



HEAD & NECK CANCER
AUSTRALIA
ENGAGE · EDUCATE · EMPOWER



THE MISSING PIECE OF THE PUZZLE

HEAD AND NECK CANCER
2025 PRE-ELECTION SUBMISSION
Addressing the unmet survivorship needs
of Head and Neck Cancer patients

Why are Head and Neck Cancer patients unique?

- Head and Neck Cancer is brutal. While 71% of people will survive Head and Neck Cancer, their short and long-term needs are complex, and their ongoing quality of life is often distressingly poor.
- The treatments for Head and Neck Cancer are widely acknowledged in the cancer community to be among the toughest on patients. These treatments can take away basic abilities that we all take for granted like speaking, eating and drinking, breathing, swallowing, hearing and seeing.



- Surgical treatment can result in devastating facial disfigurements with the removal of part of a person's face, for example a nose, eye, ear - that cannot be reconstructed or repaired surgically. Many patients cannot afford the facial prosthetics that are essential to look normal, restore social confidence and assist with the ability to return to work and contribute to society.
- Treatment may include removing all or part of a person's teeth or jaws. Oral rehabilitation including prostheses e.g. dentures, bridges, obturators (to prevent regurgitation of food and drink into the nose) and implants can restore critical functions such as chewing, eating, speaking and swallowing as well as a person's ability to smile.
- Radiation therapy can have a significant effect on a person's oral and dental health. Good oral and dental care before, during and after treatment is essential to minimise the risk of long-term consequences which may otherwise persist for the remainder of a person's life and affect their quality of life.

Key funding recommendation

Ahead of the 2025 Federal election, we are calling for a pre-election commitment from the Australian Government to support people with Head and Neck Cancer across Australia struggling with the profound and disfiguring side effects of treatment which impact their quality of life and ability to function as a normal part of society.

- Invest \$13 million per annum to establish a **Head and Neck Cancer External Facial Prosthetic Reimbursement Program** to provide priority groups living with Head and Neck Cancer assistance to meet facial prosthetic costs.
- Invest \$2.5 million to:
 - develop and implement consensus guidelines for health professionals on optimal oral prehabilitation and rehabilitation care of Head and Neck Cancer survivors. This would include developing and evaluating an oral rehabilitation plan for survivors, co-designed with patients and carers.
 - quantify the scale, nature and impact of the unmet oral prehabilitation and rehabilitation needs of Head and Neck Cancer survivors and develop sustainable options to address the financial barriers for this group.



I make spare parts for people – a nose, ear or eye.

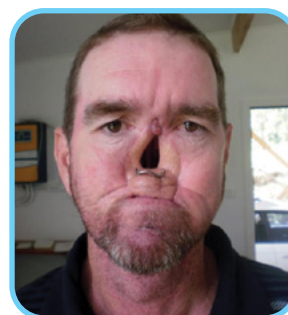
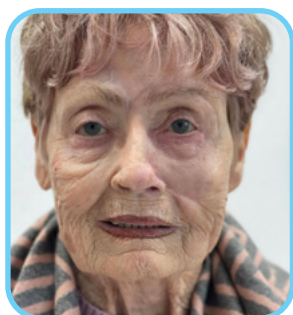
My life's mission is to help my patients get access and funding for facial prosthetics. They literally change lives. Facial prosthetics empower people to take control of their own lives.



Sophie Fleming

Clinical Anaplastologist

Maxillofacial Prosthetic Rehabilitation



Images supplied by Prosthetic Art Technology.

What is the problem?

People living with Head and Neck Cancer have unique and complex needs.

1. While the medical costs of treatment for Head and Neck Cancer are covered by Medicare, there are no funding schemes in Australia at a State/Territory or Australian Government level to cover the costs of facial prosthetics such as a prosthetic nose, ear or eye.
2. Many barriers exist at both the health professional and patient-level which prevent optimal oral prehabilitation or rehabilitation.

There are currently no guidelines to inform optimal oral prehabilitation or rehabilitation care in Head and Neck Cancer survivors in Australia.

Meanwhile current approaches to managing care in this population are highly variable depending on the availability, accessibility and expertise of local health professionals and due to the lack of accessible patient education resources.

3. There is no Medicare funding for the oral prehabilitation or rehabilitation for Head and Neck cancer patients who have had teeth or parts of their jaws removed as part of their cancer treatment. For those Head and Neck cancer patients living with poor oral and dental health because of radiation therapy treatment, there is limited access to government funded dental services which are not covered by Medicare for adults. State and Territory public dental schemes only cover pensioners and concession card holders. Even for those who have private health insurance, there are significant out of pocket costs.

58% of people living with Head and Neck Cancer are from low socio-economic areas, and from priority groups identified in the Australian Cancer Plan. They are faced with significant financial barriers to get access to the specialist services they need. Most patients who undergo major Head and Neck treatment never access the survivorship care they need. This results in a very poor quality of life for people who have been treated and cured of their cancer but are living with the lifelong side effects of treatment.



We offer the most complex and involved treatments for Head and Neck Cancer patients covered by Medicare, yet we have no reliable or affordable route for facial prosthetics or oral and dental care.

We have a duty of care for our patients to find a solution to give them quality of life.

A/Prof Bruce Ashford

Head and Neck Surgeon

Founding Director, Head and Neck Cancer Australia



Who needs support?



1.

Head and Neck Cancer patients needing a facial prosthetic e.g. nose, eye, ear

Prostheses are artificial appliances designed to restore a missing part of the body that cannot be reconstructed or repaired surgically.

External facial prostheses are required to simulate important facial features such as the nose, ear, or eye and lids, often in combination with major reconstructive surgery.

In addition to function, these types of prostheses are critical for restoring a normal appearance, social confidence and/or a person's ability to return to work after surgery for Head and Neck Cancer that results in a major facial difference.

2.

Head and Neck Cancer patients needing oral prehabilitation and rehabilitation care

Head and Neck Cancer includes oral cancers that can affect the teeth and jaws. Surgery is often recommended to remove the parts of the mouth affected by cancer. This may include removing part or all the lower jaw (mandible) or upper jaw (maxilla), including teeth.

For people needing radiation therapy, risks associated with the late side effects of treatment means that often people need to have teeth removed before they start cancer treatment.

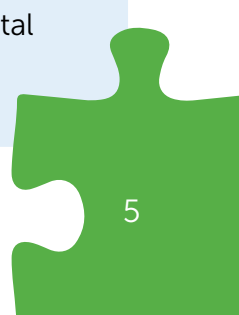
Dental prostheses including dental implants, dental prostheses (crowns/bridges/dentures) and obturators are used to restore critical functions such as chewing, eating, speaking and swallowing, as well as a person's ability to smile.

Treatments for Head and Neck Cancer, especially radiation therapy, can also have significant impacts on oral health e.g. xerostomia (dry mouth, increased risk of dental decay) and osteoradionecrosis (bone death).

Oral complications commonly occur during treatment (early effects) or are experienced later and persist for the remainder of a person's life (late effects).

An oral health assessment by a dental practitioner experienced in Head and Neck Cancer during the pre-treatment phase is key to producing the best possible outcomes for patients.

Six monthly oral health assessments including a dental checkup post treatment is integral to managing side effects and preventing complications.



Addressing the survivorship care of Head and Neck Cancer Patients: Our recommendations

Survivors of Head and Neck Cancer have long-term survival exceeding 70% but are faced with the significant challenges of often life-long, complex and unmet needs in relation to accessing facial prosthetics and oral prehabilitation and rehabilitation.

Head and Neck Cancer Australia's recommendations align with the Australian Cancer Plan.

The time to act is now to drastically improve the quality of life of people living with Head and Neck Cancer and enable them to live full and productive lives.

Recommendation 1: Facial Prosthetics

Achieving equity in cancer outcomes for priority population groups and between tumour types is a key objective of the [Australian Cancer Plan](#). Breast cancer survivors are already supported by the Australian Government through the [National External Breast Prosthesis Reimbursement Program](#).

We call on the Government to deliver on key strategic objectives of the Plan for people living with Head and Neck Cancer through the creation of a **Head and Neck Cancer Maxillofacial Prosthetics Benefits Scheme**.

The Scheme has the potential to significantly improve the quality of life of people who are left with the loss of key elements of their face after treatment for Head and Neck Cancer, isolated from society and with no practical way to access the care any of us would want for our family. Many are unable to return to work. Investing in what is arguably the most disenfranchised group of cancer patients in Australia will empower, support and enable those affected while reducing the burden on the health and social services system.



When I finally found the courage to look at myself in the mirror, I thought what have I done? How can I ever look semi-normal again? Do I have to buy a balaclava so I can walk around in public?

It's a really strange feeling to know that you've had something amputated. I became very, very withdrawn and didn't want to go out of the house.

My new ear is made of silicone. Each one lasts for around three years so I only wear it if I'm leaving the house for a social gathering."



Pete Gibson

Head and Neck Cancer Patient

Tracey had her eye, eye socket and part of her cheekbone removed following a diagnosis of Head and Neck Cancer.

Considered 'cosmetic' rather than 'functional' Tracey's facial prosthetic which cost \$6,500 was not covered by Medicare or her private health insurance.



I was lucky that I had some savings but what about those people who don't? A facial prosthetic is literally a lifesaver. It's not optional. People's faces need to be put back together at the end of all of this. You can't leave the job half done."



Tracey Sims

Head and Neck Cancer Patient

Facial prosthetics: the solution

Eligibility	Only people eligible for Medicare and diagnosed with Head and Neck Cancer by a Head and Neck Cancer specialist participating in a Head and Neck Cancer Multidisciplinary Team and referred by one of these professionals would be eligible to participate in the External Facial Prosthetic Reimbursement Program.
Service	New or replacement extraoral prostheses.
Referral required	Head and Neck Cancer clinician participating in a Head and Neck Cancer Multidisciplinary Team.
Estimated number of people annually	2,000 people (new and replacement prostheses)
Cost annually	\$6,500 average cost (includes one appointment for repairs/maintenance)
What is not covered	Ongoing repairs and/or maintenance. Replacements for lost, stolen or damaged prostheses.
Estimated total cost per annum	Total: \$13M



Recommendation 2: Oral prehabilitation and rehabilitation

We know that survivors of Head and Neck Cancer have long-term survival exceeding 70% but are faced with the significant challenges of often life-long, complex and unmet needs in relation to oral prehabilitation and rehabilitation.

Current oral prehabilitation and rehabilitation in Head and Neck Cancer survivorship is variable and significant financial, workforce, knowledge and access barriers exist to optimal care.

This is especially the case for Head and Neck Cancer patients from priority populations recognised in the Australian Cancer Plan including Aboriginal and Torres Strait Islander people, those living in rural and remote Australia, those from socio-economically disadvantaged backgrounds and culturally and linguistically diverse communities.

Head and Neck Cancer Australia in collaboration with leading multidisciplinary Head and Neck Cancer clinicians, recommend that in the medium-term funding arrangements be put in place to address the significant financial barriers facing Head and Neck Cancer patients to access optimal oral prehabilitation and rehabilitation.

The need to address financial barriers has been recognised by recent Senate inquiries. This could range from a specific program for Head and Neck Cancer patients under Medicare to the Commonwealth providing additional

support through the National Partnership Agreement on Adult Public Dental Services.

However, there is currently insufficient robust data which quantifies the scale, nature and impact of unmet needs amongst Head and Neck Cancer survivors and critical foundational evidence is lacking on what constitutes optimal care regarding oral prehabilitation and rehabilitation.

Further work is also required on the most effective way to provide sustainable financial support to allow Head and Neck Cancer survivors to meet their oral prehabilitation and rehabilitation needs.

Head and Neck Cancer Australia recommends support for two projects which will provide an evidence base for action to address key barriers to optimal oral prehabilitation and rehabilitation for Head and Neck Cancer patients.

Project 1: \$500,000

Quantify the unmet needs and develop effective and sustainable funding options for optimal oral prehabilitation and rehabilitation.

Head and Neck Cancer Australia seeks funding to lead a project to quantify the scale, nature and impact of the unmet optimal oral prehabilitation and rehabilitation needs of Head and Neck Cancer survivors and develop costed and sustainable options for addressing financial barriers to optimal care.



Project 2: \$2 million
National consensus guidelines

There are currently no best practice guidelines or resources in Australia to address the unmet optimal oral prehabilitation and rehabilitation needs of Head and Neck Cancer patients.

Head and Neck Cancer Australia seeks funding for a project to develop best practice guidelines and consumer resources.

Establishing national consensus guidelines will improve the survivorship of people living with Head and Neck Cancer by ensuring all health professionals have the guidance they need to provide consistent, evidence-based oral prehabilitation and rehabilitation care.

The project will also develop and evaluate consumer co-designed education resources and an oral rehabilitation care plan for survivors

of Head and Neck Cancer. The plan is a novel but simple solution providing resources to patients and their cancer care teams which will empower them to improve optimal oral prehabilitation and rehabilitation survivorship after Head and Neck Cancer.

By addressing challenges specific to the Australian context, we will positively impact the rational utilisation of existing healthcare resources, reduce unplanned care episodes for complications resulting in lower healthcare costs.

Ultimately, there will be improvements to patients' quality of life and ability to function in society, fewer oral and dental-related complications after treatment for Head and Neck Cancer, and consistent approaches to the management of oral prehabilitation and rehabilitation by health professionals involved in the care of Head and Neck Cancer patients.



*An oral rehabilitation scheme that was costed and sustainable would pay for itself by **reducing the incidence and cost of acute oral health conditions** that are common for long-term Head and Neck Cancer survivors e.g. preventive oral treatments can reduce the risk of dental extractions due to dental decay as a result of radiation-induced xerostomia (dry mouth).*

In turn avoiding the need for dental extractions reducing the risk of preventing or treating osteoradionecrosis (ORN) through the use of expensive medical treatments funded through Medicare including hyperbaric medicine, and surgical excision of established ORN.



A/Prof Sharon Liberali
Specialist in Special Needs Dentistry



Why now?

The impact of Head and Neck Cancer and the unmet needs of priority groups was recently highlighted at the [Select Committee into the Provision of and Access to Dental Services in Australia](#) who recommended the Australian Government review the Medicare Benefits Schedule with a view to improving the accessibility of oral health treatment, including restorative services for people living with Head and Neck Cancer.

The profound impact of Head and Neck Cancer was also raised at the [Senate Community Affairs References Committee inquiry into Equitable access to diagnosis and treatment for individuals with rare and less common cancers](#).

One of the recommendations included in the inquiry's [final report](#), released earlier this year, calls on the Australian Government to "work with state and territory governments to identify the barriers faced by cancer patients requiring rehabilitation, prosthetics and implants as a result of their treatment, with a view to ensuring they have financial support for those services".

Senator Wendy Askew, who sat on the inquiry's committee, said she and other members were moved to hear the stories of people who needed surgery to areas such as their neck and face.

"Having access to dental implants and facial prosthetics such as an eye, ear, nose or cheek is a vital step on a patient's journey to recovery, restoring their dignity and reversing the disfiguration that they have endured during their treatment," Senator Askew said.

Following the inquiry the Community Affairs Legislation Committee also questioned Professor Dorothy Keefe, Chief Executive Officer of Cancer Australia, who confirmed that the toxicities of Head and Neck Cancer treatment is an area of difficulty for patients and one that Cancer Australia would be supportive of looking at in more detail as part of the Australian Cancer Plan. [See transcript](#).

“

I'm incredibly frustrated about the cost of my oral rehabilitation and that the government doesn't class the replacement of teeth as medical even though the only reason I had them removed is because of cancer.

The implants were covered by Medicare during my surgery to remove the cancer, but I now need to pay \$23,000 for the actual teeth which are considered elective even though I need them to eat. The job is only half done, we need help to put our mouths back together.



Mandy Keleher

Head and Neck Cancer Patient



Our amazing Medicare system of course covers the removal of oral tumours in hospital. But if your tumour removal means cutting into your jaw, nose or face, Medicare does not cover the reconstruction (facial or dental prosthetics), so you might not be able to do simple and very necessary functions like eating and speaking...

Fiona Phillips, Federal Labor MP of Gilmore
House of Representatives,
Federation Chamber, Grievance Debate
2 July 2024

About us

Head and Neck Cancer Australia is the only national charity and leading peak-body dedicated to supporting people living with Head and Neck Cancer, their families and carers. We represent over 5,300 people who are newly diagnosed each year and more than 17,000 people living with Head and Neck Cancer diagnosed in the last five years and the family, friends and carers involved in their care.

Our mission is to provide vital support to empower all patients and carers to better navigate their Head and Neck Cancer journey. We also lead the national effort to raise awareness of Head and Neck Cancer among all Australians and healthcare professionals to increase early diagnosis and encourage prevention.

Our close engagement with people who have a lived experience of Head and Neck Cancer and the healthcare professionals who dedicate their days to caring for people diagnosed with Head and Neck Cancer, means that we are also an important advocate for those impacted and are well placed to identify service gaps and provide input on policy matters to address these gaps.



Stand with us as we work to ensure that every person facing Head and Neck Cancer has the support to put together all the pieces of their puzzle.

Help us create lasting change and bring hope to those who need it most.



HEAD & NECK CANCER
AUSTRALIA
ENGAGE • EDUCATE • EMPOWER

Contact us

W: headandneckcancer.org.au

T: 1300 424 848

E: contact@headandneckcancer.org.au

Follow us



ABN: 44 600 709 733

Updated December 2024

