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Optimal cancer care pathway for people with acute myeloid leukaemia

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Whakataukī

Have a sense of the message in the winds…

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

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

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

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

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

Matua Tau Huirama

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

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

Contents

For further information including:

- Achieving Pae Ora, equity and whānau insights
- Person/whānau questions
- Definitions
- Acute 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 acute 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. Acute myeloid leukaemia (AML) affects an increasing number of people with more than 1000 diagnosed with AML this year. Around 350 people will die from some form of leukaemia this year. We all believe that people and their whānau deserve the best cancer care available.

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

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

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

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

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

Ngā mihi nui,

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

Summary guide of acute 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 around screening services and ways to reduce cancer risk. ☐ Assess the individual's risk of developing cancer. ☐ Encourage eligible people to participate in national screening programmes. ☐ Discuss recent weight changes and monitor weight. ☐ Discuss and record alcohol intake. Offer support for reducing alcohol consumption if appropriate. ☐ Record person's smoking status and offer stop smoking advice/support if appropriate. ☐ Record physical activity. ☐ Consider referral to a dietitian, physiotherapist, or exercise programme. ☐ Give the person education on being sun smart.

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[1] Optimal Cancer Care Pathway Principles

Step 2: Early detection

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

Early detection

Early detection may be achieved by monitoring people with pre-existing pre-leukaemia disorders and pre-disposing genetic disorders.

The causes of acute myeloid leukaemia are not fully understood, but reducing tobacco smoking and environmental exposure of industrial chemicals such as benzene may reduce the risk of acute myeloid leukaemia.

Other risk factors that may increase the risk of acute myeloid leukaemia include:
- advanced age
- prior chemotherapy, radiation therapy or high-dose radiation exposure
- a known previous haematological disorder with a risk of leukaemic transformation
- known predisposing genetic disorders
- having a first-degree relative with acute myeloid leukaemia.

Step 2: Checklist

☐ Assess and discuss the individual's risk of developing cancer.

☐ Support the person and their whānau to follow surveillance guidance if they're at an increased risk of familial cancer.

☐ Refer to clinical genetic services where appropriate.

☐ Discuss recent weight changes and monitor weight.

☐ If signs and symptoms of cancer are present refer to 'Step 3: Presentation, initial investigation and referral' below.

Communication

Ensure the person and their whānau understands:

☐ when they should receive their results

☐ how to follow up if they don't receive their results

☐ what's involved if they need to be transferred to a specialist service.

Step 3: Presentation, initial investigations, and referral

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

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

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

Signs and symptoms of acute myeloid leukaemia to investigate include:
- fatigue, pallor, or other symptoms of anaemia
- serious infection, such as tachycardia, high fevers, rigors
- unresolving or unusual infection or fever
- abnormal bleeding or bruising
- unexpected heavy menstrual periods
- sore gums, gum bleeding or mouth ulcers
- unexplained bone pain

Step 3: Checklist

☐ Record signs and symptoms.

☐ Complete all cancer assessments.

☐ Inform the person and their whānau of preliminary results.

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

☐ Complete and record supportive care needs assessment, 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.

- unintentional weight loss
- unexplained fevers.

The following signs and symptoms require consultation as a **medical emergency:**

- sepsis, shortness of breath, or hypotension
- symptomatic anaemia – chest pain, light-headedness, dizziness, or syncope
- severe thrombocytopenia $< 20 \times 10^9$/L
- spontaneous bleeding or bruising/uncontrolled bleeding
- coagulopathy
- major laboratory abnormalities, e.g., very high white cell count ($> 50 \times 10^9$/L)
- signs of hyperviscosity, such as visual disturbance, confusion, severe headache, or breathlessness.

AML assessment includes the relevant:

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

Referral

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

Timeframe

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

☐ Laboratory results should be processed, actively followed up and acted upon on the **same day**.

☐ If the person is clinical unwell, the referral should be made **immediately** to an emergency facility without necessarily waiting for laboratory test results.

☐ Where acute myeloid leukaemia is laboratory diagnosed, a referral for an urgent assessment by a haematologist at an appropriate facility **within 24 hours** is required.

☐ Where the person is present with sepsis, bleeding or severe symptoms, a medical emergency should be declared with an **immediate** referral to an appropriate emergency facility.

☐ Where the person needs to present to an emergency department, it should be triaged as a medical emergency initially and discussed **immediately** with a clinical haematology service and/or transferred **immediately** to a specialist centre.

Communication

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

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

Step 4: Diagnosis, staging and treatment planning

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

Diagnosis for acute myeloid leukaemia may include:

Physical examination: assessing for the presence of extramedullary disease.

Laboratory:

- peripheral blood tests including coagulation status
- immunophenotyping by flow cytometry

Step 4: Checklist

☐ Confirm diagnosis.

☐ Referral to a cancer care coordinator.

☐ Record classification, performance status and comorbidities.

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

☐ Consider enrolment in clinical trial.

- cytogenetics and molecular studies to determine prognosis and potential residual disease monitoring.

Pathology:
- bone marrow aspirate (BMA)
- trephine biopsy +/- lumbar puncture
- tissue biopsy when extramedullary disease is suspected.

Radiology:
- magnetic resonance imaging (MRI) brain if central nervous system involvement is suspected
- computed tomography (CT)/positron emission tomography (PET)-CT scan if extramedullary disease is suspected.

Cardiac investigation:
Echocardiogram (ECHO) or a gated heart pool scan if considered for intensive induction chemotherapy.

Human leukocyte antigen test:
If being considered for induction chemotherapy.

Classification for acute myeloid leukaemia:
- morphological assessment
- cytogenetics
- flow cytometry
- molecular pathology (genetic testing) by next generation sequencing (NGS).

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

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

Clinical genetic testing
Newer molecular markers with prognostic and therapeutic relevance in acute myeloid leukaemia are now becoming clinically routine. Most genetic abnormalities in acute myeloid leukaemia only occur in the abnormal leukaemic blood cells and are not related to genetic abnormalities that affect the whole body and are not inherited. However, heritable genetic abnormalities may be identifiable in a very small number of people. acute myeloid leukaemia with a genetic predisposition is an entity in the World Health Organization classification, and most diagnostic centres have access to investigations which may enable identification of heritable genetic abnormalities related to leukaemia. This becomes relevant if a family member is being considered as a haematopoietic stem cell donor. Genetic counselling may be

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

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

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

☐ Referral to leukaemia specific support services as required.

☐ Give the person and their whānau information on Cancer Society, Canteen, Leukaemia and Blood New Zealand and/or relevant cultural services and support groups available.

Timeframe

For people eligible for induction chemotherapy, an MDM should occur after induction treatment.

For people not eligible for induction chemotherapy, an MDM should occur as soon as practicable.

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.

appropriate in those families where an inherited abnormality is suspected.

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

Step 5: Treatment

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

Treatment options
Systemic anti-cancer therapy – the person that may benefit from systemic anti-cancer therapy including those:

- who are fit to receive intensive chemotherapy to induce remission
- who are older and/or with significant comorbidities to receive low dose chemotherapy
- with refractory disease to receive intensive salvage chemotherapy.

Stem cell transplant - an intensive but potentially curative treatment for acute myeloid leukaemia. The type of transplant used may be either allogeneic (from a donor) or autologous (from the person themselves).

Radiation therapy - the person that may benefit from radiation therapy including those:

- who require symptom control in palliation and occasionally to treat extramedullary and/or CNS disease
- who require total body irradiation as part of conditioning for a stem cell transplant.

All-trans retinoic acid (ATRA) and arsenic trioxide treatment – the person that may benefit from ATRA and arsenic trioxide treatment including those with APL.

Targeted therapies and immunotherapy – as per PHARMAC special authority criteria or via clinical trial.

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

Step 5: Checklist

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

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

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

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

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

☐ Consider early referral to palliative care if appropriate.

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

Timeframes

☐ The person with a confirmed diagnosis of acute myeloid leukaemia receives their first treatment **within 31 days** of the decision to treat.

☐ The person referred urgently with a high suspicion of acute myeloid leukaemia receives their first cancer treatment **within 62 days**.

☐ The person requiring induction therapy should receive the treatment promptly once a diagnosis is made and a treatment for intensive chemotherapy is confirmed.

☐ The person requiring consolidation therapy should receive the treatment **within 6 weeks** of induction chemotherapy beginning.

☐ The person identified as an anticipated allo-SCT candidate should start donor searches in first remission as soon as the person's risk status is known.

	Communication The lead clinician and team are responsible for discussing these areas with the person and their whānau: ☐ treatment options including the intent of treatment, risks, and benefits ☐ advance care planning ☐ options for healthy lifestyle support to improve treatment outcomes such as exercise and nutrition.

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

Step 7: Palliative and end-of-life care	Step 7: Checklist
Palliative and end-of-life care provides the person facing life-limiting conditions and their whānau with holistic support and coordinated services based on their specific needs. Palliative care may be provided through: • hospital palliative care	☐ Early referral to generalist palliative care. ☐ Refer to specialist palliative care services as required. ☐ Refer to supportive care services as required.

• 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 services should be available if the person and their whānau raise this with the health care team. **Communication** A key way to support the person and their whānau is by coordinating ongoing, clear communications between all health providers/professionals involved in providing cancer care.	☐ Make sure the person and their whānau are aware of the prognosis and what to expect when someone is dying. ☐ Activation 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).

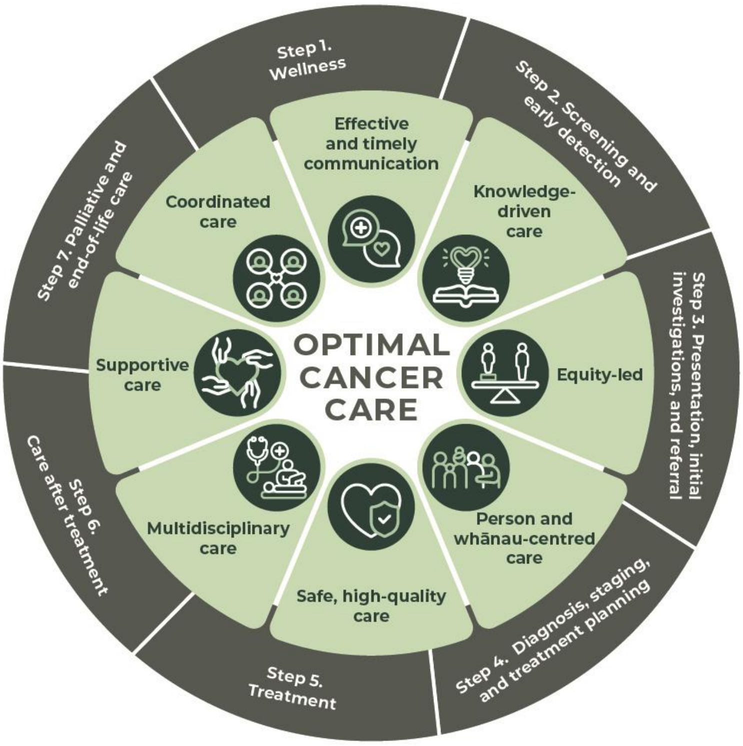
OCCPs are a framework for achieving health equity[2] in cancer control using a person and whānau centred approach to provide people with equitable, high-quality care, regardless of where they live or receive cancer treatment. OCCPs help to:

- 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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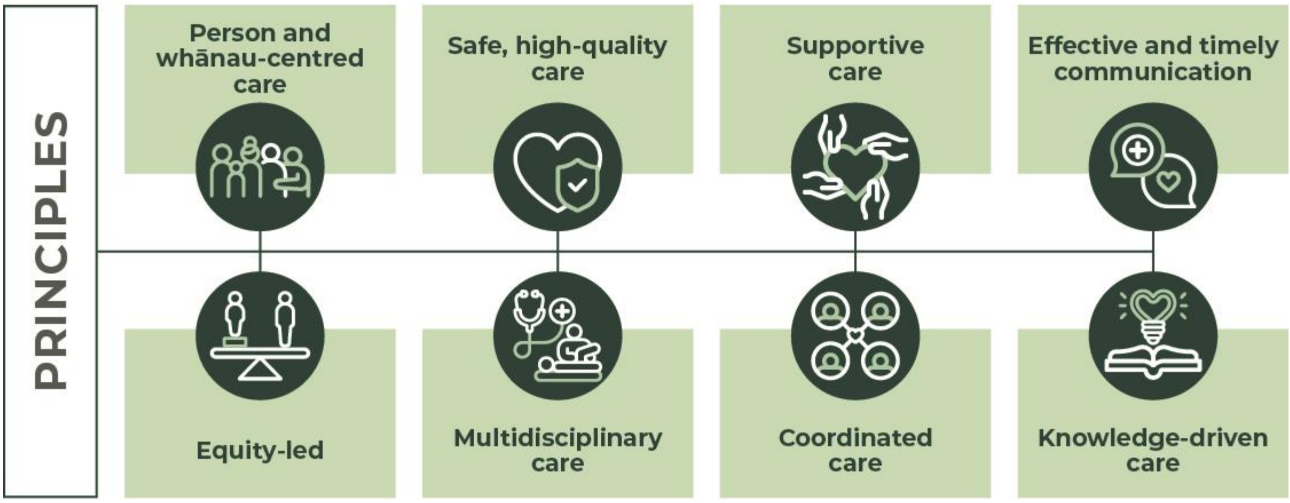
[2] Optimal Cancer Care Pathway Supplementary Information

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

Figure 3: Timeframes for care

Step in pathway	Care point	Timeframes
Step 3: Presentation, initial investigations, and referral	Signs and symptoms	A person presenting with symptoms is promptly assessed by a health professional.
	Initial investigations started by GP	If symptoms suggest AML, the general practitioner should: • conduct investigations **immediately** • have laboratory tests followed up and acted upon on the **same day**.
	Referral to a hospital specialist	The person should be referred: • **immediately** to an emergency facility without necessarily waiting for laboratory test results if clinically unwell. • for an urgent assessment by a haematologist **within 24 hours** if AML is laboratory diagnosed. • **immediately** to an appropriate emergency facility if with medical emergency. Where the person needs to present to an emergency department, it should be triaged as a medical emergency initially and discussed **immediately** with a clinical haematology service and/or transferred **immediately** to a specialist centre.
Step 4: Diagnosis, staging, and treatment planning	Diagnosis and staging	Morphological assessment to identify APL should be conducted **immediately**. Other AML results necessary for immediate management decisions should be available **within 72 hours** of the person presenting.
	Multidisciplinary team meeting and treatment planning	All newly diagnosed people are discussed in an MDM.

		For people eligible for induction chemotherapy, a full MDM often occurs after induction treatment. For people not eligible for induction chemotherapy, an MDM should occur as soon as practicable
		The person referred with a high suspicion of AML and triaged by a clinician will receive their first cancer treatment **within 62 days**.
Step 5: Treatment	Systemic anti-cancer therapy or stem cell transplant	The person begins their first cancer treatment **within 31 days** of the decision to treat, regardless of how they were initially referred. Induction chemotherapy should start promptly once a diagnosis is made and a treatment plan for intensive chemotherapy is confirmed. Consolidation chemotherapy should start **within 6 weeks** of induction chemotherapy beginning. Donor searches for allo-SCT should begin for candidates in first remission as soon as the person's risk status is known.

Optimal cancer care pathway

Seven steps of the optimal cancer care pathway

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

Acute myeloid leukaemia (AML) is characterised by the rapid expansion of abnormal myeloid-derived cell, known as blasts, in the bone marrow and peripheral blood. Acute myeloid leukaemia is more common in adults than children and is the most prevalent type of acute leukaemia diagnosed in New Zealand adults.

The incidence rate of acute myeloid leukaemia in New Zealand is approximately 2.94 per 100,000 population. Among Māori, the incidence is higher, at 3.87 per 100,000 population. Additionally, acute myeloid leukaemia appears to disproportionately affect people who are socio-economic deprived.

In general, the five-year survival rate of acute myeloid leukaemia is about 22% (Chan et al 2020).

This pathway covers acute myeloid leukaemia in adults, including acute promyelocytic leukaemia (APL).

Step 1: Wellness

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

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

1.1 Te Tiriti o Waitangi

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

- culturally safe health care providers and practices embedded in all health services and steps of the cancer care pathway
- institutional and personal bias or racism within the health and disability system being acknowledged, identified, and addressed (Harris et al 2012)
- implementation of health and wellness approaches that support ritenga Māori (Māori customary rights) framed by te ao Māori (a Māori world view), enacted through tikanga Māori (Māori customs) and encapsulated with mātauranga Māori (Māori knowledges)
- meaningful partnerships with Māori communities and organisations that benefit Māori
- support and resource health promotion activities co-designed with Māori
- 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 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
- avoiding smoking including marijuana and exposure to second-hand smoke
    - current smokers (or those who have recently quit) should be offered best practice tobacco dependence treatment and an opt-out referral to an intervention service such as Quitline.
- avoiding vaping
- screening services, such as breast, cervical and bowel cancer screening
- preventing occupational exposure to asbestos, silica, radon heavy metal, diesel exhaust and polycyclic aromatic hydrocarbons (Te Aho o Te Kahu 2022).

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

1.3 Communication with the person/whānau receiving care

Health providers

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

Communication between health services

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

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

1.4 Measuring and monitoring

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

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

Step 2: Early detection

This step outlines recommendations for early detection for the person with suspected acute 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 cancer programmes, where possible (Te Aho o Te Kahu 2022)
- implementing programmes that enhance access to cancer services.

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

2. Early detection

Early detection has several benefits, including improved survivorship.

In people with pre-existing pre-leukaemic disorders (e.g., myelodysplasia, other myeloid neoplasms) and pre-disposing genetic disorders, routine monitoring with full blood counts and bone marrow biopsies at appropriate clinical intervals would detect progression to acute myeloid leukaemia. This enables early detection in many circumstances. The frequency of blood tests and any bone marrow biopsies should be determined by standard frequency appropriate to the pre-existing or pre-disposing condition. For some conditions, such as myelodysplasia, validated risk assessment tools are available to guide practice in this regard.

Support is provided to reduce modifiable risk factors of multiple myeloma and identify any cancer risks.

2.3 Acute myeloid leukaemia risk factors

Most people have no identifiable risk factors. It is possible for acute myeloid leukaemia to run in families, but it is uncommon. In a small proportion of people, risk factors can be identified. Those risk factors include:

- advanced age
- prior chemotherapy, radiation therapy or high-dose radiation exposure
- a known previous haematological disorder with a risk of leukaemic transformation, such as myelodysplastic syndromes, myeloproliferative diseases, or congenital neutropenic syndrome
- known predisposing genetic disorders such as Down syndrome, Trisomy 8, Bloom syndrome, Ataxia-telangiectasia, Diamond-Blackfan anaemia, Shwachman-Diamond syndromes, Li-Fraumeni syndrome, neurofibromatosis type 1, severe congenital neutropenia or Fanconi anaemia
- having a first-degree relative with acute myeloid leukaemia.

2.3.1 Familial cancer risk

An individual's family cancer history is reviewed and the person and their whānau are advised of any risks of developing a familial cancer. Health providers encourage and support the person and their whānau to follow surveillance guidance. If the person and their whānau have a known genetic predisposition for acute myeloid leukaemia, or relevant family history, refer to clinical genetics where appropriate. It is possible for acute myeloid leukaemia to run in families, but it is uncommon. For further information visit **geneticheal thservice.org.nz**

2.4 Communication with the person/whānau receiving care

Health providers/professionals

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

Communication between health services:

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

2.5 Measuring and monitoring

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

- **Faster Cancer Treatment**

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

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

Step 3: Presentation, initial investigations, and referral

This step outlines the process for initiation of the right investigations and referral to the appropriate specialist in a timely manner for the person with suspected acute 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 an acute myeloid leukaemia assessment from a person's primary care presentation and referral to secondary care to specialist services (**Community HealthPathways** 2024).

3.1 Te Tiriti o Waitangi

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

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

3.2 Signs and symptoms

The person is assessed for signs and symptoms of acute 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 leukaemia.

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

Signs and symptoms of acute myeloid leukaemia at presentation, are usually nonspecific. The following symptoms should be investigated:

- fatigue, pallor, or other symptoms of anaemia
- symptoms of serious infection, such as tachycardia, high fevers, rigors
- unresolving or unusual infection or fever
- abnormal bleeding or bruising
- unexpected heavy menstrual periods
- sore gums, gum bleeding or mouth ulcers
- unexplained bone pain
- unintentional weight loss
- unexplained fevers.

The following signs and symptoms require consultation as a **medical emergency:**

- sepsis, shortness of breath, or hypotension
- symptomatic anaemia – chest pain, light-headedness, dizziness, or syncope
- severe thrombocytopenia $< 20 \times 10^9$/L
- spontaneous bleeding or bruising/uncontrolled bleeding
- coagulopathy
- major laboratory abnormalities, e.g., very high white cell count ($> 50 \times 10^9$/L)
- signs of hyperviscosity, such as visual disturbance, confusion, severe headache, or breathlessness.

People with acute myeloid leukaemia may only have mild symptoms initially. It is not uncommon that a person with few or no symptoms is diagnosed unexpectedly on a blood test conducted in primary care.

The presence of multiple signs and symptoms listed above is highly suggestive of acute myeloid leukaemia, particularly in people with a history of an underlying pre-disposing haematological condition.

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

3.3 Assessment

Acute myeloid leukaemia assessment includes relevant:

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

3.4 Initiate investigations, including referrals

- If the general practitioner confirms or suspects a diagnosis of acute myeloid leukaemia but cannot confirm it, they must refer the person to see a specialist haematologist to make the diagnosis.
- The person with a laboratory diagnosis of possible acute myeloid leukaemia should be referred for immediate assessment by a haematologist at an appropriate facility.
- Indicate if there is a high suspicion of cancer and/or it is urgent, and the person needs to be seen immediately.
- Make sure a referral receipt is obtained by the referring provider.

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

Investigations should begin **immediately** if acute myeloid leukaemia is suspected.

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

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

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

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

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

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

Timeframe for referring to a specialist

If the person is clinically unwell (presents with symptomatic anaemia, spontaneous bleeding, sepsis or has symptoms of hyperviscosity), **immediate** referral to an emergency facility is recommended without waiting for blood test results.

If acute myeloid leukaemia is laboratory diagnosed, the person will be referred for an urgent assessment by a haematologist in an appropriate facility **within 24 hours**.

Most people presenting with acute myeloid leukaemia require **acute or same day** hospital admission. The primary care clinician must speak with the on-call clinical haematologist at a secondary care facility to facilitate this. Prompt referral through to an acute leukaemia treatment centre is essential to optimise treatment outcomes.

Some people, particularly those over 60 years, and those with known pre-existing haematological conditions, can be initially managed in an outpatient/ambulatory day ward setting. Most people will need to have a diagnostic bone marrow examination performed urgently. A deferred assessment should only be done after a discussion between the referring doctor and the responsible haematologist.

The person with sepsis, bleeding or severe symptoms should be regarded as a **medical emergency** and be referred immediately to an appropriate emergency facility without necessarily waiting for results of laboratory tests (**same day**). All emergency facilities should have existing processes to receive urgent haematological advice.

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

3.5 Supportive care and communication

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

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

3.5.1 Communication with the person/whānau receiving care

Health providers/professionals

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

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

Communication between health services

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

3.6 Measuring and monitoring

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

- **Faster Cancer Treatment**

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

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

Step 4: Diagnosis, staging and treatment planning

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

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

4.1 Te Tiriti o Waitangi

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

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

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

Physical examination: including assessing for the presence of extramedullary disease (e.g., leukaemia cutis, gum infiltration and/or central nervous system symptoms).

Laboratory:
- peripheral blood tests including coagulation status to detect leukemia-related coagulopathy
- immunophenotyping by flow cytometry
- cytogenetics and molecular studies to determine prognosis and potential residual disease monitoring.

Pathology:
- bone marrow aspirate (BMA),
- trephine biopsy +/- lumbar puncture
- tissue biopsy when extramedullary disease is suspected.

Radiology:

- magnetic resonance imaging (MRI) brain if central nervous system involvement is suspected; computed tomography (CT)/positron emission tomography (PET)-CT scan if extramedullary disease is suspected. For PET-CT scans, see Health New Zealand | Te Whatu Ora National Indications for Publicly Funded PET-CT.

Cardiac investigation: including echocardiogram (ECHO) or a gated heart pool scan in people being considered for induction therapy.

Human leukocyte antigen (HLA) test: HLA typing and antibody screening at diagnosis in people being considered for induction therapy.

Pathology specimens should be collected and reviewed by a haematopathologist with expertise in diagnosing acute myeloid leukaemia before a treatment plan is agreed on. Where safe and timely to do so, it is preferable that the diagnostic blood tests and bone marrow biopsy are performed at the specialist treatment centre. This will facilitate review of blood and bone marrow results by the specialist management team and ensure all necessary tests are conducted.

Specialised testing is performed to:

- ensure accurate diagnoses
- accurately sub-classify acute myeloid leukaemia
- inform prognosis
- inform treatment decisions that are evidence-based.

It is important to evaluate and document relevant organ functions (e.g., respiratory, cardiac, hepatic, renal) and physiological robustness using validated assessment tools for all people with acute myeloid leukaemia, especially the older person.

Careful clinical and haematological assessment is required to identify people in whom the start of chemotherapy could or should be delayed. The presence of an active infection or ongoing bleeding at diagnosis is important to identify.

Each unit should have a policy about if, and when, HLA typing of available first- and second-degree family members should occur. This policy should be agreed with the allogeneic stem cell transplant (allo-SCT) unit to which referrals are usually directed.

In people with adverse or intermediate risk disease, early allo-SCT should be considered and, therefore, a donor search should be carried out as early as possible in accordance with agreed policies of the allo-SCT unit to which referrals are usually directed.

Timeframe for completing investigations

Morphological assessment to identify APL should be conducted **immediately** and the result conveyed to the treating physician as soon as possible.

For people with acute myeloid leukaemia, other results necessary for immediate management decisions should be available **within 72 hours** of the person presenting.

4.3 Classification

Classification is the principal process by which key information is collated to inform prognosis and management of the person with acute myeloid leukaemia. Classification and risk stratification involve the following tests:

- morphological assessment
- cytogenetics

- flow cytometry
- molecular pathology (genetic testing) by next generation sequencing (NGS)

Acute myeloid leukaemia is classified according to the World Health Organization's classification of acute myeloid leukaemia tumours. The European Leukaemia Net stratification system classifies the person as having favourable, intermediate, or adverse risk based on karyotype and selected molecular abnormalities.

The other most important prognostic features are age at diagnosis, performance status, presence of extramedullary disease, hyperleukocytosis, therapy-related acute myeloid leukaemia (previous exposure to cytotoxics), presence of an antecedent bone marrow failure syndrome and the response to induction chemotherapy.

Newer molecular markers with prognostic and therapeutic relevance for acute myeloid leukaemia are becoming clinically routine.

4.4 Performance status

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

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

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

4.5 Clinical genetics

Referral to clinical genetic services for acute myeloid leukaemia is considered if features of the cancer suggest a genetic predisposition, such as:

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

Most genetic abnormalities in acute myeloid leukaemia only occur in abnormal blood cells and are not related to genetic abnormalities that affect the whole body and are not inherited. However, heritable genetic abnormalities may be identifiable in a very small number of affected people. Acute myeloid leukaemia with a genetic predisposition is an entity in the World Health Organization classification, and most diagnostic centres have access to identification of heritable genetic abnormalities related to leukaemia. This becomes significantly relevant if a family member is being considered as a stem cell donor.

4.6 Multidisciplinary meeting

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

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

Induction treatment is often required before a full MDM ratifies details of the ongoing management plan (which should include full details of the response assessment). Most people will receive their initial treatment as inpatients, allowing their initial multidisciplinary treatment planning to be established on the in-patient ward. For the person undergoing intensive induction chemotherapy, presentation to, and consideration within, an MDM is most important once the outcome of the induction therapy is known. At this point, a review of the person is required to inform further management and supportive care needs.

For people not eligible for intensive induction chemotherapy, or where uncertainty of the approach exists, a review at an MDM should occur as soon as practicable (before definitive treatment commences), to establish the recommended treatment plan and all aspects of supportive care, including, early preparation for the post-treatment phase.

MDMs are managed and guided by the following standards:

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

4.6.1 Treatment options and recommendation

Following MDM, treatment options including the intent, referral options and recommendations are discussed with the person and their whānau to enable informed decision making in accordance with their rights and ability to exercise independence, choice, and control. The advantages and disadvantages of recommended treatments and associated potential side effects are discussed in plain language with interpreter support as required. Other support may be required for this discussion such as kaumātua/kuia, chaplain and nursing staff as required.

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

Because of the urgency and complexity of treatment, every clinical haematology unit should have predefined, peer-reviewed treatment models of care that have been endorsed by the multidisciplinary team. Assessment of the premorbid state is an essential component of the treatment planning process.

Prevention and management of infections in acute myeloid leukaemia include the following:

- all people should undergo screening for infections at high risk of reactivation or transmission before beginning treatment
- some infections are determined by epidemiological risk of exposure and history of recent travel and/or extended habitation in high-risk countries

- minimum requirements would include cytomegalovirus, hepatitis B, hepatitis C and HIV screening. Other tests such as for tuberculosis, strongyloides serology, and screening for multidrug-resistant pathogens as per institutional policy, should be considered
- the person with antibiotic allergy labels should have suspected allergies reassessed where possible
- all institutions should have empiric sepsis guidelines/pathways that include appropriate recommendations for the initial management of neutropenic fever. Specialists in infectious diseases may be required for advice about duration and appropriate antibiotics based on pathogens isolated and person factors (allergy, renal impairment)
- vaccination status should be assessed for all people. Vaccination with influenza and Streptococcus pneumoniae can recommence after three months if in complete remission
- prophylaxis guidelines for fungal and viral infections should accord with published national guidelines.

4.6.2 Fertility preservation

Acute myeloid leukaemia often occurs in older people, however for younger people diagnosed with acute myeloid leukaemia, a referral for contraception assessment alongside fertility preservation advice should be considered dependent on age, type of cancer and the treatment planned. An early, collaborative, and multidisciplinary approach with the person is undertaken, which maximises the opportunity for best practice contemporary care and consideration for future fertility. Those in the reproductive age group should be assessed by fertility preservation services before commencing intensive induction chemotherapy.

The person and their whānau need to be advised about fertility preservation before starting treatment and need advice about contraception before, during and after treatment. Fertility preservation options are different for males and females and may be specific to a person’s age. The need for ongoing contraception applies to both men and women.

4.6.3 Prehabilitation

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

- conducting a physical and psychological assessment to establish a baseline level of function
- identifying impairments and providing targeted interventions to improve the person’s functional level
- recognize that assessments of end organ function will impact on recommendations for various treatment options, and overall prognosis

- smoking cessation
- medications to ensure optimisation and correct adherence
- rongoā
- psychosocial support
- physiotherapy or exercise programme – aerobic, respiratory training, resistance training for the person to function at a higher level
- nutrition.

4.6.4 Clinical trials

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

Participation in clinical trials, registries, and tissue banking, where available, is considered a standard of care for people with acute myeloid leukaemia. Cross-referral between clinical trial centres should be encouraged to facilitate participation.

4.7 Supportive care and communication

4.7.1 Care coordination

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

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

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

4.7.2 Supportive Care

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

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

4.7.3 Communicating with the person/whānau receiving care

Health providers/professionals

- Ensure that person and their whānau have the option to have additional support people with them when having discussions.
- Explain and discuss with person's diagnosis, staging and treatment options and recommendations in plain language.

- Discuss the advantages and disadvantages of treatment options and associated potential side effects.
- Provide information and resources in a format that is useful to the person and their whānau (and that they can share with others as they wish).
- Identify any barriers or challenges that may prevent the person and their whānau from accessing services or attending treatment.
- Discuss with the person and their whānau ways to improve health outcomes and wellbeing prior to and during treatment.
- Advise the person and their whānau of their lead clinician and care coordinator.
- Clarify that the person and their whānau have understood the information that has been communicated.
- The person and their whānau may require time to process the information that has been relayed, prior to consenting to treatment.
- Coordinate scheduling of appointments with the person and their whānau to ensure access barriers are minimised and attendance is supported.
- Discuss with the person and their whānau the need to update or complete their advance care planning and/or advance directive.

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

Communicating between health services

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

4.8 Measuring and monitoring

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

- **Te Aho o Te Kahu Quality Performance Indicator**
    - Route to diagnosis: People diagnosed with cancer within 30-days of an emergency or acute (unplanned) hospital admission (Te Aho o Te Kahu, 2024).
- **Faster Cancer Treatment**
    - **31-day Health Target -** the MDM, person and their whānau agree to treatment as soon as possible following MDM to enable them to meet the 31-day Health Target.
    - **62-day Indicator** – If a person does not attend MDM within 28 days, they are unlikely to meet the 62-day pathway.

- **MDM Standards**

For audit compliance with standards and standards audit tool the following may be used:

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

Step 5: Treatment

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

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

- European Society of Medical Oncology: *ESMO clinical practice guidelines: acute myeloid leukaemia in adult patients* **esmo-clinical-practice-guidelines-haematological-malignancies**
- American Society of Hematology: *ACH clinical practice guidelines on acute myeloid leukemia in older adults* **clinical-practice-guidelines/acute-myeloid-leukemia-guidelines**
- American Society of Hematology: *Management of acute promyelocytic leukemia: updated recommendations from an expert panel of the European LeukemiaNet* **clinical-practice-guidelines/acute-myeloid-leukemia-guidelines**
- American Society for Transplantation and Cellular Therapy (ASTCT) practice guidelines **astct-publications**
- European Society for Blood and Marrow Transplantation (EBMT) handbook **ebmt-handbook**

5.1 Te Tiriti o Waitangi

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

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

5.2 Treatment intent

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

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

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.

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

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

- **Systemic anti-cancer therapy** – the person that may benefit from systemic anti-cancer therapy including those:
    - who are fit to receive intensive chemotherapy to induce remission
    - who are older and/or with significant comorbidities to receive low dose chemotherapy
    - with refractory disease to receive intensive salvage chemotherapy.

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).

Intensive chemotherapy is divided into two phases: induction therapy to achieve complete remission; and consolidation therapy once a remission has been achieved to maintain ongoing remission or as a bridge to curative treatment – that is, an allogeneic bone marrow transplant (also known as stem cell transplant).

Induction chemotherapy should ideally only be started when all diagnostic criteria have been satisfied. In the person with suspected APL and those with hyperleukocytosis, the risk of severe complications is high, and chemotherapy poses the risk of worsening disseminated intravascular coagulation. Leukopheresis is contraindicated in this scenario.

Starting differentiation therapy immediately needs to be considered in consultation with an expert in this area. Treatment with all-trans retinoic acid (ATRA) is frequently initiated on the suspicion of APL. In these circumstances, emergency therapy may be required before completing diagnostic sampling. The person with hyperleukocytosis may require treatment with hydroxycarbamide/hydroxyurea before commencing additional chemotherapy.

All people undergoing intensive chemotherapy will need a central intravenous line inserted (with platelet transfusion and correction of coagulopathy if necessary). Such devices should only be inserted by proceduralists experienced in such procedures.

After recovering from induction therapy, it is important to assess the response to initial treatment, including complications (e.g., the severity of side effects and sepsis), in order to plan future therapy. People who fail to achieve remission have a poor prognosis, while the outcome for people in remission depends on subsequent therapy.

Once a person is in remission, consolidation therapy is always indicated when cure is the intention. Following induction therapy, additional treatment should be given because the median disease-free survival for people who receive no additional therapy is only four to eight months. The aim of consolidation therapy is to prevent relapse with maximal efficiency and minimal toxicity. Current approaches to induction and consolidation therapy include short-term, relatively intensive chemotherapy, or high-dose chemotherapy. There is no consensus on a single ‘best’ post-remission treatment schedule, nor the optimal number of cycles of consolidation chemotherapy.

Consolidation therapy for acute myeloid leukaemia people who have achieved complete remission is determined after considering a combination of the following factors:

- the person’s age and fitness
- prognosis
- tolerance of prior therapy
- minimal (also called measurable) residual disease (MRD) status in selected AML subtypes
- whether the person is a candidate for an allogeneic stem cell transplant.

Low-dose chemotherapy is an option for older people (>75 years) or for people with significant comorbidities who are not fit for intensive chemotherapy.

Resistance to therapy (refractory acute myeloid leukaemia) is the major cause of treatment failure, rather than mortality due to infections and other treatment-related complications. People failing to respond to one or two cycles of induction treatment can be considered chemotherapy refractory and are at very high risk of ultimate treatment failure. In this circumstance other alternatives should be explored (non-chemotherapy options or clinical trials). While there are no standard salvage regimens for acute myeloid leukaemia, intensive salvage chemotherapy can result in a second remission in approximately 55 per cent of people aged 16–49, of which approximately two-thirds can then proceed to an allo-SCT (Döhner et al. 2017).

Timeframes for starting treatment

Induction therapy should start promptly once a diagnosis is made and a treatment plan for intensive chemotherapy is confirmed.

Consolidation therapy should start **within 6 weeks** of induction chemotherapy beginning.

- **Allogeneic stem cell transplant (Allo-SCT)**

For an allogenic stem cell (Allo-SCT) transplant a donor's healthy blood or bone marrow stem cells are used to replace the person with acute myeloid leukaemia diseased cells. A good match is critical.

Potential candidates for allo-SCT (scheduled for the consolidation phase) should be identified at diagnosis. Patients with higher-risk acute myeloid leukaemia are more likely to be recommended for an allogeneic transplant. These considerations can change based on the persons response to initial treatment, overall tolerance, and complications of subsequent treatment. A formal recommendation to proceed to allo-SCT should only occur after discussion at a focused bone marrow transplant MDM. Factors that need consideration include disease prognosis (incorporating response to treatment), comorbidities and functional status, and the availability of suitable donor(s). Part of this assessment should include a formal haematopoietic cell transplantation (HCT)-comorbidity assessment. People offered an allo-SCT are carefully selected and must have an appropriately HLA-matched donor.

For the person with good-prognosis and in their first complete remission, the risks of allo-SCT exceed the benefits and a survival advantage has not been proven, especially if people have low or absent levels of MRD after achieving remission.

It should be noted that people with refractory disease who undergo an allo-SCT have limited chances of success and considerable morbidity from this procedure. For people unsuited to this approach, palliative systemic treatment is often a reasonable option with limited toxic effects.

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

- **Autologous stem cell transplant (ASCT) –** The persons own stem cells are collected, frozen, and then returned to them after high-dose chemotherapy. This is done to provide a potentially better chance of cure or longer-term control.

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

Timeframes for starting treatment

Donor searches should begin for all anticipated allo-SCT candidates in first remission (CR1) as soon as the person's risk status is known.

Individual treating units should ensure referral pathways for transplantation are established to minimise delays. Rapid-access pathways are required for people for whom urgent transplantation may be appropriate.

- **Radiation therapy -** the person that may benefit from radiation therapy including those requiring:
    - symptom control in palliation and occasionally to treat extramedullary and/or CNS disease
    - total body irradiation as part of conditioning for allo-SCT and should only be given in centres with appropriately qualified and experienced staff and equipment.

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

- **Targeted therapies and immunotherapy**

The indications of using targeted therapies and immunotherapy for people with acute myeloid leukaemia are outlined in the PHARMAC special authority criteria. For therapies that are not funded, potential clinical trial options for access should be discussed with the person and their whānau.

- **Palliative care**

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

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

Early referral to palliative care and other health services is recommended to help manage:
- side effects resulting from treatments
- decline in mobility or functional status as a result of treatment
- nutritional support
- sexual dysfunction
- peripheral neuropathy
- fatigue.

5.3.1 Clinical Trials

The person and their whānau are 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).

For the person not fit for intensive chemotherapy, new therapies are starting to emerge that may offer meaningful clinical activity. Referral to a clinical trial should be a priority.

5.4 Treatment summary

A treatment summary will be provided by the treating service for the person and their whānau and clinicians involved in their follow-up care, including primary care. The summary includes:
- relevant diagnostic tests performed and results
- cancer diagnosis, characteristics, stage, and prognosis
- treatment received
- current toxicities (severity, management and expected outcomes)
- interventions and treatment plans from other health providers/professionals
- potential long-term and late effects of treatment
- supportive care services provided
- recommended follow-up and surveillance.

5.5 Supportive care and communication

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

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

- endocrine effects (gonadal), cardiac effects, osteoporosis, transfusional iron overload and secondary myelodysplasia in the late stages of therapy
- malnutrition due to ongoing treatment side effects, such as gastrointestinal symptoms, reduced appetite and reduced oral intake; this requires monitoring and nutrition intervention where indicated
- side effects resulting from high-dose therapy including fatigue, cytopenia, mucositis (oral and bowel), immunosuppression resulting in increased infection, fluid retention, dyspnoea, graft-versus-host disease (GVHD) following allo-SCT, and organ toxicity (interstitial pneumonitis, veno-occlusive disease)
- other 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
- additional supportive care required to address the immunosuppressive effects and long-term side effects of therapy for the person treated with allo-SCT – issues may include infertility, GVHD, increased risk of infection, anaemia, bleeding, mouth ulcers and fatigue
- access to expert health providers/professionals with specific knowledge about the psychosocial needs of people undergoing acute 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. Cognitive impairment, which people treated with allo-SCT report to be a major component of quality-of-life impairment and can last for years post procedure
- loss of fertility, sexual dysfunction or other symptoms associated with treatment or surgically or chemically induced menopause, which requires sensitive discussion and possible referral to a clinician skilled in this area
- decline in mobility or functional status
- management of physical symptoms such as pain, arthralgia, and fatigue
- early management for acute pain postoperatively to avoid chronic pain
- managing 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 (for further information, see Principle 5).

5.5.2 Communication with the person/whānau receiving care

Health providers/professionals

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

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

Communication between health services

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

5.6 Measuring and monitoring

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

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

- **Faster Cancer Treatment**
    - **31-day Health Target -** As a minimum, 90% of patients will receive their cancer treatment (or other management) within 31-days from the decision to treat.
    - **62-day indicator** –As a minimum, 90% of patients will receive their cancer treatment (or other management) within 62-days from date of referral to first treatment.
- **Haematology treatment timeframe**
    - Category A – urgent within 48 hours
    - Category B – semi-urgent within 2 weeks
    - Category C – routine within 4 weeks

- **Medical oncology treatment timeframes**
    - Category A – urgent within 48 hours
    - Category B – semi-urgent within 2 weeks
    - Category C – routine within 4 weeks
    - Category D – combined modality treatment (determined by scheduling of the two treatment modalities).

Step 6: Care after treatment

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

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

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

The following references inform care after treatment for the person with AML:

- European Society of Medical Oncology: *ESMO clinical practice guidelines: acute myeloid leukaemia in adult patients* **esmo-clinical-practice-guidelines-haematological-malignancies**

6.1 Te Tiriti o Waitangi

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

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

6.2 Survivorship care planning

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

In the past two decades, the number of people surviving acute myeloid leukaemia has increased. Approximately 60–70 per cent of acute myeloid leukaemia people under 60 years of age who receive intensive chemotherapy can expect to attain complete remission. More than 25 per cent of adults with acute myeloid leukaemia (about 45 per cent of those who attain complete remission) can be expected to survive three or more years and may be cured.

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

- the provision of a treatment summary
- information on what medical follow-up and surveillance is planned
- how care after treatment will be provided, including by whom and where, and contact information
- inclusion of care plans from other health providers to manage the consequences of cancer and cancer treatment

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

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

6.3 Treatment summary

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

The summary includes:

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

6.4 Rehabilitation and recovery

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

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

- Blood and Leukaemia Foundation.
- Psychological cancer services.

6.5 Follow up and surveillance

Follow up and surveillance can have multiple functions, including:

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

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

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

For people with acute myeloid leukaemia, follow up care is informed by the following guidelines:

For select people undergoing intensive initial therapy, assessing for the presence or absence of MRD after consolidation therapy has been shown to predict later overt recurrence. This is also an area of very active research, and the evidence base is evolving rapidly. Currently, MRD assessment (+/– monitoring) is appropriate for people whose acute myeloid leukaemia have certain mutations. Alternatively, flow cytometry for detecting phenotypically aberrant 'different from normal' populations in specialised laboratories may be considered.

For immediate post-therapy follow-up, the frequency of consultations will be determined by the person's needs and may range between several times a week and 6-weekly. The primary treating clinical haematologist should coordinate these, with input from the full spectrum of allied health professionals. Follow-up frequency will usually reduce over time for people in remission.

For longer term follow-up and surveillance of the person with acute myeloid leukaemia, the frequency of disease assessment will be based on whether the person is in remission or has relapsed/progressive disease. The general surveillance schedule for the person in first remission is:

- for the first 2-3 years after treatment: full blood examination (FBE), and clinical assessment with a careful history and physical examination every three months
- thereafter, up to 5 years post-treatment: FBE and clinical review every 3-6 months
- then as deemed appropriate for individual people: annual FBE and clinical review indefinitely.

People who have received allo-SCT will require specific long-term follow-up plans coordinated by the survivorship programme at the transplant unit. In some circumstances, follow-up care can be safely and effectively provided:

- in the general practice setting
- in the specialist and hospital setting, including in specialised late effects clinics staffed with members of the multidisciplinary team including physiotherapy, occupational therapy, nursing, social work, dietetics, clinical psychology, and palliative care.

Molecular monitoring for MRD is recommended for people with APL, and other selected subtypes of acute myeloid leukaemia. Comprehensive guidelines about the performance, monitoring frequency and interpretation of MRD technologies (flow cytometry and molecular) are available.

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

6.6 Signs and symptoms of recurrent disease

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

Signs and symptoms that necessitate further investigation include:

- anaemia
- bruising
- infections
- aching bones
- swollen glands
- fatigue
- fever and sweats
- headaches
- blurred vision
- breathlessness.

Relapse occurs in more than 50 per cent of people, and treatment outcomes will vary depending on individual prognostic factors. Most cases of relapsed AML are diagnosed through routine follow-up or by the person presenting with symptoms.

6.6.1 Rapid re-entry to specialty services

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

6.7 Clinical trials

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

6.8 Supportive care, care coordination and communication

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

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

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

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

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

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

Effective and timely communication

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

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

6.9 Measuring and monitoring

Currently there are no national indicators for this step.

Step 7: Palliative and end-of-life care

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

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

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

7.1 Te Tiriti o Waitangi

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

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

7.2 Palliative care

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

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

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

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

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

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

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

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

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

7.3 End-of-life care

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

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

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

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

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

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

7.4 Assisted dying

The person requesting assisted dying information are supported to access this service. Health providers/professionals are required to be aware of their rights and responsibilities 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.

7.5.4 Palliative care and end of life key national guidelines

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

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

7.6 Measuring and monitoring

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