TE AHO
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Optimal cancer care pathway for people with chronic myeloid leukaemia

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TE AHO O TE KAHU CANCER CONTROL AGENCY

Whakataukī

Have a sense of the message in the winds…

Anei he taonga nō te mātanga nō Ahitereiria
Koutou maa I takoto te koha ki a mātou

Here is a treasure from the skilled and able specialists in Australia
Greetings for this treasure you have gifted us here in Aotearoa to explore and use

E ki ana te tangi o tatou manu
Ko te manu e kai ana ki te miro, nōnā te ngahere
Ko te manu e kai ana ki te mātauranga nōnā te Ao

It has been reiterated that when our manu cries, we sit up and listen
The bird that feeds upon local berries, local knowledge will prosper
The bird that feeds upon wisdom, our world knowledge will flourish.

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

Matua Tau Huirama

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

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

Contents

For further information including:

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

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

Foreword

Kia ora,

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

Almost everyone across Aotearoa has been affected by cancer in some way. This year over 28,000 people will be diagnosed with cancer, with thousands more supporting loved ones living with this disease. Chronic Myeloid Leukaemia (CML) affects an increasing number of people with around 60 diagnosed with CML this year. Around 350 people will die from some form of leukaemia this year. We all believe that people and their whānau deserve the best cancer care available.

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

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

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

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

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

Ngā mihi nui,

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

Summary guide of chronic myeloid leukaemia OCCP information

Quick reference guide of condensed tumour stream

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

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

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

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[1] Optimal Cancer Care Pathway Principles

Step 2: Early detection	Step 2: Checklist
This step recommends options for early detection for the person/whānau with suspected chronic myeloid leukaemia. **Early detection** Health care providers/professionals support the person/whānau to identify and minimise modifiable risk factors for other types of cancer and health conditions. Risk factors that may increase the risk of chronic myeloid leukaemia include: • gender – males are at a slightly higher risk of developing chronic myeloid leukaemia • radiation exposure – exposure to high-dose radiation (e.g., nuclear disaster) can increase the risk of chronic myeloid leukaemia, but this is rarely relevant in New Zealand.	☐ 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	Step 3: Checklist
This step outlines how to initiate the appropriate investigations and referrals to specialist/s in a timely manner for the person and their whānau with suspected chronic myeloid leukaemia. The types of investigations undertaken will depend on many factors, including access to diagnostic tests, the availability of medical specialists and individual preferences. A person and their whānau may present via primary care, an emergency presentation or incidental finding indicating a high suspicion of chronic myeloid leukaemia. **Signs and symptoms** of chronic myeloid leukaemia to investigate include: • significant tiredness, fatigue, or pallor • malaise • weight loss • sweats • symptoms related to an enlarged spleen such as left upper quadrant fullness, pain, or discomfort • bony pain • visual disturbance • erectile dysfunction.	☐ All people with a high suspicion of cancer have a person to coordinate care. ☐ Record signs and symptoms. ☐ Complete all cancer assessments. ☐ Inform the person and their whānau of preliminary results. ☐ Referral options of cancer care are discussed with the person and their whānau, including cost implications if private provider requested. ☐ Complete and record supportive care needs assessment and refer to allied health services as required. ☐ Inform the person and their whānau of cultural services and relevant support groups available. ☐ Initiate referrals and arrange further investigation. **Timeframe** ☐ If there is a high suspicion of chronic myeloid leukaemia, submit referral **immediately** to hospital specialist services. ☐ High suspicion of cancer referral is triaged **within 1-2 working days** and referrer is notified.

Chronic myeloid leukaemia assessment includes the relevant:

- **medical history**, including medications
- **physical examination**: Eastern Cooperative Oncology Group (ECOG) Performance Status Scale, frailty assessment, weight, specifically looking for splenomegaly
- **laboratory investigations:** full blood count, white blood counts (WBC) differential, fluorescence in situ hybridization (FISH) or polymerase chain reaction (PCR) by secondary care
- **familial cancer history**
- **social history**.

Referral

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

The following clinical prioritisation criteria are used to triage people presenting with chronic myeloid leukaemia.

- Any person with clinical symptoms should be seen promptly. In addition, the degree of WBC count elevation and/or platelet count, and the number of circulating blast cells in peripheral blood, will help determine clinical urgency.
- Circulating blasts may be present in the blood, but if they represent more than 15% of the total WBC, the diagnosis will be either accelerated phase or blast phase disease, requiring immediate referral.

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

☐ Non-urgent cases should ideally be seen by a specialist haematologist **within 2 weeks.**

☐ Urgent cases that require **immediate** hospital admission includes:
  - people with a WBC above 100 x 10^9/L
  - people with a platelet count below 50 or above 800 x 10^9/L
  - men complaining of priapism (a persistent erection) or incipient priapism
  - any features that suggest leukostasis such as blurred vision, fainting, seizures, transient ischemic attack-like events, any other unexplained neurological syndromes
  - any other unexpected organ dysfunction or poorly controlled bone/splenic pain.

Communication

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

Step 4: Diagnosis, staging and treatment planning

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

Diagnosis for chronic myeloid leukaemia may include:
Minimum established tests:

- real-time quantitative RT-PCT test to detect and measure the level of BCR-ABL1 on the international scale
- biochemistry screen including liver function tests, electrolytes, renal function tests, urate, lipase and amylase, blood sugar level
- HIV, hepatitis B and hepatitis C serology
- electrocardiogram.

Step 4: Checklist

☐ Confirm diagnosis.

☐ Referral to a cancer care coordinator if not already done.

☐ Record phase, performance status and comorbidities.

☐ Discuss the person's diagnosis at a multidisciplinary meeting (MDM) and inform the person and their whānau of the treatment options.

☐ Consider relevant clinical trials.

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

Investigations that should be done in most circumstances:

- bone marrow aspiration including cytogenetics, immunophenotyping/flow cytometry, and morphology (exceptions can be made for frail or very elderly people)
- fasting lipids (not essential if the person will receive frontline imatinib)
- chest x-ray (not essential for young, healthy people).

The following tests may be considered in selected people:

- cardiac echocardiogram
- ankle brachial index
- doppler study of neck and leg arteries.

Phases of the disease and prognostic assessment:

- chronic phase
- accelerated phase
- blast phase.

Performance status

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

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.

☐ Ensure primary or secondary prehabilitation is initiated to optimise overall well-being.

☐ Give the person and their whānau information on Cancer Society, Leukaemia and Blood New Zealand 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 chronic myeloid leukaemia by trained and experienced clinicians and team members, in an appropriate environment.

Treatment options

Tyrosine Kinase Inhibitor (TKI) therapy – the person who may benefit from TKI therapy are those:

- with chronic phase myeloid leukaemia as the mainstay of therapy
- with blast phase chronic myeloid leukaemia alongside chemotherapy
- with accelerated phase chronic myeloid leukaemia.

Systemic anti-cancer therapy (cytotoxic agents) – is only indicated in cases of blast phase chronic

Step 5: Checklist

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

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

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

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

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

myeloid leukaemia or accelerated phase chronic myeloid leukaemia on a person-by-person basis. **Allogeneic stem cell transplant (Allo-SCT) –** The use of stem cell transplants has become less common due to targeted therapies like tyrosine kinase inhibitors (TKIs). **Initial cytoreductive therapy** – the person who may benefit from initial cytoreductive therapy where the white blood cell count and/or platelet count need to be reduced to safer levels. **Palliative care** – early referral to palliative care can improve quality of life and in some cases survival. Referral is based on need, not prognosis.	☐ Consider early referral to palliative care if appropriate. ☐ Discuss advance care planning with the person and their whānau if appropriate. **Timeframes** ☐ The person with a confirmed diagnosis of chronic myeloid leukaemia receives their first treatment **within 31 days** of the decision to treat. ☐ The person referred urgently with a high suspicion of chronic myeloid leukaemia receives their first cancer treatment **within 62 days** from date of referral. ☐ TKI therapy should begin **within the first 4 weeks** for people with chronic phase myeloid leukaemia unless there is a clinical indication to delay. ☐ Systemic anti-cancer therapy and/or TKI therapy should begin **within 1 week** of diagnosis for people with blast phase chronic myeloid leukaemia. ☐ Initial cytoreductive therapy may be used in the **first few weeks**. **Communication** The lead clinician and team are responsible for discussing with the person and their whānau: ☐ treatment options including the intent of treatment, risks, and benefits ☐ advance care planning ☐ options for healthy lifestyle support to improve treatment outcomes such as exercise and nutrition.

Step 6: Care after treatment	Step 6: Checklist
The person and their whānau access appropriate follow up and surveillance and are supported to achieve their optimal health after cancer treatment. Provide a summary of the treatment and follow-up care plan to the person, their whānau and their GP outlining: • diagnosis, including tests performed and results	☐ Provide a survivorship plan that includes a summary of the treatment and follow-up care plan to the person and their whānau and GP. ☐ Assess supportive care needs and refer to allied health services as required. ☐ Give the person and their whānau information on Cancer Society and/or relevant cultural services and available support groups.

• treatment received (types and date) • current toxicities (severity, management and expected outcomes) • interventions and treatment plans from other health providers/professionals • potential long-term and latent effects of treatment and care of these • supportive care services provided • a follow-up schedule, including tests required and timing • contact information for key health care providers/professionals who can offer support for lifestyle modification • a process for rapid re-entry to medical services for suspected relapse • ongoing assessments of the effects of treatment.	**Communication** The lead clinician and team are responsible for: ☐ explaining the treatment summary, follow up and surveillance care plan to the person and their whānau ☐ informing the person and their whānau about secondary prevention and healthy living ☐ informing the person's GP of the follow-up care plan ☐ providing guidance for rapid re-entry to specialist services.

Step 7: Palliative and end-of-life care	Step 7: Checklist
Palliative and end-of-life care provides the person facing life-limiting conditions and their whānau with holistic support and coordinated services based on their specific needs. 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. Awareness of and access to, assisted dying information should be available if the person raises this with the health care team. **Communication** A key way to support the person and their whānau is by coordinating ongoing, clear communications between all health providers/professionals involved in providing their cancer care.	☐ Early referral to generalist palliative care. ☐ Refer to specialist palliative care services as required. ☐ Refer to supportive care services as required. ☐ Make sure the person and their whānau are aware of the prognosis and what to expect when someone is dying. ☐ Discuss activation timing of advance care plan, directive, or enduring power of attorney.

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).

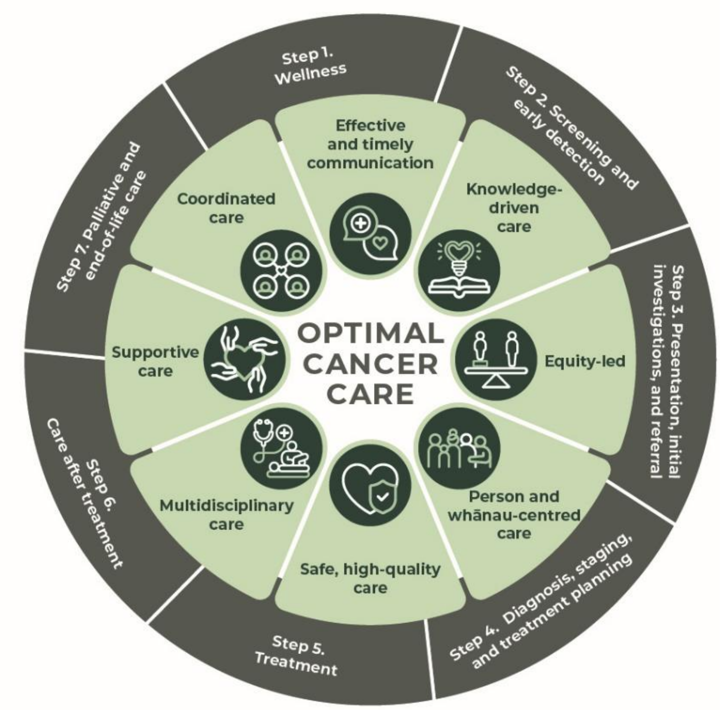
OCCPs are a framework for achieving health equity[2] in cancer control using a person and whānau centred approach to provide people with equitable, high-quality care, regardless of where they live or receive cancer treatment. OCCPs help to:

- 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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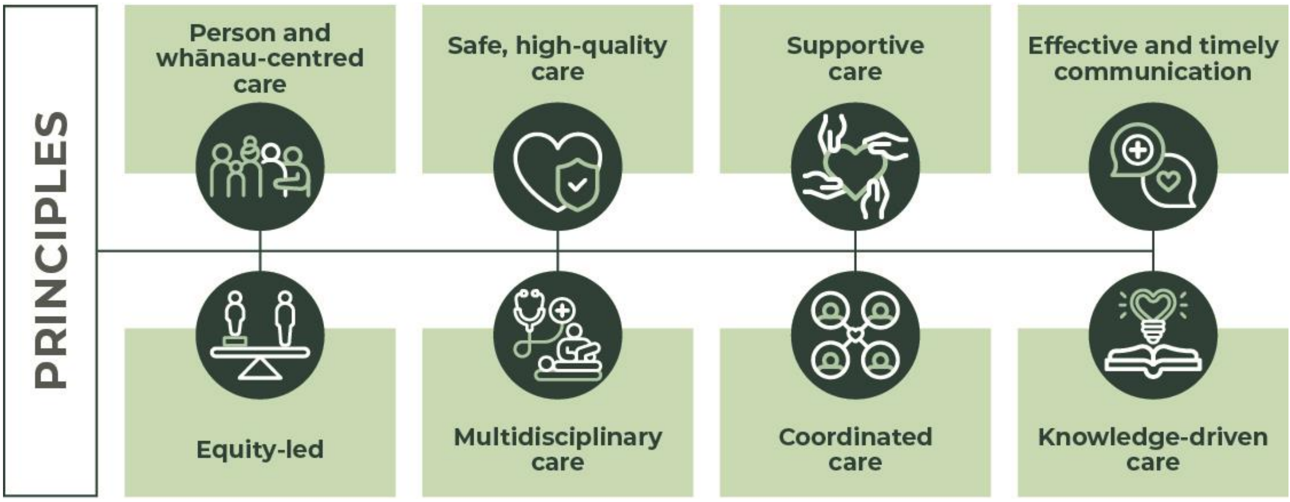
[2] Optimal Cancer Care Pathway Supplementary Information

Principles of the optimal cancer care pathway

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

Figure 2: Principles of optimal cancer care



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[3] Optimal Cancer Care Pathway Principles

Optimal timeframes

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

Figure 3: Timeframes for care

Step in pathway	Care point	Timeframes
Step 3: Presentation, initial investigations, and referral	Signs and symptoms	A person presenting with symptoms is promptly assessed by a health professional.
	Initial investigations started by GP	If the person is unwell, the primary healthcare provider should conduct a full blood count and check the results promptly.
		If symptoms suggest chronic myeloid leukaemia, the person and their whānau are referred to diagnostic service **immediately** for urgent investigation.
	Referral to a hospital specialist	The person should see a specialist **within 2 weeks** if not urgent.
		The person should be admitted to hospital **immediately** if: • WBC above 100 x 10^9/L • platelet count below 50 or above 800 x 10^9/L • complaining of priapism (a persistent erection) or incipient priapism • there are any features that suggest leukostasis – blurred vision, fainting, seizures, TIA-like events, any other unexplained neurological syndromes • there is any other unexpected organ dysfunction or poorly controlled bone/splenic pain.
Step 4: Diagnosis, staging, and treatment planning	Diagnosis and staging	Investigations should be completed **within 2 weeks.**
		Less time-critical investigations should be completed **within 6 weeks**.
	Multidisciplinary team meeting and treatment planning	Where appropriate, Chronic Myeloid Leukaemia cases are discussed in an MDM, before treatment begins.

Step 4: Diagnosis, staging, and treatment planning	Multidisciplinary team meeting and treatment planning	MDM takes place **within 2 weeks** of confirmed diagnosis and phase.
		The person referred with a high suspicion of Chronic Myeloid Leukaemia and triaged by a clinician will receive their first cancer treatment **within 62 days.**
Step 5: Treatment	Tyrosine Kinase Inhibitor (TKI) therapy or systemic anti-cancer therapy	The person begins their first cancer treatment within 31 days of the decision to treat, regardless of how they were initially referred.
		The person with chronic phase Chronic Myeloid Leukaemia begins TKI therapy within the first 4 weeks unless there is a specific indication to delay.
		The person with blast phase Chronic Myeloid Leukaemia begins systemic anti-cancer therapy and/or TKI therapy within 1 week of the diagnosis.
		The person needing initial cytoreductive therapy begins the treatment in the first few weeks.

Optimal cancer care pathway

Seven steps of the optimal cancer care pathway

Step 1: Wellness
Step 2: Early detection
Step 3: Presentation, initial investigations, and referral
Step 4: Diagnosis, staging, and treatment planning
Step 5: Treatment
Step 6: Care after treatment
Step 7: Palliative care and end-of-life care

Chronic Myeloid Leukaemia (CLL) is a blood cancer that develops when the body produces too many abnormal white blood cells called granulocytes. Granulocytes are part of the myeloid family of blood cells and include neutrophils, eosinophils, basophils, and mast cells.

In chronic myeloid leukaemia, white blood cells produced are mature or partially developed, occur gradually, and grow slowly over months to years, rendering the condition as chronic. When white blood cells are very immature, occur suddenly and grow rapidly they are referred to as acute.

The incidence rate of chronic myeloid leukaemia in Aotearoa New Zealand is approximately 0.82 per 100,000 population. Among Māori, the incidence is slightly higher, at 0.84 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) produced a report outlining evidence-based, best-practice interventions to prevent cancer. Reducing cancer risk factors addresses work to achieve the goals of fewer cancers, better survival, and equity for all.

Te Tiriti o Waitangi

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

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

1.2 Modifiable cancer and wellbeing risks

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

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

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

1.3 Communication with the person/whānau receiving care

Health providers

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

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

Communication between health services

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

1.4 Measuring and monitoring

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

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

Step 2: Early detection

This step outlines recommendations for early detection for the person suspected with chronic myeloid leukaemia.

2.1 Te Tiriti o Waitangi

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

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

2.2 Early detection

Early detection has several benefits, including improved survivorship.

General Practitioners (GPs) should be aware of the possibility of chronic myeloid leukaemia in people with leucocytosis, or those with non-specific symptoms such as fatigue, weight loss, sweats, and malaise. Early satiety and abdominal discomfort may be related to progressive splenomegaly. Most cases of mild leucocytosis with neutrophilia will be due to other causes, but a fluorescence in situ hybridization (FISH) test for t(9;22), or a polymerase chain reaction (PCR) test for BCR-ABL1 to screen for chronic myeloid leukaemia should be ordered by secondary care if the white cell count is over 25 x 10^9/L. Leucocytosis or thrombocytosis is confirmed on a repeat blood test, or features on the blood film that raise the possibility of chronic myeloid leukaemia.

2.3 Chronic myeloid leukaemia cancer risk factors

- Gender – males are at a slightly higher risk of developing chronic myeloid leukaemia.
- Radiation exposure – exposure to high-dose radiation (e.g., nuclear disaster).

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

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

- **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 chronic myeloid leukaemia.

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

3.1 Te Tiriti o Waitangi

Health providers/professionals enable and enact Te Tiriti o Waitangi through:
- prioritising Māori with a 'high suspicion of cancer' referral pathway until symptoms are proven otherwise
- engaging with kaupapa Māori services that are equipped to provide holistic Whānau Ora services in the community
- supporting Māori with access to diagnostics, investigations, and referrals through to the appropriate secondary services.

3.2 Signs and symptoms

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

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

The following suspicious signs and symptoms of chronic myeloid leukaemia include:
- significant tiredness, fatigue, or pallor
- malaise
- weight loss
- sweats
- symptoms related to an enlarged spleen such as left upper quadrant fullness, pain, or discomfort
- bony pain
- visual disturbance
- erectile dysfunction.

Presenting signs and symptoms should be promptly assessed. Although half of people with chronic myeloid leukaemia are asymptomatic. Chronic myeloid leukaemia is frequently diagnosed after blood tests are taken for unrelated reasons.

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

3.3 Assessment

Chronic myeloid leukaemia assessment includes relevant:

- medical history with related medications
- physical examination: Eastern Cooperative Oncology Group (ECOG) Performance Status Scale, frailty assessment, weight, specifically looking for splenomegaly.
- laboratory investigations:
  - a full blood count will usually indicate the strong possibility of chronic myeloid leukaemia based on the increased numbers of white blood cells (WBC) and/or platelets and the WBC differential. A pathologist report on the blood test will usually raise the possibility of chronic myeloid leukaemia based on the blood count and blood film, but this may not always be the case. Very occasionally, chronic myeloid leukaemia can present with a high platelet count and a minimally raised WBC
  - the diagnosis can be confirmed in secondary care by a FISH test or a PCR test on the peripheral blood
  - if there are potential delays in accessing these tests or getting the results, prompt referral to a specialist haematologist for a bone marrow examination may be appropriate.
- familial cancer history
- social history.

3.4 Initiate investigations, including referrals

- Whether the cancer diagnosis is confirmed, or the results are inconsistent or indeterminate, the general practitioner must refer the person to an appropriate specialist to make the diagnosis.
- A referral should 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.
- The following clinical prioritisation criteria are used to triage people presenting with chronic myeloid leukaemia:
  - any person with clinical symptoms should be seen promptly. In addition, the degree of elevation of WBC count and/or platelet count, and the number of circulating blast cells in peripheral blood, will help determine clinical urgency
  - circulating blasts may be present in the blood, but if they represent more than 15% of the total WBC, the diagnosis will be either accelerated phase or blast phase disease, which requires immediate referral.

Timeframe for completing investigations for the person with suspected chronic myeloid leukaemia

The primary healthcare provider should conduct a full blood count and check the results **immediately** if the person is unwell.

A delay in test results should not preclude a referral to a haematologist for further investigations. The suspicion of chronic myeloid leukaemia is enough to justify a referral.

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 given timeframes, and any costs for accessing services.

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

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

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

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

Timeframe for referring to a specialist

The person with a possible chronic myeloid leukaemia diagnosis should be discussed with a haematologist to decide on the urgency of the referral.

Non-urgent cases should ideally be seen by a specialist haematologist **within 2 weeks**. However, some cases may require **immediate** hospital admission.

Urgent admission to hospital for inpatient care, such as leukapheresis or plateletpheresis, should be considered for:

- people with a WBC above 100 x 10^9/L
- people with a platelet count below 50 or above 800 x 10^9/L
- men complaining of priapism (a persistent erection) or incipient priapism
- any features that suggest leukostasis – blurred vision, fainting, seizures, TIA-like events, any other unexplained neurological syndromes
- any other unexpected organ dysfunction or poorly controlled bone or splenic pain.

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

3.5 Supportive care and communication

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

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

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 service referred to has not been in contact within the expected timeframe.
- Discuss the range of services available (including private), referral options, and any costs associated with accessing these services.
- Inform the person and their whānau that they can contact or request a referral to NGOs that provide supportive care, including local Māori health service providers/professionals.
- Give written and verbal information regarding planned investigations and referral services.
- Clarify that the person and their whānau understands the information that has been communicated.

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

Communication between health services

- Include relevant information in referrals, as identified in Steps 3.3 and 3.4.
- Notify the referrer of the acceptance of referral and expected timeframes to be seen or decline of referral and reasons for decline.
- Notify changes in referral status (either changes to symptoms or wait time changes).
- Ensure roles and responsibilities are understood, including GP or lead clinician responsibility for checking results and notifying 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. Results from assessment and investigations along with discussions between appropriate multidisciplinary team members and the person and their whānau, will help to determine the recommended treatment options and subsequent treatment plan.

4.1 Te Tiriti o Waitangi

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

- prioritising access for Māori to diagnostics, staging, and treatment planning
- supporting the person and their whānau to access holistic care, including mātauranga Māori traditional practices, emotional and spiritual support to complement medical treatment
- talking with the person, their whānau and clinicians about current or intended use of rongoā and 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 chronic myeloid leukaemia)

The diagnosis of cancer should be confirmed before treatment is planned. The specialist, may then request additional investigations before or after the first specialist appointment and could include:

Minimum established tests:

- real-time quantitative RT-PCR test to detect and measure the level of BCR-ABL1 on the international scale
- biochemistry screen including liver function tests, electrolytes, renal function tests, urate, lipase and amylase, blood sugar level
- HIV, hepatitis B and hepatitis C serology
- electrocardiogram.

Investigations that should be done in most circumstances:

- bone marrow aspiration including cytogenetics, immunophenotyping/flow cytometry, and morphology (exceptions can be made for frail or very elderly people)
- fasting lipids (not essential if the person will receive frontline imatinib)
- chest x-ray (not essential for young, healthy people).

The following tests may be considered in selected people:

- cardiac echocardiogram
- ankle brachial index
- doppler study of neck and leg arteries.

Timeframe for completing investigations

Assessments should be completed **within 2 weeks** from the First Specialist Appointment (FSA). However, the ankle brachial index, doppler study and cardiac echocardiogram tests that are recommended in selected cases are less time-critical and should be completed **within 6 weeks**.

4.3 Phases of disease and prognostic assessment

For most cancers, staging is a significant contributor to providing a cancer diagnosis (Te Aho o Te Kahu 2021a). Chronic myeloid leukaemia differs, and clinicians will use three phases rather than stages to describe the disease and plan the treatment accordingly.

The three phases of chronic myeloid leukaemia are:

- chronic phase: when the leukaemia is most stable and still developing slowly, not everyone will have symptoms in this phase
- accelerated phase: may show more obvious symptoms. With blood and bone marrow tests revealing a higher number of immature cells than the chronic phase
- blast phase: also called the acute phase, blast crisis or blast transformation. This is when the leukaemia transforms into an acute leukaemia (usually acute myeloid leukaemia). In this phase, many blast cells may fill the bone marrow resulting in more blast cells circulating in your blood, with the potential for spread to other organs.

The chronic myeloid leukaemia phases are described in more detail in the *European LeukemiaNet 2020 recommendations for treating chronic myeloid leukaemia* (Hochhaus et al 2020).

More than 90% of people are diagnosed in the chronic phase. The following tests are used to determine the phase of chronic myeloid leukaemia:

- percentage of blasts and basophils in the peripheral blood
- platelet count in the peripheral blood
- bone marrow morphology and cytogenetics – a bone marrow report should specifically state the phase of disease
- investigations for extramedullary disease (disease situated outside the bone marrow medullary space).

People with chronic phase myeloid leukaemia should have their risk category assessed using an accepted scoring system. Currently, the European Treatment and Oncology Study (EUTOS) long-term survival (ELTS) score is preferred. The ELTS factors in age, spleen size, blasts in the peripheral blood and the platelet count to predict long-term survival and support treatment selection.

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) and screening tools can be used to identify those who will benefit the most.

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

4.5 Multidisciplinary meeting

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

Referral to leukaemia MDM is undertaken if required to inform treatment recommendations or further assessment and investigation are needed.

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.

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

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.

For men taking the TKIs (imatinib, dasatinib and nilotinib), there is no significant impact on fertility and no increased risk of congenital abnormalities in their offspring. Therefore, they can continue taking these TKIs and father children. There is less data on fertility with the other TKIs (ponatinib and asciminib). Males do not routinely need to store sperm if they are in chronic phase myeloid leukaemia. However, if they are in blast or accelerated phase, or if they respond poorly to initial therapy and proceed to an allograft, sperm storage should be discussed and considered.

For women, TKI's may cause birth defects or fetal death. Women of childbearing age should be advised to use at least one highly effective method of birth control and if they become pregnant while taking TKIs, they should cease taking TKI immediately.

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 example:

- conducting a physical and psychological assessment to establish a baseline level of function
- identifying impairments and providing targeted interventions to improve the person's functional level
- smoking cessation
- education support for medications to ensure optimisation and correct adherence
- rongoā
- psychosocial support
- physiotherapy or exercise programme – aerobic, respiratory training, resistance training for person to function at a higher level
- nutrition.

4.5.4 Clinical trials

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

4.6 Supportive care and communication

4.6.1 Care coordination

Care coordination supports the navigation through diagnosis, staging, and treatment planning. The person and their whānau receive tailored education and are enabled to ask questions, seek further clarity around treatment options and recommendations, and gain support around the potential next steps in the pathway. The care coordinator will assist in the coordination and navigation of care, support the person and their whānau, and complete any additional referrals that may be required.

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

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

4.6.2 Supportive Care

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

- care coordinator is in place
- prehabilitation
- contraception and fertility support
- early referral to palliative care
- information and education needs are met (refer 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 any discussion.
- Explain and discuss diagnosis, staging and treatment options and recommendations in plain language.
- Discuss the advantages and disadvantages of treatment options and associated potential side effects.
- Provide information, education support and resources in a format that is useful to the person and their whānau (and that they can share with others as they wish).
- Identify any barriers or challenges that may prevent the person and their whānau from accessing services or attending treatment.
- Discuss with the person and their whānau ways to improve health outcomes and wellbeing prior to and during treatment.
- Advise the person and their whānau of their lead clinician and care coordinator.
- Clarify that the information that has been communicated has been understood.
- Coordinate scheduling of appointments with the person and their whānau to ensure access barriers are minimised and attendance is supported.
- Discuss with the person and their whānau the need to update or complete their advance care planning and/or advance directive.

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

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

Communicating between health services

- Where possible health services should coordinate appointments, in discussion with the person and their whānau.
- Communicate the diagnosis, MDM recommendations and treatment plan between health services.
- Discuss and agree shared care arrangements, for symptom and co-morbidity management, supportive care, and referral to local services.
- 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 chronic myeloid leukaemia by trained and experienced clinicians and team members, in an appropriate environment.

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

- European LeukemiaNET: European leukemiaNET 2020 recommendations for treating chronic myeloid leukaemia ***European LeukemiaNET Chronic Myeloid Leukaemia***
- European Society of Medical Oncology: *chronic myeloid leukaemia ESMO clinical practice guidelines for diagnosis, treatment and follow up* **esmo-clinical-practice-guidelines-haematological-malignancies**
- National Comprehensive Cancer Network: *NCCN clinical guideline: chronic myeloid leukaemia, version 2.2024* **NCCN guidelines**
- British Society for Haematology: *Guideline on the diagnosis and management of chronic myeloid leukaemia* **British Society for Haematology guidelines**
- American Society for Transplantation and Cellular Therapy (ASTCT) practice guidelines **astct-publications**
- European Society for Blood and Marrow Transplantation (EMBT) handbook **ebmt-handbook.**

5.1 Te Tiriti o Waitangi

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

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

5.2 Treatment intent

The treatment intent should be established in a multidisciplinary meeting/setting 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, including where they can receive support and information
- expected timeframes.

5.2.1 Additional considerations

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

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

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

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

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

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

5.3 Treatment options

The type of treatment recommended for chronic myeloid leukaemia depends on the phases of the cancer and the person's age, health, and preferences. Treatment may include a combination of those listed below and given concurrently or sequentially to maximise outcome.

For people in the chronic phase with a white blood count under 100 x 10^9/L and platelets below 800 x 10^9/L, there is less urgency to start therapy.

Timeframes for starting treatment

- **Tyrosine kinase inhibitor (TKI) therapy** – the person may benefit from TKI therapy including those:
    - with chronic phase myeloid leukaemia as the mainstay of therapy
    - with blast phase chronic myeloid leukaemia alongside chemotherapy
    - with accelerated phase chronic myeloid leukaemia.

The choice of TKIs is guided by the special authority criteria.

People starting on TKI therapy need regular haematological monitoring, at least weekly for the **first 4 weeks** and then monthly for the next **3 months**. Haematological remission or cytopenia will require TKI dose adjustments.

Outside of clinical trials, peripheral blood monitoring of the BCR-ABL level should be undertaken at **three months**, and **then every three months** indefinitely to help assess treatment response and aid adherence. In people with stable low BCR-ABL tests and reliable compliance, testing **every 4 months** may be reasonable.

TKI-related side effects can significantly affect quality of life and have the potential to be life-threatening. Comprehensive side effect management is essential since lifelong treatment may be required. People should be informed of the common, but potentially serious, side effects of TKI medication. Education on the warning signs of pancreatitis, cardiovascular disease, pleural effusions, and pulmonary hypertension can assist people and their whānau to recognise and respond when they occur. Close liaison between the person, their whānau, general practitioner and haematologist is required.

Timeframes for starting treatment

In chronic phase myeloid leukaemia, ideally TKI therapy should be started **within the first 4 weeks** unless there is a specific indication to delay.

In blast phase chronic myeloid leukaemia, TKI therapy should be started **within 1 week** of the diagnosis alongside chemotherapy.

- **Systemic anti-cancer therapy (cytotoxic agents)**– is only indicated in cases of blast phase chronic myeloid leukaemia or accelerated phase chronic myeloid leukaemia on a person-by-person basis.

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).

Timeframes for starting treatment

Initiating therapy is urgent in blast phase chronic myeloid leukaemia. Ideally chemotherapy and/or TKI therapy should be started **within 1 week** of diagnosis.

- **Allogeneic stem cell transplant (AlloSCT)** – Stem cell transplants have become less common due to the success of targeted therapies like tyrosine kinase inhibitors (TKIs). A transplant may be considered for patients with aggressive disease or those who don't respond to TKIs, after a thorough discussion with their haematologist about the risks and benefits.

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

- **Initial cytoreductive therapy** – the person may benefit from initial cytoreductive therapy including those whose white blood cell count and/or the platelet count need to be reduced to safer levels.

Timeframes for starting treatment

Initial cytoreductive therapy should be used in the **first few weeks**.

- **Palliative care**

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

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

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

5.3.1 Treatment-free remission

People who achieve a deep molecular response that is maintained for at least 24 months have the option to consider ceasing treatment. It's important to have an informed and detailed discussion about what discontinuing TKI therapy entails, including the chance of success, the frequency of molecular monitoring required, the risk of TKI-withdrawal syndrome and the impact of re-starting therapy if that becomes necessary.

Before ceasing treatment, strict processes need to be in place to ensure that molecular monitoring is timely, and results are acted on promptly.

5.3.2 Clinical Trials

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

5.4 Treatment summary

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

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

5.5 Supportive care and communication

Supportive care needs for the person and their whānau are assessed for all cancer treatment modalities: surgery, systemic-anti cancer therapy, radiation, allogeneic stem cell transplant and palliative care.

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

- access to expert health providers/professionals with specific knowledge about the psychosocial needs of people undergoing chronic myeloid leukaemia care
- potential isolation from normal support networks, particularly for rural people who are staying away from home for treatment
- general health care issues (such as smoking cessation and sleep disturbance), which can be referred to a general practitioner
- altered cognitive function due to chemotherapy or radiation therapy, which requires strategies such as maintaining written notes or a diary and repetition of information
- loss of fertility, sexual dysfunction or other symptoms associated with treatment or surgically or chemically induced menopause, which requires sensitive discussion and possible referral to a clinician skilled in this area
- decline in mobility or functional status

- management of physical symptoms such as pain, arthralgia, and fatigue
- early management for acute pain postoperatively to avoid chronic pain
- side effects of chemotherapy such as neuropathy, cardiac dysfunction, nausea, and vomiting – managing these side effects is important in protecting the person's quality of life
- managing complex medication regimens, multiple medications, assessment of side effects and assistance with difficulties swallowing medications – referral to a pharmacist may be required
- weight changes – may require referral to a dietitian before, during and after treatment
- hair loss and changes in physical appearance – referral to Look Good Feel Better
- assistance with beginning or resuming regular exercise – referral to an exercise physiologist or physiotherapist.

The person and their whānau may also need to manage:

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

5.5.1 Care coordination

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

5.5.2 Communication with the person/whānau receiving care

Health providers/professionals

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

> ***"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

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

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

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

Step 6: Care after treatment

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

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

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

The following references inform care after treatment for the person with chronic myeloid leukaemia:

- European Society of Medical Oncology: *chronic myeloid leukaemia ESMO clinical practice guidelines for diagnosis, treatment and follow up* **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
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6.2 Survivorship care planning

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

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

- the provision of a treatment summary
- information on what medical follow up and surveillance is planned
- how care after treatment will be provided, including by whom and where, and contact information
- inclusion of care plans from other health providers to manage the consequences of cancer and cancer treatment
- information about wellbeing and primary and secondary prevention health recommendations that align with chronic disease management principles (Step 1)
- rehabilitation recommendations and any referrals

- available support services, including cancer NGO survivorship programmes/services (these may be tumour specific)
- signs and symptoms to be aware of that may indicate the cancer has recurred
- the process for rapid re-entry to specialist medical services.

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

6.3 Treatment summary

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

The summary includes:

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

6.4 Rehabilitation and recovery

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

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

- Blood and Leukaemia Foundation.
- Psychological services for cancer.

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 based on the medical guidelines for the specific type and stage of cancer, the treatment received, and the needs and wishes of the person and their whānau.

For people with chronic myeloid leukaemia, periodic outpatient review with the haematology service is required to monitor progress and, in time, to potentially consider a trial of planned treatment discontinuation.

For people on TKI therapy, regular monitoring is essential due to the ongoing risk of losing disease control, both during and after TKI therapy. Monitoring the BCR-ABL level by PCR is indicated **every 3-4 months**. People will generally need to see their haematologist every **3-6 months** to assess disease control, drug adherence and risk factors for vascular disease, and to ensure any symptoms and organ toxicities are addressed promptly.

For people with chronic myeloid leukaemia in blast phase who require chemotherapy or an allogeneic stem cell transplant, a more structured survivorship care plan is indicated.

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.

Nearly all people with chronic myeloid leukaemia are asymptomatic, so refractory or relapsed disease is generally picked up during monitoring of molecular response, as outlined in the European LeukemiaNet 2020.

6.6.1 Rapid re-entry to specialty services

Service providers should 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 issues, better manage treatment side effects, or to improve models of care and quality of life.

6.8 Supportive care, care coordination and communication

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

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

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

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

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

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 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 **Health New Zealand |Te Whatu Ora website**.

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

7.3 End-of-life care

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

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

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

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

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

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

7.4 Assisted dying

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

7.5 Supportive care and communication

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

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

7.5.1 Care coordination

Palliative care services must be integrated, responsive and well-coordinated. The person receiving palliative/supportive and end-of-life care may require several different types of care from different services and/or providers. The primary care team/palliative care team assists in coordinating care with the wider health care team. It is important that the 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.* **Health New Zealand |Te Whatu Ora website**
- *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).