



TE AHO
O TE KAHU
CANCER
CONTROL
AGENCY



Optimal cancer care pathway for people with ovarian cancer

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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; New Zealand Gynaecological Cancer Group, Genetic Health Service NZ 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.

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For further information including:

- Achieving Pae Ora, equity and whānau insights
- Person/whānau questions
- Definitions
- Ovarian cancer 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 ovarian cancer 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. Ovarian cancer affects an increasing number of people with more than 250 diagnosed with ovarian cancer this year. Around 150 women

will die from ovarian cancer 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 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 combines the expertise and experiences from many stakeholders across the country. Thank you 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 highlight 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 ovarian cancer, and those who have lost loved ones. Much of this guidance reflects the voices of those who have received cancer care. We are indebted to them for sharing their experiences to help improve cancer control outcomes in the future.

Ngā mihi nui,

A handwritten signature in dark ink, appearing to read 'Rami'.

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

Summary guide of ovarian cancer 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 principles¹: 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
<p>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.</p> <p>Evidence-based research shows that general cancer and wellbeing risks can be reduced by:</p> <ul style="list-style-type: none"> • eating a nutritious diet • maintaining a healthy weight • taking regular, moderate to vigorous-intensity activity • avoiding or limiting alcohol intake • being sun smart • identifying pre-disposing infections such as, Hepatitis C • keeping up to date with immunisations or vaccines such as, Human Papilloma Virus (HPV) • avoiding smoking including marijuana and exposure to second-hand smoke <ul style="list-style-type: none"> ○ current smokers (or those who have recently quit) should be offered best practice tobacco dependence treatment and an opt-out referral to an intervention service such as Quitline • avoiding vaping • participating in screening services such as breast, cervical, bowel cancer screening • preventing occupational exposure to asbestos, silica, radon heavy metal, diesel exhaust and polycyclic aromatic hydrocarbons. 	<ul style="list-style-type: none"> <input type="checkbox"/> Carry out a health and wellbeing assessment including discussions on ways to reduce cancer risk. <input type="checkbox"/> Assess the individual's risk of developing cancer. <input type="checkbox"/> Encourage eligible people to participate in national screening programmes. <input type="checkbox"/> Discuss recent weight changes and monitor weight. <input type="checkbox"/> Discuss and record alcohol intake. Offer support for reducing alcohol consumption if appropriate. <input type="checkbox"/> Record person's smoking status and offer stop smoking advice/support if appropriate. <input type="checkbox"/> Record physical activity. <input type="checkbox"/> Consider referral to a dietitian, physiotherapist, or exercise programme. <input type="checkbox"/> Give the person education on being sun smart.

¹ Optimal Cancer Care Pathway Principles

Step 2: Early detection	Step 2: Checklist
<p>This step recommends options for prevention and early diagnosis for the person/whānau with suspected ovarian cancer.</p> <p>There is no national screening programme for ovarian cancer.</p> <p>There is no screening programme anywhere in the world as there is no sufficient evidence to support population-based screening for ovarian cancer. However, assessment of family history of cancer should be part of a routine wellness check.</p> <p>Early detection</p> <p>Health care providers/professionals support the person/whānau to identify and minimise personal ovarian cancer risks, see step 2.3.</p> <p>Some factors that may reduce the risk of developing ovarian cancer are:</p> <ul style="list-style-type: none"> • using an oral contraceptive pill • giving birth and breastfeeding • previous surgical procedures such as tubal ligation, salpingectomy, hysterectomy, and risk-reducing salpingo-oophorectomy for women who have a known genetic predisposition for ovarian cancer. 	<ul style="list-style-type: none"> <input type="checkbox"/> Assess and discuss the individual's risk of developing ovarian cancer. <input type="checkbox"/> Support the person and their whānau to follow surveillance guidance if they're at an increased risk of familial cancer. <input type="checkbox"/> Refer to clinical genetic services where appropriate. <input type="checkbox"/> Discuss recent weight changes and monitor weight. <input type="checkbox"/> If signs and symptoms of cancer are present refer to 'Step 3: Presentation, initial investigation and referral' below. <p>Communication</p> <p>Ensure the person and their whānau understands:</p> <ul style="list-style-type: none"> <input type="checkbox"/> when they should receive their results <input type="checkbox"/> how to follow up if they don't receive their results <input type="checkbox"/> what's involved if they need to be transferred to a specialist service.

Step 3: Presentation, initial investigations, and referral	Step 3: Checklist
<p>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 ovarian cancer.</p> <p>The types of investigations undertaken will depend on many factors, including access to diagnostic tests, the availability of medical specialists and individual preferences.</p> <p>A person and their whānau may present via primary care, an emergency presentation or incidental finding with a high suspicion of ovarian cancer.</p> <p>Signs and symptoms of ovarian cancer to investigate include:</p> <ul style="list-style-type: none"> • persistent abdominal distension or bloating • increased abdominal girth • pressure in the abdomen • early satiety or loss of appetite • feeling full after only a small amount of food • pelvic or abdominal pain without a known cause • indigestion 	<ul style="list-style-type: none"> <input type="checkbox"/> All people with a high suspicion of cancer have a person to coordinate care. <input type="checkbox"/> Record signs and symptoms. <input type="checkbox"/> Complete all cancer assessments. <input type="checkbox"/> Inform the person and their whānau of preliminary results. <input type="checkbox"/> Referral options of cancer care are discussed with the person and their whānau, including cost implications if private provider requested. <input type="checkbox"/> Complete and record supportive care needs assessment, refer to allied health services as required. <input type="checkbox"/> Inform the person and their whānau of cultural services and relevant support groups available. <input type="checkbox"/> Initiate referrals and arrange further investigation.

<ul style="list-style-type: none"> • increased urinary urgency or frequency • change in bowel habits, irritable bowel symptoms, especially if new onset and aged older than 50 years • unexplained weight loss or fatigue • postmenopausal bleeding. <p>Ovarian cancer assessment includes the relevant:</p> <ul style="list-style-type: none"> • medical history, including medications • menopausal status • physical examination: may include an internal gynaecology examination • Eastern Cooperative Oncology Group (ECOG) Performance Status Scale, frailty assessment, weight • investigations and imaging: elevated CA 125 requires a pelvic ultrasound • family/whānau history: known Lynch syndrome or <i>BRCA</i> mutation • social history of the person. <p>Referral</p> <p>A clinical suspicion or laboratory/ imaging findings suggestive of cancer require further investigation and a referral to hospital specialist services.</p> <p>If the person presents with one of the following, the referral should be triaged as a high suspicion of cancer.</p> <ul style="list-style-type: none"> • Significant symptoms including abnormal vaginal bleeding, discharge, or pelvic pain, and abnormal clinical findings suspicious of gynaecological malignancy including lymphadenopathy, vaginal nodularity, or pelvic induration. • Elevated CA 125. • Pelvic ultrasound suggestive of cancer. • Rapidly growing pelvic mass or genital lump, palpable or incidentally found. • Patients with a known genetic risk who have a suspicious pelvic abnormality and/or symptoms. 	<p>Timeframe</p> <ul style="list-style-type: none"> <input type="checkbox"/> Women with postmenopausal bleeding or clinical suspicion of a pelvic mass are offered an appointment for a pelvic ultrasound that falls within 2 weeks of the date of receipt of that referral. <input type="checkbox"/> If there is a high suspicion of ovarian cancer, submit referral immediately to hospital specialist services. <input type="checkbox"/> High suspicion of cancer referral is triaged within 1-2 working days and referrer is notified. <input type="checkbox"/> Confirm that the person referred urgently with a high suspicion of cancer will attend their first specialist assessment (FSA) clinic within 2 weeks. <p>Communication</p> <ul style="list-style-type: none"> <input type="checkbox"/> Explain to person and their whānau that they are being referred to a hospital specialist service and why, including: <ul style="list-style-type: none"> ▪ 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.
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Step 4: Diagnosis, staging and treatment planning	Step 4: Checklist
<p>This step outlines the process for confirming the diagnosis and stage of cancer and the planning of subsequent treatment.</p> <p>Diagnosis for ovarian cancer may include:</p> <ul style="list-style-type: none"> • Radiology: pelvic ultrasound, CT scan, or MRI abdomen/pelvis • Pathology: Biopsy, fluid aspiration for cytology 	<ul style="list-style-type: none"> <input type="checkbox"/> Confirm diagnosis. <input type="checkbox"/> Referral to a cancer care coordinator if not already done. <input type="checkbox"/> Record staging, performance status and comorbidities. <input type="checkbox"/> Discuss the person's diagnosis at a multidisciplinary meeting (MDM) and inform the person and their whānau of the treatment options.

<ul style="list-style-type: none"> • Laboratory: routine blood tests, CA 125, and in younger people, HCG, AFP LDH • Risk of Malignancy (RMI) score may be used to determine the likelihood of a pelvic mass being cancer. <p>Staging for ovarian cancer:</p> <ul style="list-style-type: none"> • pathological staging occurs after surgery • where surgical staging is not possible, staging can be based on clinical findings and investigations. <p>Performance status</p> <ul style="list-style-type: none"> • ECOG, geriatric assessment for persons over age 70. <p>Multidisciplinary meeting</p> <ul style="list-style-type: none"> • The person with ovarian cancer is discussed at a gynaecology oncology MDM. <p>Clinical genetics referral</p> <p>Referral to clinical genetic services for ovarian cancer is considered if features of the cancer suggest a genetic predisposition, such as:</p> <ul style="list-style-type: none"> • early age at onset • multiple primary cancers • family history of similar or related cancers. <p>Treatment planning</p> <p>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.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Consider relevant clinical trials. <input type="checkbox"/> Assess supportive care needs and refer to allied health services as required. <input type="checkbox"/> Ensure primary or secondary prehabilitation is initiated to optimise overall well-being. <input type="checkbox"/> Begin Enhanced Recovery After Surgery (ERAS) protocol if for surgery. <input type="checkbox"/> Give the person and their whānau information on Cancer Society, Ovarian Cancer Foundation and/or relevant cultural services and available support groups. <p>Timeframe</p> <ul style="list-style-type: none"> <input type="checkbox"/> Radiological and other diagnostic investigations should be completed within 2 weeks of the date of receipt of referral. <input type="checkbox"/> The MDM discussion takes place within 14 days of referral. <p>Communication</p> <p>The lead clinician and team are responsible for:</p> <ul style="list-style-type: none"> <input type="checkbox"/> discussing a timeframe for diagnosis and treatment options with person and their whānau <input type="checkbox"/> explaining the role of the MDM team in treatment planning and ongoing care <input type="checkbox"/> 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. <input type="checkbox"/> communicating with the person's General Practitioner (GP) about the diagnosis, treatment plan and recommendations from the MDM.
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Step 5: Treatment	Step 5: Checklist
<p>This step describes publicly funded optimal treatments for ovarian cancer by trained and experienced clinicians and team members, in an appropriate environment.</p> <p>Establish the intent of treatment:</p> <ul style="list-style-type: none"> • curative – to cure the cancer completely • tumour control – to stop the cancer growing and spreading • palliative – to manage symptoms caused by the cancer. <p>Treatment options</p> <p>Surgery – may be used to stage the cancer and as a form of treatment. The type of surgery offered will depend on several factors such as the type, grade and stage of the disease, the person’s age, performance status and desire or not to retain fertility.</p> <p>Systemic chemotherapy – chemotherapy may be required before or after surgery. There are many different types of drugs and recommendations will depend on the tumour type, grade, and stage.</p> <p>Radiation therapy – some people with ovarian cancer may benefit from radiation therapy for symptomatic relief and palliation of metastatic or recurrent disease.</p> <p>Targeted therapies - Some people may be offered hormone therapy or targeted therapy. This may be given after chemotherapy as a ‘maintenance’ treatment.</p> <p>Palliative care - Early referral to palliative care can improve quality of life and in some cases survival. Referral is based on need, not prognosis.</p>	<ul style="list-style-type: none"> <input type="checkbox"/> Health providers/professional, treating specialist has relevant qualifications, experience, and expertise. <input type="checkbox"/> Discuss the intent of treatment and the risks and benefits discussed with the person and their whānau. <input type="checkbox"/> Discuss and provide the agreed treatment plan with the person, their whānau and GP. <input type="checkbox"/> Assess supportive care needs and refer to allied health services as required. <input type="checkbox"/> Give the person and their whānau information on the cancer non-governmental organisations (NGOs), cultural services and support groups available. <input type="checkbox"/> Discuss early referral to palliative care if appropriate. <input type="checkbox"/> Discuss advance care planning with the person and their whānau. <p>Timeframes</p> <ul style="list-style-type: none"> <input type="checkbox"/> The person with a confirmed diagnosis of ovarian cancer receives their first treatment within 31 days of the decision to treat. <input type="checkbox"/> The person referred urgently with a high suspicion of ovarian cancer receives their first cancer treatment within 62 days. <input type="checkbox"/> Time to surgery, if required after neoadjuvant radiation therapy, depends on the regimen. <input type="checkbox"/> The person with non-metastatic ovarian cancer is presented in the gynaecology oncology MDM within 3 weeks of surgery for consideration of adjuvant therapy. <input type="checkbox"/> Adjuvant radiation therapy or systemic therapy should start within 4 weeks of the decision to treat. <p>Communication</p> <p>The lead clinician and team are responsible for discussing these areas with the person and their whānau:</p> <ul style="list-style-type: none"> <input type="checkbox"/> treatment options including the intent of treatment, risks, and benefits <input type="checkbox"/> advance care planning <input type="checkbox"/> options for healthy lifestyle support to improve treatment outcomes such as exercise and nutrition.

Step 6: Care after treatment	Step 6: Checklist
<p>The person and their whānau access appropriate follow-up and surveillance and are supported to achieve their optimal health after cancer treatment.</p> <p>Provide a summary of the treatment and follow-up plan to the person and their whānau and clinicians involved in follow up care.</p> <p>The summary includes:</p> <ul style="list-style-type: none"> • diagnosis, including tests performed and results • treatment received (types and date) • current toxicities (severity, management and expected outcomes) • interventions and treatment plans from other health providers/professionals • potential long-term and latent effects of treatment and care of these • supportive care services provided • a follow-up schedule, including tests required and timing • contact information for key health care providers/ professionals who can offer support for lifestyle modification • a process for rapid re-entry to medical services for suspected recurrence • ongoing assessments of the effects of treatment such as: <ul style="list-style-type: none"> ○ fatigue ○ nutrition ○ sexual function ○ bladder function ○ peripheral neuropathy. 	<ul style="list-style-type: none"> <input type="checkbox"/> Provide a survivorship plan that includes a summary of the treatment and the follow-up care plan to the person and their whānau and GP. <input type="checkbox"/> Consider early referral to palliative care, especially for symptomatic people. <input type="checkbox"/> Assess supportive care needs and refer to allied health services as required. <input type="checkbox"/> For people with ovarian cancer, assessment for referral to the following rehabilitation or recovery services should be undertaken such as: <ul style="list-style-type: none"> ▪ nurse specialist, physiotherapist, urologist for incontinence or stoma nurse for stoma issues ▪ counsellor ideally specialising in cancer matters and/or psychosexual function ▪ physiotherapy assessment for lymphoedema. <input type="checkbox"/> Give the person and their whānau information on Cancer Society and/or relevant cultural services and available support groups. <p>Communication</p> <p>The lead clinician and team are responsible for:</p> <ul style="list-style-type: none"> <input type="checkbox"/> explaining the treatment summary plus the follow-up and surveillance care plan to the person and their whānau. <input type="checkbox"/> informing the person and their whānau about healthy living <input type="checkbox"/> informing the person's GP of the follow-up care plan providing guidance for rapid re-entry to specialist services.

Step 7: Palliative and end-of-life care	Step 7: Checklist
<p>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.</p> <p>Palliative care may be provided through:</p> <ul style="list-style-type: none"> • hospital palliative care • home and community-based care • community nursing, including access to appropriate equipment. 	<ul style="list-style-type: none"> <input type="checkbox"/> Early referral to generalist palliative care. <input type="checkbox"/> Refer to specialist palliative care services as required. <input type="checkbox"/> Refer to supportive care services as required. <input type="checkbox"/> Make sure the person and their whānau are aware of the prognosis and what to expect when someone is dying.

<p>Early referral, identification, correct assessment and treatment of pain and other symptoms prevent and relieves suffering.</p> <p>End-of-life care should consider:</p> <ul style="list-style-type: none"> • appropriate place of care • person's preferred place of death • support needed for the person and their whānau. <p>Awareness of and access to, assisted dying services should be available if the person and their whānau raise this with the health care team.</p> <p>Communication</p> <p>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.</p>	<p><input type="checkbox"/> Discuss activation timing of advance care plan, directive, or enduring power of attorney.</p>
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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).

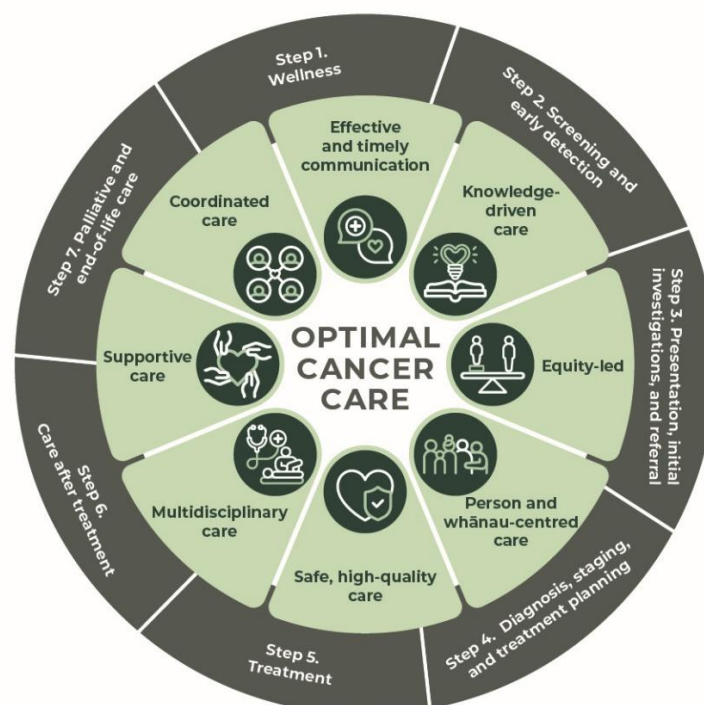
OCCPs are a framework for achieving health equity² in cancer control using a person and whānau centred approach to provide people with equitable, high-quality care, regardless of where they live or receive cancer treatment. OCCPs help to:

- 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



² Optimal Cancer Care Pathway Supplementary Information

Principles of the optimal cancer care pathway

The principles³ 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



³ Optimal Cancer Care Pathway Principles

Optimal timeframes

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

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	The person with postmenopausal bleeding or clinical suspicion of a pelvic mass are offered an appointment for a pelvic ultrasound that falls within 2 weeks of the date of receipt of that referral.
		If there is a high suspicion of ovarian cancer, submit referral immediately to hospital specialist services.
	Referral to a hospital specialist	The person should see a specialist within 48 hours for a high suspicion of cancer.
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 or registered in an MDM, before treatment begins. MDM takes place within 2 weeks of referral (provided referral criteria are met). The person referred with a high suspicion of ovarian cancer and triaged by a clinician will receive their first cancer treatment within 62 days .
Step 5: Treatment	Neoadjuvant/adjuvant chemotherapy, radiation therapy or surgery	The person begins their first cancer treatment within 31 days of the decision to treat, regardless of how they were initially referred.
		The person begins adjuvant radiation or chemotherapy within 4 weeks of the decision to treat.

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

Ovarian cancer is a tumour of the ovaries (where eggs form and oestrogen and progesterone are made). The term is sometimes used to include the fallopian tubes (which connect the ovary to the uterus) and peritoneum (lining of the abdomen). The fallopian tubes and peritoneum have similar symptoms and treatment to ovarian cancer but are not the same cancer.

Ovarian cancer is most often found in post-menopausal women; however it may also be found in younger women. Ovarian cancer registrations average over 300 cases per year, equating to 2% of all cancers. Of these registrations 13% were Māori, 7.4% Pacific people and 9.5% Asian.

Very few symptoms appear in the early stages of ovarian cancer leading to late stage and poorer prognosis at time of diagnosis. Mortality in Māori and Pacific people is disproportionate with mortality rates at 2.33 and 2.49 per 100,000⁴ respectively, compared to 1.88 for European/other and 1.17 for those of Asian descent.

⁴ Rates are per 100,000 and age-standardised to the World Health Organization's standard world population.



Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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Step 1: Wellness

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

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

1.1 Te Tiriti o Waitangi

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

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

1.2 Modifiable cancer and wellbeing risks

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

- eating a nutritious diet
- maintaining a healthy weight
- taking regular, moderate to vigorous-intensity activity
- avoiding or limiting alcohol intake
- being sun smart
- identifying pre-disposing infections, such as hepatitis C
- immunisations – for example, HPV
- 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).

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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1.3 Communication with the person/whānau receiving care

Health providers

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

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

Communication between health services

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

1.4 Measuring and monitoring

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

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

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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Step 2: Early detection

This step outlines recommendations for the prevention and early diagnosis for the person with suspected ovarian cancer.

2.1 Te Tiriti o Waitangi

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

- making sure early detection of cancer services are provided in culturally appropriate ways that recognise and support the expression of hauora Māori models of care
- providing access to co-designed kaupapa Māori early detection cancer programmes, where possible (Te Aho o Te Kahu 2022)

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

There is no national ovarian cancer screening programme.

Early detection focuses on detecting symptomatic people as early as possible, however ovarian cancer is very difficult to diagnose early, due to symptoms being subtle and non-specific. Primary and community health care services work with the person and their whānau to improve outcomes and increase the awareness of cancer, enabling access to cancer services. Health promotion/education should focus on raising awareness of ovarian cancer symptoms and the importance of knowing family history of cancer.

2.3 Ovarian cancer risk factors⁵

Women and transgender men may be at risk of developing ovarian cancer.

2.3.1 Modifiable risk factors

- higher BMI
- smoking

2.3.2 Non-modifiable risk factors

- height
- age (risk increases over 50 years of age)
- family history of ovarian, breast or bowel cancer
- mutations in genes such as *BRCA1/2* or in Lynch syndrome-associated genes *MLH1/MSH2/MSH6/PMS2*
- medical conditions such as endometriosis or polycystic ovary syndrome.

2.3.3 Reproductive and hormonal risk factors

- early onset of periods (before 12 years of age) and late menopause (55 years old or older)
- infertility
- assisted reproduction
- never being pregnant or first pregnancy after 35 years of age
- long term use of hormone replacement therapy after menopause

⁵ IARC, 2025

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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2.3.4 Familial cancer risk

Some people may have an increased risk of developing ovarian cancer. An individual's family cancer history is reviewed and the person and their whānau are advised of the risks of developing a familial cancer. Health providers encourage and support the person and their whānau to follow surveillance guidance if an increased risk of familial cancer is identified. Refer to clinical genetics where appropriate if the person and their whānau have known genetic markers for an ovarian cancer or a familial history.

People with a family history of cancers (e.g., breast cancer, ovarian cancer, colorectal cancer, endometrial cancer) are at increased risk of ovarian cancer and genetic counselling may be appropriate for those with a relevant family history.

Approximately 15% of people diagnosed with ovarian cancer have a *BRCA* mutation.

Lynch syndrome is an inherited condition that is seen in 2 – 3% of ovarian cancer diagnoses.

Genetic counselling is appropriate for women who have:

- a first- or second-degree relative with invasive epithelial ovarian, fallopian tube or primary peritoneal cancer and an additional first- or second-degree relative with one of the following:
- epithelial ovarian, fallopian tube or primary peritoneal cancer
- breast cancer
- colorectal cancer under the age of 50 years of age
- endometrial cancer under the age of 50 years of age
- three or more first- or second-degree relatives with Lynch syndrome-associated cancer such as colorectal, endometrial, small intestinal, stomach, ovarian, pancreatic, or urothelial carcinomas of the ureter or renal pelvis.

For further information visit: genetichalthservice.org.nz

2.3.5 Risk-reducing surgery for those at high risk

In people with a *BRCA* mutation, removal of both the fallopian tubes and ovaries (bilateral salpingo-oophorectomy) when childbearing is complete reduces the risk of ovarian cancer in females with hereditary cancer syndromes. Current guidelines recommend that people with a *BRCA1* mutation should have their surgery before the age of 40 after completing their families. As the onset of cancers in *BRCA2* is later, current guidelines recommend the procedure to be done in the mid 40's.

For persons who are considering risk-reducing surgery, the surgeon should:

- discuss fertility preservation before recommending treatments that will end fertility
- provide a clear description of the risk-reducing surgery technique and clear information about the objective of the procedure
- provide information about managing menopausal symptoms (including hormone replacement therapy use) and other long-term side effects of risk-reducing surgery
- a discussion about psychosocial wellbeing after risk-reducing surgery.

For further information visit: genetichalthservice.org.nz

2.4 Signs and symptoms of ovarian cancer

Early diagnosis focuses on detecting symptomatic people as early as possible. Women and transgender men are supported to see a general practitioner or a gynaecologist if experiencing any changes or any persistent symptoms. Any changes should always be investigated, and family history should always be discussed.

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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The following suspicious signs and symptoms of ovarian cancer include:

- persistent abdominal distension or bloating
- increased abdominal girth
- pressure in the abdomen.
- early satiety or loss of appetite
- feeling full after only a small amount of food
- pelvic or abdominal pain without a known cause
- indigestion
- increased urinary urgency or frequency
- change in bowel habits, irritable bowel symptoms, especially if new onset and aged older than 50 years
- unexplained weight loss or fatigue
- postmenopausal bleeding.

2.5 Communication with the person/whānau receiving care

Health providers/professionals

- Promote health checks.
- Raise and discuss any cancer risk factors.
- Raise and discuss family history of cancer.
- Provide education about potential symptoms of ovarian cancer alongside encouragement to present to primary care early if symptoms are experienced.

Communication between health services

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

2.6 Measurement and monitoring

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

• Faster Cancer Treatment (FCT)

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.

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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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 ovarian cancer.

The types of investigations undertaken will depend on many factors including the preferences of the person and their whānau.

Community HealthPathways provide a source of relevant detailed information for a prostate cancer assessment from a person's primary care presentation and referral to secondary care to specialist services (Community Health Pathways. 2024). You can read more in [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 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

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 FCT high suspicion of cancer pathways and the indicator data dictionary.

Timeframe for general practitioner consultation

A person with signs and symptoms that may suggest ovarian cancer should be seen by a general practitioner **within 2 weeks**.

The person is assessed for signs and symptoms of ovarian cancer, 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.

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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Ovarian cancer symptoms are vague and non-specific, but persistent symptoms should be investigated, particularly in older people or those with family history. Possible signs and symptoms include:

- significant symptoms including abnormal vaginal bleeding, discharge, or pelvic pain, and abnormal clinical findings suspicious of gynaecological malignancy including lymphadenopathy, vaginal nodularity, or pelvic induration
- rapidly growing pelvic mass or genital lump
- patients with a palpable or incidentally found pelvic mass (including any large complex ovarian mass larger than 8 cm)
- patients with a documented genetic risk who have a suspicious pelvic abnormality or symptoms. (**FCT business rules**, 2023).

3.3 Assessment

Ovarian cancer assessment by a general practitioner includes relevant:

- medical history, including relevant medications and menopausal status
- physical examination findings (may include internal gynaecology examination)
- investigations including imaging and tumour markers
- Risk of Malignancy (RMI) score (widely used for estimating the risk of malignancy for those with an ovarian mass)
- familial cancer history
- social history.

3.4 Initiate investigations, including referrals

General practitioners refer to HealthPathways to request investigations and send referrals appropriately.

- General practitioners will indicate if there is a high suspicion of cancer and/or it is urgent, and the person needs to be seen **within 2 weeks**.
- Referrals are receipted back to the referring provider.

Timeframe for completing investigations for the person with suspected ovarian cancer

A person with clinical suspicion of an ovarian cancer should have an appointment for a pelvic ultrasound that falls **within 2 weeks** of the date of referral.

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

When referring a person 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
- assessment and support are given to address any possible barriers of accessing services – for example:
 - transport
 - financial
 - family situation that may impact on the decision to consent to a procedure
 - coordinating appointments and/or offering the person and their whānau, whānau focused bookings.

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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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

Any person with symptoms suspicious of ovarian cancer is referred to a specialist following guidelines in HealthPathways. The specialist should see the person a high suspicion of cancer, and their whānau, **within 2 weeks**.

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](#)).

3.5 Supportive care and communication

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

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

3.6 Communication with the person/whānau receiving care

Health providers/professionals

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

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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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.

3.7 Measurement and monitoring

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

- **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.
- **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).

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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Step 4: Diagnosis, staging and treatment planning

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

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

4.1 Te Tiriti o Waitangi

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

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

4.2 Specialist investigations (diagnostic work up for ovarian cancer)

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 required for treatment. Imaging investigations follow standardised imaging pathways agreed to by the New Zealand gynaecological cancer treatment centres. This may be before or after the first specialist appointment and include:

- pelvic ultrasound (preferably transvaginal) if not already done
- contrast-enhanced CT scan, +/- MRI abdomen/pelvis for younger persons.

Other investigations that may be considered are:

- fluid aspiration for cytology – pleural or peritoneal
- image-guided biopsy
- routine blood and CA 125 tumour marker test and, in younger persons, HCG, AFP, LDH)

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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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.

Staging for ovarian cancer involves pathological assessment following surgery. Structured reporting by a pathologist is encouraged. Where surgery is not planned or possible, staging can be based on clinical findings and investigations.

Women with gynaecological cancer are staged according to the International Federation of Gynaecology and Obstetrics (FIGO) staging classification.

4.4 Performance status

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

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

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

4.5 Clinical genetics

All people diagnosed with high-grade serous epithelial ovarian cancer should be offered genetic testing to look for the presence of underlying genetic abnormalities such as *BRCA1/2*. Approximately 15% of people diagnosed with high-grade serous epithelial ovarian cancer have a *BRCA1/2* mutation.

In certain cases, other pathological subtypes of cancer or tumour tests (immunohistochemistry or somatic genetic tests) may suggest an alternative underlying cancer predisposition.

People should be assessed for the possibility of an ovarian cancer disposition gene and considered for genetic testing if appropriate and referred for genetic counselling and to the Genetic Health Service New Zealand - genetichealthservice.org.nz

4.6 Multidisciplinary meeting

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

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Referral to the gynaecology oncology MDM is undertaken to inform treatment recommendations or further assessment and investigation.

- The person with ovarian cancer is discussed at an MDM which takes place **within 14 days** of referral.
- People with a provisional histological diagnosis of ovarian cancer should have their diagnosis reviewed and confirmed by a specialist gynaecological oncology pathologist affiliated to a gynaecological oncology MDM.
- Results of all relevant tests and access to images must be available for the MDM.
- Information about the person and their whānau, their overall condition, co-morbidities, personal preferences, and social and cultural circumstances must be available for the MDM.
- The proposed treatment plan will be recorded in the person's medical record and MDM database and communicated to the referrer and primary care provider.
- The lead clinician and team discuss the recommendations from the MDM with the person and their whānau so they can make informed decisions about ongoing treatment and care.

MDMs are managed by the following standards:

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

4.6.1 Treatment options and recommendation

Following the MDM, treatment intent is discussed with the person and their whānau. Treatment intent ranges from curative, tumour control and palliation to control symptoms.

Treatment, 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 cope with the proposed cancer treatment and its effects.

4.6.2 Fertility preservation

A referral to a fertility preservation specialist alongside a contraception assessment and advice should be discussed with the person and their whānau dependent on age, type of cancer and the treatment planned. An early, collaborative, and multidisciplinary approach with the person is undertaken, which maximises the opportunity for best practice contemporary care and consideration for future fertility.

General guidance on fertility preservation for persons with cancer can be found here: **Fertility Preservation for People with Cancer in Aotearoa Clinical Practice Guideline.**

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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4.6.3 Prehabilitation

Prehabilitation is the process of optimising a person's overall wellbeing prior to undergoing cancer treatment. Ideally, prehabilitation should begin as early as possible after a cancer diagnosis to allow adequate time for interventions to take effect.

Prehabilitation is initiated and assessed by primary or hospital services and may require referral to additional services for example:

- nutrition
- physiotherapy or exercise programme – aerobic, respiratory training, resistance training for person and their whānau preparing for surgery
- smoking cessation
- medications to ensure optimisation and correct adherence
- rongoā
- psychosocial support
- psychosexual counselling.

4.6.4 Clinical trials

Where eligible, the person 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.

4.7 Supportive care and communication

4.7.1 Care coordination

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

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

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

4.7.2 Supportive Care

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

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

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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4.7.3 Communicating with the person/whānau receiving care

Health providers/professionals

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

“A lot of people need to travel hours to get to an appointment and don’t have vehicles or family support.”

Person/whānau insights

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

Communicating between health services

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

4.8 Measuring and monitoring

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

- **Te Aho o Te Kahu Quality Performance Indicator**
 - Route to diagnosis: Proportion of people who are diagnosed with cancer within 30 days of an emergency or acute (unplanned) hospital admission (Te Aho o Te Kahu, 2024).
- **Faster Cancer Treatment (FCT)**
 - **31-day Health Target** - 90% of patients will receive their cancer treatment (or other management) within 31-days from the decision to treat.
 - **62-day indicator** – 90% of patients will receive their cancer treatment (or other management) within 62-days from date of referral to first treatment.

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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- **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).

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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Step 5: Treatment

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

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 programme (Cancer Society) occurs as required
- the person and their whānau have all the information and resources to support their mana motuhake (empowerment).

5.2 Treatment intent

The treatment intent should be established in a multidisciplinary meeting/setting (see Step 4.6), documented in the person's medical record, and shared with the person and their whānau. Discuss the advantages and disadvantages of recommended treatments and associated side effects in plain language to support the person and their whānau to make an informed decision. If there is more than one suitable treatment option, services could facilitate the decision making of the person and their whānau by having all specialties involved in a single appointment.

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

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

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

5.2.1 Additional considerations

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

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

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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Initiate advance care planning discussions with the person and their whānau before treatment begins (this could include appointing a substitute decision-maker and completing an advance care directive).

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

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

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

5.3 Treatment options

The type of treatment recommended for ovarian cancer depends on the type, stage and location of the cancer and the person's age, health, and preferences. Treatment may include a combination of the items listed below, concurrently, or sequentially, to maximise outcome.

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

Surgery

- Quality of surgery is one of the most important determinants of the outcome for the person with ovarian cancer.
- Evidence shows that ovarian cancer surgery performed in a high-volume centre is associated with a higher likelihood of favourable outcomes.
- Specialised gynaecology cancer surgeons are usually grouped in centres where this care is frequently provided leading to better surgical expertise.

Surgery may be used to stage the cancer, and as a form of treatment. The type of surgery offered will depend on several factors such as the stage of the disease, the person's age, and performance status. If the cancer is found early, then surgery to remove the affected ovary and fallopian tube may be the only treatment that is required.

Often the cancer is not found early, and more extensive surgery is needed. This can involve removing the uterus, both fallopian tubes and ovaries, omentum (the fatty layer that sits on the surface of organs), lymph nodes, part of the large bowel with or without a stoma, appendix, spleen, and diaphragm.

Timeframes for starting treatment

- Where surgery is the first treatment, treatment should begin **within 31 days** of the decision to treat, regardless of how the person was initially referred.
- Time to surgery, if required after neoadjuvant therapy, depends on the regimen prescribed.

Systemic therapy

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

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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The appropriateness and type of chemotherapy or drug therapy will be determined by the multidisciplinary team. Some people may benefit from chemotherapy or drug therapy:

- before surgery in suspected stage III or IV ovarian cancer, to reduce the volume of the tumour before surgery
- after surgery for all stages of cancer except in limited cases where the cancer was clearly confined to one or both ovaries and considered low risk for recurring or for some rare cancer types.
- timely access to operating theatres is crucial especially for people treated with neoadjuvant chemotherapy.

Timeframes for starting treatment

- Where chemotherapy is the first treatment, treatment should begin **within 31 days** of the decision to treat, regardless of how the person was initially referred.
- Adjuvant chemotherapy should begin **within 4 weeks** of the decision to treat.

Radiation therapy

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

Some people with ovarian cancer may benefit from radiation therapy for symptomatic relief and palliation of metastatic or recurrent disease (Jiang et al. 2018).

Timeframes for starting treatment

- Where radiation is the first treatment, treatment should begin within 31 days of the decision to treat, regardless of how the person was initially referred.

Targeted therapies

Depending on the cancer, some people may instead or later, be offered hormone therapy or targeted therapy or given this treatment after chemotherapy as a ‘maintenance’ treatment:

- PARP inhibitors – these drugs may typically benefit people who have been diagnosed with specific gene mutations. Benefits and risks of PARP inhibitors for people without specific gene mutations should be discussed with their clinical team.
- angiogenesis inhibitors – these prevent the growth of blood vessels related to tumours

Palliative care

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

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

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

- physical symptoms such as pain or fatigue
- nutrition

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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- psychosocial needs
- bowel dysfunction, gastrointestinal or abdominal symptoms.

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 to principle 8).

5.4 Treatment summary

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

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

5.5 Supportive care and communication

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

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

- access to expert health providers/professionals with specific knowledge about the psychosocial needs of people undergoing ovarian cancer 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 for 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
- disfigurement and scarring from appearance-altering treatment (and possible need for a stoma) – referral to a specialist psychologist, psychiatrist or social worker may be required

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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- 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
- assessment and management for lower limb lymphoedema by a lymphoedema specialist if a lymphadenectomy has been performed, which can restrict mobility – referral to a physiotherapist or trained lymphoedema specialist may be appropriate.

The person and their whānau may also need to manage:

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

5.5.1 Care coordination

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

5.5.2 Communication with the person/whānau receiving care

Health providers/professionals

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

Communication between health services

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

“A whānau need to have a choice of services including rongoā, mirimiri etc. and know how to access tohunga, particularly for whānau who may be disconnected from te ao Māori”

Person/whānau insights

5.6 Measuring and monitoring

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

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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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 (FCT)**

- **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.
- **62-day indicator** – All first treatment will be started within 62 days from referral or 31 days from decision to treat (includes surgery, chemotherapy, and radiation therapy). As a minimum, 90% of patients will receive their cancer treatment (or other management) within 62 days from receipt of referral to first treatment. (Ministry of Health | Manatū Hauora. 2023.)

- **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).

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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Step 6: Care after treatment

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

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

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

The following references inform care after treatment for the person with ovarian cancer: **Best Practice Advocacy Centre New Zealand (bpacNZ) guidance.**

6.1 Te Tiriti o Waitangi

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

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

6.2 Survivorship care planning

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

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

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

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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As people are often followed up for five or more years after treatment, this plan needs to be regularly reviewed and updated to reflect changes in the person's clinical and psychosocial status. All health providers involved in the follow-up care are responsible for updating the care plan.

6.3 Treatment summary

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

The summary includes:

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

6.4 Rehabilitation and recovery

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

For people with ovarian cancer, assessment for referral to appropriate rehabilitation or recovery services should be undertaken including:

- nurse specialist, physiotherapist, urologist for incontinence, stoma nurse for stoma issues
- counsellor ideally specialising in cancer and/or psychosexual function
- lymphoedema physiotherapy assessment for lymphoedema.

6.5 Follow up and surveillance

Follow up and surveillance can have multiple functions, including:

- evaluation of treatment response
- early identification of recurrence
- if only one side affected initially, early detection of new primary in unaffected ovary and/or fallopian tube
- monitoring and management of complications
- optimisation of rehabilitation
- provision of support to the person and their whānau.

Care after treatment is driven by predicted risks and individuals' clinical and supportive care needs. Care includes regular physical examinations and medical tests and is based on the medical guidelines for the specific type and stage of cancer, the treatment that's been received, and the needs and wishes of the person and their whānau.

For people with ovarian cancer, care is informed by the following **Best Practice Advocacy Centre New Zealand (bpacNZ) guidance.**

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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Follow up is based on the:

- treatment given
- stage and risk of recurrence
- person's co-morbidities.

Cervical cytology is not useful after treatment for people who have had a hysterectomy for ovarian cancer.

Planning needs to include:

- who will be providing follow up care for example, specialists, primary care provider (including palliative care) or if there will be a shared care approach (refer 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 recurrent disease

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

Ovarian cancer signs and symptoms that necessitate further investigation may include:

- fatigue
- abdominal or back pain
- bloating
- nausea
- vomiting
- changes in bowel or bladder function
- weight loss
- some cases of recurrent disease will be detected by routine follow-up, such as a rise in the CA 125 tumour marker, when the person may be asymptomatic.

6.6.1 Rapid re-entry to specialty services

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

6.7 Clinical trials

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

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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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.

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.

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

6.9 Measuring and monitoring

Currently there are no national indicators for this step.

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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Step 7: Palliative and end-of-life care

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

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

“You matter because you are you. You matter to the last moment of your life, and we will do all we can to help you not only die peacefully, but also to live until you die.”

Dame Cecily Saunders

7.1 Te Tiriti o Waitangi

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

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

7.2 Palliative care

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

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

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

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

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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Palliative care is provided in different settings, depending on availability and the needs and preferences of the person and their whānau. Settings include:

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

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

Referral to specialist palliative care services will be appropriate for those with a level of need that exceeds the resources of the primary/generalist palliative care provider. Referral criteria for adult palliative care services in New Zealand are available on the [Health New Zealand | Te Whatu Ora website](#).

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

7.3 End-of-life care

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

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

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

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

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

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

7.4 Assisted dying

The person requesting assisted dying information is supported to access this service. Health providers/professionals are required to be aware of their rights and responsibilities regarding assisted dying services should the person raise this with the health care team. For more information visit [Assisted Dying Service](#)

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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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. Several 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.

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.

“The difference in his wellbeing after rongoā was huge. He was still dying, but he didn’t look sick anymore.”

Person/whānau insights

“Palliative care is a tapu space and requires a careful, holistic approach.”

Person/whānau insights

Wellness	Early detection	Presentation, initial investigations, and referral	Diagnosis, staging and treatment	Treatment	After care	Palliative and end of life care
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7.5.3 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/our-work/advance-care-planning
- *A Guide for Carers.* (Hospice New Zealand 2019). hospice.org.nz
- *Mauri Mate: A Māori palliative care framework* (Hospice New Zealand.2019) hospice.org.nz/mauri-mate
- *Te Ara Whakapiri: Principles and guidance for the last days of life* (Ministry of Health | Manatū Hauora 2017b) health.govt.nz/publication/te-ara-whakapiri-principles-and-guidance-last-days-life
- *The Palliative Care Handbook* (Hospice New Zealand 2019b) hospice.org.nz/resources/palliative-care-handbook
- *Information on assisted dying for the public* (Health New Zealand | Te Whatu Ora, nd) tewhatauora.govt.nz/for-the-health-sector/assisted-dying-service/assisted-dying-information-for-the-public/information-on-assisted-dying-for-the-public

7.6 Measuring and monitoring

- *Ngā Paerewa Pairuri Tāngata | Standards for Palliative Care* (Hospice New Zealand 2019a) **Standards for palliative care.**
 - 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).