

Tasmanian Cancer Plan Consultation

Submitted online via [Tasmanian Cancer Plan - Have Your Say](#).

The Tasmanian Department of Health is developing a new cancer plan for Tasmania. This work started in early 2024 and is due to be completed in 2025. The cancer plan is a State Government initiative and deliverable in response to the vision and policy direction of the *Long-Term Plan for Healthcare in Tasmania 2040* which was released in June 2023. This new cancer strategic plan will guide how cancer care is provided to Tasmanians over the next five years.

1. What is working well in how cancer services are provided in Tasmania?

Tasmania's cancer care is shaped by the "One State, One Health System, Better Outcomes" initiative, which promotes a centralised, state-wide service delivery model. This approach has enabled more consistent cancer services, streamlined referrals, and patient-centred care, integrating allied health support to address both physical and emotional needs for patients with cancer. Resources like the Royal Hobart Hospital Cancer Support Centre provide practical assistance, emotional support, and wellness programmes, complementing medical treatment and addressing individual patient needs.

In northern Tasmania, the Northern Cancer Service offers care through facilities in Launceston, Burnie, Latrobe, and surrounding areas, including outpatient haematology clinics for blood cancer patients. Telehealth service have also improved accessibility for care delivery for patients by facilitating follow-up appointments and consultations with interstate specialists, reducing the travel burden for regional patients and improving access to clinical trials and ongoing care.

2. What challenges or barriers have you faced or seen, in accessing cancer services and support in Tasmania?

Around 41% of blood cancer patients in Australia live in non-metropolitan areas, with one in five Tasmanians residing outside major cities. Patients in regional areas face significant challenges, being 17 times more likely to report locational and financial barriers to care than those in metropolitan areas. While outpatient haematology-oncology services are available in the North and North-West of Tasmania, many blood cancer patients require inpatient treatment, particularly those with acute cancers like AML or ALL, which necessitate hospital stays for treatment cycles and for those who require autologous stem cell transplants. This is especially challenging in Tasmania, where the only inpatient services for blood cancer patients are at the Royal Hobart Hospital. However, it does remain concerning that for patients who require allogenic stem cell transplants, that this is not possible in Tasmania, forcing patients and families to temporarily relocate to interstate.

The intensive treatment often forces patients to take extended leave from work, with one-third requiring more than three months off, further straining finances. Blood cancers are the most expensive cancers to treat, with 43% of patients reporting out-of-pocket expenses. Rising costs of living have worsened these issues, leading to a 37% increase in people seeking financial assistance from the Leukaemia Foundation in the past year. Patients and their families, particularly those from regional areas, face additional stress as they often need to relocate near treatment centres for extended periods, compounding the already significant financial burden of a blood cancer diagnosis, even with PTAS subsidies.

3. What future initiatives or changes are you aware of which may impact how cancer care is planned for or provided in Tasmania?

N/A

4. What are the opportunities for improving how we plan or provide cancer prevention, research, survivorship, or care in Tasmania?

Blood cancers differ significantly from many solid tumours as they are neither preventable nor easily identified through population screening. Despite this, consistency of care across the country remains a major challenge. The Leukaemia Foundation's 2020 National Strategic Action Plan for Blood Cancer, and "State of the Nation" reports (2019 and 2023), has highlighted considerable variation in service delivery depending on where patients reside. Modelling shows that inconsistent treatment accounts for a 13% variation in survival nationally, 8% between states, and 5% between metropolitan and regional or rural areas. These reports also emphasise the need for greater support across treatment planning, active treatment, and post-treatment stages.

The 2022 Survey of People Living with Blood Cancer, which included more than 4,600 Australians, found that ensuring equitable access to care is patients' highest priority for government action. One area for improvement is expanding the Patient Travel Assistance Scheme (PTAS) eligibility to include clinical trials, as current Tasmanian guidelines exclude access to trials without exceptional rulings. Clinical trials have advanced and are now also accepted as routine care, particularly for rare and less common cancers. Additionally, for many blood cancer patients, clinical trials can often be a patient's last line of treatment or the result of targeted treatment matching from genomic testing.

Advances in research and genomics are revolutionising healthcare for blood cancer patients. Genomic testing enables more precise subtype diagnoses, improving survival outcomes by better matching patients to targeted therapies. However, access to genomic diagnostics in Australia

remains limited and inequitable. In Tasmania, genetic testing through Government-funded services is restricted to individuals with a personal or strong family history of cancer, focusing on risk assessment and not the genetic make-up of the cancerous tissue (i.e. genomic testing). The State of the Nation 2023 report reveals that 31% of patients who underwent genomic testing had their diagnosis and treatment plans altered, demonstrating its critical role in patient care. The Medical Services Advisory Committee has also warned that without genomic testing specifically for blood cancers, patients may be misdiagnosed and receive incorrect treatment.

Tasmanian blood cancer patients and other cancer patients alike would significantly benefit from access to genomic testing to both confirm diagnoses and identify the most effective treatments, whether that be through accessing local services or via cancer networks interstate.

5. What types of support are essential for individuals and families affected by cancer in Tasmania?

Individuals and families affected by cancer in Tasmania require comprehensive and accessible support throughout their cancer journey. For blood cancers in general, but particularly for acute blood cancers, there are many critical decisions required from a patient and their family which can have long lasting impacts on their quality of life and potentially the length of their life. Navigating to effective support services at the very beginning of the journey can have life-changing impacts for patients and their carers.

Supportive care is essential for individuals and families affected by cancer and refers to the services, information and resources patients may need to meet their physical, psychological, social, information and spiritual needs from the time of diagnosis. Its benefits are well established and it is recognised in optimal care documentation as the minimum standard for cancer care.

Broadly speaking, evidence has demonstrated that supportive care services can:

- improve symptom control
- improve quality of life
- reduce emergency room attendances
- reduce hospital admissions
- shorten hospital admissions
- reduce chemotherapy deferrals
- reduce 30-day mortality after chemotherapy
- improve overall survival, and
- reduce healthcare-related costs.

The 2022 Survey of People Living with Blood Cancer found that the top three areas where patients said more assistance would have helped during treatment were:

1. Through patient support organisations
2. Nutritional and dietetic support
3. Emotional/psychological support

6. What information or resources are lacking in cancer care in Tasmania?

At the time of diagnosis, according to the 2022 Survey of People Living with Blood Cancer, many patients felt uncertain or had numerous questions about their condition and treatment options, with 38% reporting having a lot of questions or felt completely uncertain about their diagnosis and 16% expressing uncertainty about their treatment plan. Providing clear, tailored information and referrals to ensure patients know where to access further resources is essential for blood cancer patients.

Support needs evolve during treatment planning and active treatment. At the treatment planning stage, patients identified a strong need for information about support organisations (28%), emotional and psychological support (27%), and physical support (20%). Additionally, practical assistance such as nutrition and dietetic guidance (19%) and social support (18%) are critical. Active treatment brings specific challenges, with patients highlighting the importance of help in understanding and managing side effects (31%), emotional and psychological support (21%), and connections to patient support services (17%).

A recurring concern is the lack of awareness about available services and assistance, with one in four patients unsure of where to seek help. Patients have also cited gaps in peer and nurse support, accommodation assistance, and transport support to access treatment, including from government schemes.

The Blood Cancer Taskforce, supported by the Leukaemia Foundation, has developed a total of 11 blood cancer-specific Optimal Care Pathways which include a Guide to Best Cancer Care booklet (available for download from the Cancer Council website). This booklet helps to explain what the cancer care journey might look like for a patient diagnosed with a specific type of blood cancer and also contains questions a patient might consider asking their treating doctor. Alongside an educational disease booklet – these tangible resources can help make it easier for patients to understand the information conveyed to them by healthcare professionals, make informed decisions, know what questions to ask about their condition and/or treatment, and feel more supported and engaged through the cancer treatment journey.

Addressing these needs through improved information dissemination, better access to emotional and practical support, and increased awareness of available services is vital for improving outcomes for blood cancer patients and their families in Tasmania.

7. How could the community better support people affected by cancer in Tasmania?

We recommend leveraging disease-specific supportive care organisations such as the Leukaemia Foundation to fast-track the delivery of supportive care.

For example, over the past three years in Tasmania, the Leukaemia Foundation has provided:

- 1,765 nights of accommodation for 17 patients to access the care they need.
- \$33,019 in financial assistance provided to 102 patients to support them living with blood cancer with costs associated with utility bills and groceries.
- \$40,631 in transport assistance provided to 192 patients to support them to access the care they need.
- 13,185 instances of support for the 1,449 people who reached out to our trained healthcare professionals.

This illustrates areas of unmet need where patients rely on non-government funded services to support them and their families during their blood cancer journey.

The Leukaemia Foundation regularly engages in visits and meetings with health services and other non-government organisations (NGOs) to build and maintain relationships with haematologists and oncology staff to increase awareness of Leukaemia Foundation as an organisation and provides general updates and information regarding our range of services and supports. We provide disease brochures and other helpful materials for people living with blood cancers to health services. Our community support services can alleviate pressure on the acute health system through the provision of information to patients, emotional support, early identification problems, and appropriate referral to other NGOs.

Referrals to those supportive care services are critical but lacking. In addition to practical supports with bills, accommodation and transport, the Leukaemia Foundation provides a range of resources from booklets and factsheets to seminars and education sessions, and emotional support and assistance with our highly trained support services team. Yet the Leukaemia Foundation's July 2023 "Voice of Customer" service user survey received over 300 responses and shows only one-third were told about our services at diagnosis. This is despite diagnosis being an important time for treatment decisions and a very stressful time for patients.

Previous research shows that just 1 in 3 people have a supportive care discussion as part of their treatment planning. Similarly, the Leukaemia Foundation's July 2023 "Voice of Customer" service

user survey shows only one-third were told about our services at diagnosis. This is despite diagnosis being an important time for treatment decisions and a very stressful time for patients, and that almost all patients felt, as a result of our support, that they could better navigate healthcare systems.

8. How can awareness and education campaigns be improved?

Blood cancers, affecting over 150,000 Australians with more than 120 subtypes, are the second leading cause of cancer-related death and cannot be detected early through screening, and yet not many Australians can identify the signs and symptoms of the disease.

According to the 2024 Living Consumer Intelligence Blood Cancer Access and Equity survey, 78% of Australians reported a lack of knowledge when it came to being aware of any main symptoms of blood cancers.

More awareness and education campaigns that explain what blood cancers are, what symptoms are involved, and what to do if you experience symptoms is vital in increasing awareness and identification of signs of the disease.

Blood cancers are individually uncommon, non-hereditary, and challenging to readily diagnose in primary care settings. Many primary healthcare providers have limited experience with blood cancers, particularly the rarer subtypes, and especially in those in regional and rural areas. OCPs (as previously mentioned) are useful resources for healthcare professionals and include information and appropriate timelines for testing and early detection, diagnosis, treatment planning, treatment, cancer care and recovery, survivorship, and end-of-life care.

More awareness and circulation of these resources among healthcare professionals is needed to work towards reducing variation in cancer care and associated outcomes, especially considering the metro vs rural disparities in survival outcomes.