TE AHO
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# Optimal cancer care pathway for people with multiple myeloma

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# Whakataukī

Have a sense of the message in the winds…

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

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

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

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

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

Matua Tau Huirama

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

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

# Contents

**For further information** including:

- Achieving Pae Ora, equity and whānau insights
- Person/whānau questions
- Definitions
- Multiple myeloma 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 Multiple Myeloma 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. Multiple Myeloma affects an increasing number of people with more than 460 diagnosed with multiple myeloma this year. Around 200 people will die from multiple myeloma 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 multiple myeloma, 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 multiple myeloma 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.**<br>Evidence-based research shows that general cancer and wellbeing risks can be reduced by:<br>• eating a nutritious diet<br>• maintaining a healthy weight<br>• taking regular, moderate to vigorous-intensity activity<br>• avoiding or limiting alcohol intake<br>• being sun smart<br>• identifying pre-disposing infections such as, Hepatitis C<br>• keeping up to date with immunisations or vaccines such as, Human Papilloma Virus (HPV)<br>• avoiding smoking including marijuana and exposure to second-hand smoke<br>  ○ 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<br>• avoiding vaping<br>• participating in screening services such as breast, cervical, bowel cancer screening<br>• 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.<br>☐ Assess the individual's risk of developing cancer.<br>☐ Encourage eligible people to participate in national screening programmes.<br>☐ Discuss recent weight changes and monitor weight.<br>☐ Discuss and record alcohol intake. Offer support for reducing alcohol consumption if appropriate.<br>☐ Record person's smoking status and offer stop smoking advice/support if appropriate.<br>☐ Record physical activity.<br>☐ Consider referral to a dietitian, physiotherapist, or exercise programme.<br>☐ 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 multiple myeloma.**

**Early detection**

Multiple myeloma modifiable cancer risks include:

- being overweight
- exposure to radiation and chemicals.

Multiple myeloma non-modifiable cancer risk factors include:

- advanced age
- clinically defined monoclonal gammopathy of uncertain significance (MGUS)
- family history: having a first-degree relative with multiple myeloma
- ethnicity: Māori and Pacific people have a higher risk of developing multiple myeloma
- gender: slightly more common in males.

Early detection may be achieved through monitoring people with MGUS or smouldering myeloma to assess possible progression to multiple myeloma. However, there is currently no established benefit to early detection of MGUS.

## Step 2: Checklist

☐ Assess and discuss the individual's risk of developing 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 multiple myeloma.**

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 a high suspicion of multiple myeloma.

**Signs and symptoms** of multiple myeloma to investigate include:

- fatigue and generalised weakness
- bone pain or pathological fracture (broken bone often with minimal trauma)
- frequent infections
- unintentional weight loss

## Step 3: Checklist

☐ Record signs and symptoms.

☐ Complete all cancer assessments.

☐ Inform the person and their whānau of preliminary results.

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

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

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

☐ Initiate referrals and arrange further investigation.

**Timeframe**

- symptoms of hypercalcaemia including mental fogginess and/or confusion, new onset constipation and/or abdominal pain, polyuria, and increased thirst
- new-onset back pain particularly with neurological symptoms such as leg weakness loss of bladder or bowel control, or loss of sensation
- symptom of hyperviscosity (easy bruising, bleeding gums, cloudy vision), although this is rare, and typically associated with IgA type myeloma.

Blood test abnormalities that may suggest multiple myeloma include:

- anaemia
- elevated creatinine
- hypercalcaemia
- an elevated globulin level, typically associated with an increased protein-albumin gap in the absence of infection of inflammation
- presence of a paraprotein on serum protein electrophoresis
- elevated serum Kappa or Lambda free light chain level, with an abnormal Kappa to Lambda light chain ratio.

End-organ complications that are often associated with multiple myeloma include:

- enhanced bone loss/generalized osteoporosis
- renal failure
- hypercalcaemia
- immune suppression (reduction in the non-paraprotein immunoglobulin sub-types).

**Multiple myeloma assessment** includes the relevant:

- **medical history** including medications
- **physical examination**: Eastern Cooperative Oncology Group (ECOG) Performance Status Scale, frailty assessment, weight
- **laboratory**: serum protein electrophoresis (SPEP), immunofixation (IF), lambda free light chain (SFLC) and light chain ratio, full blood count and differential, creatinine, urea, electrolytes, liver function tests, calcium, magnesium, phosphate, urate, and urine dipstick full ward test
- **radiology**: X-ray, computed tomography (CT)
- **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.

☐ If there is a high suspicion of multiple myeloma, submit referral **immediately** to hospital specialist services.

☐ High suspicion of cancer referral is triaged **within 1-2 working days** and referrer is notified.

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

☐ If there are indicators of end organ damage, the person should be seen by a haematologist as soon as possible, ideally **not longer than 1 week**,

☐ If there are no concerns of end-organ damage, the person should ideally be seen by a haematologist **within 4 weeks**.

☐ If there are severe hypercalcaemia, renal failure, symptoms of hyperviscosity, severe new-onset back pain or acute neurological symptoms, the person should be **immediately** referred to a haematologist or emergency department.

**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.

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

M-protein in serum and/or urine and one or more of the following:

- unexplained hypercalcaemia (>2.75 mmol/L)
- unexplained renal impairment – creatinine clearance < 40ml/min
- unexplained anaemia – Hb < 100g/L
- bony lytic lesions on radiologic imaging
- serum monoclonal protein (IgG or IgA > 30g/L or involved: uninvolved serum free light chain radio > 100 to the power of 13.

## 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 multiple myeloma may include:

**Radiology:** CT scan, magnetic resonance imaging (MRI), positron emission tomography (PET) CT scan

**Pathology:** bone marrow biopsy including flow cytometry and trephine biopsy, tissue biopsy occasionally for bony or extramedullary plasmacytoma

**Laboratory:** blood test including full blood count, differential and blood film, U&E panel, calcium, immunoglobulins, protein electrophoresis (PEP), IF, SFLCs, 24-hour urine collection

**Bone densitometry:** when osteoporosis is suspected.

**Staging:** Revised Internal Staging System (R-ISS).

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

International Myeloma Working Group (IMWG) geriatric assessment tool is commonly used for people with multiple myeloma.

**Clinical genetic testing**
Currently there are no genetic tests applicable to predict family risk of multiple myeloma.

**Treatment planning**

## Step 4: Checklist

☐ Confirm diagnosis.

☐ Referral to a cancer care coordinator.

☐ Record staging, performance status and comorbidities.

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

☐ Consider enrolment in clinical trial.

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

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

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

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

**Timeframe**

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

**Communication**

The lead clinician and team are responsible for:

| | |
|---|---|
| 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. | ☐ discussing a timeframe for diagnosis and treatment options with person and their whānau<br>☐ explaining the role of the MDM team in treatment planning and ongoing care<br>☐ 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<br>☐ providing appropriate information and referral to support services as required<br>☐ communicating with the GP of the person and their whānau about the diagnosis, treatment plan and recommendations from the MDM. |

| Step 5: Treatment | Step 5: Checklist |
|---|---|
| **This step describes publicly funded optimal treatments for multiple myeloma by trained and experienced clinicians and team members, in an appropriate environment.**<br>**Treatment options**<br>**Systemic anti-cancer therapy** – most people treated for multiple myeloma will receive systemic therapy.<br>**Autologous stem cell transplant (ASCT)** – may be indicated as per American Society for Transplantation and Cellular Therapy (ASTCT) guidelines and European Society for Blood and Marrow Transplantation (EMBT) handbook.<br>**Radiation therapy** - the person/whānau that may benefit from radiation therapy may include those with:<br>• Multiple myeloma or plasmacytoma that is causing pain or acute organ compromise such as spinal cord compression<br>• solitary bone plasmacytoma or solitary extramedullary plasmacytoma.<br>**Surgery** – no routine therapeutic role except for preventing or stabilizing long-bone pathological fractures, vertebral column instability as well as spinal cord compression that are not treatable by radiation therapy.<br>**Supportive therapy** – should be offered where indicated concurrently with anti-myeloma therapies from the beginning of treatment. | ☐ Health providers/professional, treating specialist has relevant qualifications, experience, and expertise.<br>☐ Discuss the intent of treatment and the risks and benefits with the person and their whānau.<br>☐ Provide the agreed treatment plan with the person, their whānau and GP.<br>☐ Assess supportive care needs and refer to allied health services as required.<br>☐ Give the person and their whānau information on the cancer non-governmental organisations (NGOs,) cultural services and support groups available.<br>☐ Consider early referral to palliative care if appropriate.<br>☐ Discuss advanced care planning with the person and their whānau.<br>**Timeframes**<br>☐ The person with a confirmed diagnosis of multiple myeloma receives their first treatment **within 31 days** of the decision to treat date.<br>☐ The person with multiple myeloma presented in the myeloma MDM **within 2 weeks after** diagnosis.<br>☐ **Systemic anti-cancer therapy** should begin:<br>▪ **within 2 weeks** of establishing the diagnosis and staging |

| | |
|---|---|
| **Palliative care** – early referral to palliative care can improve quality of life and in some cases survival. Referral is based on need, not prognosis. | ▪ **within 24 hours** of diagnosis in cases where there is critical organ compromise or rapid clinical progression.<br>☐ **Radiation therapy** should begin:<br>▪ **within 24 hours** of referral where possible, with a maximum acceptable waiting time of **48 hours** in cases where there is acute critical organ compromise<br>▪ **within 48 hours** of referral where possible, with a maximum acceptable waiting time of **14 days** in cases where symptomatic tumours are causing pain<br>▪ **within 14 days** of referral where possible, with a maximum acceptable waiting time of **28 days** in cases where there is a solitary bone plasmacytoma or extramedullary plasmacytoma and treatment intent is curative.<br>**Communication**<br>The lead clinician and team are responsible for discussing these areas with the person and their whānau:<br>☐ treatment options including the intent of treatment, risks, and benefits<br>☐ advance care planning<br>☐ 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.**<br>Provide a summary of the treatment and follow-up care plan to the person, their whānau and their GP outlining:<br>• diagnosis, including tests performed and results<br>• treatment received (types and date)<br>• current toxicities (severity, management and expected outcomes)<br>• interventions and treatment plans from other health providers/professionals<br>• potential long-term and latent effects of treatment and care of these<br>• supportive care services provided<br>• a follow-up schedule, including tests required and timing | ☐ Provide a survivorship plan that includes a summary of the treatment and follow-up care plan to the person, whānau and their GP.<br>☐ Assess supportive care needs and refer to allied health services as required.<br>☐ Give the person and their whānau information on Cancer Society and/or relevant cultural services and support groups available.<br>**Communication**<br>The lead clinician (or delegated representative) is responsible for:<br>☐ explaining the treatment summary and follow up and surveillance care plan to the person and their whānau<br>☐ informing the person and their whānau about secondary prevention and healthy living |

| | |
|---|---|
| - contact information for key health care providers/professionals who can offer support for lifestyle modification<br>- a process for rapid re-entry to medical services for suspected relapse<br>- ongoing assessments of the effects of treatment. | ☐ discussing the follow-up care plan with the GP of the person and their whānau<br>☐ 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.**<br>Palliative care may be provided through:<br>- hospital palliative care<br>- home and community-based care<br>- community nursing, including access to appropriate equipment.<br>Early referral, identification, correct assessment, treatment of pain and other symptoms prevent and relieves suffering.<br>End-of-life care should consider:<br>- appropriate place of care<br>- person's preferred place of death<br>- support needed for the person and their whānau.<br>Awareness of and access to, assisted dying information should be available if the person raises this with the health care team.<br>**Communication**<br>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. | ☐ Early referral to generalist palliative care.<br>☐ Refer to specialist palliative care services as required.<br>☐ Refer to supportive care services as required.<br>☐ Make sure the person and their whānau are aware of the prognosis and what to expect when someone is dying.<br>☐ Discuss activation timing of advance care plan, directive, or enduring power of attorney. |

# How optimal cancer care pathways improve outcomes

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

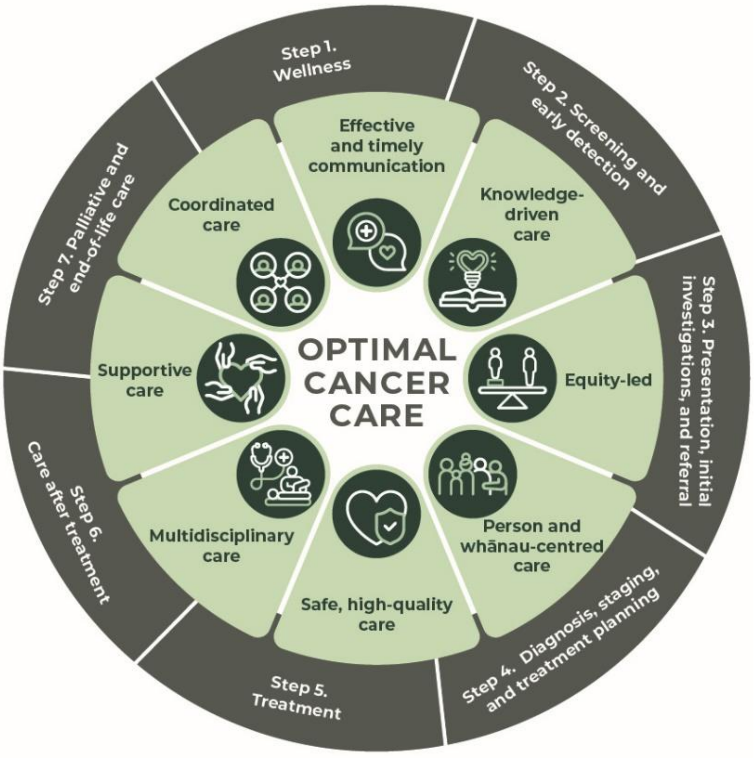
OCCPs are a framework for achieving health equity[2] in cancer control using a person and whānau centred approach to provide people with equitable, high-quality care, regardless of where they live or receive cancer treatment. OCCPs help to:

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

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

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

Figure 1: Optimal Cancer Care model



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[2] Optimal Cancer Care Pathway Supplementary Information

# Principles of the optimal cancer care pathway

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

Figure 2: Principles of optimal cancer care

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[3] Optimal Cancer Care Pathway Principles

# Optimal timeframes

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

Figure 3: Timeframes for care

| Step in pathway | Care point | Timeframes |
|---|---|---|
| **Step 3: Presentation, initial investigations, and referral** | Signs and symptoms | A person presenting with symptoms is promptly assessed by a health professional. |
| | Initial investigations started by GP | If symptoms suggest multiple myeloma, the person and their whānau are referred to diagnostic service **within 2 weeks** for urgent investigation. |
| | Referral to a hospital specialist | The person should see a specialist:<br>• **immediately** if with severe hypercalcaemia, renal failure, symptoms of hyperviscosity, severe new-onset back pain or acute neurological symptoms<br>• **within 1 week** if indicators of end-organ damage<br>• **within 4 weeks** if without overt end-organ damage. |
| **Step 4: Diagnosis, staging, and treatment planning** | Diagnosis and staging | Investigations should be completed **within 2 weeks** |
| | Multidisciplinary team meeting and treatment planning | All newly diagnosed people are discussed in an MDM, before treatment begins. |
| | | MDM takes place **within 2 weeks** of confirmed diagnosis and staging. |
| | | The person referred with a high suspicion of multiple myeloma and triaged by a clinician will receive their first cancer treatment **within 62 days.** |

| | | |
|---|---|---|
| Step 5: Treatment | Systemic anti-cancer therapy or radiation therapy | The person begins their first cancer treatment **within 31 days** of the decision to treat, regardless of how they were initially referred. |
| | | Systemic anti-cancer therapy should begin **within 2 weeks** of establishing the diagnosis and staging. |
| | | Systemic anti-cancer therapy should begin **within 24 hours** of diagnosis in cases with critical organ compromise or rapid progression. |
| | | Radiation therapy should begin **within 24 hours** of referral where possible, with a maximum acceptable waiting time **within 48 hours** in cases with acute critical organ compromise. |
| | | Radiation therapy should begin **within 48 hours** of referrals where possible, with a maximum acceptable waiting time of **14 days** in symptomatic cases. |
| | | Radiation therapy should **begin within 14 days** of referral where possible, with a maximum acceptable waiting time of **28 days** in cases with solitary bone plasmacytoma or extramedullary plasmacytoma where the treatment goal is curative. |

# 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

Multiple Myeloma (MM) is a cancer that forms from plasma cells in the bone marrow. Amongst the haematological cancers MM has the second highest number of registrations with over 460 this year in Aotearoa New Zealand.

MM has two precursor phases:

- Monoclonal gammopathy of uncertain significance (MGUS) occurs when plasma cells secrete abnormal monoclonal proteins into the blood. MGUS is a benign precursor to MM, is more common in older age groups and has a 1% risk of progressing to MM.
- Smouldering multiple myeloma (SMM) is an asymptomatic precursor condition for multiple myeloma. The average risk of SMM developing into MM is 10% per year.

The incidence rate of multiple myeloma in New Zealand is approximately 5.2 per 100.000 population. Among Māori, the incidence is higher at 6.8 per 100,000 population.

In general, the 5-year survival rate has improved from 36% to 45% over the period 2004-2016. Overall survival was worse for young Māori/Pasifika people compared to other ethnicities, and those living in the most deprived regions.

# Step 1: Wellness

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

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

## 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
- 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 Attorney (EPA) as required (refer Principle 1).

**Communication between health services**

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

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

## 1.4 Measuring and monitoring

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

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

# Step 2: Early detection

**This step outlines recommendations for early detection for the person with suspected multiple myeloma.**

## 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 early detection for cancer programmes, where possible (Te Aho o Te Kahu 2022)
- implementing programmes that enhance access to services.

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

## 2.2 Early detection

Early detection has several benefits, including improved survivorship.

People with MGUS or smoldering myeloma require regular monitoring to assess for possible progression to multiple myeloma. There is currently no established benefit to early detection of MGUS.

## 2.3 Multiple myeloma risk factors

- Age: multiple myeloma occurs mainly in older people. About 83% of cases diagnosed with multiple myeloma are aged over 60 (AIHW 2021). Very few people are diagnosed below age 40.
- Clinically defined MGUS: the average risk of someone with MGUS developing multiple myeloma is about 1% per year.
- Family history: people who have a first-degree relative with multiple myeloma have a two-fold or higher increased risk of developing multiple myeloma however, the absolute risk for anyone with a relative with multiple myeloma is low. An underlying genetic cause has not been identified and there is no available screening test for genetic predisposition.
- Ethnicity: Māori and Pacific peoples are more likely to develop multiple myeloma.
- Gender: multiple myeloma is slightly more common in males than females.

### 2.3.1 Familial cancer risk

Having a first-degree relative with multiple myeloma increases the risk of developing multiple myeloma, however no causative genes have been identified.

## 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 Multiple Myeloma.**

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

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

## 3.1 Te Tiriti o Waitangi

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

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

## 3.2 Signs and symptoms

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

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

Multiple myeloma can present with many otherwise unexplained, non-specific symptoms and/or blood test abnormalities, as well as end-organ complications or related organ tissue injury.

The following suspicious signs and symptoms of Multiple Myeloma include:

- fatigue and generalised weakness
- bone pain or pathological fracture (broken bone often with minimal trauma)
- frequent infections
- unintentional weight loss
- symptoms of hypercalcaemia include mental fogginess and/or confusion, new onset constipation and/or abdominal pain, polyuria, and increased thirst
- new-onset back pain particularly with neurological symptoms such as leg weakness loss of bladder or bowel control, or loss of sensation

- symptom of hyperviscosity (easy bruising, bleeding gums, cloudy vision), although this is rare, and typically associated with IgA type myeloma.

Blood test abnormalities that may suggest multiple myeloma include:
- anaemia
- elevated creatinine
- hypercalcaemia
- an elevated globulin level, typically associated with an increased protein-albumin gap in the absence of infection of inflammation
- presence of a paraprotein on serum protein electrophoresis
- elevated serum Kappa or Lambda free light chain level, with an abnormal Kappa to Lambda light chain ratio.

End-organ complications that are often associated with multiple myeloma include:
- enhanced bone loss/generalized osteoporosis
- renal failure
- hypercalcaemia
- immune suppression (reduction in the non-paraprotein immunoglobulin sub-types).

The presence of multiple signs and symptoms, particularly in combination with other underlying risk factors, may indicate an increased risk of cancer.

If the person presents with one of the following red flags, the referral should be triaged as an urgent 'HSCAN'.

M-protein in serum and/or urine with one or more of the following:
- unexplained hypercalcaemia (>2.75 mmol/L)
- unexplained renal impairment – creatinine clearance < 40ml/min
- unexplained anaemia – Hb < 100g/L
- bony lytic lesions on radiologic imaging including symptoms suggestive of possible spinal cord compression
- serum monoclonal protein (IgG or IgA > 30g/L or involved: uninvolved serum free light chain radio > 100 to the power of 13 (IgG paraprotein > 30g/L, IgA paraprotein >20g/L)
- back pain
- a recent bone marrow with >30% plasma cells.

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.

### Timeframe for general practitioner consultation

A person with signs and symptoms that may suggest multiple myeloma cancer should be promptly assessed by a health professional.

## 3.3 Assessment

Multiple myeloma assessment includes relevant:
- medical history, including relevant medications: e.g., persistent backpain

- physical examination: Eastern Cooperative Oncology Group (ECOG) Performance Status Scale, frailty assessment, weight
- investigations (laboratory, radiology):
    - blood test to identify paraprotein and/or elevated light chains that may indicate underlying multiple myeloma including serum protein electrophoresis (SPEP) and immunofixation (IF), serum kappa and lambda free light chain (SFLC), and light chain ratio
    - blood and urine test that may indicate end-organ dysfunction including full blood count, differential, creatinine, urea, electrolytes, liver function tests, calcium, magnesium, phosphate, urate, and urine dipstick full ward test to look for proteinuria
    - X-ray or computed tomography (CT) imaging of painful areas to assess for fractures, lytic lesions and/or soft tissue plasmacytomas.
- familial cancer history
- social history.

## 3.4 Initiate investigations, including referrals

- If the diagnosis of multiple myeloma is confirmed or the results are inconsistent or indeterminate, the general practitioner must refer the person to an appropriate specialist (haematologist) or a health service with a multiple myeloma-specific multidisciplinary team to make the diagnosis.
- First specialist assessment (FSA) appointment with same day bone marrow examination.
- MRI skeletal survey – urgent if there is back pain or symptoms suggestive of pending spinal cord compression.
- Primary care monitoring of people with MGUS or smouldering myeloma should be in accordance with agreed GP guidelines. Specialist referral criteria should be followed, as per these guidelines.
- Indicate if there is a high suspicion of cancer and/or it is urgent, and the person needs to be seen **within 2 weeks**.

### Timeframe for completing investigations for the person with suspected multiple myeloma

Optimally, investigations should be completed **within 2 weeks**.

Referral options are clearly communicated with the person and their whānau, including details of expected timeframes, who to contact if they don't hear from the service referred to within the timeframe given, and if there is a cost 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

The timing of specialist referral is guided by clinical severity and the presence of end-organ damage. Indicators of end-organ damage in people with multiple myeloma include:
- hypercalcaemia: corrected serum calcium 0.25 mmol/L above the upper limit of normal or higher than 2.75 mmol/L
- renal impairment: creatinine clearance 177 µmol/L (> 2 mg/dL)
- anaemia: haemoglobin below 100 g/L or 20 g/L below the lower limit of normal
- bone lesions: one or more osteolytic lesions on skeletal radiography, CT, or positron emission tomography (PET) CT. For PET-CT scans, see Health New Zealand | Te Whatu Ora National Indications for Publicly Funded PET-CT.

People with evidence of end-organ damage should be seen by a haematologist as soon as possible, ideally **not longer than 1 week**.

People without overt end-organ damage and are non-urgent should ideally be seen by a haematologist **within 4 weeks.**

People with severe hypercalcaemia, renal failure, symptoms of hyper-viscosity, severe new-onset back pain or acute neurological symptoms should be **immediately** referred to a haematologist or emergency department.

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

If symptoms are concerning and the referral is not accepted, primary care ’safety netting’ for re-assessment is recommended. Arranging a bone marrow examination though community laboratory providers can be helpful in this situation.

## 3.5 Supportive care and communication

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

### 3.5.1 Communication with the person/whānau receiving care

**Health providers/professionals**

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

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

**Communication between health services**

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

## 3.6 Measuring and monitoring

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

- **Faster Cancer Treatment**

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

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

# Step 4: Diagnosis, staging and treatment planning

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

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

## 4.1 Te Tiriti o Waitangi

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

- prioritising access for Māori to diagnostics, staging, and treatment planning
- supporting the person and their whānau to access holistic care, including mātauranga Māori traditional practices, emotional and spiritual support to complement medical treatment
- talking with the person 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 multiple myeloma)

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:

- **Radiology:**
    - CT scan: whole body low dose CT skeletal survey is recommended as the first-line imagery in all multiple myeloma cases (both suspected and confirmed)
    - MRI: assess for multiple myeloma lesions in people with a histological diagnosis of multiple myeloma but negative or inconclusive CT skeletal survey
    - PET CT scan: is particularly useful for people with extramedullary disease or oligo/non-secretory myeloma.

- **Laboratory:**
    - blood tests including full blood count, differential and blood film, urea, and electrolyte (U&E) panel, calcium, Immunoglobulins, protein electrophoresis (PEP), IF, and SFLCs
    - 24-hour urine collection: protein excretion, creatinine clearance, Bence Jones Protein.

- **Pathology:**
    - a bone marrow biopsy, including flow cytometry and trephine biopsy
    - tissue biopsy is occasionally performed for bony or extramedullary plasmacytoma.
- **Bone densitometry** when osteoporosis is suspected.

To justify the commencement of active treatment for multiple myeloma, an assessment of the diagnostic criteria for multiple myeloma called SLiM CRAB is required to ascertain whether the criteria have been fulfilled.

### Timeframe for completing investigations

Diagnostic investigations should be completed **within 2 weeks** of the initial specialist assessment.

## 4.3 Staging

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

The most widely accepted prognostic model for multiple myeloma is the Revised International Staging System (R-ISS). This incorporates the presence of high-risk genetic lesions based on cytogenetics and/or fluorescence in situ hybridization (FISH), and the level of beta-2 microglobulin, albumin and lactate dehydrogenase (LDH) (IMF 2019).

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

It is also important to evaluate and document comorbidities involving major organ systems (e.g., renal, cardiac, respiratory), overall functional status and physiological robustness because these may impact on treatment strategies. These issues are particularly important in the geriatric context of multiple myeloma, given that the median age of diagnosis is over 70 years old. There are many well established geriatric assessment tools that incorporate comorbidities, individual performance status, frailty, and vulnerability. For multiple myeloma, the most widely used is the International Myeloma Working Group (IMWG) geriatric assessment tool.

## 4.5 Multidisciplinary meeting

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

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

MDMs are managed and guided by the following standards:

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

### 4.5.1 Treatment options and recommendation

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

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

### 4.5.2 Fertility preservation

Multiple myeloma often occurs in older people, however around 2% of people are diagnosed younger than 40 years of age. People of child-bearing potential need to be advised, and potentially referred, for a discussion about fertility preservation and/or contraception before starting treatment. Effective contraception, before, during and after treatment, is particularly important for those taking immunomodulators (IMiDs) such as thalidomide, lenalidomide and pomalidomide as these can cause serious birth abnormalities in the fetus. While taking IMiDs males should not conceive or donate sperm, and women should not become pregnant.

### 4.5.3 Prehabilitation

Prehabilitation (preparing for treatment) is the process of optimising a person's overall wellbeing prior to undergoing cancer treatment. Ideally, prehabilitation should begin as early as possible after a cancer diagnosis to allow adequate time for interventions to take effect. In haematological malignancies, the urgency of starting treatment in 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. Prehabilitation may be initiated and assessed by primary or hospital services. Referral for additional services may include:

- conducting a physical and psychological assessment to establish a baseline level of function, including assessing coping strategies/abilities

- identifying impairments and providing targeted interventions to improve the person's function level
- specialist renal physician
- radiation oncologist
- smoking cessation
- education support for medications to ensure optimisation and correct adherence
- rongoā
- psychosocial support
- physiotherapy or exercise programme – aerobic, respiratory training, resistance training for person to function at a higher level
- nutrition.

### 4.5.4 Clinical trials

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

## 4.6 Supportive care and communication

### 4.6.1 Care coordination

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

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

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

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

### 4.6.2 Supportive Care

Assess the supportive care needs of the person and their whānau, including:
- care coordinator is in place
- prehabilitation
- early referral to palliative care
- information and education needs are met (refer Step 3.5).

### 4.6.3 Communicating with the person/whānau receiving care

#### Health providers/professionals

- Ensure that person and their whānau have the option to have additional support with them when having any 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, education support and resources in a format that is useful to the person and their whānau (and that they can share with others as they wish).
- Identify any barriers or challenges that may prevent the person and their whānau from accessing services or attending treatment.
- Discuss with the person and their whānau ways to improve health outcomes and wellbeing prior to and during treatment.
- Advise the person and their whānau of their lead clinician and care coordinator.
- Clarify that the 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

- Where possible health services should coordinator appointments, in discussion with the person and their whānau
- Communicate the diagnosis, MDM recommendations and treatment plan between health services.
- Discuss and agree shared care arrangements, in symptom and co-morbidity management, supportive care and referral to local services.
- Confirm the lead clinician and provide handover details, as necessary.

## 4.7 Measuring and monitoring

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

- **Te Aho o Te Kahu Quality Performance Indicator**
    - Route to diagnosis: People diagnosed with cancer within 30-days of an emergency or acute (unplanned) hospital admission (Te Aho o Te Kahu, 2024).
- **Faster Cancer Treatment**
    - **31-day Health Target -** 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 multiple myeloma by trained and experienced clinicians and team members, in an appropriate environment.**

The treatment of multiple myeloma is informed by the following guidelines:

- European Society of Medical Oncology: *Multiple myeloma EHA-ESMO clinical practice guidelines for diagnosis, treatment and follow up* **esmo-clinical-practice-guidelines-haematological-malignancies**
- Medical Scientific Advisory Group (MSAG): *Clinical practice guideline multiple myeloma* **myeloma.org.au/health-professional-resources/**
- Medical Scientific Advisory Group (MSAG): *Bortezomib, lenalidomide and dexamethasone (Vrd) for initial treatment of multiple myeloma* **myeloma.org.au/health-professional-resources/**
- Medical Scientific Advisory Group (MSAG): *Consensus clinical practice guidelines for the prevention of infection in patients with multiple myeloma* **myeloma.org.au/health-professional-resources/**
- American Society for Transplantation and Cellular Therapy (ASTCT) practice guidelines **astct-publications**
- European Society for Blood and Marrow Transplantation (EMBT) handbook **ebmt-handbook.**

## 5.1 Te Tiriti o Waitangi

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

- services achieve equity of access and outcomes irrespective of where treatment occurs
- equity in access to treatment is facilitated through active and coordinated support of financial and social barriers to treatment
- tikanga Māori and rongoā is integrated and applied in discussion with treating clinicians
- a referral to 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. Discuss the advantages and disadvantages of recommended treatments and associated side effects in plain language to support the person and their whānau to make an informed decision. If there is more than one suitable treatment option, services could facilitate the decision making of the person and their whānau by having all specialties involved in a single appointment.

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

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

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

### 5.2.1 Additional considerations

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

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

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 multiple myeloma depends on the type, stage and location of the cancer, the person's age and health status, and individual preference. Treatment may include a combination of the items listed below, concurrently, or sequentially, to maximise outcome.

For people with solitary bone plasmacytoma or extramedullary plasmacytoma, radiation therapy can offer potential cure.

For people with multiple myeloma, there are two pathways for initial therapy. One incorporates autologous stem cell transplant (ASCT) as part of upfront treatment, and the other does not.

The ASCT pathway typically consists of induction therapy, followed by ASCT, with or without consolidation therapy, then maintenance therapy.

The person may 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 specific trial centres.

- **Systemic anti-cancer therapy –** most people treated for multiple myeloma will receive systemic therapy.

**People suitable for systemic anti-cancer therapy (SACT) please refer to The Model of Care for Adult Systemic Anti0Cancer Therapy Services in Aotearoa (Te Aho o Te Kahu 2024).**

Induction therapy is the first phase of initial therapy and is usually a combination of different types of drugs. It aims to rapidly reduce the burden of multiple myeloma.

Induction regimens will differ depending on whether the person is eligible for a transplant and/or fit for high-dose chemotherapy. Factors such as potential toxicity and the person's fitness should be considered when choosing a combination.

Consolidation therapy used to further reduce the burden of myeloma, is a short course of drugs with similar intensity to induction therapy given after ASCT. Consolidation therapy is not routine but may benefit some people who have not had effective induction therapy and who have not achieved complete remission after ASCT.

Maintenance therapy is continuous drug treatment to keep the multiple myeloma in remission and is usually given for at least 2 years or until disease progression.

### Timeframes for starting treatment

Treatment should begin **within 2 weeks** of establishing the diagnosis and staging. However, in cases with critical organ compromise, such as renal failure and cord compression, or rapid clinical progression, it may be vital to start treatment **within 24 hours** of diagnosis.

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

**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).**

ASCT uses the person's own stem cells to facilitate a faster bone marrow recovery after high-dose chemotherapy. When incorporated into initial treatment, ASCT improves both progression-free survival and overall survival compared with a non-ASCT approach for people who are eligible for transplant. It is recommended for people up to age 70 who have good performance status and organ reserve.

- **Radiation therapy -** the person that may benefit from radiation therapy including those with:
    - pain or acute organ compromise such as spinal cord compression
    - a solitary bone plasmacytoma or solitary extramedullary plasmacytoma.

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

### Timeframes for starting treatment

The Royal Australian and New Zealand College of Radiologists (RANZCR 2013) use the following timeframes for multiple myeloma:

For those with acute critical organ compromise, such as symptomatic spinal cord compression, radiation therapy should start **within 24 hours** of receiving a referral. Maximum acceptable waiting time is **within 48 hours**.

For symptomatic tumours radiation therapy should begin within **48 hours** of receiving a referral where possible, with a maximum acceptable waiting time of **14 days**.

For solitary bone plasmacytoma or extramedullary plasmacytoma where the treatment goal is curative, radiation therapy should begin **within 14 days** of receiving a referral where possible, with a maximum acceptable waiting time of **28 days**.

- **Surgery**

Surgery for people with multiple myeloma involves preventing or stabilising long-bone pathological fractures, vertebral column instability, and spinal cord compression that is not treatable by radiation therapy.

- **Supportive therapies**

Supportive therapies are important in the management of multiple myeloma and should be offered where indicated. The following should be considered:

- bisphosphonate therapy for bone strengthening in people requiring multiple myeloma treatment unless contraindicated with calcium and vitamin D supplements
- venous thromboembolism (VTE) prophylaxis is recommended for people who are treated with IMiDs
- recombinant erythropoietin (rEpo) may be considered in selected people with transfusion dependent anaemia, especially those with renal failure
- infection prophylaxis where indicated, including:
    - immunoglobulin replacement therapy for people with frequent infections – in the absence of national criteria for immunoglobulins, New Zealand Blood Service has adopted the National Blood Authority: Criteria for the Clinical Use of Immunoglobulin in Australia to inform and support clinical decision and review
    - pharmaceutical prophylaxis including that against varicella zoster reactivation and Pneumocystis jiroveci should follow institutional guidelines
    - vaccinations against hepatitis B, pneumococcus, influenza, and other pathogens that are deemed necessary because of epidemiologic prevalence (live vaccines should be avoided).

- **Palliative care**

Palliative care is an integral part of cancer treatment, by offering 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 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:

- back pain or bone pain
- side effects resulting from treatments, especially the effects of high dose corticosteroids
- nutritional support
- sexual dysfunction
- peripheral neuropathy
- fatigue.

### 5.3.1 Clinical Trials

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

## 5.4 Treatment summary

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

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

## 5.5 Supportive care and communication

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

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

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

The person and their whānau may also need to manage:

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

### 5.5.1 Care coordination

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

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

### 5.5.2 Communication with the person/whānau receiving care

#### Health providers/professionals

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

#### Communication between health services

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

## 5.6 Measuring and monitoring

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

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

- **Faster Cancer Treatment**
    - **31-day Health Target -** 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).

- **Radiation oncology treatment timeframes**[4]
  - Category A – treat within 24 hours.
  - Category B – treat within 10 working days.
  - Category C (palliative intent) – treat within 10 working days
  - Category C (curative intent) – treat within 20 days.
  - Category D – combined modality treatment (determined by scheduling of the two treatment modalities).
  - Category E (benign disease) – treat within 80 working days.

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

# Step 6: Care after treatment

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

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

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

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

- European Society of Medical Oncology: *Multiple myeloma EHA-ESMO clinical practice guidelines for diagnosis, treatment and follow up* **esmo-clinical-practice-guidelines-haematological-malignancies**
- Medical Scientific Advisory Group (MSAG): *Clinical practice guideline multiple myeloma* **myeloma.org.au/health-professional-resources/**

## 6.1 Te Tiriti o Waitangi

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

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

## 6.2 Survivorship care planning

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

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

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

- signs and symptoms to be aware of that may indicate the cancer has relapsed
- the process for rapid re-entry to specialist medical services.

Because Multiple Myeloma is an incurable cancer with eventual relapse after each line of therapy, people are rarely discharged permanently from specialist care. 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 Multiple Myeloma, 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 relapse
- early detection of new primary tumours
- monitoring and management of complications
- optimisation of rehabilitation
- provision of support to the person and their whānau.

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

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

Planning needs for follow up and surveillance include:

- who will be providing follow-up care for example, their specialists, their primary care provider (including palliative care) or if there will be a shared care approach (see Principle 1). Generally, people will have at least one clinic visit with the specialist(s) involved in a person's treatment and care to date
- what tests (such as blood or radiological tests) need to be carried out, who is responsible for ordering them, how frequently they need to be done, and who will discuss the results with the person and their whānau
- the frequency people should be seen and for what timeframe. Follow-up appointments are more frequent initially, becoming less frequent as time goes on
- who the person and/or their whānau should contact if they have any concerns.

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

## 6.6 Signs and symptoms of relapsed or progressive disease

Virtually all people with multiple mMyeloma will relapse after responding to initial treatment. Access to the best available therapies, including clinical trials and treatment with a multidisciplinary team, are crucial to achieving the best outcomes for relapsed disease.

Signs and symptoms will depend on if there is end-organ damage as a result of clinical relapse. People may be asymptomatic when there is progressive disease without end-organ damage.

Multiple myeloma signs and symptoms of relapse or progression that necessitate further investigation include:

- new or increased size of plasmacytomas or bone lesions
- new or worsening end-organ damage (e.g., anaemia, hypercalcaemia, renal impairment)
- progressive rise in paraprotein, serum free light chain or urinary Bence Jones proteins.

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

## 6.8 Supportive care, care coordination and communication

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

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

### Supportive care

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

### Coordinated care

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

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 base d on their specific needs.**

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

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

## 7.1 Te Tiriti o Waitangi

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

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

## 7.2 Palliative care

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

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

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

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

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

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

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

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

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

## 7.3 End-of-life care

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

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

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

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

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

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

## 7.4 Assisted dying

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

## 7.5 Supportive care and communication

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

- assistance for dealing with emotional and psychological distress from grief and fear of death and dying

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

### 7.5.1 Care coordination

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

### 7.5.2 Communicating with the person/whānau receiving care

**Health providers/professionals**

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

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

### 7.5.3 Communicating between health services

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

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

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

### 7.5.4 Palliative care and end of life key national guidelines

- *Advance care planning.* (Te Tahu Hauora | Health Quality & Safety Commission New Zealand. 2022.) **hqsc.govt.nz**
- *A Guide For Carers.* (**Hospice New Zealand** 2019).
- *Mauri Mate: A Māori palliative care framework* (**Hospice New Zealand**.2019).

- *Te Ara Whakapiri: Principles and guidance for the last days of life* (**Ministry of Health** | Manatū Hauora 2017b).
- *The Palliative Care Handbook* (**Hospice New Zealand** 2019b).
- *Information on assisted dying for the public* (**Health New Zealand** | Te Whatu Ora, nd).

## 7.6 Measuring and monitoring

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

- **National palliative care outcomes and reporting framework** (under development).