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Optimal cancer care pathway for people with chronic lymphocytic leukaemia

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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 specialist 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
- Chronic lymphocytic 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 chronic lymphocytic 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. Chronic lymphocytic leukaemia (CLL) affects an increasing number of people with over 300 diagnosed with CLL 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 chronic lymphocytic leukaemia, 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 chronic lymphocytic 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 on 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.

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[1] Optimal Cancer Care Pathway Principles

Step 2: Early detection

This step recommends options for early detection for the person/whānau with suspected chronic lymphocytic leukaemia.

Early detection

Health care providers/professionals support the person and their whānau to identify and minimise modifiable risk factors for other types of cancer and health conditions.

Risk factors for chronic lymphocytic leukaemia include:
- older age
- family history
- gender – chronic lymphocytic leukaemia is more common in males and those of European descent, and less common in those of Asian descent
- chemical exposure.

Monitoring risk factors are particularly important for people with chronic lymphocytic leukaemia as they have an increased risk of developing other cancers including skin cancers, lung and upper aerodigestive cancers such as pharyngeal and oesophageal cancer.

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 chronic lymphocytic leukaemia.

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

A person and their whānau may present via primary care, an emergency presentation or incidental finding indicating a high suspicion of chronic lymphocytic leukaemia.

Signs and symptoms of chronic lymphocytic leukaemia to investigate include:
- painless swelling of lymph nodes that may fluctuate in size but don't completely resolve (within six to 12 weeks)
- unexplained weight loss of more than 10% of body weight within the past six months
- fever without signs of infection (rarely)

Step 3: Checklist

☐ All people with a high suspicion of cancer have a person to coordinate care.

☐ 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 investigations as required. Not everyone with suspected chronic lymphocytic leukaemia will

- severe, often drenching night sweats without signs of infection (uncommon)
- extreme fatigue (prevents person from working or doing their usual activities)
- frequent infections or first onset of herpes zoster reactivation
- lymphadenopathy
- splenomegaly
- hepatomegaly
- hypogammaglobulinemia
- autoimmune haemolytic anaemia
- symptoms/signs related to severe thrombocytopenia with a lymphocytosis.

Chronic lymphocytic leukaemia assessment includes the relevant:

- **medical history** including medications
- **physical examination**: Eastern Cooperative Oncology Group (ECOG) Performance Status Scale, frailty assessment, weight, careful palpation of all lymph node areas, spleen, and liver
- **laboratory investigations** including full blood count and blood film review, flow cytometry, urea, electrolytes, uric acid, creatinine, liver function tests, serum immunoglobulin levels and direct antiglobulin test if applicable
- **familial cancer history**
- **social history**.

Referral

If chronic lymphocytic leukaemia is diagnosed with minor peripheral blood lymphocytosis and the person is either well or have minimal symptoms, they can be managed by their GP.

If the chronic lymphocytic leukaemia diagnosis is in doubt or the results are inconsistent or indeterminate, GP will create a referral for advice and the triaging specialist will determine if a specialist appointment is required or the person can be managed by their GP.

If there is severe or symptomatic thrombocytopenia, anaemia, bulky/widespread/locally compressive lymphadenopathy, the general practitioner must refer the person to hospital specialist service urgently.

require a specialist referral as they can be managed by their General Practitioner (GP).

Timeframe

☐ The GP will conduct a full blood count and check the result promptly.

☐ Early stage, asymptomatic disease may be managed by the GP and not require a specialist referral.

☐ GP’s have the option to refer to hospital specialists for advice only and all referrals should be triaged **within 1-2 days.**

☐ If a hospital specialist review is required it will be prioritised according to clinical need with ‘immediate’ priority cases seen **within 48 hours,** urgent **within 1 week,** semi-urgent **within 4 weeks** and routine cases seen **within 4 months**.

Communication

☐ Explain to the 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 chronic lymphocytic leukaemia may include:
Physical examination: careful palpation of all lymph nodes areas, spleen, and liver.

Laboratory: surface markers of the peripheral blood, serum chemistry, serum immunoglobulin levels, direct antiglobulin test, serum protein electrophoresis and viral serology if applicable.

Selective investigations under certain circumstances (refer 4.2):

- marrow aspirate and biopsy
- computed tomography (CT) scans and other imaging
- molecular genetic tests
- tissue biopsy.

Staging:

There are two staging systems for chronic lymphocytic leukaemia: Binet and Rai. The Binet staging system is more commonly used across Australasia.

Binet stage A (low risk): fewer than 3 areas of lymphoid tissue are enlarged, with no anaemia or thrombocytopenia (with both axillae and both groins counted as a single site).

Binet stage B (intermediate risk): 3 or more areas of lymphoid tissue are enlarged, with no haemoglobin greater than 100 or platelets greater than 100).

Binet stage C (high risk): Haemaglobin and/or platelets less than 100. Any number of lymphoid tissue areas may be enlarged.

Performance status

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

Treatment planning
The majority of patients will undergo a period of watch and wait under the supervision of the GP with referral to a specialist team once the disease has progressed.

Step 4: Checklist

- ☐ Confirm diagnosis.
- ☐ A cancer care coordinator or cancer navigator should be available if required.
- ☐ Record phase, performance status and comorbidities.
- ☐ Discuss with the person and whānau the diagnosis and treatment options which includes watch and wait by the GP.
- ☐ Consider relevant clinical trials where treatment is indicated.
- ☐ Assess supportive care needs and refer to allied health services as required.
- ☐ Ensure primary or secondary prehabilitation is initiated to optimise overall well-being.
- ☐ Give the person and their whānau information on Cancer Society, Leukaemia and Blood New Zealand, Chronic Lymphocytic Leukaemia Advocates New Zealand[2] and/or relevant cultural services and support groups available.

Timeframe

If required, an MDM should occur **within 2 weeks** of the suspected or confirmed diagnosis.

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 person's General Practitioner (GP) about the diagnosis, treatment plan and recommendations from the MDM.

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[2] Chronic Lymphocytic Leukaemia: A guide for patients in New Zealand

Step 5: Treatment

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

Treatment options

Disease-directed therapy should not be initiated unless there are disease-related symptoms or evidence of disease progression.

Observation – the person that may benefit from observation including those with asymptomatic chronic lymphocytic leukaemia (modified Rai stage 0-1).

Systemic anti-cancer therapy (cytotoxic agents) – the person who may benefit from systemic therapy including those with advanced stage disease (modified Rai stage 2,3 or 4).

Targeted therapies and immunotherapy
Chemoimmunotherapy is the funded option for the majority of patients in New Zealand as of 2025.

Targeted therapy with BCL2 inhibitors and funded BTK inhibitors are used for certain mutations and relapsed chronic lymphocytic leukaemia.

Surgery – there is no routine therapeutic role for surgery except for very rare instances where splenectomy can be beneficial.

Radiation therapy – has very limited role but can be used to treat obstructive/bulky nodes or massive symptomatic splenomegaly, or to reduce symptoms during palliative treatment (e.g., pain resulting from lytic bone lesions).

Allogeneic stem cell transplant (Allo-SCT) – is rarely used for chronic lymphocytic leukaemia but may occasionally be used for very aggressive disease if the person is fit enough to tolerate the treatment, and when other treatment options are not likely to be successful.

Palliative care – early referral to palliative care for patients with treatment resistance disease 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 with the person and their whānau.

☐ Provide the agreed treatment plan with the person and 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 available support groups.

☐ Consider early referral to palliative care if appropriate.

☐ Discuss advance care planning with the person and their whānau.

Timeframes

☐ People requiring urgent treatment will begin **within 48 hours**.

☐ Those determined to be semi-urgent will begin **within 2 weeks**.

☐ Routine cases requiring treatment will begin **within 4 weeks**.

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 relapse • 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 and their whānau and GP. ☐ Assess supportive care needs and refer to allied health services as required. ☐ Give the person and their whānau information on Leukaemia and Blood Cancer New Zealand, Chronic Lymphocytic Leukaemia Advocates and the Cancer Society and/or relevant cultural services and available support groups. **Communication** The lead clinician and team are responsible for: ☐ explaining the treatment summary, follow up and surveillance care plan to the person and their whānau ☐ informing the person and their whānau about secondary prevention and healthy living ☐ informing the person's GP of the follow-up care plan ☐ 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. However, most people will die **with** chronic lymphocytic leukaemia and **not from** it. 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, treatment of pain and other symptoms, prevent and relieves suffering. End-of-life care should consider: • appropriate place of care • person's preferred place of death • support needed for the person and their whānau.	☐ Early referral to generalist palliative care if indicated. ☐ 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 timing of advance care plan, directive, or enduring power of attorney.

Awareness of and access to, assisted dying information should be available if the person raises 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 Pathways (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).

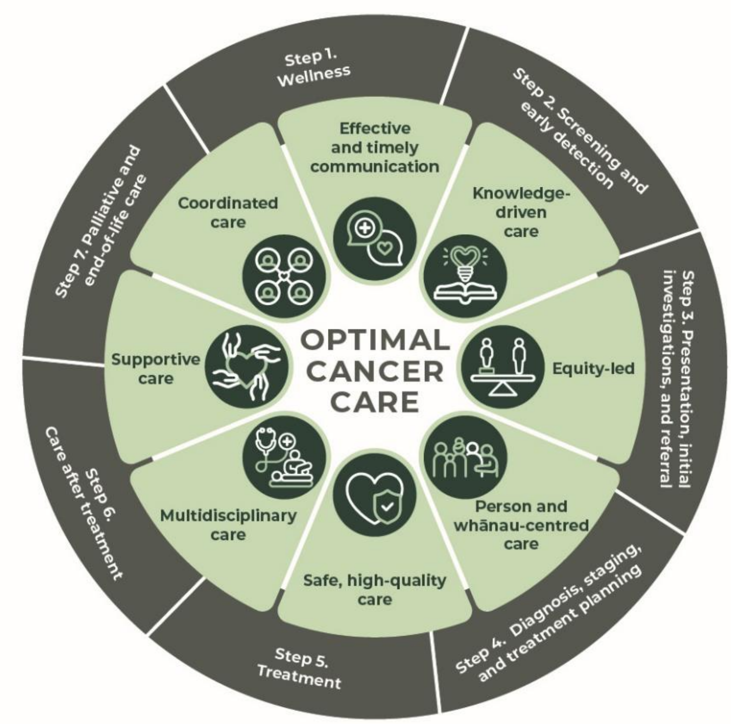
OCCPs are a framework for achieving health equity[2] in cancer control using a person and whānau centred approach to provide people with equitable, high-quality care, regardless of where they live or receive cancer treatment. OCCPs help to:

- 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



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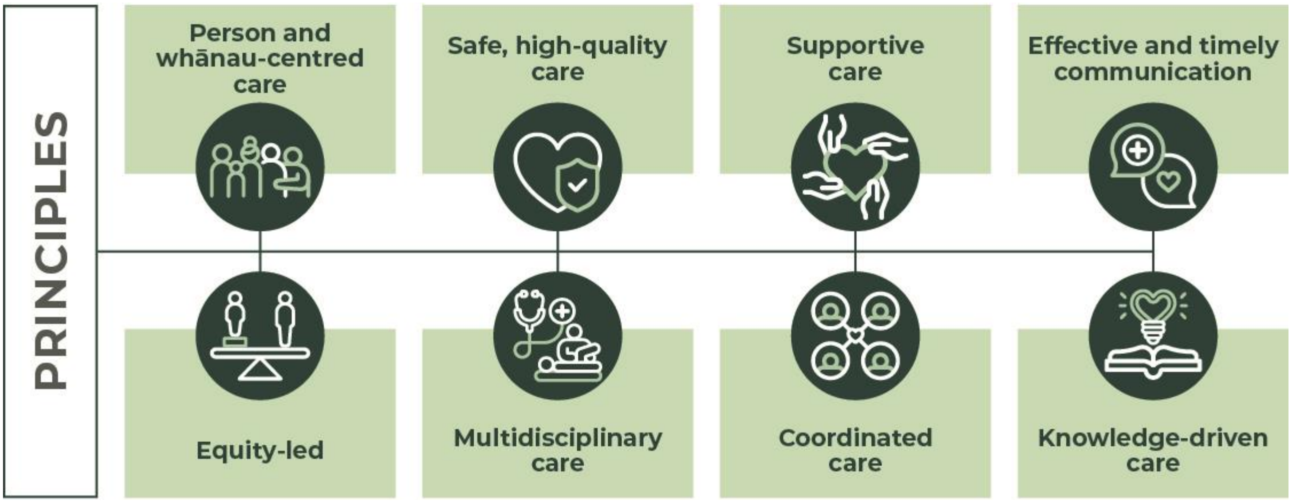
[2] Optimal Cancer Care Pathways Supplementary Information

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



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[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 and their 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	People with symptoms suggesting chronic lymphocytic leukaemia, the GP should conduct a full blood count and surface markers check the results **within 1-2 days**.
		If the chronic lymphocytic leukaemia diagnosis is in doubt or the results are inconsistent or indeterminate, the person and their whānau may be referred to a specialist service for advice and/or FSA with timeframes dependant on clinical urgency.
		If displaying the below symptoms or signs, the person and their whānau are referred to specialist service **within 72 hours**. • severe/symptomatic thrombocytopenia or anaemia such as haemoglobin under 70 g/L or platelets under 30×10^9 /L. • bulky (> 5 cm) and/or widespread lymphadenopathy or locally compressive lymphadenopathy.
	Referral to a hospital specialist	The person with symptomatic or advanced stage chronic lymphocytic leukaemia will require a referral to a specialist. Referrals should be triaged **within 1-2 days**
		Early stage and/or asymptomatic chronic lymphocytic leukaemia may be monitored by a person's GP
Step 4:	Diagnosis and staging	Most baseline studies should be performed **in the 2-4 weeks before** initiating treatment. CT scans can be done **up to 2 months prior.**

Diagnosis, staging, and treatment planning		Molecular cytogenetics, marrow aspirate and biopsy can be performed **up to 12 months before** starting treatment.
	Multidisciplinary team meeting and treatment planning	Where appropriate, chronic lymphocytic leukaemia cases are discussed in an MDM, before treatment begins. MDM takes place **within 2 weeks** of confirmed diagnosis and staging.
Step 5: Treatment		Timing of systemic anti-cancer therapy should be discussed to align with the person and their whānau's preference but not delayed to the point where impaired performance status, compromised organ function or recurrent severe infection occur.
		Radiation therapy should begin **within 72** hours where organ preservation is the goal.
		Radiation therapy should begin **within 2 weeks** in most cases for symptom control or palliation.

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

Chronic Lymphocytic Leukemia (CLL) and Small Lymphocytic Lymphoma (SLL) are two manifestations of the same disease process, which affects B-cell lymphocytes. When the malignant cells are present in the blood, it is referred to as chronic lymphocytic leukaemia. When they occur exclusively in the lymph nodes or other tissue, it is referred to as small lymphocytic lymphoma. However, the treatment is the same in both cases, and there is evidence that one can change into the other.

In this optimal cancer care pathway, we are referring to chronic lymphocytic leukaemia, but the information applies to both forms.

Data for chronic lymphocytic leukaemia is limited. A New Zealand based study from 2024 found cases per year (as an average from 2007 to 2019) had 252 total cases of which 229 were European and 23 Māori (Clough, Wheeler, Stanley et.al, 2024).

The aged-standardised incidence rate of chronic lymphocytic leukaemia in Aotearoa New Zealand is approximately 3.7 per 100,000 population. Among Māori, the aged-standardised incidence is slightly higher, at 4.2 per 100,000 population (cancer registry, 2024).

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 non-governmental organisations (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.

1.1 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

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 (EPA) as required (refer Principle 1)[1].

Communication between health services

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

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

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 suspected with chronic lymphocytic 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 cancer programmes, where possible (Te Aho o Te Kahu 2022)
- implementing programmes that enhance access to cancer services.

Māori and Pacific people 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

Chronic lymphocytic leukaemia is usually slow growing, and in most cases, it is picked up early during routine blood tests for unrelated conditions. It is important for people with early-stage chronic lymphocytic leukaemia to be monitored as they may become mildly immunocompromised and have an increased risk of developing other cancers.

2.3 Chronic Lymphocytic Leukaemia risk factors[4]

- Older age – majority of the people diagnosed with chronic lymphocytic leukaemia are over the age of 50.
- Family history – people with a first-degree relative (parent, sibling, or child) with chronic lymphocytic leukaemia or other lymphoproliferative disorders have a six- to nine-percent increased risk of developing chronic lymphocytic leukaemia, but the underlying genetic cause is unclear and there is no available screening test for a genetic predisposition.
- Chronic lymphocytic leukaemia is more common in males than females.

Exposure to certain chemicals such as pesticides, herbicides and some industrial chemicals.

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[4] IARC, 2025

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 including other cancers such as skin cancers.
- 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).

Communication between health services:

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

2.5 Measuring and monitoring

Measuring and monitoring 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.

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 chronic lymphocytic 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 a chronic lymphocytic 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

The person is assessed for signs and symptoms of chronic lymphocytic leukaemia, including any unexplained, persistent signs and symptoms lasting more than three weeks (or earlier in people with known risk factors). The presence of multiple signs and symptoms, particularly in combination with other underlying risk factors, may indicate an increased risk of cancer.

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

Most people with chronic lymphocytic leukaemia are asymptomatic when they are diagnosed. Often chronic lymphocytic leukaemia is recognised after lymphocytosis is found from a routine blood test performed for other reasons.

Signs and symptoms suspicious for chronic Lymphocytic leukaemia include:

- painless swelling of lymph nodes that may fluctuate in size but don't completely resolve (within six to 12 weeks) – this can affect any lymph nodes but often occurs around the neck
- unexplained weight loss of more than 10% of body weight within the past six months
- fever without signs of infection (rare)
- severe, often drenching night sweats without signs of infection (uncommon)
- extreme fatigue (prevents person from working or doing their usual activities)
- frequent infections or first onset of herpes zoster reactivation.

- lymphadenopathy – 50 to 90% of people with chronic lymphocytic leukaemia experience enlarged lymph nodes (cervical, supraclavicular, and axillary are the most common areas). High suspicion of chronic lymphocytic leukaemia should be considered with generalized or bulky lymphadenopathy and a significant lymphocytosis
- splenomegaly – 25 to 55% of cases. High suspicion of chronic lymphocytic leukaemia should be considered in people with unexplained moderate to severe splenomegaly and significant lymphocytosis
- hepatomegaly – 15 to 25% of cases.

If any of the following abnormalities are found, chronic lymphocytic leukaemia should be investigated as a possible underlying cause:

- hypogammaglobulinemia – present in a quarter of people with chronic lymphocytic leukaemia at initial diagnosis and becomes more prevalent as the disease progresses
- autoimmune haemolytic anaemia
- signs and symptoms related to severe thrombocytopenia with a lymphocytosis.

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

Chronic lymphocytic leukaemia assessment includes relevant:

- medical history with related medications
- physical examination: Eastern Cooperative Oncology Group (ECOG) Performance Status Scale, frailty assessment, weight, careful palpation of all lymph node areas, spleen, and liver
- laboratory investigations:
    - a full blood count to establish the extent of the lymphocytosis, the presence of any cytopenia, and blood film review to assess lymphocyte morphology
    - flow cytometry (surface markers) to confirm the clonal nature and immunophenotypic pattern of the lymphocytes
    - urea, electrolytes, uric acid, and creatinine
    - liver function tests
    - serum immunoglobulin levels and direct antiglobulin test if applicable (Coombs' test).
- familial cancer history
- social history.
- lymph node biopsy is generally not necessary even if lymphadenopathy is present clinically or on imaging
- imaging should only be performed when there are concerns around local symptoms, compression, or very bulky nodes to exclude a local complication such as hydronephrosis or vascular compression.

3.4 Initiate investigations, including referrals

- If chronic lymphocytic leukaemia is diagnosed with minor peripheral blood lymphocytosis and the person is either well or has minimal symptoms, haematology specialist referral and work-up are not required in these typical cases. The person should have a full blood count **3-6 monthly.**
- General practitioners should provide reassurance and clearly explain the slow-growing nature of chronic lymphocytic leukaemia, noting that typical intervention is not needed for several years, and up to one-third of people with chronic lymphocytic leukaemia may never require treatment. This is in sharp contrast to people who develop acute forms of leukaemia.
- The diagnosis of chronic lymphocytic leukaemia can be very stressful for some people and their whānau, and they may choose to have a haematology consultation in private.
- If the chronic lymphocytic leukaemia diagnosis is in doubt or the results are inconsistent or indeterminate, the general practitioner must refer the person to the haematology service.
- Referral to a specialist should take place once significant lymphocytosis and/or a leukaemic cell population is identified.
- Referring provider should receive acknowledgment of referral.

According to the International Working Group Guidelines (2018), chronic lymphocytic leukaemia is diagnosed when there are more than 5.0×10^9 /L B-lymphocytes in the peripheral blood for at least three months and clonality is confirmed by demonstrating immunoglobulin light-chain restriction on flow cytometry. Lower levels of clonal B-cell lymphocytosis may suggest the related disorder known as monoclonal B-cell lymphocytosis (MLUS) and should be monitored in a primary care setting.

Timeframe for completing investigations for the person with suspected Chronic Lymphocytic Leukaemia

The primary healthcare provider should conduct a full blood count and surface markers and check the results promptly.

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
- chronic lymphocytic leukaemia specific symptoms and signs, see above.

Timeframe for referring to a specialist

People that require prompt referral to a specialist **within 72 hours** are:
- severe/(symptomatic) thrombocytopenia or anaemia such as haemoglobin under 70 g/L or platelets under 30×10^9 /L
- locally compressive lymphadenopathy.

The specialist should assess the person **within 48 hours**, or sooner if medically warranted.

Presumed chronic lymphocytic leukaemia with widespread small volume lymph nodes, the person should be assessed according to urgency.

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 and 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
- if necessary, referral to a counsellor may be required to help the person and their whānau come to terms with the uncertainty of a chronic lymphocytic leukaemia diagnosis and the challenges of the ‘watch and wait’ approach.

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.

> ***“Whānau face multiple barriers to primary care”. “That safety net had been taken away.”***
> Person/whānau insights

- Request that the person notify the delegated clinic or their own GP practice if the service referred to 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.

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

There are no national measures that inform this step

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 stage the cancer, provide treatment options and recommendations, and help meet any identified needs. For the majority of people with chronic lymphocytic leukaemia this will be in primary care initially. 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 and subsequent treatment plan.

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, 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 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 chronic lymphocytic leukaemia)

Once the full blood count and immunophenotyping have confirmed the diagnosis of chronic lymphocytic leukaemia, the clinician, may then request additional investigations before or after the first appointment and could include:

Physical examination:

- careful palpation of all lymph node areas, spleen, and liver
- thorough skin check for any pre-cancerous or cancerous skin lesions.

Laboratory: flow cytometry serum chemistry (creatinine, uric acid, bilirubin, lactate dehydrogenase, haptoglobin, transaminases, alkaline phosphatase, ß2-microglobulin), serum immunoglobulin levels, direct antiglobulin test and serum protein electrophoresis if applicable to look for the presence of any paraprotein. Viral serology (hepatitis B, hepatitis C, HIV, Epstein-Barr virus, and cytomegalovirus).

The following investigations are only recommended under certain circumstances.
Marrow aspirate and biopsy: when the cause of any cytopenia (neutropenia, anaemia, thrombocytopenia) is unclear, disease phenotype is inconclusive, or the exact diagnosis is uncertain.

Computed tomography (CT) scans and other imaging:

- the person with symptoms, or where treatment will be initiated, CT scans may be necessary to assess the tumour burden and risk of tumour lysis syndrome
- they can be used in clinical trials to form a baseline and assess treatment response
- CT scans are not recommended for asymptomatic people or during routine evaluation

Molecular genetics tests: although not recommended at diagnosis, these should be done before initiating treatment or when there are signs of disease progression that may lead to treatment initiation. Molecular genetic tests inform the most appropriate therapy and are useful to predict prognosis.

Tissue biopsy: features that can suggest the presence of Richter's transformation include:

- new-onset B-cell symptoms (fevers, night sweats, weight loss)
- rapidly growing, or a specific site of dominant or bulky, lymphadenopathy
- markedly elevated serum LDH level, or a new onset of hypercalcaemia
- atypical extranodal site of disease involvement such as central nervous system, kidney, lytic bone lesions etc. or significantly elevated avidity (SUVmax above 5 – 10) on FDG-PET scanning.

Five to 10% of people with chronic lymphocytic leukaemia will develop a more aggressive form of lymphoma (diffuse large B-cell lymphoma or Hodgkin lymphoma) at some point during their disease course. This is termed Richter's transformation. The managing team need to consider this possibility at every instance of disease evaluation and weigh up the potential need for a tissue biopsy. For more information see the optimal cancer care pathway for people with Hodgkin and diffuse large B-cell lymphomas.

Timeframe for completing investigations

Most baseline evaluation studies should be performed in the **2-4weeks** before initiating treatment.

CT scans can be done **up to 2 months** prior, unless Richters transformation is suspected.

Molecular cytogenetics (FISH), marrow aspirate and biopsy can be performed **up to 12 months** before starting treatment, provided there has been no intervening therapies and the general disease course is unchanged.

4.3 Staging system

Accurately staging cancer helps guide treatment decisions and is a significant contributor to providing a cancer prognosis (Te Aho o Te Kahu 2021a). Chronic lymphocytic leukaemia does not normally form solid tumours, generally appearing in bone marrow and blood. In many cases chronic lymphocytic leukaemia will spread to organs such as spleen, liver, and lymph nodes. There are two staging systems (Binet system used mostly in Europe and Australasia and Rai system used mostly in the United States of America) that can be used to determine whether active treatment is required.

4.3.1 Binet system

Binet stage A (low risk): fewer than 3 areas of lymphoid tissue are enlarged, with no anaemia or thrombocytopenia (with both axillae and both groins counted as a single site).

Binet stage B (intermediate risk): 3 or more areas of lymphoid tissue are enlarged, with no haemoglobin greater than 100 or platelets greater than 100).

Binet stage C (high risk): Haemoglobin and/or platelets less than 100. Any number of lymphoid tissue areas may be enlarged.

4.3.2 Modified Rai system

Low risk:

- Rai Stage 0 – an isolated peripheral blood lymphocytosis > 5 × 10^9 /L

Intermediate risk:

- Rai Stage 1 – lymphocytosis and lymphadenopathy on clinical examination
- Rai Stage 2 – lymphocytosis and hepatomegaly and/or splenomegaly with/without lymphadenopathy

High risk:

- Rai Stage 3 – lymphocytosis and haemoglobin < 110 g/L with/without lymphadenopathy/ organomegaly
- Rai Stage 4 – lymphocytosis and platelets < 100 × 10^9 /L with/without lymphadenopathy/organomegaly.

It may be more useful to define Chronic Lymphocytic Leukaemia as:

- early-stage disease - modified Rai Stages 0 or 1
- late-stage disease - modified Rai Stages 2, 3 or 4.

4.3.2 Prognostic model

Newer prognostic models such as the **Chronic Lymphocytic Leukaemia International Prognostic Index** can identify people with high-risk disease who may benefit from investigational therapy, as well as those who have a good prognosis despite an advanced stage.

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 the most.

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

4.5 Multidisciplinary meeting

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

Referral to leukaemia or lymphoma MDM is undertaken if indicated to inform treatment recommendations or further assessment and investigation, although most cases of chronic lymphocytic leukaemia are not dealt with by a MDM.

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)

4.5.1 Treatment options and recommendation

The medical team will discuss, treatment options including the intent, referral options and recommendations 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.

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.

4.5.2 Fertility preservation and contraception

If applicable the person and their whānau need to be advised about contraception before, during and after treatment, including fertility preservation if appropriate. The need for ongoing age-appropriate contraception applies to both men and women.

4.5.3 Prehabilitation

Prehabilitation 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 (preparing for treatment) 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 functional level
- smoking cessation
- education support for 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.

4.5.4 Clinical trials

Where eligible, the person with cancer is 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.

4.6 Supportive care and communication

4.6.1 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 Principle 6).

4.6.2 Supportive Care

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

- care coordinator is in place
- prehabilitation
- contraception and fertility support
- early referral to palliative care
- information and education needs are met (refer to Step 3.5).

4.6.3 Communicating with the person/whānau receiving care

Health providers/professionals

- Ensure that people and their whānau have the option to have additional support with them when having any discussion.
- Explain and discuss 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, education support 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.
- 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.

> ***“A lot of people need to travel hours to get to an appointment and don’t have vehicles or family support.”***
> Person/whānau insights

- Clarify that the information that has been communicated has been understood.
- 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.

The person and their whānau may require time to process the information that has been relayed, prior to consenting to treatment.

Communicating between health services

- Where possible health services should coordinate appointments, in discussion with the person and their whānau.
- Communicate the diagnosis, MDM recommendations and treatment plan between health services.
- Discuss and agree shared care arrangements, for symptom and co-morbidity management, supportive care, and referral to local services.

4.7 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 chronic lymphocytic Leukaemia by trained and experienced clinicians and team members, in an appropriate environment.

Chemoimmunotherapy is the funded option for the majority of patients in New Zealand as of 2025.

Targeted therapy with BCL2 inhibitors and funded BTK inhibitors are used for certain mutations and relapsed chronic lymphocytic leukaemia.

Internationally accepted guidelines for the treatment of chronic lymphocytic leukaemia used to inform clinical practice are listed below:

- European Society of Medical Oncology: *Chronic lymphocytic leukaemia ESMO clinical practice guidelines for diagnosis, treatment and follow up* **esmo-clinical-practice-guidelines-haematological-malignancies**
- British Society for Haematology: *Guideline for the treatment of chronic lymphocytic leukaemia* **British Society for Haematology guidelines**
- International Workshop on Chronic Lymphocytic Leukaemia (iwChronic Lymphocytic Leukaemia): *iwChronic Lymphocytic Leukaemia guidelines for diagnosis, indications for treatment, response assessment, and supportive management of Chronic Lymphocytic Leukaemia* **iwChronic Lymphocytic Leukaemia-guidelines-Chronic Lymphocytic Leukaemia**
- American Society for Transplantation and Cellular Therapy (ASTCT) practice guidelines **astct-publications**
- European Society for Blood and Marrow Transplantation (EMBT) 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 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 established in a multidisciplinary meeting/setting (see Step 4.6), documented in the person's medical record, and shared with the person and their whānau. 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 a 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, including 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).

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.

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 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 chronic lymphocytic leukaemia depends on the stage of the cancer and the person's age, health, and preferences. Treatment may include a combination of the items listed below, concurrently, or sequentially, to maximise outcome.

Disease-directed therapy should not be initiated unless the person is symptomatic or shows evidence of progression. The *iwChronic Lymphocytic Leukaemia Guidelines* for signs of 'active' chronic lymphocytic leukaemia may include any of the following:

- new or worsening anaemia or thrombocytopenia
- massive, progressive, or symptomatic splenomegaly or lymphadenopathy
- sustained progressive lymphocytosis (50% or greater increase over two months or lymphocyte doubling time in under six months)
- autoimmune complications including anaemia or thrombocytopenia that respond poorly to corticosteroids

- extranodal involvement impacting organ function or causing symptoms (e.g., skin, kidney, lung, spine)
- any of these disease-related symptoms: unintentional weight loss of more than 10% within the last six months; extreme fatigue (unable to work or perform usual activities), fever of 38°C for two or more weeks without evidence of infection; night sweats for a month or longer without evidence of infection.

For more detailed information on the criteria for initiating treatment, see the ***iwChronic Lymphocytic Leukaemia Guidelines.***

Treatment decisions will be based on molecular test results, age, comorbidities, potential interactions with other medicines and the person and their whānau preferences.

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.

- **Watch and wait**

The person with asymptomatic chronic lymphocytic leukaemia (modified Rai stage 0-1) may benefit from observation as early-stage status does not change survival, therefore an initial 'watchful waiting' approach is recommended. People should be monitored **every 3 months during the first year, and then every three to 12 months**, depending on the stability and specific characteristics of their cancer.

- **Systemic anti-cancer therapy -** the person with advanced stage disease may benefit from systemic anti-cancer 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).

Chemotherapy is not recommended for a small cohort of people with certain mutations. However, most people with advanced stage chronic lymphocytic leukaemia will benefit from systemic anti-cancer therapy.

Chemoimmunotherapy has established curative potential for the subset of affected people with favourable biologic features, and can be considered in younger, fit people with adequate renal function (age < 65 with creatinine clearance ≥ 70 mL/min).

People with significant comorbidities or impaired organ function, less intensive chemoimmunotherapy may be used. These treatments can be life-prolonging but do not have curative potential.

Pneumocystis jirovecii pneumonia prophylaxis may be required for affected people receiving certain types of chemoimmunotherapy.

Rate of progression is usually gradual, and treatment initiation is rarely urgent. Timing should be discussed to align with the person and their whānau's preferences but not delayed to the point where impaired performance status, compromised organ function or recurrent severe infections occur.

- **Targeted and immuno-therapies** are offered according to stage of chronic lymphocytic leukaemia, molecular target test results, general health status of the person, their ability to tolerate side effects and the person and whānau preference.

- **Surgery -** there is no routine therapeutic role for surgery in managing people with chronic lymphocytic leukaemia, except for very rare cases where splenectomy can be beneficial.

- **Radiation therapy -** has a limited role in chronic lymphocytic leukaemia but can be used to treat obstructive and/or bulky nodes, severe symptomatic splenomegaly, or to reduce symptoms during palliative treatment (e.g., pain resulting from lytic bone lesions).

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

Allogeneic stem cell transplant (Allo-SCT) – is rarely used for chronic lymphocytic leukaemia but may occasionally be used for very aggressive disease if the person is fit enough to tolerate the treatment, and when other treatment options are not likely to be successful.

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

Timeframes for starting treatment

Where organ preservation is the goal, as in hydronephrosis, radiation should commence **within 72 hours** of determining the need.

Where symptom relief and palliation are the goals, appropriate timing is guided by the severity of symptoms and can be commenced **within 2 weeks.**

- **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 may experience.

Early referral to palliative care and other health services are recommended to help manage disease-related symptoms and side effects from treatment.

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 to the person and their whānau and clinicians (including primary care) involved in their follow up 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: surgery, systemic-anti cancer therapy, radiation, allogeneic stem cell transplant and palliative care.

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

- access to expert health providers/professionals with specific knowledge about the psychosocial needs of people undergoing chronic lymphocytic 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, 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.

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.

> ***"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

5.6 Measuring and monitoring

Measuring and monitoring 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).

- **Radiation oncology treatment timeframes**[5]
    - Category A – treat within 24 hours.
    - Category B – treat within 10 working days.
    - Category C (palliative intent) – treat within 10 working days
    - Category C (curative intent) – treat within 20 days.
    - Category D – combined modality treatment (determined by scheduling of the two treatment modalities).
    - Category E (benign disease) – treat within 80 working days.

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[5] Radiation Oncology Waitlist Data Business Rules – Te Whatu Ora

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 primary healthcare provider 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.
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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 Chronic Lymphocytic Leukaemia, assessment for referral to rehabilitation or recovery services such as psychological services for cancer should be undertaken.

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. Ongoing monitoring will look for evidence of significant disease progression, response to therapy, and subsequent disease relapse. Ready access to community laboratory testing is essential, with access to haematology specialist care if active treatment is required or complications develop.

After completing time-limited treatment, a clinical review follow up should occur **three monthly,** with **monthly** full blood count testing. After the first year of follow up this may extend out to **six monthly** with **three monthly** full blood count testing. From the third year onwards, follow up may move to a clinical review **annually** and full blood count testing **≥ 3 monthly**. These principles also apply to those people with controlled disease who are receiving continuous therapies.

Given the chronic and often incurable nature of chronic lymphocytic leukaemia, as well as the frequent use of continuous therapies, long-term management is recommended to retain strong engagement with the primary specialist.

Long-term disease remission, whether on continuous therapy or after completing time-limited therapy, people with chronic lymphocytic leukaemia may have a prolonged compromised immune system, increased risk of developing hypogammaglobulinemia, and significantly increased risk of both melanoma and non-melanoma skin cancers.

UV precautions and regular skin checks are recommended. It is also important to ensure people stay up to date with recommended vaccinations including the annual seasonal influenza and five-yearly pneumococcal vaccinations.

While people with chronic lymphocytic leukaemia have an ongoing risk of herpes zoster reactivation, they are also immunocompromised and may not be suitable for zoster vaccinations with live attenuated formulations, however inactivated formulations are now available, and fully funded for those aged over 65. For some affected people who are very immunocompromised, specialist infectious diseases guidance may be appropriate.

Chronic lymphocytic leukaemia, along with the cumulative physical and psychological effects of prolonged or repeated phases of treatment, pose substantial psychological burdens for the person, their whānau and carers. This should be a focus throughout all phases of care.

Responsibility for follow up care should be agreed between the lead clinician, the general practitioner, relevant members of the multidisciplinary team and the person and their whānau and may be a shared care arrangement.

Note that for some people follow up appointments are reassuring; however, for others this may be anxiety-inducing.

6.6 Signs and symptoms of relapsed or progressive disease

Chronic lymphocytic leukaemia is rarely cured, and in most cases, disease will recur or progress after initial therapy. The rate of progression is usually gradual, although typically it is slightly more rapid after initial diagnosis. An increase in lymphocyte count does not automatically mean further treatment is needed. Many people who have relapsed chronic lymphocytic leukaemia, without symptoms can be safely and appropriately monitored. Therapy should only be restarted when there are other signs or symptoms of disease progression.

Five to 10% of people with chronic lymphocytic Leukaemia will develop a more aggressive form of lymphoma (diffuse large B-cell lymphoma or Hodgkin lymphoma) at some point during their disease course (termed Richter’s transformation). The team managing the persons care, need to consider this possibility at every instance of disease recurrence and weigh up the potential need for further investigation with a tissue biopsy.

Features that can suggest the presence of Richter’s transformation and prompt repeat tissue biopsy of the most suspicious site include:

- new-onset B-cell symptoms (fevers, sweats, weight loss)
- rapidly growing, or a specific site of dominant or bulky, lymphadenopathy
- markedly elevated serum LDH level or new onset of hypercalcemia
- atypical extranodal site of disease involvement such as central nervous system, kidney, lytic bone lesions etc. or significantly elevated avidity (SUVmax above 5 – 10) on FDG-PET scanning.

Other signs and symptoms of recurrent or progressive chronic lymphocytic leukaemia include:

- increasing fatigue
- recurrent infections.

These symptoms are usually recognised by the person and reported at routine reviews. Lymphocytosis or developing cytopenia may be identified by regular full blood counts.

The signs of active disease are:

- new or worsening anaemia and/or thrombocytopenia
- massive or worsening splenomegaly or lymphadenopathy
- lymphocyte doubling in less than six months, or lymphocytosis increasing by more than 50% over two months
- autoimmune complications that don't respond well to corticosteroids
- extranodal involvement impacting organ function or causing symptoms (e.g., skin, kidney, lung, spine)
- night sweats, fatigue, unintentional weight loss or fever.

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:

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.

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

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 age and stage in a serious illness.

Most people die **with** their chronic lymphocytic leukaemia, **not from it**.

> **"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 primary/generalist palliative care provider. Referral criteria for adult palliative care services in New Zealand are available on the **Health New Zealand |Te Whatu Ora 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 regarding assisted dying services, should the person 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 person and their whānau 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.

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

7.5.4 Palliative care and end of life key national guidelines

- *Advance care planning.* **Health New Zealand | Te Whatu Ora**
- *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)

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).