

Optimal care pathway for Aboriginal and Torres Strait Islander people with cancer

Quick reference guide



Please note that not all patients with cancer will follow every step of this pathway:

This Quick Reference Guide provides guidance to health practitioners and service planners on optimal care for Aboriginal and Torres Strait Islander people with cancer, across the cancer continuum. Refer to the relevant tumour-specific Optimal Care Pathway at cancerorg.au/OCP.

For Aboriginal and Torres Strait Islander people, health and connection to land, culture, community and identity are intrinsically linked. Health encompasses a whole-of-life view and includes a cyclical concept of life-death-life.

Key considerations to support the delivery of optimal care for Aboriginal and Torres Strait Islander people with cancer:

Understanding your patient

- Understand the philosophies of holistic health and wellbeing and the role of Aboriginal and Torres Strait Islander knowledge, values, beliefs, cultural needs and health history in decision-making processes about treatment and ongoing care.
- Care coordination for each person should be informed by factors such as gender, kinship, family ties, language barriers and socio-economic issues.
 - Offer an option to see a health professional of the same gender as the patient, referral to an alternative service provider if this is not possible, or the option of having a support person present.
 - Acknowledge that family may include people who are not genetically related.
- When discussing family history and genetic testing, understand that the concept of family is broader than being genetically related, discussing family members who are part of the Stolen Generation may be distressing.
- Be sensitive when discussing cultural taboos about cancer, Sorry Business (referring to people that have died), Men's and Women's Business and concerns about research exposure.

- Practise trauma-informed care and take steps to address intergenerational and contemporary trauma through culturally informed approaches.

Communication

- Provide plain English information in accessible and culturally appropriate formats. Use an interpreter if required.
- Only use traditional terminology, such as referring to people as 'Aunty' or 'Uncle' if invited to do so.

Practical considerations for consultations

- Allow time to build rapport and trust with patients, while also ensuring timeframes meet evidence-based guidelines.
- Encourage and include family and/or community members/ Elders/support people at appointments, if preferred.
- Ask if the individual identifies as Aboriginal and/or Torres Strait Islander and record this if a person wishes to identify as such.
- Ask permission before touching a patient and explain the reasons why it is necessary to touch them.
- Ensure the multidisciplinary team includes an expert in providing culturally appropriate care to Aboriginal and Torres Strait Islander people.¹

Step 1

Prevention and early detection

Risk reduction: Encourage Aboriginal and Torres Strait Islander people to:

- quit smoking
- maintain a healthy body weight
- be physically active
- avoid or limit alcohol intake
- eat a healthy diet
- reduce ultraviolet exposure
- consider risk-reducing surgery or medication for people with a high hereditary or genetic risk of certain cancers.

Screening and immunisation:

- encourage screening for colorectal, breast and cervical cancer
- support uptake of immunisation for HPV and hepatitis B
- encourage regular Medicare health assessments and use these opportunities to discuss prevention and early detection, and to assess cancer risk
- discuss privacy concerns.

Early detection: Timely diagnosis can be enabled by:

- sharing knowledge about cancer, its symptoms and survivability
- discussions addressing concerns or fears
- increasing awareness of, and access to, affordable, convenient quality health services in remote and regional areas
- considering comorbidities masking cancer symptoms.

¹ A culturally appropriate healthcare professional may be an Aboriginal and Torres Strait Islander Health Worker, Health Practitioner, or Hospital Liaison Officer.



Step 2

Presentation, initial investigations and referral

Presentation: Some Aboriginal and Torres Strait Islander people may:

- present with multiple comorbidities
- have multiple risk factors
- present with a later stage of disease
- avoid discussing gender-specific matters in the presence of a member of the opposite gender
- feel culturally unsafe accessing health services
- face financial, transport or other barriers to accessing health services
- have family and community responsibilities
- experience feelings of shame or discomfort from heightened attention, sharing personal information, previous experiences or perceptions about cancer or mainstream medical services.

Referral: If test results are equivocal, or if the diagnosis of cancer is confirmed, referral to an appropriate specialist is warranted. Timely follow up regarding status of referral is essential.

- Ensure contact details are up to date to enable follow-up, and Aboriginal and/or Torres Strait Islander status is recorded (with consent).
- Designate a culturally appropriate healthcare professional² to follow up on the referral and keep in contact with the patient.

Timeframes: Communication technologies and additional discussions may facilitate the involvement of family members and carers in decision making within optimal care timelines.

Support and communication – lead clinician to:³

- ask whether the patient wishes a support person to be present during discussions
- routinely identify the supportive care needs of the patient and their families, ideally through using a tool validated for use with Aboriginal and Torres Strait Islander people, for example SCNAT-IP⁴
- provide the patient with information that clearly describes who they are being referred to, the reason for referral and the expected timeframe for appointments
- provide information about local support services
- support the patient while waiting for the specialist appointment. Local health professionals and/or Cancer Council nurses can provide information and reassurance via the national 13 11 20 information and support service. Health Professionals can also access this service.

Step 3

Diagnosis, staging and treatment planning

Care coordination is critical to facilitate and optimise the timeline between diagnosis, staging and treatment planning.

Diagnosis and staging: The diagnostic workup depends on the type of cancer involved. Some procedures may require the patient to travel to receive care at a specialised centre, which could be arranged through jurisdictional Patient Assistance Travel Schemes and with assistance by an Aboriginal and/or Torres Strait Islander Hospital Liaison Officer. All patients should be assessed for medical comorbidities during the diagnostic workup.

Treatment planning: Newly diagnosed patients should be discussed by a multidisciplinary team that includes an expert in providing culturally appropriate care to Aboriginal and Torres Strait Islander people⁵, to recommend a treatment plan.

Research and clinical trials: Consider enrolment in relevant clinical trials for patients as part of treatment planning. To achieve equity of access for Aboriginal and Torres Strait Islander people, clinicians should use culturally appropriate resources to explain the benefits of the clinical trials.

Support and communication – lead clinician to:

- discuss the reason investigations are being conducted to help the patient understand their situation and discuss concerns before providing informed consent for the diagnostic workup
- establish if the patient has a regular or preferred general or primary practitioner
- discuss a timeframe for diagnosis and treatment with the patient/carer support person
- explain the role of the multidisciplinary team in treatment planning and ongoing care
- invite the general practitioner to multidisciplinary team meetings (consider video or teleconferencing)
- notify the general or primary practitioner, Aboriginal and/or Torres Strait Islander Health Worker or Hospital Liaison Officer and family or carer if the person does not attend clinic appointments
- provide appropriate information or refer to support services as required. Cancer Council nurses can provide information and reassurance via the national 13 11 20 telephone support service.

² This may be an Aboriginal and/or Torres Strait Islander Health Worker, Health Practitioner or Hospital Liaison Officer, or a Primary Healthcare Coordinator.

³ Lead clinician – the clinician who is responsible for managing patient care. The lead clinician may change over time.

⁴ The Supportive Care Needs Assessment Tool for Indigenous People, available at <http://www.scnatip.org/>.

⁵ A culturally appropriate healthcare professional may be an Aboriginal and Torres Strait Islander Health Worker, Health Practitioner, or Hospital Liaison Officer.

Step 4

Treatment

Treatment intent: Establish and document if treatment is

- curative
- anti-cancer therapy to improve quality of life and/or longevity without expectation of cure or
- symptom palliation.

When discussing death or dying with Aboriginal and Torres Strait Islander people, the terms 'passing', 'not going to get better' or 'returning to Country' may be more accepted due

to spiritual belief around the life cycle (seek guidance from Aboriginal and/or Torres Strait Islander Health Worker or Hospital Liaison Officer).

Treatment options: Aboriginal and Torres Strait Islander perception and view of health, illness and treatment may impact on decision making. When discussing treatment options with the patient and carer/support person, lead clinician to consider:

- preferred place of treatment
- travel and accommodation needs
- cultural obligations, including family and community
- engagement with identified health professionals (for example an Aboriginal and/or Torres Strait Islander Health Worker)
- involvement of spiritual advisors, traditional healers and traditional medicine.

Pain management: Aboriginal and Torres Strait Islander patients may not actively report pain or other needs. The lead clinician should be proactive about determining the appropriate time for referral to palliative care for symptom control. Consider:

- offering the option for patients to discuss pain management with a health professional of the same gender
- offering oral pain relief options where appropriate
- using a pain tool that is culturally appropriate for the local community
- fully explaining options, usage and side effects of pain relief.

Palliative care: Early referral can improve quality of life and, in some cases, survival. Referral should be based on need, not prognosis.

Support and communication – lead clinician to:

- discuss treatment options with the patient/carer/support person including the intent of treatment and expected outcomes
- discuss advance care planning with the patient/carer/support person where appropriate
- discuss the treatment plan with the patient's general practitioner
- discuss and document the patient's use (or intended use) of traditional or complementary or alternative medicine therapies.

Step 5

Care after initial treatment and recovery

Consider if additional support is needed to support a healthy lifestyle.

Strategies to assist with the transition to survivorship after treatment ends include:

- engaging Aboriginal and/or Torres Strait Islander Health Workers, Health Practitioners, the Primary Healthcare Coordinator and/or Hospital Liaison Officer to support the person
- discussing the patient's beliefs and definition of living well to ensure health services are working towards the patient's ideal outcome

- offering referral pathways to social and emotional wellbeing services and mental health services.

Treatment summary (provide a copy to the patient/carer and general practitioner) outlining:

- diagnostic tests performed and results
- tumour characteristics
- type and date of treatment(s)
- interventions and treatment plans from other health professionals
- supportive care services provided

- contact information for key care providers.

Follow-up care plan (provide a copy to the patient/carer and general practitioner) outlining:

- medical follow-up required (tests, ongoing surveillance)
- care plans for managing the late effects of treatment
- potential barriers to the follow-up plan (travel or cost) and strategies or referrals to support services to address these
- a process for rapid re-entry to medical services for suspected recurrence.

Support and communication – lead clinician to:

- explain the treatment summary and follow-up care plan to the patient/carer
- provide culturally appropriate information about the signs and symptoms of recurrent disease, secondary prevention and healthy living
- discuss the follow-up care plan with the general practitioner
- consider that the term 'survivor' may have negative connotations for historical reasons.

Step 6

Managing recurrent, residual and metastatic disease

Treatment: Where possible, refer the patient to the original multidisciplinary team. Treatment will depend on the type, location and extent of disease, previous management and patient preferences.

Pain management: Aboriginal and Torres Strait Islander patients may not actively report pain or other needs, therefore the lead clinician should be proactive about determining the appropriate time for referral to palliative care for symptom control.

Consider:

- offering the option for patients to discuss pain management with a health professional of the same gender
- offering oral pain relief options where appropriate
- using a pain tool that is appropriate for the local community
- fully explaining options, usage and side effects of pain relief.

Palliative care: Early referral can improve quality of life and, in some cases, survival. Referral should be based on need, not prognosis.

Support and communication – lead clinician to:

- explain the treatment intent, possible outcomes, adverse effects and the supportive care options available
- consider that when discussing death or dying with Aboriginal and Torres Strait Islander people, the terms ‘passing’ or ‘not going to get better’ or ‘returning to Country’ may be more accepted due to spiritual belief around the life cycle (seek guidance from Aboriginal and/or Torres Strait Islander Health Worker or Hospital Liaison Officer)
- initiate a discussion regarding advance care planning if appropriate.

Step 7

End-of-life care

Wherever possible and requested by the patient and/or their family or carers, health services should support the inclusion of cultural practices, which may include the services of a spiritual advisor, traditional healer or Elders, access to traditional foods, and performing ceremonies.

Return to Country: The need to ‘return to Country’ before the end or at the end of life can be both culturally and spiritually significant. Where the patient prefers to be cared for at home, health services should act to support the family and carers in providing appropriate palliative care.

Multidisciplinary palliative care: Consider referral to palliative care if not already involved. Ensure that an advance care plan is in place.

Pain management: When assessing pain and pain management, health professionals should be aware that there are significant cultural practices regarding which family members can assist with providing pain relief, how pain medication is administered, and fears that pain relief medicines may accelerate the passing of the patient.

Effective strategies to manage pain for Aboriginal and Torres Strait Islander people include:

- offering the option for patients to discuss their pain and pain management with a health professional of the same gender
- offering oral pain relief options where appropriate
- using a pain tool that is culturally appropriate for the local community
- fully explaining options, usage and side effects of pain relief.

Practices around death and dying: The practices observed around death and dying can vary significantly between both individuals and Aboriginal and Torres Strait Islander communities. Health services should discuss cultural preferences with all patients and consult with their local Aboriginal and Torres Strait Islander personnel and communities for further guidance about this. It may be inappropriate to say or write the name of a deceased person, or for a non-Indigenous health professional to relay the news that an Aboriginal and/or Torres Strait Islander person has died.

Support and communication – lead clinician to:

- be open to and encourage discussion about the expected disease course while considering the patient’s personal and cultural beliefs and expectations
- establish transition plans to ensure the patient’s needs and goals are addressed in the appropriate environment.

Visit www.cancerpathways.org.au for consumer friendly guides. Visit www.cancer.org.au/OCP for the full clinical version and instructions on how to import these guides into your GP software.