TE AHO O TE KAHU
CANCER CONTROL AGENCY

Optimal cancer care pathway for adults with acute lymphoblastic leukaemia

February 2025 | Edition One

Citation: Te Aho o Te Kahu. 2025. *Optimal cancer care pathway for adults with acute lymphoblastic leukaemia cancer*. Wellington: Te Aho o Te Kahu.

Published in 2025 by Te Aho o Te Kahu | Cancer Control Agency, PO Box 5013, Wellington 6140, New Zealand

ISSN 3021-5277 (online)
TP0036

TE AHO O TE KAHU CANCER CONTROL AGENCY

This document is available at **teaho.govt.nz**

Whakataukī

Have a sense of the message in the winds...

Anei he taonga nō te mātanga nō Ahitereiria

Koutou maa I takoto te koha ki a mātou

Here is a treasure from the skilled and able specialists in Australia

Greetings for this treasure you have gifted us here in Aotearoa to explore and use

E ki ana te tangi o tatou manu

Ko te manu e kai ana ki te miro, nōnā te ngahere

Ko te manu e kai ana ki te mātauranga nōnā te Ao

It has been reiterated that when our manu cries, we sit up and listen

The bird that feeds upon local berries, local knowledge will prosper

The bird that feeds upon wisdom, our world knowledge will flourish.

It is an exciting time to feed off the wisdom of other cultures

Matua Tau Huirama

We would like to acknowledge The Voices of Whānau Māori Affected by Cancer (2023); He Ara Tangata – Te Aho o Te Kahu Consumer Group; the project team; clinicians; and national and special interest working groups that contributed to the development of the Optimal Cancer Care Pathways.

Special acknowledgement is extended to the Cancer Council Australia, who generously shared their Optimal Care Pathways framework and provided permission for it to be adapted to support people and whānau across Aotearoa New Zealand experiencing cancer.

Contents

For further information including:

- Achieving Pae Ora, equity and whānau insights
- Person/whānau questions
- Definitions
- Acute lymphoblastic leukaemia references and bibliography

Refer to **Optimal Cancer Care Pathway (OCCP) supplementary information.**

Foreword

Kia ora,

On behalf of Te Aho o Te Kahu| Cancer Control Agency, the clinician community, and the people and whānau who contributed to developing this guidance, I am proud to present the acute lymphoblastic leukaemia Optimal Cancer Care Pathway (OCCP) for Aotearoa New Zealand.

Almost everyone across Aotearoa has been affected by cancer in some way. This year over 28,000 people will be diagnosed with cancer, with thousands more supporting loved ones living with this disease. Acute lymphoblastic leukaemia (ALL) affects an increasing number of people with over 250 diagnosed with ALL this year. Around 350 people will die from some form of leukaemia this year. We all believe that people and their whānau deserve the best cancer care available.

OCCPs are designed to guide the planning, coordination and delivery of best practice cancer prevention and care services across Aotearoa for different types of cancer. Each OCCP has been designed:

- with the needs of the person and their whānau at the heart
- to reflect the best capabilities available in Aotearoa
- to provide a national standard for high-quality cancer prevention and care that we expect for all New Zealanders.

While cancer control services are expanding and improving across the motu | country, there are often unwarranted variations in the risk of getting cancer and in the care experienced by people with cancer. Also, many continue to face barriers in accessing timely and effective cancer care because of where they live, their circumstances, or their ethnic background. Research shows that following best practice guidance like OCCPs, helps to reduce variations and disparities and improves cancer outcomes for people and their whānau. In turn, this will help our overall aim of reducing the burden of cancer on people and communities.

This resource reflects the expertise and experiences from many stakeholders across the country. Many thanks to everyone involved in this initiative, particularly Cancer Council Australia, who granted permission to adapt and adopt their Optimal Care Pathways framework to meet the needs of people in Aotearoa | New Zealand. We would also like to acknowledge the insights from The Voices of Whānau Māori Affected by Cancer (2023); He Ara Tangata – Te Aho o Te Kahu Consumer Group; the project team; clinicians; and national and special interest working groups.

Our thoughts are with the many people and whānau who are living with cancer, and those who have lost loved ones. Much of this guidance reflects the voices of those who have received cancer care. We are indebted to them for sharing their experiences to help improve cancer control outcomes and achieve equity.

Ngā mihi nui,

Rami Rahal
Tumuaki | Chief Executive
Te Aho O Te Kahu | Cancer Control Agency

Summary guide of acute lymphoblastic leukaemia OCCP information

Quick reference guide of condensed tumour stream

The Optimal Cancer Care Pathways (OCCP) describe the standard of care that people and whānau across Aotearoa, New Zealand should expect the public health system to be striving for.

They follow eight principles[1]: person and whānau-centred care; equity-led; safe, high-quality care; multidisciplinary care; supportive care; coordinated care; effective and timely communication; and knowledge-driven care.

The OCCP guides health providers in ensuring the person and their whānau receive optimal, supportive care at each stage of their cancer diagnosis and treatment.

Step 1: Wellness	Step 1: Checklist
Cancer prevention efforts should be part of all cancer control pathways. This step recommends actions the person/whānau can take to improve their wellbeing and reduce the overall risk of cancer. Evidence-based research shows that general cancer and wellbeing risks can be reduced by: • eating a nutritious diet • maintaining a healthy weight • taking regular, moderate to vigorous-intensity activity • avoiding or limiting alcohol intake • being sun smart • identifying pre-disposing infections such as, Hepatitis C • keeping up to date with immunisations or vaccines such as, Human Papilloma Virus (HPV) • avoiding smoking including marijuana and exposure to second-hand smoke ○ current smokers (or those who have recently quit) should be offered best practice tobacco dependence treatment and an opt-out referral to an intervention service such as Quitline • avoiding vaping • participating in screening services such as breast, cervical, bowel cancer screening • preventing occupational exposure to asbestos, silica, radon heavy metal, diesel exhaust and polycyclic aromatic hydrocarbons.	☐ Carry out a health and wellbeing assessment including discussions around screening services and ways to reduce cancer risk. ☐ Assess the individual's risk of developing cancer. ☐ Encourage eligible people to participate in national screening programmes. ☐ Discuss recent weight changes and monitor weight. ☐ Discuss and record alcohol intake. Offer support for reducing alcohol consumption if appropriate. ☐ Record person's smoking status and offer stop smoking advice/support if appropriate. ☐ Record physical activity. ☐ Consider referral to a dietitian, physiotherapist, or exercise programme. ☐ Give the person education on being sun smart.

[1] Optimal Cancer Care Pathway Principles

Step 2: Early detection

This step recommends options for early detection for the person/whānau with suspected acute lymphoblastic leukaemia.

Early detection

There are no specific tests to detect acute lymphoblastic leukaemia in its early stages. People with an increased risk of developing acute lymphoblastic leukaemia should be monitored closely with their routine carer and blood tests (including a blood film examination) should be performed if symptoms develop.

Risk factors that may increase the risk of acute lymphoblastic leukaemia include:

- radiation exposure
- certain chemical exposures (chemotherapy drugs/benzene)
- some genetic syndromes
- age – children and adults over the age of 50
- gender- males at a slightly higher risk
- prior chronic myeloid leukaemia (CML) that undergoes blast crisis.

Step 2: Checklist

- ☐ Assess and discuss the individual's risk of developing cancer.
- ☐ Discuss recent weight changes and monitor weight.
- ☐ If signs and symptoms of cancer are present refer to 'Step 3: Presentation, initial investigation and referral' below.

Communication

Ensure the person and their whānau understands:

- ☐ when they should receive their results
- ☐ how to follow up if they don't receive their results
- ☐ what's involved if they need to be transferred to a specialist service.

Step 3: Presentation, initial investigations, and referral

This step outlines how to initiate the appropriate investigations and referrals to specialist/s in a timely manner for the person and their whānau with suspected acute lymphoblastic leukaemia.

The types of investigations undertaken will depend on many factors, including access to diagnostic tests, the availability of medical specialists and including preferences.

A person and their whānau may present via primary care, an emergency presentation or incidental finding with a high suspicion of acute lymphoblastic leukaemia.

Signs and symptoms of acute lymphoblastic leukaemia to investigate include:

- anaemia related symptoms
- thrombocytopenia related symptoms
- neutropenia related symptoms
- enlargement of the liver, spleen, lymph nodes or testicles
- bone pain
- joint pain
- cranial nerve palsies
- headache
- visual or auditory symptoms

Step 3: Checklist

- ☐ Record signs and symptoms.
- ☐ Complete all cancer assessments.
- ☐ Inform the person and their whānau of preliminary results.
- ☐ Referral options of cancer care are discussed with the person and their whānau, including cost implications if private provider requested.
- ☐ Complete and record supportive care needs assessment and refer to allied health services as required.
- ☐ Inform the person and their whānau of cultural services and relevant support groups available.
- ☐ Initiate referrals and arrange further investigation.

Timeframe

- ☐ The general practitioner should begin investigations **immediately** if acute lymphoblastic leukaemia is suspected.

- seizures or fits
- dizziness
- nausea
- transient ischemic attack or stroke.

ALL assessment includes the relevant:

- **medical history**, including medications
- **physical examination**: Eastern Cooperative Oncology Group (ECOG) Performance Status Scale, frailty assessment, weight
- **laboratory investigations**: full blood count, peripheral blood film
- **familial cancer history**
- **social history.**

Referral

A clinical suspicion or laboratory/imaging findings suggestive of cancer require further investigation and a referral to hospital specialist services.

- ☐ Laboratory results should be processed, actively followed up and acted upon on the **same day**.
- ☐ Where there is sepsis, bleeding or severe symptoms, medical emergency should be declared, and referral should be made **immediately** to an appropriate emergency facility without necessarily waiting for results of laboratory tests.
- ☐ Where the person needs to present to an emergency department, it should be triaged as a medical emergency initially and discussed **immediately** with a clinical haematology service and/or transferred **immediately** to a specialist centre.
- ☐ Where a laboratory diagnosis of possible acute lymphoblastic leukaemia is made, a referral for an urgent assessment by a haematologist at an appropriate facility **within 24 hours** is required. A deferred assessment should only be done after a discussion between the referring doctor and the responsible haematologist.

Communication

- ☐ Explain to person and their whānau that they are being referred to a hospital specialist service and why, including:
  - how long this may take
  - who to contact if their symptoms change
  - how to follow up if they do not receive their specialist appointment within the specified time.

Step 4: Diagnosis, staging and treatment planning

This step outlines the process for confirming the diagnosis and stage of cancer and the planning of subsequent treatment.

Diagnosis for acute lymphoblastic leukaemia may include:

Radiology:

- computed tomography (CT) of neck, chest, abdomen, and pelvis
- positron emission tomography (PET)-CT scan if any extramedullary involvement is suspected
- CT/magnetic resonance imaging (MRI) of head if major neurological signs or symptoms present
- echocardiogram (ECHO) or multigated acquisition scan.

Step 4: Checklist

- ☐ Confirm diagnosis.
- ☐ Referral to a cancer care coordinator.
- ☐ Record prognostic assessment, risk stratification, staging, performance status and comorbidities.
- ☐ Discuss the person's diagnosis at a multidisciplinary meeting (MDM) and inform the person and their whānau of the treatment decision.
- ☐ Consider enrolment in clinical trial.
- ☐ Consider fertility consequences with treatment and refer to fertility specialist as required.

Laboratory:

- routine blood tests
- tumour lysis syndrome panel
- viral serology
- pregnancy testing
- blood grouping.

Other diagnostic tests:

- bone marrow aspiration
- cytogenetics, molecular studies, and flow cytometry
- lymph node biopsy
- opportunistic infection evaluation
- initial work up for donor identification if applicable.

Prognostic assessment and risk stratification for acute lymphoblastic leukaemia:

- morphological assessment
- cytogenetics
- flow cytometry
- molecular pathology (genetic testing)

Staging for acute lymphoblastic leukaemia:

- scrotal ultrasound for male with testicular disease
- lumbar puncture for the presence of CNS disease

Performance status
Assess performance status using the Eastern Cooperative Oncology Group (ECOG) Performance Status Scale to inform prehabilitation and treatment recommendations.

Multidisciplinary meeting
Induction treatment is often required before a full MDM ratifies details of the ongoing management plan.

Clinical genetic testing
Most genetic abnormalities in acute lymphoblastic leukaemia only occur in abnormal blood cells and are not related to genetic abnormalities that affect the whole body and/or are inherited. However, heritable genetic abnormalities may be identifiable in a very small number of affected people. This becomes highly relevant if a family member is being considered as a stem cell donor. Genetic counselling may be appropriate for those families where an inherited abnormality is suspected.

Treatment planning
Optimal cancer care requires a multidisciplinary approach to ensure treatment plans are tailored to an individual's needs in collaboration with the whānau and health care team.

- ☐ All people with a high suspicion of cancer have a person to coordinate care.
- ☐ Assess supportive care needs and refer to allied health services as required.
- ☐ Ensure primary or secondary prehabilitation to optimise overall well-being is initiated.
- ☐ Referral to leukaemia specific support services as required.
- ☐ Give the person and their whānau information on Cancer Society, Canteen, Leukaemia and Blood New Zealand and/or relevant cultural services and support groups available.

Timeframe

If required, an MDM should occur after induction treatment.

Communication

The lead clinician and team are responsible for:

- ☐ discussing a timeframe for diagnosis and treatment options with person and their whānau
- ☐ explaining the role of the MDM team in treatment planning and ongoing care
- ☐ encouraging discussion about the diagnosis, prognosis, advance care planning and palliative care while clarifying wishes, needs, beliefs, and expectations of the person and their whānau and their ability to comprehend the communication.
- ☐ providing appropriate information and referral to support services as required.
- ☐ communicating with the GP of the person and their whānau about the diagnosis, treatment plan and recommendations from the MDM.

Step 5: Treatment

This step describes publicly funded optimal treatments for acute lymphoblastic leukaemia by trained and experienced clinicians and team members, in an appropriate environment.

Treatment options

Systemic anti-cancer therapy – active treatment for acute lymphoblastic leukaemia will always include systemic therapy.

Stem cell transplant - may be indicated for people with acute lymphoblastic leukaemia. The procedure may be autologous (using the persons own stem cells) or autologous (using a donor's stem cells.

Supportive therapies – people who may benefit from supportive therapies include those who require:

- platelet and red blood cell transfusions
- antimicrobials treatment
- treatment for tumour lysis syndrome
- pain management
- prophylactic granulocyte colony-stimulating factor to shorten the duration of neutropenia.

Radiation therapy – can be considered as an emergency treatment for people with CNS disease or testicular disease at diagnosis, to prevent acute lymphoblastic leukaemia from spreading to the brain or to prepare for a bone marrow transplant.

Targeted therapies and immunotherapy – can be considered in people with certain subtypes of acute lymphoblastic leukaemia.

Emerging therapy – includes novel targeted therpaies, immunotherapies and cellular therapies.

Palliative care – early referral to palliative care can improve quality of life and in some cases survival. Referral is based on need, not prognosis.

Step 5: Checklist

- ☐ Health providers/professional, treating specialist has relevant qualifications, experience, and expertise.
- ☐ Discuss the intent of treatment and the risks and benefits discussed with the person and their whānau.
- ☐ Provide the agreed treatment plan with the person, their whānau and GP.
- ☐ Assess supportive care needs and refer to allied health services as required.
- ☐ Give the person and their whānau information on the cancer non-governmental organisations (NGOs,) cultural services and support groups available.
- ☐ Consider early referral to palliative care if appropriate.
- ☐ Discuss advanced care planning with the person and their whānau.

Timeframes

- ☐ The person with a confirmed diagnosis of acute lymphoblastic leukaemia receives their first treatment **within 31 days** of the decision to treat.
- ☐ The person referred urgently with a high suspicion of acute lymphoblastic leukaemia receives their first cancer treatment **within 62 days**.
- ☐ The person requiring induction therapy should receive the treatment **as soon as possible**.
- ☐ The person requiring intensification and consolidation therapy should receive the treatment **immediately** after induction chemotherapy.
- ☐ Supportive therapies should be guided by clinical presentation, urgency and disease progression over time.
- ☐ Where organ preservation is the goal, the person begins radiation therapy **within 72** hours of recognizing the issue.

Communication

The lead clinician and team are responsible for discussing these areas with the person and their whānau:

- ☐ treatment options including the intent of treatment, risks, and benefits
- ☐ advance care planning

	☐ options for healthy lifestyle support to improve treatment outcomes such as exercise and nutrition.

Step 6: Care after treatment	Step 6: Checklist
The person and their whānau access appropriate follow up and surveillance and are supported to achieve their optimal health after cancer treatment. Provide a summary of the treatment and follow-up care plan to the person, their whānau and their GP outlining: • diagnosis, including tests performed and results • treatment received (types and date) • current toxicities (severity, management and expected outcomes) • interventions and treatment plans from other health providers/professionals • potential long-term and latent effects of treatment and care of these • supportive care services provided • a follow-up schedule, including tests required and timing • contact information for key health care providers/professionals who can offer support for lifestyle modification • a process for rapid re-entry to medical services for suspected recurrence • ongoing assessments of the effects of treatment.	☐ Provide a survivorship plan that includes a summary of the treatment and follow-up care plan to the person, whānau and their GP. ☐ Assess supportive care needs and refer to allied health services as required. ☐ Give the person and their whānau information on Cancer Society and/or relevant cultural services and support groups available. **Communication** The lead clinician (or delegated representative) is responsible for: ☐ explaining the treatment summary and follow up and surveillance care plan to the person and their whānau. ☐ informing the person and their whānau about secondary prevention and healthy living ☐ discussing the follow-up care plan with the GP of the person and their whānau ☐ providing guidance for rapid re-entry to specialist services.

Step 7: Palliative and end-of-life care	Step 7: Checklist
Palliative and end-of-life care provides the person facing life-limiting conditions and their whānau with holistic support and coordinated services based on their specific needs. Palliative care may be provided through: • hospital palliative care • home and community-based care • community nursing, including access to appropriate equipment. Early referral, identification, correct assessment and treatment of pain and other symptoms prevent and relieves suffering. End-of-life care should consider: • appropriate place of care	☐ Early referral to generalist palliative care. ☐ Refer to specialist palliative care services as required. ☐ Refer to supportive care services as required. ☐ Make sure the person and their whānau are aware of the prognosis and what to expect when someone is dying. ☐ Discuss activation of advance care plan, directive, or enduring power of attorney.

• person's preferred place of death • support needed for the person and their whānau. Awareness of and access to, assisted dying services should be available if the person and their whānau raise this with the health care team. **Communication** A key way to support the person and their whānau is by coordinating ongoing, clear communications between all health providers/professionals involved in providing cancer care.	

How optimal cancer care pathways improve outcomes

Optimal Cancer Care athways (OCCPs) are critical tools for guiding the national delivery of consistent, safe, high-quality, evidence-based cancer care for people and whānau across Aotearoa New Zealand. Research shows OCCPs improve the outcomes and experiences of people and their whānau affected by cancer to guide the design and delivery of cancer care services that are systematic, equitable, connected, and timely (Cancer Council Australia, nd).

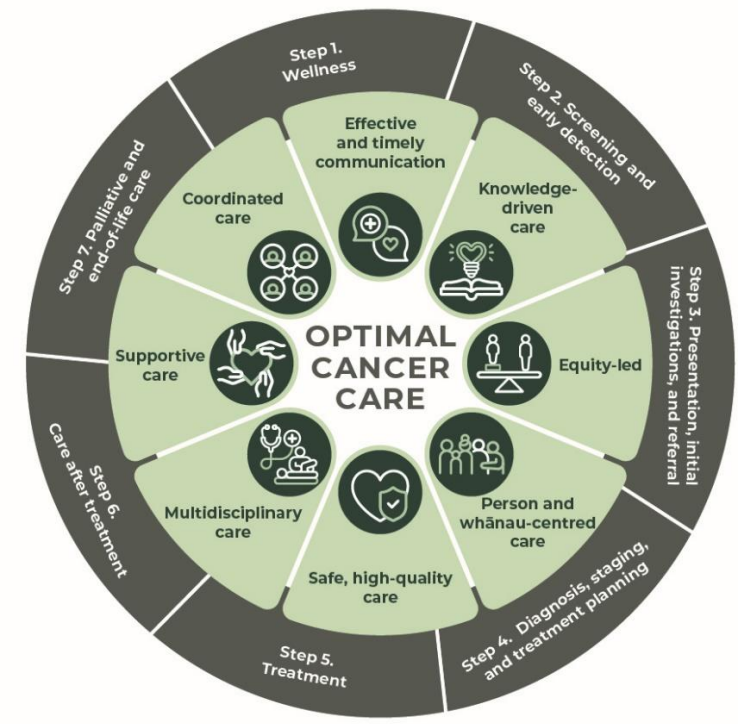
OCCPs are a framework for achieving health equity[2] in cancer control using a person and whānau centred approach to provide people with equitable, high-quality care, regardless of where they live or receive cancer treatment. OCCPs help to:

- identify gaps in existing cancer services
- address barriers and unwarranted variations in accessing high-quality care
- identify opportunities for system improvements
- continually improve the way services are planned and coordinated.

As shown in Figure 1, the OCCPs map seven key steps in providing cancer care based on evidence-based practice, underpinned by eight principles to deliver the optimal level of care. While the seven steps appear linear, in practice, the care a person receives may not be. The steps provided will be tailored to their specific situation and needs, for example the type of cancer they have, when and how the cancer is diagnosed and managed, the person's decisions, and how they respond to treatment.

OCCPs are designed to be used alongside clinical guidelines. The OCCPs do not constitute medical advice or replace clinical judgement or guidance.

Figure 1: Optimal Cancer Care model

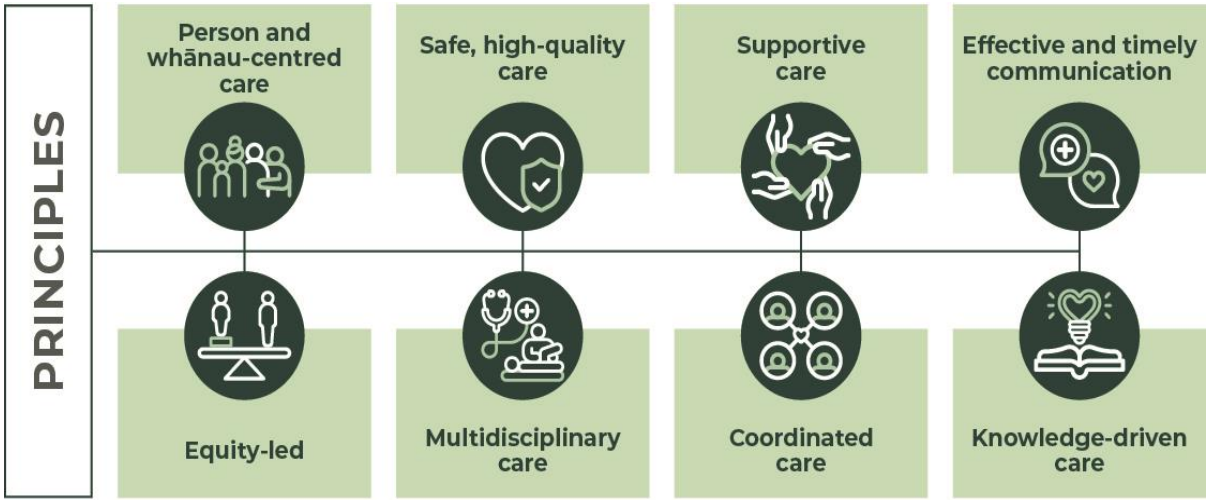


[2] Optimal Cancer Care Pahtways Supplementary Information

Principles of the optimal cancer care pathway

The principles[3] underpinning OCCPs are essential to achieving the best cancer care, experience, and outcomes of the person and their whānau. OCCPs put the person and their whānau at the centre of care planning throughout their treatment/care and prompt the health care system to coordinate high-quality care. The person and their whānau are informed and involved in decisions throughout their cancer experience, according to their preferences, needs and values.

Figure 2: Principles of optimal cancer care



[3] Optimal Cancer Care Pathway Principles

Optimal timeframes

Evidence based guidelines, where they exist, are used to inform clinical timeframes. Shorter timeframes for appropriate investigations, consultations and treatment can provide an improved experience for people and their whānau and better cancer outcomes. The three steps shown below are a guide for health providers/professionals and the person/whānau on the optimal timeframes for being assessed and receiving treatment.

Figure 3: Timeframes for care

Step in pathway	Care point	Timeframes
Step 3: Presentation, initial investigations, and referral	Signs and symptoms	A person presenting with symptoms is promptly assessed by a health professional.
	Initial investigations started by GP	If symptoms suggest acute lymphoblastic leukaemia, the general practitioner should: • conduct investigations **immediately** • have laboratory tests followed up and acted upon on the **same day**.
	Referral to a hospital specialist	The person should be referred: • **immediately** to an appropriate emergency facility without necessarily waiting for results of laboratory tests if there is sepsis, bleeding or severe symptoms displayed and a medical emergency should be declared • **within 24 hours** for an urgent assessment by a haematologist at an appropriate facility if there is a laboratory diagnosis of possible acute lymphoblastic leukaemia. Where the person needs to present to an emergency department, it should be triaged as a medical emergency initially and discussed **immediately** with a clinical haematology service and/or transferred **immediately** to a specialist centre. Note that most initial referrals of acute lymphoblastic leukaemia will be to an emergency department.
	Diagnosis and staging	Initial diagnostic workup should all be performed **within 48 hours** of the person's presentation with results received **within 24 hours** of the procedure.

		Lymph node biopsies where required should be performed **within 72 hours** of the person's presentation. Lumbar puncture must be performed **within 72 hours** of stating therapy. The results of cytogenetics, fluorescence in situ hybridization (FISH), and excisional or core biopsies, should be available **within 72 hours**.
Step 4: Diagnosis, staging, and treatment planning	Multidisciplinary team meeting and treatment planning	All newly diagnosed people are discussed in an MDM. A full MDM often occurs after induction treatment.
		The person referred with a high suspicion of ALL and triaged by a clinician will receive their first cancer treatment **within 62 days**.
Step 5: Treatment	Systemic anti-cancer therapy, supportive therapy, or radiation therapy	The person begins their first cancer treatment **within 31 days** of the decision to treat, regardless of how they were initially referred. Induction chemotherapy should start **as soon as possible**. Intensification and consolidation therapy should begin **immediately** after induction chemotherapy. Supportive therapies should be guided by clinical presentation, urgency and disease progression over time. Where organ preservation is the goal, radiation therapy should be started **within 72 hours** of recognizing the issue.

Optimal cancer care pathway

Seven steps of the optimal cancer care pathway

Step 1: Wellness

Step 2: Early detection

Step 3: Presentation, initial investigations, and referral

Step 4: Diagnosis, staging, and treatment planning

Step 5: Treatment

Step 6: Care after treatment

Step 7: Palliative care and end-of-life care

Acute lymphoblastic leukaemia (ALL) is characterized by the excessive production of immature while blood cells called lymphoblasts or leukaemic blasts.

The incidence rate of acute lymphoblastic leukaemia in New Zealand is approximately 1.51 per 100,000 population. Among Māori, the incidence is slightly higher, at 1.82 per 100,000 population.

Acute lymphoblastic leukaemia primarily affects children, with less frequent occurences in adolescents and adults.

The treatment outcomes for adults with acute lymphoblastic leukaemia are less favorable compared to children, partially due to the requirement of using less intensive treatment regimen because of comorbidities (Wong et al 2022).

This pathway does not discuss the treatment for children with acute lymphoblastic leukaemia.

Step 1: Wellness

Cancer prevention efforts should be part of all cancer control pathways. This step recommends actions the person/whānau can take to improve their wellbeing and reduce the overall risk of cancer.

Health care providers and services such as primary care, public health units, hospitals and NGOs work collaboratively to prevent cancer (and other conditions) with the person and their whānau and communities. Te Aho o Te Kahu (2022) produced a report outlining evidence-based, best-practice interventions to prevent cancer. Reducing cancer risk factors addresses work to achieve the goals of fewer cancers, better survival, and equity for all.

Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:

- culturally safe health care providers and practices embedded in all health services and steps of the cancer care pathway
- institutional and personal bias or racism within the health and disability system being acknowledged, identified, and addressed (Harris et al 2012)
- implementation of health and wellness approaches that support ritenga Māori (Māori customary rights) framed by te ao Māori (a Māori world view), enacted through tikanga Māori (Māori customs) and encapsulated with mātauranga Māori (Māori knowledges)
- meaningful partnerships with Māori communities and organisations that benefit Māori
- support and resource health promotion activities co-designed with Māori
- prioritise achieving equity for screening participation rates in national cancer screening programmes (cervical, breast, bowel).

1.2 Modifiable cancer and wellbeing risks

Evidence-based research shows that general cancer and wellbeing risks can be reduced by:

- eating a nutritious diet
- maintaining a healthy weight
- taking regular, moderate to vigorous-intensity activity
- avoiding or limiting alcohol intake
- being sun smart
- identifying pre-disposing infections, such as hepatitis C
- immunisations – for example HPV, influenza, shingles
- avoiding smoking including marijuana and exposure to second-hand smoke
    - current smokers (or those who have recently quit) should be offered best practice tobacco dependence treatment and an opt-out referral to an intervention service such as Quitline.
- avoiding vaping
- screening services, such as breast, cervical and bowel cancer screening
- preventing occupational exposure to asbestos, silica, radon heavy metal, diesel exhaust and polycyclic aromatic hydrocarbons (Te Aho o Te Kahu 2022).

Most cancer risk factors are not unique to cancer and are shared by other chronic diseases such as diabetes, heart disease and strokes (Te Aho o Te Kahu 2022).

1.3 Communication with the person/whānau receiving care

> ***"Whānau look at prevention holistically."***
> Person/whānau insights

Health providers

- Raise and discuss any modifiable risk factors.
- Provide information and education regarding access to wellness programmes, including kaupapa Māori services.
- Discuss advance care planning, advance directive and/or Enduring Power of Attorney as required (for more information, see Principle 1)[1].

Communication between health services

- Inform the person and their whānau of any referrals between health care services and wellness programmes.

1.4 Measuring and monitoring

Below is a list of national measures that inform this step and can be used to monitor and measure cancer care.

- **Smoking and vaping rates** (note: these measures apply to every step on the pathway).
    - The number of current smokers (aged 15 years and above) who smoke daily and have smoked more than 100 cigarettes their whole life as measured by the New Zealand Health Survey, by gender and ethnicity.
    - The number of vapers (aged 15 years and above) who have tried vaping and vape at least once a day as measured by the New Zealand Health Survey, by gender and ethnicity.
- **The New Zealand Health survey** (NZHS) provides information about the health and wellbeing of New Zealanders.
    - Health status and behaviours.
    - Risk factors.
    - Access to health care.

Step 2: Early detection

This step outlines recommendations for early detection for the person with suspected acute lymphoblastic leukaemia.

2.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:

- making sure early detection of cancer services are provided in culturally appropriate ways that recognise and support the expression of hauora Māori models of care
- providing access to co-designed kaupapa Māori cancer early detection for cancer programmes, where possible (Te Aho o Te Kahu 2022)
- implementing programmes that enhance access to cancer services.

Māori and Pacific peoples often present at an earlier age than the general population, so awareness and consideration of this needs to factor into assessment and review of signs and symptoms.

2.2 Early detection

There are no specific tests to detect acute lymphoblastic leukaemia in its early stages. People with an increased risk of developing acute lymphoblastic leukaemia should be monitored closely with their routine carer and blood tests (including a blood film examination) should be performed if symptoms develop.

Support is provided to identify any acute lymphoblastic leukaemia risks.

2.3 Acute lymphoblastic leukaemia risk factors

Currently known risk factors for developing acute lymphoblastic leukaemia include:

- radiation exposure
- certain chemical exposures (chemotherapy drugs/benzene)
- some genetic syndromes for example: Down syndrome, Fanconi's anaemia, Bloom's syndrome, Li-Fraumeni syndrome, ataxia-telangiectasia
- age – children and adults over the age of 50 have an increased risk of acute lymphoblastic leukaemia gender – males are at a slightly higher risk of developing acute lymphoblastic leukaemia
- prior chronic myeloid leukaemia (CML) that undergoes blast crisis.

2.4 Communication with the person/whānau receiving care

Health providers/professionals

- Promote health checks.
- Raise and discuss any cancer risk factors.
- Provide information and education regarding early detection.
- Discuss any investigation results and follow-up care as required.
- Discuss available supports, such as funding for travel and accommodation, one-stop clinics, community and/or marae-based services (where available), and same-day access to a chest x-ray.

Communication between health services

- Share results and further tests or referrals required with the appropriate service/specialty.

2.5 Measuring and monitoring

Monitoring and measuring is a key component of contemporary best practice. Below is a list of national measures that inform this step and can be used to monitor and measure cancer care.

- **Faster Cancer Treatment**

Early detection through primary care that identifies a high suspicion of cancer and requires an urgent referral to specialist will be seen **within two weeks**. The following FCT business rules will apply:

  - **31-day Health Target -** All people will receive their first cancer treatment (or other management) within 31-days from decision to treat. As a minimum, 90% of patients will receive their cancer treatment (or other management) within 31-days from the decision to treat. (FCT business rules, 2023).
  - **62-day indicator** – All people with a high suspicion of cancer (without a confirmed pathological diagnosis of cancer at referral) will receive their cancer treatment within 62-days from date of referral. As a minimum, 90% of patients will receive their cancer treatment (or other management) within 62-days from date of referral to first treatment.

Step 3: Presentation, initial investigations, and referral

This step outlines the process for initiation of the right investigations and referral to the appropriate specialist in a timely manner for the person with suspected acute lymphoblastic leukaemia

The types of investigations undertaken will depend on many factors, including access to diagnostic tests, the availability of medical specialists, and the preferences of the person and their whānau. Community HealthPathways provide a source of relevant detailed information for an acute lymphoblastic leukaemia assessment from a person's primary care presentation and referral to secondary care to specialist services (**Community HealthPathways** 2024).

3.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:

- prioritising Māori with a 'high suspicion of cancer' referral pathway until symptoms are proven otherwise
- engaging with kaupapa Māori services that are equipped to provide holistic Whānau Ora services in the community
- supporting Māori with access to diagnostics, investigations, and referrals through to the appropriate secondary services.

3.2 Signs and symptoms

Signs and symptoms of acute lymphoblastic leukaemia may present weeks or days before diagnosis. Some people may be asymptomatic and diagnosed incidentally through other testing. The presence of multiple signs and symptoms, particularly in combination with other underlying risk factors, may indicate an increased risk of leukaemia.

Māori and Pacific peoples often present at an earlier age than the general population, so awareness and consideration of this needs to factor into assessment and review of signs and symptoms.

The most common presenting symptoms arise due to disrupted haematopoiesis and should be investigated:

- anaemia-related symptoms including fatigue, weakness, pallor, dyspnea on exertion, tachycardia and/or exertional chest pain
- thrombocytopenia-related symptoms including mucosal bleeding, easy bruising, petechiae/purpura, epistaxis, bleeding gums, heavy menstrual bleeding and spontaneous haemorrhage including intracranial or intra-abdominal haematomas
- neutropenia-related symptoms including with fevers and severe and/or recurrent bacterial, fungal, or viral infections.
- other signs and symptoms resulting from organ, bone marrow and/or Central Nervous System (CNS) infiltration by leukemic cells include:
    - enlargement of the liver, spleen, lymph nodes or testicles
    - bone pain
    - joint pain
    - cranial nerve palsies

- headache
- visual or auditory symptoms
- seizures or fits
- dizziness • nausea
- transient ischemic attack or stroke.

Constitutional symptoms such as fevers, fatigue and sweats may also be experienced. This list is not exhaustive and there may be unusual manifestations in some people.

Signs and symptoms suspicious of cancer that prompt initial investigations may be via primary care, elective care, or an acute admission. Primary care services work with the person and their whānau to assess, investigate, review, and refer to appropriate services within recommended timeframes (see Optimal Timeframe section). These timeframes are indicated by national Faster Cancer Treatment (FCT) high suspicion of cancer pathways and the **FCT** Indicators: Business Rules and Data Definitions.

3.3 Assessment

Acute lymphoblastic leukaemia assessment includes relevant:

- medical history, including relevant medications:
- physical examination: Eastern Cooperative Oncology Group (ECOG) Performance Status Scale, frailty assessment, weight
- laboratory investigations: full blood count, peripheral blood film
- familial cancer history
- social history.

It is important that there is a thorough clinical examination because the finding of significant lymphadenopathy or hepatosplenomegaly with petechiae/significant pallor and bruising will be an alert to the potential diagnosis.

3.4 Initiate investigations, including referrals

- If acute lymphoblastic leukaemia is confirmed or the results are indeterminate, the general practitioner must speak with either a haematologist or medical oncologist with appropriate specialist training in the management of acute leukaemia to make the diagnosis.
- If the person is clinically unwell (e.g., they present with symptomatic anaemia, spontaneous bleeding, sepsis and/or symptoms of hyperviscosity), immediate referral to an emergency facility is recommended without waiting for blood results.
- Indicate if there is a high suspicion of cancer and/or it is urgent, and the person needs to be seen immediately.
- Make sure a referral receipt is obtained by the referring provider.
- Most initial referrals for acute lymphoblastic leukaemia will be to an emergency department.

Timeframe for completing investigations for the person with suspected acute lymphoblastic leukaemia

The general practitioner should begin investigations **immediately** if acute lymphoblastic leukaemia is suspected.

Laboratory results should be actively followed up and processed on the **same day**. It is the responsibility of both the referring doctor and pathology laboratory to identify the possibility of a diagnosis of acute lymphoblastic leukaemia and take appropriate action.

Pathology laboratories should directly contact the referring doctor if leukaemia is suspected (e.g., unexplained pancytopenia or blasts detected in the blood). Results should be actively followed up by the general practitioner and acted upon on the **same day**.

Referral options are clearly communicated with the person and their whānau, including details of expected timeframes, who to contact if they don't hear from the service referred to within the timeframe given, and any costs for accessing services.

When referring a person and their whānau for investigation or procedures, referrers must ensure that:

- the person is aware and encouraged to have a support person with them
- the procedure or investigation is explained to them in a way that they can understand, including in different formats and with a translator, as required
- Māori are referred to kaupapa Māori services if they choose and as available
- an investigation assessment is undertaken to identify if an individual can tolerate the preparation, procedure, or investigation
- assessment and support are given to address any possible barriers of accessing services – for example:
    - transport
    - financial
    - family situation that may impact on the decision to consent to a procedure
    - coordinating appointments and/or offering the person and their whānau, whānau focused bookings.

To support accurate triage, referral information must include the following information:

- signalled as high suspicion of cancer or urgent
- medication and allergies
- past medical history and current comorbidities
- results of relevant investigations
- notification if an interpreter service is required
- concerns that may require support or affect ability to attend appointments, undergo investigations or treatment.

Timeframe for referring to a specialist

The timeframe for referring a person with suspected acute lymphoblastic leukaemia to a specialist depends on the severity of their symptoms and where they present.

People with sepsis, bleeding or severe symptoms should be regarded as a medical emergency and be referred **immediately (on the same day)** to an appropriate emergency facility without waiting for laboratory test results. All emergency facilities should have existing arrangements in place to receive urgent haematological advice.

People with suspected acute lymphoblastic leukaemia who present to an emergency department should be triaged as a medical emergency initially and **immediately** discussed with a clinical haematology service and/or transferred **immediately** to a specialist centre.

People with a laboratory diagnosis of possible acute lymphoblastic leukaemia should be referred for an urgent assessment to a haematologist at an appropriate facility **within 24 hours**. A deferred assessment should only be done after a discussion between the referring doctor and the responsible haematologist.

If symptoms are concerning and the referral is not accepted, primary care 'safety netting' for re-assessment is recommended.

3.5 Supportive care and communication

Assess the supportive care needs of the person and their whānau. Where appropriate, give them:

- access to investigations and care following referral, such as financial, transport and personal support
- help to deal with psychological and emotional distress – for example, anxiety, depression, interpersonal concerns, and adjustment difficulties to a potential diagnosis of cancer
- information regarding supportive services that they can engage with at a time suitable to them
- referrals to kaupapa Māori and Whānau Ora services at their request.

3.5.1 Communication with the person/whānau receiving care

Health providers/professionals

- Provide information regarding their role in the health care team.
- Explain who the person and their whānau is being referred to, the reason for the referral and the expected timeframes for appointments.
- Explain the need for the person and their whānau to return to the GP if signs and symptoms change while waiting for investigations and/or assessment.
- Request that the person notify the delegated clinic or their own GP practice if the specialist has not been in contact within the expected timeframe.
- Discuss the range of services available (including private), referral options, and any costs associated with accessing these services.
- Inform the person and their whānau that they can contact or request a referral to NGOs that provide supportive care, including local Māori health service providers/professionals.
- Give written and verbal information regarding planned investigations and referral services.
- Clarify that the person and their whānau understands the information that has been communicated.

"Whānau face multiple barriers to primary care". "That safety net had been taken away."
Person/whānau insights

Communication between health services

- Include relevant information in referrals, as identified in Steps 3.3 and 3.4.
- Notify the referrer of the acceptance of referral and expected timeframes to be seen or decline of referral and reasons for decline.
- Notify changes in referral status (either changes to symptoms or wait time changes).
- Ensure roles and responsibilities are understood, including GP/lead clinician responsible for checking and notifying results to the person and their whānau.
- Acknowledge receipt of referrals.

3.6 Measuring and monitoring

Below is a list of national measures that inform this step and can be used to monitor and measure cancer care.

- **Faster Cancer Treatment**

Early detection through primary care that identifies a high suspicion of cancer and requires an urgent referral to specialist will be seen **within 2 weeks**. The following FCT business rules will apply:

  - **31-day Health Target -** All people will receive their first cancer treatment (or other management) within 31-days from decision to treat. As a minimum, 90% of patients will receive their cancer treatment (or other management) within 31-days from the decision to treat (**FCT business rules**, 2023).
  - **62-day indicator** – All people with a high suspicion of cancer (without a confirmed pathological diagnosis of cancer at referral) will receive their cancer treatment within 62-days from date of referral. As a minimum, 90% of patients will receive their cancer treatment (or other management) within 62-days from date of referral to first treatment.

Step 4: Diagnosis, staging and treatment planning

This step outlines the process for confirming the diagnosis and stage of cancer and the planning of subsequent treatment in discussion with the person and their whānau.

Health services work with the person and their whānau to diagnose and prognosticate the cancer, provide treatment options and recommendations, and help meet any identified needs. This generally occurs in secondary or tertiary health care services. Assessment and investigation results, including discussions between the appropriate multidisciplinary team members and the person and their whānau, will help to determine the treatment options recommendations and plan.

The person/whānau with acute lymphoblastic leukaemia should be managed by a specialist clinical haematology service, with expertise in acute lymphoblastic leukaemia management. Adolescence and Young Adults(AYA) with acute lymphoblastic leukaemia under the age of 25, should be referred on to tertiary clinical haematology services managing acute lymphoblastic leukaemia in AYA age group (currently either Auckland City Hospital or Christchurch Hospital). Other AYA people with acute lymphoblastic leukaemia should be managed at either Auckland City, Waikato, Palmerston North, Wellington, Christchurch, or Dunedin Hospitals.

4.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:

- prioritising access for Māori to diagnostics, staging, and treatment planning
- supporting the person and their whānau to access holistic care, including mātauranga Māori traditional practices and emotional and spiritual support to complement medical treatment
- talking with the person and their whānau and clinicians about current or intended use of rongoā or other complementary therapies to understand the potential benefits, risks and/or other implications
- consultation with the person and their whānau regarding what they would like to happen to any bodily tissue or organs removed as part of their diagnostic workup and treatment.

4.2 Specialist investigations (diagnostic work up for acute lymphoblastic leukaemia)

4.2.1 Urgent pathway

Some people may present with oncological emergencies including, but not limited to, hyperleucocytosis, tumour lysis syndrome, mediastinal mass, sepsis, and coagulopathies. For the person, urgent, immediate emergency assessment and diagnostic investigations need to be completed to allow early commencement of therapy. The person/whānau may require initial intensive care support during their inpatient admission to a tertiary haematology centre.

4.2.2 Standard pathway

For clinically stable people with a new diagnosis of acute lymphoblastic leukaemia, the diagnostic interventions can be planned for the next business day. These people still will require inpatient admission to a tertiary oncology/haematology centre.

Where possible the diagnosis of cancer is established or confirmed before treatment is planned. The specialist, either before or after taking a medical history and making a medical examination of the person, may request additional investigations. This may be before or after the first specialist appointment and include:

laboratory

- complete blood count with differential
- chemistry profile
- liver function tests
- coagulation studies (including measurements for D-dimer and clottable fibrinogen)
- tumour lysis syndrome panel (including measurements for serum lactate dehydrogenase, uric acid, potassium, phosphate, and calcium)
- hepatitis B and C serologies, HIV serology, CMV serology
- pregnancy testing
- blood grouping.

Radiology

- Computed Tomography (CT) scan of the neck, chest, abdomen, and pelvis with intravenous contrast are conducted as indicated by symptoms
- Positron Emission Tomography (PET)-CT scan maybe considered if any extramedullary involvement is suspected. For PET-CT scans, see Health New Zealand | Te Whatu Ora National Indications for Publicly Funded PET-CT.
- CT/magnetic resonance imaging (MRI) of head should be performed to detect meningeal disease, chloromas or CNS bleeding for people with major neurological signs or symptoms at diagnosis.
- echocardiogram (ECHO) or multigated acquisition scan due to the use of anthracyclines in nearly all treatment regimens.

Other diagnostic tests

- bone marrow aspirate noting that marrow may not be involved in lymphoblastic lymphoma.
- flow cytometry to determine whether the case is T-cell acute lymphoblastic leukaemia (T-ALL) or B-cell acute lymphoblastic leukaemia (B-ALL)
- cytogenetics and molecular studies to determine prognosis and potential residual disease
- lymph node biopsy in cases where there is lymphadenopathy and particularly if there is an absence of bone marrow disease (e.g., in lymphoblastic lymphoma). This should ideally be performed as an excisional biopsy with a radiologically guided core biopsy being an acceptable alternative. Fine-needle aspiration should generally not be used unless evaluating for other possible diagnoses (e.g., solid tumours) or in areas where either surgical biopsy or radiological-guided core biopsy would be impossible
- evaluation for opportunistic infections as appropriate
- initial workup for donor identification for allogeneic stem cell transplant if they are of an appropriate age and comorbidity status to consider this.

Timeframe for completing investigations

Initial diagnostic workup including bone marrow aspirate (+/- trephine depending on institutional practices), blood workup and imaging should all be performed **within 48 hours** of the person's presentation with results received **within 24 hours** of the procedure.

Lymph node biopsies where required should be performed **within 72 hours** of the person's presentation.

Lumbar puncture must be performed **within 72 hours** of starting therapy given the possibility of false-negative results by delaying lumbar puncture until completion of the steroid pre-phase.

The results of cytogenetics, fluorescence in situ hybridization (FISH), and excisional or core biopsies, should be available **within 72 hours**.

Some tests such as molecular genetics may take longer, though this should not delay the start of therapy.

4.3 Prognostic assessment and risk stratification

A prognostic assessment is critical to informing risk stratification and management of people with acute lymphoblastic leukaemia. Prognosis is determined by clinical and laboratory indicators.

Classification and prognosis/risk stratification for acute lymphoblastic leukaemia involves the following tests:

- morphological assessment
- cytogenetics
- flow cytometry
- molecular pathology (genetic testing).

Prognostic markers for acute lymphoblastic leukaemia include:

- age
- ECOG
- white blood count
- immunophenotype
- cytogenetics and FISH
- molecular genetics
- CNS involvement.

Classification is based on a combination of immunophenotype to define cell lineage of origin along with cytogenetics (karyotype), FISH and molecular features to identify subclassifications.

Newer molecular markers with prognostic and therapeutic relevance in acute lymphoblastic leukaemia are likely to become clinically routine in the future (Roberts et al. 2015). Complete molecular evaluation including next-generation sequencing should be considered in all newly diagnosed cases of acute lymphoblastic leukaemia.

The other most important prognostic features are presence of extramedullary disease, hyperleukocytosis, therapy-related acute lymphoblastic leukaemia (previous exposure to cytotoxins), presence of an antecedent bone marrow failure syndrome and response to induction chemotherapy.

4.3.1 Staging

There is no standard staging system for acute lymphoblastic leukaemia. However, staging may be relevant in acute lymphoblastic leukaemia for the presence of CNS disease and, in males, testicular disease, and include:

- **scrotal ultrasound:** to evaluate for any testicular involvement of disease in all males with acute lymphoblastic leukaemia – testicular involvement is common in cases of T-ALL
- **lumbar puncture:** to determine CNS involvement (should not be delayed on account of residual excess blast in the blood).

4.4 Performance status

Performance status is assessed to inform prehabilitation and treatment recommendations and documented using the Eastern Cooperative Oncology Group (ECOG) Performance Status Scale (ECOG-ACRIN Cancer Research Group, nd). The degree of benefit of treatment for an individual may vary according to diagnostic, staging and prognostic factors and performance status.

In older people with cancer, a geriatric assessment measures their level of fitness and treatment tolerability. People over the age of 70 years should undergo some form of geriatric assessment (COSA 2022). Screening tools can be used to identify those who will benefit most from these comprehensive assessments.

Geriatric assessments can help tailor the treatment plan, address any issues found with the multidisciplinary team, and provide interventions to optimise the person's general health status (Seghers et al 2023).

4.5 Clinical genetics

Referral to clinical genetic services when acute lymphoblastic leukaemia is considered to have features suggestive of a genetic predisposition, such as:

- family history of the same or related cancers
- physical findings that suggest a predisposition syndrome
- specific tumour types or certain pathological subtypes of cancer (determined by tumour genetic tests) that frequently occur in genetic predisposition.

Most genetic abnormalities in acute lymphoblastic leukaemia only occur in abnormal blood cells and are not related to genetic abnormalities that affect the whole body or have been inherited. However, heritable genetic abnormalities may be identifiable in a very small number of affected people. Most diagnostic centres can identify heritable genetic abnormalities related to leukaemia. This becomes highly relevant if a family member is being considered as a stem cell donor. Genetic counselling may be appropriate for those families where an inherited abnormality is suspected.

4.6 Multidisciplinary meeting

Optimal cancer care requires a multidisciplinary approach to tailor treatment plans to the person's needs in collaboration with their whānau and the health care team.

Referral to acute leukaemia MDM following nationally agreed referral criteria is undertaken if indicated to inform treatment recommendations or further assessment and investigation.

New diagnostic techniques in the biology of acute lymphoblastic leukaemia continue to develop rapidly. The multidisciplinary team needs to be aware of these changes and advances to ensure they are translated to clinical management.

Clinical trials are important and have been associated with superior outcomes. The team must know which clinical trials are suitable and available for those with acute lymphoblastic leukaemia. If there is no open clinical trial, then every acute lymphoblastic leukaemia specialist service should have a predefined, peer-reviewed treatment model of care that the multidisciplinary team has endorsed.

Acute lymphoblastic leukaemia should be discussed at an appropriate MDM as soon as possible after diagnosis, however induction treatment is often required before a treatment plan is discussed at MDM. All people with acute lymphoblastic leukaemia will be inpatients when treatment starts, allowing their initial multidisciplinary management to be performed on the ward.

MDMs are managed and guided by the following standards:

- ***Standards for High-Quality Multidisciplinary Meetings (MDMs) in Aotearoa New Zealand*** (Te Aho o Te Kahu 2024)
- ***HISO 0038.4:2021 Cancer Multidisciplinary Meeting Data Standard*** (Te Aho o Te Kahu 2021b)

4.6.1 Treatment options and recommendation

If treatment has not started prior to a MDM, treatment options including the intent, referral options and recommendations are discussed with the person and their whānau to enable informed decision making in accordance with their rights and ability to exercise independence, choice, and control.

The advantages and disadvantages of recommended treatments and associated potential side effects are discussed in plain language with interpreter support as required. Other support may be required for this discussion such as kaumātua/kuia, chaplain and nursing staff as required.

Further discussion between health services (primary care and specialists) and the person and their whānau will ensure comorbidities are well managed. This optimises the person's health to be able to cope with the proposed cancer treatment and its effects.

4.6.2 Fertility preservation

A referral for fertility preservation alongside a contraception assessment and advice should be discussed with the person and their whānau dependent on age, type of cancer and the treatment planned. An early, collaborative, and multidisciplinary approach with the person is undertaken, which maximises the opportunity for best practice contemporary care and consideration for future fertility.

Infertility can range from difficulty having a child to the inability to have a child. Infertility after treatment may be temporary, lasting months to years, or permanent (AYA Cancer Network Aotearoa 2021).

The person/whānau need to be advised about and referred for discussion about fertility preservation before starting treatment and need advice about contraception before, during and after treatment. The person and their whānau should be aware of the ongoing costs involved in optimising fertility. Fertility management may apply in both males and females.

Fertility preservation options are different for males and females and may be specific to a person's age. The need for ongoing contraception applies to both men and women.

The potential for impaired fertility should be discussed and reinforced at different time points as appropriate throughout the diagnosis, treatment and after care phases of care. These ongoing discussions will enable the person and, if applicable, the whānau to make informed decisions.

4.6.3 Prehabilitation

Prehabilitation (preparing for treatment) is the process of optimising a person's overall wellbeing prior to undergoing cancer treatment. Ideally, prehabilitation should begin as early as possible after a cancer diagnosis to allow adequate time for interventions to take effect. In haematological malignancies, the urgency of starting treatment in certain cases, such as aggressive or rapidly progressing conditions, may limit the opportunity to implement these measures. When circumstances allow, prehabilitation should still be considered to enhance the person's ability to tolerate intensive treatment. This is particularly beneficial for those undergoing haematopoietic stem cell transplantation. A nominated service provider is tasked with coordinating prehabilitation. Prehabilitation is initiated and assessed by primary or hospital services and may require referral to additional services for example:

- conducting a physical and psychological assessment to establish a baseline level of function
- identifying impairments and providing targeted interventions to improve the person's function level
- recognize that assessments of end organ function will impact on recommendations for various treatment options, and overall prognosis
- smoking cessation
- medications to ensure optimisation and correct adherence
- rongoā
- psychosocial support
- physiotherapy or exercise programme – aerobic, respiratory training, resistance training for the person to function at a higher level
- nutrition.

4.6.4 Clinical trials

Where eligible, the person with cancer and their whānau are offered and supported to participate in research or clinical trials. Many emerging treatments are only available as clinical trials and may require referral to specific trial centres.

Participation in clinical trials, registries, and tissue banking, where available, is encouraged for people with acute lymphoblastic leukaemia. Clinical trial protocols are rigorously peer reviewed and are a means to ensure people with acute lymphoblastic leukaemia are receiving the best available treatment. Enrolment in a clinical trial should be considered the standard of care for acute lymphoblastic leukaemia, whenever possible.

4.7 Supportive care and communication

4.7.1 Care coordination

Care coordination supports the navigation through diagnosis, staging, and treatment planning. The person and their whānau receive tailored education and are enabled to ask questions, seek further clarity around treatment options and recommendations, and gain

support around the potential next steps in the pathway. The care coordinator will assist in the coordination and navigation of care, support the person and their whānau, and complete any additional referrals that may be required.

People and their whānau who have someone coordinating their care are often more satisfied with the opportunities provided to them and the decision-making process about their care (Cancer Institute NSW 2010).

The person and their whānau will have a clear understanding of what to expect at each step of the cancer pathway, with a clear point of contact should they require support or further information (refer to Principle 6).

4.7.2 Supportive Care

Assess the supportive care needs of the person and their whānau, including:

- management of physical symptoms such as pain and fatigue (Australian Adult Cancer Pain Management Guideline Working Party 2019), including pain management for mucositis or peripheral neuropathy
- physiotherapy/exercise support in managing chemotherapy induced peripheral neuropathy and muscle weakness
- referral to neuropsychology should be considered for the person who has experienced potential neurocognitive insult from triggers such as CNS-directed therapy (cranial radiation and intrathecal chemotherapy), those receiving high-dose methotrexate and any people who experience significant CNS morbidity during treatment such as cerebral bleed, stroke, acute meningitis, and encephalopathies
- nutritional assessment at diagnosis and subsequently for all people undergoing treatment, should include malnutrition or undernutrition, noting that many people with a high BMI may also be malnourished (WHO 2018)
- care coordinator is in place and/or other
- prehabilitation
- contraceptive and fertility support
- early referral to palliative care
- information and education needs are met (refer to Step 3.5).

4.7.3 Communicating with the person/whānau receiving care

Health providers/professionals

- Ensure that person and their whānau have the option to have additional support people with them when having discussions.
- Explain and discuss with person's diagnosis, staging and treatment options and recommendations in plain language.
- Discuss the advantages and disadvantages of treatment options and associated potential side effects.
- Provide information and resources in a format that is useful to the person and their whānau (and that they can share with others as they wish).
- Identify any barriers or challenges that may prevent the person and their whānau from accessing services or attending treatment.

"A lot of people need to travel hours to get to an appointment and don't have vehicles or family support."
Person/whānau insights

- Discuss with the person and their whānau ways to improve health outcomes and wellbeing prior to and during treatment.
- Advise the person and their whānau of their lead clinician and care coordinator.
- Clarify that the person and their whānau have understood the information that has been communicated.
- The person and their whānau may require time to process the information that has been relayed, prior to consenting to treatment.
- Coordinate scheduling of appointments with the person and their whānau to ensure access barriers are minimised and attendance is supported.
- Discuss with the person and their whānau the need to update or complete their advance care planning and/or advance directive.

Communicating between health services

- Coordinate appointments among health services, in discussion with the person and their whānau to make best use of their time and resources and to support access.
- Communicate the diagnosis, MDM recommendations and treatment plan between health services.
- Discuss and agree shared care arrangements, in symptom and co-morbidity management, supportive care and referral to local services.
- Confirm the lead clinician and provide handover details as necessary.

4.8 Measuring and monitoring

Below is a list of national measures that inform this step and can be used to monitor and measure cancer care.

- **Te Aho o Te Kahu Quality Performance Indicator**
    - Route to diagnosis: People diagnosed with cancer within 30-days of an emergency or acute (unplanned) hospital admission (Te Aho o Te Kahu, 2024).
- **Faster Cancer Treatment**
    - **31-day Health Target -** 90% of patients will receive their cancer treatment (or other management) within 31-days from the decision to treat. (**FCT business rules**, 2023)
    - **62-day indicator** – 90% of patients will receive their cancer treatment (or other management) within 62-days from date of referral to first treatment.
- **MDM Standards**

  For audit compliance with standards and standards audit tool the following may be used:
    - ***Standards for High-Quality Multidisciplinary Meetings (MDMs) in Aotearoa New Zealand*** (Te Aho o Te Kahu 2024)
    - ***HISO 0038.4:2021 Cancer Multidisciplinary Meeting Data Standard*** (Te Aho o Te Kahu 2021b)

Step 5: Treatment

This step describes publicly funded optimal treatments for acute lymphoblastic leukaemia by trained and experienced clinicians and team members, in an appropriate environment.

Internationally accepted guidelines for the treatment of acute lymphoblastic leukaemia, used to inform clinical practice are listed below:

- European Society of Medical Oncology: *ESMO clinical practice guideline: acute lymphoblastic leukaemia in adult patients* **esmo-clinical-practice-guidelines-haematological-malignancies**
- European Society of Medical Oncology: *ESMO clinical practice guideline interim update on the use of targeted therapy in acute lymphoblastic leukaemia* **interim update on the use of targeted therapy in acute lymphoblastic leukaemia**
- National comprehensive Cancer Network: *Acute lymphoblastic leukemia, version 2.2021, NCCN clinical practice guidelines in oncology* **NCCN guidelines/category**
- *The European Guidelines on Diagnosis and Management of Neutropenia in Adults and Children: A Consensus Between the European Hematology Association and the EuNet-INNOCHRON COST Action*. 2023. **The_European_Guidelines_on_Diagnosis**
- American Society for Transplantation and Cellular Therapy (ASTCT) practice guidelines **astct-publications**
- European Society for Blood and Marrow Transplantation (EBMT) handbook **ebmt-handbook**

5.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through ensuring that:

- services achieve equity of access and outcomes irrespective of where treatment occurs
- equity in access to treatment is facilitated through active and coordinated support of financial and social barriers to treatment
- tikanga Māori and rongoā is integrated and applied in discussion with treating clinicians
- a referral to the Kia Ora E Te Iwi (KOETI) programme (Cancer Society) occurs as required
- the person and their whānau have all the information and resources to support their mana motuhake (empowerment).

5.2 Treatment intent

The treatment intent should be clearly documented in the person's medical record and shared with the person and their whānau as appropriate. Discuss the advantages and disadvantages of recommended treatments and associated side effects in plain language to support the person and their whānau to make an informed decision. If there is more than one suitable treatment option, services could facilitate the decision making of the person and their whānau by having all specialties involved in the single appointment.

Timeframes for starting treatment are informed by evidence-based guidelines where available. The treatment team recognises that shorter timeframes for appropriate consultations and treatment often provide a better experience for people.

Confirm decisions, and consent for treatment. If treatment is agreed, develop a treatment care plan that includes:

- what the treatment and intent is, alongside likely impacts
- ways to improve health outcomes and wellbeing during treatment, this includes where they can receive support and information
- expected timeframes.

5.2.1 Additional considerations

Undertake a needs assessment and address any possible barriers or challenges (such as financial, social, care coordination and cultural obligations) that may prevent the person and their whānau from accessing treatment. Formally involving the palliative care team/service early can benefit the person receiving care, so it is important to know and respect each person's preference.

The person's current or intended use of any traditional or complementary therapies, including rongoā, will need to be discussed. Information resources should be provided so the person and their whānau can review and take these away for further reflection and sharing, including contact information for services and key care coordinators.

Initiate advance care planning discussions with the person and their whānau before treatment begins (this could include appointing a substitute decision-maker and completing an advance care directive).

If initial treatment is declined, discuss next steps fully with the person and their whānau. This includes the option to re-engage with initial treatment if they change their minds, with the understanding it may no longer be viable and/or suitable.

Ensure prehabilitation is underway (as appropriate) to optimise treatment outcomes, and manage any comorbidities, prior to treatment. Depending on the treatment decided, additional prehabilitation activities may need to be initiated.

Ensure an escalation plan with key contact people is developed if the person becomes unwell before treatment begins.

5.3 Treatment options

The type of treatment recommended for acute lymphoblastic leukaemia depends on the sub-type, whether there is CNS involvement, the likelihood of haematopoietic stem cell transplantation being required, the person's age, general health, and treatment preferences. Treatment may include a combination of the items listed below, concurrently, or sequentially, to maximise optimal outcome.

The person may also be supported to participate in research or clinical trials where available and appropriate. Many emerging treatments are only available as clinical trials and may require referral to certain trial centres.

- **Systemic anti-cancer therapy** – active treatment for acute lymphoblastic leukaemia will always include systemic therapy.

People suitable for systemic anti-cancer therapy (SACT) please refer to The Model of Care for Adult Systemic Anti-Cancer Therapy Services in Aotearoa (Te Aho o Te Kahu 2024).

Induction therapy is the first phase of initial therapy and may include a combination of costicoseteroids, chemotherapy agents and Tyrosine Kinase Inhibiters (TKIs) (in Philadelphia-positive disease).

Intensification, consolidation and maintenance therapy may involve the use of other agents.

Treatment for newly diagnosed acute lymphoblastic leukaemia generally consists of nine to 12 months of intensive chemotherapy, followed by up to three years of maintenance chemotherapy.

The goal of initial treatment is complete remission. Further treatment will consist of ongoing blocks of treatment to eliminate residual disease and prevent relapse.

Therapy should ideally be performed as part of a clinical trial. If not on a clinical trial, people should be treated with age-appropriate treatment protocols. Young adults (as defined within individual protocols) should be treated with paediatric-inspired or similar protocols. Young adults can be treated with adult regimens where enough evidence exists for their use in this group. Adults should be treated with adult treatment protocols once they are outside the age where paediatric regimens have demonstrated benefit. Elderly and unfit people should either be treated with dose-modified adult protocols or, where they are unfit for such therapy, palliative cytoreduction.

People with Philadelphia-positive disease should receive treatment with regimens incorporating TKIs.

Timeframes for starting treatment

Induction therapy should start as soon as possible.

Intensification and Consolidation therapy begins immediately after induction chemotherapy.

Emergency treatment with corticosteroids or chemotherapy to control high white cell count or high burden disease with cytoreduction may be required.

Stem cell transplant - may be indicated for people with acute lymphoblastic leukaemia. The procedure may be autologous (using the persons own stem cells) or autologous (using a donor's stem cells.

People suitable for stem cell transplant please refer to The Model of Care for Transplant & Cellular Therapy Services in Aotearoa (Te Aho o Te Kahu 2024)

- **Prevention and treatment of CNS disease**

Treatment to prevent acute lymphoblastic leukaemia from spreading to the CNS is called CNS prophylaxis. This treatment is typically given throughout the entire course of ALL therapy (i.e., through the induction, consolidation, and maintenance phases).

In cases where acute lymphoblastic leukaemia travels to or relapses in the CNS, special treatment is needed. Treatment of CNS disease includes systemic chemotherapy able to penetrate the blood–brain barrier, direct intrathecal chemotherapy and/or cranial irradiation. In some people with CNS disease, particularly where lumbar puncture is difficult or where it will be frequent, the insertion of an Ommaya reservoir can be considered.

- **Supportive therapies**

Platelet and red blood cell transfusions

Transfusions of red blood cells and platelets should be administered as needed to people with anaemia and thrombocytopenia respectively. Anaemia (haemoglobin of <70 to 80 g/L)

is treated with transfusions of red blood cells. Prophylactic platelet transfusion is required when platelets fall to under $10x10^9$/L or when there is evidence of bleeding.

Antimicrobials

As people are immunosuppressed, infections can progress quickly with few early symptoms. Antimicrobials are often needed for prophylaxis and treatment. After appropriate cultures have been completed, febrile people with neutrophil counts less than 500/mcL ($<0.5x10^9$/L) should begin treatment with a broad-spectrum bacterial antibiotic that is effective against gram-positive and gram-negative organisms.

Fungal infections, especially pneumonias, may develop and are difficult to diagnose. A chest CT to detect fungal pneumonia should be performed early (i.e., within 72 hours of presentation of neutropenic fever depending on the degree of suspicion). Empiric antifungal therapy should be given within 72 hours if antibacterial therapy is not effective. Because there is a significant drug–drug interaction between vincristine (commonly used in ALL treatment regimens) and azole antifungals, this must be considered when choosing the most appropriate therapy.

Tumour lysis syndrome

Hydration and appropriate pharmacological intervention can prevent and treat the hyperuricaemia, hyperphosphataemia, hypocalcaemia and hyperkalaemia caused by the rapid lysis of leukaemic cells during initial therapy.

Analgesia

Analgesia must be used for pain (e.g., bone pain), particularly at diagnosis.

Prophylactic granulocyte colony-stimulating factor

Prophylactic granulocyte colony-stimulating factor may be used during induction therapy to shorten the duration of neutropenia.

Timeframes for starting treatment

The timeframe for starting treatment should be guided by clinical presentation and urgency and disease progression over time.

- **Radiation therapy**

Radiation therapy can be considered as an emergency treatment. Those with leukaemia in the CNS at diagnosis may receive radiation to the brain area. Radiation to the testicles can also be considered in people with testicular disease at diagnosis that remains after induction therapy. Cranial irradiation can be given to prevent acute lymphoblastic leukaemia from spreading to the brain. Total body irradiation may also be administered in preparation for a bone marrow transplant.

People suitable for radiation therapy please refer to The Radiation Oncology Model of Care (Te Aho o Te Kahu 2024).

Timeframes for starting treatment

Where organ preservation is the goal (e.g., hydronephrosis), radiation should be started **within 72 hours** of recognizing the issue. Where applied with symptomatic/palliative goals, appropriate timing is guided by the severity of the relevant symptoms.

- **Targeted therapies and immunotherapy**

Targeted therapies and immunotherapy should be considered in people with certain subtypes of acute lymphoblastic leukaemia. Potential benefit of using these therapies must be balanced against toxicity.

- **Emerging therapy**

Some emerging therapies are currently being investigated for acute lymphoblastic leukaemia. Therapies that show promise for treating acute lymphoblastic leukaemia include novel targeted therapies, immunotherapies, and cellular therapies (Shah et al 2021). These novel therapies are in various stages of clinical development and assessment. It is anticipated that some will become Medsafe approved in the coming years.

- **Palliative care**

Palliative care is an integral part of cancer treatment and care. It offers specific assessments, supportive care programmes, and services focused on living with and dying from cancer. Early referral and access to palliative care is a critical aspect of best practice. The person and their whānau who cannot be offered curative treatment, or declines curative treatment, as well as those with a significant symptom burden, should be offered prompt access to palliative care services.

Treatment includes managing the impact of cancer therapy, including the management of physical symptoms, distress, and other clinical issues a person and their whānau may experience.

Early referral to palliative care and other health services is recommended to help manage:

- side effects resulting from treatments
- decline in mobility or functional status as a result of treatment
- nutritional support
- sexual dysfunction
- peripheral neuropathy
- fatigue.

The person/whānau with an uncertain prognosis and a high symptom burden should be able to access palliative care support alongside curative-intent therapies. Cases of relapse should trigger a referral to palliative care services.

5.3.1 Clinical Trials

The person is supported to participate in research or clinical trials where available and appropriate. Many emerging treatments are only available as clinical trials and may require referral to certain trial centers (refer principle 8).

5.4 Treatment summary

A treatment summary will be provided by the treating service for the person and their whānau and clinicians involved in their follow-up care, including primary care. The summary includes:

- relevant diagnostic tests performed and results
- cancer diagnosis, characteristics, stage, and prognosis
- treatment received
- current toxicities (severity, management and expected outcomes)
- interventions and treatment plans from other health providers/professionals
- potential long-term and late effects of treatment

- supportive care services provided
- recommended follow-up and surveillance.

5.5 Supportive care and communication

Supportive care needs for the person and their whānau are assessed for all cancer treatment modalities, including surgery, chemotherapy, radiation, and palliative care.

Assess challenges and changes in health status that may arise for the person and their whānau due to their treatment, including:

- access to expert health providers/professionals with specific knowledge about the psychosocial needs of people undergoing acute lymphoblastic leukaemia care
- potential isolation from normal support networks, particularly for rural people who are staying away from home for treatment
- general health care issues (such as smoking cessation and sleep disturbance), which can be referred to a general practitioner
- altered cognitive function due to chemotherapy or radiation therapy, which requires strategies such as maintaining written notes or a diary and repetition of information
- loss of fertility, sexual dysfunction or other symptoms associated with treatment or surgically or chemically induced menopause, which requires sensitive discussion and possible referral to a clinician skilled in this area
- decline in mobility or functional status
- management of physical symptoms such as pain, arthralgia, and fatigue
- early management for acute pain postoperatively to avoid chronic pain
- side effects of chemotherapy such as neuropathy, cardiac dysfunction, nausea, and vomiting – managing these side effects is important in protecting the person's quality of life
- managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications – referral to a pharmacist may be required
- weight changes – may require referral to a dietitian before and after alteration of chemotherapy doses, during and after treatment
- hair loss and changes in physical appearance – referral to Look Good Feel Better
- assistance with beginning or resuming regular exercise – referral to an exercise physiologist or physiotherapist.

The person and their whānau may also need to manage:

- financial issues related to loss of income (through reduced capacity to work or loss of work) and additional expenses as a result of illness or treatment
- advance care planning, which may involve appointing a substitute decision-maker and completing an advance care directive
- legal issues (completing a will, care of dependent children) or making an insurance, superannuation or social security claim based on a terminal illness or permanent disability.

5.5.1 Care coordination

Care coordination will support the person and their whānau through treatment. The care coordinator supports the implementation and activation of supportive care needs through the provision of information, education and referral regarding the concerns and issues that have been raised by the person and their whānau (refer Principle 5).

5.5.2 Communication with the person/whānau receiving care

Health providers/professionals

- Confirm lead clinician and other treatment teams/members involved in care.
- Advise the person and their whānau of the expected timeframes for treatment and ensure they have a key contact person.
- Clarify that the person and their whānau understand the information that has been communicated.
- Refer the person to supportive care and other health care services to optimise wellbeing.

"A whānau need to have a choice of services including rongoā, mirimiri etc. and know how to access tohunga, particularly for whānau who may be disconnected from te ao Māori"
Person/whānau insights

Communication between health services

- Confirm the lead clinician and handover as necessary.
- Confirm the diagnosis, treatment intent, recommendations, and plan, including potential side effects.
- Communicate supportive care treatment plan and referrals between health services.
- Advise of any enrolment in clinical trial as appropriate.
- Advise of changes in treatment or medications.

5.6 Measuring and monitoring

Monitoring and measuring are key components of contemporary best practice. Below is a list of national measures that inform this step and can be used to monitor and measure cancer care.

For those who have started on the FCT pathway, the FCT wait time indicators will apply. FCT applies to a person's first cancer treatment of a new cancer.

- **Faster Cancer Treatment**
    - **31-day Health Target -** 90% of patients will receive their cancer treatment (or other management) within 31-days from the decision to treat.
    - **62-day indicator** – 90% of patients will receive their cancer treatment (or other management) within 62-days from date of referral to first treatment.
- **Haematology treatment timeframe**
    - Category A – urgent within 48 hours
    - Category B – semi-urgent within 2 weeks
    - Category C – routine within 4 weeks.
- **Medical oncology treatment timeframes**
    - Category A – urgent within 48 hours
    - Category B – semi-urgent within 2 weeks
    - Category C – routine within 4 weeks
    - Category D – combined modality treatment (determined by scheduling of the two treatment modalities).

Step 6: Care after treatment

The person accesses appropriate follow up and surveillance and is supported to achieve their optimal health after cancer treatment.

The transition from active treatment to care after treatment is critical to supporting long-term health. Survivorship care planning is the umbrella term for care described in this step, and whilst aspects of this care begin at diagnosis (prehabilitation, supportive care, etc) the term itself is not often used until this part of the pathway.

In some cases, people will need ongoing specialist care, and in other cases a shared follow-up care arrangement with their general practitioner may be appropriate. This will be informed by the type and stage of a person's cancer, the treatment they have received and the needs of the person and their whānau (refer Principle 5).

6.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:

- offering options for holistic recovery and wellness care within hauora Māori models of care
- providing access to clinical, psychological, social, financial, and cultural support to transition back into recovery and life after cancer treatment.
- offering options for holistic recovery and wellness care within hauora Māori models of care
- provide access to clinical, psychological, social financial and cultural support to transition back into recovery and life after cancer treatment.

6.2 Survivorship care planning

After completing initial treatment, a designated member of the multidisciplinary team (most commonly nursing or medical staff involved in the person's care) should undertake survivorship care planning with the person and their whānau.

The survivorship care plan should cover, but is not limited to:

- the provision of a treatment summary
- information on what medical follow-up and surveillance is planned
- how care after treatment will be provided, including by whom and where, and contact information
- inclusion of care plans from other health providers to manage the consequences of cancer and cancer treatment
- information about wellbeing and primary and secondary prevention health recommendations that align with chronic disease management principles (Step 1)
- rehabilitation recommendations and any referrals
- available support services, including cancer NGO survivorship programmes/services (these may be tumour specific)
- signs and symptoms to be aware of that may indicate the cancer has recurred
- the process for rapid re-entry to specialist medical services.

As people are often followed up for five or more years after treatment, this plan needs to be regularly reviewed and updated to reflect changes in the person's clinical and psychosocial status. All health providers involved in the follow-up care are responsible for updating the care plan.

6.3 Treatment summary

A treatment summary will be provided by the treating service(s) to the person and their whānau and to those clinicians involved in follow-up care.

The summary includes:

- the diagnostic tests performed and results
- cancer diagnosis, characteristics, stage, and prognosis
- treatment received (types and dates)
- current toxicities (severity, management and expected outcomes), including who to contact should they have any concerns about these
- interventions and treatment plans from other health providers
- potential long-term and late effects of treatment.

6.4 Rehabilitation and recovery

Rehabilitation may be required at any point in the care pathway. Issues that may need to be dealt with at this stage include managing cancer-related fatigue, coping with cognitive or physical changes, returning to study or work, and ongoing adjustment to cancer and its sequelae.

For people with acute lymphoblastic leukaemia, assessment for referral to the following rehabilitation or recovery services should be undertaken.

- Blood and Leukaemia Foundation.
- Psychological cancer services.

6.5 Follow up and surveillance

Follow up and surveillance can have multiple functions, including:

- evaluation of treatment response
- early identification of recurrence
- early detection of new primary tumours
- monitoring and management of complications
- optimisation of rehabilitation
- provision of support to the person and their whānau.

Care after treatment is driven by predicted risks and an individuals' clinical and supportive care needs.

Care includes regular physical examinations and medical tests and is based on the medical guidelines for the specific type and stage of cancer, the treatment that's been received, and the needs and wishes of the person and their whānau.

Regular follow up is recommended in a specialist clinical haematology clinic, with either the lead haematologist, other medical staff in-training, a haematology nurse practitioner or haematology-trained clinical nurse specialist. In some cases, follow-up appointments will be offered in regional haematology outreach clinics, or undertaken remotely, via telemedicine.

6.6 Signs and symptoms of recurrent disease

The likelihood of recurrence depends on many factors usually related to the type of cancer, the stage of cancer at presentation and the effectiveness of treatment.

Educating the person and their whānau about potential symptoms of recurrence is critical for timely management.

Signs and symptoms that might raise concern about recurrence and necessitate further investigation include:

- anaemia
- bone and joint pain
- bruising or petechiae (small red spots on the skin)
- fever
- recurrent infections
- abdominal pain
- swollen lymph nodes
- dyspnea or difficulty breathing.

The relapse may be discovered by the person or by surveillance in the post-treatment period. Access to the best available therapies, including clinical trials, as well as treatment overseen by a multidisciplinary team, are crucial to achieving the best outcomes for anyone with relapsed or refractory disease. There should be an immediate referral to a leukaemia multidisciplinary team specialist cancer service for all people with suspected or confirmed relapse.

Relapsed or refractory acute lymphoblastic leukaemia should be managed by a specialist haematologist service, at least initially. From the time of diagnosis, the team should offer people appropriate psychosocial care, supportive care, advance care planning and symptom-related interventions as part of their routine care. The approach should be personalised to meet the person's individual needs, values, and preferences.

6.6.1 Rapid re-entry to specialty services

Service providers have a process for rapid re-entry to specialty services for suspected recurrence and advise people and their whānau of how to do this if required.

6.7 Clinical trials

Where eligible, the person with cancer and their whānau are offered and supported to participate in research or clinical trials. These might include studies to understand survivor's issues, to better manage treatment side effects, or to improve models of care and quality of life.

6.8 Supportive care, care coordination and communication

As the person and their whānau transition from active treatment, their needs often change, and health providers need to support people and their whānau to cope with life beyond their active treatment (refer Principles 5, 6 and 7).

Health providers work with people and their whānau to assess and address their needs, including:

"The need for care doesn't stop when treatment finishes."
"Whānau feel forgotten when treatment ends."
Person/whānau insights

Supportive care
Health providers undertake a needs assessment to inform the survivorship care plan and make appropriate referrals.

Coordinated care

Follow-up care is provided closer to home and appointments coordinated to make access easier for the person and their whānau, where possible.

Continuity of care is provided where possible and appropriate – for example, people and their whānau should have the ability to continue to be supported by members of the care coordination team who they have developed a relationship with during their journey.

Effective and timely communication

The person and their whānau are provided with a copy of their survivorship care plan, including information on any referrals that have been made.

Health providers involved in the follow-up care of an individual have access to the up-to-date care plan, especially if primary care is involved, and can update the plan as required.

6.9 Measuring and monitoring

Currently there are no national indicators for this step.

Step 7: Palliative and end-of-life care

Palliative and end-of-life care provides the person facing life-limiting conditions with holistic support and coordinated services based on their specific needs.

Palliative and end-of-life care is an essential health service to optimise the person's quality of life until they die. This involves supporting the person's physical, psychosocial, spiritual, and cultural needs, and supporting their whānau with bereavement support. It is appropriate at any stage in a serious illness.

> **"You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you not only die peacefully, but also to live until you die."**
>
> Dame Cecily Saunders

7.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through ensuring that:

- the person and their whānau have the choice to access Kaupapa Māori support services for living with cancer (stable, progressive or end-stage)
- rurality does not restrict access to critical clinical, social, cultural and resource support for the person and their whānau
- palliative and end-of-life care is integrated across health services.

7.2 Palliative care

Palliative care prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other symptoms, whether physical, psychosocial, or spiritual, and improves the quality of life (World Health Organisation 2020).

Palliative care should be provided by all health professionals. Palliative care uses a team approach with non-specialist services (primary care, community care and generalist hospital services) supported by specialist palliative care services (hospitals, hospices). Palliative care services must be integrated with primary, community and secondary care, responsive and locally appropriate.

In many cases the whānau are the primary caregivers, and it is the responsibility of health providers/professionals to support the whānau. Health and social service providers/professionals will work together to ensure that the care for the person and their whānau is seamless, and that resources are used efficiently and effectively.

Primary, secondary, and palliative care services work alongside the person and their whānau to decide an appropriate place of care and the support required to implement the advance care plan.

Palliative care is provided in different settings, depending on availability and the needs and preferences of the person and their whānau. Settings include:

- in the community/a person's own home
- aged residential care

- hospice care
- hospital care.

Palliative care is most effective when considered early in the course of an illness. Early palliative care not only improves quality of life for the person and their whānau but also reduces unnecessary hospitalisations and use of health care services.

Referral to specialist palliative care services will be appropriate for those with a level of need that exceeds the resources of the generalist palliative care provider. Referral criteria for adult palliative care services in New Zealand are available on the **Ministry of Health | Manatū Hauora website**.

Clinical trials may improve palliative care and support the management of a person's symptoms of advanced cancer (Cancer Council Australia, nd; Cancer Council Victoria, nd). The treatment team should support the person and their whānau to participate in research and clinical trials where available and appropriate.

7.3 End-of-life care

The person with advanced cancer may reach a time when active treatment is no longer appropriate, symptoms are increasing, and functional status is declining. Dying is a normal part of every person's life course and every person has the right to die well.

Te Ara Whakapiri: Principles and guidance for the last days of life (Ministry of Health | Manatū Hauora 2017b) defines the essential components (baseline assessment, ongoing assessment, after-death care) and considerations required to provide quality end-of-life care for adults. This covers all care settings, including the home, residential care, hospitals, and hospices.

The multidisciplinary team needs to share the principles of a palliative approach to care when making end-of-life decisions with the person and their whānau. Honest communication is essential to ensure they have time to prepare and appropriate support is in place.

If the person does not already have an advance care plan or advance directive in place, a designated member of the team should encourage them to develop one in collaboration with their whānau.

It is essential for the treatment team to consider the appropriate place of care, the person's preferred place of death, and the support needed for the person and their whānau.

The treatment team should also ensure that whānau receive the information, support, and guidance about their role according to their needs and wishes.

7.4 Assisted dying

The person requesting assisted dying information is supported to access this service. Health providers/professionals are required to be aware of their rights and responsibilities should the person and their whānau raise this with the health care team. For more information visit: **regulation-health-and-disability-system/assisted-dying-service.**

7.5 Supportive care and communication

An essential component of palliative and end-of-life care is assessing and ensuring the needs of the person and their whānau are met. A number of supportive care needs may arise, including:

- assistance for dealing with emotional and psychological distress from grief and fear of death and dying
- specific support for the person and their whānau where a parent is dying and will leave behind bereaved children or adolescents
- facilitating conversations with the person and their whānau regarding an advance care plan, an advance directive and appointing an EPA
- access to appropriate equipment
- supporting whānau with carer training
- information and education around 'What to expect when someone is dying'
- identifying a key contact person.

7.5.1 Care coordination

Palliative care services must be integrated, responsive and well-coordinated. The person receiving palliative/supportive and end-of-life care may require several different types of care from different services and/or providers. The primary care team/palliative care team assists in coordinating care with the wider health care team. It is important that the different providers and services are aware of and responsive to the various facets of care that the person and their whānau require.

7.5.2 Communicating with the person/whānau receiving care

Health providers/professionals

- Encourage the person and their whānau to designate a lead person(s) to communicate with care providers.
- Encourage discussions about the expected disease course, considering personal and cultural beliefs and expectations.
- Discuss shared goals of care.
- Discuss palliative care options, including community-based services as well as dying at home.
- Empower the person and their whānau to determine the care that they may want to provide, with or without support services.
- Refer the person to palliative care in the community according to their wishes.
- Discuss supportive care options available.

"The difference in his wellbeing after rongoā was huge. He was still dying, but he didn't look sick anymore."
Person/whānau insights

7.5.3 Communicating between health services

Clear communication between all providers/professionals involved in coordinating care is essential. This includes:

- confirming the lead clinician and handover as necessary
- providing updates on the person's prognosis
- initiating supportive and palliative care referrals
- advising on end-of-life care planning.

7.5.4 Palliative care and end of life key national guidelines

- *Advance care planning.* (Te Tahu Hauora | Health Quality & Safety Commission New Zealand. 2022.) **hqsc.govt.nz**
- *A Guide For Carers. (***Hospice New Zealand** 2019).
- *Mauri Mate: A Māori palliative care framework* (**Hospice New Zealand**.2019)
- *Te Ara Whakapiri: Principles and guidance for the last days of life* (**Ministry of Health** | Manatū Hauora 2017b)
- *The Palliative Care Handbook* (**Hospice New Zealand** 2019b)
- *Information on assisted dying for the public* (**Health New Zealand** | Te Whatu Ora, nd)

"Palliative care is a tapu space and requires a careful, holistic approach."
Person/whānau insights

7.6 Measuring and monitoring

- **Ngā Paerewa Pairuri Tāngata | Standards for Palliative Care (Hospice New Zealand 2019a)**
    - Standard 1: Assessment of needs
    - Standard 2: Developing the care plan
    - Standard 3: Providing the care
    - Standard 4: Supporting and caring for the family, whānau and carers
    - Standard 5: Transitions within and between services
    - Standard 6: Grief support and bereavement care
    - Standard 7: Culture of the organisation
    - Standard 8: Quality improvement and research
    - Standard 9: Staff qualification and training
- **National palliative care outcomes and reporting framework** (under development).