



2022

Federal Election Priorities

As the only national charity dedicated to helping more Australians with leukaemia, lymphoma, myeloma and related disorders survive their blood cancer and live well, the Leukaemia Foundation is dedicated to fighting for positive change for people living with blood cancer.

This Federal election we're asking all political parties to work with the blood cancer community to achieve the goal of zero lives lost to blood cancer by 2035.

To achieve this goal we need to:



Set national standards of care



Facilitate access to new and specialised therapies for all patients, no matter where they live



Provide national leadership to improve outcomes for people living with blood cancer

Blood Cancer Facts

Blood cancer can develop in anyone, at any age, and at any stage of life. There are no screening programs available and there is no way to prevent a blood cancer through lifestyle changes.

Today, more than 110,000 people are living with a blood cancer or blood disorder in Australia. By 2035, more than 275,000 Australians are expected to be living with a blood cancer or blood disorder.

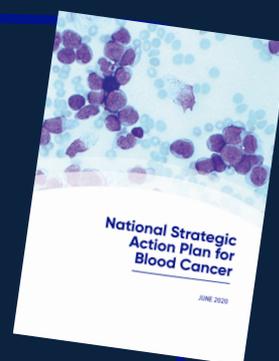
When combined, blood cancers are the second most diagnosed cancers in Australia today and the second most common cause of cancer death.

Getting the best blood cancer treatment can be challenging, depending on where a person lives and, in some instances, whether they can afford to pay for tests and treatments. A person with blood cancer needs to be diagnosed quickly and correctly, and they need the right plan and support in place to live well before, during and after treatment. **Every year, 1,375 Australians die unnecessarily from blood cancer because they don't get the best treatment available. We can change this!**

The Blood Cancer Taskforce

We have brought together 31 of Australia's leading haematologists, researchers, people living with blood cancer, and members of the blood cancer community into the Blood Cancer Taskforce. Together we are committed to decreasing the number of people who die from blood cancer and achieving our goal of zero lives lost to blood cancer by 2035.

The National Strategic Action Plan for Blood Cancer (National Action Plan), developed by the Blood Cancer Taskforce, is an evidence-based blueprint to coordinate national efforts to improve survival and quality of life for people diagnosed with blood cancer. Blood cancer affects Australians in remote, regional, suburban and metro settings. There is no one-size fits all solution to the access, information and affordability issues facing these Australians. The National Action Plan makes 21 recommendations for change, including setting national quality standards for treatment and care, implementing best practice, increasing access to information, treatment and clinical trials for all Australians and accelerating research.



Priorities 2023–25

Among its 21 recommendations, the National Strategic Action Plan for Blood Cancer outlined a number of actions that we could take immediately, to set a consistent national approach to treatment and care which will save lives.

With support from the Federal Government, the Blood Cancer Taskforce has already developed six blood cancer Optimal Care Pathways and is set to develop five more, alongside clinical and diagnostic guidelines.

Through a public-private partnership, the Leukaemia Foundation will fund two recommendations outlined in the National Strategic Action Plan:

- **to identify research priorities, pathways to increase partnerships and collaborations and incentives to increase research in Australia**
- **establish networks and a study to understand the impact of blood cancer in First Nations communities.**

However, more work needs to be done to address critical gaps in patient-centred care, access to novel treatments for all Australians and empowering people living with blood cancer through information to make decisions about their treatment and care. To achieve zero lives lost to blood cancer by 2035 we need longer term support to implement the projects in the National Action Plan identified by the experts in the blood cancer community.

1. Continue setting standards for all blood cancers

National consistent standards are needed for blood cancer diagnosis, treatments and care.



Optimal Care Pathways, clinical and diagnostic guidelines, and written treatment and survivorship care plans are all critical and interconnected parts of providing treatment that is standard of care. This standard of care has been consistent in many other conditions for a long time in Australia, but for many blood cancers these are not consistent.

The National Action Plan recommended developing Optimal Care Pathways and clinical and diagnostic guidelines for all major blood cancer subtypes. The Taskforce has completed six Optimal Care Pathways and has recently received funding to undertake a further five alongside preparing clinical and diagnostic guidelines. But this will not finish this work, and there needs to be an ongoing commitment to completing and regularly updating these pathways and guidelines for all major sub-types.

2. Written treatment and survivorship care plans

People living with blood cancer should be empowered to be at the centre of their own care.



Written treatment and survivorship care plans are recognised as an important part of best practice care and should be provided to patients during treatment and follow-up care. These care plans summarise diagnosis and treatment, and outline important follow-up and supportive care issues like immunosuppression, infections, vaccination, diet and exercise.

The National Action Plan recommends the development of templates for written treatment and survivorship care plans to improve care and support for people living with blood cancer.

3. Patient Reported Outcomes systems for blood cancer

The patient experience should be at the centre of care.



Patient reported outcomes (PROs) are systems that allow patients to provide live feedback on their symptoms, side-effects and other aspects of their health and wellbeing. PRO systems implemented as part of a cancer care plan have been shown to improve treatment experiences, reduce presentation to emergency departments and frequency of hospitalisation, and improve overall survival and health-related quality of life.

The National Action Plan recommends that a scoping study be undertaken for PROs in the blood cancer setting as a necessary first step, which will also identify the national coordination necessary for success.

4. A national information strategy for cancer

Patients need access to appropriate, accurate and reliable information to make decision about their treatment and care.



Australia's healthcare system is excellent but complex, and accessing reliable, evidence-based information can be difficult for patients, from understanding their diagnosis and managing their disease to making decisions about their care.

For people facing cancer, there are complicated issues involved in diagnosis, choosing a specialist, treatment options, living with their cancer, maintaining quality of life, palliative and end of life care. An information pathway that guides people through their journey is a high priority.

The National Action Plan recommends a broad national information strategy for all cancers to ensure the provision of quality, trusted, evidence-based information to people affected by cancer.

5. Address challenges for access to novel and specialised therapies

Everyone should be able to access the best available diagnostics and treatment available, no matter where they live or where they receive treatment.



There are a number of medicines and diagnostics that are considered clinically-important and currently being used as standard of care that are not subsidised in Australia today. In some instances, even if a treatment is PBS or MBS listed, it may not be available to all people living with blood cancer depending on hospital funding arrangements. These are complex and interrelated issues requiring sustained leadership and focus to remedy.

The National Action Plan recommends the establishment of a multidisciplinary Enabling Access Working Group, including consumers and other relevant specialists, to work with governments and the blood cancer community to address challenges for patient access to novel and specialised therapies.

6. Cancer patient-friendly exercise clinical trial

People living with blood cancer should have every avenue open to them to help improve their treatment outcomes.



We know that exercise substantially improves outcomes for people with cancer: reductions in fatigue, pain, distress, anxiety, and depression; improvements in bone health and cognitive and cardiovascular function; and increases in health-related quality of life.

Current strategies to engage people with cancer in exercise are not working. As a result, very few people with cancer are realising the widespread benefits exercise provides to restoring health and wellbeing during and after treatment. The benefits of exercise programs are not specific to blood cancers however could be trialled in the blood cancer setting to generate the required evidence of benefit for greater public subsidy to access such programs.

The National Action plans recommends the development of a cancer patient-friendly exercise clinical trial.

7. Ongoing commitment to the Blood Cancer Taskforce

National leadership to improve outcomes for people living with blood cancer



The Blood Cancer Taskforce is the oversight and advisory body coordinating development and implementation of the National Action Plan. It was established in September 2019 with support from Federal Government and brings together leading haematologists, researchers, and patient and consumer group representatives. The Leukaemia Foundation is the secretariat and is responsible for managing Taskforce meetings and activities.

The Federal Government have provided funding and support until mid-2023, but ongoing commitment is needed to continue the operations of this important oversight body.

Working collaboratively: Key project initiatives

Blood cancers, by the nature of the diseases, have challenges to address that are specific to blood cancers. However there are a number of areas where necessary reforms are relevant to all cancers, and the Leukaemia Foundation supports the following project proposals from other organisations which are complementary to the aims of the National Action Plan.

1. Cancer Council

Support and fund the development of a national information strategy for cancer

The Cancer Council has proposed a broader national information strategy for all cancers, which is needed now to improve the provision of information to people affected by cancer. The National Action Plan also identified the need for a blood cancer information strategy as part of a broader digital health and information strategy for people with cancer.

2. The McGrath Foundation

Advanced Cancer Care Nurse Pilot

The McGrath Foundation is seeking funding to support the implementation of a pilot project deploying 25 Specialist Nurses for People with Advanced Cancer and 4 Patient Navigators across four services. This model will inform and educate people with advanced cancer and their families about their disease, support the consideration of treatment options, provide symptom management including the management of the adverse effects of the treatment and provide psychosocial support to the person and their family or caregivers.



GPO BOX 9954 BRISBANE QLD
1800 620 420 info@leukaemia.org.au

The Leukaemia Foundation acknowledges the traditional owners of country throughout Australia and recognises their continuing connection to land, sea and community. We pay our respects to their Elders past, present and emerging.

 The Leukaemia Foundation cares about our environment. Please recycle or dispose of thoughtfully.