



31 August 2023

Dear Committee Members

Thank you for the opportunity to make a submission to the Senate Standing Committee on Community Affairs on behalf of the Head and Neck Cancer community in Australia.

Head and Neck Cancer Australia is the only national charity in Australia dedicated to providing evidence-based information, education, support and advocacy for people affected by Head and Neck Cancer (HNC).

Over the past 18 months we have been grateful to the Australian Government for listening to the HNC community and supporting the delivery of [two new resources](#) giving people a better chance of early detection and supporting those who are newly diagnosed with our inaugural grant received in April 2022. While these resources are welcome there remains significant unmet needs for people living with HNC and a decision on our latest submission presented to the Department of Health and Aged Care in December 2022 is still pending.

### **About Head and Neck Cancer**

HNC is not one type of cancer. It is a complex and diverse group of cancers that can affect a person's mouth, tongue, throat, salivary glands, skin or voice box.

In 2022 over 5,100 people were diagnosed with a type of HNC and approximately 17,000 people diagnosed in the last five years are living with the side effects of treatment. With an ageing population and advances in diagnosis and treatment, the number of people living with HNC continues to rise.<sup>1,2</sup>

HNC is brutal. Treatment can leave a person unable to smile or laugh and take away basic abilities that we all take for granted like speaking, eating, breathing, and swallowing. For some it can result in devastating facial disfigurements that cannot be hidden by clothing, displayed for all the world to see.

Most people in Australia know very little about HNC. The majority of those who have heard about it are under the false impression that the main contributing lifestyle factor is smoking or alcohol. While in the past this was true, what many people don't know is that today in Australia the face of HNC has changed.

Seventy per cent of tonsil and base of tongue cancers are caused by the human papilloma virus – the same virus that causes cervical cancer. These cancers are increasingly seen in people aged in their 40s to 50s who are otherwise healthy.<sup>3</sup> There has also been an alarming 385% increase in tongue cancers in otherwise healthy, young women.<sup>4</sup> The cause is unknown.

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## **Barriers to screening, diagnosis and appropriate treatment**

There is no screening for Head and Neck Cancer: early detection is key.

HNC are a sinister disease – they produce signs and symptoms which mimic many benign diseases – a sore throat, mild earache, tongue ulcer or neck lump. Patients and HNC clinicians rely heavily on GPs and Dentists to catch these cancers early.

There is, however, a lack of awareness about the ‘changing face’ of HNC in the general public, dentists and GPs.

HNC are largely curable if detected early but they are typically highly aggressive and a delay in diagnosis can have an enormous impact on what treatment a patient is offered and their subsequent quality of life. It can also increase a person’s chances of developing recurrent or metastatic disease.

To give people the best chance of cure and encourage prevention, the Australian community and GPs and Dentists need to be educated about the early signs, symptoms and risk factors of HNC.

GPs and Dentists also need to be educated about the importance of early diagnosis and referral to a HNC specialist who is an active member of a Head and Neck Cancer Multidisciplinary Team (HNC MDT).

### ***Patient quote:***

*I was 44 years old when I was diagnosed with tongue cancer after repeated visits to my Dentist, GP and an orthodontist. During a follow up appointment, I was told by my HNC specialist that my story was not unusual – most people with HNC have seen at least four people in the medical profession before finally being referred to a HNC specialist. Patient NSW*

## **Adequacy of support services after diagnosis**

The treatments for HNC are widely acknowledged in the cancer community to be among the toughest on patients. While 71%<sup>5</sup> of people will survive HNC their short- and long-term needs are complex and their ongoing quality of life is often distressingly poor.

There is, however, currently no Federal Government funding for HNC patient navigation, education or for supporting access to supportive care for people who are newly diagnosed, recovering from acute treatment or cured of HNC but living with the long term or late onset side effects of treatment, unlike more common cancers.

Treatments for HNC, especially radiation therapy, can have a significant effect on oral and dental health resulting in a detrimental effect on quality of life and psychological wellbeing. These issues may arise early during treatment, or be experienced later and persist for the remainder of a person’s life.

The unique side effects and complications of HNC treatment can include:

- **Oral health complications**
  - **Surgery to the mouth or jaw involving loss of teeth**
  - *Radiation therapy specific*

- **Inflammation in the mouth or throat (mucositis): including sores that can result in discomfort and** debilitating pain, increased mucus or thick saliva impacting the ability to eat and drink and a person's quality of life.
- **Difficulty or pain swallowing (dysphagia)** which can lead to aspiration and poor nutrition.
- **Dry mouth (xerostomia).** Radiation therapy can affect the salivary glands and change the quality and quantity of saliva produced. Saliva is the body's natural defence against tooth decay. Without adequate saliva to wet the mouth, wash away food and neutralise the acids produced by plaque, the teeth are at a greater risk of rapid and aggressive tooth decay.
- **Difficulty opening your mouth fully (trismus):**  
This may be permanent or temporary and can limit a person's ability to eat normal food leading to poor nutrition. Trismus can also affect a person's ability to speak and clean their teeth.
- **Bone death (Osteoradionecrosis):**  
The death of some of the jawbone after radiation therapy significantly impacting a person's health-related quality of life.
- **Deterioration in speech and voice quality (dysarthria)** which can leave people feeling frustrated, isolated or upset due to difficulties being understood or impact a person's ability to return to work.
- **Removal of voice box (laryngectomy)** which permanently changes the way a person talks, breathes, eats and looks and often results in significant psychological impacts.
- **Lymphoedema** – swelling in the head and neck that can impact swallowing, speaking or breathing and a person's appearance.
- **Long term or delayed onset psychological distress** e.g., due to facial disfigurement (removal of a nose, eye, ear as a result of the cancer, low self-esteem, stigma associated with HPV diagnosis, changes to intimacy and sexual health impacting mental health and wellbeing.

An Australian study by Joe Jabbour et al published in 2017 found that patients with HNC want “information regarding the entire patient journey, including illness, treatment, side effects, physical fitness, impact on functioning, duration of recovery time and impact on quality of life”. The study found it was areas such as “psychosexual health, support groups, coping with stress and anxiety, work after treatment, and coping with cosmesis after treatment that patients reported as being poorly covered with health professionals unable to provide adequate emotional support.”<sup>6</sup>

International research also shows that GPs find it hard to engage in this type of ongoing care for people living with HNC. An American study of primary care physicians published in 2018 found that the majority of physicians are “uncomfortable managing late/long term side effects of HNC.”<sup>7</sup>

**Patient quote:**

*I was diagnosed with tongue cancer in 2020. I had part of my tongue and lower jaw removed and after that radiation. I am not sure what to do next. Appearance has been a major issue; I get depressed and upset. I feel like I am lost in the system. I have been told all my top teeth have to be removed because they are decayed. I still have a feeding tube so I am very dependent on my top teeth. All I can think about is how I'm going to look and how hard it will be for people to understand me with no teeth, no tongue and constant dribbling. I just don't know what to do. Patient, Victoria*

### Any other related matters

The economic cost of HNC per person is twice that of breast cancer yet there is currently no Federal Government funding for awareness or patient support, unlike more common cancers.<sup>8</sup>

HNC is three times more common in men, 58% higher in lower socio-economic areas and Aboriginal and/or Torres Strait Islander peoples are disproportionately impacted with a 30% gap in survival rates compared with non-Indigenous Australians.<sup>9,10</sup>

In Australia people are offered the most complex and involved surgery covered by Medicare, yet there is currently no reliable or affordable route for oral rehabilitation including dental and maxillofacial prosthetic services after treatment. This includes for dental implants and facial prosthetics to replace anatomy inside the mouth (intra-oral) or a part of the face such as the eye, ear, nose, or cheek (known as extra-oral prostheses).

#### **Patient quote**

*I will require a section of my jaw to be removed and most of my bottom teeth and gums with a bone graft from my leg to reconstruct the jaw. I have been in contact with someone who had the same surgery. She said that I should be expecting a cost of about \$5000 per tooth to get implants and my gum rebuilt after surgery and said that this is not covered by either Medicare or private health as it is considered cosmetic even though we require teeth to eat! Patient, QLD*

#### **What are the solutions?**

- 1) **Head and Neck Cancer Awareness Campaign:** targeted education campaign to improve awareness and understanding of HNC among the general public, GPs and dentists about the different types of HNC and the importance of prevention, early detection, prompt diagnosis and treatment by a HNC MDT.
- 2) **Head and Neck Cancer Helpline:** delivered by a specialist HNC team including nurse, counselling and allied health professionals with expertise in supporting the unique needs of people living with HNC to help improve patient navigation, education and access to supportive care in particular once the acute phase of treatment is over and people are managing the complex impacts of treatment which include long term or late onset side effects.
- 3) **National Dental & Maxillofacial Financial Support** – to guarantee all people living with HNC a reliable and affordable route for oral and maxillofacial rehabilitation.

#### **About Head and Neck Cancer Australia**

Head and Neck Cancer Australia is the only national charity in Australia dedicated to providing evidence-based information, education, support and advocacy for people affected by HNC.

Since 2014 we have worked with over 80 expert HNC clinicians and patients and carers across Australia and invested over \$1,000,000 to develop the world's most comprehensive library of HNC resources including fact sheets, videos, 3D animations, podcasts and webinars. We also host the only database of HNC patient and carer support groups and HNC services in Australia.

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Our free resources are used by HNC multidisciplinary teams in public and private hospitals across Australia to support people diagnosed with HNC. The HANCA website has reached **237,000 new users** across Australia since 2016, with an average of **1,200 new users** every week in the last 12 months.

HANCA has received over **320 phone calls and email requests** for support from patients, carers and healthcare professionals in the last 18 months. Over **600 people** registered for our free education webinars in the last 12 months, including healthcare professionals across the HNC MDT, and the webinar recordings have been viewed over 3,000 times.

Our close engagement and collaboration with people who have a lived experience of HNC and leading HNC healthcare professionals who dedicate their days to caring for people diagnosed with HNC and peak health bodies, demonstrates that we are well placed to provide input on policy matters, identify service gaps and draw on our extensive collaborations with a wide range of stakeholders to address these gaps to improve outcomes for people affected by HNC.

We would welcome the opportunity for members of our community including patient, carer and clinical representatives to provide further information and answer any questions at the Public Hearings of the Senate Standing Committee on Community Affairs.

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## Sources

- 1, 2 Head and Neck Cancer: [Cancer Australia](#)
- 3 Head and Neck Cancers: [Cancer Council Australia](#)
- 4 The incidence of squamous cell carcinoma of the oral tongue is rising in young non-smoking women: [Oral Oncology](#)
- 5 Head and Neck Cancer: [Cancer Australia](#)
- 6 [A web-based comprehensive head and neck cancer patient education and support needs program](#)
- 7 [Knowledge and Preferences of Primary Care Providers in Delivering Head and Neck Cancer Survivorship Care](#)
- 8 Cost of Cancer in NSW, Access Economics/Cancer Council NSW 2007
- 9 [Cancer Australia's National Cancer Control Indicators August 2018](#)
- 10 [AIHW Cancer in Aboriginal & Torres Strait Islander Peoples of Australia](#)

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