right side of my face was numb and my right eye felt like it had sand in it. That's when everything happened in fast motion. I was referred to a local specialist who did an MRI, then in turn referred me to the Chris O'Brien Lifehouse in Camperdown Sydney, into the brilliant care of Assoc. Prof. Jonathan Clark. My wonderful head and neck surgeon was concerned about my irritated eye and an operation was scheduled. It was malignant, adenoid cystic carcinoma, or salivary gland cancer – 80% are benign, mine was not.

The cancer had run along my facial nerves damaging two, so after my operation I couldn't close my eyelid. Five weeks later I had another operation to insert a gold weight into my eyelid so I could blink. Then 20 rounds of radiation, that was the hard part – mouth ulcers, sore throat, burning/peeling skin, weight loss, nausea, vomiting, trismus (minimal mouth opening) and (hooray) puree food!!! But through it all I had the most brilliant doctors helping and guiding me, every problem I had they seemed to have a solution to make things a little easier, including emotional support.



*"I feel so lucky we have such an incredible facility with the most dedicated and compassionate medical professionals"*

My husband became my carer and never flinched at any point, not once, and 35 years of marriage put us in good stead for the road in front of us. My wonderful children enveloped me in love and support, along with my close network of friends I held onto. My employer Anglican Care supported me all the way through and especially my boss Karen. I got back to work gradually. A few hours a week at first, until I regained my strength. My scans are clear, next review now 12 months away.

The Chris O'Brien Lifehouse was initially a very frightening place, full of uncertainty and disbelief, but in time it became a place of comfort, of positivity and, most importantly, of hope. I feel so lucky we have such an incredible facility with the most dedicated and compassionate medical professionals. It gives me hope for the future.



*"I am also lucky that the cancer experience has brought me closer to my partner, Melissa and our two children."*

## Celebrity Patient Story - Julie McCrossin

Julie McCrossin is a radio and television presenter with over 25 years' experience on ABC TV, ABC Radio National and Network Ten. She is best known as a team leader on the comedy quiz show Good News Week and as a presenter of Life Matters on ABC Radio National. Julie now writes for the NSW Law Society Journal and facilitates events across Australia. Julie was diagnosed with Head and Neck Cancer in 2013. She was treated at St Vincent's Hospital in Sydney.

### **Julie's Story**

The treatment from my multidisciplinary team sent the stage four cancer in my tonsils, throat and tongue into remission over four years ago. My cancer was caused by the HPV virus. I hadn't drunk alcohol or smoked for over 30 years.

I have to be honest, the side effects of treatment were tough. My capacity to swallow was limited to liquid food for some time, so I lost 20kg over six to eight weeks. I lost the capacity to talk for quite a few weeks. I used an iPad to communicate by downloading an app that made the screen behave like a blackboard. I could write words on the screen with my finger or a rubber pen and then wipe it clean.

For 30 days I had chemotherapy once a week

and radiation every day. I had to wear a special mask to keep me totally still while the radiation treatment took place. It is called an "immobilisation mask". The mask keeps you safe by ensuring the radiation is delivered to the precise locations necessary.

I found this aspect of the treatment challenging. I had never seen a mask like this and I had never heard about their purpose. I waited too long before I told a nurse on my team that I was very distressed by the mask. She arranged for me to have mild sedation before each radiation treatment. I started listening to the same four songs during every treatment. This calmed me and helped me know how long it would take. A psychologist also gave me good things to think about while I was in the bunker.

The result made the rigours of treatment absolutely worthwhile. I can talk and swallow. I am back to work and the joy of daily life.

I really recommend asking for help from speech pathologists, dieticians, psychologists and senior nurses, as well as the medical team. Find a dentist who understands the effects of treatment and get advice for the health of your teeth long term.

Tell your trusted family members and friends what you need and ask directly for help. At this point in my recovery, I find I am susceptible to anxiety and depression at times. I seem to be more emotionally vulnerable since cancer. I take anti-depressants and I see a psychiatrist regularly. I am also still checked every six months by my cancer doctors. I have found it really helps me emotionally to be active in advocacy for better cancer services. I am also lucky that the cancer experience has brought me even closer to my partner, Melissa and our two children, Luke and Amelia. Their loving support has been my anchor.



# CUP

## - Robyn Wagner

In January 2012, I found a lump under my jaw, like a pea under my skin. I was immediately sent for a scan and biopsy. The results came back as a SCC (Squamous Cell Carcinoma). The tests showed this was my secondary cancer. After all available tests, there wasn't any sign of where my primary cancer was. Finding out I had cancer was devastating, but not knowing where it was raised even more emotions – all I could think was 'how can they treat me correctly if they don't know where all my cancer is?'

I was diagnosed with Cancer of Unknown Primary, or CUP. It's one of the forgotten cancers that is drastically under-researched here in Australia. Statistically I was told I had 65% chance of surviving three years, and 85% chance of surviving five years. Weeks and weeks of tests followed but my primary site was never found. I eventually had a full neck dissection, followed by six weeks of daily radiation on my neck. I suffered many after effects from the radiation, especially tingling in my jaw and constant dry mouth.

People diagnosed with CUP tend to feel pretty alone and confused. CUP is not as well known by members of the public as other cancers such as breast, lung or prostate. It made telling my family and friends even more confusing – "I have cancer but I don't know where".

I am a very strong minded and positive person. I have had health challenges in the past, having had emergency surgery for ruptured appendicitis at 18, and my gall bladder out at age 35, but a CUP diagnosis was a real shock. I lost my beautiful mother 21 years ago to bowel cancer. I often thought that if I was ever going to get a cancer, it would be bowel. But my determination and strong will got me through. I always choose the high road and focus on the positives in my life. My cancer battle was the same. Another mountain to

conquer.

There isn't much information available on CUP and it was difficult trying to find someone going through the same experience. This added to the emotional rollercoaster of dealing with a cancer you can't even picture in your body.

At times, it would make me angry. How can something so life threatening come into my body, do damage and disappear without leaving any trace of where it had been?

My friends ask me when I'll be in remission and the honest answer is probably never, because they haven't found all the cancer. There's a great need for more awareness, support and funding for CUP, and I want to help others get through their journey.

I met some really inspiring people following my diagnosis. I was invited to speak at Cancer Council NSW in Sydney as they were conducting a research study on CUP. They released a short video and I was able to share my story. The videos are available on the Cancer Council website. Going public was a scary process. However, I am determined to continue to advocate for Cancer of Unknown Primary and offer as much hope and support as I can.

I have just passed my five-year anniversary. I am still being checked every 12 months. When my treatment finished I made a bucket list of all the places I wanted to see in the world and have been in awe at what my husband and I have achieved.

Embrace life every day. Life is a precious, priceless gift that should never be taken for granted.

To find out more about Robyn's story visit [www.cupofhope.net.au](http://www.cupofhope.net.au)

# Oral Health during cancer treatment & beyond

## A Patient Guide

Queries to [deborah.buick@health.qld.gov.au](mailto:deborah.buick@health.qld.gov.au)

Many patients will have radiation or chemoradiation to treat their head and neck cancer. This may cause permanent side effects which can affect your oral health particularly if the cancer has been in the region.

You will notice a dryness of the mouth during radiation treatment. It is important to keep your oral tissues moist by having frequent sips of water, using a water-based rinse or by sucking on ice. Also keep lips well lubricated. If the salivary glands are not positioned in the high dose field of radiation this dryness will improve once radiation is complete. The location of the field of radiation is dependent on the site of the tumour of your oral cavity.

The latest methods of radiotherapy are designed to target the tumour very specifically with less scatter of radiation to surrounding healthy tissue. This is important in the oral cavity where minimal impact on teeth, bone and salivary glands is desired. The location of your tumour and the subsequent positioning of the radiation field will determine which healthy structures may be adversely affected.

The following is a guide to what you can expect during radiation treatment, and also the possible long-term side effects of radiation treatment. We will discuss the management of these side effects and a dental routine to ensure optimum oral health.

### Side effects experienced during radiation therapy

- Dry mouth (xerostomia)
- Mucositis



- Loss of taste – will improve after completion of radiation treatment

### Mucositis

Mucositis is the inflammation and ulceration of the mucous membrane lining the oral cavity and digestive tract. It is a common and often debilitating complication of chemotherapy and radiotherapy. Typically oral mucositis develops 5-10 days after radiation commences and resolves 1-2 weeks after radiation is complete. It ranges in severity with some patients noticing only mild symptoms, while others experience ulceration which is slow to heal and painful. Secondary bacterial and fungal infections may develop.

If you are suffering from mucositis please talk with your radiation oncologist or nurse. They will recommend and provide mouthrinses such as Biotene, Bi-Carb Soda & saline. Your radiation oncologist may prescribe antiviral or antifungal medication. If stronger pain control is required Xylocaine Viscous or oral painkillers may be prescribed.

It is important to keep plaque to a minimum – if your usual toothbrush is too harsh you may need to use a very soft toothbrush, or children's toothbrush to help maintain your oral hygiene through this difficult time. If your usual toothpaste is too harsh, a children's toothpaste or Biotene toothpaste is recommended.

Please remember, mucositis will resolve following completion of radiation treatment.

## **Summary of Oral Care Needed During Radiation Treatment**

- Brush teeth at least twice/day. You may need to use a special soft toothbrush.
- If toothpaste is too harsh try Biotene toothpaste (available at pharmacy), or a children's toothpaste
- Keep mouth & lips well lubricated with frequent sips of water & lip moisturizer
- Use a bland mouth rinse such as Saline or Bi-Carb Soda especially after eating
- Avoid foods which irritate (spicy, dry, acidic, abrasive)
- Avoid tobacco, alcohol and strong mouthrinse
- If mouth is ulcerated, consider rinsing with xylocaine viscous 15 minutes before eating. Over the counter ulcer preparations are also available.
- Leave dentures out if they are causing irritation

### **Long-term side effects of radiation treatment**

The long-term side effects of radiation treatment which can affect the oral cavity include

- Dry mouth (xerostomia)
- Rapid decay (radiation caries)
- Poor or no bone healing (osteoradionecrosis)

### **Dry Mouth**

If the salivary glands, particularly the parotid glands, are damaged from radiation treatment a rapid and profound reduction in salivary output and quality occurs. Your saliva may no longer be able to:

- wash food & debris away
- neutralise acid
- reduce the bacteria which cause decay
- remineralise teeth

If salivary glands are damaged, rapid decay of the teeth may result. It is more important than ever for you to look after your oral health.

### **Rapid Decay**

Radiation affects the teeth by weakening the

biological bond between the enamel and dentine. This means that teeth in the radiation field have the potential to decay quickly unless they are being well looked after. This is an avoidable side effect.

### **Poor or No Bone Healing**

Sometimes bone in the high field of radiation may lose its ability to heal after trauma. This condition is called osteoradionecrosis (ORN). For this reason, dentists will not extract teeth which have been in a high field of radiation. It is important that any dentist in the future knows your radiation history. Your radiation oncologist will need to be consulted before any tooth which may have been in the radiation field is extracted. This remains important for your lifetime.

ORN can also occur from ill-fitting dentures. If dentures are rubbing they will need to be removed. If teeth were extracted prior to radiation, new dentures must not be constructed for at least 12 months (lower) and 6 months (upper) following completion of radiation.

It is important to see a dentist prior to radiation commencing, so that any poor teeth are identified and extracted. This will reduce the need for extractions following radiation.

If soft tissue irritation or ulceration appears in an area that has received radiation see your dentist. Also, if you notice an exposed area of bone at any stage, see your dentist.

### **Dr Deborah Buick**

**Principal Dentist Cancer Care  
Brisbane Dental Hospital and Adult  
Specialist Services  
Metro North Hospital and Health Service**



## A Nurse's Story - Cheryl Kelly

It started 33 years ago

As a young and newly registered nurse I returned to the public hospital where I trained and was allocated to the unit I thought I least wanted to go. Little did I know it would shape my career and consequently my life for the next 33 years.

What I initially thought would be difficult and unpleasant proved to be yes – very difficult, incredibly challenging both physically and psychologically but mostly it proved to be enormously rewarding to care for and be involved in the lives of this patient cohort.

In the early 1980's the surgical management of head and neck cancer was, in my eyes and I expect in the eyes of the patients and relatives, quite brutal and severe. Some surgical techniques were still being refined and the early post-operative management was challenging for both patients and staff.

Some of our patients – particularly in those early days – had very long and torturous recoveries and consequently spent an extended time in hospital. Although we 'connect' with all patients it is these 'long termers' with whom you build a close and personal bond. I remember many of them fondly. Back in the early 80's some of the patients who presented with Head and Neck Cancer were those with advanced disease which was often the

consequence of many years of heavy smoking and alcohol intake. We, at one point, thought the training surgeons were regularly frequenting one of the local hotels for clients as some of these patients did indeed know each other from the front bar. These men (most often) were lovely and difficult in equal measure. If we all survived the first week of alcohol withdrawal unscathed (I recall one gentleman swinging from the curtain rails!) we got on much better and formed good working relationships. That's not to say they didn't remain headstrong and roguish. Seeing and treating these patients every day was definitely about their health and treating their disease but it just as much about being a positive and sometimes the only caring thing in their lives. Saying goodbye at time of discharge (or sometimes death) was as difficult for us as it was for them.

With the identification of HPV positive cancers we see the age group and social status of our patients has changed immeasurably. We definitely still see those patients who rely heavily on alcohol and cigarettes to get by but our interaction and communication skills now have to extend to a younger, often income earning patient who is much more in tune with their own health expectations and management. However, our core business hasn't changed. Nurses observe vital signs, monitor and treat wounds and administer medications and treatments but I believe our major strength is in just being there, every day and every night. Interacting like nothing has changed, worrying about the basics – comfort, pain, food, fluids, bowels, sleep (the list is infinite), encouraging the patient to regain their independence and feel confident and comfortable with their current physical condition however challenging that may be.

I recall many past Head and Neck Cancer patients fondly. These remarkable people met the challenge of a very confronting disease and in addition taught me about the strength and resilience of the human spirit. Cancer of any kind is threatening. Cancer of the head and neck threatens how a patient looks, how they interact verbally and socially (eating/drinking) and further challenges their life expectancy. As a professional body we cannot change any of those things but we can influence the period of transition from what it was to what it is now.

**Cheryl Kelly, President Otorhinolaryngology Head and Neck Nurses Group Australia**

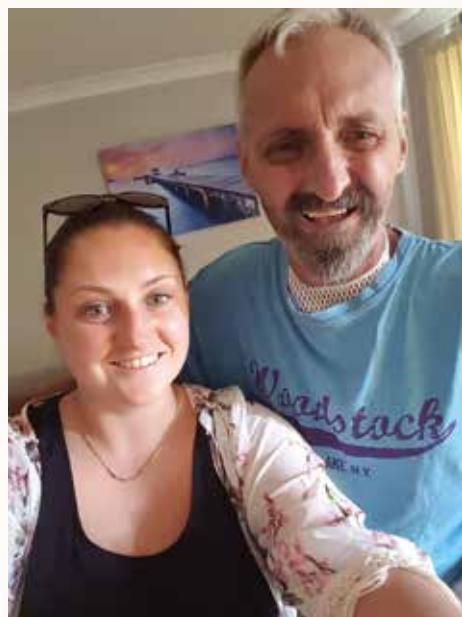
## You've been great thanks - Eric Scarman

Well it started just like the rest of you – a bad, new diagnosis quickly followed by surgery to remove most of my throat and neck.

I will never forget the first day in ICU just thinking I was going to choke any minute. The nurse didn't leave me alone all day. I thought, what the heck, I must be at risk. Then I moved to the ward and became slightly more relaxed. Three days later the original operation didn't work so it was back to surgery and replace the throat and neck again.

A couple of days later I was awake in bed feeling not too bad, maybe a bit depressed. The guy in the bed across from me is crying, though there was no noise because his voice box is gone as well. I think, well we are alive, so no point being sad, it could be the alternative!!

My daughter Cassandra and her husband Rick were very good to me. They fully renovated their shed into a fully functioning granny flat. It's the best. All my kids were great. They continually promoted a positive approach any time I was down. They let me know that feeling down all the time really wasn't helping anyone and I am certain without that attitude I could have really struggled through the chemotherapy and radiotherapy. By having a good outlook, it was not too bad an experience. The nurses and the doctors were absolutely fantastic with their kindness and help with all facets of recovery and anything I needed. So, while it was a long three months,



it wasn't as horrible as I was led to believe it would be.

Life has moved on since the treatment phase and I am extremely thankful. Tracey, the ENT nurse, got me into the gym program at my hospital which has really helped me with my confidence and wellbeing. The physiotherapist Ellen, who runs the classes, does such a great and positive job. I know the people in the class enjoy every minute of it twice a week.

Another big help for me has been the head and neck cancer support group meetings, also run by Tracey, where we discuss various issues facing all of us. The participants all put in their ideas and helpful tips and I know when I leave I always feel better than when I go in.

So, all in all, what I thought was the saddest and worst thing that could happen to anyone hasn't turned out that bad. Without all the help and support from family and close friends and the wonderful doctors and nurses, who do such a great job tirelessly, it could be worse.

Well, I am six months from that first operation, just about to get the speaking valve inserted and I have the next chapter to look forward to. Thanks to everyone, you've been great.

# If Not For The Nurses I Don't Know What I Would Have Done

- Con Kanellis

At the age of 48, I had a highly successful business, two teenage children, a great marriage, and then I was told I had Stage 4 squamous cell carcinoma in the tonsils and lymph nodes. Boom!

My initial reaction to this development was a combination of overwhelming fear and a fierce determination to fight and win. My son had just started university and my daughter high school. I just wasn't ready to give up because of cancer.

The initial phase of the treatment involved an operation to remove the tumour from my throat, a process that was painful, but relatively easy to get through over a two-week period. What followed, however, was a physical and mental challenge like no other.

The tumour in the lymph nodes could not be surgically removed and I was prescribed a combined treatment of chemotherapy and radiation (one day of chemo and five days of radiation a week for seven weeks.)

My struggle started even before the treatment commenced with the insertion of a peg tube in my stomach. This was a complete nightmare that had both physical and emotional implications because of the discomfort that it created and the fact that it became an ever present reminder of the horrible experience that I was undertaking.

The physical impact of the treatment was excruciating. Pain in my mouth and around my throat, loss of strength/energy due to the fact that I could not eat normally, weight loss, sleep deprivation, constipation, and an inability to speak due to my mouth/throat/tongue being "burnt".



I could only communicate by writing notes and in very short sentences. This was extremely frustrating, disempowering and completely overwhelming. I felt completely lost and useless.

Inevitably, these physical symptoms had a significant impact on my emotional wellbeing. I broke down completely and fell into a state of depression that spiralled downward at a rapid pace. This mental regression was exacerbated by my adverse reaction to the various medications, especially pain killers, that were prescribed to curtail the side effects of the treatment. Logical thinking became impossible and I was functioning in a thick emotional cloud that prevented any clarity of thought and suicidal thoughts became ever present.

It's within this highly volatile and highly emotional framework that I would present myself to the nurses and the medical team at the RNS cancer centre daily. Suffice to say, I was not an easy patient to care for and treat. Despite this, the nursing team that looked after me were highly professional and caring. My coordinating nurse took charge of the process and she guided both my wife and I methodically and with sensitivity. She is simply superhuman and an inspiration. The surrounding team seemed to understand what was required was empathy and emotional support. They can provide the reassurance that was lacking elsewhere.

The nursing team's methodology was inspiring and despite my anger, frustration and disillusionment during the treatment phase, I felt reassured while I was at the hospital and in their care. Post treatment, I realised the monumental challenge that confronted the nurses. These individuals deal with very ill and often emotionally traumatised patients and their carers on a daily basis.

# Laryngectomy Story

## India - Shrenik Shah

My name is Shrenik Shah. I am a 64-year-old Indian businessman in Global Marketing and have travelled to over 30 countries promoting exports in Chemicals & Dyestuffs. I have also been a Cancer Survivor for the past 20 years.

Until I was 44, I spoke normally but then my voice gradually turned into a whisper. Several doctors and ENT surgeons examined me but could find nothing unusual. I had never smoked, used tobacco or consumed alcohol. However, I had been travelling extensively seven or eight times a year for over 10 years which might have been a factor.

Then, in 1997, I started to have difficulty breathing and was unable to sleep on my back. I also began to lose weight; 10 kilograms in just 10 months. In August I found blood in my sputum or saliva. My family physician referred me immediately to a cancer specialist who carried out an endoscopy or internal examination of my throat using an endoscope – a long, thin flexible tube. They found a huge tumour on the opening of my windpipe. This eventually led to a Total Laryngectomy which involved the partial removal of my thyroid gland and 56 other nodes together with much of my neck muscle. I was discharged from hospital after a week and was back at work in under three months.

I was advised to use an Electrolarynx, a hand-held, battery-operated device which produces vibrations so allowing you to speak. It took me a couple of weeks to get used to it and I now use it in face-to-face conversations, over the phone and in public speaking as I travel all over the world in my work. It may



sound robotic but, to me, it's a blessing in disguise as it has given me a unique identity. I never need announce my name when I speak to someone for a second time!

When the doctors diagnosed my cancer and told me they needed to remove my voice box, my answer was quite simple. I said they should do whatever was required. Since then I have never dwelt on the fact I had cancer. Ten years after my surgery, I began to get involved in motivational work with cancer patients in hospital and to spread awareness of cancer among the business community, particularly during World Cancer and No Tobacco Days. Over the last six months, I have been a regular visitor to Cancer Hospital Outdoor & Indoor Patient Departments. I have spoken to them about fighting cancer and how to lead independent and active lives and helping others to fight Cancer too. I am also actively connected with the Memorial Sloan Kettering Cancer Centre in New York and regularly take part in their webinars. In July there was the launch of the book "10/10 Immersive Narratives of 10 Cancer Survivors" which tells the stories of 10 Head & Neck Cancer patients who have survived over 10 years. I am one of those lucky ones and my story is told in chapter 1: "I am going to stay".

During my 20 years as a cancer survivor, I have been committed to helping, protecting and comforting cancer patients and carers. I now ask for your support please in carrying on this commitment.

# Losing your sense of smell - Gillian Kreijter

When I was diagnosed with esthesioneuroblastoma in October 2015, I had no idea what it was or what it meant for the future.

When the ENT doctor told me it was cancer, I remember not reacting much. No fear, no anger, no sadness – just a thought of, right, this is something to deal with. The doctor started his sentence with "I don't want to scare you, but..." which is never a good beginning to a sentence, but it took me a few days to process and react. I started getting the shakes and shivers, and thinking about the consequences – what would happen to my kids who were both under five at the time – would I survive, would there be any lasting effects if I did? I felt like I was dying. It was just my body going into shock from the news, and once I came to terms with my new reality, the shakes and shivers disappeared.

What I didn't realise at the time was that this type of cancer is a cancer of the smell organs, and in the process of cutting out the tumour they had to cut out those nerves which enable me to smell.

One of the hardest things in losing my sense of smell was realising how lonely the experience is. Most people take smell for granted and have no sympathy or understanding for what it is you've lost. Nobody makes light of a cancer diagnosis, surgery, radiotherapy, or chemotherapy, but tell people that you've lost your sense of smell, and the reaction is usually a blank look, and some comment about how there are worse things. That might be true, but it's not helpful! People would say, "At least it's just your sense of smell. You've still got your sense of taste." Well, actually since sense of taste is 80% smell, not so much! Sweet, salty, sour and bitter flavours are still there – but truffle, herbs and spices are now all indistinguishable. Smell is integral to every experience, and when you lose it, it's



disconcerting and incredibly disorientating.

It took me a while to reorient myself to a world without smell. I burnt pies in the oven – I was lucky it wasn't the house. I woke up in a panic in my bed, because the familiar and comforting smells of my room and home were no longer there. My favourite foods tasted bland. I was unsure if I should wear the perfumes I used to love, or not. I sat in an empty carriage on a train because unlike anybody else, I didn't realise somebody had vomited all over the floor and the smell was terrible. I silently raged at the insensitive things friends and family would say that related to my loss of smell. Could I change their kids' nappies, since I wouldn't need to gag at the smell? The bottle of perfume received as a Christmas present.

Once I made peace with the fact that if you haven't lost your sense of smell you can't possibly understand what it is to lose it, and that insensitive comments are not deliberate, I stopped being so angry at the world and moved on. Surviving cancer has made me more grateful for the little pleasures in life. Even without my sense of smell and a diminished capacity for experiencing flavour, I still enjoy warm hugs with my children, the crunch and sweetness of an apple, and the wonderful colour palette of a sunset. I'm alive – and that's a gift.

*"Smell is integral to every experience, when you lose it, its disconcerting and incredibly disorientating"*

# Occupational Therapy in Head and Neck Cancer - Jodie Nixon

## Occupational Therapy

Treatment for head and neck cancer can be a distressing experience for some and can affect the way you do your everyday activities. Occupational Therapy can work with you to help you maintain or maximise your independence, enabling you to do the things that are meaningful to you. The treatment, and side effects may affect your everyday functioning; we can support you with strategies to make this as smooth as possible for you.

We know that people who have a good balance with self-care, work (paid and unpaid), leisure and sleep, manage treatment and recovery, so that they can get back into doing the things that are important to them.

## Tips & Tricks

- Self-care: make sure you are safe when you doing things such as showering, dressing. An excellent website that can show you useful adaptive devices that might help is <https://lifetec.org.au/>
- Work (paid or unpaid): most work places will support a graded return to work after treatment for cancer, sometimes you need to pace yourself. Talk to your doctor or occupational therapist about time frames and strategies for returning to work.
- Fatigue Management: most people experience some form of fatigue during treatment and recovery for head and neck cancer
- Staying active during treatment can help the way you manage treatment, however its equally important to say No if things are getting too much
- Pace the way you do things e.g. mow the front lawn one day, then the back the next
- Leisure: sometimes when health care gets overwhelming, it is easy to stop doing the things that give you enjoyment. However, we know that doing meaningful things in your every-day routine give you purpose and can bring balance. Some suggestions:
  - start (or restart)doing your favourite things: fishing, knitting, going to the rugby
  - visit with friends, family or your community groups who make you feel supported
  - maybe its time to explore new leisure interests: relaxation, volunteering
  - Sleep: sleep can be affected by treatment, medications, and challenges with breathing.
  - Try to keep the a similar sleep/wake cycle- go to bed and get up around the same time most days
  - adjust the sleep environment: make sure the room is a comfortable temperature and minimise noise
  - avoid naps during the day if it is impacting your sleep at night
  - Relaxation: Going through cancer treatment can be a distressing experience. Relaxation or meditation are techniques that can assist to give a balance to the stress of undergoing or recovering from treatment for head and neck cancer. There are different techniques that can be used, and sometimes it may be worthwhile to try a few different techniques before you find the one that works for you.
  - Stay active- people who stay active during treatment seem to manage the side effects and have an easier recovery period. The current guidelines recommend at least 30 minutes a day of physical activity. This can be anything activity that you enjoy, whether its walking the dog, going to the gym, or working in the garden.
  - Be kind to yourself- going through head and neck cancer treatment and the recovery can be a distressing time. Make sure you are kind to yourself, remember to do things that give you pleasure, such as walking along the waterfront, stop and appreciate the flowers, and remember if things are getting a little tough talk to a friend, the head and neck cancer support group or health professionals.

You don't have to do it alone.

Jodie Nixon, Clinical Team Leader, Occupational Therapy Team Cancer Care,  
Princess Alexandra Hospital, Brisbane

# Laryngectomy story

## Australia

### - Trev Jones

Hi, my name is Trev Jones from Brisbane in Queensland. I'm 71 and still able to work.

In 2012 I noticed my voice starting to go "hoarse" and thought, "she'll be right". Then I developed a really annoying persistent cough and still took no action (at no time was my throat really sore). In 2014, I started coughing up blood clots and eventually my throat started bleeding quite profusely and I lost 30 kilos. The point had come where I had to take positive action and was driven to Emergency at Caboolture. Here I was placed into an induced coma and transported to the Royal Brisbane and Women's Hospital (RBWH) and given emergency surgery by a doctor who later introduced himself as Marty. He informed me he had "hot knifed" the T4 tumour on my larynx as a stop-gap measure (my sincere thanks Marty).

Meetings were held with the Multidisciplinary Clinic at the RBWH and I was told that, owing to the limited lung capacity (I was a smoker of many many years), they doubted that I'd survive the surgery associated with the removal of my larynx. However, after discussions, I was informed they felt they could offer me a 60% survival for five years and the decision was made to go ahead with surgery.

My brilliant surgeons were Dr Maurice Stevens and Dr Elizabeth Hodge who performed a total voice box removal and a double neck dissection. The procedure took some six hours and I emphasise that there was never any pain or soreness from the operation. The medical team told me they were sure "they got it all", but to be on the safe side I was to have seven weeks of radio therapy at a later date. The next phase was to perform the "swallow test" successfully, which took place seven days after surgery (it's a test that defines if it's okay to return to a solid diet without food entering your lungs). I passed and over the next 48 hrs I was back on normal foods and was discharged. During the seven-day wait period the people from Speech Pathology visited and introduce me to the refinements of using an artificial larynx, thus enabling me to speak. In

2014 the Servox was the only device available, however, we are now able to have a choice from three devices. My personal choice is the True Tone Plus.

I commenced radiotherapy for five days a week over seven weeks. First they made a plastic face mask (holes for nose, eyes and mouth) so they can pinpoint the exact spot to aim the "beam". Then they partly insert you into the Linear Accelerator (sounds like Star Trek), while the treatment happens in two halves over 10 minutes. There is a docking station in the machine enabling you to place your phone in it and play your music (I found each session took three songs) and the staff can see you at all times. As we can't speak, if you're having a "worry", raise your hand and they will be there immediately. I stress at no time during the therapy did I experience any nauseous feelings. A few side effects will commence at week five, being burning and skin blistering. Yes, it is sore, but I managed to continue work (as a bus driver) whilst continuing the therapy. Around the time you start to burn, the ward will immediately apply a numbing gel and dressing to the affected area each day before you go home. When your therapy is finished totally, they will organise for a home care group to come to your house and do the dressings daily if you wish.

Total full recovery of your skin after therapy is surprisingly only about seven days. After surgery a "Larry tube" was fitted to my stoma, Post therapy, I experienced a few night sweats and feel very sleepy quite often. I was told on rare occasions that you can lose your sense of taste and smell. I didn't lose my sense of taste, but my sense of smell is still returning. I'm still "all clear" and have moved to three-monthly checks instead of two-monthly.

My eternal thanks to Maurice and Elizabeth and the great nurses in ward 8A North at the RBWH. Also, thanks to the wonderful Sarah and Belinda from speech pathology who asked me to participate in a few seminars and presentations.



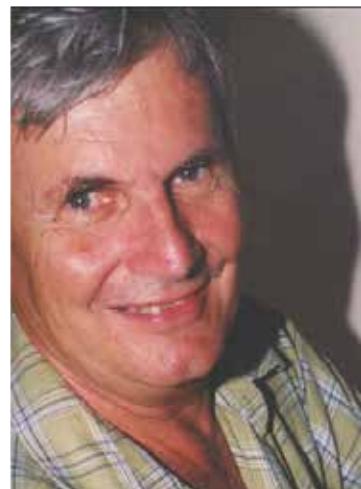
## Even on the Gold Coast - Neil Raward

At 73 years of age I believed that I was bullet proof, as I had never suffered any health problems, except for a knee replacement in 2011. In February 2016 I noticed a lump under my chin and immediately visited my GP. After various scans and a biopsy by a ENT specialist, I was diagnosed with Squamous Cell Carcinoma of the left tonsil caused by the Human Papilloma Virus. Now what did all this mean? I had no idea of my problem or the treatment that would follow.

I was referred to the Gold Coast University Hospital (GCUH) to undertake further tests as part of an ongoing Head and Neck Cancer program. During this initial program, I was subjected to further tests from the ENT team and there were talks provided by speech therapists and dieticians, after which I was referred to a Radiation Oncologist and a Medical Oncologist (35 sessions of radiotherapy and seven sessions of chemotherapy). I was still none the wiser of what lay ahead as there was no one available who could really tell me what all this meant and what changes my body would undergo.

I will not go into great detail of the following few months – the changes my mouth and throat were undergoing -- was it a dream or reality? Loss of saliva and taste, horrendous radiation burns, being fed liquid through a stomach tube for four months, the loss of 18kgs in weight, being a social recluse – what more can a human body take? Although, throughout the treatment and recovery period, I remained very positive of the outcome. My dreams were rewarded in August 2016 when I was given the all clear. Although I still have five years of follow-up tests to be declared that I am in remission.

I have always been a good communicator and decided from the beginning that I was going to keep my family and friends informed of the treatment, the changes to my body and my thoughts and feelings throughout the entire



ordeal. In the 12 months since I was first diagnosed with the cancer I have produced 18 bulletins entitled *My Journey* which to date total 12,000 words and many photographs. Without the support and care from my wife throughout the program I believe that my recovery would not have been as successful as it was.

The health professionals have used my bulletins for lectures to university students, students undertaking study for their Masters degrees have requested copies and a compilation of the bulletins into booklet form has been forwarded to many patients about to undergo treatment for throat cancer. I have recently completed a Head and Neck Cancer Peer Support Volunteer Program conducted by the GCUH which hopefully will allow me to be a support to those patients who are having difficulty in handling the treatment program.

Many people who battle cancer do not confide with friends regarding their treatment. Some have spoken with me saying they wish that they had handled things differently by being forthcoming with their ongoing progress during their treatment. This, they say, was to allow for not sympathy but encouragement during their treatment.

If any person would like a copy of *My Journey* please contact me at [neil.raward@bigpond.com](mailto:neil.raward@bigpond.com) The document is there for all to read and hopefully for those unfortunate enough to be diagnosed with throat cancer to have an awareness of what lays ahead.

# BRAVERY UNMASKED

## - Associate Professor Dion Forstner

Associate Professor Dion Forstner is a radiation oncologist at Liverpool and Campbelltown Hospitals in South Western Sydney and Dean of the Faculty of Radiation Oncology at the Royal Australian and New Zealand College of Radiologists (RANZCR)

### The Mask

Patients getting radiation therapy to the head and neck area or brain may need a radiation therapy treatment mask. During treatments for cancers of the head and neck and brain regions the head needs to be kept still to make sure the radiation therapy is delivered to exactly the area where the cancer is and to avoid, as much as possible, giving radiation to healthy areas that don't contain cancer. This treatment is given with millimetre accuracy. Each day during the treatment the radiation therapist gets the patient in the treatment position with the mask on and then will check that the patient is set up in exactly the same position as they were when the mask was first made and a treatment planning scan was performed. Each radiation therapy treatment session can last from 5 to 30 minutes depending on the treatment type, area and dose prescribed by the radiation oncology doctor (known as a radiation oncologist). The actual treatment is given by radiation therapists.

The mask feels very tight and so can be frightening for patients not well prepared for it. Patients who are known to be claustrophobic may need to see a psychologist before their mask is made to make the experience less difficult and some may need medication to relax them. Even patients who are not known to be claustrophobic can struggle with the mask and should always feel comfortable to talk to their doctor or nurse about their concerns – it is very normal to find the mask difficult to tolerate,



especially initially when it is all new and patients are scared about the treatment and whether it will work or not.

### Bravery Unmasked Exhibition

The Bravery Unmasked programme in South Western Sydney was inspired by another innovative program called Courage Unmasked from Tennessee in the USA ([www.courageunmaskedtn.org](http://www.courageunmaskedtn.org)). It involves decorating radiation therapy immobilisation masks. The idea to have this exhibition in Sydney came from a group of radiation therapists from Liverpool and Campbelltown Hospitals. The masks were decorated by the patients, their carers and some hospital patients with illnesses other than cancer who were participating in art therapy classes. These decorated masks were displayed at the Casula Powerhouse Arts Centre, in June 2016. Since then the mask exhibition has formed a travelling exhibition and has been displayed at Westmead, Blacktown and Orange Hospitals. The aim is to make staff more aware of the distress that can be associated with these masks, so that options for help can be offered prior to treatment, such as mild sedation and music to play during treatment.

Creative art therapy allows patients or their carers to express their feelings about a difficult experience, explore imagination and creativity, develop coping skills, identify and clarify concerns, improve self-esteem and confidence, identify blocks to emotional expression and personal growth, and sharing in a safe nurturing environment.

In 2017 The Bravery Unmasked exhibition will again be held at Casula Powerhouse Arts Centre in Liverpool, South Western Sydney and will run from August 24th to September 17th 2017.

# Hyperbaric Medicine Post Treatment

## Fran's Story

### - Fran Levy

In 2004, at the age of 47, I was diagnosed with a rare and aggressive cancer called Rhabdomyosarcoma. This is a children's cancer, which goes from nothing to life-threatening in 8-10 weeks. My tumour was in my soft palate, was very advanced and I was not expected to live. I was given very intense chemo for 10 months, with six weeks of radiation in the middle. It was a shock to all when my treatment stopped and we discovered that the cancer was gone! What a relief, as I had young children still at the time. The side effects from radiation began to show soon after, with the worst ones in my mouth and jaw, which had taken the full brunt of the radiation.

My major ongoing problem was, and still is, non-healing ulcers in my gums and osteoradionecrosis of my jawbone. The limited saliva that I have left has no healing properties, resulting in ulcers that become extremely painful, open wounds.

Soon after my first bout of these ulcers, someone I knew recommended the Wesley Hyperbaric Centre to me. I contacted them, was referred by their doctor, and commenced my first round of treatment, known as 'dives'. It was so successful that the ulcers closed and healed completely, and I have been back many times since with the same fantastic outcome. I also have pre and post dives when I need teeth removed, and my specialists are always amazed that the wounds heal so quickly and so well.

The chamber is comfortable, the staff are extremely helpful and understanding and the treatment clinic for wound dressing of non-healing Diabetic ulcers is outstanding. I

have seen several patients in my treatment times have limbs and/or digits saved from amputation by the hyperbaric treatment they have received. I tell everyone I know about this treatment, and cannot recommend it highly enough. It has meant that I have been able to successfully slow down the inevitable degeneration of my jaw and gums.



*"My specialists are always amazed that the wounds heal so quickly and so well"*



## Coping as a Carer - Melissa Gibson

In 2013, Melissa's partner of 22 years, Julie was diagnosed with Stage 4 cancer in the tonsils, tongue and throat. When Julie recovered, they got married in New York.

### **Lessons as a Carer**

I learnt many things supporting my wife in her cancer journey.

**You probably won't take in many of the details that are told to you by the team, particularly at the time of diagnosis and in the early days.** It was such a shock to hear your partner being told "You have stage four cancer, and there are only four stages" what was said afterwards was a bit of a blur for me.

**You may not remember what questions you wanted to ask at the next appointment.** I learnt early that the level of stress and anxiety meant that I needed to keep a notebook where I could record all my questions or concerns, so I was ready for the appointments.

**There are different options for treatment and it's important to discuss all of them.** I assumed surgery would be the obvious outcome of the diagnosis, and was really surprised that radiation and chemotherapy were the best options to treat my wife's cancer.

**The difficult side effects of treatment didn't occur immediately.** I took time off work straight after the diagnosis because I wanted to be with my wife as much as possible. Some of our closest times were early in the radiation and chemotherapy journey, before the physical pain and side-effects started happening three weeks into treatment.

**The roles in relationships can reverse for a time.** My wife had always been fiercely

independent, and moving into the 'patient' role, where she relied on me for so many things, wasn't easy for her. It was helpful for us to talk about this change of role, and remind her (and me!) that this was probably temporary.

**Swallowing really matters!** My wife was given great advice early on that it was important to continue eating by swallowing food for as long as possible. As the radiation treatment progressed, it became more and more painful for her to eat and it was very hard for me to witness this. Liquid food was a great help.

**Letting good friends help look after YOU is terribly important.** One of the most important things a carer can do is accept help from people they are comfortable with. Some of the kindest gestures came from friends who offered to help – washing the floors, walking our dogs, and sending group emails about my wife's progress so we didn't need to take or make millions of phone calls. Sharing my feelings freely (including the yukky ones!) with close friends I trusted and talking to others who had had the same experience as a carer were vital. I was a much better carer when I didn't neglect my own needs. It's also OK to say no to people who might offer to help that you don't feel comfortable with. Accept help from friends, and kindly reject offers from those where it doesn't feel right. Keeping yourself strong is your gift to your partner.

**Your kids are in this too.** Involve them, let them help, let them give as much as they want to or are able to. If we had tried to 'shield' the kids, we would have missed the gift the cancer journey gave us – a strongly bound family that counts all our days together as a blessing.

# Radiation Oncology: The Targeting Cancer Campaign

## - A/Prof Sandra Turner

Associate Professor Sandra Turner is Staff Specialist in Radiation Oncology at Westmead Hospital in Sydney and Clinical Lead of the Targeting Cancer Campaign

### Radiation Therapy

Radiation therapy is a central part of treatment for many patients with Head and Neck Cancers, either alone or in combination with chemotherapy, surgery or both. For head and neck cancers, having radiation therapy, as a non-invasive treatment, often enables people to keep their normal functions such as speech and swallowing. In addition, the highly-targeted nature of modern radiation therapy has meant that long term troublesome side effects are declining all the time.

In Australia and New Zealand, while half of patients diagnosed with cancers of all types could potentially benefit from radiation therapy, less than a third will actually receive this treatment. Thousands of cancer patients are missing out on radiation therapy that might help cure them or alleviate distressing symptoms, such as pain. This gap arises mostly because many people with cancer, their families, carers and even their doctors (including general practitioners), are not aware of the benefits of radiation therapy.



(RANZCR). Its objectives are to raise awareness of radiation therapy as an effective, safe and sophisticated treatment option and to provide information for patients, carers, health care practitioners and policy makers.

We are proud to have Julie McCrossin, a head and neck cancer survivor, as an Ambassador for the Campaign. Since its launch in 2013, the Radiation Oncology: Targeting Cancer Campaign has developed lots of resources for patients and their families, including a multi-award-winning website – [www.targetingcancer.com.au](http://www.targetingcancer.com.au) or [www.targetingcancer.co.nz](http://www.targetingcancer.co.nz) – a trusted source of information with content written by radiation oncology professionals. There is an interactive map to help patients to locate their nearest treatment centre and videos including many real patient stories. Julie's story of oropharyngeal cancer is featured in 6 videos on the website.

### GP Education

The other major focus for the campaign is around GP education to ensure that GPs are able to advocate for their patients and know when to refer them to radiation oncologists for more information about non-surgical treatment options and/or for control of symptoms.

For more information, please email [info@targetingcancer.com.au](mailto:info@targetingcancer.com.au).

#### News & Media

### Radiation Oncology: Targeting Cancer Campaign

The Radiation Oncology: Targeting Cancer Campaign is an initiative of the Faculty of Radiation Oncology within the Royal Australian and New Zealand College of Radiologists



# The Big 'C' Picked Me

## - Peter Rabe

Late in April 2015 I notice a lump on the side off my neck and I didn't think anything of it. I just thought it was the glands doing their work. A couple of days went by and the lump went away. Three weeks went by and I noticed it came back; I had a sore throat and by this time my wife, Michelle had noticed my neck was extremely swollen. The doctors were closed so I went to our local hospital. The doctor there was a bit concerned and rang her boss at the Redlands hospital. She came back with a letter for me and recommended that I go to the Redlands hospital early the next morning.

Two days were spent at Redlands hospital getting Blood Test, Ultrasounds, Chest x-rays, CT scans and Biopsies. A lot of waiting was done for the results, only to be sent to Logan Hospital for another two days of the same tests and scans. Again, waiting for the results. I was sent to the Princess Alexandra hospital early Tuesday morning to attend the Head and Neck clinic. After four long hours of examinations by doctors of all sorts, the doctors had their meeting to make plans for my treatment. With my wife by my side we sat in the room where we were told, "the big C picked me" (cancer of the tonsils) that just felt like the world came crushing down, as it was so unexpected. After a long discussion, good news was told; it could be treated and it is manageable.

From early May it was full on, visiting the dentist to get five teeth removed, a PET scan, CT scan, X Ray, mask fitting (which looks like something from Star Wars) and a chemo awareness meeting. After my PET scan, I met a guy called Mark who was there for the same reason. We had the same cancer. We are now good friends. He lives near Bundaberg and whenever he has an appointment he stays at our place.

On the 9th of June 2015 at 4pm I had my first of 36 radiation treatments over six weeks. Ten minutes later it was over. 'That was okay'; only 35 to go, no problem. As the days went by my



mind changed. I also ended up changing my mind about the chemo (Cetuximab) which were one session a week. After the first week, my skin started to peel and looked like I had acne. Three weeks later, my throat was getting very sore and the skin on my neck was blistering which looked like severe sunburn. In between all the treatments I had regular visits to oncology, dietitian appointments, speech therapists, progress evaluations and a weekly blood test. From here on in it was getting tougher physically, with the change of my body. Having my family, my wife Michelle, daughter Stephanie, son Joshua and friends by my side helped me through it. Seeing me be strong and positive impacted them and made the world of difference.

Thursday the 16th and Friday 17th of July 2015 were great days. It was the last chemo and radiation treatment, YAHOOOO! Still I had many visits to the hospital, Dr. Foote and the dietitians were impressed that I only lost 7kg and I was on no strong medication. On the 11th of December I was waiting anxiously to hear about the important PET scan results. At 2:15pm I heard "All Clear, you're Cancer Free". If you are going through this now just remember you will beat it.

Be Strong and Stay Positive.

*"if you are going through  
this now just remember you  
will beat it. Be Strong and  
Stay Positive"*

# Life with a feeding tube

## - Rob and Lynne Humphries

When I first had the tube and I left hospital, I was given a large amount of food, a box of big syringes that I had never seen before and the pump machine. I was sent home and told, "Give us a call if you have any trouble." After the shock of coming home with a box of food and all the attachments, you develop a routine that works for you. Especially the rate of feed and how much you have during the day.

I have a back pack for food. I have a pump. I like to be mobile, so I put my pump in a back pack. I have learnt I have to flush the tube out with water, or the formula will set like cement and I will have a trip to the hospital. I flush the tube with water slowly. If go too fast, it feels like I am filling up with water. I tend to have two thirds of a bottle of water every two hours. For somebody else, that might be too much water. It is important for professionals to realise that tube feeding is not just about equipment and formula and syringes. It is about people's everyday lives and it should not just revolve around how many kilojoules or how much protein we are getting. It needs to fit in with our lives and be individualised.

When I first came out of hospital it was like hitting a brick wall. Being involved with the Scouts has helped me. They were my support. I didn't know how I would react when people were sitting in front of me with a nice meal. I was looking at food but I couldn't have it. It was a nightmare. It took a long time to adjust to that. Even now I still have issues. I just feel like walking away and having a few tears. Sometimes I just walk away and suck it up and come back as if nothing has happened.

In the early days my surgeon gave me some good advice. He asked me to stop looking over my shoulder and asking, "Why did this happen to me?" He told me, "You have a wife, three sons and your future lies with them." That



was 16 years ago and in that time I have seen my sons grow up. I have seen my eldest son get married and have his first daughter. I've been overseas with Lynne.

Here are some comments from my wife, Lynne who is my great support: "We don't go out to dinner, like a restaurant, as much as we used to. We still see our friends. We'll go and have dinner at their place. They are aware of what has happened, so Rob just brings his own food. Rob is a Scout Leader. He shows the children his syringe. He has a good sense of humour. That has really helped him through. The person going through it needs support. And the carer is there to give the support. You work through it together. I'd say to anyone, do ask lots of questions if you are unsure. Rob is a great example of someone who has faced a lot of challenges. It hasn't really stopped us. We've just modified our lives. You've got to think, don't let it get you down, because there is always somebody out there that is worse off. You've got to keep going."

**See NSW Agency for Clinical Innovation for Rob's Story on video in several languages.**  
<https://www.aci.health.nsw.gov.au>

***"It hasn't really stopped us. We've just modified our lives."***

# Head and Neck Cancer Support Group Brisbane

## - Judy Lowry

My name is Judy and I am very proud to be part of a wonderful support group for those with Head and Neck Cancer (H&N), or as Gary calls us, "Neckies", in the Brisbane and surrounding areas. We meet at the Cancer Council Queensland headquarters at Bowen Hills on the second Tuesday of every month except for January and December and we are greatly supported by the Cancer Council for which we are truly grateful.

Marty and Gary are two of the founding members who work tirelessly, not only with the cancer patients and their carers, but they also liaise with the endless medical professions that are associated with H&N Cancer and other support groups all around the world. A date has been set for World Head and Neck Cancer Day which is 27 July. The aim is to raise more awareness of the disease, celebrate that we are here and learn to live each day as it comes.

We regularly have guest speakers such as Dental Practitioners, Speech Pathologists, Dieticians, Physiotherapists, Exercise Physiologists and Mindfulness sessions just to name a few. From them, we take away lots of valuable tips and information on how to manage or deal with the aftermath/fallout from our treatment. In return, some of these speakers use our experiences to help them with greater understanding of the disease from a patient's perspective. We are always more than happy to participate in the conversation.

New members that come along are very keen to speak with others in a quest to help them overcome the difficulties they are experiencing. We realise that we are all different in our journey and on offering advice. We make them aware that what has helped us



may not necessarily be ideal for them. One thing we constantly hear from newcomers that attend, even after one meeting, is that they walk away knowing they are not alone and can see that we are a very upbeat group that have learnt to live life, or should I say our new life, which we call 'the new norm', to the fullest. It's not to say that we don't experience pain and difficulties, but accept that we are very fortunate to live in a lucky country where support is available to us. Unfortunately, it is not quite as easy for our regional counterparts but it is wonderful to see them when they are in town, normally for treatment or check-ups.

There is one band of people in our group, namely the carers, with whom we take our hats off to, as without them, life going through treatment would be absolutely miserable instead of just being miserable.

After having radical surgery before the start of my treatment, my wonderful Ear Nose and Throat Specialist very calmly said to me that I would have days where I wouldn't be very pleasant to be around due to pain, anxiety etc and he was 100% correct. However, he asked me to be very mindful of my friends and loved ones as they would be hurting just as much, but in a very different way. That is one critical piece of advice that I do pass onto people as it will forever resonate in my mind.

Our group does not meet in December, because we celebrate another year by going out to dinner. We go to a restaurant call The King of Kings. Because we consider ourselves royalty and we deserve it. It is normally a small but very happy group as you can see by the photo enclosed.

# Psychosocial Aspects of Head and Neck Cancer

- Jane Turner

Head and neck cancer is an “equal opportunity cancer” – it doesn’t discriminate in terms of age, relationships, work or caring roles. Over the past 25 years I have been involved in the care of many people with head and neck cancer, and this story is about Jeff (not his real name), a 43-year old man who was working as an IT consultant before his diagnosis. Jeff coped with the diagnosis by going into overdrive about information. He got second opinions, increased his exercise, and kept a blog documenting his experience. When he was admitted to hospital because of pain and problems with his intake he glossed over the problems and discharged himself after a few days because he felt he was “on top of it”.

After discharge from hospital, things started to get really tough for Jeff. He found going to work exhausting, and he couldn’t concentrate the way he used to. He worried about his job and the impact on his family if he took time off. He tried to put on a brave face so that his wife Karen wouldn’t worry. She did worry. She tried to prepare meals he would enjoy, and felt frustrated when he didn’t want to eat. The harder she tried to help him, the more Jeff seemed to withdraw. During a routine follow-up appointment, his oncologist said that he thought Jeff looked stressed, and Karen burst into tears, saying “We need help”.

When I saw Jeff, I thought he was depressed. He thought he wasn’t trying hard enough. But depression is common for people treated for head and neck cancer. Depression is low mood and not being able to “snap out of it”, not being able to enjoy things, and having low energy and interest in things. A common part is withdrawing and feelings of being a burden on others. Depression happens when people



*Jane Turner,  
Professor,  
Discipline of  
Psychiatry  
Faculty of  
Medicine, The  
University of  
Queensland.*

have cancer because of a combination of factors – grief about the cancer, pain, weight loss, treatments, not being able to work (at least temporarily) and concerns about the future to name just a few!

Depression doesn’t mean that the person hasn’t tried hard enough.

In fact, trying hard was actually causing problems for Jeff. When he came to see me, he talked about his expectations of himself and always having to be in control. No wonder he felt dreadful after his admission – not in control, and having unrealistic expectations of how he should cope with really challenging treatment. Because he couldn’t live up to his ideals of how he should be coping he felt guilty. Jeff wanted to protect Karen from how awful he felt, so avoided talking with her to “protect” her.

No two people are affected in the same way by head and neck cancer. We all bring our unique strengths and frailties. Jeff had coped all his life by being independent and working hard, and it was great until he got cancer – but then he couldn’t control everything.

Over time Jeff came to see that sharing his feelings was not a sign of weakness – it meant that people who loved him could support him and share the experience. Jeff talked with other people treated for head and neck cancer and started to be kinder to himself. Jeff is no longer depressed. He is enjoying life, and feels closer to Karen.

Jeff’s advice, to talk about feelings, to admit to feeling down if that is an issue, and to get help if you need it.

# I'm still standing

## - Maureen Jansen

### New Zealand

After four cancer diagnoses for two different cancers, I'm surprised I'm still standing, but I am fit and well, in spite of one serious bout of ovarian cancer in 1996 and three occurrences of head and neck cancer.

The latter was building up for years. I had lichen planus, a pretty harmless white rash in my mouth that made it sting when I ate anything spicy. It eventually turned into an ulcerated lesion on the side of my tongue: erosive lichen planus. This went on for years with lots of medical visits. Eventually in 2007 it became cancerous and I had a couple of small surgeries to biopsy and remove the tumour. Unfortunately, the patches of precancerous tissue were close to the margins and it came back after two years near the scar on my tongue.

This time in 2009 I had the works in Auckland: neck dissection, partial glossectomy, radial forearm flap and three miserable weeks in hospital as everything healed.

But I bounced back, even returned to teaching, until four years later in 2014 another primary cropped up, this time in the inside of my cheek, the buccal mucosa. It was a nasty little tumour that necessitated splitting my chin open and sawing off a part of my lower jaw bone and covering the inside of the cheek and part of the gum with a flap from my other forearm. This wasn't quite so bad as the initial operation but it left me very scarred with a paralysed lower left lip, trismus and very few teeth left. They had to make me a temporary plate so I could go to my son's wedding!

Radiation followed. After the horrors of surgery I found it to be the easiest part of the process. I was told my treatment would be easier than for some because of location. My throat wasn't affected and I was able to keep the pain of



mucositis at bay with medication. However, I dreaded the moment when the mask came down on the tongue depressor. It stretched my tight jaw to breaking point. I had a little rhyme I had memorised to chant in my head and the six weeks went by quickly.

The first year after radiation was hard for various reasons but what saved my life and sanity was finding a support group. By 2014, I was living in Auckland and could attend the Head and Neck Cancer Support Group which was run by the hospital's ORL staff in the pleasant Cancer Society building over the road. Being with other scarred people, being able to use my skills to write minutes and eventually a newsletter gave me a sense of purpose.

In a quirk of luck, two other people joined in 2014 who wanted to turn the Support Group that had been run by the hospital for over 20 years into a head and neck cancer network. We wanted all New Zealanders to have access to the support and education we received at the Auckland group. Gradually we became incorporated as a society and fundraised for a website and stationery. We started a closed Facebook group and now have a presence on a number of social media platforms.

Head and neck cancer is a terrible thing but joining forces with other patients and carers in this mission has been a highlight of my life.

You can find us at [www.headandneck.org](http://www.headandneck.org)  
Facebook Group Head & Neck Cancer  
Support:<https://www.facebook.com/groups/1116515895074395/>

Maureen Jansen, 70. Auckland, NZ  
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# Things happen for a reason

- Yasmine Poole

I have had cancer twice, and at the end of 2014 received the news that I had it again, first thyroid, now tongue. It was beyond shocking to get the phone call and hear the words "we are sorry, it is cancer". Then the calls really started as I was told I had to be in hospital in 10 days for a very big operation.

One of the many calls came from Paula Macleod, who is the Head and Neck Cancer Nurse Co-coordinator at RNS. She told me that over the coming months she would be my best friend ... and she was. It was also very reassuring to have a consistent team – a surgeon, oncologist, speech therapist and the plastic surgery team.

As I underwent the tests getting ready for my operation, Paula was always at hand, explaining the process and what would happen next. It is a process and your mind is a blur so you need an advocate. You need someone with you, guiding you and making sure that you keep going. It is a tremendous fight, not just with your body, but with your mind as well, facing not only the prospect of your mortality but trying to keep it together for your family, particularly your children.

My operation was more than 10 hours; I had a partial glossectomy, radical neck dissection and forearm flap to rebuild my tongue. I woke in ICU with a tracheostomy, which is beyond confronting as you cannot speak. I felt defenseless. I knew it would take all my strength to get up and get on, and I broke down the process by working each day towards a small goal – standing up, walking and the countdown of tube by tube going, each was a milestone and a step closer to getting home to my family. I wondered if I would ever be able to speak again and be understood or even if I would eat again. I now do both a lot! Recently, I spoke to a young



woman who was still in hospital and had gone through what I had. I walked out hoping I had given her hope that things get better, and for myself I thought how lucky am I to be on the other side of this, strong and well.

They say things happen for a reason, and you should try and take some learning from hardships. I learnt that you know who the good people are in your life, the friends that step up, the acquaintance that drop food to your children, the family that has your back. Treasure those people.

You also learn that cancer is very frightening for some people who run in the other direction almost as if you are contagious. They don't know what to say, so say nothing. I have learnt to accept that when people ask me how I am, there is a tone implying are you going to make it? Yes I am!

One of the outcomes of me having had this journey was that it spurred many people I know into action of having their tests done. Hopefully this will ensure they too, if unfortunate enough to get cancer, will be a survivor. My outcome would have been very different if I had not had such a vigilant dentist who insisted I investigate the white spot under my tongue, something I never would have spotted. I felt something was not right so I was persistent, returning again and again to the surgeon telling him something was wrong. Listen to your body and never underestimate its messages.

# A Cancer Researcher's Journey

## - Cindy Macardle

Associate Professor Cindy Macardle PhD, FFSc. (RCPA) BSc (Hons)  
Flinders Medical Centre South Australia

My career in cancer research began in the early seventies and was driven by the discovery of monoclonal antibodies and their use in lab based cancer diagnostics.

Time passed and I found myself running a department responsible for the diagnosis of hematological malignancies using monoclonal antibodies in high throughput and exquisitely sensitive techniques. I had my own research grants and PhD students, including some, prophetically, from a new Fellowship Training Program for Ear Nose and Throat Surgeon-Scientists.

One reason for burying myself in science was to cope with my gender identity. I was assigned male at birth, yet I identified as female from when I was about five or six. However, it was a different era and my gender identity issues were suppressed but, as is so common for transgender people, never forgotten and always on my mind.

Eventually it became too much and Cindy emerged from her shell with surprisingly little fanfare and a general acceptance with the common comment of "Your eyes have lost that haunted look".

I was finally happy.

Then the cough that wouldn't go away, then the medical appointment: "I'm just here for a check-up." Then the conveyer belt of scans and biopsies until finally: "You have squamous cell carcinoma in the larynx it is advanced and aggressive, we recommend a laryngectomy" and my response, "That's not going to happen, what is plan B?"

I opted for chemoradiation and it was hard, it was my decision and taken without regret. I

had strength in being me and from my friends and partner. We faced it together.

As a cancer professional I knew everything and I knew nothing. All I really knew was the science and the medicine. I knew the map but I had no concept of the patient's journey.

The loneliness, anger and frustration were hard but my inner strength held and finally it was over and the fight to recover began. I've done it. I've beaten it!

But I hadn't, and slowly I could feel the cancer again. It hadn't gone, it had regressed and it started to grow.

Now I was down to two options, palliative care or a laryngectomy.

As a transgender woman hospitalization for surgery was my greatest fear rather than surgery itself. Would I be laughed at and humiliated? Would I be miss-gendered? Would my old male name be used? These are not uncommon occurrences for transgender patients and they are hard to deal with, particularly with the added burden of cancer and surgery.

The hospitalization, surgery and recovery went in a blur. I have vivid memories of holding the hands of my ENT support nurse as I went under and then waking up in ICU breathing through my neck and being surprised how natural it felt.

I recall my gradual recovery, my drifting in and out of consciousness and my fierce resolve: I've come this far I am not going to lose now. My fears were unfounded. The care I received from every staff member was wonderful, respectful and supportive.

Now I'm home and I realize that I'm happy and I understand that there is no reason not to be. I have a future and I have had a look at death. I accept both and I fear neither but for now life calls me and I shall embrace it.

My thanks to all of the staff at Flinders Medical Centre in Adelaide for their care and support. My special thanks to Tracey, Sheree and Jenny.

# **Swallowing and Speaking Problems**

## **- Pauline Dooley**

### **Swallowing Problems**

You may have trouble with eating and drinking during or after your cancer treatment. Difficulty with swallowing (dysphagia) will depend primarily on the location of your cancer and your treatment regime including surgery, radiation and chemotherapy. A rehabilitation team including speech pathologists, doctors, nurses, dieticians, and physiotherapists will help you throughout your treatment, aiming to create minimal changes to your daily routine and lifestyle.

At the time of your surgery a tracheostomy tube may be inserted in your neck to assist your breathing. In the main this is a temporary procedure but impacts on the normal swallowing pattern. The presence of a tracheostomy tube may irritate your throat and cause coughing and discomfort, so the aim is to have the tube removed as soon as you can manage.

To assist your mouth or throat to heal nutrition may be given via a NG (nasogastric) tube through the nose. Should you need alternative feeding the surgeon may discuss the option of having a PEG (gastrostomy) tube inserted in your stomach. These alternate methods of nutrition take the pressure from eating but do not mean you will be unable to eat and drink normally before going home or in the future. You may be able to drink fluids from day 1, others require several weeks for mouth and throat swelling to settle. Surgery can impact on the muscles of swallowing, create discomfort or dryness in the throat and be helped by medication or advice. Protection of your airway when eating and drinking is a priority. You may be given techniques to prevent any aspiration or need to modify the consistency of food, including vitamised (pureed) foods or thickened drinks.

Radiation treatment may lead to specific swallowing difficulties especially dry mouth, reduced chewing ability and food being caught in your throat when swallowing. The speech pathologist will work with the dietician to ensure you have a manageable consistency of foods with good nutrition during and after radiation. Moist, soft foods may be advised. Exercises for the muscles of the mouth, jaw and throat may be given to reduce the time taken to eat and drink, and to protect your lungs and avoid chest infections. Advice for oral care to keep your mouth clean will be given. It is essential to continue these when home. In general, difficulty with eating and drinking increases in the later stages of treatment.

A MBS (modified barium swallow) test may be advised to identify any swallowing problem. No anaesthetic or fasting is required. You will swallow food/drink containing a small amount of radio-active dye of barium. This locates any swallow difficulty arising from the mouth, throat or particularly any spillage into the larynx (aspiration) on or after swallowing. Modifying the consistency of food may be advised from the results.

### **Speech Difficulty**

Speech difficulties may result from surgery or radiotherapy to the muscles of the mouth (oropharynx) especially the tongue, and the voice box (larynx). Your speech pathologist will assist with methods of improving functional communication either by exercises to the muscles of speech or, in the case of surgery to remove vocal folds (a laryngectomy), trialling options of alternative communication.

### **Quality of life**

This is a priority in all cancer care and your speech pathologist is focused on maintaining your general well-being with advice and support of your speech and swallowing rehabilitation. Individualized care is a priority and no two patients face the same journey to recovery.

*Pauline Dooley, Speech Pathologist*

*St Vincent's Private Hospital and St Vincent's Clinic,  
Sydney*



## When is your Dentist, your best friend

- Walter Jennings

Thanks to my family dentist; who I only ever thought was there to look after my teeth, he saved my life.

He asked, "Walter did you know you have a lump on your left side," to which I replied "no". After all, I felt well and was unaware of the lump as there was no pain or discomfort.

Tests proved It was malignant and was a Squamous Cell Carcinoma located in my left tonsil.

Then it was off to the Radiation and Medical Oncologists.

Next it was a specialist Dentist who removed perfectly good teeth to ensure the radiation beam had a clear path to the tumour. The treatment plan consisted of 34 daily radiations and weekly chemo treatments.

A special mask had to be made for the radiation sessions covering my face and shoulders so I could not move on the table, avoiding collateral injury from the radiation.

**November 2013, first Radiation and Chemo.**  
My first radiation session, 33 more to go, I was led into a large room housing the machine and table, through a huge bank like vault door. I was strapped down with the mask pinning me to the table and then the people doing the set up left, I well remember the beeping as the door closed 34 times.

Truth is I never got used to it and was glad when number 34 was over.

I dealt with it with a mantra to myself. "Everything has an end and this is one day less". Then it was over. I could not believe it had been 34 times.

By the end of my chemo and radiation I was 16kg lighter, (my top weight pre treatment was 85kg, down to 69kg) had zero taste and had faced six weeks of a liquid-supplement-only diet. That was tough! Or you get a tube into your stomach. I was determined that was not going to happen to me.

It was three months before my taste returned and, three and a half years on, I am still cancer free, heading for the goal of five years. The side effects that remain for life are, as with many H&N cancer survivors,

- Dry Mouth
- Damaged blood supply to the Jaw
- Fatigue

I got critical advice along the way from the specialists in the health system (Doctors, Dieticians, Psychologists, Speech therapists, Physiotherapists, Dental Hygienists) on these and other areas to help me. It is imperative to your physical and mental health to follow their advice.... Listen and do as they say!

The dentist who removed my teeth said, "Right now your blood supply to your jaw is like an 8 lane highway post treatment it will be a bush track". I never forgot his words., and looked after my mouth with multiple daily cleansing using Bicarb soda. This I will continue for life.

My gratitude goes out to all those who treated me and saved my life, thank God for these dedicated people and for modern medicine that gets better and better every day.

Just 3 years back everyone came out of treatment with dry mouth, today with new, more accurate radiation it is less damaging and many are not having to suffer this life long problem .

This year, 2017, I have taken on the role of chairperson for The Gold Coast Queensland Australia. H&N support group. This is my small way of giving back.

My Beautiful Wife Michelle was with me every day and without her I may have thrown in the towel.

Be positive and believe.



## A New Zealand Story - Liz Gray

In 2015, I had a bit of a nagging cough, which is not unusual for me, but it just did not seem to go away, so I went to my doctor. Glands were a bit swollen and I was given two different inhalers to use. The cough improved and so did my sore throat, but for some reason things did not seem right. I put my fingers down my throat and found a lump on my tongue which I did not like the feel of, so back to the doctor. Three weeks later he referred me to an ENT specialist who took a biopsy. My life totally changed forever. I had cancer, something I never wanted to hear.

Following a CT Scan and a PET Scan, the doctor said, It had spread to my lymph glands in my neck and in my groin. I went to see another specialist who wanted me to have biopsies done of the glands in my neck and groin and the result of this was better than I expected. They had downgraded the cancer.

My treatment consisted of chemotherapy in the morning and radiation in the afternoon for the first week, second week off, third week the same as the first, then the fourth week off. The next three weeks was radiation in the morning and again in the afternoon. I had to wait for six hours before I had the second dose for the day.

On my first day of treatment I ended up in hospital with very high blood pressure.

At the end of week six of my treatment I hit a brick wall and went downhill very fast. I was given morphine to help me with the pain and I was put on a PEG feeding tube to help me with my food as there was no way I could eat. I also struggled with the pain in my mouth from



ulcers over the next few weeks as they were not healing. I got the feeding tube taken out after a month which made me feel so much better. Food was still a struggle though and I had no taste and no saliva glands.

During March 2016 my days were spent in bed sleeping, as I was on a fairly high dose of morphine and the pain from the ulcers. During April I finally got medication to help the healing process, plus I was put on anti-depressants as I had hit another brick wall.

As time went by my days seemed to be getting better. I lost 15kg in weight, but I was very lucky that I had the weight to lose.

It is now eight months since treatment finished, I am no longer taking any medication apart from multi vitamins and probiotic tablets. My eating is pretty good but I do struggle with taste. I have no saliva glands so I have my drink bottle with me all the time. I feel good. I feel I am getting more energy every day.

I have my support group that got me through, which consisted of my partner, my children, my grandchildren and my friends. I still go to the doctor monthly to get blood tests and have my blood pressure taken. I am down to three monthly visits with my oncologist, two monthly visits with my ENT specialist and three monthly visits with my dentist.

My goal next year is to travel to Canada, go on then do an Alaskan and a Caribbean cruise. I look at myself as a very lucky person and I treasure every day.

# HPV p16

## - Mark McLaughlin

My first hint of a problem came when I had a persistent sore throat and I noticed a little difficulty swallowing particularly drier foods like bread. I didn't think much of it to start with it could easily have just been some variety of a cold. However, I noticed over the next few days that it wasn't getting any better – in fact swallowing was more difficult if anything.

On my first visit to the GP we discussed family history. My grandfather had oesophageal cancer so it isn't really surprising that the oesophagus was the first suspect. My GP arranged for gastroscopy a few days later.

During the procedure, the gastroenterologist noticed a "soft mass" on the base of my tongue. Nothing else of major interest showed up further down the digestive system. He recommended that I get to an Ear Nose and Throat (ENT) specialist to check out the lump.

My GP managed to get me an appointment the next day with an ENT specialist. He used a nasal endoscope and showed me the results immediately afterwards - the lump he described as around the same diameter as a ten cent piece and several millimetres high. He sent me for a CAT scan nearby and told me to wait for the results and to return to his rooms.

The CAT scan revealed that the "mass" extended a little inside my tongue but did not show much happening with my lymph nodes (a good thing!) The ENT specialist did discuss cancer as a possibility with me. He scheduled me for a biopsy a few days later.

From discovering my first symptoms to scheduled biopsy was just over a month. A lesson here is to make sure if you do notice something unusual do discuss it with your GP. Even in the best scenario these things take time.

The biopsy was a week before Easter. A few days later I was finding it easier to eat as



during the biopsy they took off most of the lump. The Easter break meant I did not get the results until nearly two weeks later.

My wife came with me to the next few visits. It definitely helps to have someone there to support you when trying to process this sort of news.

The result of the biopsy was a tongue cancer caused by HPV p16. The specialist described having this particular variety as being the best possible bad news as it responds well to treatment.

He had already arranged for me to see a radiation oncologist that same afternoon. The oncologist suggested a PET scan to check exactly how large the cancer was as in some cases surgery is an option.

A phone call that afternoon from the oncologist confirmed that radiation and some chemo was going to be the best option. Two days later I was meeting with the radiation oncologist and chemotherapy oncologist to start the planning for my treatment.

One thing I've found hard is telling people about this. They usually ask the same three questions: how did you find out, what is the treatment, and what is the prognosis? People mean well but is quite draining having to tell the same story over and over again.

That's why I decided to set up "Mark's Tongue - in Aspic" on Facebook to record my story. People can go and look whenever without feeling like they are intruding.

# Hyperbaric Oxygen Therapy for Osteoradionecrosis

Radiotherapy can be a life saving treatment for head and neck cancer sufferers. Unfortunately there are side effects associated with radiotherapy such as scarring and a reduction of blood vessels and oxygen within the area irradiated. This decreased blood supply can sometimes result in the death or Necrosis of tissues in the area.

This complication involving skin, muscle or internal organs is known as Soft Tissue Radionecrosis, while death to the bone is termed Osteoradionecrosis. With a quoted incidence of 5 – 15%, Osteoradionecrosis (ORN) can be defined as exposed irradiated bone that fails to heal over a period of 3 months<sup>(1)</sup>. It may occur spontaneously or result from injury or incision to the affected area.



An example of ORN to the L lower jaw. This Radiograph shows severe osteoradionecrosis with a pathological (ie spontaneous, without precipitating trauma) fracture of the left side of the mandible.

Hyperbaric Oxygen Therapy (HBOT) is known to increase blood vessel growth in hypoxic (low in oxygen) tissue and support wound healing, stimulating collagen synthesis and fibroblast proliferation, as well as enhancing the effects of antibiotics. In the 1970s surgeons began to recognize the value of HBOT for the treatment and prevention of damage to the jaw bone following radiation therapy.

1980s saw the 'Marx Protocol' developed. Marx et al. randomised two groups of patients with previous radiation to the head and neck, requiring tooth extraction. Group 1 received Penicillin pre and post op. Group 2 received no antibiotic cover, but instead received the protocol of 20 pre-op and 10 post op HBOT sessions, each session involving administration of 100% Oxygen at a pressure of 2.4 ATA for 90 minutes.

The results to this preventative protocol are summarised in table 1.

Table 1. Tooth removals in bone-irradiated to dose 6,800 rads (68 cGy)<sup>(2)</sup>

	Patients	Teeth	Osteoradionecrotised sockets	Osteoradionecrotised patients
Penicillin Group	37	135	31 (22.9%)	11 (29.9%)
Hyperbaric Group	37	156	4 (2.6%)	2 (5.4%)

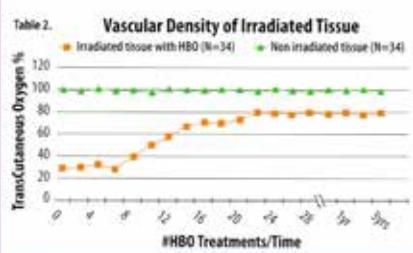
In this study, Osteoradionecrosis was defined as the presence of exposed bone in the study socket after 6 months. As you can see, significantly fewer patients developed ORN when receiving Hyperbaric Oxygen.

## For patients suffering established

Osteoradionecrosis, a protocol of 30 preoperative and 10 post-op Hyperbaric treatments is recommended.

Transcutaneous Oxygen measurements have demonstrated oxygen induced angiogenesis (blood vessel growth) becomes measurable after 8 HBO treatments and rapidly progresses to up to 85% of non irradiated vascularity by 20 sessions. Follow-up of these patients at 1, 2 and 3 years indicated there was no reduction in these improved levels.

Table 2 demonstrates the prolonged effect HBOT has on the vascular density of irradiated tissue<sup>(3)</sup>



## Costs Effectiveness

A Medical Services Advisory Committee (MSAC) report in 2000 reviewed the cost effectiveness of HBOT for treatment of ORN compared to penicillin. This reported an estimated incremental cost avoided per case of osteoradionecrosis of \$28,480.00.<sup>(3)</sup>

Treatment costs for ORN –(both preventative and established) at The Wesley Centre For Hyperbaric Medicine are fully covered by most Private Health Funds and fully funded for DVA Gold Card holders. Please contact our facility for confirmation of costs or funding details.

## Reference

- Shaha AR et al. Resection and immediate microvascular reconstruction in the management of osteoradionecrosis of the mandible. Head Neck 1997.
- Marx RE, Johnson RP, Kline SN. Prevention of osteoradionecrosis: A randomized prospective clinical trial of hyperbaric oxygen versus penicillin. J Am Dent Assoc 1985.
- Medicare Services Advisory Committee. Hyperbaric Oxygen Therapy. 2000 MSAC applications 1018-1020.

X-ray supplied with thanks to Dr C Acton & her patient.

# It's better to get help early - Garry Power

At the time of my diagnosis, I was working as a senior lawyer. One morning, I was on the phone to a client and looking out the window. I was running a hand over my chin when I felt the lump. I actually said to the client, "I've just felt this lump, so I'm going to see my GP. Goodbye." I had a needle biopsy the next day and the results were significant. It was squamous cell carcinoma and it was metastatic.

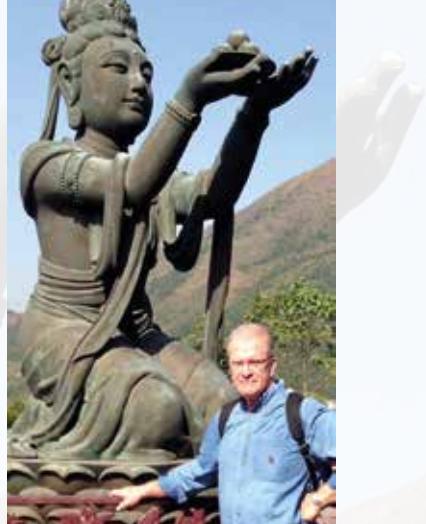
The cancer diagnosis knocked me for six. I went into a deep black hole. The fact that it was "unknown primary" didn't affect me at the time – I didn't grasp what metastatic meant.

Within a week or so, I'd had surgery to remove all the lymph nodes down one side of my neck and most of my molars. They did another couple of biopsies to look for the primary, but couldn't find it. The doctors guessed the cancer had started in my mouth, but I had a fair complexion and red hair, so it might also have started somewhere on my skin.

I talked about further treatment options with my doctors and we agreed to forge ahead regardless. I was 51 and fit, so we decided on a broad approach that combined strong chemotherapy and radiotherapy.

I got a great deal of help from the allied health professionals at the hospital. The dietitians helped me work out what I could eat. A speech pathologist helped me develop new chewing and swallowing techniques. A physiotherapist helped restore the range of movement in my neck and shoulder – the radiotherapy had cemented all the muscles. However, I didn't see a psychologist at that stage, and I think it would have been better if I had.

Once the acute phase of treatment was over, I went back to work. With hindsight, I can see it was too early. The chemo and radiotherapy had broken down my body's systems and I



ended up with chronic fatigue, a problem that I still have to manage. It led to a loss of productivity, and my employer didn't really grasp the issues. A lawyer's work is all about performance indicators and meeting budget, but no allowances were made. I never got back to normal at work and about six or seven years after treatment, I accepted redundancy. I'm now semi-retired and run my own consultancy – I find that working for myself allows me to manage the fatigue well.

If I had my time over, I probably would have asked more questions of the treatment team. They were magnificent – it was like they picked me up in their big warm hands and carried me through the initial stages. But in the blackness of the initial diagnosis, I wasn't going to ask many questions and I didn't press them for information. I felt that I wasn't really forewarned about the fatigue and the cognitive changes – the long-term impact. It meant I didn't think to raise the issues with my manager. The changes aren't just physical, they are also cognitive and psychological.

I probably come across as a fairly optimistic and together person, but after the treatment was over, I struggled with anxiety about the cancer recurring. The fact that the primary cancer wasn't found added to that anxiety – it was an extra element. It was recommended that I see a psychiatrist about a year or so after my treatment had finished, but it would have been better to get help earlier.

# My Story

## - Brad Walker

"Will I die?"

"Possibly" the Surgeon replied. "We won't know if its spread until we do some fairly invasive surgery."

I had mouth cancer.

I'm sitting opposite my surgeon, Jonathan Clark at the Chris O'Brien Lifehouse. He is explaining the invasive surgery I'm about to endure.

They will cut the golf ball size tumour from my mouth. That will need to be plugged with a golf ball size piece of flesh they will cut from my wrist. They will also need to connect that up with the blood supply system in my mouth, so by the way, we'll be cutting you up to your elbow to take the artery as well. Next we will need to see if the cancer has spread, so the next part of the operation will be to cut you from ear to ear while we remove 20 lymph nodes from each side of your neck. As we expect your tongue to swell, we will probably need to insert a Tracheostomy. And last but not least, is cover the hole in your wrist with some plastic surgery.

Wow, was all I could think. I'm in for one miserable time.

AND, I couldn't have been more wrong.

For me it was a walk in the park. Well, sort of. I'm not making light of my situation, but what I had envisaged in my minds-eye was so far from reality.

So what was my reality?

Did they cut it all out? – yes.

Were there any signs in my lymph nodes? – no.

Did I endure unimaginable pain? – no. My pain relief was only Panadol, I kid you not.

Were there any side effects? – yeah a few.

Were they serious? – No I don't think so.



What were they?

I had a fair amount of swelling in my neck which made sleeping in bed difficult (I'm a side sleeper), so for the next 8 weeks after release from Hospital I slept in a reclining chair. No great hardship. I still have a little Lymphedema, but Jonathon says it's not to be unexpected as they did cut me ear to ear and would have damaged channels the lymph nodes use to funnel fluid away. Again, no biggie. I need to massage the fluid that has built up in my neck up towards my ears where another set of lymph nodes moves the fluid on. A slow process, but it's getting there. I'm confident it will be gone in a few more months.

I have a bit of a speech impediment. This was of concern to me as I'm a trainer. 8 days after release from hospital I did my first training session. My customers had no problems understanding me although my speech was quite thick. To me it sounded like I was pretty drunk. As I write this now, 8 months after my operation, the only one aware of my speech impediment is me. So, no great hardship with that.

A catheter left me with what is known as a "lazy bladder". Of a night I needed to visit the bathroom every 20 minutes or so. That concerned me a little and I bought it up with Jonathon on my next visit. He assured me it would be a temporary problem, he was spot on and now I'm back to normal.

All in all, considering what has been done to my body, I've come thru this pretty well.

This has been my story.

My story could be your story – AND.....

I hope it is.

# HPV-Related Oropharyngeal Cancer - Assoc Prof Richard Gallagher

*Richard Gallagher is a Head and Neck Surgeon and Director of Cancer Services and the Head and Neck Service in the St Vincent's Health Network Sydney.*

## Changes in Head and Neck Cancer

Traditionally head and neck cancer has been related to smoking and drinking alcohol. Over the past 15 years a big change has occurred. Increasingly patients are developing oropharyngeal cancer (arising in the tonsils and back of the tongue) due to exposure to the Human Papilloma Virus (HPV). This is a family of viruses with over 100 recognised types. There is a lot we do not know about HPV. We do know that type 16 is the strain which causes oropharyngeal cancer.

In the 1980's the HPV virus was recognised as the cause of cervical cancer in women. It was also acknowledged that this was a sexually transmitted virus. Research in the 1990's led the development of the HPV vaccine which became available in 2006.

So why has a virus which causes cervical cancer suddenly started causing cancer in the throat? When we become sexually active we are all exposed to HPV. Since the late 1960's oral sex has become increasingly popular. Gradually it has replaced vaginal sex as the normal first sexual experience of teenagers and young adults. Consequently the rate of oral HPV infection has increased. Most people who develop an infection will be unaware and the infection is cleared by the immune system. Oral infection is more common in men who have oral sex with women and in women who have oral sex with women. It is known that as the number of sexual partners a person has increases the risk of developing an HPV related cancer also increases. This is because



the risk of recurrent infection increases and this seems to be linked to the development of oropharyngeal cancer.

What we really do not understand is why the virus causes cancerous/malignant change in one person and not another. It is also not clear why there is a delay of years before a cancer occurs. Someone can be in a monogamous relationship for an extended period between contracting an HPV infection and developing a cancer.

HPV related oropharyngeal cancer is more common in men. It typically occurs in a younger age group than traditional head and neck cancer. Most patients will be non or ex-smokers. Surprisingly most patients will have few symptoms and may present only with a neck lump (metastatic cancer). The typical symptoms of a sore throat, difficulty swallowing and earache are much less common.

The good news is that people who develop an HPV related oropharyngeal cancer tend to have a very good prognosis and should expect to be cured despite often being classified as Stage IV cancer. These cancers are very sensitive to treatment. The benefit is however negated if the patient is a smoker or continues to smoke.

Patients will usually be referred to an ENT/Otolaryngology-Head and Neck Surgeon who will question and examine the patient. Investigations will include a biopsy to prove the diagnosis, CT scan neck and chest, as well as a full body PET/CT scan. The patient's case will then be presented and discussed at a Multidisciplinary Team Meeting (MTD) which enables the surgeon, radiation oncologist and medical oncologist to meet together and make a recommendation about the best treatment

for each individuals' case. It is also important that the other members of the team are present and involved, for instance the cancer care coordinator, social worker dietitian and speech pathologist.

Treatment options include surgery, radiotherapy and if appropriate chemotherapy. Each treatment has their pros and cons. Chemotherapy is used in combination with radiotherapy in certain cases. Surgical advances mean that traditional open operations are increasingly being replaced by transoral approaches with reduced complications.

The HPV vaccine has been very successful in decreasing the incidence of cervical cancer in women. It is hoped that this will be replicated in oropharyngeal cancer. It is very important that boys are

also vaccinated as a preventative measure so as to increase "herd immunity". Vaccination is best performed before sexual activity starts, so in the early teens. It is still beneficial to be done into a persons' early twenties. Presently there is no recommendation to vaccinate older adults.

The majority of patients treated for HPV related oropharyngeal cancers will be cured. They usually look the same, speak the same and swallow the same as they did before.

**Head & Neck Cancer survivor, Julie McCrossin hosts a new series of podcasts The Thing About Cancer produced by Cancer Council New South Wales. The 10 episodes can be found at [www.cancercouncil.com.au/podcasts](http://www.cancercouncil.com.au/podcasts) or ring Cancer Council 13 11 20 for Information and Support.**



## Trust and Friendship - Paul Pascall

In March 2016, I went for a check-up with my GP as I was feeling very tired and run down. I had been working long hours for some time and thought that was the issue. I had full bloods done and all were OK. In May I had a 24/48 hour cold, three days later I noticed a painful lump on my neck. Back to the GP with a diagnosis that it's more than likely a secondary infection in my lymph glands from the cold and will go away in a day or so, which it did. In July I noticed some hard lumps where the original lump was. Back to the GP and it is now my story begins.

Immediate scans and biopsies revealed I had HPV Virus cancer at the base of the tongue with approximately nine tumours in the neck. The specialist said statistically this type of cancer affects fit, healthy males, predominantly in their 50's and early 60's. Ninety-six percent of males have the virus in their bodies from possibly a young age and 4% get cancer. Basically, in the words of my specialist, "It's just Bad Luck". Patients have been known to be in their 20s and it can affect females. The incidence of this cancer had quadrupled in the last 10 years.

The prognosis for this cancer is very good with particularly high survival rates and the treatment consists of radiation (the weapon) and chemotherapy (the kicker).

From the outset I had the most amazing confidence and trust in all the medical staff I came into contact with – the specialists, radiography staff, chemotherapy staff, nurses, nurse co-ordinator, administrators and the entire team at Royal North Shore Head and Neck Cancer Clinic. I was truly blessed with being in possibly the best medical unit on the



planet with the most capable, expert professionals.

Everybody's cancer journey is totally unique with no two being alike. Some similarities yes, but at the end of the day the journey is totally yours and your body and mind will react in its own unique way.

My mental headspace for getting well was to look at the treatment as having two pathways. 1 - The medical team(s) would kill the cancer and 2 - I will take care of handling the treatment and do everything possible to aim for the best survival and recovery. I asked lots of questions (no question is a stupid question), learned what I needed to do and did it. I became very focussed. The staff do this every day, so they know what it is all about. I had total trust in them all. I followed their advice on everything the best I could.

I would like to thank from the bottom of my heart, my partner (wife to be) Toni who was there every day during my treatment and beyond. Preparing food and doing her best to keep me comfortable. She is amazing and I love her dearly. To my parents who are always there for me and are totally wonderful humans who gave a me a strong body to fight and stay focused.

To the numerous friends and colleagues of whom many have had their own journey through cancer, be it direct or supportive, who gave enormous support and advice. One standout was to "be kind to yourself".

Everybody above contributed to the saving of my life. I am now six months out from treatment and the cancer is GONE.

I am so grateful and blessed to have such wonderful people be with me on my journey.

# Head and Neck Cancer Survivors Support Network - New Zealand

The Head and Neck Cancer Survivors Support Network Inc evolved from an Auckland Head and Neck Cancer Support group run by ORL, Auckland City Hospital. We untied the apron strings in 2016 and became an incorporated society representing head and neck cancer patients throughout New Zealand and beyond. Towards the end of 2016 we set up a closed Facebook group [https://www.facebook.com/groups/1116515895\\_074395/](https://www.facebook.com/groups/1116515895_074395/) and a website, [www.headandneck.network](http://www.headandneck.network).

Our stated aims are to connect head and neck cancer patients online, to provide peer support and finally to advocate to fill unmet needs. We are pleased with the progress so far with over 100 people connected to us via Facebook and over 60 on the website. Our advocacy role is proceeding well. We have been invited to

participate in reviews of services and we are pushing hard for better dental care.

This year we hope to adjust our name and logo to reflect our broad reach to all head and neck people who find us, whether they are newly diagnosed, long term survivors or in palliative care. We have adopted a New Zealand bird as our symbol, the tui, and will eventually incorporate it into our logo. We are New Zealand based but here for head and neck patients and carers from all over the world.

Diana Aylng and Maureen Jansen NZ



# What is a speech pathologist? - Bena Cartmill



## The journey

During your journey through diagnosis and treatment for head and neck cancer, you are likely to be referred to a speech pathologist. Speech pathologists are integral members of the team of health professionals who will support you along the way, in respect to looking after your mouth/throat, assisting with optimising your communication (either producing voice or speech) and ensuring you can eat, drink, swallow, and enjoy mealtimes as normally as possible before, during and after your treatment.

Speech pathologists often work closely with a dietitian, and in many centres in Australia you may see the speech pathologist and dietitian together. National and international guidelines recommend routine speech pathology involvement for patients with head and neck cancer – to prevent long-term difficulties with swallowing, eating, drinking, and communication.

The Cancer Council has recently published Optimal Care Pathways on a number of tumour streams. Find out what to expect, as well as care and support you can receive at the website below:

<http://www.cancerpathways.org.au/>

## Why a speech pathologist?

Some of the common side effects related to head and neck cancer and its treatment can affect your ability to eat, drink, swallow and communicate as you usually would. A speech pathologist is a health professional with expertise in optimising swallowing, eating and drinking, and communication, or preventing you developing long-term treatment-related changes.

## How a speech pathologist can help you?

Speech pathologists are experts in the functions of the mouth and throat, especially related to the swallowing, voice, and speech processes. If you have surgery as part of your treatment, a speech pathologist may give you exercises or strategies

to improve your eating/drinking/swallowing, or communication. If you receive radiotherapy as treatment, the speech pathologist will also discuss preventative ways to limit the impact of treatment on your swallowing mechanism, and to modify the way you eat/drink or communicate.

The speech pathologist may want to have a closer look at your swallowing, especially if you are experiencing food or drink going down the wrong way, or you develop a chest infection. A moving x-ray of your swallowing, called a videofluoroscopy, can show you and your speech pathologist where the swallowing mechanism is breaking down, and can assist you to make decisions about the kinds of food and drink safest for you, and the target areas for swallowing exercises or rehabilitation. Another swallowing test using a small camera inserted into the nose, called a fibreoptic endoscopic evaluation of swallowing, may also be helpful to look at the tissue inside your throat, and the way you swallow your saliva, food and drink.

The speech pathologist, together with the dietitian and nurses, may offer you advice about the best ways to look after your mouth and throat – including frequent mouth washes, humidification, safe voice use, and modifying your diet to avoid foods/drinks that cause discomfort.

## What about my family?

We also understand that your journey through treatment for head and neck cancer is a team approach – with you and your family the most important members of that team. The speech pathologist may also provide support to your family regarding your treatment, meal/food choices, cooking methods, and ways to maintain your family routines and interactions as much as possible.

If you are experiencing any difficulties related to swallowing, eating/drinking, or communicating, please discuss these concerns with your doctor for a referral to a speech pathologist.

*Bena Cartmill PhD*

*Advanced Speech Pathologist (Oncology) and Health Research Fellow*

*Radiation Oncology Department, Princess Alexandra Hospital and Centre for Functioning and Health Research (CFAHR)*

*Metro South Hospital and Health District, Queensland Health*

# **TRANS TASMAN RADIATION ONCOLOGY GROUP**

## **- TROG Cancer Research**

As a not-for profit organisation, TROG Cancer Research is an internationally recognised radiotherapy cancer group conducting world-class research involving radiotherapy to improve outcomes and quality of life for people affected by cancer. A group of like-minded Radiation Oncologists who saw the need for this area of oncology treatment to have a dedicated research group across Australia and New Zealand established the organisation in 1989.

The group originated with five members and today has a membership of over 1,400. The membership consists of radiation oncologists, other oncologists, physicists, radiation therapists, research nurses, trial coordinators and allied health professionals working in the cancer area. We have recruited over 14,000 patients to our clinical trials. Radiotherapy is used to treat most cancers so our research involves numerous tumour sites including head and neck, breast, lung, prostate, brain, bladder and skin cancer.

Through the dedication of our membership, we have been able to conduct and complete over 100 cancer clinical trials. Many of these trials have led to recommendations which have changed treatment practices, ultimately benefiting the patient, carers, family, community and the health team delivering treatments.

Some examples of improved treatments and outcomes of our research include:

TROG 07.03 RadioHum trial evaluated the impact of humidification on mucositis in patients treated for head and neck cancer. Although it did not demonstrate a significant difference



between the mucositis experienced by the two groups, the results show that humidification can play a role in reducing symptoms during radiotherapy for head and neck cancer. On average, patients who received humidification only spent 57% hospital days to manage side effects compared to patients who did not receive humidification. The return of eating patterns to close to normal was also significantly higher at three months after radiotherapy in the group using humidifiers. The secondary analyses of the trial are currently underway.

TROG 14.03 EAT: trial of a health behaviour change intervention provided by dietitians to improve nutrition in head and neck cancer patients undergoing radiotherapy. Patients who received the intervention experienced improved nutrition and quality of life with reduced treatment interruptions and depression.

We recognise the importance of the consumer and community and their involvement in our research. TROG has established a Consumer Advisory Panel (CAP) to assist and advise our investigators on the perspective of a patient or carer in the real world of a cancer diagnosis and the patient's own cancer journey. This panel consists of 8 – 10 members who have suffered cancer, with many participating in one of our clinical trials for their individual cancer treatment. An eLearning portal specific to radiotherapy is in development to allow access by consumers to understand radiotherapy research. Members of this important panel will assist us to develop all areas of the clinical trial from a patient perspective.

# DIET AND NUTRITION

## - Merran Findlay

Merran Findlay AdvAPD is the Executive Research Lead-Cancer Nutrition and Oncology Specialist Dietitian across the Royal Prince Alfred Hospital-Chris O'Brien Lifehouse partnership in NSW where she specialises in nutrition support of people with head and neck cancer. She is an Advanced Accredited Practising Dietitian. Merran led the development of internationally endorsed evidence-based guidelines for nutritional management of people with head and neck cancer. She was awarded an NH&MRC Translating-Research-Into-Practice Fellowship to implement an innovative model of nutrition care for patients with head and neck cancer.

### DIET AND NUTRITION

Maintaining good nutrition before, during and after cancer treatment is important to help maintain strength, reduce infection, avoid malnutrition and help your recovery. The location of the cancer and treatment side effects can make eating and drinking difficult. A dietitian is a university-qualified health professional with specialist training in medical nutrition therapy and is an essential part of the multidisciplinary team. Your dietitian is there to help you maintain good nutrition and stay well hydrated.

### Maintain Weight

- Rapid weight loss as a result of cancer or its treatment can lead to malnutrition, muscle loss and slow recovery. You will need more energy (calories) and protein than usual to avoid unplanned weight loss and malnutrition.
- Monitor your weight regularly and discuss any unplanned weight loss with your care team.



### Stay well-nourished

- Try small, frequent meals, especially if you are unable to eat your usual amount at meal times. Include foods that are high in protein and energy (calories) at each meal or snack. These include meat, poultry, fish, eggs, dairy or soy products, legumes and pulses.
- Add extra energy (calories) by cooking with oil, adding butter or margarine or adding cheese, cream or sour cream to meals.
- Drink fluids that are nourishing such as milk or soy milk, milkshakes, smoothies or juice. Your dietitian may recommend special supplement drinks that are high in protein and energy.

### Feeding Tubes

- For some people, a feeding tube may be necessary to help you maintain enough nutrition and hydration, as well as take medications. Feeding tubes are usually temporary, although, in some cases, it may be permanent. If a feeding tube is part of your care plan, your doctor, dietitian and nurse will talk to you about how to manage this and support you and your caregiver throughout your care.

### Symptom Management

- Common side effects that can reduce your ability to eat well are reduced appetite, difficulty swallowing, sore or dry mouth, pain, taste changes, nausea, vomiting, anxiety and change in bowel habits. Your dietitian will work closely with your care team to provide advice on how best to manage these.
- You may need to modify the texture of foods so they are soft and moist enough for you to



swallow easily. Choosing soft foods and adding gravy or sauces are simple ways to start. It may help to avoid any foods that irritate your mouth, such as citrus, spicy foods or hard/crunchy foods.

- Maintain regular mouth care during treatment.

### Vitamin & Mineral Supplements

• Evidence suggests there may be interaction between some over-the-counter vitamin and mineral supplements and cancer treatments. Check with your doctor and dietitian before taking any vitamin or mineral supplements.

### A Note for Caregivers

• Caregivers are a unique and important member of the care team. From preparing nourishing meals to assisting with tube feeding if

needed, it can be difficult to support a loved one during treatment and recovery. Take time out to nurture yourself and lean on others who are there to support you.

Find more information regarding diet and nutrition for people with head and neck cancer at:

- Beyond Five <https://www.beyondfive.org.au>

## My glass is always full - Hans Ede

In 2011 I was working in a high pressure job when one day I came down with a cold. Of course, like any other man I just kept working and taking Codral to be able to handle the work. When a big lump started to grow on my neck I sought help from my family GP who sent me to have a biopsy. The biopsy came back inconclusive, which meant that we still didn't know what the problem was. My GP now sent me to a Head and Neck surgeon. I was fortunate to see Professor Jonathan Clark who performed a neck dissection on my right side and the pathology result was positive. I had an SCC cancer but the primary source was not located, which means that the cancer had spread from an unknown location. This is called a CUP (Cancer of Unknown Primary). I was given a 50% chance of surviving that cancer another five years. I took it quite well as I have always believed that my glass is not half empty or half full, but in my mind always full. The timing was not too good as we were very busy at work, but I was advised that we needed to start Radiation in Campbelltown as soon as I recovered from the operation.

The treatment was not at first too bad but after 25 radiation sessions my body could take no more and I ended up in the ICU. It was decided to cease treatment early. I lost 25 Kg and had big problems swallowing and also keeping food down. My life-saving diet consisted of Weet-Bix with yoghurt and for a snack, I had my favourite drink which was a coffee frappe which is full of calories. Life was looking good again and I was grateful to be back at work and returning to a normal lifestyle.

Unfortunately, two years down the track, during the three-monthly check-up, Professor Clark found a lump on my left side and we needed



another biopsy. I still felt pretty resilient and thought everything would be just fine. The result came back positive. This time I didn't take it as well. It felt like the whole world fell apart. It took me a few days to get over the shock. I now needed a neck dissection on the left side and also a glossectomy using the Da Vinci robot to try to locate the primary source in the back of the tongue. The robot is not covered by Medicare or private health cover yet, but the operations were successful and the cancer removed, but they still couldn't locate the primary source.

We started another 30 sets of radiation but this time at Liverpool with a more sophisticated "TOMO radiation machine". The body handled it a bit better and I only lost 20Kg. I now had to retire as I developed Chronic Fatigue.

I'm the luckiest bloke on earth having been given an extra two leases of life. I have been able to walk one of my daughters down the aisle and have seen our first grandchild. Without the excellent service and care of the doctors and nurses at Liverpool and Campbelltown Hospitals that wouldn't have been possible. I am now trying to give something back to the community that's been so good to me by involving myself with the Head and Neck Cancer Support Group in Liverpool and also being part of the Cancer Consumer Advisory Committee.

My wife and I, along with our dachshund, Sizzle, are enjoying doing some travelling with our caravan and life is great!

# Beyond Five

## - The Face of Head & Neck Cancer

In 2014 a group of leading Head & Neck Cancer specialists around Australia came together to establish Beyond Five; a national not-for-profit organization, created to provide information and support for patients, caregivers, family and health professionals. Head & Neck Cancer is the 6th most common cancer in the world. There are an estimated 378,500 new cases diagnosed worldwide annually.

With 17,160 people living with Head & Neck Cancer in Australia, and nearly 5,000 people newly diagnosed each year, it became glaringly apparent that there was a need to provide a comprehensive resource that collectively offers reliable and easily accessible information and support to everyone, regardless of where they live.

Beyond Five is the first organisation of its kind in Australia to dedicate itself to the awareness, education and support of people affected by head and neck cancer. The website is a comprehensive, reliable and always available hub for education, information, comfort and shared experience. Easy to access. Easy to understand.

As health care professionals caring for people affected by head and neck cancer, we see daily the impact of this diverse group of cancers. Whether it is due to advanced skin cancer, thyroid cancer, mouth, throat or voice box cancer; the diagnosis, treatment and experience of living with cancers of the head and neck has an enormous impact on patients and their carers. Our aim is to provide trusted, reliable and accessible information and to facilitate discussion and education about head and neck cancer.

"Head and neck cancer is incredibly complex – it can affect a person's tongue, salivary glands, skin or voice box. When we initially tell someone about their diagnosis of cancer, the

only word they remember is cancer. In those early days, information is key..." Dr Bruce Ashford

The Beyond Five website and educational content was painstakingly developed over 24 months by our nation's leading experts in the field of head and neck cancer management, launching in October of 2016. Multi-institutional and multi-disciplinary by design, the contributor list exceeds 60 industry experts, which enables us to provide accurate information that is based on the best available evidence and clinical consensus.

"One feature of the site which we believe will be incredibly useful is the 3D animations for each type of head and neck cancer that guide people through the location of the cancer, how it affects a person and what treatment is available." Professor Jonathan Clark

The name Beyond Five refers to the long-term support that patients with different types of head and neck cancer often need.

Forever evolving, the initiative is a thriving collaboration of multi-disciplined & multi-institutional medical teams across Australia & New Zealand committed to raising awareness, providing education and utilising best practice and research in order to advance optimal treatment for Head & Neck Cancer. We are a resource for patients, care givers, family and health professionals. A portal for knowledge, empowerment and hope.

"It's not easy. But you can go through it, come out the other side and continue to live a great life..."

Find out more at: [www.beyondfive.org.au](http://www.beyondfive.org.au)

Follow us on Twitter | Instagram | Facebook | LinkedIn | Google+  
#headandneckcancer  
@beyondfiveorg

Beyond Five is all about a strong community. If you have any comments, thoughts, or wish to request more information, reach out to us at [contact@beyondfive.org.au](mailto:contact@beyondfive.org.au)



# Useful websites

The internet has many useful resources, although not all websites are reliable. The websites listed below are good sources of support and information

## Australian

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Cancer Council Australia	cancer.org.au
Cancer Australia	canceraustralia.gov.au
Carers Australia	carersaustralia.com.au
Department of Health	health.gov.au
healthdirect	healthdirect.gov.au
beyondblue	beyondblue.org.au
Look Good Feel Better	lgfb.org.au
Beyond Five	beyondfive.org.au
Australian and New Zealand	
Head & Neck Cancer Society	anzhncs.org
Targeting Cancer	targetingcancer.com.au
Australasian Lymphology Association	lymphoedema.org.au
Speech Pathology Australia	speechpathologyaustralia.org.au
Dietitians Association of Australia	daa.asn.au

## International

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The Swallows Head & Neck Cancer Support Charity	theswallows.org.uk
American Cancer Society	cancer.org
Cancer Research UK	cancerresearchuk.org
Macmillan Cancer Support (UK)	macmillan.org.uk
National Cancer Institute (US)	cancer.gov
Head and Neck Cancer Alliance	headandneck.org
Mouth Cancer Foundation (UK)	mouthcancerfoundation.org
The Oral Cancer Foundation	oralcancerfoundation.org
Web Whispers	webwhispers.org

# LINK HEALTHCARE ARE PROUD TO SUPPORT THE PUBLICATION OF THIS BOOKLET



For over 20 years, Link Healthcare have been working with healthcare professionals in Australia and New Zealand to provide the right medicine for the right patient at the right time.

Link Healthcare recently joined the rapidly growing Clinigen Group. Together we are dedicated to ensuring patients across the world with rare cancers are able to access the treatment and supportive care they need.

**LINK**  
—  
*Healthcare*

[www.clinigengroup.com](http://www.clinigengroup.com)

*Part of the Clinigen Group*

**Right Medicine, Right Patient, Right Time**

# The Swallows

**Head & Neck Cancer Support Group**  
Registered Charity Number : 1149794

Support for all affected by

## **HEAD & NECK CANCER**

Patients, Carers & Family Members

24/7 Support line:

**+44 7504 725 059**

[www.theswallows.org.uk](http://www.theswallows.org.uk)

 [www.facebook.com/theswallowsupport](https://www.facebook.com/theswallowsupport)

 [@swallowsgroup](https://twitter.com/swallowsgroup)



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