TE AHO
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Optimal cancer care pathway for people with low grade lymphoma

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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
- Low grade lymphoma 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 low grade lymphoma 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. Lymphoma affects an increasing number of people with more than 750 diagnosed this year. Around 300 people will die from some form of lymphoma this year. We all believe that people and their whānau deserve the best cancer care available.

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

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

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

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

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

Ngā mihi nui,

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

Summary guide of low grade lymphoma OCCP information

Quick reference guide of condensed tumour stream

The Optimal Cancer Care Pathways (OCCP) describe the standard of care that people and whānau across Aotearoa, New Zealand should expect the public health system to be striving for. They follow eight principles[1]: person and whānau-centred care; equity-led; safe, high-quality care; multidisciplinary care; supportive care; coordinated care; effective and timely communication; and knowledge-driven care.

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

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

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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 low grade lymphoma.

Early detection

Modifiable low grade lymphoma risks include:
- exposure to chemicals like pesticides and benzene
- being overweight or obese.

Non-modifiable risk factors for low grade lymphoma include:
- increasing age
- having a first-degree relative with a low grade lymphoma
- radiation exposure with previous radiotherapy +/-chemotherapy for other cancers
- autoimmune diseases
- infections.

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 low grade lymphoma.

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 low grade lymphoma.

Signs and symptoms of low grade lymphoma:
- a lump or mass in any organ
- lymphadenopathy, particularly if persistent beyond 2 weeks
- splenomegaly, with or without systemic symptoms, in the absence of, or resolution of, any infection
- one or more systemic symptoms even in the absence of lymphadenopathy: fever, drenching night sweats, unexplained weight loss, frequent infections
- unexplained cytopenia
- persistent lymphocytosis.

Indicators of concerns that should lead to prompt referral to a specialist include:

Step 3: Checklist

☐ Record signs and symptoms.

☐ Complete all cancer assessments.

☐ Inform the person and their whānau of preliminary results.

☐ Referral options of cancer care are discussed with the person and their whānau, including cost implications if private provider requested.

☐ Complete and record supportive care needs assessment and refer to allied health services as required.

☐ Inform the person and their whānau of cultural services and relevant support groups available.

☐ Initiate referrals and arrange further investigation.

Timeframe

☐ If there is a high suspicion of low grade lymphoma, submit referral **immediately** to hospital specialist services.

☐ Confirm that the person referred urgently with a high suspicion of cancer will attend their first specialist assessment (FSA) clinic.

- symptoms or results indicating organ dysfunction and low blood counts
- symptoms that suggest neurological involvement
- markedly elevated LDH
- marked B symptoms (weight loss > 10%, persistent fevers > 38°C, or persistent drenching night sweats).
- very widespread or bulky lymphadenopathy.

Low grade lymphoma assessment includes the relevant:

- **medical history**, including medications immunosuppressive medications or immunosuppressed for other reasons, underlying autoimmune disease
- **physical examination:** skin, lymph node groups, oral examination for enlarged Waldeyer's ring, abdominal examination for evidence of splenomegaly, cardiorespiratory examination
- **radiology:** ultrasound scan, chest X-ray, computed tomography (CT)
- **laboratory:** full blood count, routine electrolytes and renal function, calcium, urate, liver function, lactate dehydrogenase
- **familial cancer history**: family history of lymphoma
- **social history**.

Referral

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

If the person presents with one of the following red flags, the referral should be triaged as a high suspicion of cancer:

- persistent lymph node enlargement > 2 weeks in the absence of infective symptoms
- lymphadenopathy persistent for 4 weeks or lymph nodes rapidly increasing in size (otherwise unexplained)
- lymph nodes > 2cm, widespread nature, firm, non-tender
- unexplained drenching night sweats or fevers or weight loss of greater than 10% of body weight
- radiology suspicious for lymphoma.

☐ Where there is clinical urgency, contact the relevant specialist for advice and prompt consultation. Inform the person and their whanau, where to present i.e., emergency department, clinic rooms.

☐ Where there are indicators of concern i.e., organ dysfunction or neurological involvement, urgent referral to a specialist centre is required and the person is contacted. Rapid access pathways should be in place to ensure evaluation and urgent review.

☐ Where lymphoma is identified by biopsy or strongly suggested, referral to a specialist should occur **within 72 hours**.

☐ For the person who does not need an urgent referral to a specialist i.e. indolent lymphoma, all investigations should be completed, and a path of action decided, **within 2 weeks**.

Communication

☐ Explain to person and their whānau that they are being referred to a hospital specialist service and why, including:

- how long this may take
- who to contact if their symptoms change
- how to follow up if they do not receive their specialist appointment within the specified time.

Step 4: Diagnosis, staging and treatment planning

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

Diagnosis for low grade lymphoma may include:
Surgery: least invasive surgical method is recommended for diagnosis.

Pathology: excisional biopsy is the preferred method where possible. Fine needle aspiration may be appropriate when biopsy is overly invasive or not feasible.

Laboratory: blood test including B2M, immunoglobulin, lactate dehydrogenase (LDH), serum protein electrophoresis, autoimmune screening, and viral screening

Staging:

- bone marrow biopsy
- CT
- positron emission tomography (PET)-CT
- gastroscopy +/- colonoscopy (for mantle cell lymphoma)
- endoscopy ultrasound (for gastric marginal zone lymphoma)
- magnetic resonance imaging (MRI) (for orbital/ocular adnexa marginal zone lymphoma).

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

Clinical genetic testing
Currently there are no genetic tests applicable to predict family risk of low grade lymphomas.

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

Step 4: Checklist

- ☐ Confirm diagnosis.
- ☐ Referral to a cancer care coordinator.
- ☐ Record staging, performance status and comorbidities.
- ☐ Discuss the person's diagnosis at a multidisciplinary meeting (MDM) and inform the person and their whānau of the treatment decision.
- ☐ Consider enrolment in clinical trial.
- ☐ All people with a high suspicion of cancer have a person to coordinate care.
- ☐ Assess supportive care needs and refer to allied health services as required.
- ☐ Ensure primary or secondary prehabilitation to optimise overall well-being is initiated.
- ☐ Referral to lymphoma specific support services as required.
- ☐ Give the person and their whānau information on Cancer Society, Canteen, Leukaemia and Blood New Zealand and/or relevant cultural services and support groups available.

Timeframe

If required, an MDM should occur **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 GP of the person and their whānau about the diagnosis, treatment plan and recommendations from the MDM.

Step 5: Treatment

This step describes publicly funded optimal treatments for low grade lymphoma by suitably trained and experienced clinicians and team members, in an appropriate environment.

Treatment options

Watch and wait – people who may benefit include those with:

- stage II follicular lymphoma (FL) (non-contiguous lymph nodes, or not amendable to radiation therapy)
- advanced stage FL (stages III and IV)
- asymptomatic average-stage nodal marginal zone lymphoma (MZL)
- indolent form of mantle cell lymphoma (MCL).

Radiation therapy - people that may benefit include those with:

- early-stage FL (stage I and stage II in which lymph nodes are contiguous)
- low-volume, advanced-staged disease (in a highly select group of people)
- localized relapsed low grade lymphoma
- advanced-stage low grade lymphoma for symptom control.

Systemic anti-cancer therapy – people who may benefit from systemic anti-cancer therapy include most people with non-contiguous stage II or stage III-IV disease who are symptomatic by GELF/BCNI criteria and considered fit enough to experience a positive risk-benefit balance of ongoing treatment.

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

Step 5: Checklist

☐ Health providers/professional, treating specialist has relevant qualifications, experience, and expertise.

☐ Discuss the intent of treatment and the risks and benefits with the person and their whānau.

☐ Provide the agreed treatment plan with the person, their whānau and GP.

☐ Assess supportive care needs and refer to allied health services as required.

☐ Give the person and their whānau information on the cancer non-governmental organisations (NGOs,) cultural services and support groups available.

☐ Consider early referral to palliative care if appropriate.

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

Timeframes

☐ The person with a confirmed diagnosis of low grade lymphoma receives their first treatment **within 31 days** of the decision to treat.

☐ The person referred urgently with a high suspicion of low grade lymphoma receives their first cancer treatment **within 62 days.**

☐ In FL and MZL, if the person meets GELF/BCNI criteria to start, systemic anti-cancer therapy should begin **within 4 weeks**.

☐ Most people with symptomatic MCL should begin treatment with systemic anti-cancer therapy **within 2 weeks** of completing staging.

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

The person and their whānau access appropriate follow up and surveillance and are supported to achieve their optimal health after cancer treatment.

Provide a summary of the treatment and follow-up care plan to the person, their whānau and their GP outlining:

- diagnosis, including tests performed and results
- treatment received (types and date)
- current toxicities (severity, management and expected outcomes)
- interventions and treatment plans from other health providers/professionals
- potential long-term and latent effects of treatment and care of these
- supportive care services provided
- a follow-up schedule, including tests required and timing
- contact information for key health care providers/professionals who can offer support for lifestyle modification
- a process for rapid re-entry to medical services for suspected recurrence
- ongoing assessments of the effects of treatment.

Step 6: Checklist

☐ Provide a survivorship plan that includes a summary of the treatment and follow-up care plan to the person, whānau and their GP.

☐ Assess supportive care needs and refer to allied health services as required.

☐ Give the person and their whānau information on Cancer Society and/or relevant cultural services and support groups available.

Communication

The lead clinician (or delegated representative) is responsible for:

☐ explaining the treatment summary and follow-up and surveillance care plan to the person and their whānau

☐ informing the person and their whānau about secondary prevention and healthy living

☐ discussing the follow-up care plan with the GP of the person and their whānau

☐ providing guidance for rapid re-entry to specialist services.

Step 7: Palliative and end-of-life care

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

Palliative care may be provided through:

- hospital palliative care
- home and community-based care
- community nursing, including access to appropriate equipment.

Early referral, identification, correct assessment and treatment of pain and other symptoms prevent and relieves suffering.

End-of-life care should consider:

- appropriate place of care
- person's preferred place of death
- support needed for the person and their whānau.

Step 7: Checklist

☐ Early referral to generalist palliative care.

☐ Refer to specialist palliative care services as required.

☐ Refer to supportive care services as required.

☐ Make sure the person and their whānau are aware of the prognosis and what to expect when someone is dying.

☐ Discuss activation of advance care plan, directive, or enduring power of attorney.

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

How optimal cancer care pathways improve outcomes

Optimal Cancer Care 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).

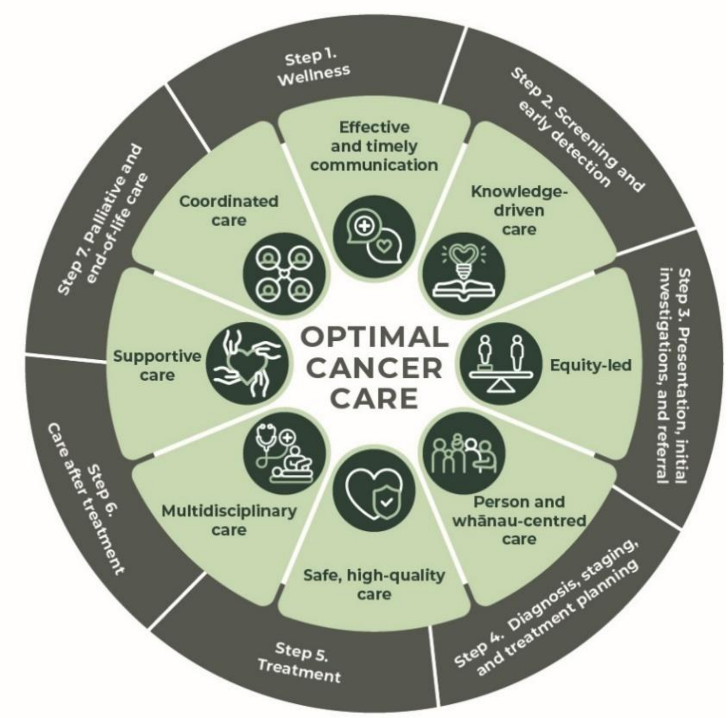
OCCPs are a framework for achieving health equity[2] in cancer control using a person and whānau centred approach to provide people with equitable, high-quality care, regardless of where they live or receive cancer treatment. OCCPs help to:

- 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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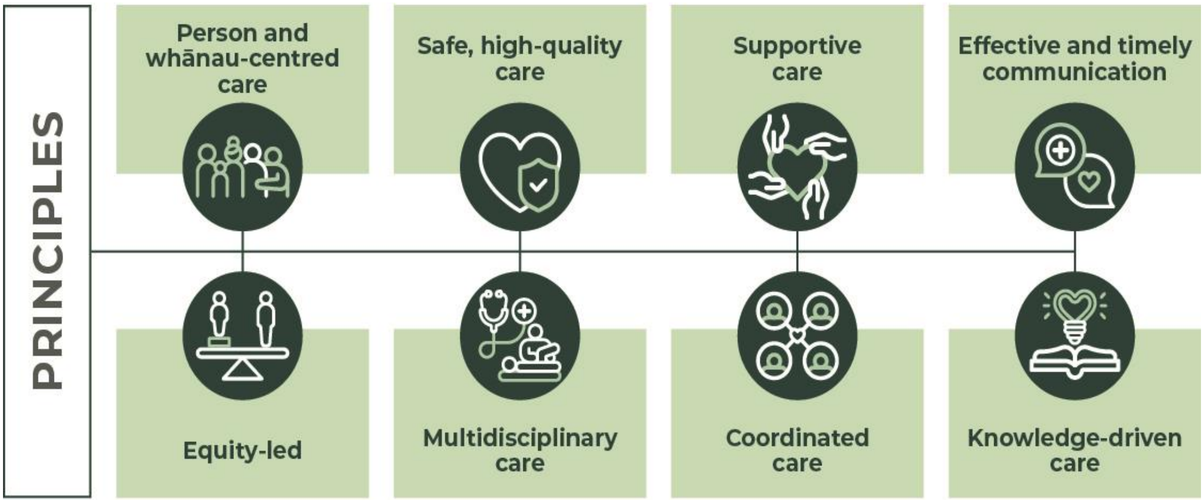
[2] Optimal Cancer Care Pathways Supplementary Information

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/whānau on the optimal timeframes for being assessed and receiving treatment.

Figure 3: Timeframes for care

Step in pathway	Care point	Timeframes
Step 3: Presentation, initial investigations, and referral	Signs and symptoms	A person presenting with symptoms is promptly assessed by a health professional.
	Initial investigations started by GP	If there is a high suspicion of low grade lymphoma, submit referral **immediately** to hospital specialist services. For the person who does not need an urgent referral to a specialist i.e. indolent lymphoma, all investigations should be completed, and a path of action decided, **within 2 weeks**. Where there is clinical urgency, contact the relevant specialist for advice and prompt consultation. Where there are indicators of concern i.e., organ dysfunction or neurological involvement, urgent referral to a specialist centre is required and the person is contacted. Rapid access pathways should be in place to ensure an evaluation and urgent review is carried out. Where lymphoma is identified by biopsy or strongly suggested, referral to a specialist should occur **within 72 hours**.
	Referral to a hospital specialist	The person should see a specialist within **appropriate graded timeframe** for a high suspicion of cancer dependent on symptoms and clinical urgency.
Step 4: Diagnosis, staging, and treatment planning	Diagnosis and staging	Investigation timeframes should be guided by the severity of symptoms.
	Multidisciplinary team meeting and treatment planning	Where appropriate, people with low grade lymphoma are discussed in an MDM, before treatment begins.

		MDM takes place **within 2 weeks** of confirmed diagnosis and staging.
		The person referred with a high suspicion of low grade lymphoma and triaged by a clinician will receive their first cancer treatment, if required, **within 62 days**.
Step 5: Treatment	Systemic anti-cancer therapy or radiation therapy	The person begins their first cancer treatment **within 31 days** of the decision to treat, regardless of how they were initially referred. Radiation therapy should begin earlier for life- or organ-threatening indications. In FL and MZL, the decision of when to start systemic therapy is guided by the presence of symptoms and organ dysfunction according to the GELF/BCNI criteria. Once the person meets the criteria to start, treatment should begin **within 4 weeks**. Most symptomatic MCL people should begin treatment with systemic therapy **within 2 weeks** of completing staging.

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

Low grade lymphomas are a heterogenous group of mostly slow-growing Non-Hodgkin Lymphomas (NHL), representing about 40% of all NHL. With respect to other low grade lymphoma subtypes, small lymphocytic lymphoma is addressed in the chronic lymphocytic leukaemia (CLL) OCCP. This OCCP will cover follicular lymphoma (FL), marginal zone lymphoma (MZL) and mantle cell lymphoma (MCL).

Follicular lymphoma (World Health Organization grades 1–3A) is the second most common subtype of NHL. FL makes up 20–30% of all NHL and can progress to diffuse large B-cell lymphoma in approximately 10% of people.

Marginal zone lymphoma accounts for approximately 8% of all NHL. The three main types of MZL are distinct clinical entities with specific diagnostic criteria and different genetic features, clinical behaviour and therapeutic implications (ESMO. 2020). Extranodal or mucosa-associated lymphoid tissue (MALT) lymphoma accounts for around 70% of all MZL, Splenic MZL (SMZL) 20% and Nodal MZL (NMZL) 10%.

Mantle cell lymphoma is a B-cell lymphoma that is less common but may behave either as an aggressive disease or develop more slowly.

Low grade lymphomas are traditionally perceived as ‘incurable’, however, many people survive for more than 20 years. With a diagnosis commonly appearing late in life, and longer survival, people may enter lifelong follow up, have periods where their lymphoma is monitored and not treated, or have many different treatment regimes.

In Aotearoa New Zealand, the incidence rate of low grade lymphoma is approximately 3.79 per 100,000 population. Among Māori, the incidence is lower at 2.33 per 100,000 population.

Step 1: Wellness

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

Health care providers and services such as primary care, public health units, hospitals and NGOs work collaboratively to prevent cancer (and other conditions) with the person and their whānau and communities (Te Aho o Te Kahu 2022).

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.

1.2 Modifiable cancer risks

Evidence-based research shows that general cancer 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
- smoking cessation (including vaping and cannabis)
- 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 exposure to second-hand smoke
- 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. The more we do for cancer prevention, the more we do for these other conditions that also cause loss of life, preventable suffering, and significant inequities (Te Aho o Te Kahu 2022). All health care providers will encourage and support the person and their whānau to reduce their modifiable risk factors.

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 EPA as required (refer Principle 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 with suspected low grade lymphoma.

Early detection of cancer has the potential to improve treatment outcomes and enhance long-term survivorship. Primary and community health care services work with the person and their whānau to improve outcomes and increase the awareness of cancer.

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 programmes, where possible (Te Aho o Te Kahu 2022)
- implementing programmes that enhance access to services.

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

2.2 Low grade lymphoma risk factors

Risk factors in common across all low grade indolent lymphomas include the following:
- age – incidence of low grade lymphomas increases with age
- family history – individuals with a first-degree relative (parent, child, sibling) with a low grade lymphoma have a small increased risk of developing NHL
- race/ethnicity – there is a higher incidence of indolent NHL in white Caucasian populations compared with non-Caucasian ethnicities
- radiation exposure – people treated with radiation for other cancers have slightly increased risk of developing a low grade lymphoma. This risk is greater for people treated with both radiation therapy and chemotherapy
- autoimmune diseases – people with autoimmune diseases such as rheumatoid arthritis, systemic lupus erythematosus, Sjogren's disease and coeliac disease may have an increased risk of developing a low grade lymphoma
- weakened immune system – people with weakened immune systems as a result of immunosuppressive drugs, chronic infection or some genetically inherited syndromes are at a higher risk of developing a low grade lymphoma.

Follicular lymphoma (FL)

- Gender – women have a slightly higher risk of developing FL than men.
- Race/ethnicity – FL occurs more commonly in Caucasian populations.
- Viral infections – viruses that have been implicated in developing FL include Epstein-Barr Virus (EBV), human T-cell lymphotropic virus type I and Kaposi sarcoma-associated herpes virus causing MZL.

Mucosa-associated lymphoid tissue (MALT) lymphoma

- MALT lymphomas are associated with a variety of infectious and autoimmune disorders:
    - 90% of gastric MALT lymphoma are associated with *helicobacter pylori gastritis*

  - ocular adnexal MALT lymphoma may be associated with *chlamydia psittaci*
  - cutaneous MALT lymphoma may be associated with *borrelia burgdorferi*
  - MALT lymphoma of the small intestine and immunoproliferative small intestine disease may be associated with *campylobacter jejuni*
  - thyroid MALT may be associated with Hashimoto's thyroiditis
  - salivary gland MALT may be associated with Sjogren's syndrome.

- SMZL may be more common in those with chronic Hepatitis C infection and associated with autoimmune conditions such as haemolytic anaemia and immune thrombocytopenia.

Mantle cell lymphoma (MCL)

- Gender – men have a greater risk of developing MCL than women, although the reasons for this remain unclear.

2.2.1 Familial cancer risk

Some people may have an increased risk of developing low grade lymphoma. An individual's family cancer history is reviewed and the person and their whānau are advised of the risks of developing a familial cancer. Health providers encourage and support the person and their whānau to follow surveillance guidance if an increased risk of familial cancer is identified. A thorough family history for NHL is recommended but no specific genetic tests are recommended.

2.3 Early detection

Early detection has several benefits, including improved survivorship.

Support is provided to reduce modifiable risk factors of low grade lymphoma and identify any other cancer risks.

2.4 Communication with the person/whānau receiving care

Health providers/professionals

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

Communication between health services

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

2.5 Measuring and monitoring

Monitoring and measuring 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.

- **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.
- **Faster Cancer Treatment**

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

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

Step 3: Presentation, initial investigations, and referral

This step outlines the process for initiation of the right investigations and referral to the appropriate specialist in a timely manner for the person with suspected low grade lymphoma.

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 low grade lymphoma assessment from a person's primary care presentation and referral to secondary care to specialist services (**Community HealthPathways**).

The Community-referred radiology (CRR) Referral Criteria are criteria to provide nationally consistent access to imaging. The criteria set out a mandatory minimum level of radiology access to help primary care manage imaging in the community. Refer to: **National Community Referral Criteria for Imaging » Radiology**.

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 low grade lymphoma, 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 of this needs to factor into assessment and review of signs and symptoms.

Low grade lymphomas frequently present with symptoms of gradual onset occurring over many weeks or several months. People can sometimes be asymptomatic at diagnosis, with low grade lymphomas discovered incidentally after imaging or laboratory tests reveal an abnormality.

The following suspicious signs and symptoms of low grade lymphoma include:

- a lump or mass in any organ
- lymphadenopathy, particularly lymphadenopathy persistent beyond 2 weeks
- splenomegaly, with or without systemic symptoms, in the absence of, or after resolution of, any infection
- one or more of these systemic symptoms even in the absence of lymphadenopathy: fever, drenching night sweats, unexplained weight loss, frequent infections

- unexplained cytopenia
- persistent lymphocytosis.

Indicators of concern that should lead to prompt referral to a specialist include:

- symptoms or results indicating organ dysfunction and low blood counts
- symptoms that suggest neurological involvement
- markedly elevated lactate dehydrogenase (LDH)
- marked B symptoms (weight loss >10%, persistent fevers >38°C, or persistent drenching night sweats)
- very widespread or bulky lymphadenopathy.

If the person presents with one of the following red flags, the referral should be triaged as a high suspicion of cancer:

- persistent lymph node enlargement >2 weeks in the absence of infective symptoms
- lymphadenopathy persistent for 4 weeks or lymph nodes rapidly increasing in size (otherwise unexplained)
- lymph nodes >2cm, widespread nature, firm, non-tender
- unexplained drenching night sweats or fevers or weight loss of greater than 10% of body weight
- radiology suspicious for lymphoma.

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

Low grade lymphoma assessment includes relevant:

- medical history, including relevant medications
- physical examination: of the skin, all lymph node groups, oral examination for enlarged Waldeyer's ring, abdominal examination and cardiorespiratory examination, Eastern Cooperative Oncology Group (ECOG) Performance Status Scale, frailty assessment, weight
- investigations (laboratory, radiology):
    - blood tests to assess organ dysfunction including full blood count, urea, electrolytes, creatinine, liver function tests, LDH; other tests may include beta-2 microglobulin (no laboratory test can exclude these lymphomas)
    - imaging of the affected area: ultrasound, chest X-ray and computed tomography (CT) scan as appropriate
    - biopsy as appropriate, depending on local access (referral to a specialist prior to biopsy may be appropriate where there is a high clinical suspicion for lymphoma)
    - fine-needle aspiration (FNA) is generally considered inadequate for diagnosing low grade lymphomas but in some instances may be an appropriate initial investigation (e.g., in evaluating an enlarged lymph node when a non-haemopoietic neoplasm is strongly suspected (such as head and neck cancer).
- familial cancer history: family history of lymphoma
- social history.

3.4 Initiate investigations, including referrals

- If a low grade lymphoma diagnosis is confirmed by biopsy, the general practitioner must refer the person to a haematologist or medical oncologist with professional expertise in lymphoma management.
- If the general practitioner considers the likelihood of lymphoma is high based on the initial consultation, referral for urgent tissue diagnosis and ongoing management at a specialist centre with access to lymphoma multidisciplinary team support should occur.
- General practitioners should make referrals in consultation with the person and their whānau after considering the clinical care needed, cost implications, waiting periods, location, and facilities, including discussing the persons preference for health care through the public or the private system.
- Referral documentation for a suspected low grade lymphoma should incorporate all appropriate documentation to allow an accurate triage regarding the level of clinical urgency.
- Indicate if there is a high suspicion of cancer and/or it is urgent, and the person needs to be seen **within 2 weeks**.

- Referring provider should receive acknowledgment of referral.

Timeframe for completing investigations for the person with suspected low grade lymphoma

For the person who does not need an urgent referral to a specialist i.e. indolent lymphoma, all investigations should be completed, and a path of action decided, **within 2 weeks**.

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

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

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

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

- signalled as high suspicion of cancer or urgent
- medication and allergies
- past medical history and current comorbidities
- results of relevant investigations
- notification if an interpreter service is required

- concerns that may require support or affect ability to attend appointments, undergo investigations or treatment.

Timeframe for referring to a specialist

Where there is clinical urgency as indicated by the features described in 3.2, contact the relevant specialist directly for advice, and to ensure prompt consultation.

For the person with indicators of concern such as organ dysfunction or neurological involvement, urgent referral to a specialist centre is needed. Specialist healthcare providers should provide clear routes of rapid access for specialist evaluation to ensure people with indicators of concern (outlined above) are contacted and reviewed urgently.

Where lymphoma is identified by biopsy or strongly suspected, referral to specialist should occur **within 72 hours**.

Referrals must be triaged in a timely manner **within 1–2 working days** by an appropriately trained person (nurse specialist or doctor) and consistent with FCT Business Rules and/or other prioritisation classification criteria **(FCT data dictionary).**

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

3.5 Supportive care and communication

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

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

3.5.1 Communication with the person/whānau receiving care

Health providers/professionals

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

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

- 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

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

- **Faster Cancer Treatment**

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

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

Step 4: Diagnosis, staging and treatment planning

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

Health services work with the person and their whānau to diagnose and stage the cancer, provide treatment options and recommendations, and help meet any identified needs. This generally occurs in secondary or tertiary health care services. Assessment and investigation results, including discussions between the appropriate multidisciplinary team members and the person and their whānau, will help to determine the treatment options 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 and emotional and spiritual support to complement medical treatment
- talking with the person and their whānau and clinicians about current or intended use of rongoā or other complementary therapies to understand the potential benefits, risks and/or other implications
- consultation with the person and their whānau regarding what they would like to happen to any bodily tissue or organs removed as part of their diagnostic workup and treatment.

4.2 Specialist investigations (diagnostic work up for low grade lymphoma)

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

- **Biopsy:** excisional or large incisional biopsy. If unable to be achieved, a core needle biopsy that samples the maximum number of cores with the largest calibre biopsy needle possible should be considered (NICE 2016).

  A definitive tissue diagnosis is always required before initiating lymphoma-specific treatment. Biopsy may have been performed before referral. Both fresh and fixed tissue samples should be collected from the tissue biopsy for anatomical pathology and potentially flow cytometry, cytogenetics, and gene mutation testing (e.g., TP53 mutation testing for MCL). Additional immunohistochemical stains may provide information that affects therapy (e.g., Ki67 for FL).

  Pathology specimens should be reviewed by a pathologist with expertise in diagnosing low grade lymphomas. This should be done at the treatment centre conducting the MDM, before a treatment plan has been instituted.

- **Fine needle aspiration (FNA):** is not suitable for diagnosing lymphomas. However, FNA may be an appropriate investigation in circumstances where excision or needle core biopsy is overly invasive or not feasible (e.g., mediastinal disease). Construction of tissue blocks from cytological samples may aid diagnosis.
- **Surgery:** for low grade lymphomas, surgery is a diagnostic procedure and rarely therapeutic. Therefore, the least invasive surgical method is recommended for diagnosis. If a highly invasive or extensive surgical procedure is being considered, consultation with the lymphoma multidisciplinary team is required.
- **Blood test:**
    - additional blood tests – B2M, immunoglobulins, LDH, serum protein electrophoresis – are part of the diagnostic work-up
    - autoimmune screens are sometimes warranted in MZL, specifically autoimmune haemolytic anaemia
    - test for occult or latent infections (e.g., HIV, hepatitis B and C, tuberculosis) that may be affected by therapy or pose a risk of reactivation due to the immunosuppressive effects of treatment
    - for MZL, site-specific infectious disease testing should be performed.
- **Other investigations**: relevant organ function based on history, clinical examination and, where appropriate, laboratory or imaging investigations (cardiac, respiratory, renal, hepatic).

Timeframe for completing investigations

The timing of diagnostic investigations will be guided by the severity of symptoms.

4.3 Staging

Accurately staging cancer helps guide treatment decisions and is a significant contributor to providing a cancer prognosis (Te Aho o Te Kahu 2021a). When cancer is diagnosed, additional investigations are often conducted to establish how much the cancer has grown and if, and how far, it has spread. The following additional tests may be required.

Clinical examination and history: for assessment of B symptoms. It is particularly important to document the sites and extent of FL involvement that are not easily visible on imaging (e.g., skin, conjunctiva).

Radiology:

- Positron Emission Tomography (PET)-CT: should be performed for the staging of indolent lymphomas, in particular FL and MCL. For PET-CT scans, see Health New Zealand | Te Whatu Ora National Indications for Publicly Funded PET-CT
- CT scan: may be preferable for some cases, such as MZL with low positivity on PET- CT
- magnetic resonance imaging (MRI): is of value in orbital/ocular adnexa MZL.

Bone marrow biopsy: the decision to do a bone marrow biopsy should be according to evidence-based guidelines for the specific type of lymphoma. A routine bone marrow aspirate and trephine is not required for all low grade lymphomas and may not be necessary at diagnosis where the planned initial approach is watch and wait, nor before starting treatment if the results before and/or after treatment will not impact on prognosis or therapeutic approach.

Endoscopy:

- gastroscopy/colonoscopy: for MCL, symptoms that suggest gastrointestinal involvement should be investigated with gastroscopy and colonoscopy
- endoscopic ultrasound: for gastric MZL can be used to characterise gastric wall infiltration and peri-gastric lymph node involvement.

Additional tests are recommended to calculate the relevant prognostic scores for each low grade lymphoma.

4.4 Performance status

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

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

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

4.5 Multidisciplinary meeting

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

Referral to lymphoma MDM is undertaken if indicated to inform treatment recommendations or further assessment and investigation.

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

Following MDM, treatment options including the intent, referral options and recommendations are discussed with the person and their whānau to enable informed decision making in accordance with their rights and ability to exercise independence, choice, and control.

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

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

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

- conducting a physical and psychological assessment to establish a baseline level of function, including assessing coping strategies/abilities
- identifying impairments and providing targeted interventions to improve the person's function level
- an integrated and structured approach to self-care enquiry – identifying Social Health, Exercise, Education, Diet and Sleep Hygiene (SEEDS) is one such practical tool (Arden 2015)
- referral to a psycho-oncology service to improve their knowledge and motivation towards healthy self-care care behaviours and to emotionally regulate throughout the course of the disease and treatments
- smoking cessation
- medications to ensure optimisation and correct adherence
- rongoā
- psychosocial support
- physiotherapy or exercise programme – aerobic, respiratory training, resistance training for the person to function at a higher level
- nutrition.

4.5.4 Clinical trials

Where eligible, the person with cancer is offered and supported to participate in research or clinical trials. Access to some established treatments is 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 to 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 person and their whānau have the option to have additional support people with them when having discussions.
- Explain and discuss with person's diagnosis, staging and treatment options and recommendations in plain language.
- Discuss the advantages and disadvantages of treatment options and associated potential side effects.
- Provide information and resources in a format that is useful to the person and their whānau (and that they can share with others as they wish).
- Identify any barriers or challenges that may prevent the person and their whānau from accessing services or attending treatment.
- Discuss with the person and their whānau ways to improve health outcomes and wellbeing prior to and during treatment.
- Advise the person and their whānau of their lead clinician and care coordinator.
- Clarify that the information that has been communicated has been understood.
- The person and their whānau may require time to process the information that has been relayed, prior to consenting to treatment.
- Coordinate scheduling of appointments with the person and their whānau to ensure access barriers are minimised and attendance is supported.
- Discuss with the person and their whānau the need to update or complete their advance care planning and/or advance directive.

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

Communicating between health services

- Coordinate appointments among health services, in discussion with the person and their whānau to make best use of their time and resources and to support access.
- Communicate the diagnosis, MDM recommendations and treatment plan between health services.

- Discuss and agree shared care arrangements, in symptom and co-morbidity management, supportive care and referral to local services.
- Confirm the lead clinician and provide handover details as necessary.

4.7 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 low grade lymphoma by trained and experienced clinicians and team members, in an appropriate environment.

The treatment of low grade lymphoma is informed by the following guidelines:

- Lymphoma Network New Zealand: *Follicular lymphoma protocol 2014* **referrals-and-resources/lymphoma-network-of-new-zealand/**
- Lymphoma Network New Zealand: *MALT lymphoma LNZ protocol 2019* **referrals-and-resources/lymphoma-network-of-new-zealand/**
- Lymphoma Network New Zealand: *Mantle Cell Lymphoma Protocol* **referrals-and-resources/lymphoma-network-of-new-zealand/**
- Lymphoma Network New Zealand: *Splenic marginal zone lymphoma protocol (SMZL).* **referrals-and-resources/lymphoma-network-of-new-zealand/**
- European Society for Medical Oncology: *ESMO clinical practice guidelines: newly diagnosed and relapsed follicular lymphoma* **esmo-clinical-practice-guidelines-haematological-malignancies**
- European Society for Medical Oncology: *ESMO clinical practice guidelines: newly diagnosed and relapsed mantle cell lymphoma* **esmo-clinical-practice-guidelines-haematological-malignancies**
- European Society for Medical Oncology: *ESMO clinical practice guidelines: marginal zone lymphomas* **esmo-clinical-practice-guidelines-haematological-malignancies**
- American Society for Transplantation and Cellular Therapy (ASTCT) practice guidelines **astct-publications**
- European Society for Blood and Marrow Transplantation (EBMT) handbook **ebmt-handbook**

5.1 Te Tiriti o Waitangi

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

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

5.2 Treatment intent

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

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

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

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

5.2.1 Additional considerations

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

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

Initiate advance care planning discussions with the person and their whānau before treatment begins (this could include appointing a substitute decision-maker and completing an advance care directive). If initial treatment is declined, discuss next steps fully with the person and their whānau. This includes the option to re-engage with initial treatment if they change their minds, with the understanding it may no longer be viable and/or suitable.

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

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

5.3 Treatment options

The type of treatment recommended for low grade lymphoma depends on the type, stage and location 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.

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 that may benefit from watch and wait approach including those with:
    - stage II FL (non-contiguous lymph nodes, or not amendable to radiation therapy)
    - advanced-stage FL (stages III and IV)
    - asymptomatic advance-stage nodal MZL
    - indolent form of MCL.

For stage II FL (non-contiguous lymph nodes, or not amenable to radiation therapy) and advanced stage FL (stages III and IV), the decision to start treatment is guided by symptoms and disease bulk.

Approximately one-third of initial presentations occur in people with low-volume disseminated disease. The importance of 'watch and wait' is true even in the modern immunochemotherapy era. The frequency of clinical review during this observation is based on the tempo of the disease, the comfort the person has with a 'watch and wait' approach and the likelihood that they will recognise and re-present in the event of signs of progression.

Watchful waiting can cause significant anxiety in people. Appropriate support should be made available (see 5.5). Asymptomatic advance-stage nodal MZL can also be managed with a watchful waiting approach. An indolent form of MCL, commonly a leukaemic presentation, indicated by lack of symptoms and low tumour burden, can be followed with watchful waiting.

- **Radiation therapy** – the person who may benefit from a watch and wait approach include:
    - early-stage FL (stage I and stage II in which lymph nodes are contiguous)
    - low-volume, advanced-staged disease (in a highly select group of people)
    - localized relapsed low grade lymphoma
    - advanced-stage low grade lymphoma for symptom control.

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

Radiation therapy has an important role in specific scenarios within indolent lymphoma subtypes. Early-stage FL (stage I and stage II in which lymph nodes are contiguous) is potentially curable with radiation therapy. Further adjuvant immunochemotherapy may confer additional progression-free survival.

In centres with specialised equipment, total nodal irradiation may be appropriate in a highly select group of people with low-volume, advanced-stage disease.

Radiation therapy is appropriate in early-stage MZL (including gastric, cutaneous, unilateral, and bilateral orbital MALT, and other localised MZLs) with potential curative intent. Note eradication of Helicobacter pylori infection should be performed first – it may induce remission without the need for radiation therapy in some cases.

Radiation therapy for localised relapse of low grade lymphomas, may defer the need for systemic immunochemotherapy and in advanced-stage low grade lymphomas where quality of life is impaired, radiation therapy may be used for symptom control.

Timeframes for starting treatment

If treatment is required, the first treatment should begin within 31 days of decision to treat. Start earlier for life- or organ-threatening indications.

- **Systemic anti-cancer therapy** – those who may benefit from systemic anti-cancer therapy include most people with non-contiguous stage II or stage III–IV disease who are symptomatic by GELF/BCNI criteria and considered fit enough to experience a positive risk-benefit balance of undergoing treatment.

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).

The choice of initial systemic therapy needs to consider the potential for sequencing of subsequent therapies, including potential future stem cell mobilisation.

Follicular lymphoma

Initial treatment with chemotherapy and anti-CD20 monoclonal antibody is often followed by continued therapy with anti-CD20 antibody maintenance for another 2 years.

Given that ongoing maintenance antibody therapy increases progression-free survival but does not prolong overall survival, it is important that the person understands both the benefits in prolonging remission as well as the additional infectious toxicities of using maintenance antibody therapy.

Nodal marginal zone lymphoma

Initial treatment with chemotherapy and anti-CD20 monoclonal antibody is recommended.

Extra nodal marginal zone lymphoma

Helicobacter pylori eradication therapy should be given to the person with gastric MALT, irrespective of stage and Helicobacter pylori status. In those who remain Helicobacter pylori positive, second line eradication therapy is recommended. Regression of lymphoma following successful eradication of Helicobacter pylori may be delayed, and so it is appropriate to wait 6-12 months before starting another treatment.

In other instances of localised MALT (e.g., conjunctival MALT), a trial of systemic therapy with antibiotics may be appropriate before radiation therapy.

MALT can also be treated with chemotherapy and an anti-CD20 monoclonal antibody.

Splenic marginal zone lymphoma

Recognised first-line therapeutic options are rituximab monotherapy, splenectomy (after appropriate vaccinations) or chemotherapy and an anti-CD20 monoclonal antibody combination. Access to certain therapy may be subject to special authority criteria.

Mantle cell lymphoma

MCL causing symptoms should be treated with systemic chemotherapy and an anti-CD20 monoclonal antibody combination, with treatment regimen tailored based on a person's fitness and overall health status.

Autologous stem cell transplant (ASCT) – may be indicated as per American Society for Transplantation and Cellular Therapy (ASTCT) guidelines and European Society for Blood and Marrow Transplantation (EBMT) handbook.

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

Timeframes for starting treatment

If treatment is required, the first treatment should begin **within 31 days** of decision to treat.

In FL and MZL, the decision of when to start systemic anti-cancer therapy is guided by the presence of symptoms and organ dysfunction according to the GELF/BCNI criteria. Once the person meets the criteria to start, treatment should begin **within 4 weeks**.

Most people with symptomatic MCL should begin treatment with systemic therapy **within 2 weeks** of completing staging.

- **Targeted therapies**

CAR T-cell therapy
CAR T-cell therapy is an increasingly proven option for people with blood cancer, improving outcomes often where other treatment options have been exhausted.

Internationally this treatment is considered a standard of care. However New Zealanders can only access CAR T-cell therapy by travelling overseas or through a local clinical trial, which has limited access.

- **Palliative care**

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

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

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

- nutritional support
- sexual dysfunction
- peripheral neuropathy
- fatigue.

Referral to the following services may also be helpful for the person who requires increased physical and psychosocial support:

- cancer psychology services
- chaplaincy services
- physiotherapy
- occupational therapy
- social work.

5.3.1 Clinical Trials

Participation in clinical trials, disease registries and tissue banking, where available, are encouraged for people with low grade lymphomas. Many emerging treatments are only available as clinical trials and may require referral to specific trial centers (refer principle 8).

5.4 Treatment summary

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

- relevant diagnostic tests performed and results
- cancer diagnosis, characteristics, stage, and prognosis
- treatment received

- current toxicities (severity, management and expected outcomes)
- interventions and treatment plans from other health providers/professionals
- potential long-term and late effects of treatment
- supportive care services provided
- recommended follow up and surveillance.

5.5 Supportive care and communication

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

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 low grade lymphoma 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
- managing side effects of chemotherapy such as neuropathy, cardiac dysfunction, nausea, and vomiting 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.

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

Communication between health services

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

5.6 Measuring and monitoring

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

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

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

- **Radiation oncology treatment timeframes**[3]
    - 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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[3] 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 general practitioner may be appropriate. This will be informed by the type and stage of a person's cancer, the treatment they have received and the needs of the person and their whānau (refer Principle 5).

The following references inform care after treatment for the person with low grade lymphoma:

- Lymphoma Network New Zealand: *Guidelines for the follow-up of patients in complete remission following curative treatment for non-Hodgkin lymphomas* **referrals-and-resources/lymphoma-network-of-new-zealand/**
- European Society for Medical Oncology: *ESMO clinical practice guidelines: newly diagnosed and relapsed follicular lymphoma* **esmo-clinical-practice-guidelines-haematological-malignancies**
- European Society for Medical Oncology: *ESMO clinical practice guidelines: newly diagnosed and relapsed mantle cell lymphoma* **esmo-clinical-practice-guidelines-haematological-malignancies**
- European Society for Medical Oncology: *ESMO clinical practice guidelines: marginal zone lymphomas* **esmo-clinical-practice-guidelines-haematological-malignancies**

6.1 Te Tiriti o Waitangi

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

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

6.2 Survivorship care planning

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

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

- the provision of a treatment summary
- information on what medical follow up and surveillance is planned
- how care after treatment will be provided, including by whom and where, and contact information

- inclusion of care plans from other health providers to manage the consequences of cancer and cancer treatment
- information about wellbeing and primary and secondary prevention health recommendations that align with chronic disease management principles (Step 1)
- rehabilitation recommendations and any referrals
- available support services, including cancer NGO survivorship programmes/services (these may be tumour specific)
- signs and symptoms to be aware of that may indicate the cancer has recurred
- the process for rapid re-entry to specialist medical services.

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

6.3 Treatment summary

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

The summary includes:

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

6.4 Rehabilitation and recovery

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

For people with low grade lymphoma, assessment for referral to the following rehabilitation or recovery services should be undertaken.

- Blood and Leukaemia Foundation.
- Psychological cancer services.

6.5 Follow up and surveillance

Follow up and surveillance can have multiple functions, including:

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

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

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

For people with low grade lymphoma, specific monitoring for complications of therapy should include:

- after local radiation therapy with curative intent – history and physical examination every 6 months for 2 years, subsequently once a year or as clinically indicated
- evaluation of thyroid function – yearly in people who receive radiation therapy to the neck (ESMO 2020)
- after (during continuous) systemic treatment – history and physical examination every 3-6 months for 2 years, and every 6-12 months subsequently (ESMO 2020)
- after chemo-immunotherapy – history, physical examination, and blood tests every 3 months for at least 2 years, then clinician-directed follow up intervals indefinitely (ESMO 2020)
- the person who has had prior anthracycline chemotherapy have an increased risk of cardiac sequelae such as cardiomyopathy – follow up echocardiography 2-5 years after therapy if symptomatic
- endocrinopathies such as premature gonadal insufficiency and bone density loss can increase following systemic therapy for low grade lymphomas – consider periodic evaluation of bone mineral density.

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. Ongoing communication between healthcare providers involved in care and a clear understanding of roles and responsibilities is key to effective survivorship care.

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

6.6 Signs and symptoms of recurrent disease

The likelihood of recurrence depends on many factors usually related to the type of cancer, the stage of cancer at presentation and the effectiveness of treatment. Educating the person and their whānau about potential symptoms of recurrence is critical for timely management.

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

- new lymphadenopathy
- abdominal or back pain
- recurrent fatigue, night sweats or weight loss
- development of new anaemia or other laboratory abnormalities.

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

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

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.

Effective and timely communication

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

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

6.9 Measuring and monitoring

Currently there are no national indicators for this step.

Step 7: Palliative and end-of-life care

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

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

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

7.1 Te Tiriti o Waitangi

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

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

7.2 Palliative care

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

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

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

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

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

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

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

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

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

7.3 End-of-life care

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

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

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

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

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

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

7.4 Assisted dying

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

7.5 Supportive care and communication

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

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

7.5.1 Care coordination

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

7.5.2 Communicating with the person/whānau receiving care

Health providers/professionals

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

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

7.5.3 Communicating between health services

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

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

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

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).