

Head and neck cancer experts created Beyond Five as a resource for medical professionals, as well as their patients and carers.

FOR A DISEASE that manifests itself in such a visible way, head and neck cancer has a low profile in the public consciousness compared to many other common cancers. As a group, it is one of the seven most common cancers affecting Australians. But because it includes more than 10 different types of cancer and these are quite separate, it is incredibly complex and diverse.

Head and neck cancers affect a person's mouth, tongue, salivary glands, skin or voice box. Smoking has long been the most common cause of cancers of the mouth, throat and voice box. However, cancers caused by the human papilloma virus are rapidly increasing in incidence. Thyroid cancer is one type of head and neck cancer that we don't know the cause of. Skin cancers also make up the group and may extend to the eyes, ears, nose and salivary glands. These cancers can affect all age groups.

In terms of pathology, many head and neck cancers manifest as squamous cell carcinoma (SCC). This is because most surfaces in the region are lined by mucosa and cells within the mucosa can grow abnormally and at uncontrolled rates, giving rise to SCC.

Because of this complexity, a diagnosis of head and neck cancer can be difficult for patients and their families, as well as for the healthcare professionals that treat them.

In 2014, a team of passionate people working in the field of head and neck cancer care identified a lack of information and resources for patients and professionals. There was no organisation in Australia offering support to patients and their families along the road from diagnosis to treatment and life

And so, the idea for Beyond Five was born.

Beyond Five was set up in December 2014 and is a national not-for-profit organisation that provides access to comprehensive and easy to understand information about head and neck cancer. The name refers to the long-term support that patients with head and neck cancer

often need, due to head and neck cancer treatment. These can include disfigurement and difficulties with speech, eating, swallowing and talking. Patients often need support beyond the typical five years after diagnosis.

The information and resources on the Beyond Five website were developed and reviewed by head and neck cancer experts from Australia and New Zealand and are based on the best available evidence and clinical consensus. Beyond Five is a collaboration across multiple specialties and was founded by a diverse group made up of head and neck and ENT surgeons, radiation oncologists, medical oncologists, specialist nurses, speech pathologists, dietitians, dentists, plastic surgeons, psychologists, health literacy experts and consumer representatives.

Healthcare professionals will find a wealth of resources to help them treat and support their patients. These include optimal cancer care pathways, 3D animations that guide people through the anatomy of the head and neck, information sheets on surgical procedures and information on research, clinical trials and funding opportunities.

Practical information for patients includes explanations of the different types of head and neck cancer in terms that are simple and easy to understand, treatment options and where to get support for the emotional, social and mental effects of the illness. There is a section on health and wellbeing covering topics like nutrition, exercise, skin care and mouth care. There is also a database of support groups across Australia for patients with head and neck cancer and a selection of patient stories.

For those looking after someone with cancer, there is advice on how to support that person. And for those who need it, there is advice on coping with grief and loss.

For more information visit

www.beyondfive.org.au and to order
your free Beyond Five patient cards
or A3 poster for your clinic email
contact@beyondfive.org.au

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## BEYOND FIVE AMBASSADOR: JULIE MCCROSSIN

Beyond Five welcomed its first ambassador, broadcaster and journalist Julie McCrossin in October 2016. Julie was diagnosed with stage 4 oropharyngeal cancer in mid-2013.

"Prior to diagnosis I had repeatedly seen my GP complaining of an ear ache, a sore throat and two lumps on my neck. I was taking soluble pain relief twice a day, but I wasn't sick. I was never referred by my GP for any tests or assessment by a specialist.

"Finally, I saw an ear, nose and throat surgeon and he immediately diagnosed my cancer and confirmed the diagnosis with a biopsy the next day.

"I had cancer in my tonsils, the back of my tongue and the side of my throat. I was successfully treated with 30 sessions of radiation and four sessions of chemotherapy," says Julie.

Since her diagnosis, Julie has been committed to getting evidence-based information and sources of support to all that are touched by head and neck cancer, whether that is patients and their families and carers, or the healthcare professionals that care for them. She also co-edited the Head and Neck Cancer Patient Book earlier in 2017 with two patient groups: The UK Swallows Group and Head and Neck Cancer Support Australia.

"I believe that it is very important to work with all the professional organisations for general practitioners, including Primary Health Networks, to provide the latest information about the diagnosis, treatment and recovery of head and cancer patients. Primary care teams have a vital role to play throughout a head and neck cancer patient's journey," says Julie.

To read more about Julie visit www.beyondfive.org.au.

