



# Ngununggula

## *Walking and Working Together*

A MANUAL FOR HEALTH PROFESSIONALS SUPPORTING ABORIGINAL PEOPLE WITH CANCER



# Ngununggula - Walking and Working Together

A Manual for Health Professionals Supporting Aboriginal People with Cancer

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**Ngununggula can be downloaded from the AHMRC website:**

<https://www.ahmrc.org.au/resources/> or ordered by email [reception@illawarraams.com.au](mailto:reception@illawarraams.com.au) or telephone from Illawarra Aboriginal Medical Service Tel 61 2 42299495

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**Title note:** Ngununggula means walking and working together in Gundungurra.

**Cover artwork by Auntie Trish Levett:** The painting represents Men & Women who have been affected by Cancer. The blue in the background and at the bottom of the painting represents the ocean of the Illawarra, pink is for the women who have suffered with breast cancer, yellow is for all cancers, blue for men cancers, purple is for those who have gone through Chemo treatment, red is for the changing blood cells. The feet with the white arch are women, black feet are men who have accessed the Cancer Care Team at the Illawarra Aboriginal Medical Service. The hands show support to all clients with all different Cancers.

**Back cover photo by Kyla Wynn**

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**Statement of Acknowledgment:** We acknowledge the Traditional Owners of Country throughout Australia and their continuing connection to the land, sea and community. We pay our respects to them and their cultures and to Elders past, present and future.



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Photo by Kyla Wynn



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*Like thousands of women across the country, I was diagnosed with breast cancer in 2012. Only those who have been through this journey can know how frightening it is. Questions went through my mind every minute of my waking hours: ‘Can it be treated?’, ‘What are my chances?’ and ‘What will happen to my family?’*

*The health system is not easy to navigate. At the time, I was CEO at the IAMS [Illawarra Aboriginal Medical Service], and I had an idea of how it worked. Many don’t.*

*I realised people who have breast cancer and other cancers needed help getting to appointments, understanding cancer treatments and procedures and counselling. The idea for the Cancer Care Program was born.*

*The Rural Doctors Network funded the program, and the CCT [Cancer Care Team] flourished. I am very proud of this program, replicated by other Medical Services across the state, which has helped many cancer patients and their families.*

– Julie Booker, Former CEO  
Illawarra Aboriginal Medical Service (IAMS)

*I’m just so grateful for the blessing of knowing these women. I love them dearly. They offer themselves. Not many medical services do that.*

*They care. The people that read this book can go out and learn more to add to what they know. It’s all about education. And that brings growth.*

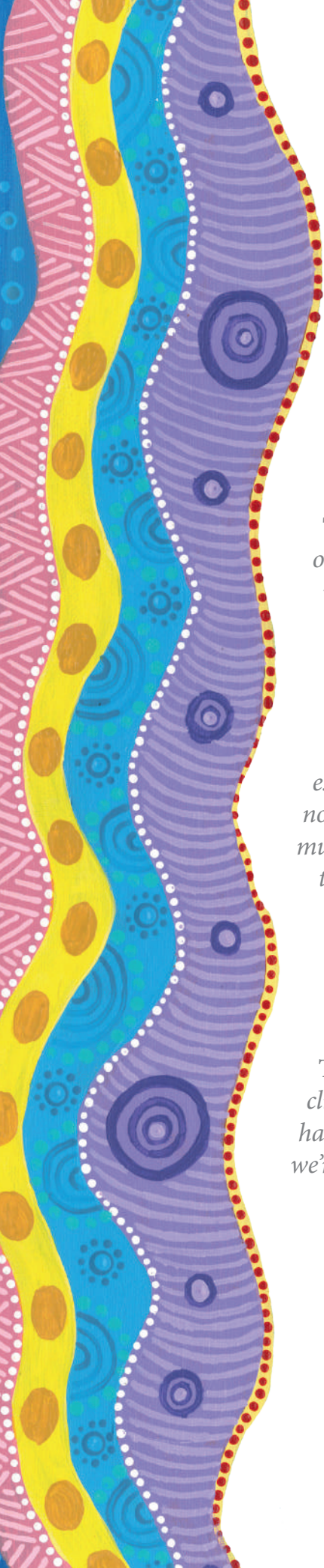
– Marjorie Campbell,  
Community Elder and Client



*We’ll make ourselves available to anyone that wants to tread this path because we know all the pitfalls. We’ve learned. We’ve tripped over. We’ve had to climb up again. Anyone who wants the shortcuts, here they are. We are more than willing to share.*

*I want the message to get out all over the place, and I want to share the resources to support anyone else who wants to run programs or build a team like we did.*

– Kyla Wynn, Counsellor/Co-ordinator  
Cancer Care Team, IAMS



**Trish:** *We've been working together for about four years now. We are the original Cancer Care Team workers. We've had two other workers who've worked with us, as well.*

*Kyla and I have that connection. We have that passion. We want to see the Cancer Care team go forward. We see results.*

**Kyla:** *One of the keys to our relationship is the respect we hold for each other. I'm truly blessed to work with an Aboriginal lady with significant experience in Aboriginal health and a respected Elder in her Community. I'm not that. Trish's generosity in sharing culture allows me to get into this work so much more. We each have a different history, and we both totally respect what the other can offer.*

*It all gets thrown on the table to share. We don't hold anything back from each other. And we open ourselves to our clients so that we're real, as well.*

*We've had to take the dints and bruises. Our focus is never on ourselves. We focus on results for our clients.*

**Trish:** *You need to have the right people in those positions to start with. Our clients get to know us, not just on a professional level but also personally. We'll have a muck around with them – have a yarn, have a laugh. They can see what we're like.*

## CHAPTER 1

# ABOUT THIS BOOK



### ● Cancer has affected us

As health workers, we all care for clients who want to prevent cancer, who need cancer screening, and clients who have cancer and need treatment. We've cared for people who have died of cancer. Most of us have a family member who has cancer or had it.

We all know Aboriginal people in Australia are more likely to get a cancer diagnosis and are more likely to die from cancer. So we work, every day, to avoid our clients and family members becoming part of the bad news statistics. This book is a tool to help you do that.

Many people survive cancer: sharing our knowledge of this strengthens our clients and communities. Our work makes people feel better. Sometimes it saves lives. Sometimes it helps heal their spirit, even if we cannot save them in this lifetime. We accept that death is part of the cycle of life.

Some of our work aims to restore harmony and healing before our clients get sick. We also help healing happen after a person has left this life.

We hope that what's been learned, shared through this book, will inspire you and give you ideas and tools to aid you in the work you do at your place.

Some stories come from Aboriginal Community-Controlled Health Organisations (ACCHOs) and Aboriginal Medical Services (AMs) in New South Wales. Other stories come from colleagues who work with people with cancer in hospitals.

We've included stories from different parts of the country too. All these stories have been de-identified, except for quotes where people wanted their names shown. With a few exceptions, we do not identify clients. We acknowledge the experience the stories come from while keeping confidentiality by changing people's age, gender, family set-up, or Country.

Our clients are among our most important teachers.

We created this book to support workers at ACCHOs and AMs, hospitals, and non-government organisations. It's for Aboriginal Health Workers (AHWs) and Practitioners (AHPs), Integrated Team Care (ITC) workers, Palliative Care Workers, Allied

Health Professionals (like counsellors, physiotherapists, Massage therapists, social workers, podiatrists), and the nurses and doctors who look after Aboriginal people with cancer.

We hope you find useful tools here. You might want to read the book all through. Or you might prefer to go to the chapter you need on the day. Maybe you're running a special day for women to get their mammograms done, or you're taking a client for his chemotherapy, so you could turn to chapter 13.

You might be planning Quality Improvement (QI) activities to improve cancer prevention and support in your service. The online appendices to this manual includes QI activities using Communicare®, a patient information management system used in many Aboriginal health services. QI resources can be found in the appendices in the online version of Ngununggula. While it is written firstly for Aboriginal people, everyone is welcome to learn.

### ● Who wrote this

**Trish Levett** is a Gundungurra knowledge holder with a Bachelor of Adult Education and Community Management. She was born in the Southern Highlands of New South Wales and now lives on the NSW South Coast, teaching about Aboriginal culture and bush medicines, and running traditional spiritual healing ceremonies. An Aboriginal artist and activist, Trish fights for justice on many levels. She also works as an Aboriginal Health Worker at the IAMS, having worked in Aboriginal health for more than twenty years.

Trish has a passion for working at the grassroots level to improve the social and emotional wellbeing of Aboriginal Community members. Her holistic approach to healing includes taking community members to her Country, visiting sacred sites to heal. Gundungurra Country borders Dharawal Land to the west.

Trish's work within the Cancer Care Team over the past six years has sustained and nourished her spirit. She supports her people and her Country, and is cared for in return.

**Kyla Wynn** grew up in the Illawarra. She has lived in and around Batemans Bay and Cootamundra and was happy to return to Wollongong as her children became adults. Kyla's career began as an Enrolled Nurse at Bulli Hospital, where the region's first Palliative Care ward was established (in the 1980s). She worked in cancer and palliative care services for many years.

Seeing her child through cancer treatment played a crucial role in Kyla's education as a healer. The experience enriched her understanding of the challenges patients and families face with cancer.

With a Diploma in Counselling, Kyla draws on her counselling, support worker, and coordinator skills to care for Aboriginal community members within the Cancer Care Team. 'I feel truly blessed to be able to work within the Aboriginal Community,' she says. She has worked in the CCT for the past six years.

**Dr Rowena Ivers** has worked in Aboriginal health for over twenty years and was a member of the Illawarra AMS Cancer Care Team for five years. She is a GP and an Associate Professor in the Faculty of Medicine at the University of Wollongong.

**Dr Janelle Trees** is the fourth writer and editor of this book. Janelle is a descendant of the Dhangati people of northern NSW and works as a GP in rural and remote health. She worked at IAMS and in palliative care in the Illawarra before leaving the area to work remotely for a decade, mainly in Aboriginal communities in the Northern Territory and Western Australia.

She was the first Indigenous student to graduate from the University of Sydney with Honours in their Medicine faculty. As well as her Master of Surgery, Bachelor of Medicine from there, she has a Bachelor of Science with first class honours and is a Fellow of the Royal Australian College of General Practice.

## ● Where this book comes from

The Illawarra is the southeast of NSW. To the west are mountains, to the east the sea, with an ancient sandstone escarpment dominating the region's north. It changes colour and gathers clouds throughout the day.

When the British invaded around 230 years ago, they took advantage of the bounty of our land and sea, particularly cedar felling and whaling. The Illawarra is rich with lakes, coastal plains and sandhills, estuaries, surf beaches, and has commanding lookouts.

We live and work in Dharawal Country in the northern part of the Illawarra. People who spoke Dharawal as their first language lived in an area extending from present-day Kurnell (on the southern side of Sydney) to the Shoalhaven region around Nowra, 145 kilometres to the south.

We know at least thirteen of their clan names, reflected in the place names of the area. The clans live on in their present-day descendants. Their spirits live in the forests and the waves, and they might visit in a cloud, a bird or a rainbow.

Their spirits guide and influence those among us who thrive in, sustain, and celebrate Aboriginal and First Nations cultures.

## ● What does the cancer team do?

Aunty Trish and Kyla provide support through the cancer journey, including a range of health promotion, prevention, early intervention, and support services to people with cancer.

They are advocates for patients and their families, engaging with services and other organisations.



Trish Levett

Kyla Wynn

Dr Rowena Ivers



Dr Janelle Trees

Group photo courtesy Cancer Care Team  
Photo of Janelle by Claudia Jocher

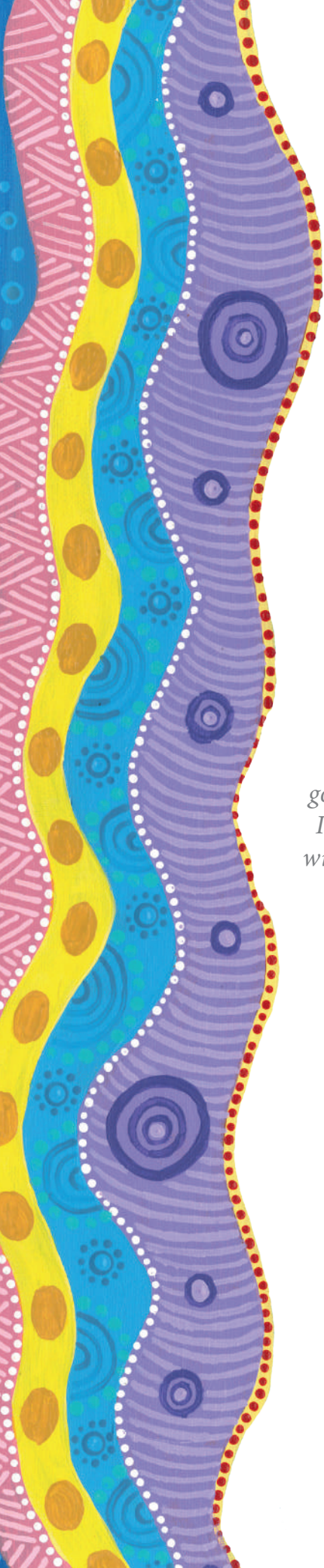




Photo by Kyla Wynn

## ● Their work includes:

- a monthly Yarning Circle for mob with cancer; to have a yarn, do cultural activities, and have some respite
- connecting people with Country and culture, with healing ceremonies and bush medicine, including visits to healing and sacred sites on Gundungurra Country
- holding mammogram days twice a year at Breast Screen NSW
- running the 'Bling a Bra' health promotion for breast cancer awareness and screening through community displays of painted, decorated bras
- working with the Koori Men's Support Group in the Illawarra; including holding a men's health day with a focus on bowel cancer screening
- participating in a local Melanoma March, raising awareness and funds
- providing support to patients, their families, and carers, attending medical appointments with patients, and referring them to other services where necessary
- advocating on behalf of patients and their families; such as ensuring hospital staff understand their cultural needs or arranging pro bono legal services for the preparation of a will
- producing and distributing accessible, culturally appropriate resources
- funeral planning
- grief counselling – which is not time-limited – for the families until they are ready to stop. Individual and group counselling sessions often happen by the river or the beach. Not in an office.



*The roots of the higher burden of cancer and cancer deaths Aboriginal and Torres Strait Islander people endure are in their dispossession.*

*Dispossession and loss of sovereignty are the fundamental cause of the poverty, the lack of physical and cultural safety people face, and so many of the challenges in accessing the best available cancer treatment and care.*

*Racism is the ideological justification of dispossession. So it permeates government institutions and business, as well as affecting us in everyday life. It's not just about being denied service at a hotel. It's about living in a place without clean water or not feeling safe to go to a hospital.*

*That is why we must fund programs like the Cancer Care Team adequately and sustainably. Good care of patients, families and communities affected by cancer is not only a humanitarian issue. It is a social justice issue.*

– Janelle,  
Dhanggati GP

## CHAPTER 2

# ABORIGINAL PEOPLE, CANCER & PREVENTION



*It's not just saying, 'You need to have your health checks.' It's about making sure people can do their health checks and can do their screening. It's facilitating and opening those doors. It's no good just telling people, 'You've got to have your health check every year, and you've got to do your bowel screening every two years, and you've got to go and have your mammogram.'*

*It's no good unless you're supporting people in doing that, giving them the tools or the understanding that they need so that it's something real... A lot of people have got their backs up. 'That's white man's stuff.' Well, it may be white man's stuff, but it can save your life.*

– Kyla, CCT

### ● Cancer: Caring & Prevention

Cancer is the leading cause of death in Aboriginal and Torres Strait Islander people.

Every cancer death places a heavy load on the sick person, the people who love them and the Community or Communities where they lived and participated.

In 2014-2018, cancer caused 23% of Aboriginal and Torres Strait Islander deaths – more than any other cause. Aboriginal and Torres Strait Islander people are 1.4 times more likely to die of cancer than non-Aboriginal Australians.

Our mob faces a higher burden of preventable diseases, like lung and head and neck cancers caused by smoking. And women's cancers, which could have been caught early with cervical and breast screening and treated.

Much of the solution is about access to good, culturally safe treatment and care, as well as getting the things that can prevent cancer in the first place: fresh, good quality food, a safe and clean home environment, safe working conditions and education.

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## ● The CCT's Leaflets

Kyla: *We've created our own resources. Look at these.*

Janelle: *That's a great idea. These are lovely!*

Kyla: *Yeah, we did 'em all ourselves. We just weren't happy with what was around. We picked the most common questions to make the topics. You could go on forever.*

Janelle: *But this is what you're always talking to people about because it's hard for them to remember.*

Kyla: *Yes. These are the common-ish things to talk about. You'll find there's really basic information in there. It is just enough to start a conversation. Just enough to answer the first questions.*

Janelle: [Looking through a leaflet on Lung cancer prevention and care] *Yeah, but they're all the important questions! Like, what happens if you get lung cancer? Who will help you?*

Kyla: *They look good. They're appealing. People pick 'em up.*

Janelle: *Yes, bright colours. I appreciate the artwork.*

Kyla: *That was the idea. To get people to pick them up, for knowledge.*

### RESOURCES

**Cancer Australia** – [www.canceraustralia.gov.au/key-initiatives/aboriginal-and-torres-strait-islander-health](http://www.canceraustralia.gov.au/key-initiatives/aboriginal-and-torres-strait-islander-health)

**Cancer Institute NSW** – [www.cancer.nsw.gov.au](http://www.cancer.nsw.gov.au)

**Quit** – [www.quit.org.au](http://www.quit.org.au)



## ● Health Checks

The National Preventive Health Assessment for Aboriginal and Torres Strait Islander People – (Health Check, MBS Item 715) is an annual health check which can be done any time in a lifetime.

Many parts of the Health Check are part of preventing cancer, like asking about family history, asking about tobacco use and alcohol intake, and measuring body mass index. Most ACCHOs have systems for promoting these including:

- booked appointments for health checks
- being able to do health checks opportunistically – that is, if a person comes in for another issue but is willing to do a health check at the same time
- Health Check days or carnivals
- T-shirts, vouchers or other incentives for taking part
- promotion of Health Checks via advertising, including social media.

## ● Health Check Templates

Most medical software contains templates for completing health checks.

### RESOURCES

**RACGP, Item 715 Health Check Templates** – Accessed at [www.racgp.org.au/the-racgp/faculties/atsi/cultural-safety/resources/2019-mbs-item-715-health-check-templates](http://www.racgp.org.au/the-racgp/faculties/atsi/cultural-safety/resources/2019-mbs-item-715-health-check-templates)

**Continuous Quality Improvement** – Continuous Quality Improvement (CQI) activities support and improve health care quality, including cancer care in our communities, through continuous and repeated cycles of changes. Refer to online Appendix.

*Gently clarify that we are asking about blood relatives when we ask about genetic diseases. People want to acknowledge the suffering of other family members – adoptive parents, foster children or someone we call a sister who was not born to the same parents. This is important for understanding the person's journey with cancer.*

*It can be recorded in their social history as a formative life experience, especially if they have been (or are) a carer for that person.*

*Sickness in these relations impacts their lives but not their genetic screening or risks. Most people understand that.*

*Given the complexity of Aboriginal kinship, asking that can be part of the conversation. 'Is he your brother-brother?' 'Your sister or cousin-sister?' 'Is your Dad your birth Dad?' Learning about people's families is worth the time.*

– Janelle,  
Dhanggati GP

## ● Family history and genetics

Asking people about others in their family with cancer can give important information about their risk of cancer in the future or their need for extra tests or checks.

Asking about family history is a part of the Aboriginal and Torres Strait Islander Health Check. Recording it on the person's file is also required for practice accreditation for primary care.

If someone has a strong family history of some cancers, this may change how often they undergo screening or checks for that cancer. Some people might be eligible for genetic testing for cancer.

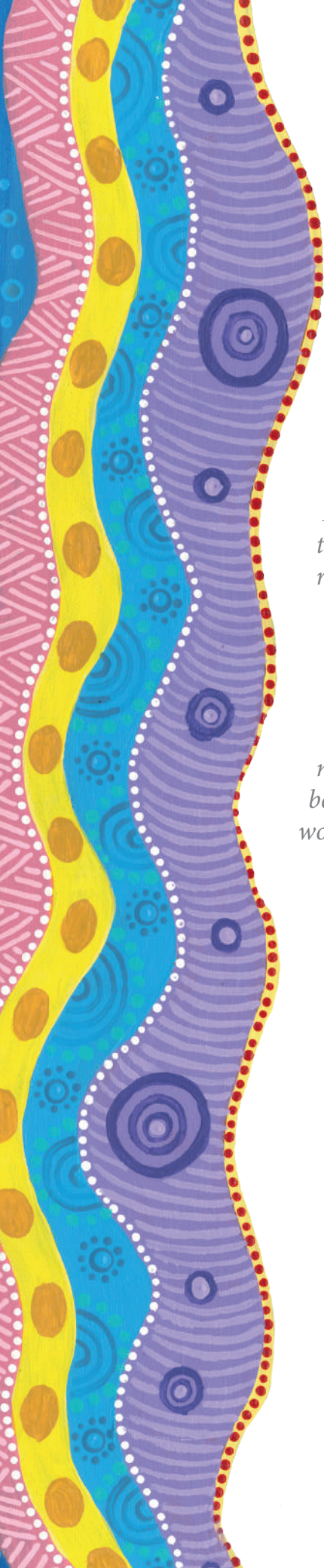
Understanding a person's experience with cancer in their family helps us connect with them. It makes us more compassionate and understanding, so that we can help people better.

Helpful questions to ask to understand genetic risks of cancer:

- Did any of your close relatives have bowel cancer before 55 years of age?
- Do you have more than one relative on the same side of the family who had bowel cancer? Please think about your birth parents, children, brothers, sisters, grandparents, aunts, uncles, blood cousins, nieces, nephews and grandchildren.
- Have any close male relatives had prostate cancer before 60 years of age?
- Have any of your close female relatives had ovarian cancer?
- Did any close relatives have breast cancer before 50 years of age? Do you have more than one relative on the same side of your family who has had breast cancer at any age? Please think about your parents, children, brothers, sisters, grandparents, aunts, uncles, nieces, nephews and grandchildren.
- Do you have any close relatives who had or have melanoma?

Only first-degree and second-degree relatives need be considered in a screening questionnaire. But in some cases, it is useful to ask about more distant family members. Drawing a family tree with genetics (genogram) can be useful.

**Continuous Quality Improvement** – Refer to online Appendix for family history QI.



“

*Bling a Bra! We do that once a year. We bring a heap of bras in. Mob paint them up and decorate them, and then we hang them up in the hospital. That raises awareness around women's breast cancer and helps the people affected by it know that they're not alone.*

*The management at the Breast Screen clinic allows us to put up paintings, so the space feels more culturally safe for clients. We take food and set up paints and craft things in the waiting room. It's something we have negotiated with them over the years. Their staff enjoy the day we come because the women are happy to be there. They know they're doing lifesaving work that day.*

– Trish, CCT

## CHAPTER 3

# BREAST CANCER



Breast cancer is the most common type of cancer found in Aboriginal and Torres Strait Islander women.

Your role is vital in helping Aboriginal and Torres Strait Islander people access culturally safe, affordable screening and treatment.

### ● Prevention

There are some risk factors for breast cancer that we might be able to change with support: being overweight or obese, and drinking alcohol.

Eating a healthy diet, exercising and keeping a healthy weight, limiting alcohol and breastfeeding all help prevent breast cancer.

### ● Screening

A screening mammogram is an X-ray used to find small changes in the breast which you might not find otherwise. It can find cancer when it is still small and easier to treat.

BreastScreen Australia does mammograms for women who don't have symptoms.

Women with no symptoms should be screened every two years between the ages of 50 and 74 years old but can commence screening from the age of 40 if they want.

Many AMSs have great programs to encourage and help women to have their regular breast screening:

- use the reminder system to make sure clients have their mammograms when they are due
- check if a client's mammogram is due by using the National Cancer Screening Register (NCSR) <https://www.ncsr.gov.au>
- focus on clients who have never had a mammogram, who are high at risk or who have not had them regularly
- make phone calls to offer support to go along with them to the appointment and provide transport if needed
- deal with the cultural needs of a client needing a mammogram

- book group appointments at Breastscreen to make it a fun day or organise for the mobile screening bus to visit. Set up cultural activities, including arts and crafts, in the waiting room of the Breast Screen clinic
- support women if they are nervous. Attend the appointment with them. Or show them the machine before their appointment and explain how it works
- support clients who are asked to attend a 'call-back'. This is common. Explain that it can be a false positive, but it is important to attend the follow-up appointment; and
- support clients if they need to go for a biopsy or ultrasound.

**Continuous Quality Improvement** – Refer to online Appendix for breast cancer prevention QI.

*When we are talking with the women about mammograms, we always talk about this is screening to look to make sure that you don't have cancer, not about looking for it but making sure you don't have it.*

*We reframe for the support and empowerment of mob. It's about making this a positive experience, giving some power and control back to sisters.*

– Kyla, CCT

### ● Could it be breast cancer?

Let Community know that if they have these symptoms (things they feel) or signs (physical changes), they need to book an appointment to see the GP. These warning signs could be things to talk about at a Woman's Health Day:

- a lump in the breast or armpit
- a change in the size or shape of the breast
- changes in the nipple, including a rash, scab, itchiness or discharge
- skin changes on the breast, a new dimple, area of redness or other discolouration; or
- pain that keeps coming back or other unusual pain in the breast or armpit.

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## ● Breast Screening Days

If you would like to have a Breast Cancer Screening Day at your clinic, see the 'Sample program request to hold a mammogram screening day' on page 98 for guidance and inspiration.

*In 2017, we discussed what works and what doesn't work for Aboriginal members engagement in screening. We found that group sessions would work far more effectively in engaging women. So, we tried it. We decided to give it a go with breast cancer awareness and all of those other triggers in the community.*

*We organised the Boobie Bus, a community transport bus we decorated for twenty-one women. They were really positive about the experience; they enjoyed it. We provided morning tea or afternoon tea and gift bags – little pamper packs and a t-shirt.*

*We did that for a couple of sessions and then followed up from there. Sometimes we didn't get any engagement at all. And then there were times when people would be involved.*

*We give them a call and ask them if they want to engage. It's really up to each woman.*

*A lot of women were afraid of the process itself. They had the idea their boobs would get crushed between metal plates, which was the old system. The new mammography machines are plastic. So, a lot of it was just about the fear of the process itself. Many women came out of the screening and said, "That wasn't as bad as I thought." Plenty of positive feedback.*

*We encourage people to take responsibility for themselves. Aboriginal people are over-pathologised – they go through an awful lot of intensive scrutiny. We don't want to be a part of the problem; we want to be a part of the solution, so we just offer the service.*

– Carisa, nurse

Yerin Eleanor Duncan Aboriginal Health Service

*Doing it as a group is important. You're not feeling so alone because everyone is feeling the same. I got along to one myself, and even I found it a bit daunting. But it was really nice – we were chatting on the way in on the bus, having a yarn. The ladies at BreastScreen Australia were absolutely lovely. They were accommodating. It was just a good experience. Word of mouth changes things when you get the mob together and they have a yarn.*

– Vicki, Wiradjuri,

Yerin Eleanor Duncan Aboriginal Health Service

## ● Diagnosis

Younger women at higher risk of breast cancer or women with an abnormal mammogram can see the GP. They will send a client for tests which may include an ultrasound, mammogram (at the radiologist and not at BreastScreen) or an MRI. They may also need a Fine Needle Biopsy or Core Biopsy at the radiologist or surgeon's rooms; both are day procedures. If you have questions about what happens to the client having these tests, go to page 37 for Support during investigations or ask your clinic nurse or doctor.

## ● Treatment

A client who might have breast cancer will need a multidisciplinary team (MDT) to help decide on the best treatment. The GP will make a referral. See page 63 for more information about MDTs.

The type of treatment a client will have depends on the type of breast cancer they are diagnosed with, the stage of the disease and the client's individual situation. Treatment of breast cancer can include surgery, chemotherapy, immunotherapy and radiotherapy. It is often a combination of these.

Sometimes the cancer is too far advanced for treatment. In this sad situation, palliative care will keep the woman as comfortable as possible as the disease brings her to the end of her life. See page 79 for more information about Palliative Care.

### Optimal care pathways for breast cancer

Optimal care pathways are produced by Cancer Australia and the Cancer Council and provide the most up-to-date recommendations on treatment for cancer care for people with cancer.

Go to <https://bit.ly/2SzR35L>

### RESOURCES

**Cancer Council NSW** – [www.cancercouncil.com.au/aboriginalcancer/](http://www.cancercouncil.com.au/aboriginalcancer/)



## EXERCISE GROUP

After the surgery for her breast cancer, Sam felt worn out. First, she had the drain out, then the check-up in the city, then chemo and radiation. She spent about three months away from home – staying at a hostel – in and out of the hospital.

She felt unfit, overweight and suddenly old, even though she was a young woman. Her wounds healed slowly, and she had all kinds of aches and pains.

She read on the internet that exercising, losing weight, and cutting down on grog could help prevent cancer from coming back. Why didn't the surgeon tell her that?

The oncologist talked about a private gym at the specialist rooms. She couldn't afford that. And she wanted to go home, anyway. At her local AMS, the nurse sat her down with a cup of tea and asked how it all went. She said that a healthy lifestyle was important for recovery – and just feeling better again. She invited Sam to join the '12-week Challenge' and booked her in for her health check. When Sam had her health check, she got a deadly shirt. An old school friend designed it!

The AMS women met every Friday for their 'challenge'. Young, fit, bubbly women ran it and kept the ladies on their toes. Sam never imagined herself doing push-ups, squats or running around the block. She got used to sweating and found she could do unexpected sporty things, which encouraged her to buy some exercise gear thinking, 'I deserve it.'

She had a fitting for a mastectomy bra at the bra shop – and also bought an exercise bra. The girls – including her new chicken fillet – felt right at home in that new bra.

Soon she was going for a long walk three times a week before work with one of the women from the group. She felt good when she woke up in the mornings – like her body was her own.

Sam found the healthy cooking sessions helpful, upped her fruit and veg. The kilos dropped off. When she was in the shower, she could feel her ribs and hip bones again – now she could pick up the soap, or the grandkids, without thinking about it.

Sam felt stronger and more powerful every day.

*My breast prosthesis, the 'chicken fillet,' was a source of hilarity in our family. It would flop out when I bent down to the bottom shelf in the supermarket, and the kids would wear it as an alternative to my various wigs at funny family dinners. Then there was the famous phone call to my husband to ask where he'd put my boob as I was rushing out to a meeting. He had me on speakerphone, so the whole office – of men – were killing themselves laughing!*

– Lucinda, Southern Highlands NSW





*The AMS Women's Health Day. It was hard to say no because it was a great set up. The Health Worker called to ask me and made sure we could get there. They put on a jumping castle and face-painting for the kids in the carpark. Nice lunch. You could choose where your nails get done or a little massage. They had girls, students from TAFE there, to do it. Kids were looked after. So, I got some of my Aboriginal Health Check done. I got my women's check done.*

*It isn't hard. I wasn't embarrassed, no. But then I've had kids. So I know where my cervix is. I like it in the clinic with only women there for Women's Business. Sister there was quick and gentle. Ready to explain anything.*

*I was worried when I got that result. Saying HPV was there. I knew that could cause cancer.*

*I needed another test in a year, they said. I was a bit frightened. The doctor was sensible about it.*

*We'd see in a year. See if that virus, HPV is a virus, went away.*

*The clinic sent me a text to remind me when it was time for the second test. A year goes quick. The second test showed that the virus that could have turned into cancer was gone. The abnormal cells were gone, too. I need to have another test in a year to make sure it's really gone for good.*

*I'm glad that's not a path I had to go down, that cancer. Too much to do in life.*

– Brooke, Warumungu and Torres Strait Islander  
from Darwin

## CHAPTER 4

# CERVICAL CANCER



More than twice as many Aboriginal and Torres Strait Islander women had cervical cancer than non-Indigenous Australian women in 2021.

*Kyla: We're making this an experience for women to ensure that they don't have cancer. We want a strong healthy mob that aren't afraid to get screening done so that they can be cleared from cancer.*

### ● Prevention

The good news is that we have vaccination against the strains of the virus (HPV) that cause almost all cervical cancers. So, the number of women getting cervical cancer and dying from it is likely to keep decreasing. It's important that Indigenous Aboriginal and Torres Strait Islander women don't get left behind.

Vaccination against HPV stops people from getting two of the most dangerous types of the virus. The national HPV vaccination program provides this for 12-13 year olds, and immunisation is recorded on the Australian Immunisation Register.

Stop smoking programs save lives: A woman with HPV 16 (one of the cancer-causing strains of HPV) who smokes is twice as likely to develop cervical cancer than a woman who has HPV 16 who doesn't smoke.

#### RESOURCES

**National HPV Program** – [www.hpvvaccine.org.au/](http://www.hpvvaccine.org.au/)  
**Cancer Council Victoria** – Help Keep Our Mob HPV free [www.cancervic.org.au/downloads/cpc/aboriginal-hpv-brochure.pdf](http://www.cancervic.org.au/downloads/cpc/aboriginal-hpv-brochure.pdf)

### ● Screening

The cervical screening test (CST) is the way of finding abnormal cells in a woman's cervix. The CST has replaced the Pap Test. Using a speculum ('duck's bill') to part the walls of the vagina and see the cervix, a small brush gathers cells of the cervix. The cells it catches

are put in a jar of fluid and sent to the lab. The CST is screening for HPV (the virus which causes almost all cervical cancer), not just abnormal cells.

By screening, we can test for abnormalities in the cells and treat them to prevent cervical cancer before it starts. It takes ten or fifteen years for abnormally growing cells to become cervical cancer. Women with no symptoms should be screened every five years between the ages of 25 and 74 years old.

Many AMSs have great programs to encourage and help women to have their regular cervical screening. Here are some things you can do:

- use the reminder system to make sure clients have their CST when they are due
- check if clients are due for their cervical screening at the National Cancer Screening Register [www.ncsr.gov.au](http://www.ncsr.gov.au)
- focus on clients who have never had a CST or who have not had them regularly. Never having been screened or not being screened regularly are significant risk factors for cervical cancer
- a client might need support (like holding her hand), depending on her personal history with genital exams.

Many women have no problem with the test. But a woman might need extra support if she has had an unpleasant experience, including being treated disrespectfully or roughly, in the past.

- survivors of sexual abuse particularly need encouragement, reassurance and support during an intimate exam. Talk to an experienced, trusted colleague if you are learning to support a woman who is a survivor of sexual abuse. Seek her permission to tell the doctor.
- support clients if they need to go for a colposcopy;
- for our mob, lack of access to screening is a big part of the picture. AHWs, midwives, nurses and doctors who have the proper training can do the Cervical Screening Test (CST), but it takes sensitivity and a learned set of skills. Becoming a CST provider is a valuable thing to do for Community.

## ● Self-collected tests

Self-collection of a cervical sample is available for women over 29, never screened or under-screened (at least four years since their last negative result). The woman needs information and support to take the test. The test is a little less specific than the CST a health provider takes, but there is plenty of evidence for its benefits in overcoming barriers to screening. The Australian Government has announced that self-collection will be an option for all participants under the National Cervical Screening Program (NCSP) from 1 July 2022.

### Resources

**RACGP Self-collection of HPV samples: a Guide for GPs** <https://bit.ly/3q6Aj2D>

### Continuous Quality Improvement

Refer to the online Appendix F page 105 for QI for cervical cancer prevention.

## ● Could it be Cervical Cancer?

The cervix is up inside a woman's vagina. Let Community know that if they have these symptoms or signs, they need to book an appointment to see the GP:

- vaginal bleeding between periods (or after menopause)
- menstrual bleeding that is longer and heavier than usual
- bleeding after intercourse or pain during intercourse
- unusual vaginal discharge
- excessive tiredness
- leg pain or swelling; or
- unexplained abdominal pain
- some of these symptoms can also be caused by ovarian cancer.

## ● Diagnosis

A low-grade abnormality means the woman needs a repeat test earlier than the standard five-yearly test.

If abnormal cells persist (or there's a higher-grade abnormality), she will need a colposcopy. Using a speculum, the doctor inserts a brightly lit microscope, called a colposcope, to see the cervix and any abnormal cells more clearly.

If necessary, the doctor will take a tissue sample (a biopsy) from the cervix. The size of the biopsy depends on the abnormality. Sometimes the biopsy takes the abnormal cells or cancer out all in one go, and that is all the treatment needed. Sometimes they use a laser to remove the abnormal cells.

## ● Treatment

The type of treatment a client will have depends on the stage of the disease and the client's individual situation.

Some early cancers can be treated by laser or by a biopsy (as described above). Sometimes a hysterectomy, taking the uterus out by surgery, might be necessary.

Advanced cancers require surgery, chemotherapy and radiotherapy and treatment may be discussed by a Multidisciplinary Team (MDT). See Chapter 15 about MDTs on page 63.

Sometimes the cancer is too far advanced for treatment. In this situation, palliative care will keep the woman as comfortable as possible as the disease brings her to the end of her life. See the Chapter 20 about Palliative Care on page 79 for more information.


**Optimal care pathways for cervical cancer**  
Cancer Australia and the Cancer Council produce optimal care pathways. They provide the most up-to-date recommendations on treatment for cancer care for people with cancer. Go to: [www.cancer.org.au/assets/pdf/cervical-cancer-optimal-cancer-care-pathway](http://www.cancer.org.au/assets/pdf/cervical-cancer-optimal-cancer-care-pathway)

### RESOURCES

**Cervical Cancer in Australia Statistics** - <https://bit.ly/35wGtiT>

**AIHW** - <https://bit.ly/3vvZkoZ>

**Cancer NSW HPV and Cervical Cancer** - <https://bit.ly/3wDP671>



*I worked in palliative care for a few years and unfortunately met several women dying of cervical cancer. None of them had ever had a Pap test or women's check.*

*One young Aboriginal woman, I remember her suffering.*

*The cancer had invaded her liver, and fluid accumulated on her belly. We call it ascites (pronounced a-sigh-tees). She was only in her thirties and had kids.*

*Her swollen belly got in the way of her moving. The cancer blocked circulation to her legs which were terribly swollen and sore. Even breathing was hard when she was carrying too much fluid.*

*One of my tasks was to put a giant needle in her belly to drain the fluid – it was the colour of straw. It took an hour or two to drain a litre or more of the fluid out. She did feel better then.*

*Her pain was hard to control. And the emotional*

*pain made the physical pain harder to bear. I don't know how she accepted it, dying of a disease like that and knowing it could have been prevented. By the time I saw her in pall care, she had already been through a lot, of course. She had no choice. She was calm and loving with her kids and patient with her poor body.*

*Once she was more comfortable, I talked to her daughters about screening to prevent cervical cancer, at their mum's request. Even though they were still young, their mother needed them to know that this wouldn't happen to them. I'm grateful that she felt her daughters were safe enough with the nurses and me to learn about it in a culturally safe way. Proper Women's Business, education that their mum, tragically, didn't get. Knowledge is power to live a long, healthy life.*

*– Janelle*



*My Dad had prostate cancer. He had problems early on, and the doctor was pleased he come in. Dad had an operation and was on medicine. And we forgot about it for a long time, oh, maybe seven or eight years.*

*Then he went to the clinic with pains in his hip and lower back. He'd been moaning about it for months. Till we all got annoyed with him carrying on and told him, 'Go to the doctor, would you?'*

*The doctor did a scan and found that the cancer had got into his bones, then. It was a blow. I always felt like he'd live forever, and he sorta downplayed the cancer. I don't know if anyone coulda done anything to stop that. He took his medicine and everything.*

*Never did go steady on the beer. Or the smokes. But you can't do it for a person, can you? 'Specially when it's your father. He'd just argue with me. They didn't have the kind of help they have for people now to give up, you know.*

*There was a meeting with the family – a few doctors and nurses. Dad was there. We was all there. One of the Health Workers from the AMS came, too. He was able to help us understand what was going on. They put him on palliative care. Anything else they did woulda hurt him for no point.*

*Dad lived longer than they all expected then. Good on him! The pall care drugs suited him. He still had pain. They say you can never get rid of it completely. You saw pain in his face sometimes when he got up or rolled over. He wasn't thrilled with taking pills three times a day. Didn't eat much. We was always tryin' to feed him. He got very thin.*

*He went to hospital cause none of us could keep him at home. We worried he'd be distressed or have a fall when we were at work. I think he felt safer with the nurses nearby to bring him medicine if he needed it, truth be told.*

*When he got a lot weaker and sicker, they put him on a syringe driver that puts the medicine in under the skin all day and night. He was pretty good on that. I mean, he could walk around a bit, still. Sit and have a bit of a chat if it was a nice day. He ate the bikkies and chocolates we brought. Had a tipples from the cart the ladies took around on Friday nights. Some of his mates took a couple of beers in, too. He just had a quiet one in the afternoons. He liked the view from the pall care ward. He was there for a month or two. I think he was their easiest patient.*

– Jim, Yorta Yorta

## CHAPTER 5

# PROSTATE CANCER



Aboriginal and Torres Strait Islander men have a lower incidence of prostate cancer than non-Aboriginal Australian men. But they die from it at a higher rate and have a lower survival rate after five years, particularly for men over 65, than non-Aboriginal men. This points to the need for culturally safe health services and education for our men to be seen, diagnosed and treated earlier to stay well.

### ● Prevention

There are no proven recommendations to prevent prostate cancer. But keeping a healthy weight and eating well is important. Smokers have a higher risk of prostate cancer and do not do as well after treatment.

### ● Screening

Population-based screening (that is, screening all the men of a certain age) is not recommended. Too many men have been subjected to unnecessary distress and treatment.

For men requesting information about prostate cancer screening, a GP can provide information on the risks and benefits of prostate-specific antigen (PSA)

testing to help them decide.

Men aged 50-69 can consider PSA testing every two years after giving informed consent. The doctor will do a digital rectal examination (using a gloved finger inserted into the rectum) combined with the PSA blood test.

Talk to men who might be at higher risk due to their family history of prostate cancer. Understanding the risks and benefits, they can consider PSA testing from age 40 or 45 years.

If men have family members with breast or ovarian cancer (particularly with BRCA1 or BRCA2 gene mutations), they may be at higher risk of prostate cancer.

### ● Could it be Prostate Cancer?

Prostate cancer is slow-growing cancer that usually affects older men. Let Community know that if they have these symptoms (things they feel) or signs (physical changes), they need to book an appointment to see the GP.

- blood in the urine
- slowed urine flow
- weight loss or bone pain





## ● Talking about Prostate Cancer

In 2012 a Yarning Circle at Mount Keira saw 95 men talk about prostate cancer. Here is what they said about spreading the word to men about prostate cancer:

- materials should provide facts and deal with culturally sensitive issues appropriately
- trusted people in the Community should give the information, including Community leaders
- culturally appropriate resources need straightforward explanations, no medical language, with pictures; and
- because of our strong oral tradition, spoken advice and storytelling is important.

## ● Diagnosis

Most men will receive their diagnosis using blood tests, including the PSA test and other blood tests (such as liver function tests and calcium tests) and scans (ultrasound, CT scan or MRI) of the prostate. Sometimes men need referral to a urologist for a biopsy: a piece of tissue taken from their prostate. This procedure is a day surgery that involves a small cut via the anus or the perineum (skin between the anus and the scrotum). Men usually need a few days to recover, and many have light rectal bleeding or blood in the urine or stool afterwards.

## ● Treatment

The GP will refer a client who might have prostate cancer to a multidisciplinary team (MDT p63) to help them decide on the best treatment.

The type of treatment a client will have depends on the stage of the disease and the client's individual situation. Treatment of prostate cancer can include 'watchful waiting,' hormonal treatment to slow cancer growth, surgery, radiotherapy (including brachytherapy) or chemotherapy. See Supporting people during investigations (p37) and Supporting people during treatment (p47) for more information about these. Prostate cancer treatment is often a combination of these.

Sometimes the cancer is too far advanced for treatment. In this situation, palliative care will keep the man as comfortable as possible as the disease brings him to the end of his life. See Chapter 20 about palliative care on page 79.

## Optimal care pathways for prostate cancer

Optimal care pathways are produced by Cancer Australia and the Cancer Council and provide the most up to date recommendations on treatment for cancer care for people with cancer. <https://bit.ly/35uxQFK>

## ● A Brother Shows the Way

*My older brother had prostate cancer. The doctor told him not to have surgery because he couldn't guarantee that he'd be able to hold his water afterwards. That was the kind of surgery they had then. It's better now.*

*Anyway, the urologist put him on tablets. And he did well on them. Took them every morning. After a few years, the GP said if his PSA was any better, he'd have to be a woman. Huh. He thought that was hilarious. It all went away, the cancer. Was never a problem to him. He passed from dementia in the end, poor old fella.*

*I have a check-up every year with the GP now – my Aboriginal Health Check.*

*I've talked to the doc about it. You've got to be careful what you look for. If you get a result that makes it look like you might have cancer when you don't. That's the risk. You'd have to trust yourself to stay calm and hope for the best.*

*Given my brother did so well, I reckon it's worth the unpleasantness but. For the peace of mind of knowing I haven't got prostate cancer and that I'd catch it early if I did.*

*I have an enlarged prostate. It's benign. Which is pretty ordinary in my age, I'm told.*

*I take medicine for that, and the AMS helps me keep an eye on it. I do a blood test and give them a wee in a jar. The doctor puts the finger in the back passage. Takes a bit of a self-muster to get myself to go for it all.*

*Then the nurse or health worker asks me the seven silly questions. The last one makes me laugh when they ask about how you'd feel about keeping on with your bladder and prostate as they are. It goes from 'delighted' to 'terrible.' I always say delighted.*

– Frank, Arrente

## RESOURCE

Find the Prostate Cancer Distress Score screening tool at [www.prostate.org.au/media/790557/pcf-a-distress-screening-tool-september-2019.pdf](http://www.prostate.org.au/media/790557/pcf-a-distress-screening-tool-september-2019.pdf)



*Kyla: I've looked after plenty of people with lung cancer in palliative care over the years. Lung cancers frustrate me. It's so preventable. This is me, an ex-smoker – because I can now see how pointless it all is.*

*Janelle: It's very addictive, though. You've got nicotine receptors all through your body. It's a stimulant drug. The tobacco companies worked out the packets so that they're basically a daily dosage of nicotine for most people.*

*We work hard in smoking prevention. Educating people, supporting them. Then when you're at the other end of life, looking after people with lung cancer, it is so sad, isn't it?*

*Kyla: Yeah, it's challenging. People need a lot of emotional support. Smokers tend to have a lot of regrets, because I think because it's one of the most preventable ones. They really suffer. That's the other thing. When they're dying, they can have so much grieving and loss.*

*Janelle: People dying from lung cancer need palliative care. They're frightened of suffocating and, of course, that makes them anxious. So, it's harder to breathe.*

*We have good medicines for them in pall care. We get oxygen for people and set them up with fans to help them to be able to breathe.*

*And I don't know, do you find some doctors blame them for their illness, like, aggravate that regret?*

*Kyla: Yeah, I think any non-smokers can be very judgmental. I don't think it's just doctors. They're in the firing line, seeing it up close. Unless you've been a smoker, most people are judgmental. You should be able to give it up, they think.*

*It's hard work, and anyone that gives it up, they're fantastic.*

*And it's not just giving up. Giving up is one bit but staying off it, that's hard. We've got tools to help you now, though.*

## CHAPTER 6

# LUNG CANCER



Lung cancer is the most common cause of cancer deaths for Aboriginal and Torres Strait Islander people – probably from exposure to tobacco smoke. Aboriginal and Torres Strait Islander people are more than twice (2.1 times) as likely as other Australians to be diagnosed and nearly twice (1.8 times) as likely to die from lung cancer.

### ● Prevention

Many Aboriginal medical services have tobacco programs in place to support people giving up smoking. Preventing and stopping tobacco smoking is part of our everyday work.

Aboriginal or Torres Strait Islander people qualify for up to two 12-week courses of nicotine patches per year via the Pharmaceutical Benefits Scheme (PBS).

Other medicines to help stop smoking, such as varenicline and bupropion are also available under the PBS.

People registered under the Indigenous Health Incentive scheme/Close the Gap (CTG) are eligible for discounted or free PBS-listed medications.

Exposure to other people's cigarette smoke, bushfire, campfire or other smoke, cannabis smoke or asbestos also increases lung cancer risk.

### RESOURCES

**Tackling Indigenous Smoking Resources Centre** – <http://tacklingsmoking.org.au/about-the-tackling-indigenous-smoking-resource-information-centre/>  
**Quitline** – Smokers can call the Quitline for advice about smoking and follow-up calls. And ask for the Aboriginal Quitline worker if they wish. Health professionals can also call the Quitline for health promotion material about ceasing smoking on 13QUIT (13 78 48).  
**Icanquit** – [www.icanquit.com.au](http://www.icanquit.com.au)

### ● Could it be Lung Cancer?

Let your Community know that if a person has these symptoms, they need to book an appointment to see the GP as soon as possible, even if they don't smoke:

- cough lasting longer than three weeks
- coughing up blood
- shortness of breath
- rapid weight loss without trying.

Non-smokers can also get lung cancer (about one in ten people diagnosed with lung cancer are non-smokers).

### ● Diagnosis

Diagnosis usually involves chest X-rays, and a CT. Some clients need referral to a respiratory physician for bronchoscopy, a day procedure putting a lighted tube into the lungs to look and take a biopsy.

### ● Treatment

The GP will refer a client who might have lung cancer to a multidisciplinary team (MDT) to help them decide on the best treatment. See chapter 15 about MDTs on page 63. The type of treatment a client will have depends on the type of lung cancer they are diagnosed with, the stage of the disease and the client's individual situation. Treatment of lung cancer can include surgery, chemotherapy, immunotherapy and radiotherapy. It is often a combination of these. Sometimes the cancer is too far advanced for treatment. In this situation, palliative care will keep the person as comfortable as possible as the disease brings him/her to the end of their life. See Chapter 20, page 79.

### RESOURCES

**Cancer Australia, Lung Cancer in Our Mob Handbook**  
<https://bit.ly/3pXiWB5>



Karen got a bowel cancer screening kit in the mail when she turned 50, then another one when she was 52. She looked a bit embarrassed when Janine, an Aboriginal Health Practitioner, asked her about it.

She sat with her head down for a minute before she spoke. *'I want to look after myself, you know? I want to live a long life,'* Karen said. *'But I'm not gonna touch anything in the toilet. I mean, who looks at their goona? I threw them kits out.'* She shrugged awkwardly.

Janine unwrapped the blood pressure cuff. *'Your BP's good. I can tell you're taking your medicine.'*

*'I do take it. Me and Sharni are eating better too,'* Karen said. *'Plenty of veggies at lunch and salads at dinner.'*

Janine smiled. *'That'll do you good. That's one of the best things you can do to stop yourself from getting cancer.'*

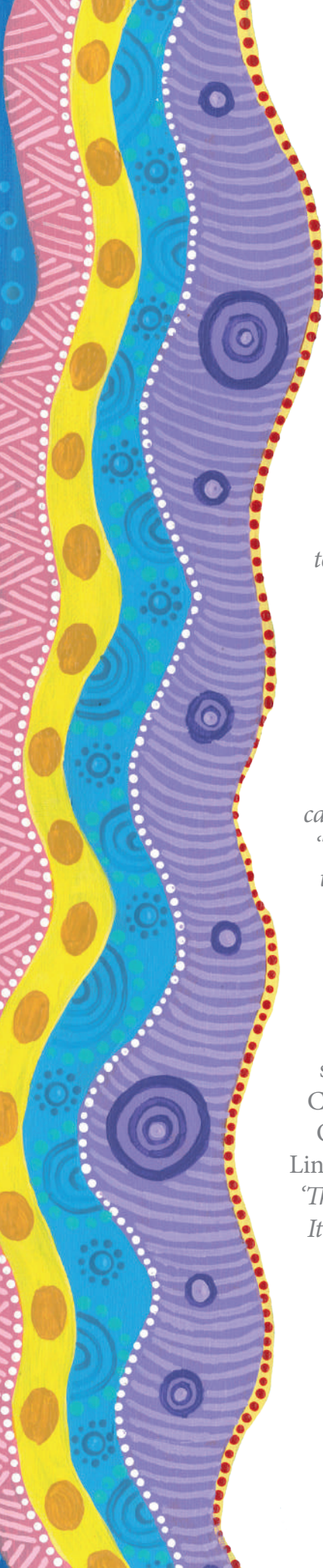
*'The bowel cancer screening's not hard, you know. You don't have to touch any goona. And it's good to know that you're in the clear. Or to know you can get it treated when it's still very small if there is a problem.'*

*'It's not looking for cancer. It's looking for small changes that might turn into cancer if you don't know about them and treat them.'*

*'I can show you what's in the kit and how to do it if you like,'* Janine said, looking through the cupboard and finding a sample Bowel Cancer Screening Kit.

Opening the cardboard box, she unfolded tissue paper with 'Toilet Liner. This side up' written on it. She pulled a little plastic stick out. *'This is what you use to take the sample. Let me show you how. It's easy. It's important.'*

Janine had seen a video online, training with other team members, so she knew how.



## CHAPTER 7

# BOWEL CANCER



Bowel cancer (also called colorectal cancer) is Australia's second-biggest cancer killer. And it's the third most common cancer in Aboriginal and Torres Strait Islander people (after lung and breast cancers).

### ● Prevention

When you lose weight you reduce your risk of bowel cancer. Eating fruit and veggies, not smoking and staying physically active all reduce risk, too. The Cancer Council also recommends limiting red and processed meats.

Physically inactive people, those who have too much alcohol and/or poor diet, people with inflammatory bowel disease, Crohn's disease or polyps in the bowel are at higher risk of bowel cancer. A review by a gastroenterologist will help people manage their risk. They may need regular (e.g. 5-yearly) colonoscopy: a light on a tube into the bowel to examine it, done under sedation (see Diagnosis below for details).

### ● Screening

A bowel cancer screening test can detect bowel cancer early. If found early, more than 90% of bowel cancers can be treated and cured. The government sends out test kits to screen people aged 50 - 74 every two years.

Aboriginal Medical Services can help by teaching people how to use the kits, understanding that the test is clean and easy.

#### **Continuous Quality Improvement**

Refer to online Appendix for QI for bowel cancer prevention.

### ● Could it be Bowel Cancer?

Let Community know that if they have these symptoms (things they feel) or signs (physical changes), they need to book an appointment to see the GP.

- blood in the stool (poo or goona)
- losing a lot of weight, getting thin for no reason
- toileting changes – unusually loose or constipated, incomplete emptying (not all coming out)
- feeling tired all the time
- pain, bloating, or cramps in the belly
- a lump in the anus or rectum

### ● Diagnosis

The test used to look for bowel cancer is a colonoscopy – an examination of the entire length of the inside of the bowel. This procedure is done under a mild anaesthetic to make the client sleepy (sedated). It's a day surgery done by the gastroenterologist or colorectal surgeon.

A few days before the tests, the client needs to go on a special diet low in fibre or only having clear fluids (like tea without milk, water, black coffee, soup water).

According to the surgeon's directions, they should stop taking aspirin or other blood thinners to lessen the chance of bleeding during the procedure.

The night before a colonoscopy, the client needs to drink jugs of 'bowel prep'. This medicine cleans the bowel out so that the doctor can see the bowel clearly. It's essential to take the bowel prep (and stay near the toilet through the evening). Otherwise, the procedure will be cancelled if the bowel isn't clean the next morning.

Some people don't like taking the bowel prep, but everyone understands that the doctor needs a clear view.

At the hospital, once sedated, a flexible tube is inserted into the client's anus to pump air into the colon. A lighted camera on the end of the tube allows the doctor to look for any abnormal tissue or small polyps. The doctor will remove the abnormal tissue for further examination. Colonoscopy usually doesn't hurt and any bleeding is minor.

Other tests used to look for bowel cancer include a CT scan or MRI.

## ● Treatment

The type of treatment a client will have depends on the stage of the disease and the client's individual situation. Most bowel cancer is treated with surgery.

Radiotherapy may be used before surgery to shrink a tumour. Sometimes chemotherapy is used to prevent cancer from coming back. This is called 'adjuvant therapy,' which means additional therapy. Treatment of more advanced disease might include a referral to a multidisciplinary team (MDT) to help decide on the best treatment which may include chemotherapy, immunotherapy, radiotherapy or a combination of these. Treatment for metastatic cancer might also include more surgery to remove secondary cancers – small cancers that have grown in areas away from the bowel's first (primary) cancer. For more information see Chapter 15 about MDTs on page 63, and Chapter 12 about Surgery on page 51.

Sometimes the cancer is too far advanced for treatment. In this situation, palliative care will keep the person as comfortable as possible as the disease brings her to the end of his/ her life. See Chapter 20 about palliative care on page 79.

### Optimal care pathways

Cancer Australia and the Cancer Council produce optimal care pathways. They provide the most up-to-date recommendations on treatment for cancer care for people with bowel cancer.

Go to [www.cancer.org.au/assets/pdf/colorectal-cancer-optimal-cancer-care-pathway](http://www.cancer.org.au/assets/pdf/colorectal-cancer-optimal-cancer-care-pathway)

### RESOURCES

**Information for Aboriginal and Torres Strait Islander people about the bowel screening test**, includes video on how to do the test - [www.cancer.org.au/bowelscreening/first-nations-communities](http://www.cancer.org.au/bowelscreening/first-nations-communities)

**Bowel screening and Aboriginal people** - information for GPs - [www.health.gov.au/sites/default/files/documents/2019/10/bowel-screening-and-aboriginal-and-torres-strait-islander-people-information-for-gps.pdf](http://www.health.gov.au/sites/default/files/documents/2019/10/bowel-screening-and-aboriginal-and-torres-strait-islander-people-information-for-gps.pdf)

**Colonoscopy: what you need to know** - information for Aboriginal and Torres Strait Islander people - [www.safetyandquality.gov.au/sites/default/files/2021-03/colonoscopy-aboriginal\\_torres\\_strait\\_islander-fact-sheet-feb-2021.pdf](http://www.safetyandquality.gov.au/sites/default/files/2021-03/colonoscopy-aboriginal_torres_strait_islander-fact-sheet-feb-2021.pdf)

## ● Koori Men's health day

Trish: *I'd see Uncle in the clinic and ask him, 'Can we come out and do some education?' And he's going, 'Yeah, yeah, I know you mean well, but women are not allowed there. Men's group. Men's day.' Eventually, the men decided that we could come, with special conditions.*

Kyla: *This was a rare invitation as females are not permitted at men's group. We put together a Men's health day. We took a male nurse and male doctor with us.*

*It's important to remember that people fear cancer – it's not a conversation everyone wants to have.*

*The Cancer Care Team did a demonstration of how to use the bowel screening kit, using fake poo. We made a demo kit, including brown play-doh. It got a laugh or two, especially when we ate some. Some people can never be put off their food.*

*Anyway, during the demonstration, there was lots of feedback and comments. Men said, 'I've had one of those kits in my drawer for ages,' and 'Yeah, me too. Didn't really know what to do with it.'*

*I find with a lot of mob, the screening kit itself is too complicated with everything written in it. Mob just won't do it. They just throw it in the drawer.*

*We showed how easy it is to do the poo test. We agreed that the instructions were confusing and hard to read. We encouraged the uncles to get their kits out and have a go.*

Trish: *Joking around and yarning with them and mucking around with the play-doh poo. 'Does yours look like this?' Stuff like that. You wanna talk to them about what normal poo looks like. We wrote down simple instructions to take home.*

Kyla: *We were able to come back later and stay for a while and join them for lunch. For one-on-one chats and a chance to answer some questions that were not asked in the public arena.*

Trish: *They had lots of questions. But you know, I'd said before we started, I am not doing Men's Business. So, a male doctor and an Aboriginal male health worker came out as well.*

*When they started talking about the men's business stuff, we left for a few hours till they'd finished doing that stuff. Because I won't cross those boundaries.*

*Some of the men did go home and do the test. And three of them were positive, with blood in their goona. Detected early, thank God.*

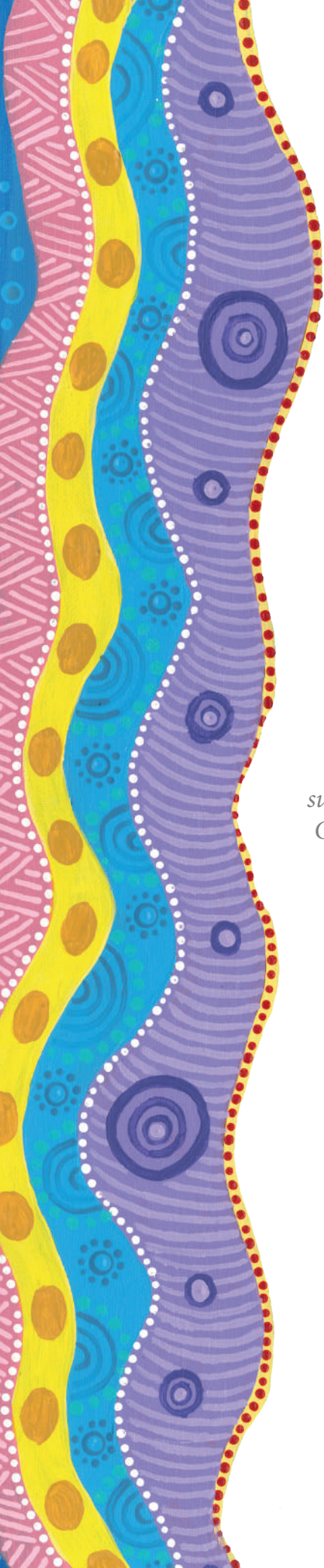
*So, you know, one of the uncles, every time he sees me now, he goes, 'You saved my life.'*

*It's always good to get out there with the uncles and the men in community, have a yarn. And you never know, you could save a life.*



Doing us proud.  
Illawarra Koori Men's  
Support Group in  
their healing and  
empowering work.

Photos courtesy Illawarra  
Koori Men's Support Group.



“

*My Mum was a redhead, and I've worked outside all my life, so the doctors say I've got high-risk skin. I'm very fair. Always had freckles.*

*I've had that many little things on my skin that could have come serious. Burnt 'em off, cut 'em out. Used cream on them little, scaly ones that woulda turned into something nasty if they were left. I had them all on my hands, on the top of me head.*

*Us fair ones wish we were darker sometimes! We'd be better off in the sun. Never mind.*

*Gotta look after your skin and accept it whatever colour it is.*

*I look out for anything strange on it. My wife does, too. And get it treated if need be.*

*Well, it's worth it if it saves your life, isn't it?*

–Al, Wiradjuri



## CHAPTER 8

# SKIN CANCER



### ● Prevention

Help Community stop skin cancers starting by being Sun-Smart. Everyone, especially children, needs protection when ultraviolet (UV) levels are greater than or equal to 3, which is a low-moderate level. The most extreme level of UV is 11. People need to protect themselves by avoiding the sun, wearing a hat, covering up and using sunscreen. Read about the UV index here: <https://bit.ly/3xoufox>

### ● Screening

Screening of people who have a low risk of skin cancer is not recommended but talk to them about looking for the early signs of skin cancer, particularly people over 40 years old.

People at an increased risk of melanoma include those who have:

- family history of melanoma in a first-degree relative (a birth parent or sibling)
- fair complexion, a tendency to burn rather than tan, freckles, lots of moles (>100), light eye colour, light or red hair colour or sun-damaged skin;
- a history of skin cancer, including melanoma; or
- more than five atypical (unusual) moles.

These people need preventive advice. Examine their skin (with or without photography) and advise them how to check their own skin every six months. Ask the GP to check people's skin as part of their health check or whenever they are concerned about a skin lesion or spot.

### ● Could it be Skin Cancer?

Let Community know that if they have any of these symptoms (things they feel) or signs (physical changes), they need to see the GP and help them book an appointment:

- skin spot that has increased in size
- a skin spot that has changed in colour (particularly if dark) or has bled
- a new mole
- a mole that gets bigger or changes or develops a lump
- a spot changes colour from brown to black or is more than one colour
- the surface of a mole becoming rough or ulcerated or bleeds; or
- any spot that looks different from their other spots

See the Cancer Council website for pictures of skin cancers: <https://bit.ly/35dTT3g>

*We've got a couple of visiting skin physicians here who look at the skin and treat skin cancers. Unless the patient identifies something for themselves, we do skin checks when we're doing our Aboriginal health assessments. We ask them if they've noticed any lumps, bumps, rashes or anything that they're not sure about, and they might identify it.*

– Carisa, nurse



## ● Diagnosis

Often a GP will refer people to a dermatologist or a GP who specialises in the skin for a spot they're unsure about. Rarely, people may require blood tests or imaging (X-rays, CT scans, bone scans or PET scans) if there is concern that cancer has spread.

## ● Treatment

Some GPs can treat minor skin cancers with a biopsy, excision or creams. Treatment can include referral to a dermatologist, plastic surgeon or surgeon for excision, or wide excision for melanoma. Rarely, skin cancers such as melanoma might require surgery for biopsy or removal of lymph nodes, chemotherapy, immunotherapy or radiotherapy and involvement of a Multidisciplinary Team. See Chapter 12 about Surgery on page 51, and chapter 15 about MDT meetings on page 63.

### Optimal care pathways

Cancer Australia and the Cancer Council produce optimal care pathways. They provide the most up-to-date recommendations on treatment for cancer care for people with skin cancer such as melanoma. Go to <https://bit.ly/3wrqa2I>

## ● Planning a skin check day

*No matter what you do, you will never please everybody but remember the objective of getting as many mob in as you can for their skin check.*

*Think about your mob. What brings them in? Is it a good feed? Is it a gift or gift card? Is it a shirt?*

*Think about the structure of the day. Do you want to have a group set up? If so, plan a group activity while everyone is waiting their turn. You may want to set up a large canvas for everyone to add some art. Or some simple weaving craft of their own.*

*A good feed is always part of a successful day. Make it simple, healthy and fun.*

*Funding is always a challenge. Can your AMS support you in any way?*

*Try the Cancer Council in your state. Are there any healthy activities grants available? Even local businesses might want to help.*

*It can take a bit to start. And you always learn a lot from the first time you hold a health check day.*

*But get mob in, and you can start to get the message across that screening is checking to make sure that you are cancer-free, not looking for cancer.*

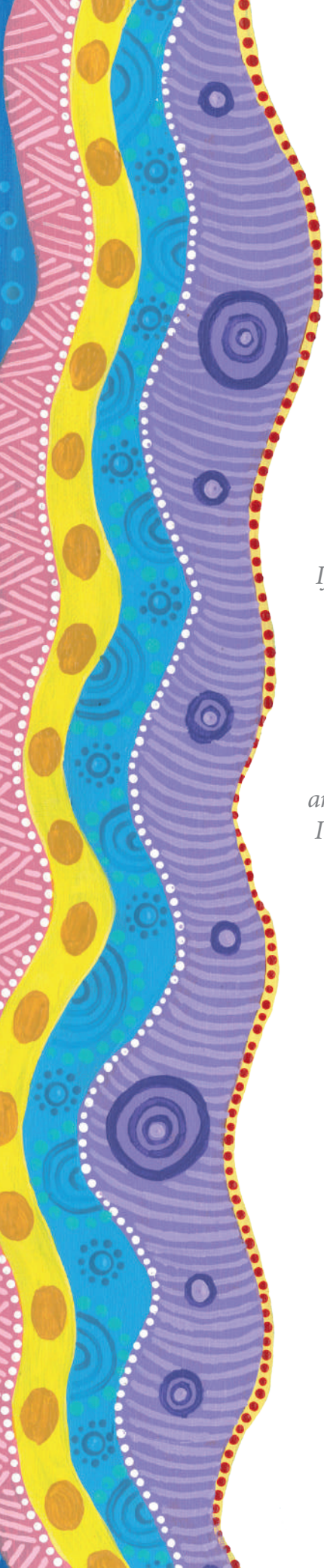
– Kyla, CCT

## End of Section Wisdom Box

Remember People Fear Cancer.

- It's essential to explain to clients that screening is checking to make sure you don't have cancer, not looking for it.
- A cancer prevention conversation is not one everybody wants to have. Explain why catching early signs of cancer leads to better outcomes. Encourage them to do the test before there are any symptoms.
- Privacy is important.
- Have a gender-specific (and age-specific) screening day. Make it fun.
- Spend some time talking about what the results could be, but don't get bogged down – just mention it before the results come back. Make this about the screening for reassurance, knowing you're in the clear.
- Have some simple written culturally appropriate information for them to take home.
- Be available for a follow-up chat or to answer questions and provide reassurance.





“

*If you ask me about my cancer diagnosis, I can describe everything that was in the cancer surgeon's office that day. I remember the layout of her office, where we all sat – my mother and husband came with me – the half-closed blind, the photo of her kids on her desk.*

*I listened, but I couldn't take in a word because my brain was so busy trying to process the fact I had cancer. Neither could my husband.*

*Only my mother could tell you my diagnosis and the surgery, chemo and radiation treatment plan.*

*I'm so grateful she was there with me that day.*

– Lucinda,  
Southern Highlands, NSW

## CHAPTER 9

# SUPPORTING PEOPLE DURING INVESTIGATIONS



### ● Could this be Cancer?

Let the Community, including people at our services, know about the warning signs of cancer. These signs are important in people with existing cancer or at high risk of cancer, like people with a strong family history of bowel or breast cancer.

*Symptoms* are things that the person feels or notices, such as shortness of breath.

*Signs* are physical things that are seen, heard or felt, such as fast breathing, or sounds in the lungs.

### ● What we can do as health professionals

- listen carefully if people are worried
- have a yarn about what they are noticing
- get them in quickly to see a doctor
- support them to have tests done; and
- follow up to make sure they had their tests done.

Let people know the importance of watching out for signs and symptoms of cancer, for example, during their health checks. Some of these are:

- weight loss (especially over 5kg, without trying)
- poor appetite
- fever
- extreme tiredness
- pain in bones
- a cough or blood in the sputum
- blood in the bowel motion (poo or goona)

- bowel changes, such as more constipation or constipation alternating with diarrhoea or pain in the abdomen
- hoarseness
- jaundice – skin or whites of the eyes turning yellow
- enlarged lymph nodes (lumps) in the neck or armpits
- blood in the urine
- irregular vaginal bleeding
- a sore that won't heal, or changes in moles or warts
- a lump in the breast, changes in the nipple or breast pain
- indigestion or difficulty in swallowing.

Any of these signs or symptoms need investigating. The prevention chapters in this book cover common cancers, but there are many different types of cancers, including rare cancers.

### ● Investigations for Cancer

- may include pathology (blood tests, urine tests), radiology (Xrays, ultrasounds and CT scans) or nuclear medical tests (thyroid scan or bone scan)
- explain to your client what the test involves, especially whether it hurts, and how long it takes. This can reduce fear
- assist the person in making an appointment and helping arrange transport; and
- remember, shock can mean the person listens but doesn't 'hear' what is said to them – most people benefit from a worker or family member escort attending the test with them.

## ● Supporting people during investigations

- take time to find out and explain the tests required, what they are for and why they are essential
- help people with tests that they might need (ECG, chest X-ray, blood tests)
- book appointments for investigations such as CT scans, MRIs or ultrasounds
- organise transport to the tests; and
- accompany people who need it, particularly those who are frail, have an intellectual disability or are anxious, to their MRI or CT scan.

## ● Escorts: 'Can my wife come with me?'

Some people need to travel between remote, rural, or regional centres and urban centres for tests or treatment for cancer. They may qualify for financial assistance to be accompanied by an escort.

The patient escort:

- is usually a close family member who is a real support to the person having the investigations
- can assist by interpreting or explaining to the person being cared for
- plays a vital role in reducing anxiety and helping the person feel safe.

## ● Interpreters and translation services

If a person's first language is not English, use an interpreter service, especially at critical times such as:

- giving a diagnosis
- explaining the pros and cons of serious treatment and obtaining consent for this treatment
- end of life and Advance Care planning conversations.

Interpreting services include: on-site (e.g. hospital services), phone, video, scripting and recordings.

Interpreters should ideally be accredited under NAATI (National Accreditation Authority for Translators and Interpreters Ltd).

### Interpreting Services

- NT Aboriginal Interpreter Services AIS 1800 334 944 or <https://bit.ly/35jmSCS>
- Aboriginal Interpreting WA <http://aiwaac.org.au/> booking forms at <https://bit.ly/3gvpoem>
- National Interpreting and Communicating Services provide Auslan interpreters for the deaf (free services for Aboriginal clients) 1800 24 69 45 or <https://bit.ly/3zoUHJK>
- Ask local Aboriginal Liaison Officers (ALOs) or AHWs about local speakers, being aware of possible conflicts through family relationships. A professional interpreter is always preferred but not always available.

*As CCT workers, it is essential to pay attention not only to what is being said but often to what is not being said.*

*Look at your client. Take some time. Slow things down.*

*Usually, when there is a cancer diagnosis, everything seems to be rushed and sped up, but it can be important to take a bit of time to check in with your client.*

*Are they understanding what is going on when they are nodding their head that they get it?*

*It can be that walk outside away from the office where you will get the best insight into where your client is at.*

*Check in, answer their questions, take your time and be honest. Listen and answer their questions.*

*Most importantly remember that this is their cancer journey.*

– Kyla, CCT

## ● Reviewing results in primary care

Pathology results, imaging reports, investigation reports and clinical correspondence that our health services receive must be:

- reviewed by a GP electronically and, if on paper, signed or initialled
- acted on where required; and
- incorporated into the patient health record.

Advise clients of the clinic's process for follow-up of tests and results, talking to them in person, or they can find out via the practice website or a pamphlet.

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## ● Recalls

A recall usually means the GP is calling someone back to the clinic to tell them the results of a test or investigation. The doctor may also talk about the possible need for treatment or further investigations.

Clinics must have a system to recall people with significant tests and results. If a test result is clinically significant, the GP has a legal (and moral) duty to take steps to follow up the person, to let them know their results and what they should do.

It is the doctor's responsibility to communicate the test results to the patient via:

- phone calls (at different times of the day)
- SMS messages to call the practice
- letters; and finally
- a Registered Mail recall letter to their home or visit them.

Document every attempt made to contact the client in the electronic medical record.

## ● After hours results

Sometimes urgent results for people with cancer arrive after hours. When seriously abnormal and life-threatening (high risk) results come outside regular opening hours, your service needs to have a policy or procedure for handling this, including contacting the person.

## ● Steps to improve recall systems in your service

- developing a recalls policy and procedure
- having a team member who is responsible for the recall process
- educating all team members, including drivers and reception, so they can tell people about how they will receive results
- ensuring all team members document all conversations about test results in the person's notes
- many electronic medical record programs have a recall/ reminder box, and some have a 'pop-up' for preventive investigations due when the person attends the service.

## ● Reminders

Reminders can be for a test (such as cervical screening) or procedure (such as HPV immunisation) and may support national programs, such as recalls for cervical screening, breast cancer and bowel cancer screening through the National Cancer Screening Register

(NCSR) (<https://www.ncsr.gov.au/>). ACCHO staff can access information from the NCSR if they want to find out who is due for screening.

There is no legal requirement for health services to send reminders to patients about routine preventive care. But a reminder system is 'best-practice' and is especially helpful for people who have many competing pressures in their lives. One reminder is usually enough, even if some practices send more than one.

## ● Breaking bad news

Sometimes test results show new cancer or that cancer has returned. Arrange a time to let the person know about these results.

Other times this news is given by a specialist in their rooms or at the hospital. Often people are aware that it might be bad news and are very anxious. It is often devastating for the person with cancer. Be there with them.

When telling a person that the treating team need to see them:

- it is better to do this in person, in a private room
- ask them to bring a family member or support person
- be honest when giving bad news
- give people time to process the information before making significant treatment decisions
- help them (including the support person) to ask questions; and
- keep in mind that often people need a few days to process the news and then want to come back and talk more. They may not remember information given in the first consultation. Many people report hearing nothing after the delivery of bad news.



## ● Preparation questions

It can be useful to prepare questions to ask the treating team before attending important appointments. The person might do this themselves, or family members or staff at an ACCHO can help them work out questions. HealthDirect Question Builder allows people to prepare for medical appointments by creating a list of questions to ask the doctor. The list can be printed or emailed. Find this tool at <https://bit.ly/3pMWaM0>.

## ● Helping people find information about their cancer

Most people with cancer will be searching the internet for information. It can be confronting, especially if they have cancer with a poor outcome. But it can be reassuring for others. Elders or people with low literacy may struggle with finding or understanding information on the internet.

As health professionals, we can:

- direct people with cancer to websites with high-quality information that matches their needs
- sit down and have a yarn about the information;
- print out fact sheets or give the person pamphlets to take home to read.

### Consumer Information about Cancer: Websites

**Cancer Council** – [www.cancer.org.au](http://www.cancer.org.au)

**Cancer Council Resources** include Cancer Information for Aboriginal and Torres Strait Islander People – <https://bit.ly/35kMbnQ>

**For Health Professionals** looking for information for Aboriginal and Torres Strait Islander people affected by cancer – <https://bit.ly/3gl8WYj>

**Cancer Australia** – [www.canceraustralia.gov.au](http://www.canceraustralia.gov.au)  
**Health professional guidelines for treatment** – <https://bit.ly/3pPzHhy>

## ● Supporting clients through a painful or scary procedure

**Janelle:** *During investigations, like a biopsy, people are vulnerable.*

**Trish:** *That's right. Because most of them haven't had a biopsy done before, they're very scared.*

*I've gone in with clients where they've had biopsies in their necks and breasts and wherever. And I've actually been in that room with them, which has been a challenge sometimes.*

*Staff have been like, 'You can go out now,' and I go, 'No, I'm not. You know, I'm here as their support person, and I'm not leaving. They need me in this room.'*

*Once a medical person said, 'No, you actually can't be in this room,' and I said, 'Culturally, I can be in this room, and I'm going to be in this room. I am not leaving my client by themselves.' The Aunty was terrified, asking me to stay. That was a private service. The hospital has always been good because they know us there.*

*The other mob learnt pretty quickly, you know. If I'm walking in there with a client, I'm not walking out and just leaving them there if they're anxious about having their biopsies done by themselves. So they're all really good now...*

**Janelle:** *If people are going to be cut, or they're going to have a big needle put in, they're frightened. Especially if they think it could be cancer.*

**Trish:** *Hell yeah, terrified. And I'll do meditation with my clients that have biopsies. I'll talk them through a meditation while they're having it done.*

**Janelle:** *So you help their spirit go somewhere else.*

**Trish:** *Yep, I take them wherever they want to go. I always ask them, where's your favourite place? They'll tell me. Then I'll use that within the meditation to guide them slowly to that place and get them to look around while their eyes are shut and tell me what's there, you know. So, it just takes that whole experience away from what they're having done.*

**Janelle:** *That's going to reduce their fear and pain. And if they have a wound, it's going to help them heal quicker too.*

**Trish:** *Yeah, that's right. I've had some clients go, 'I saw so-and-so the other day when we went to have that test.' Like someone they love came to them in the meditation. They're going, 'I didn't feel anything.' It works. It's good.*





Photo by Jan-Niklas Kö / Pixabay

*My uncle was a vibrant man. Funny, charming, good-looking and a bit wicked. Not much older than me, he was that cheeky youth who stole one thong from the beach and laughed at the person looking for it. Then went back for the pair. Thought that was so clever. We did too, when we were kids.*

*Teachers never had time for him in school. He struggled. He was brown, so he faced that skin colour prejudice, too.*

*But after lots of ups and downs, he found work looking after the local sports ground. Later in life he started to feel pride and a sense of achievement. The fields and the pitch always looked beautiful. He kept them so green even in drought. He was proud to see people playing there, winning, losing, enjoying themselves.*

*By then, he'd been addicted to tobacco since he was a child of around eight years old. So, it wasn't too much of a surprise, but still horrible, when he was diagnosed with terminal lung cancer. For years he'd been getting thinner and weaker, with a bad cough. I guess he knew. He was always fit before, got on well with his body except for the smoking.*

*My aunty and cousins tried to persuade him to see the doctor. He'd had bad experiences with doctors before, see, that he never recovered from. The trauma from that racism, including the institutional racism we didn't have a name for then, kept him away, shortened his life.*

– Janelle,  
Dhanggati GP



*We have the patients referred to us from their different GPs, externally or internally. We are part of the cancer journey.*

*What we do is provide clinical support, which means that if they have to go and see a specialist, then we've got an ITC [Integrated Team Care] worker involved in going to their appointments.*

*We provide transport where necessary. We provide a clinical care supporter. We support them with specialist payments if they require specialist payments. We'll organise their shuttle for them to get to their radiation or chemotherapy appointments.*

*We pay for nutritional supplements to support them if they're not entitled to an aged care package. We provide lymphoedema machines. We provide compression bandages if they are required. If they need to go and have further testing done, then we provide financial support for that and transport.*

– Carisa, nurse,  
Yerin Eleanor Duncan Aboriginal Health Services ITC Program  
(Darkinjung land)

# FINANCIAL SUPPORT FOR PEOPLE WITH CANCER



Most people with cancer experience financial pressures:

- they need to give up work
- their partner needs to give up work to support them
- costs for specialist appointments/transport/accommodation and parking; or
- cost of medications and medical aids

*Be honest and explain that this could be a long journey, and now is not the time to be proud. Now is the time to access the support that is available to them to make the journey a bit easier.*

– Kyla, CCT

## ● Integrated Team Care program

Integrated Team Care programs provide support to Aboriginal and Torres Strait Islander people, whether they are seen at ACCHOs or in other primary care services. ITC funding can be used to assist people with cancer to attend specialist appointments, including specialist fees, transport and coordination of care.

The aims of the ITC program are:

- to contribute to improving health outcomes for Aboriginal and Torres Strait Islander people with chronic health conditions (such as cancer) through access to care coordination, multidisciplinary care, and support for self-management; and
- to improve access to culturally appropriate mainstream primary care services for Aboriginal and Torres Strait Islander people.

ITC workers may be based in ACCHOs or other organisations, and often play a significant role in assisting people with cancer to attend appointments to see doctors, for tests and treatment.

## ● Informed financial consent

Many people with cancer need to consider options for their treatment and will have to weigh the cost of tests, specialist appointments, surgery or other therapies – against waiting times and the benefit of these treatments.

The cost of some treatments in the private system can be much higher than in the public system and can lead to serious financial consequences for some people. ACCHO staff may be able to offer support to people when they are making these decisions, for example trying to identify costs of treatment or obtaining quotes for treatment.

Informed consent means that a patient is aware of all the risks and benefits of a treatment, as well as any alternatives. With this information, they can agree to go ahead. As a health worker you can make sure:

- each person is informed about the treatment options and associated costs of all of the reasonable alternatives by their clinician
- clients know that treatment can be done in the public system (at no cost to the patient) or in the private system (may be a shorter wait, but higher cost)
- that people know to ask for information about the cost of their treatment in writing, and to not be embarrassed to speak to a doctor about costs; and

- that people who have Private Health Insurance might be required to pay substantial 'gaps' on the cost of their treatment, particularly in private hospitals. There may be extra 'hidden' costs such as the cost of anaesthetics, of equipment used in hospital and for dressings.

#### RESOURCES:

**Cancer Council Practical and Financial Help** – [www.cancercouncil.com.au/cancer-information/when-you-are-first-diagnosed/emotions-and-cancer/getting-support/practical-and-financial-help/](http://www.cancercouncil.com.au/cancer-information/when-you-are-first-diagnosed/emotions-and-cancer/getting-support/practical-and-financial-help/)

### ● Transport costs

Many people with cancer need to travel to regional centres or large cities. Treatment for their cancer may not be available in their hometown.

State and Territory government schemes can support people for transport and accommodation if they need to travel a long way for cancer treatment. Most are subsidy schemes – the person with cancer must pay part of the payment.

These programs may also cover (or subsidise) the cost of accommodation.

#### RESOURCES

Eligibility varies from state to state. You can find details here:

**NSW Isolated Patients Travel and Accommodation Assistance Scheme (IPTAAS)** – <https://bit.ly/3vHzIvJ>

**Queensland Health Patient Travel Subsidy Scheme (PTSS)** – <https://bit.ly/3cE6y3E>

**South Australia Patient Transport Assistance (PATS)** – [www.pats.sa.gov.au/](http://www.pats.sa.gov.au/)

**Western Australia Patient Assisted Travel Scheme (PATS)** – <https://bit.ly/3pDhiWe>

**Northern Territory: Patient Assistance Travel Scheme (PATS)** – <https://bit.ly/3veCnWX>

**Tasmania: Patient Travel Assistance Scheme (PTAS)** – <https://bit.ly/2SwJ2OZ>

**Guide to all schemes nationally** – <https://bit.ly/3wufbW4>

*Benefits available were fought for by our parents, uncles, aunts and other Ancestors of all of us. We stand on their shoulders. Our parents and grandparents made sacrifices to claim and create support for us. We should use that in time of need. Sometimes I remind my clients of that, if they need encouragement to understand that they're entitled.*

– Janelle,  
Dhanggati GP

### ● Supporting people with cancer and financial issues

- sit down and have a yarn with the person and their family about their financial situation
- assist with accessing Centrelink payment by assisting the person to complete application forms for Sickness Benefits or Disability Support Pension
- assist family members or carers to complete application forms for Carer Payment or Support
- call or do electronic referral to MyAgedCare to access personal care, cleaning, shopping, workers to take to appointments
- call the National Disability Insurance Scheme, obtain an application for NDIS and help complete the NDIS application form (or refer them to someone who can)
- refer to a social worker
- assist with completing Housing forms, or supporting the person to meet with the Housing Department
- assist with organising care for their pets (for example temporary care with family or at a pet shelter).

#### RESOURCES

**Cancer Council financial assistance service** – 13 11 20

**MyAgedCare** – [www.myagedcare.gov.au](http://www.myagedcare.gov.au)

**NDIS** – [www.ndis.gov.au](http://www.ndis.gov.au)

**Go fund me** – Ideally, most costs should be covered by the health system, but many people are disadvantaged because they have to stop work. Some people may choose to use fund-raising websites to cover other costs during their treatment. [www.gofundme.com](http://www.gofundme.com)



*A client with leukaemia came into the clinic. Some of us know her.*

*She was not talking. Wouldn't tell the new doctor her name. Just sat there. Tears streaming down her face. Took an hour before she talked.*

*Turned out the main thing was that she was hungry. We gave her golden syrup and butter on toast and a cup of tea. We don't keep much food in the clinic. Just a loaf in the freezer in the tearoom. She ate about half the loaf of bread. She was just so hungry.*

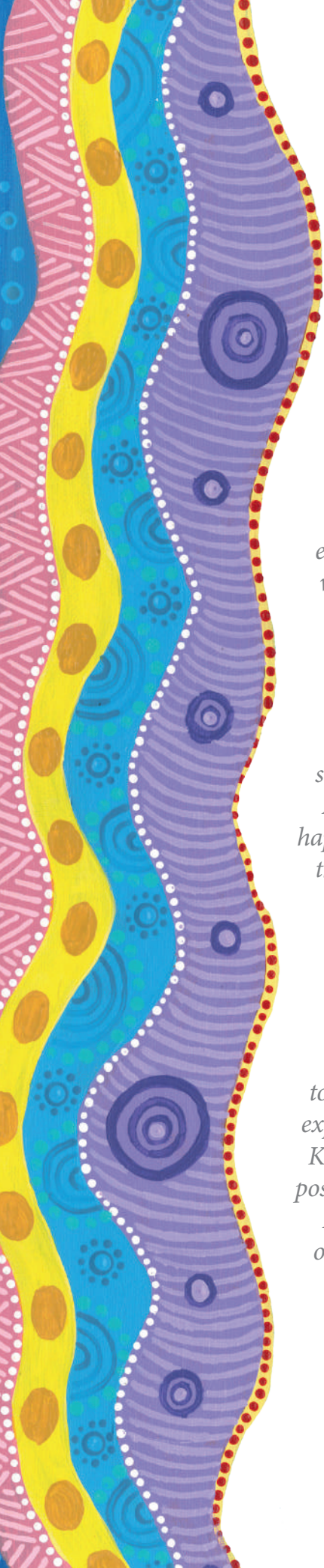
*She's very small for an adult. She's not got an eating disorder. Just maybe the last to get fed in a big household stricken by poverty.*

*That kind of poverty is going to make people sicker, faster.*

*We can't change the widespread poverty. Not today, anyway. We should keep working on that.*

*But for this young woman we were able to help. We connected her up with the Home and Community Care service so that she got a meal delivered each day. And eventually had a locked cupboard at the clinic for her. So that if other people took her food, she could get some cereal and milk, or protein shakes, from the cupboard. It really is that hard sometimes.*

*– Janelle,  
Dhangati GP*



*Remember that this is that person's own journey. It may be their first step into the cancer world, or they may have lost family members to cancer.*

*First, listen to your client and talk to them to learn where they are and what they understand. Also their wishes for the journey ahead. It's important not to put our preferences on them but to support them and ensure they fully understand, to make informed decisions. Ngununggula: walking and working together.*

*Attending medical appointments that discuss treatment is a good opportunity for support workers to hear the treatment plan and understand how best to support the client.*

*CCT spent time at the Cancer clinic at Wollongong Hospital without clients to create a strong working relationship with the staff and better support our clients.*

*Always check in with your client. Be sure they understand what is happening and why. Take the time to support the family but be sure that this is with the blessing of your client. It is not for the worker to 'tell-all' if the client wishes their information to stay private.*

*Ask questions of the doctor if you know your client is not up for it. But don't assume that you know everything yourself because you have done it before. Be sensitive.*

*It can be good for the client to hear from the doctor even if they are not able to ask themselves. Always remember this experience; coming to see an oncologist and talking about cancer treatments is a first-time experience for the client.*

*Keep checking in to see how your client is. Sometimes they are strong and positive. Other times they flounder.*

*During treatment, ensure that clients feel culturally safe. This depends on knowing what the client needs for this. For example, they may want extra support people around them. They may want to be near a window to see outside. These things can be negotiated with the hospital staff. We have found that our clients can usually be supported by talking with the staff and explaining their needs.*

– Kyla, CCT

# SUPPORTING PEOPLE DURING TREATMENT



## ● Supporting your client during treatment

- Illness and treatment are unique to each person. Patient-centred care is vital to keeping people culturally safe
- avoid imposing your ideas. Listen actively, reflecting your understanding back to the person when needed. This can help them clarify their thoughts and prioritise their values
- time spent with staff at the cancer care ward, in chemotherapy outpatients and imaging, is valuable.
- be an advocate for the client
- do they understand what's going on that day? Do they know the purpose of the appointment or the treatment? If you don't know what's going on, find out. Your client does not have the same medical knowledge or experiences that you do
- in a meeting with the doctor, consider asking a question on behalf of your client if you think it will help them understand
- give them time and space to understand and process information
- you have a vital role in liaising with the sick person's family. But don't share anything without the person's permission. Confidentiality is an essential aspect of their trust in you
- continue your life-long learning about Aboriginal cultures by listening and responding to your client's cultural needs.

*Avoid asking people for instant agreement with something they may not yet have time or adequate knowledge to understand. Health workers tend to bustle people along by speaking quickly and adding 'Okay?' to the end of a sentence. It is a part of hospital and clinic culture. Don't do this.*

– Janelle,  
Dhanggati GP

## ● Support in hospital

Some Aboriginal people need support in hospital. It can be provided by:

- Aboriginal Liaison Officers/ Aboriginal Health Practitioner/ Aboriginal Health Workers
- Aboriginal Palliative Care Workers
- other Aboriginal staff including nurses, doctors
- social workers
- Aboriginal orderlies, reception staff and catering staff also play a role in making people feel welcome;
- other ACCHO staff including ITC workers may be able to visit or support the client.

Many hospitals have an Aboriginal family room for mob to meet in and make a cuppa. Many hospitals have art by local artists in their Cancer Care Unit to make people feel more welcome. Some provide health promotion material or information packs about services for Aboriginal clients.





## ● Supporting the whole person

The small office of the Cancer Care Team is a cultural resource, decorated with Aboriginal art, including work by Trish and the CCT's clients.

Trish's phone interrupts her. Her energy reaches out of the room to the man at the end of the line. Trish's mind and voice are clear: like the glassy, sea-grass water where fish are born, near the lake edge. 'Go to Centrelink. Go to Housing. Sort all that stuff out,' she says.

She takes a breath. Pays close attention. Out the window, trees toss in the wind. The little room fills with what it's like to have no money and maybe nowhere safe to live. The long queues and bureaucratic processes at government offices. The pressure of dealing with all that when you have cancer.

Trish has her head down, looking in her book. She sighs. *'It's not urgent that you go to this appointment. The doctor was going to check in on you, that's all. You've been for your tests. He's not gonna do anything today. Well, I'll call to let them know if you like. Yeah.'*

She writes a note to herself. Still concentrating, she raises her eyebrows. *'I'll be in and out of the office today if you wanna come in and have a yarn. Get that stuff off your chest.'*

The man living with cancer at the end of the line lets it all out. She waits. Heeds him, then says, *'Y'know what? At least you acknowledge you're not*

*copied. That's good.'*

The conversation deepens. *'Can you give up your house?'* She has to ask. It's a hell of a question; his house has become unbearable.

*'That's right,'* Trish says. *'They're adults, and if they're not taking responsibility...'* She frowns a little, shakes her head gently as she listens. Her bottom lip is firmly set.

*'Well then, you ring the police. You need to get access to your stuff.'*

Trish takes a deep breath, relaxes her shoulders which had been creeping up towards her ears. *'Sometimes you gotta be cruel to be kind.'*

He's hurting, this man with cancer. He's in a tight spot.

*'You really need to come and see me. You can't go down that road,'* Trish says firmly. *'That's not our cultural way.'* She pauses. *'I want you to think about that.'*

She listens to him pull himself back from the brink. Her healer's intuition kicks in: *'Before you head back, you need to go to the water. You go and stick your feet in that water.'* A spiritual prescription.

*'You're not interrupting me. You can give me a ring anytime. Please go to the water now. I'll see you this arvo then.'* She takes a sip of her cold coffee.

Murmurs, *'I'll need to be here for him this afternoon.'*

She writes it in her diary.

## Supportive Care Needs Assessment Tool for Indigenous People (SCNAT-IP)

The SCNAT-IP is a tool for health workers to discover unmet needs of Aboriginal people with cancer, developed by Menzies School of Health Research. It takes about 15 minutes to ask the client the 27 questions. [www.scnatip.org/](http://www.scnatip.org/)

It consists of questions about:

- physical and psychological needs - keeping you strong in your spirit
- hospital care needs - being treated like a person, not just another case or number
- information and communication needs - being shown or given information; and
- practical and cultural needs - money worries.



*The doctor might say, 'I'm not getting anywhere with this. Louise, will you go and see the family and patient and talk to them? What's the best way?' Or, 'How are we going to do this?'*

*It's the same when they come into the hospital. Like when I worked as the Liaison Officer. I would go and be with the patient, talk to them, and find out what's going on, what their needs are.*

*And then I'd report it back to the nurses and doctors. So, all the nurses and doctors would come and do what they need to do and leave the communication up to me.*

– Louise, Gamilaroi Palliative Care Worker,  
Western NSW LHD

*We go to appointments with our clients. It's getting them to establish relationships with the doctor or the specialist or whoever it may be.*

*It's not a matter of sitting there and doing the talking for them. It's supporting them to establish that trust so that they're comfortable.*

*Because there's that much distrust with providers, that's part of our job; to stop that and say, 'They are here to help you, they actually are, they do want to help, that's their job, and they may not be culturally appropriate, but that's got to do with their education as well. Most of the time, it's not done on purpose. Most people don't want to be like that. They're just not educated.'*

*We help our clients navigate that when they're vulnerable.*

– Vicki, Wiradjuri,  
Yerin Eleanor Duncan Aboriginal Health Service  
(Darkinjung land)

## CHAPTER 12

# SURGERY



### ● Supporting clients during consultation with a surgeon

Encourage culturally appropriate discussion by sensitively educating the surgeon or other doctor such as the surgeon's intern or registrar (doctors in training) on how to interact. Aim for shared decision making.

The goal of the surgery may be:

- to find out about the cancer (investigative)
- it might cure the person by taking the cancer out (curative)
- or it might be to make the person more comfortable without curing the cancer (palliative)

Help the client understand issues by asking questions such as:

- What will happen if I do nothing?
- What is the chance I will feel better/not be in pain/be cured after surgery?
- What could go wrong?
- How long will I be in hospital?
- What is the chance that I will have complications, long term issues, or problems afterwards?
- How would those be managed?

Once a person has seen their surgeon, they might need help getting ready for surgery.

There are different types of surgeons: a colorectal surgeon treats bowel cancer, a urologist treats prostate cancer, a general surgeon treats breast cancer, and a cardiothoracic surgeon treats lung cancer.

Some surgeries diagnose or investigate the cancer (such as biopsies), and some remove the tumour for different reasons, as described above.

### ● Preparing for surgery

- ask the client how they're feeling about the surgery. Are they anxious or relieved? Be sure they understand the purpose of the surgery. Is it to investigate? To cure? Or to help them feel better as part of a palliative approach?
- help people fill in their hospital admission papers
- assist them in organising their appointment with the anaesthetist or any tests that they need (ECG, chest X-ray, blood tests)
- prepare them for going to the hospital; help arrange care for other family members, such as respite for elders, or aunties to look after children or pets
- will you be acting as a liaison for the family? Perhaps

- 
- introduce them to the hospital ALO, so they have a contact
- organise transport to the hospital (often very early in the morning)
  - check when they need to stop medications before surgery. People need to stop blood thinners such as aspirin for up to ten days before surgery for some operations. Find out for each person. Check what medications they should take on the morning of their surgery or procedure
  - find out when they should commence fasting, often at midnight before the day of the procedure. They might be Nil By Mouth (NBM – which means no food and no water). Or sometimes they can drink water, black tea or clear juice up to 2 hours pre-op
  - arrange accommodation and travel for carers from rural areas
  - be available for support but don't take over. Let mob guide you through their journey. Help them feel safe to ask you about what they need.

## ● After surgery

- check on them by phone or with a face-to-face visit
- review the discharge summary and nursing summary to see if any treatments are required, such as dressings, suture removal or drain reviews
- you might need to call the hospital to request the discharge summary urgently if the person has been discharged from hospital but does not have one with them. Your client's GP or the hospital GP Liaison Officer can help
- book an appointment for the person with the GP soon after discharge from the hospital
- arrange transport to go home - often people cannot drive for 4-8 weeks after operations. Check with the surgeon when they can drive (sometimes it is in the discharge summary).

## ● Follow up in your clinic

- ask how they're feeling. People will usually tell you about any problem in the first few minutes if you give them time
- review the discharge summary. Take time to explain this to the person to be sure they understand what went on during their admission
- check that their carer also understands what happened in hospital

- ask about symptoms or common problems after surgery, such as stinging wee or going to the toilet frequently (urinary tract infection), constipation, cough or fever (infection or pneumonia)
- check wounds and change dressings that need it (or ask a nurse to help)
- see when sutures or staples should be removed (this should be in the discharge summary)
- inspect and empty drains if you are trained to do so
- talk to the community nurses if they are helping the person
- organise a review by the GP to ensure that the person has enough medication, including pain medications or their usual chronic disease medications for diabetes, hypertension and so on
- do they need to have any follow-up tests such as chest Xray?
- Look for when they have a follow-up appointment with the specialist
- arrange to see them again soon, for reassurance.

## ● Surgery consults for telehealth

Telehealth can work for follow-up after surgery. If a person lives in a rural area or is frail and elderly, it saves unnecessary travel.

People may be eligible for a telehealth consultation with the specialist if they go to an Aboriginal Medical Service, are in Residential Aged Care or are from a rural area.

The person still needs a referral from their GP to the specialist.

If the specialist accepts telehealth referrals, you can book an appointment as usual. It may be via video link, and the admin person from the specialist's office will talk to you about which video system they use. Somebody at your clinic needs to check that your system works with the specialist's videoconferencing system. Skype is good if you don't do a lot of telehealth. It can be good as a backup, too, if other systems fail.

An AHW or nurse should sit with the person while they are in their appointment. Most doctors on telehealth want a set of obs (blood pressure, temperature, oxygen saturation, respiratory rate, heart rate) at the time of the consult.

The specialist sends a letter back to the GP by mail or by encrypted (private) email.



*I'd been home for a few days when the wound opened. One afternoon it just came on.*

*I was bleeding, and I couldn't walk. Could hardly talk on the phone to my wife to ask her to come home. Partly from pain but mainly because I was that frightened.*

*There was an infection. Pus inside. The antibiotics I was on weren't working. I had to go back in for them to wash the wound out and stitch it again.*

*Yeah, it was rough. I was in hospital nearly two weeks.*

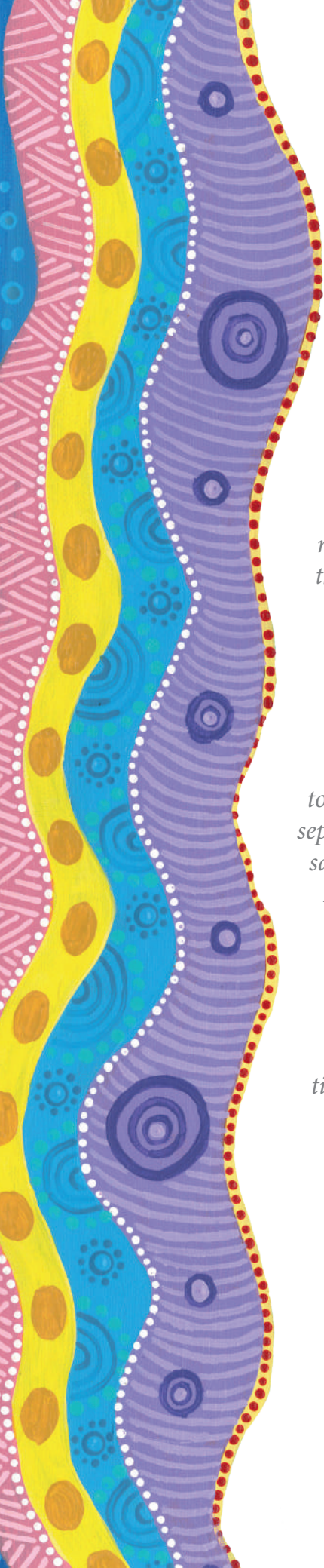
*I probably did too much when I got home, I suppose. I was sweeping and picking up and hanging out clothes. All about learning. I'm only human. Learned to pace meself the hard way, fair to say.*

– Michael, Kamileroi

## Surgery Wisdom Box

- Make sure the client understands the surgery.
- Help the client with their admission.
- Be available for questions from family and mob.
- Get a copy of the discharge summary after they leave the hospital.
- Check on them as they are recovering.





*Two chemo drugs in a drip. It only took a couple of hours, once I was there.*

*Yeah, it was every three weeks for four cycles. I had nausea a few times at home when I ran out of tablets. Long hours. Miserable. I didn't run out of them again! Nausea is so bad. I'd almost rather have pain than nausea. It was that bad.*

*I felt like my skin smelled funny. Nobody else noticed. Food tasted different. My mouth got sore. I lived on Weetbix and mashed potatoes for a week.*

*The girls [in the CCT] told me to rinse my mouth out with a pinch of bicarb in a cup of warm water after I ate. Better then.*

*One night, I was unwell. With a fever. And my partner brought me to the Emergency Department. They took me straight in. Kept me in a separate room so other people couldn't make me sick. The nurse was kind, said I was special. How brave and so forth. How much she liked my scarf. It is a good colour on me. But I was afraid.*

*They called my oncologist, even though it was after 9 pm. It had to be Saturday night. Anyway, he said straight into hospital. Start me on antibiotics. Felt like a lot of faffing around to get them started. It's hard to know how long things take when you're in a fever, though, isn't it?*

*I came good. Home again in a few days. Felt a bit sorry for myself at times, true. But the treatment worked.*

– Leigh, Yorta Yorta

# CHEMOTHERAPY



## ● What is chemotherapy?

Chemotherapy (chemo) is medicine that destroys cancer cells. It can be one or several medications at the same time. Chemo can be in several forms:

- tablets
- medication through a drip or catheter inserted into the person's chest (a 'port')
- in a cream or through patches on the skin
- other methods, such as medicine placed directly around the tumour.

Most often, it is delivered via a drip during a day stay at the hospital. It's given regularly, for example, once a week for a set time, in cycles. Sometimes it can be administered at home. And occasionally, people need to be admitted to hospital for chemo.

Chemo may be used before or after surgery and it can also be used with or without radiotherapy.

## ● Why is chemo used?

The person, and their carers, need to know why they are having chemotherapy. It could be for one or more of these reasons:

- to cure cancer
- stop the spread or reduce the chances of a tumour spreading
- shrink cancer to help cure it or reduce symptoms before other treatment, like surgery
- reduce the symptoms from cancer, such as pain (which can be palliative chemo).

## ● Preparing for chemo

Help people organise appointments, see the oncologist or go for treatment. Help organise payment if needed.

You can help arrange transport, access parking vouchers if necessary and available. Offer to accompany them to the first specialist appointment and the first treatment session. Be a second set of ears, especially (but not only) if the person has no appropriate family

member or friend as a support person, has an intellectual disability or a mental illness. Some people will require more support through their treatment course.

Assist the person in making a list of questions to help make decisions about their care.

You might provide information about chemotherapy before going to their treatment to help them plan and make decisions. People are less stressed and feel more in control when they are well-informed about chemo choices and treatments.

People with cancer and their families may need help to prepare for going to the hospital regularly if necessary, or if they need to travel to a city for treatment. They often need help arranging accommodation.

Finally, you might be the one to put in place a care plan for other family members, like respite for elders, or finding aunties to look after children, or family or animal shelter to look after pets.

## ● During chemo

- encourage the person to carry a folder of information about their treatment
- check that they know the common side effects of their chemo
- encourage the person to ask questions of the doctor or oncology nurses involved in giving the treatment
- hospitals may have specialist nurses such as Clinical Nurse Consultants, breast care nurses or nurses who support people with blood cancers - look for them
- at times chemo causes a drop in white cells in the blood so a person cannot fight off infection. They must go to the ED or their doctor if they get a fever
- some chemo can result in a drop in the platelets that make the blood clot. If the person has any unusual bleeding, they need to let the doctor know
- ask about common chemo side effects like nausea, lack of appetite or diarrhoea. Be vigilant for fever. Check their obs when you see them and organise a review by a GP if needed.

- enquire whether a portacath – often called a ‘port’ – will be used to access the veins in their chest, avoiding the need to be cannulated every week. It is a surgical procedure inserted under anaesthetic
- a nurse may need to change a dressing over the port regularly and might also ‘change the lock,’ which means cleaning the device in a very clean (sterile) way in the hospital or clinic. Only trained clinicians should access ports, using special needles
- if the person doesn’t have a port and has intravenous (IV) chemo, encourage them to look after their veins. Drink lots of water and keep warm before going in for chemo, so it is easier to insert a cannula into their vein
- check whether they need to have any follow-up tests such as blood tests (a full blood count is common) before their next treatment session
- if they have a follow-up appointment with the specialist, help them find out the cost and organise transport and accommodation if needed.

## ● Adverse effects of chemo

Some people tolerate chemo very well – it doesn’t bother them much at all. But it’s very individual. Different people respond to different chemos in different ways.

Sometimes if the medication is not well-tolerated (it makes the person feel sick), the oncologist can suggest other medicines to make them feel better (such as anti-nausea agents or steroids for poor appetite).

*They put my port in when I was under, in surgery. It was just another thing I had in lots of sudden changes in my body. All a bit weird and uncomfortable for the first week or two. I was the bionic man.*

*The grandkids were freaked out by the idea of the port. Of course, I kept it covered up. They forgot about it, and so did I. To tell the truth, I was happy to get my medicine in easily and get on with treatment.*

*Having chemo was no big deal at the time. They hooked me up to a bag, just like a drip. My wife came and sat with me, and we talked and talked.*

*Sometimes she did crosswords, and I just rested.*

*The nurses are very good. Sometimes they’d get you something to eat and that. I was laid out flat for days after chemo, though. Fagged out.*

*Sounds funny, but I sort of missed the port after I had it out. It was part of my toolkit for getting better.*

– Neil, Barkinji


## ● What is immunotherapy?

Immunotherapy is a cancer treatment that helps the person’s immune system to fight cancer:

- it can work by boosting the immune system or removing barriers to the immune system fighting back against the cancer
- this treatment is used mainly for bladder and renal cancer, melanoma, leukaemia and lymphoma
- the most common form is intravenous fluid but can also be as a cream; and
- side effects can include tiredness, rashes, diarrhoea, abdominal pain or joint pain

| Side Effect                        | Management   |
|------------------------------------|--|
| Nausea and vomiting                | Anti-nausea meds: ondansetron (tablet or wafer), metoclopramide (tablet or injection), intravenous fluid if dehydrated           |
| Diarrhoea or constipation          | Anti-diarrhoeal meds, laxatives or enemas, healthy diet, fluids  |
| Hair loss, nail changes            | Cold cap or scalp-cooling system while having chemotherapy might prevent hair loss. It needs to begin before the first treatment |
| Increased risk of infection        | Healthy diet. No contact with people with infection (even a cold). Measure temp. Go to hospital if fever is 38 or over           |
| Tiredness, muscle weakness         | Healthy diet, rest, drinking water. Exercise can really help   |
| Anaemia                            | Healthy diet, iron supplements, iron or blood transfusion  |
| Mouth ulcers, sore tongue          | Plain food, soft food or liquids, using a straw, local anaesthetic gel for the mouth, bicarb mouthwash                           |
| Poor appetite                      | Healthy diet, soft food, diet supplements like ‘Sustagen,’ steroid tablets   |
| Hearing problems, balance problems | Hearing tests, hearing aids, medications for vertigo   |





Sarsaparilla *Smilax glycyphylla*  
cleanses organs and blood.  
Normally only leaves are used.  
Not to be taken with blood  
thinners or while on treatment.

## Talking chemo & bush medicine

**Trish:** *I'll always suggest to mob: if you're going to have Bush Medicine, have it before treatment. Otherwise, our Bush Medicine wipes out that treatment and the doctor ups the medicine, thinking it's not working.*

**Janelle:** *Ah yes! So, their white cells come up because they've had the Bush Medicine, then the docs think the chemo hasn't worked well enough, and they give them a bigger dose of it. That'd be bad.*

**Trish:** *And then once your treatment's finished, you can take it.*

Sometimes clients will decide, after talking to their doctors and family, that they do not want to go ahead with treatment.

### RESOURCES:

**Cancer Council Chemotherapy**

– <https://bit.ly/3vi1DeY>

**Cancer Council chemotherapy fact sheet**

– <https://bit.ly/3xlqTCJ>

### ● Terry's dad said no

*The doctor sent Dad down to the city. My niece went with him. They did an MRI and saw that poor old Dad had metastatic cancer of the pancreas. Must've had it for years. From the days they used to pay him in tobacco, from a boy, I suppose. You know, they used to use it to keep the kids workin'.*

*It was far gone, that horrible thing. Dad said it didn't hurt. Only it was starting to get in the way of him swallowing. And breathing. He couldn't keep his food down. And he was short wind sometimes.*

*The docs had a meeting to talk about Dad. They talked about the different kinds of chemo they used but the chances of them working were, like, almost none.*

*Chemo would have made him sicker. Dad didn't*

*want anything that would make him even weaker.*

*In the end, he had a couple of doses of radiotherapy to try to stop the tumours growing so fast. Then he come back home. No surgery, no chemo.*

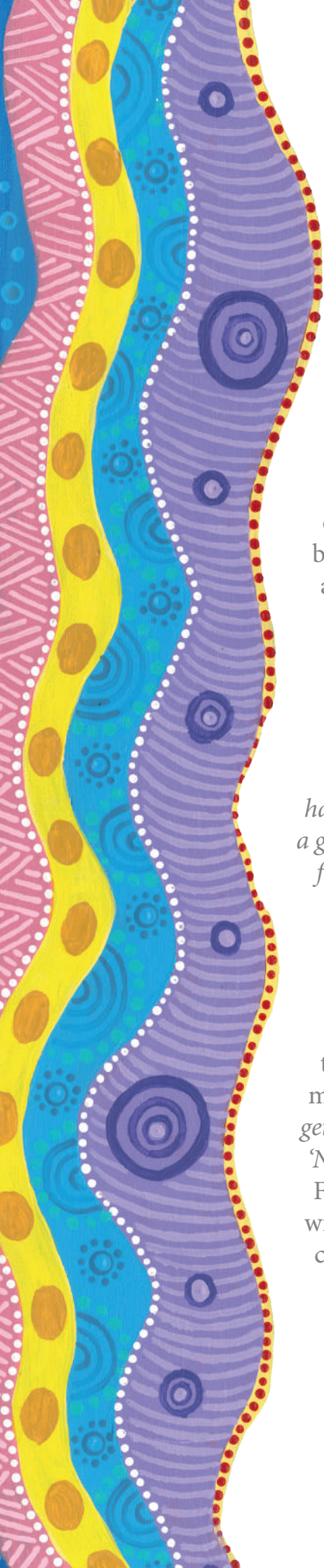
*We have a big family. We had a couple of meetings with the doctors to talk about it. It was about Dad being able to all right in himself for as long as possible.*

*They put him on tablets to help him breathe and pep him up, so he'd eat a bit. Told some stories I'll always treasure.*

*Saying no to chemo and a feeding tube was important. Helping him keep his dignity, you know? Enjoy the time he had left.*

*Making decisions together gave us a little bit of control when the whole world was upside down.*

– Terry, Noongar



I was out with Trish at work one day when she went to pick up a woman for her radiotherapy appointment. We waited in the car outside a small, thin-walled house. There was a toy car, a plastic ball and a broken swing in the long grass. Kids voices bounced around the street.

Trish said hello, and a spiky-haired child ran inside to find Grandma.

Our client came out of the house eventually, hauling herself with effort to the car. Her head was smooth under her colourful scarf, the muscles of her brown arms and legs soft and wasted under old cotton and denim. She'd been sleeping.

*'I've had a rubbish day,' she said. 'I had a call to go and pick up a food hamper [from the local charity]. I walked down there in the heat – it's a good twenty-minute walk. And the woman there said, "No. Food is finished." She didn't say sorry or anything. It was like she was angry with me. I told them they'd called me, you know? She said, "We've got nothing for you." So, I come up the hill again, tired, hot, starvin' hungry. I just went to bed.'*

Trish drove to a local shop. *'You'd be having treatment with nothing to eat. We'd better get you some feed, sis.'* Twenty dollars from the team's petty cash paid for milk, potatoes, a loaf of bread and eggs. A meal or two for the family. Remembering later, I asked Trish, *'She didn't get to her treatment that day, did she?'*

*'No, she didn't. But she went for it again a few days later.'*

Food insecurity is a major barrier to treatment for Aboriginal people with cancer. The CCT couldn't fix that, but they do their best to help clients navigate around it.

– Janelle,  
Dhaggati GP

# RADIATION THERAPY



## ● What is radiotherapy?

Radiation therapy, also called radiotherapy, uses high energy rays to treat cancer. It is:

- painless
- a common way to treat cancer; and
- focused on the area of the person's body where the cancer is.

This treatment may help to:

- cure cancer
- shrink or stop cancer from getting bigger
- control the spread of cancer; or
- reduce pain and other problems caused by cancer (for example, bone pain from cancer).

It can be used alone or combined with other treatments. There are two types of radiation therapy that a doctor may recommend, depending on the type of cancer.

## ● External beam radiation

The person lies on a table, and the radiation is targeted at the cancer location. The machine makes a noise like a vacuum cleaner and may move around the body. People often need to wear a shield to guard parts of their body from radiation that do not have cancer. This shield, or cast, can also keep that part of a person's body still as the radiation must go to precisely the right place. Other people might lie between closely-fitting supports or in a purpose-built cradle.

The radiation therapist might mark the person with a felt-tip pen while working out where to direct the radiation beams. When they have worked out exactly where they need to go, they might permanently mark their skin to ensure that the machine lines up correctly each time. These radiation tattoos are between one and five tiny dots on the client's skin. The therapist might draw circles around the dots with a felt pen to help them see where the dots are.

Radiotherapy can be one treatment only. But more often, doctors prescribe courses, like once a day, five days a week for several weeks.

## ● Internal radiation

Also called brachytherapy (pronounced brakkee-therapy), this treats the cancer with internal radiation from implanted, sealed capsules containing a short-range radiation source. Doctors put these small x-ray 'seeds' inside the body, directly on the cancerous tissue.

Internal radiotherapy can treat the tumour with strong doses of radiation without affecting healthy tissue nearby. Commonly used for cancer of the cervix, vagina, uterus and prostate, it can also be used for other types of cancer. Implants can be inserted for a short period only or made to remain in place in the body.

## ● Preparing for radiotherapy

You can help:

- arrange appointments with the radiation oncologist
- organise payment or transport if required
- offer to accompany the person to the first appointment with the radiation oncologist, the planning session and the first treatment session appointment. Be a second set of ears. Some people might require more support through the treatment
- help the person make a list of questions, so they are well-informed about their care. Before they go to the oncologist, information about radiotherapy can help them understand what's going on at the appointment
- help them prepare for regular hospital visits if they will be receiving frequent treatment or need to travel to a city for treatment. Assist in arranging care for other family members, such as respite for elders, or organising aunts to look after children or pets
- arrange transport to the hospital with parking vouchers if these are available.

## ● The planning visit

- at a planning meeting, people are measured and sometimes marked with a felt pen to indicate where the radiation tattoos will be and they detail the course of radiotherapy

- radiation therapists assist in planning and delivering the radiotherapy in consultation with the radiation oncologist (a doctor)
- the person may receive tiny blue or black tattoo dots to ensure that the radiation beams are targeted in the correct place ('field'), for example, for breast cancer
- some people may have a fitted mask made specially for them, particularly for head and neck radiotherapy. The mask excludes the radiation from healthy tissue and helps the radiation therapist target the cancerous tissue.

## ● Side effects

External beam radiotherapy does not make people radioactive. It is safe to be in contact with other people, including pregnant women and children.

Internal radiation can send a small amount of radiation outside of the body. If a short term, high dose implant is required, the person will need to stay in hospital and visitors are restricted (especially at the beginning of treatment).

A person with a permanent implant may need to stay away from pregnant women and children, even though the radiation from a permanent implant does fade with time.

The implant itself can cause minor discomfort, too.

You may need to support people to understand these conditions by discussing and questioning their doctor. They need a clear understanding to decide whether to have it.

Radiotherapy is generally easier on the client than chemotherapy, and the side effects of radiotherapy mostly go away in 4–6 weeks.

## ● Supporting people with cancer during radiotherapy

Reassure the person that they may see the machine moving around them and hear a buzzing sound, but radiotherapy does not hurt. Talk about the common side effects of radiotherapy and ask if they have any questions. Make sure they have things to help with skin side effects (see box opposite).

If the radiotherapist has used non-permanent, felt pen marks to map the treatment spot, make sure the person understands they can't wash them off until the treatment is complete.

Radiotherapy can result in a slight reduction in immunity. The person must go to the ED or see a doctor if they have a fever.

Check what they need before their next treatment session, such as x-rays or other scans. If they have a follow-up with the specialist, help organise the cost of the appointment, transport and accommodation.

*The best advice I got was to book my radiation sessions first thing in the morning. The machines inevitably break down, pushing the later appointments back even further. Being one of the first appointments meant I never had to wait while they fixed the machine. And I could get on with my day.*

– Lucinda  
Southern Highlands, NSW

| Effects of radiation   | What a person might experience   |
|--|--|
| General  | Tiredness<br>Itchy or skin that feels like it has been sunburnt<br>Affected skin may be permanently darker or have broken blood vessels<br>Hair loss |
| Chest radiation<br>(e.g. breast cancer, lung cancer, lymphoma) | Cough  |
| Head and neck<br>(e.g. throat cancer, lymphoma)                | Dry mouth, no saliva   |
| Upper abdomen  | Heartburn  |
| Lower abdomen  | Bladder irritation, urinating more frequently<br>Diarrhoea   |

## Treating skin affected by radiation

- apply a moisturising cream (like sorbolene or zinc cream) twice a day to the affected area if the skin is unbroken
- avoid using soap, even liquid soap. Baby soap or plain water is okay
- avoid hot water. Some people get irritated by chlorine in pool water
- gently pat skin dry
- wear loose-fitting cotton or rayon clothes. Avoid tight-fitting or synthetic clothes
- avoid underwire bras if the chest is the area treated
- drink plenty of water
- avoid exposing the treated skin to direct sunlight. Be careful of strong wind, too
- avoid massage to the affected area.

Adapted from: Breast Cancer Network 'Cancer Skin Care' <https://bit.ly/2S9WjNk>



Governo do Estado de São Paulo CC BY 2.0 / Wikimedia Commons

*It didn't hurt at all. I had to go five days a week for seven weeks, so it was my full-time job then. Organising to be there was a bit of a hassle sometimes. I was tireder than usual. But I felt well. I was glad to get it done.*

*If I really think back, I remember that my skin got a bit red and tender about halfway through my course of radiation. My breast got heavy and swollen.*

*It's still numb in the area, five years later. I've still got the four dots, too, like freckles. The skin's a bit darker where I had the radiation. Not really my choice for my first tattoo! But a reminder of my survival of breast cancer.*

– Pat, Dharug



*We had three meetings with the doctors over the television and at the hospital when Dad was sick. Our senior Health Worker explained how it works.*

*The doctors find out how Dad's feeling and what we think and take all that to a big meeting of the cancer docs, the ones that do the x-rays and that, the ones that give chemo and radiation, the physios, someone from the lab and the surgeons. With all their numbers and pictures.*

*Nurses, too, that know Dad from the ward. The ALO went. He looked out for us. I appreciated that because I know the ALOs are run off their feet. Whole mob of people there for our Dad.*

*They were all there talking about what's best for Dad, and then they'd come and report back to all of us. My niece was in Melbourne with him, and the rest of us had a videoconference at the AMS. They did everything they could to give him the best care then, putting all their strongest minds together.*

*It's not so different to what our mob do when Elders from different families and Communities meet together to make important decisions.*

– Terry, Noongar

# MULTIDISCIPLINARY TEAM MEETINGS



## ● What is a multidisciplinary team (MDT)?

A multidisciplinary team is a team of cancer care professionals who meet regularly, for example, weekly, to discuss the best approach to cancer diagnosis, treatment and supportive care for people with cancer.

Teams comprise members with a range of different skills, to make more balanced and knowledgeable decisions about care.

The type of cancer the person has determines who is in their MDT, including any of the following specialists: oncologists, senior oncology nurses, radiation oncologists, radiation therapists, radiologists, surgeons, social workers, oncology psychologists or palliative care physicians or nurses, physios and occupational therapists. General practitioners can also be invited – perhaps by telehealth.

Sometimes MDT meetings include the person with cancer, sometimes not.

### Multidisciplinary Teams:

- work to make sure that treatment decisions are based on the best available evidence, local policies and clinical practice guidelines
- also take into account the views or concerns of the person, for shared decision making
- develop an individualised cancer treatment plan for each person
- are not always available in smaller or rural hospitals. In this situation, teams from tertiary hospitals meet by telehealth to ensure that people get the best care possible.

Sometimes the Aboriginal cancer care workers are invited to join the MDT meeting, such as when the team plans a person's discharge from the hospital or to discuss starting palliative care.

### REFERENCE

**Cancer NSW Planning Treatment –**  
<https://bit.ly/35zhj30>



*I tried to listen to what the oncologist said about the drug trial. I didn't understand much. I was still shocked about having cancer at all. Mum has worked as a cleaner in the hospital. She came with me. She understood the doctor better. She's got a memory like a rabbit trap when something important's going on. She had the doctor write things down.*

*We talked to the Health Worker at the clinic about it. She sat in with us and the GP. The GP emailed the oncologist, and we all looked at the details of the study together. We talked for more than an hour. I understood what they were offering well enough.*

*Even with all that, it felt like a very serious kind of a lottery. It was me this was happening to, you know?*

*Would I get the new medicine or not? I wouldn't know if I did. My doctor wouldn't know. Would it still help me to be in the trial if I didn't get the new medicine? I had to think about that. I'd have more blood tests and check-ups. Could I handle that? Did I want that? Would I be better off if I stayed away from the study? Did I even want their new drug?*

*Thoughts went round and round in my head day and night. I was sure. I'd decided. Then in the next two hours or the next day, I was totally convinced of the opposite! You wouldn't believe it.*

*I had to be patient with myself. I tried to eat well, get decent sleep, drink my water. When I had the chance away from all of life's distractions, I started to pull into myself more, in a good way, I mean.*

*In the end, I went down to the Point a few times. There's a place in the rocks there where people have sat to listen since before the water came up at the end of the last Ice Age. You know, five thousand years of bums on that rock. It's shiny now.*

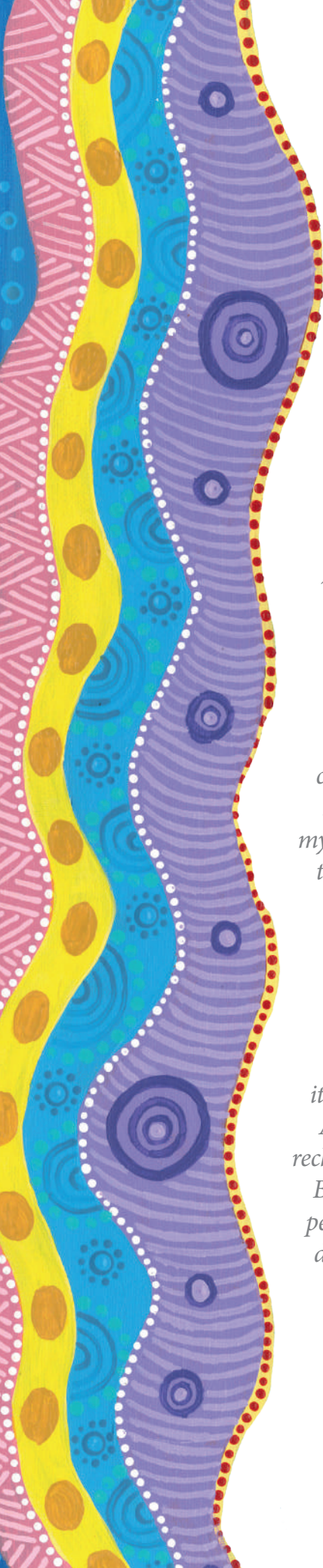
*So, I sat and listened. I'm going to be honest with you. I participated in the study, in the end, because the voices in the wind and the waves told me it would be all right.*

*After all that, I don't think I got the new medicine they were trialling. I reckon they gave me the placebo, the sugar pill.*

*But somehow, the whole process of going there and interacting with the people fitted into my journey with the illness and healing. The tests and that didn't matter much in the end.*

*My conversation with my body and Spirit continued, and I got better. This might sound strange, but I felt like even if I didn't get better, everything would've been all right. That's the feeling of security Indigenous people can have in our spirit, you know? It was the wind and the rocks and the sea that told me.*

– Gwynn, Dharug





# CLINICAL TRIALS



A clinical trial for cancer is a study or trial of a new treatment – trying to see if it works to cure or slow down cancer.

## ● Being in a trial

During a hospital visit or doctor's appointment, a person living with cancer might be asked if they want to join a clinical trial. Clients know that they need to decide for themselves. Be a sounding board for your client:

- they can talk to RNs or GPs at your AMS who can review the information about the trial and talk through the pros and cons of being in it
- allow time to speak to family members or friends
- encourage them to talk to other people with the same type of cancer (at yarning circle or on social media)
- help them contact health consumer organisations (like the Cancer Council) and speak to the Aboriginal workers there
- be sure the person with cancer doesn't feel pressured by medical carers or family to participate in a clinical trial.

### RESOURCES

**Mainstream Fact Sheet** download

– <https://bit.ly/3cB6jWY>

**Cancer Council of NSW Booklet** download

– <https://bit.ly/3pBlkyi>

**Australian Cancer Trials**

– <https://australiancancertrials.gov.au>

**HealthMatch** (Australian website that matches people with trials) – <https://healthmatch.io/>

**Register for health research for cancer**

– <https://register4.org.au>

## ● This is your decision

**Trish:** *A lot of our mob don't know their rights. They don't know that they have a right to refuse treatment. They think that they must have treatment. They feel like it's taken out of their hands very quickly. It's like, 'Okay. Next week you're having treatment.' Sometimes, they're not given time to think about whether they want it or not. They don't feel they have time to make any choices.*

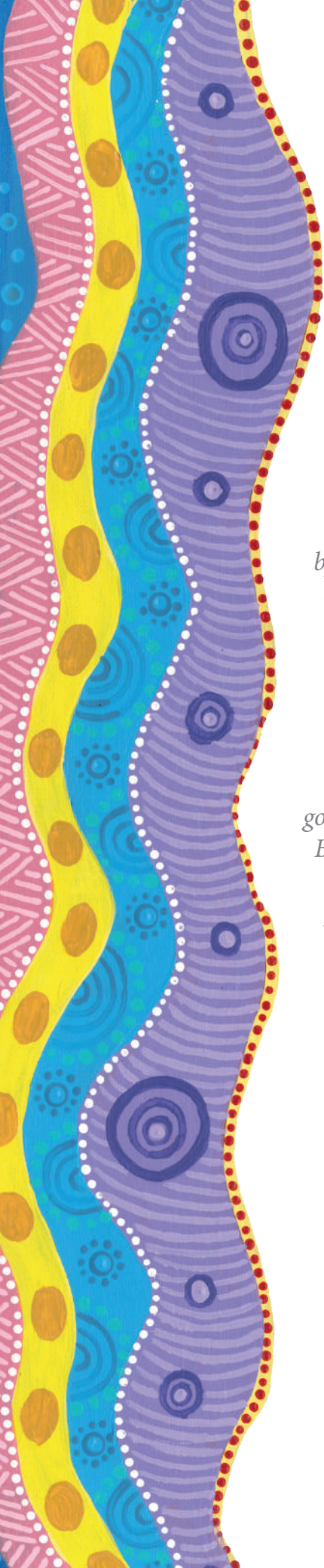
*I've said to them, 'This is your decision. It's not your specialist's. It's not your doctor's. You have a right to choose or refuse treatment if that's what you wanna do.'*

*I spoke to someone the other day. They're unwell. I told them that they have a choice. They can ask about drug trials. Half the time, people don't know. They got told, 'You're going to have chemo.' But what about all these new trials? A lot of the time, they're not suggested for our mob. But when you've got nothing to lose...*

**Janelle:** *Part of that is that explaining how a trial works – the use of placebo, randomisation – maybe some doctors are not confident about conveying those concepts to someone who's desperately sick in the first place, and then they've got cultural barriers in talking to Aboriginal people. My colleagues are aware of cultural differences and cultural barriers, but some are not well trained to work across cultural barriers.*

**Trish:** *Yeah, that's true.*

**Janelle:** *And that's a shame. Sometimes a trial means a person finds more meaning in their life. Even if the medicine isn't helping them, other people can learn from it. And sometimes it does help save them or make them better.*



“

*I was disappointed how hard it was when I got better. I was bothered by hot flushes and not having my hair. I grieved about my hair and it was about the loss of who I'd been before. I didn't like how I looked. I couldn't stand a wig or a beanie all the time because I was so hot... I'd be up in the middle of the night putting a bag of frozen peas on my head.*

*Little things that I know aren't that important got on top of me because I was so tired. And I'd growl at myself for being upset about shallow things like my looks.*

*When I was having chemo, I dreamed of getting my life back. It was good to be alive. To walk on the beach at sunset, have time with my kids. But this body of mine. Even if I was fatter, I'd lost my strength.*

*I needed treatment for lymphoedema in my arm, and it was hard to find a specialist who could do that. There's not many of them around, apparently.*

*It took a long time to get over it all. Well, it took a long time to realise I would never be the same. I like who I am now. But it took a few years to trust myself and the world again.*

– Gwynn, Dharug

## CHAPTER 17

# CANCER SURVIVORSHIP



### ● Life changes after cancer

People often notice that they:

- feel more anxious about their health
- appreciate life more
- are more accepting of themselves.

Cancer survivorship is the time after a person has cancer. Cancer survivors include those who are living with, through and beyond cancer:

- having treatment
- in remission following treatment
- who are cured, or
- have active or advanced disease.

Other people who have had cancer do not identify with being a 'cancer survivor'. They may instead consider themselves to be someone who 'had cancer'. And someone who is living with cancer, preferring to get on with life.

People in remission might still have treatment to lower the chance of the cancer coming back or help to keep the cancer from spreading.

But some people identify strongly as 'a cancer survivor'. Some survivors get involved in cancer support groups or fundraising for cancer research.

### ● Supporting cancer survivors

The Cancer Care Team supports people through their whole cancer journey. After treatment ends, care for people in some of these ways:

- organise follow-up with team members, including ACCHO staff, psychologists, oncologists, radiation oncologists and haematologists
- facilitate payment for Allied Health through Enhanced Primary Care arrangements (see Appendix page 104 on financial issues)

- provide transport
- continue preventive care
- arrange an exercise group
- keep listening
- encourage people to go to the Yarning Circle for support.

### ● Side effects & consequences of cancer and treatment

People who have come to the end of their cancer treatment still need a high level of care. Common side effects of cancer treatment include:

- tiredness
- heart failure or lung scarring
- 'foggy' brain or impaired memory ('chemo-brain')
- irritable bladder – having to urinate a lot
- vulvodynia – painful vulva
- diarrhoea
- numbness or tingling in fingers and toes (peripheral neuropathy)
- deafness (nerve damage from chemo)
- fractures (due to osteoporosis, a side effect of some medications)
- lymphoedema (from lymph nodes being removed or affected by radiation)
- sexual dysfunction
- issues related to 'ostomies' (such as from colostomies for bowel cancer), stoma management
- psychological adjustment to changes in the body, significant (e.g. amputations) or relatively minor (like sensitive skin or hair growing back differently)
- pain
- secondary cancer such as lymphoma
- mental health challenges, including grief and reactive depression
- social effects, including change in income or ability to work or care for the family.

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## ● Watching for symptoms of the original cancer

As health staff, we need to let people know to keep looking out for suspicious new symptoms and organise appointments with the GP as soon as possible if any come up. Some signs to watch out for include:

- weight loss
- tiredness
- new lumps in the neck, armpits or groin, which could mean that cancer has spread or is occurring in the lymph nodes
- jaundice, which could indicate that cancer has spread to the liver

- bone pain which could signal cancer that has spread to bones such as the lower back or ribs
- coughing, coughing up blood or shortness of breath – these may be caused by cancer metastases in the lung
- feeling ‘Something’s not right’ – people often have an intuition of something wrong

Most people who have had cancer need regular tests and monitoring visits to ensure it doesn’t return. This can be stressful, emotional and frightening.

Regular health checks, care plans and ITC referrals are healing and empowering.

See Appendix C page 100 for details.

*Looking after people who have survived cancer is almost as challenging as being there for them at the time of cancer diagnosis. It’s that hard and that important.*

*People survive the disease in three ways: physically, mentally and emotionally. Many clients aren’t prepared for the reality when treatment ends. They feel unsure.*

*Staff, friends and family are often excited by the end of treatment. But the client often isn’t. That can be hard to understand and explain.*

*It’s scary. People worry about a lack of support when they do not see medical staff as often as previously.*

*They’re unsure of how they should feel. The head says one thing, but their emotions don’t follow. ‘If treatment is finished, why don’t I feel better?’*

*The body needs to recover from treatment. It’s fought hard to recover from cancer and the treatments for it. Exhausted, it needs lots of time to fix itself.*

*The treatment may have changed the person’s body.*

*They might have experienced surgical removal or amputation of part of their body, scarring treatments that cause injury. They might have gained or lost a lot of weight (fat or muscle or fluids or all of these). They might be dealing with baldness. They might have trouble recognising themselves or identifying with the person they see in the mirror.*

*Emotionally, they might now have a different attitude to what is, or was, important.*

*Many people undergo treatments and plan to pick up life where they left off, unprepared for changes they’ve experienced. People need lots of support. Like one-on-one counselling, support groups or the Cancer Care Team Yarning Circle. The client needs reassurance that what*

*they are experiencing is completely normal. And that it will take time to heal.*

*They can never be who they once were. But the person they are becoming has all sorts of strengths and knowledge that they might just now be discovering.*

*Give them support to start again. This means patience and self-compassion. Maybe they don’t need any huge lifestyle changes straight away. They are recovering to their new normal, and then they can make changes. Just not straight away.*

*There’s a lot of fear in having had cancer. Clients may be scared whenever they feel a lump or feel unwell – anything that reminds them of what triggered their diagnosis. They could be frightened when they’re due for a scan or when the medical practice rings them.*

*Many small things can trigger fear in a survivor.*

*Through treatment, clients strike up friendships with others on the journey. Some friends survive, and others don’t. Be sensitive to survivor guilt. It’s a real thing.*

*One way to support clients through this time is by not pointing out how lucky they are. Just let them talk and share what they need to.*

*Some clients never have survivor guilt. They still need help to get on with their new phase in life.*

*Check-in with them. Ask them if they learnt things about themselves that they didn’t know.*

*Were they surprised at how strong they were? What helped them the most? What’s the best bit of advice they could offer to someone else?*

*Talk about the positive aspects of finishing treatment. Ask them, ‘Where to now, for you?’*

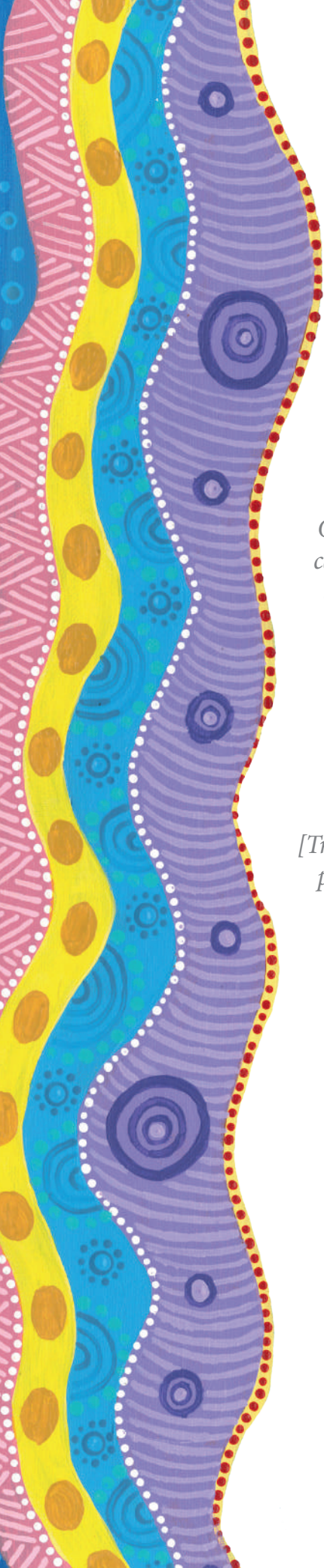
– Kyla, CCT

## Cancer Survivorship Wisdom Box



- Not everyone is excited to finish treatment.
- Clients take time to heal – let them.
- Start a Yarning Circle – see page 71.
- Cancer survivors need ongoing support: physical, emotional and spiritual.
- Early on is not the best time to make life-changing decisions. Support them to be patient.





*Once a month, we have a cultural Yarning Circle for our mob that have cancer. Or maybe they've lost somebody with cancer. We do cultural activities: painting, weaving, making dream catchers.*

*This is part of their own healing journey. Creativity takes them away from cancer for a little while, you know. To have some down time without thinking about their cancer.*

– Trish, CCT

*[Trish] being Koori, being a traditional owner, knowing her cultural practices, and practicing them, having that craft and bush medicines, it definitely strengthens that cultural component and people do, they love it. And being here at the AMS, it's even more culturally supportive.*

– Shayne, RN

## CHAPTER 18

# YARNING GROUP



Yarning Groups, also called Yarning Circles, provide a welcoming and supportive, culturally safe environment for cancer clients and their family members.

The Yarning Group is for Aboriginal and Torres Strait Islander people who live in the Illawarra. It is open to those with cancer, who had cancer (and are in remission), or who care (or cared) for someone with cancer. So, carers of people who passed from cancer are there, alongside newly diagnosed people or clients and their carers undergoing treatment. Supporting each of them is a balancing act.

The group meets at the AMS. About half a dozen to a dozen people attend. It is a supportive environment where everyone is free to share about their journey with cancer. Or not.

Our people have strong traditions of working creatively alongside one another, telling stories as we go. Sometimes people in the group enjoy travelling alongside to listen and learn from others who understand. Experiencing companionship and not having to talk. Others understand without words.

When they're not sculpting clay or making dream catchers, people join in traditional cooking. They practice using different media, like scratch boards, watercolours, beading or painting lampshades and making wind chimes.

Every year the Yarning Group also hosts a Biggest Morning Tea to raise awareness around cancer and cancer research. The Biggest Morning Tea is initiated and supported by Cancer Councils in each state.

Women also contribute their art and craft work to Bling a Bra, a Cancer Council breast cancer awareness program.

The Yarning Group includes traditional healing activities, conducting Welcome to Country ceremonies, enjoying bush tucker and trying bush medicine. Sometimes people visit healing sites.

The Yarning Group program overlaps with the Cancer Care Team's Women's Traditional Healing Days when women head out bush for healing.

## ● Setting up a Yarning Group

Where to set up your Yarning Group:

- in ACCHOs
- off-site in community organisations, but hosted by ACCHO staff
- in hospital oncology services
- at Non-Government Organisations such as the Cancer Council.

You want a room with natural light, where people have space to sit and enough table space to do their painting and craft.

It needs to be comfortable (preferably air-conditioned). Being able to make a cup of tea there or get snacks out of the fridge makes for a friendly space.

The advantages of Yarning Groups/Circles based at ACCHOs include that they are:

- culturally safe and familiar bases for cancer treatment and discussion
- linked into the client's primary care system, including care for other members of the family
- conveniently near health providers
- relatively low cost and
- allow access to ACCHO transport services.

At Yarning Group, clients:

- share stories of cancer journeys
- travel alongside others, access knowledge
- enjoy morning tea or lunch
- make arts and crafts
- can get transport, especially for frail Elders

They are run monthly, weekly or as often as practical, with people gathering inside or outside.

Ensure you have a channel for support (a doctor or nurse) for clients in case of new clinical issues. Running the Yarning Group at an ACCHO facilitates continuity of care.



Photo and art by Trish Levett

## ● Commanding respect

A Yarning Circle (or Yarning Group) can also be a formal occasion for exploring and resolving conflicts. Just because it has a friendly name doesn't mean that the Circle is a casual event. It can be serious, with boundaries and rules strictly imposed.

**Trish:** *We need to get back to old ways when our mob used to sit in Yarning Circles. Get the men to do the men's business, women to do women's business. I've been pushing for that.*

*The other week, I held a Yarning Circle at a local Aboriginal Community Organisation. There were serious issues to discuss.*

*So, I said, 'Why don't we have a Yarning Circle? And if mob don't wanna speak up, they can write things down on bits of paper. And we'll draw them all out and deal with them one by one.'*

*I explained that this is our old ways. You need to respect each other. You don't speak when anyone else is speaking. I had a talking stick, which I handed to the ones that wanted to speak. When they had the stick, it*

*was their turn. No one else was to speak.*

*But there was this one, a nurse. She sat there chatting away. I said to the person who was speaking, 'Please stop for a minute.' I glared at that nurse. I said, 'Are you finished? Don't disrespect the rest of this mob in this Circle. You were told what the rules were before we started.' I pulled that one straight into line.*

*And then there was another giggling and carrying on. I looked at her and told her, 'Get out.'*

*Some people were shocked.*

*I said, 'They need to learn protocol, and they need to learn it the proper way.'*

*I dealt with it there and then. I said, 'You were all given notice that it was a Yarning Circle, and these are the rules. You're not just disrespecting the people in the circle. You're disrespecting the old people and our Ancestors. You can't do that. If you've got a problem with that, come and see me later.'*

*Some of the mob that know their culture came to thank me later. They said, 'Oh, sis. You shoulda seen the fierce look on your face. We've never heard you angry like that.'*

*I said, 'When it comes to culture, if people disrespect it, you will see that side of me.'*





Photos courtesy of Cancer Care Team

## ● Relaxed and safe

**Kyla:** We chose not to make this a formal group. It's not a support group with guest speakers and a focus on a topic. We wanted a space where the energy could flow. Participants can give and get what they need. We always have the both of us there in Yarning Circle, in case someone is triggered by something and needs to leave the group. One of us can stay, one of us can go with them. Everyone gets supported.

We have not had to intervene in conversations. Mob respect each other. We've always been able to manage Men's Business and Women's Business. We encourage men to come, but it is predominantly women. Some men feel supported at the local Koori Men's Support Group.

Yarning Circle allows Trish and I to sit in with the group and join in. We all enjoy the change of pace and the change of dynamic.

**Trish:** Yarning group was set up when I first started, five years ago. It is a safe space where mob can come and do some activities, because you know, a lot of our mob haven't learnt culture either. It is a chance for them to learn how to paint and use all different sorts of media to tell their stories. Not only their cancer stories but their stories in life as well. And to learn.

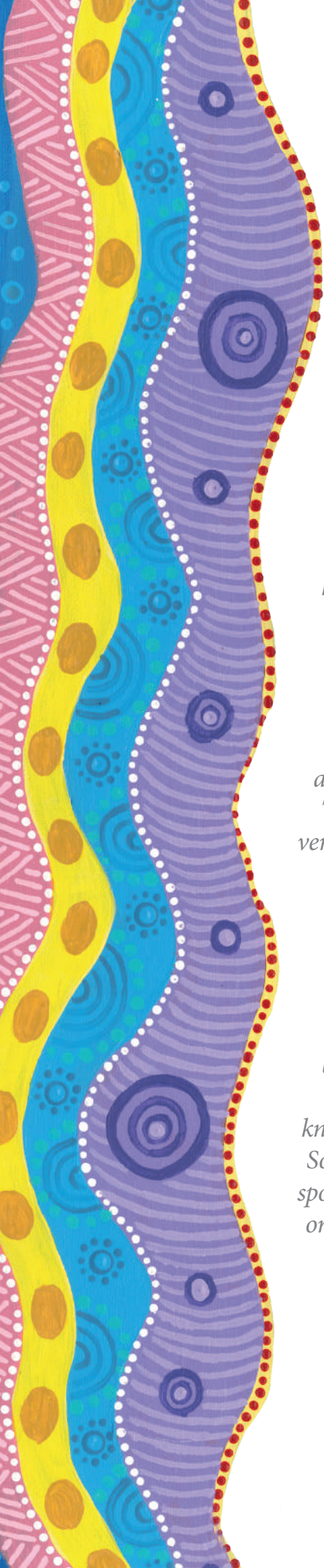
We do art and craft. Even tie-dyeing. All different arts and crafts. Get away from cancer for a day and not having to think. Sit and yarn and laugh, and learn their culture itself. Because a lot of them haven't painted before, they don't know the symbols, so it is taking them on a journey as well, with culture.

A safe space for mob to do that, to discuss culture and what they want to learn, using the different symbols to tell their stories. If cancer is brought up, you know, someone brings something up within the group, we discuss it, and then it's dealt with. Mostly, it's all just how are you doing today? They yarn about day-to-day stuff. People get so involved in what they're doing that cancer doesn't come up.

They're so consumed in what they're doing, they're just doing their stuff. Sometimes you can hear a pin drop in there. People busy doing their own designing or making stuff.

Oh, it's beautiful. It's awesome to stand back sometimes and just look at the group and watch them being so creative and being in a safe space. Being able to teach them to paint and, you know, this is what you can do at home if you've got materials. Sometimes I say, 'Here, take some paint home, take a canvas.'

Some mob make presents for their children, or whoever, their own design. To be able to pass that on to someone. Which is really nice because especially when some of them do pass away, you know, they're precious gifts to keep. Like, someone says, this is my Mum's first painting she ever done. Or this is the T-shirt that my uncle made. And they can wear it, and yeah, it's lovely.



*Medicines from Nature are central to Aboriginal cultures. Many people use plant medicines on a regular basis.*

*People use old ways of staying healthy and getting rid of sickness. For example, they might use a plant-based rubbing medicine for a sore knee, aromatic smoke to keep a baby clean and healthy, or make a cool compress from a certain seaweed for a headache.*

*Many mothers know which parts of the kangaroo are richer in iron, which foods will warm them and restore their energy, making their blood strong after heavy periods or birthing and breastfeeding.*

*There are resinous dried tree saps that have an antiseptic, styptic effect and thorns that kill warts.*

*There's still a lot of that everyday knowledge around. Other people had a very intensive, higher level of knowledge of the plant medicines.*

*Initiated and trained Traditional Aboriginal Healers are often chosen as children. Some are initiated as adults by a spouse who is a healer.*

*One of my friends in Central Australia described four different ways of being a traditional healer. There were people with specialised knowledge of the plants and animals used as medicine. Then there were people with physical skills. They did massage and manipulation. Some were bonesetters. All with skills going back generations.*

*Then there were healers who worked exclusively on the spirit. Some were known to visit sick people in spirit at night, like astral travel.*

*Some could pull or suck out the sickness, which was concentrated into a spot of bad energy. The sickness was spat out or came out in a piece of rock or in a stick.*

*Trish uses healing places in the proper ways she has been taught. She also uses song, dance, smoke and other ceremonies to allow people to heal. Visits to a sacred Women's site are part of the Cancer Care team's program.*

– Janelle,  
Dhanggati GP

# TRADITIONAL & CULTURAL HEALING



## ● Supported by Country

**Trish:** *Being on a cancer journey brings up lots of issues for our mob. I love taking them home to Country and I'm blessed that it's only an hour's drive away from work.*

*I do a smoking healing ceremony on Country, and you know, ochre them up and get the ochre to dry, and then get them into their healing hole. And it's just mind blowing. It's amazing. Oh, it's just beautiful.*

*But I've also done a rebirthing ceremony, to ground people back to Mother Earth. For that strength while they're going through their treatments, or if they've finished their treatments, or anything like that, just to reground them. To give them that spiritual strength from Mother, so they can keep going with their journeys.*

**Janelle:** *Do you think that feeling disconnected is one of the hardest things for people undergoing treatment, with cancer?*

**Trish:** *Yep, it sure is. Especially for people of the Stolen Generations, they can be so disconnected from culture. Sharing that culture and taking them home to Country, for learning: that's empowerment.*

**Janelle:** *Now, you're taking them back to your Country, it's not necessarily their Country.*

**Trish:** *To my Country. No, no, it's my Country.*

**Janelle:** *It's all Mother Earth.*

**Trish:** *Country's under your feet everywhere.*

**Janelle:** *And it's going to support you wherever you are.*

**Trish:** *That's right. And I teach 'em to do their own little rituals. If you're not feeling good, go outside and get your shoes off and dig your feet back into Mother Earth. You know, she's going to give you that energy.*

*Or, if you're down by the water at the ocean and you need to get rid of bad feelings, you go down when the tide's going out and you stick your feet in. Let all that stuff go. And then you go back when the tide's turning, and when that new energy's coming back in, you go and stick your feet back in the water, and that gives you that new energy and that new flow back into your body. It's about teaching them that stuff as well, that they can do when I'm not around. They can do that stuff for themselves.*

**Janelle:** *Very important. I got taught that when my energy was low or in a bad state, I can ask a tree or a rock to take it from me.*

**Trish:** *To take it, yeah, I've taught them with the rock as well, hand it over to rock and throw the rock in the water.*

**Janelle:** *Oh. So, what I was taught was, say it's a big rock or the right tree, I can leave my energy there with them and then I can come and pick it up again later. It's been transmuted. That's another thing.*

**Trish:** *Yeah, that's right. Yep. Yeah, it's all those little things that make you stronger. The whole cultural, spiritual side of stuff is important, isn't it?*

**Janelle:** *So that hole is a Women's place. How about the men?*

**Trish:** *I am only allowed so far in on the men's site. I point those other sites to the males. I have had men near there. Only at the right time. I won't let them swim together. I've shown men stuff that they can do there, that I've been taught. But yeah, I won't let the women and men swim together in the water.*

**Janelle:** *And you probably take them on separate trips?*

**Trish:** *Yeah, never together.*

**Janelle:** *Those gendered experiences still matter. Especially in urban spaces, it tends to be disregarded, just because urban Aboriginal people have learned to cope with cross-gender interactions, in a way that our ancestors wouldn't have.*

**Trish:** *Yes, that's right.*

**Janelle:** *When it's about healing, or intimate education, or relationship with your body, you know, much of that knowledge is still gendered in our cultures.*

**Trish:** *Yeah, that's right.*

**Janelle:** *Do you want to say anything about herbs or bush medicines?*

**Trish:** *Yeah. While we are on Country I show people the different medicines. I talk about what those medicines are used for, and when's the appropriate time to pick them. So, while we're healing up there, they're also learning about traditional medicines and what types they can use.*

*I talk about native currants, too. They boost your immune system up. They come out just before wintertime.*

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They're really important to our mob. Just before winter, especially if they're having treatment, eat the native currants. One tiny berry holds five times more Vitamin C than an orange.

**Janelle:** Everywhere you go in Australia, you'll find a fruit like that. Here in Perth it's the lilly pillies.

**Trish:** Oh yeah, we've got lilly pillies down here as well... I am starting to eat them now.

**Janelle:** They're also really high in Vitamin C and bioflavonoids. Up in the Kimberley they have a fruit called gubinge. In Darwin, it's called Kakadu plum. People are talking about using those fruits to keep themselves well against viruses, keep their immunity up.

**Trish:** Yep, that's right. So, I start picking native currants before winter... I do take them into the AMS, it's quite funny, even when the doctors are sick. Makes them better.

They're like, 'Oh, have you got any of them berries yet, or have you got any of them leaves that we can have?' Which is cool, working out of an AMS and doctors that are of non-Aboriginal descent wanting to have the bush medicine and I'm like, 'What's wrong with your medicine?' I can be real cheeky sometimes.

**Janelle:** That sounds healthy, good on them.

**Trish:** They're always willing to give it a go. There was a really bad flu last year, and some of them just couldn't shake it, you know. And they started wandering down the hallway and 'Oh, have you got any bush medicine?' And I go, 'Yeah, I'll bring you some in.'

## ● Supported in body, mind and soul

CCT client Marjorie Campbell chatted with CCT member Kyla and Janelle.

**Marjorie:** The spiritual strength that Trish gives with her knowledge and experience, going on Country, being with other women on the same types of journeys, it's like our own little sisterhood.

**Janelle:** It is. But it's not little.

**Marjorie:** No, it's not. It's huge. You're right.

**Janelle:** Because going on Country ceremonially is not just the key to healing the individual souls who participate. When you're healed that way, you're helping other people to gain insight into what it means to grow. So, they open that door.

**Marjorie:** I'm so grateful for these girls both, equally. I'm their Aunty. I love that they have that respect for me. They call me Aunt. And I feel so close to them. I hug them so tightly every time I see them.

The information, the knowledge that they pass on, culturally, medically, they're all connected, you know?

**Janelle:** Yep. Keeping you safe in that industrial, medical culture. Interpreting what those doctors and nurses are saying, what this means in your body, what this means

in your life. How you're gonna get there. How tired you're gonna be. Is this gonna make you sick? Is there medicine if it does? From little details to that bigger picture.

**Marjorie:** Yes. Totally. It's not just about the cancer journey. It's about interlinking other aspects of our journeys. Interlinking concepts for healing: it's such a major thing.

**Janelle:** And Country. Caring for Country. Country caring for us.

**Marjorie:** Definitely. When I first went on Country with Trish, I felt like a little girl on this big adventure. All of us on the bus were talking, chatting away. It was such an amazing experience. It took a lot of time and effort for the girls to put it together. They had a really supportive manager to help make it happen.

When we went on Country, we could actually feel the spirits. We all laugh. Poor Kyla gets inundated with the spirits. She sits on the bus and we know what's gonna happen to her.

**Janelle:** She's one of those 'bridge' people – connecting between realities?

**Marjorie:** Yes. She's like 'Gimme a blanket. Gimme a cardigan.' And it's stinking hot. This poor woman is freezing. She's got all of these women in spirit connecting in to her. We'd have a good laugh. We don't think about what we're going through then.

**Janelle:** It's not about the cancer then?

**Marjorie:** No. It's about being on Country, girls together. Listening to Country. Learning what helps us heal. There's a big pond that we go to. Trish tells us some of the things that happen in that place. It's magnificent.

**Kyla:** [to Marjorie] I can feel you now, calling someone in.

**Marjorie:** One day, all of us there, eight of us, wanted to swim in the pond. It's a very important pond. It was Women's Business. We heard a couple, a man and a woman, walking towards us at the pond. Trish secretly said a few words. That man went straight back outside. He wasn't supposed to be there.

**Janelle:** She put that energy up and he just bounced off it and moved away?

**Kyla:** That's right.

**Marjorie:** Because that was where the women needed to be. That's the thing about these women. They're so connected within themselves. Anyone that we don't need around, they just bounce off 'em. I see that happening all the time. It's brilliant. They can finish sentences. Start sentences that you were thinking. They connect in such an amazing way about what they're going to do with their service that they offer. [Pause] Sorry Kyla.

**Kyla:** It's all right. I can feel the mob coming around us.

**Marjorie:** Trish has this cultural, healing knowledge and experience. Also in art. Also in dance. All of these wonderful things that we as Aboriginal people need. Not just the women. They also offer their service to our men.

*That's vital. They need to be included.*

*These ladies, my darlings – my life has been blessed having them there and available when I need them.*

## ● Dreaming a garden

*We're looking at putting a bush medicine garden in. So in the hospital, we've got this atrium...*

*We'll look at native plants from this region, but also particularly bush medicine and we'll put them in there.*

*And we'll get all of the botanical names and Koori names and what they're for and so forth and on the outside of the atrium. We'll have signage put onto the windows and things.*

*So, honouring the local traditions, talking about bush medicines, growing the plants. That's another thing to make the hospital feel a little bit more culturally friendly, you know.*

– Chana, Yorta Yorta, Aboriginal Health Practitioner, ISLHD / Wollongong Hospital

### RESOURCES

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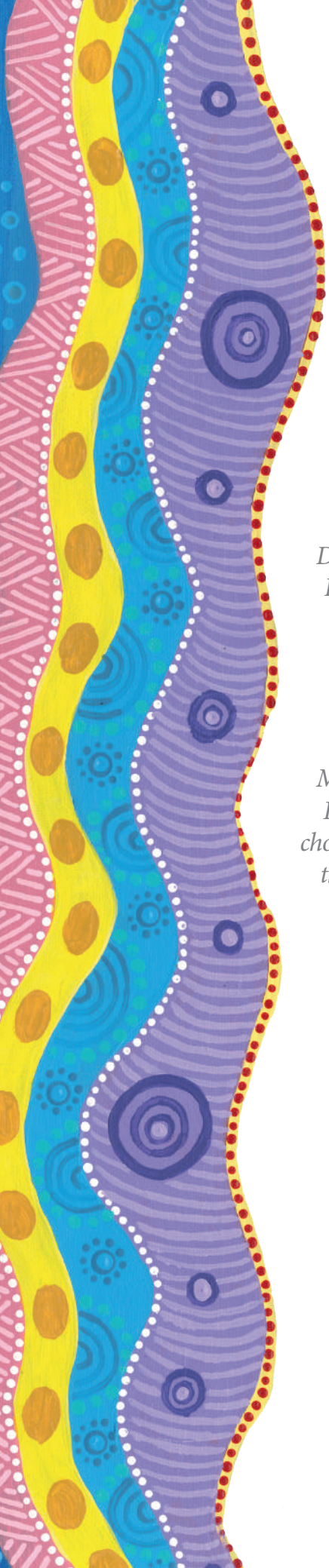


Photo by Kyla Wynn

## Using Bush Medicine Wisdom Box

- Herbal remedies, from roots, berries, leaves and flowers of plants, are used in many traditional medicine systems. They contain active ingredients.
- There are no human studies that have shown the benefits of herbal medicines to cure cancer, but some can assist with symptoms related to the cancer.
- If a person is considering using traditional herbal medicines, encourage them to discuss this with their oncologist or GP, particularly if they are having chemotherapy, or surgery, or plan to do so soon.





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*Dad got the help he needed at the end of his life. We were able to visit him. He was on the syringe driver in the end. The constant medicine took the edge off the pain. He was in and out of it, as people sometimes are at the end. Sleeping most of the time but waking up and whispering things. He squeezed my hand. Knew when Mum was there.*

*He was an important man, my father. Not just for me but in the Community. The pall care mob and the nursing home treated him and Mum with respect, all of us really. It was a very, very hard time.*

*I still feel him around, especially when I'm out hunting. He helps me choose a spot. When I'm in the yard, I can hear him going on about that gate that needs to be fixed.*

– Terry, Noongar

# PALLIATIVE CARE IS ABOUT QUALITY OF LIFE



Palliative care aims to help people feel better when they have an incurable, life-limiting disease. It's not just medicine. Pall care staff help the person with cancer live well. They offer emotional support when there's conflict. Or can be a sounding board for the person, and those who love them, to work out how to enjoy the rest of their life.

Pall care supports the person's functioning. Like accessing equipment to keep people walking and self-toileting. Or for eating or washing in bed when they can't get up anymore.

People can receive palliative care:

- in home in Community
- in a hospice or palliative care ward
- in the hospital or
- in a nursing home

When people feel better they can be stronger in spirit.

Clients with good palliative care feel comfortable, have less pain and difficulty, and sometimes have more energy. They can feel comforted and communicate better. They might even have a new lease on life, connect with people they want to see or sort things before they die.

Most people understand that palliative care is important to help a person pass from this life with less pain and suffering. People retain their dignity at the end of life and in death.

Palliative care does nothing to make a person die sooner. It is completely different to euthanasia (voluntary dying) – when a person chooses to die because their life has become unbearable.

It can be short or long-term supportive care. Some

people are in palliative care for years. Others only access it in the last days of their lives. Starting palliative care soon after an illness diagnosis is better for the sick person and their carers. The palliative care team might be able to help with symptom control. Referrals to palliative care should be made because of need, not because a person will pass soon.

The client's GP or specialist doctor can refer them to palliative care. Don't be shy about asking your client if they would like to meet the palliative care team.

GPs, AHWs and nurses based at ACCHOs sometimes deliver palliative care in a person's home. Doing home visits is an important way of supporting our clients in their last weeks.

The palliative care team can include volunteer support workers, social workers, allied health workers (like physios and dietitians), nurses and doctors.

One of the main reasons people come to palliative care is to manage pain. For example, by changing tablets. Or organising a syringe driver for pain medications when a person is not able to swallow medicine.

But the palliative care team is not only interested in pain. Palliative care provides the best treatment for many other problems people with cancer can have, including lack of appetite, bowel or digestive problems and difficulty sleeping.

Some radiotherapy, chemotherapy or surgical treatments are referred to as 'palliative' because they don't cure the cancer but can slow down its spread or help the person feel better while living with the disease.

Practical problems pall care can help with include getting dressings or nappies, a hospital bed or a shower seat at home or an oxygen concentrator (to help a

person breathe). All to make supporting someone at home easier.

The palliative care doctor might hold a family meeting to help family members understand what is happening to their relative and what their disease is likely to do. Or they might help find a place for the person to pass away if they can't be cared for at home for any reason. Sometimes the palliative care team helps a family who wants to bring a person home to Country to pass on.

Palliative medicine is an individual approach that considers the person's mind, environment and spirit, and body. It supports them and their family as the patient approaches and passes through the end of this life.

*Dad had terminal pancreatic cancer, and it had spread to other parts of his body. None of the treatments was going to help him. We had meetings in the hospital with the surgeon and the oncologist.*

*The GP worked with the palliative care nurse in town to get Dad on the medicine that suited him. She had phone calls and we all had videoconferences. When Dad got home, he was on steroids for energy and a tablet three times a day so that he didn't bleed. Another tablet to help his little bit of food go down. He lived on icecream. We had decided that a feeding tube would have been a bad thing for him. Dad kept his dignity without it.*

*He was on medicine for pain when he needed it and also had drops he put under his tongue if he was feeling short of breath. He wasn't in much pain, he said.*

*My brother, who lives about 500 kilometres away, came home and was angry with us because we had worked with the GP to find a place in a nursing home for Mum and Dad together. We were all feeling all right about it. Because it's an Indigenous-run place near the hospital. It's only an hour and-a-half away. They had friends there and they got a unit together. We felt lucky. The aged-care people were really pleased to organise it for them.*

*Mum had Parkinson's Disease and couldn't walk properly, see. She wasn't thinking straight a lot of the time and she'd had falls, some of them bad. Sometimes she saw zoo animals out the house.*

*The GP called an urgent meeting for me and my brother after she heard that he was planning to take Mum and Dad home from the nursing home.*

*The doc was respectful. She said we all want our old people to die at home. But she didn't think it would work for Dad. Poor old Dad needed medicine nearby. And we live a long way from hospital. Even the pharmacy is two hour's drive away when they're open.*

## ● Common treatments in palliative care

The palliative care specialist, nurse or GP can always help. Common symptoms and treatments in palliative care include:

- Cough/ shortness of breath – positioning, opening the window, home oxygen
- Poor appetite – diet supplements (Ensure, Sustagen), medicines
- Constipation – laxatives or enema
- Ascites (fluid in the abdomen) – drainage
- Nausea – anti-vomiting medications (such as onansetron or metoclopramide)

*If Dad felt like he couldn't breathe, we had syrup to give him, as well as his little pills for under the tongue. The doc explained to my brother that Dad and Mum could come home for a couple of days sometimes but that it would be too hard for anyone to look after them outside the nursing home for more than a night or two. The nurses in Community would get too tired if they were up all night with them both. Then the clinic would be closed the next day.*

*Turned out my brother was crook because other people in his Community gave his wife a hard time, saying that we dumped the old man in the nursing home and that we didn't care about our parents.*

*That was so far from the truth! The GP said, 'Those people don't know what they're talking about. I'm a doctor, and I've nursed family at home when they were dying, and it was the hardest thing I ever did.'*

*And her family didn't have the difficult symptoms Dad had. If he started bleeding into his gut from that cancer, you'd want to be next door to the hospital or have that buzzer in the nursing home to call for help. It could be bloody scary.*

*She said we'd need the pall care team to handle it. Keep him safe when he got sicker or when he was passing. He might feel better with the nurses nearby, and you can be with him without having that burden, that fear.*

*That doc's not one to scare you. It was true, what she said. After that, my brother accepted that we were right. Being able to visit Mum and Dad and knowing someone else was taking good care of them was good for all of us.*

*Especially them. Mum even started taking her pills, something she used to fight about three times a day. She even got a bit better. And after Dad passed she could stay in the same place where she felt at home.*

– Terry, Noongar





## Palliative Care Wisdom Box

- Palliative care is about quality of life rather than life-ending.
- Introduce the words ‘palliative care’ and explain what it is early in the cancer journey.
- Make yourself known to the closest pall care team and build a relationship with them.
- Clients still might resist ‘palliative care.’ So, discuss pain relief, supportive equipment and support people who can drop by and re-introduce these words gently.
- Palliative care can be short or long term.
- Admission to a palliative care unit can be helpful to sort out issues so that clients can come home (this can happen more than once).
- Health teams try, when possible, to provide palliative where the client wants to be.



### ● Talking about those words

**Kyla:** *I use the words ‘palliative care’ with people who are living with a life-limiting disease (and their carers) very early on. ‘Palliative’ does not mean death and dying. Palliative means quality of life. And I say that. I get that word out early, so we can use it a lot. Because once you get palliative care, it really improves your life and sometimes even your longevity.*

**Janelle:** *Your comfort in life goes up. And because you’re comfortable, having enjoyable moments, it can be very sweet. Sometimes, when people are taken off many other medicines they were on, they feel better.*

**Kyla:** *Absolutely. Explaining what ‘palliative’ means early in their illness gives people a chance to process the idea that being under palliative care doesn’t mean you’re dying tomorrow.*

*It’s got the most unfortunate connotation. Health workers who are part of the dying process need to put their own fears aside to be able to talk about death. Listen to knowledge holders in Community about the dying process, what happens. Family’s gonna need to be reassured. If you’re unsure about what you’re talking about...*

**Janelle:** *...you can’t reassure them. So, don’t be afraid to learn. Don’t be afraid to have those experiences. Everything you learn and experience helps you to help other people. Aboriginal people who are culturally rich have an advantage because we understand that death is not the end; that spirit goes on. We come from there, we go back there, we come from there again. Dying is usually not scary.*

**Kyla:** *And to be able to sit with someone at the end of their life is such a gift. It is a privilege when someone knows they have a very limited time frame, and they’ll allow you to be there with them. I’ll thank people, ‘Thank you for allowing me into that space.’ It can be a bit overwhelming at times, though.*

**Janelle:** *Yeah, if people are suffering. If they don’t have the care or medicine that they need. You can be frightened that they’re going to die from their pain or that they’re going to die from not being able to breathe properly. That’s terrifying. The family or carers need to be able to call the nurses. You need to be able to get the right help to hand. Sometimes people’s illness needs them to be in hospital.*



### RESOURCES

**Symptom Management and Prescribing Advice, Palliative Care Therapeutic Guidelines.** If your workplace subscribes – <https://bit.ly/3xzbLBO>

**Help with Palliative Care in Children,** including managing symptoms, organising a family meeting or bringing a child needing pall care home – <https://bit.ly/3ttwLJR>

**Victorian Aboriginal palliative care service** – <https://bit.ly/2UcVrrP>

**Queensland Centre for Palliative Care Research and Education, for Aboriginal and Torres Strait Islander People** – <https://bit.ly/3vD5x2b>

**Kimberley Palliative Care Service** – <https://bit.ly/3gC0URV>

**Care search, Palliative Care Australia** – <https://bit.ly/3xws3LF>



*As can happen in any family, five siblings were living all over the place, scattered in New South Wales and Victoria. One middle sibling died and was buried on her Country. She was still living close to there before she died.*

*We met the fourth sister when she was dying. She was a wife and mum – not living on her Country and very established in the Community where she lived. She and her husband and children wanted her to be buried where they could continue to be together.*

*The eldest siblings decided that she should be buried with her sister back on Country, which is five hours travel away. This caused a lot of issues within the family with conflicting stories from her husband and her siblings as to her wishes. It was unfortunate that she did not do an Advance Care Plan [ACP] that could have prevented tensions.*

*The Cancer Care Team were aware of her wishes and supported the family for the outcome of keeping the family together when grieving.*

*In another family, this son was very caring and supportive of his dying Mum. But there was already conflict between the Mum's son and daughter. Mum had very definite ideas on how she wanted her funeral and burial. And things she would like to happen after she passed.*

*I explained the concept of the ACP and how this could support Mum and her son. I gave them an ACP, discussed and explained everything, and left it with them for a week. Mum was in palliative care in hospital then. They discussed the ACP and filled in the details that Mum wanted followed. The ACP was witnessed by a social worker (that is, an independent person) at the hospital.*

*In this example, there was no need for all the medical issues to be gone through with a doctor as the client was already in palliative care, so what she wanted medically had already been discussed.*

*The ACP worked well. After Mum passed, there was some conflict in planning the funeral and burial. The ACP served its purpose and ensured that Mum got the funeral and burial that she wanted.*

– Kyla, CCT

# ADVANCE CARE PLANNING



Advance Care Planning is about a person making choices about their future health care and sharing their thoughts and decisions with family, friends and health care professionals. An Advance Care Plan (ACP) allows the person with cancer to ensure their wishes are followed when they are not strong or well enough to speak for themselves. Everybody should have ACP. And it is especially beneficial for people who have had a diagnosis of cancer.

Having an ACP eases the family's decision-making and allows the person to be treated as they wish. Not what others think is best for the client or themselves. It stops family arguing and fighting over decisions, taking pressure off everyone.

**An Advance Care Plan (ACP)** is not a legal document, but it expresses the person's wishes, so family, friends and health professionals know their thoughts and feelings regarding treatments or no treatment. More details about an ACP are spelled out below.

**An Advance Care Directive (ACD)** is a document expressing a person's wishes and medical choices if they lose the capacity to make decisions in the future. The directive is completed with a doctor, who ensures the patient is competent, making sure they are well enough to make decisions and say who they trust to speak for them if they can't. The doctor can explain to the person any questions they do not understand.

An ACD can be recorded on a template or simply by writing the person's preferences and signing and dating the document. An ACD can be updated if the person has a change of choices later. An ACD is not legally binding but serves as an important guide.

**A Substitute Decision Maker** is a person chosen to make medical decisions if a person is no longer able to. This person should be over 18, someone who the person trusts to make decisions in difficult situations.

They are often a partner, child or sibling. The title of this role varies between states. In NSW they are known as an Enduring Guardian or person responsible.

## ● Advance care planning (ACP) templates

There are ACP templates available tailored to the laws of each state or territory. Things considered in an ACP:

- the person's loves in life – who they want around them
- their cultural and spiritual values. What they want to happen at the end of their life
- the person's care goals and where they wish to be cared for (at home, in a hospital, palliative care ward, hospice or residential aged care)
- the person's instructions for when they can no longer do day-to-day activities like toileting or eating. Having a feeding tube can prolong life without maintaining the quality of life
- the person's view on what should occur if they are permanently not able to make decisions for themselves
- whether a person prefers to have life-prolonging treatment (treatment that may make their life longer). These might include:
  - Cardiopulmonary resuscitation (CPR), including whether the person wants a "Do Not Resuscitate" order placed on their record
  - Ventilation machines (breathing machines used in Intensive Care Units)
  - Tube feeding
  - Renal dialysis
  - Other treatments such as blood transfusion, intravenous fluids, antibiotics or surgery; and their wishes about organ donation

The ACP can also hold information on preferences for funerals and sorry business. And whether the person has a will and where it is kept.

## ● Supporting people with cancer in advance care planning

Helping your client have a voice when they are very ill or after they have passed is a powerful way to be of service. To do this:

- find an Advance Care Plan (ACP) or Directive (ACD) template online (or adapt the one in the Appendix of this book on page 101). Print it for the person to take home and think
- provide other printed information about Advance Care Planning and Directives or give the person directions to the online site or hotline
- they can make notes and write down questions
- encourage them to talk to family and friends, so they feel confident
- make an appointment at the Aboriginal Medical Service to complete the ACP or ACD
- once completed, make sure that there is a copy on file at the AMS medical record
- at least one trusted family member or Enduring Guardian needs to know the location and contents of the ACD. Take a copy to the hospital if the person is admitted
- upload the scanned Advance Care Plan or Directive to MyHealthRecord
- make a wallet card so other health workers can be aware of the ACP or ACD when needed.

The Cancer Care team at the Illawarra Aboriginal Medical Service has adapted the NSW Advance Care Directive Template. (See a copy in the Appendix page 101). You can adapt a state template for the Country and mob you work with.

*We just needed something a bit more user-friendly and culturally appropriate for us. Just pare it all back to the fundamental questions people need to communicate, put in simple language, you know?*

– Kyla, CCT

The CCT's ACP form includes Trish's Aboriginal artwork. It addresses important questions for Aboriginal people in the Illawarra. It has space to describe personal and spiritual concerns.

For example, a person might prefer to be somewhere quiet and natural when dying. They can use the form to request that at the end of their life, they will be taken from a clinical hospital environment to a room that is more comfortable and less frightening for family and friends, or, if possible, outside under a tree.

Documents that reflect the values and wishes of Aboriginal and Torres Strait Islander people during grief and difficulty are important in making hospitals and medical centres culturally safe.

A properly completed Advance Care Directive takes pressure off the family and encourages health workers to be gentle in caring for the person.

### RESOURCES

**Advance care planning Australia** – <https://bit.ly/2SEEDtu>

**NSW Advance Care Directive Form download** – <https://bit.ly/35tmdyH>

**NSW Enduring Guardian Form download** – <https://bit.ly/2SEYWae>

**Advance care planning for Aboriginal and Torres Strait Islander people** – <https://bit.ly/3vrKXlu>

**Advance Care Planning for Children needing Palliative Care** – <https://bit.ly/3ttwLJR>

## Advance Care Plan (ACP) Wisdom Box

- Use the ACP or ACD to open the conversation when the person is still well enough.
- ACPs allow clients to have control about what happens when they can't speak for themselves.
- Discuss the idea of an ACP with the client and their family.
- Allow plenty of time at home to talk and think. But sometimes a gentle nudge to get it done can help the person focus on their desires and needs.
- Make space for the client to share their ACP with family. You might facilitate this if you have the skills.
- Take care that their needs and wishes are shared with family as far as possible. Some clients will need your support to do this.
- An ACP can ease stress and conflict in families at the end of life and in Sorry Business.







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*We're permitted now to make smoking ceremony in the hospital, which was never allowed to happen. It took a lot of patient negotiation. Now, we're able to do that ceremony. It's a measure of the trust the team has earned.*

*We don't use a lot of smoke because it is a hospital system, but we get them to turn the fire alarms off on the whole floor until we've finished performing what we need to do.*

*So, when someone's passed, the Sister will ring me and ask me to go in. I'll take stuff in for them, so they can be painted up: the body of that person that's passed. And then I'll take stuff in so people can do a smoking ceremony in the room with them.*

*It's breaking down massive barriers.*

*That person's spirit is free. It doesn't stay there at the hospital or around that room.*

– Trish, CCT

# SORRY BUSINESS, LOSS AND GRIEF



Many Aboriginal people live with a high level of grief and loss in their lives. ‘Too many funerals,’ people say sadly. Indigenous people worldwide are subject to ongoing dispossession and colonisation, resulting in higher rates of sickness and death (morbidity and mortality), including higher rates of mental illness, self-harm and suicide. We all live with the consequences of that.

The effects of direct and intergenerational trauma are evident. Distress is shown and caused by intense, devastating substance abuse and addiction.

Aboriginal peoples’ poverty comes from being denied our Land, source of food, shelter and spirit. We see the Land ill-used. Grief wells from the loss of our world. The loss of our transcendence and security.

Healing ourselves and each other is essential to our survival and flourishing.

It is the Land that looks after our youth as they come to terms with the world they were born into. The Land holds our older people close as they grieve for injustice and tragedy they have witnessed.

Cancer brings its own load of loss and grief. People who have cancer grieve for losses you can see. Like hair lost during chemotherapy. Like not being able to dress themselves because their muscles are weak. Not enjoying their food. Or the loss of a limb or a breast.

They also have losses that you don’t see. They might lose their sense of trust in their body. Something might have shifted in their marriage when their spouse lost the confidence that they’d always be there for them. People with a life-limiting illness have anticipatory grief: knowing that they won’t see their grannies grow up. Anyone with cancer must process the loss of the future they’d planned.

Grief takes many forms. There’s no right or wrong way to grieve. Elisabeth Kübler-Ross, in her book *On Death and Dying* described five stages of grieving.

People don’t necessarily go through these stages in the order written here. They don’t have to go through all of these stages, or they might re-enter a stage they’ve

already experienced. But the Kübler-Ross model helps people talk about grief and understand that it has its own course.

## ● 5 stages of grief

1. Denial – *This can’t be happening. There must be a mistake.*
2. Anger – *Who’s fault is this? This is so wrong!*
3. Bargaining – *I’ll do all the chemo. Just let me stay for my son’s next birthday.*
4. Depression – *What’s the point of doing anything? Life’s meaningless.*
5. Acceptance – *I’ve been through tough times before. This is just a part of my life. I’ll be right. I know what to do.*

In a book published after her death, Kübler-Ross added a sixth stage to grieving: Meaning. Finding meaning in our losses and gaining knowledge through difficulty is an important source of Aboriginal peoples’ resilience.

An Aboriginal perspective on time helps, too. Elders teach us patience, connection with the changing seasons. That time is more of a spiral than an arrow. We re-visit lessons, learning them in different ways, hopefully making growth easier. ‘Everything happens for a reason,’ they say. With patience and love comes understanding.

The Cancer Care team supports people holistically.

*It doesn’t matter where the grief and loss come from. People don’t have to go back there and re-live it to heal. They need to be accepted where they are when we meet. Just that acceptance can give them the space to know themselves again and heal.*

– Trish, CCT

Find out more about how the CCT helps people accept their loss in the chapters about Yarning Group page 71, Cancer Survivorship page 67 and Traditional Healing page 75.



**Marjorie:** My sister was going through some really tough stuff. She was dealing with a lot of trauma, aside from the cancer. So, the combination of it all meant she felt lost.

**Janelle:** A dark night of the soul, eh.

**Marjorie:** Really! She came across as this very strong person. She had a blasé front. But I knew. And the ladies [from the Cancer Care Team] knew: Here's this little person having a terrifying time. Without the ladies, she wouldn't have been able to do what she was able to do – to bring her strength back. That's what they helped with.

Trish's spiritual knowledge meant that she was able to connect. My older sister, you see, learned a lot from our great-grandmother and our grandmother. For her to be able to reconnect all of that Gumbaynggirr women's knowledge is very important.

**Janelle:** It's healing for the family.

**Marjorie:** For her, it was. She didn't have this sense of having real importance in the family. But it was huge. I said to her, 'Sister, you've got to understand that in our culture, you're the keeper of the stories. You have learned of this knowledge from our great-grandmother and our grandmother.'

She had these huge brown eyes. All of a sudden, it was like stars came out of them! She made the connection.

**Janelle:** That strong spirit! That bright spirit.

**Marjorie:** She was! But she didn't believe that she was of any importance in the family. She was just my sis, the older sister. She didn't understand that 'til the end of her life. She got through breast cancer, and then she had an aneurysm. I thought we were going to lose her. But she came through again. She's like a dog with a bone.

**Janelle:** Wasn't ready to go yet.

**Kyla:** Nah, she wasn't. She had nine lives. She was very cluey, wasn't she?

**Marjorie:** She was streetwise. I said to her, 'You are the matriarch in our family. Now that Mum's not here, you are the oldest in our family. And you have all this knowledge sister, jinda.'

**Janelle:** You elevated her to her Elder status because she was the knowledge holder.

**Marjorie:** I had to. She felt she had no purpose. Still, I see her and feel her – I can feel her now – and I love her, I still do. Beautiful soul and very cheeky.

Then she was diagnosed with Acute Myeloid Leukaemia. That was really something difficult for her to deal with. She believed she could take on anything. 'Ah, I'll be right,' she'd say. But she wasn't right. She needed support, not just family but other people around her.

That's where Kyla and Trish came in. Because they're so culturally knowledgeable, they knew exactly how to support her. She had a love of gambling, playing the pokies. She'd go into hospital, and when she was there, she'd ask for Day Passes.

**Kyla:** And we'd have to go and find her.

**Marjorie:** She went AWOL. No one would know where she was. The hospital would be ringing me, 'Marjorie, do you know where your sister is?' They'd ring Kyla and Trish...

**Kyla:** 'All right. Let's go to the club. We'll go find 'er!'

**Marjorie:** And that was where she was! That's how these ladies connect with their clients. They aren't just ticking the boxes. They're outside that system, in the great big world.

They connect with each individual client, each individual spirit. And celebrate and enjoy them. They used to have lots of laughs with my sister.

**Kyla:** One day, we're out the back of Warrawong, in Coomaditchie. We were looking for your sister for hours – could not find this woman anywhere. Not for love or money. In the end, we were so fed up. We were whinging. 'That's it. We're done.'

As we pulled into a driveway to turn around and give up, no word of a lie, she shot straight past us. How we did not run her over is beyond comprehension.

**Janelle:** Did she live out there at Warrawong?

**Kyla:** No. She knew people at Warrawong. She used to walk out there.'

**Janelle:** What? From the hospital?

**Kyla:** Yeah, or from town. Ten kilometres away. She lived in the centre of Wollongong.

Trish and I couldn't get ourselves up off the floor of the car for laughing. We were just about to give up, and then we nearly ran her over.

**Marjorie:** And that's exactly the spirit of my older sister. That's how she was. You'd search everywhere, going crazy and then, up she pops! That's 5 or 6 years ago now. I feel her. And I have dreams. That's how she comes to me.

## Loss and Grief Wisdom Box



- Not only dying causes grief.
- People move through grief in different ways, in their own time.
- Stay open to what the client is saying.
- Allow time and space for them to talk.
- Find a comfortable place to yarn. Maybe under a tree or down by the water.





● The second year

*It's important to keep the long-term perspective in mind with grieving clients.*

*It's not just about initial grief counselling. Three weeks of grief counselling might be fine for some people, but it's not enough for others who might have to rebuild their lives. The first year of grieving someone is very difficult. The second year can be much tougher. The first year, everyone's there for support – for the first birthday or the first Mother's Day or the first Christmas.*

*In the second year, a lot of that support drops off, so you find people are starting to feel isolated.*

*In the first year of grieving, people are numb for a lot of it. They're sort of protecting themselves.*

*In the second year that numbness is wearing off, the support is falling away. So, I'll let the clients guide the number of appointments we have, the frequency of them and what level of support they need.*

– Kyla, CCT



*It's different when you care for a close relative. You have to put aside that this is your mother who you'd normally look up to. When she can't do anything herself, you have to help her with all the daily tasks, and more than that.*

*I cooked for her, cut up the food, fed her, got her drinks and gave her coffee with a straw. I bathed her, toileted, and dressed her. She was so weak and helpless at the end of her life. I had to help her with everything.*

*People came to the house from a company whose leaflet said they were caring and all that. When they come, it should be time for the carer, working 24/7, you know, to have a chance to sit and have a coffee. Or go to the chemist or the shops. That company charged a lot of money to the government, but they sent untrained people. Mum was scared of them.*

*Like, one of them washed her, he started at the feet, then went to the intimate parts. Then he was going to wash her face with the same washer! Mum screamed.*

*I came in and stopped him, but these are basic things they should know. Mum had a bad wound on her back that she got in the hospital. Her skin was like paper from the treatment, and they didn't turn her often enough when she was very ill – it was a pressure sore because there were not enough nurses. It shouldn't happen.*

*It needed a big, expensive dressing. One of the assistants put the dressing on the wrong way round, so it wouldn't absorb the pus. They wouldn't believe me when I tried to correct them.*

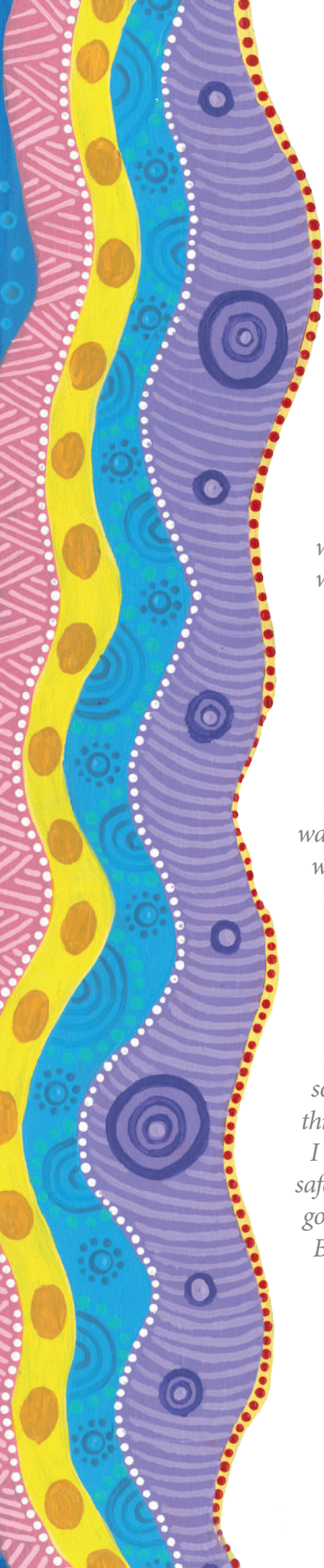
*Another wouldn't wear gloves to open the dressing packet because they couldn't figure the right way to open it. And if I tried to show them or say something, they didn't listen. They didn't respect me and that I was doing this work all the time.*

*I never got a break. I wished for a break, but I wished more that Mum was safe. I know I did the right thing. It felt good to do it. Sometimes I felt like it's gonna kill me, and I might die before her because there was no break at all. But I'm glad I did it. I would do it again, yes.*

*When I asked about how hard she and Dad worked when we were little, and all the times she'd been a carer in her life, I said, 'Things you do for love, eh?'*

*Mum said, 'Sometimes even love isn't enough.' She could see how hard it was.*

– Britt, Ngunnawal



# CARING FOR CARERS



Many people with cancer have an unpaid or minimally paid carer. Aboriginal and Torres Strait Islander people are more likely to be carers, compared to the non-Indigenous Australian population. Our cultures place a high value on caring for our older people and others in need.

Caring for someone with cancer is tiring and stressful—but can be rewarding.

Carers of Aboriginal and Islander people with cancer face difficulties accessing health and welfare services, including cultural barriers when attending mainstream services. They need support to deal with institutionalised racism or ignorance.

Carers feel a strong responsibility to care for those in their family and their community. This often means caring for someone at a personal cost to themselves.

## ● What do carers experience?

- chronic tiredness – caring for a person with cancer can be 24 hours a day
- neglect of their own health problems and preventive care
- additional health problems, like back injury due to lifting, turning or assisting their family member with cancer or depression due to grief and feelings of powerlessness
- loss of income from inability to work
- increased living expenses due to medical costs, additional transport costs
- social isolation
- changed relationship with the person who is sick. A parent isn't a protector and mentor in the same way as they could be before

- impact on other members of the family such as children
- an impact on relationships, loss of friendships and other roles the carer had in the community
- loss of intimacy, including sexual relationship, if the person being cared for is their partner.

## ● What do carers feel?

- anxiety about their family member's condition. Anticipatory grief about how the person will change or might die
- grief and anger about the loss of their own role outside of being a carer
- anger or annoyance with other family members who may be 'interfering' or not helping with the care.

But caring for someone with cancer can also bring families together. The Cancer Care Team plays an important role in protecting and nurturing carers, encouraging family harmony when possible, as well as offering support in creating and keeping healthy boundaries.

## ● How can you support carers?

- listen to them
- validate their experience
- acknowledge their role – without judgement
- allow them to express painful and difficult feelings, and
- link them to other carers for peer support – a cup of tea and a yarn helps.

Yarning Groups can help carers and people with cancer. Making art, visiting Country, listening and telling stories are all culturally safe ways to support people when they are confused, exhausted, grieving and healing (see page 73).

## ● Practical ways to work with carers

- assist with organising appointments, financial assistance for medical care and transport for both the person with cancer and the carer
- help access medical, social and financial services. Centrelink payments to support the carer can make a big difference
- organise services through MyAgedCare or, in some cases NDIS
- arrange respite care
- provide aid in connecting with others who are cancer carers for peer support.

### RESOURCES:

**Carers Australia.** Sign up for their newsletter and benefits - <https://bit.ly/3iPSTdr>

**Information on Centrelink payments for carers** - <https://bit.ly/3gAZ9nQ>

**Koori Yarning Manual from Carer's NSW** - <https://bit.ly/2TJ3nAQ>



## ● A client and a carer

At Marjorie's lunch with Kyla and Janelle.

**Marjorie:** *I became my sister's carer at one stage. Kyla offered advice about their services. She said, 'Because you're her carer, you can access our service, too.' Well, I didn't realise that. It was a godsend.*

**Kyla:** *Let me add that this lady had already been through cancer. Without us being aware of it, she had her own cancer journey. That came up after.*

**Janelle:** *That's tough. Being a carer's about the hardest thing you'll ever do in the world. Oh, for anybody in your family – it's just so intense.*

*Especially if you've been through it. Through your sister, as you're caring for her, you're reflecting on your own experience and re-living that and trying to integrate it. While you're probably exhausted.*

**Marjorie:** *When I went through my journey, nothing was out there. You'd go to the doctors. You see the nurses. There was nothing to support you after the fact. Or during the experience, for that matter.*

Janelle imagined her then, sitting in sterile waiting rooms, marshalling her strength to submit her body to treatments that could be frightening or painful. She imagined her taking herself home to recover from the illness, the treatment, the industrial culture of the hospital.

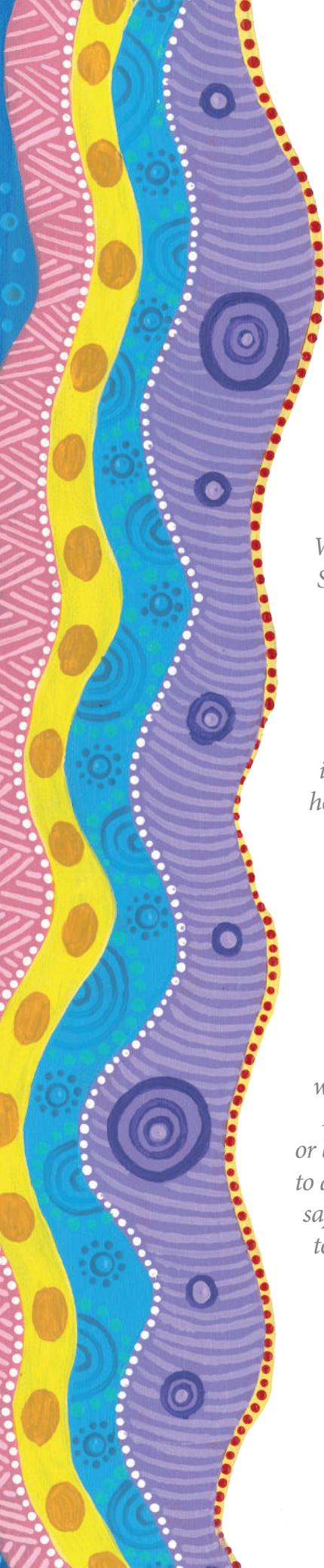
**Janelle:** *A lot of us doctors and nurses are not culturally safe. They can be brutal.*

**Marjorie:** *They're there to do their job.*

**Janelle:** *Kindness matters. We all need to look after ourselves and keep learning, or we're no good to anyone.*

**Marjorie:** *Well, learning about Kyla and Trish and the work they do in the team was absolutely a relief. Spirit brought them to us. I really believe that. Women like these two have made my life whole again.*





*We go to the op-shop to get supplies for people's art at the Yarning Circle. Saves money, and we do find good materials. But that's hunting and gathering, too, you know. It relaxes us.*

*We might've had family conflicts about a client's last wishes and then taking someone for their chemotherapy, and they're feeling crook and arranging medication pick-up at the pharmacy next door.*

*Going into the op-shop and sorting through coloured rags at lunchtime is therapeutic. Sometimes I'll stop at the lake for five minutes on the way home. Just watch the pelicans. Breathe.*

– Trish, CCT

*I don't go to funerals since I worked in palliative care. I say 'goodbye' and 'good journey' to my clients in my own way, in my own self.*

*Knowing I cared for them – as best I could – can be enough. It can be hard to miss a funeral, especially when I know it'll be a loving farewell.*

*I understand that some of my colleagues want to show their respect that way (and I'm glad they do).*

*But I don't even make it to all of the funerals in my family because of work or being far away. And the communities I work in notice which funerals I go to and which I don't. I don't want to cause jealousy. It's easier for me just to say, 'I don't go to funerals,' and leave it at that. I need to make a special effort to give myself time to grieve and connect with others in a personal way, though. I don't recommend that approach to everyone. It's just what works for me.*

– Janelle,  
Dhangati GP

# SELF CARE FOR TEAM MEMBERS



Working in health is tough. And working with Aboriginal people with cancer can be draining and demoralising. Understanding that our peoples are living with the consequences of ongoing dispossession and colonisation helps us keep perspective. There's a lot of love, humour and healing in our work. But there's also a lot of stress, sadness and Sorry Business. Sustained self care needs to be high on your list of things to do.

## ● Self Care is

- what we choose to do regularly to keep ourselves well in mind, body and spirit
- being strong for our communities
- staying balanced to be able give to our families
- loving and respecting ourselves to be able to keep looking after our clients; and so
- we are more powerful.

## ● Some ways to look after yourself

Prioritising your own health and wellbeing begins with changing your mind. Being kind, sustaining and nourishing yourself is not self-indulgent. Our Elders will encourage you to take care of yourself.

Self-respect and peace of mind grow from learning to quiet your mind and think encouraging and good thoughts. Practice smiling at yourself in the mirror until it feels natural. Try meditation, which can be through headphones. Or colouring in, knitting or weaving.

Learn to be as kind to yourself as you would be to those you care for and love. Be your own best friend. Get enough sleep, go to bed early. Take pleasure in Nature. Breathe deeply.

Take holidays or breaks for a rest. Looking after a sick relative or going to a funeral does not count as a holiday. Review your workload. See what changes you can make.

Eat food that didn't come out of a factory. Use your body – walk, have a stretch or dance with the kids. Yoga can be restorative, and there are plenty of free classes on the net.

Value your colleagues. A de-brief over lunch is time well spent. Keeping a journal or seeing a counsellor can help a lot too.

## ● Grief and loss

*As health professionals, we are affected by grief, not just related to our clients passing away. For example, we can experience grief when our client loses relationships, employment or their current identity. We build unique, sometimes close and loving relationships with them. Our clients affect our lives. We learn from them. We grow from the experiences we share with them. That's our great privilege.*

*Letting yourself honestly experience grief may open you to healing other losses you have been through in your life. But sometimes, especially when we've already experienced too much grief in our personal lives, it can feel overwhelming.*

*It is not only dying that causes grief. Grief is the normal response to loss. Be patient with yourself. Our grief takes its own path and time.*

*Talking helps. Find someone who's a good listener for you. Don't be afraid to lean on others. If your colleagues, friends or family suggest that you get professional help, it's usually because they can see you suffering and feel unable to help.*

*Counsellors, psychologists and social workers can be great as they know how to listen, they accept you as you are and can gently offer a different perspective.*

*Many books on this subject can help, too.*

– Kyla, CCT

### RESOURCES:

**Black Dog Institute.** Self Care for Health Professionals <https://bit.ly/3gOmCBB>

**Burnout: Your First Ten Steps.** Dr Amy Imms, Australia 2019

## Are You Burnt Out? Wisdom Box

In her book *Burnout: Your First Ten Steps*, Dr Amy Imms lists signs and symptoms of burnout. If some of these changes are showing up for you lately, you need to take more care.

How many of these do you have now?

- |  |  |
|--|--|
| <input type="checkbox"/> Sinking feelings or apprehensiveness before or at work              | <input type="checkbox"/> Being more irritable, angry and frustrated than usual |
| <input type="checkbox"/> Feeling unusually emotional or teary                                | <input type="checkbox"/> Making more mistakes than usual                       |
| <input type="checkbox"/> Thinking less clearly   | <input type="checkbox"/> Feeling exhausted a lot of the time                   |
| <input type="checkbox"/> Doubting your skills and abilities                                  | <input type="checkbox"/> Withdrawing, avoiding socialising                     |
| <input type="checkbox"/> Being less patient than usual                                       | <input type="checkbox"/> Feeling overwhelmed by responsibilities               |
| <input type="checkbox"/> Feeling no joy or hope about life or work                           | <input type="checkbox"/> Feeling cynical                                       |
| <input type="checkbox"/> Finding decision-making difficult                                   | <input type="checkbox"/> Loss of empathy                                       |
| <input type="checkbox"/> Second guessing yourself  | <input type="checkbox"/> Feelings of guilt                                     |
| <input type="checkbox"/> Turning up to work late or taking days off for no particular reason | <input type="checkbox"/> Reduced concentration                                 |

If you can see these changes in yourself or a colleague, seek support and help.



Photo courtesy of Cancer Care Team





Juiced Life

GENERAL WASTE

12

CANCER CARE TEAM

NOVEMBER

# APPENDIX A SAMPLE PROGRAM REQUEST TO HOLD A MAMMOGRAM SCREENING DAY

NAME OF PROGRAM: Breast Screening Day  
 DATE OF PROGRAM:  
 PROGRAM ORGANISER/S: Cancer Care Team / Women's health worker

## PROGRAM TARGET GROUPS AND OBJECTIVES

### 1. Target group and explanation (reasons why):

Our main target group will be Aboriginal and Torres Strait Islander female community members who have a family history of breast cancer, previous abnormal results, or who have never had a mammogram or are overdue on the recall list in our medical records. Check if a client's mammogram is due by contacting BreastScreen 132 050.

We will focus on Aboriginal and Torres Strait Islander females from 50-74 years of age. This is the recommended age for screening but women will be welcome to attend if 40 or over. We will encourage those that have never had a mammogram to attend the BreastScreen Event.

Previous BreastScreen Days have found people who needed or have never had a mammogram. In evaluations, participants wanted more BreastScreen events. The participants felt safe in the BreastScreen Clinic and said that staff made the event enjoyable. They felt like the venue was an appropriate place for the event.

### 2. Estimated amount of people expected to attend:

Anticipating 16 Aboriginal Torres Strait Islander community members. 10-minute appointments.

### 3. Aims of the program:

- Improve the breast screening rates to ensure early detection and increase survival of breast cancer for our community members.
- Increase awareness among female community members regarding the importance of screening for early detection of breast cancer.
- Provide culturally safe education and resources about breast cancer, the screening process, breast awareness, treatments and survival rates.
- Create a community shared experience through art therapy at the BreastScreen clinic while the clients wait for their appointments.

### 4. Brief explanation of the program content:

- Book the BreastScreen Centre for one day (9am-1pm).
- Provide platter which includes dip, carrot sticks, fruit, and tea and coffee for everyone.
- Provide culturally safe education and resources with the assistance of other organizations including BreastScreenNSW.
- Gift Vouchers for all participants.
- Lucky Door Prize.
- Craft day whilst participants wait.

#### LOCATION AND DATE

Proposed date and location of program: Breast Screen clinic

#### PLANNING TIME FRAME

Estimated planning time: 4 weeks

#### EQUIPMENT

Equipment needed: Transport. Tea & Coffee, plates and cups, food, serviettes. Art supplies.

#### PROMOTION

Program promotion: Personal invitations to clients, posters and announcements Cultural Centre, Women's Health Centre, Neighborhood Centre, emails and social media

#### COLLABORATION

Staff and other people involved, including outside stakeholders: BreastScreen Australia, Cancer Care Workers/ women's health workers

#### FINANCE

|                              |              |
|------------------------------|--------------|
| Budget:                      | \$           |
| Total Funds required:        | \$150        |
| Funding received externally: | \$           |
| <b>TOTAL:</b>                | <b>\$150</b> |

- Please attach Expense Form listing all expenses.
- Please attach a Run Sheet outlining details of the event

#### Approved/Declined - Manager

\_\_\_\_\_  
 Manager

\_\_\_\_\_  
 Date

#### Approved/Decline - CEO

\_\_\_\_\_  
 CEO

\_\_\_\_\_  
 Date

## APPENDIX B SUPPORTING CANCER PREVENTION AT YOUR SERVICE

There are many ways your team can support cancer prevention programs in your health service.

### *On your website:*

- include details of the time and location of clinics, or contact details of your women's health nurse or AHP, or smoking cessation worker
- include details of special events, like World No Tobacco Day or Australia's Biggest Morning Tea
- link to online health promotion material supporting prevention, e.g. information about quitting smoking, cervical screening, breast cancer screening and bowel cancer screening, especially videos of Indigenous people teaching; and
- link to other websites that provide unbiased and evidence-based information (like Quit or the Cancer Council websites).

### *SMS health messages:*

- send text health messages if people consent when they come to the AMS; and
- text reminders for appointments or check-ups.

### *Smartphone apps:*

- encourage staff to recommend apps to help with weight loss, exercise, or to quit smoking.

### *Practice newsletter:*

- email a newsletter, feature it on your website or social media site, and have printed copies for the waiting room
- include details of upcoming events: Women's Health Day, Mammography Day, Quit support.

### *Waiting room materials:*

- display posters and leaflets from the Cancer Council, Cancer Australia and Quit, which provide clear, simple, engaging, evidence-based and unbiased information
- ensure materials are culturally appropriate for your area – using language and local people
- if you have a TV in the waiting room, show videos or advertisements about programs or upcoming events
- consider having iPads or computers in the waiting room for patients to browse educational material from selected websites; and
- people love noticeboards with pictures of Community. Always ask permission to display a person's photos.

### *Train reception staff:*

- include reception staff in your orientation cultural training and organise mentoring. Ensure staff have information about health promotion resources and events; and
- set a policy to check each person's contact details are complete for recalls and reminders when they are in the waiting room or at reception.

### *Patient education materials:*

- seek out health promotion materials produced locally or specifically for Aboriginal people. Or, of course, you can use mainstream resources
- ask Aboriginal staff to review materials to ensure they are appropriate, and seek feedback from Community
- education materials handed directly to patients by the AHP, RN or GP can have an impact – provide access from consulting room computers; and
- review your materials regularly to ensure they are current, evidence-based, unbiased and produced by a reliable source.

### *Many AMSs have skin cancer programs:*

- provide sun protection education with information such as pamphlets on sun protection. If you can, provide hats, sunglasses and sunscreen samples
- offer skin lesion education – information and pamphlets on how to recognise abnormal skin lesions. Posters in the clinic are a good tool
- enter reminder for skin checks for those at higher risk of melanoma
- hold skin check days for those at high risk, with the GP.

### *Enhancing involvement in prevention programs:*

- establish Aboriginal control of service design and delivery and engage Aboriginal staff
- ensure gender-appropriate staff are involved in programs
- train staff, for example, upskilling RNs and AHPs in cervical screening
- provide appropriate health promotion resources
- offer cross-cultural training for staff
- arrange transport for people
- organise mobile outreach services (like mammography vans)
- adopt new technologies (e.g. self-collected cervical screening)
- improve recall and reminder systems
- provide comprehensive care, combined with other primary care; and
- deliver continuity of care by supporting staff.

## APPENDIX C CARE PLANS & TEAM CARE ARRANGEMENTS

Thoughtful and informed care plans help the person with cancer feel more in control of their health. The primary care team can prepare these in conjunction with the person with cancer and other health professionals caring for them.

### GP MANAGEMENT PLANS & TEAM CARE ARRANGEMENTS

ACCHO staff can prepare Care Plans and Team Care Arrangements (TCA), billed through Medicare. Item number 721 is for a Care Plan / GP Management Plan (GMP), and item number 723 is for a TCA. There need to be at least three members in a team to make a TCA. The GP is one team member. A nurse or nurse practitioner, Aboriginal and Torres Strait Islander health practitioner or Aboriginal health worker can also be team members as long as they provide care that is different to the care provided by the other team members.

These plans can be prepared and billed annually, with reviews visits (item 732) every three months. There are different item numbers available for clients in a nursing home. Care plans can be prepared by another team member (such as the nurse or AHW), then the GP needs to sign them and coordinate the arrangement.

People are eligible for a GPMP and TCA if they suffer from at least one medical condition that has been present or is likely to be present for at least six months or if the condition is terminal.

Each person in the team must provide a different type of ongoing treatment or service. They do not need to be Medicare-eligible providers, (but the person's carer does not qualify). TCAs are often used to access services provided by Allied Health, like podiatry, physiotherapy or acupuncture.

### SURVIVORSHIP CARE PLANS

A survivorship care plan is a written document detailing a client's cancer diagnosis, summarising their current and future treatment plans. It specifies follow-up and monitoring

appointments, and other strategies to help the patient stay well. Many oncology services provide care plans for patients, focussing on cancer treatment and follow-up. Or an Aboriginal and Torres Strait Islander Health care plan can have cancer treatment and follow up in their GPMP (see above). The primary care team at an ACCHO needs a holistic care approach, as the person may also have a chronic disease like diabetes or a mental illness.

#### *A survivorship care plan or GPMP could include:*

- the name and stage of the cancer for which the survivor received treatment
- the treatments they received
- short-term and long-term effects of treatment
- symptoms and signs to watch for
- how often and when follow-up should be undertaken
- suggestions for lifestyle changes that reduce the risk and severity of treatment side effects and prevent future cancer. For example, healthy diet, stop smoking, manage alcohol, reduce obesity and overweight, maintain exercise and sun protection; and
- future dates for screening for breast cancer, bowel cancer and cervical cancer.

#### *A copy of the care plan should be:*

- sent to all other health care professionals involved in the survivor's care
- sent with referrals
- given to the patient in a folder or plastic sleeve
- uploaded to MyHealthRecord

### RESOURCES:

**Australian Cancer Survivorship Centre (2020) Survivorship Care plans -** <https://bit.ly/3vfVQXA>  
**Cancer Council Aboriginal Cancer Journeys -** <https://bit.ly/3ix4wGh>

### EXAMPLE OF A CARE PLAN (GPMP): Elsie Wannabee 12.10.52 Breast cancer survivor

| GP MANAGEMENT PLAN (GPMP)                      |                                |   |  |
|--|--------------------------------|---|--|
| Patient problems / needs / relevant conditions | Goals - changes to be achieved | Required treatments and services, including patient actions   | Arrangements for treatments/services (when, who, and contact details)  |
| Breast cancer                                  | Stay cancer-free               | <ul style="list-style-type: none"> <li>• No longer needs to see the surgeon but yearly breast check with GP</li> <li>• Annual check with oncologist due March</li> <li>• Check with radiation oncologist due Sep this year</li> <li>• ITC team to organise appointments, pay specialist gap, organise transport</li> <li>• Attend Elders' Exercise Group</li> <li>• An exercise physiologist to supervise an exercise plan</li> </ul> | <ul style="list-style-type: none"> <li>• Breast surgeon</li> <li>• Oncologist</li> <li>• Radiation oncologist</li> <li>• Breast care nurse at the hospital</li> <li>• AHW Pat, RN Sandy, GP Alison</li> <li>• ITC Worker Shelley</li> <li>• Exercise physiologist Shane</li> </ul> |
| Housing  |                                | Welfare worker to assist with Housing Application   | Welfare Worker Narelle   |
| Depression and grief                           | Stabilise mood                 | <ul style="list-style-type: none"> <li>• Social and Emotional Wellbeing team to continue support</li> <li>• Attend the Mental Health craft group - organise transport.</li> <li>• GP Alison to complete Mental Health Care Plan</li> <li>• GP to refer to psychologist Allan</li> </ul>   | <ul style="list-style-type: none"> <li>• GP Alison</li> <li>• Psychologist Allan</li> </ul>  |
| Prevention                                     |                                | <ul style="list-style-type: none"> <li>• Health Check due July</li> <li>• Influenza imms due April</li> <li>• CST, May 2026</li> <li>• Bowel screening April</li> </ul>   | AHW Pat  |

## APPENDIX D ADVANCE CARE DIRECTIVE

I, \_\_\_\_\_  
(Full Name)  
 of, \_\_\_\_\_  
(Home Address)  
 DOB: \_\_\_\_\_

Make this directive for my future health care of my own free will. I have made this in consultation with my Doctor, who has discussed treatments, options and consequences and has deemed me to have capacity to make the following decisions. (Please sign on completion of form)

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Dr Name: \_\_\_\_\_

Clinic Address: \_\_\_\_\_

Signature: \_\_\_\_\_ Date: \_\_\_\_\_

If at any time I am unable to make decisions about my medical care and treatment, the Advance Care Directive (ACD) reflects my wishes and choices concerning my health, care and treatment. This document **should only be used** if I am **NOT** able to speak for myself competently.

If I am not able to speak for myself I would like health professionals to speak with: (list person or persons that you are happy to speak for you)

\_\_\_\_\_

### LEGALLY APPOINTED PERSONS

| <i>Document</i>  | <i>Yes / No</i> | <i>Name and Contact Details</i> |
|--|-----------------|---------------------------------|
| Enduring Guardian (Health decisions)                   |                 |                                 |
| Enduring Power of Attorney (Money & Finance decisions) |                 |                                 |
| Will   |                 |                                 |

Who has copies of these:

Name: \_\_\_\_\_

Address: \_\_\_\_\_

Contact: \_\_\_\_\_

Is the Enduring Guardian aware of the Advance Care Directive?  Yes  No

Have you discussed the Advanced Care Directive with anyone other than your Doctor?

Yes Who: \_\_\_\_\_

Do they have a copy?  Yes  No

No Where are copies of the Advance Care Directive located?

\_\_\_\_\_

### MEDICAL CHOICES:

If I am unable to make decisions about my health or treatment due to illness or injury, the following things are very important to me and I would like them to be considered when making decisions for me:

\_\_\_\_\_

\_\_\_\_\_

In the event of being severely ill or badly injured, where there was very little possibility of recovery to a meaningful existence and you are unable to make medical decisions for yourself, what following options would you choose for yourself: (Please initial the box of your choice)

### Cardiopulmonary Resuscitation (CPR):

If my heart or breathing stops due to old age or irreversible health problems my choice if CPR is an option:

|                          |  |
|--------------------------|--|
| <input type="checkbox"/> | Please attempt CPR to try to restart my heart and or breathing |
| <input type="checkbox"/> | Please DO NOT attempt CPR and do allow me to die naturally     |
| <input type="checkbox"/> | Unsure let the treating Doctor decide                          |

Please initial the box of choice

| <i>Treatment Offered</i>  | <i>Yes</i> | <i>No</i> | <i>Unsure</i> |
|---|------------|-----------|---------------|
| Antibiotics for serious infections  |            |           |               |
| Intravenous fluids (Drip) for life support and maintenance  |            |           |               |
| Artificial Feeding: Nasogastric Tube (tube from nose to stomach) or PEG tube (through abdomen to stomach) |            |           |               |
| Surgical Procedure including anaesthetic  |            |           |               |
| Blood transfusion   |            |           |               |

## APPENDIX D ADVANCE CARE DIRECTIVE

This page is optional. (Please remove if not being used)

### MY PERSONAL AND SPIRITUAL CARE REQUESTS

If I am unable to communicate my wishes, this is what I would like to be considered: \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

In the event of my death, I would like to be returned home to my country  Yes  No

Location: \_\_\_\_\_

\_\_\_\_\_

**I am for** *(Please initial)*

|  |                  |
|--|------------------|
|  | <b>Burial</b>    |
|  | <b>Cremation</b> |
|  | <b>Other:</b>    |

### DONATIONS:

Are you a registered organ donor?  Yes  No

My family and friends are aware of my wish to donate

Yes  No  Not applicable

Is there a funeral payment plan?

Yes  No

Who is the funeral payment plan with?

\_\_\_\_\_

\_\_\_\_\_

*(Please initial appropriate box)*

| <i>Donation</i> | <i>YES</i> | <i>NO</i> |
|-----------------|------------|-----------|
| <b>TISSUE</b>   |            |           |
| <b>ORGAN</b>    |            |           |
| <b>BODY</b>     |            |           |

If I have given consent for organ donation, I understand that in some situations the intensive care unit may be required to use some life sustaining treatments to comply with my wish to donate. I understand and accept that this may occur.

\_\_\_\_\_  
Full name

\_\_\_\_\_  
Witness Name

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Witness Signature

\_\_\_\_\_  
Date

*Adapted from NSW Ministry of Health Making an Advance Care Directive 2018. Accessed at: <https://www.health.nsw.gov.au/patients/acp/Publications/acd-form-info-book.pdf>*

## APPENDIX E FUNDING FOR CANCER SERVICES

Aboriginal Community Controlled Health Organisations (ACCHOs) fund programs for Aboriginal people with cancer in a variety of ways. This might include:

- Cancer Care Team (delivering cancer care programs from prevention through to end of life care)
- General prevention (such as conducting Health Checks), done by AHW, RNs and GPs
- Tobacco Workers
- Women's Health Workers (cervical screening and mammography programs)
- Integrated Team Care Workers (including supporting people with cancer); and
- Palliative Care Workers.

### INDIGENOUS HEALTH INCENTIVE

This incentive supports practices and Indigenous health services to provide better health care for Aboriginal and Torres Strait Islander patients. The patient must agree to have the practice written on the Indigenous Health Incentive and PBS Co-payment Measure patient registration and consent form (IP017) at [servicesaustralia.gov.au/pip](http://servicesaustralia.gov.au/pip)

This consent means they expect the practice will be their usual care provider and oversee their chronic disease management.

### PHARMACEUTICAL BENEFITS SCHEME (PBS) CO-PAYMENT MEASURE (ALSO KNOWN AS CLOSE THE GAP – CTG)

This is available to all Aboriginal and Torres Strait Islander people, even if they do not have a chronic disease such as cancer. This means that participants can obtain PBS medications at no cost (if they are on a Health Care card) or at discounted rates. This does not apply to over the counter medications (such as most vitamins, cough mixtures).

CTG scripts cannot be written by junior doctors within hospitals, so a person being discharged from hospital will need an appointment with the GP so as to get CTG scripts for new medications. Some specialists also need reminders about how to ensure scripts are dispensed under CTG. Some newer or difficult to obtain treatments such as immunotherapy are not covered by the Pharmaceutical Benefits Scheme.

### PIP INDIGENOUS HEALTH INCENTIVE

The PIP Indigenous Health Incentive supports general practices and Aboriginal health services to support health care for Aboriginal and Torres Strait Islander patients with chronic diseases, including cancer, who:

- Are of Aboriginal and/or Torres Strait Islander origin;
- Are 15 years or older; and
- Have a chronic disease (such as cancer).

### MEDICARE SERVICES

The Medicare Benefits Scheme and Practice Incentive Payments (PIP) can be used effectively to support cancer care.

Primary care services usually received a large proportion of their income to support services – including those for people with cancer – through PIP and Medicare Benefits Scheme (MBS) items.

Most ACCHOs use Health Professional Online Services (HPOS), an online site that lets you search and confirm a patient's Medicare number and concessional eligibility. You can also check which Medicare items they are eligible for (for example, if an Aboriginal Health Check has been billed in the last 9 month claiming period).

### HOW TO USE THE MBS ITEMS ONLINE CHECKER FUNCTION IN HPOS

- Go to [servicesaustralia.gov.au/hpos](http://servicesaustralia.gov.au/hpos) and log on to HPOS using your PRODA account
- Select 'MBS Items Online Checker'
- Enter the patient's Medicare details
- Select the provider details. There are two drop-down boxes. In the first, select the provider stem. In the second, select the location and check digit
- Select the MBS item you wish to check
- Select 'Search' to perform the check. The search results will show you patient eligibility for any of the items you selected.

*You will find a list of Medicare Item numbers and descriptions on page 104.*

### CANCER GRANTS

A range of organisations offer grants for cancer care programs. This might include on-off grants for World No Tobacco Day or to promote breast screening, to funding for salaries for workers. Organisations such as Aboriginal peak bodies (e.g. the AHMRC), Local Health Districts, state-based cancer organisations (such as Cancer Institute NSW) and Cancer Councils may offer grants for cancer programs.

### NSW RURAL DOCTORS NETWORK

NSWRDN funds Outreach Workers in a range of health services, including ACCHOs and LHDs, including Aboriginal Health Workers or Practitioners, nurses, general practitioners, smoking cessation workers, psychologists, pain management teams and cancer care workers.

Contact the Rural Doctors Network in your state to find out about their programs. Your organisation could consider how to use a position to support cancer care services. Accessed at: <https://www.nswrdn.com.au>

### RESOURCES

**Indigenous Health Incentive Forms** available at <https://bit.ly/3sKDJuN>

**PIP programs: RACGP (2020) Practice Incentives Program Quality Improvement Incentive (PIP QI) fact sheet download** - <https://bit.ly/3pCu7A3>

## MEDICARE ITEMS USEFUL IN CANCER CARE FOR ABORIGINAL PEOPLE

| ITEM No. | DESCRIPTION   | ITEM No. | DESCRIPTION  | ITEM No. | DESCRIPTION  |
|----------|---|----------|--|----------|--|
| 3        | Consultation at consulting rooms (brief)  | 10997    | Monitoring and support for a person with a Chronic Disease Care Plan ( <i>Max 5 per calendar year, practice nurse or Aboriginal and Torres Strait Islander Health Practitioner</i> ) | 2715     | Prepare GP Mental Health Treatment Plan, lasting at least 20 minutes (medical practitioners who have undertaken mental health skills training)   |
| 23       | Consultation at consulting room < 20 minutes  |          |  |          |  |
| 36       | Consultation at consulting rooms, at least 20 minutes   | 10988    | Immunisation (Aboriginal and Torres Strait Islander Health Practitioner)   | 2717     | Prepare GP Mental Health Treatment Plan, lasting at least 40 minutes (medical practitioners who have undertaken mental health skills training)   |
| 37       | Consultation at a place other than consulting rooms eg home visit, at least 20 minutes  | 10989    | Wound Management (Aboriginal and Torres Strait Islander Health Practitioner)   |          |  |
| 44       | Consultation at consulting rooms, at least 40 minutes   |          |  | 10983    | Telehealth service - the patient, at the time of the consultation, must be either located in an eligible telehealth area at least 15 kilometers by road from the treating specialist, physician or psychiatrist or getting a service from an Aboriginal Medical Service, or Aboriginal Community Controlled Health Service |
| 10990    | Additional payment for each bulk billed medical service provided to Commonwealth concession cardholders and children under 16 years                       | 82200    | Brief consultation (Nurse Practitioner)  |          |  |
|          |   | 82205    | Short consultation, less than 20 minutes (Nurse Practitioner)  |          |  |
|          |   | 82210    | Detailed consultation, at least 20 minutes (Nurse Practitioner)  |          |  |
| 10991    | Additional payment for each bulk-billed medical service provided to Commonwealth concession cardholders and children under 16 years- specified areas only | 82215    | Extensive consultation, at least 40 minutes (Nurse Practitioner)   |          |  |
|          |   | 721      | Prepare GP Management Plan   |          |  |
|          |   | 723      | Coordinate development of Team Care arrangements   |          |  |
| 715      | Aboriginal and Torres Strait Islander peoples' health Assessment  | 2700     | Prepare GP Mental Health Treatment Plan, lasting at least 20 minutes   |          |  |
| 81305-60 | Allied health services after health check   | 2701     | Prepare GP Mental Health Treatment Plan, lasting at least 40 minutes   |          |  |
| 10987    | Follow up for a patient who has received an Aboriginal and Torres Strait Islander peoples health assessment (Maximum 10 services per calendar year)       | 2712     | Review GP Mental Health Treatment Plan   |          |  |
|          |   | 2713     | Mental health consultation (not associated with a GP Mental Health Plan), lasting at least 20 minutes  |          |  |
| 10950-58 | Allied health services after care plan  |          |  |          |  |

Dept Health (2020) MBS items for Aboriginal Community Controlled Health Services and other Primary Health Care Providers. Accessed at: <https://www1.health.gov.au/internet/main/publishing.nsf/Content/indigenous-mbs-frequently-claimed-items>  
<http://www.medicareust.com/OTHER/indigenoushealthservicesguide.pdf>  
 Department of Human Services Indigenous Access line on 1800 556 955.

### CASE STUDY- ALICE RUSSELL

The Aboriginal Medical Service (AMS) already received \$1000 as a practice sign-on payment to undertake activities to provide health care for Aboriginal people.

Alice Russell is a 58 year old woman who has been recently diagnosed with bowel cancer.

Alice is already signed up for CTG (for which the practice receives a payment), and has a regular Aboriginal health check.

Many of the items that are recorded during her health check (and contribute to cancer prevention) contribute to Practice Incentive Payments (PIP) for the practice, including recording smoking status, weight, alcohol consumption, and up to date cervical screening.

The general practitioner (GP) refers to the local radiologist who bulk bills for CT scans and for ultrasounds rather than the one that charges a gap fee. Her treating team has good relationship with the local gastroenterology team and the specialists normally bulk bills consultations and procedures in hospital are free.

Her surgeon does not bulk bill. The team at the ACCHO completed a Chronic Disease Care Plan and Team Care Arrangement, and referred her to the Integrated Team Care (ITC), who organised to pay the gap for the consultation fee with the surgeon. There was no cost for the surgery as it was undertaken in a public hospital. One of the follow-up visits is done by telehealth and she does this from the AMS with the Aboriginal Health Practitioner (AHP) accompanying her.

The AHPs at the AMS review her before consults, take her observations and can bill up to five 10987 consults, especially as they

are also trying to support her to stop smoking at each visit.

Her team at the ACCHO also signs her up for the Indigenous Health Incentive Chronic Disease program each year, for which the service can receive a payment each year for coordination of her chronic disease. Her team can also bill five 10997.

She has consults billed by the GP for every visit as usual.

She can access five Enhanced Primary Care (EPC) services from her health check and five EPC services from her care plan to visit allied health practitioners, and uses these to be seen by the dietitian to improve her diet and lose weight, and the exercise physiologist, to give advice on exercise.

Three months later she has also developed some back pain, and this is added to the Chronic Disease Care Plan, along with a referral to a physiotherapist, for which she can use some of her EPC referrals.

She develops depression and her GP also completes a Mental Health Care Plan (MHCP) so she can access the psychologist, who has expertise in counselling those with cancer, and after six sessions she has a MHCP review.

The primary care team discusses having a case conference with Alice, which includes her AHP, RN, GP, psychologist and radiation oncologist, to discuss her treatment plan after discharge.

She is now on a range of medications, including for her pain. The GP refers to the local pharmacist for a Domiciliary Medication Management Review (Home Medication Review) and then reviews her after the pharmacist has made recommendations for changes to her medications.



## APPENDIX F CONTINUOUS QUALITY IMPROVEMENT

Continuous Quality Improvement (CQI) is part of a range of activities that support and improve quality in health care, including in cancer care, in our communities.

- CQI drives service improvements through continuous and repeated cycles of changes;
- CQI is for teams to use data to identify areas for action, develop and test strategies, and make changes in service delivery; and
- CQI is part of the core business of providing health care.

This book was developed to support Quality Improvement (QI) in ACCHOs, using the software Communicare®.

The online appendix developed as part of this project provides QI 'recipes' and ideas for quality improvement for: All cancers; Breast cancer; Cervical cancer; Lung cancer; Bowel cancer; and Advance care planning

These resources can be accessed at - <https://www.ahmrc.org.au/resources/>

### GLOSSARY

**Aboriginal (adjective):** A person of Aboriginal descent who identifies as Aboriginal and is accepted as such by the community in which he [or she] lives.

**Coronial autopsy:** Post-mortem investigation on a reportable death.

**Death:** May also be referred to as 'passing' of a person.

**Dying:** Dying may also be referred to as the final stage/ journey of life.

**Hospital autopsy:** Post-mortem investigation on a non-reportable death.

**Aboriginal and Torres Strait Islander Health Worker (Indigenous Health Worker):** A person who provides Aboriginal primary health care, provides cultural security and safety, may be involved in disease prevention and health

promotion, and who possessed local community knowledge and a holistic approach to health care (may include Aboriginal Health Practitioners, Aboriginal Liaison Officer and Aboriginal Health Workers)

**Aboriginal and Torres Strait Islander Hospital Liaison**

**Officer:** Hospital employee who provides support to Aboriginal and Torres Strait Islander people presenting to or admitted in hospitals

**Sorry Business:** The death/ passing of a person.

**Torres Strait Islander:** A person of Torres Strait Islander descent who identifies as a Torres Strait Islander and is accepted as such by the community in which he [or she] lives (the original inhabitants of the Torres Strait Islands).

### ACRONYMS

|       |   |      |                                    |          |  |
|-------|---|------|------------------------------------|----------|--|
| ACCHO | Aboriginal Community Controlled Health Organisation | CT   | computerised tomography            | PBS      | Pharmaceutical Benefits Scheme         |
| ACP   | Advance Care Plan                                   | CTG  | Close the Gap                      | PHC      | primary health care                    |
| ACD   | Advance Care Directive                              | EMR  | electronic medical record          | PHN      | Primary Health Network                 |
| AHMRC | Aboriginal Health and Medical Research Council      | GP   | general practitioner               | PIMS     | patient information management systems |
| AHW   | Aboriginal Health Worker                            | GMP  | GP management plan                 | PIP      | Practice Incentive Payments            |
| AHP   | Aboriginal Health Practitioner                      | ITC  | Integrated Team Care               | PSA      | prostate specific antigen              |
| AIHW  | Australian Institute of Health and Welfare          | KPI  | key performance indicator          | RN       | registered nurse                       |
| AMS   | Aboriginal Medical Service                          | MBS  | Medicare Benefits Schedule         | SA       | South Australia                        |
| ALO   | Aboriginal Liaison Officer                          | MDT  | multidisciplinary team             | SCNat-IP | Supportive Care Needs Assessment Tool  |
| CPR   | cardiopulmonary resuscitation                       | MRI  | magnetic resonance imaging         | TCA      | Team Care Arrangement                  |
| CQI   | continuous quality improvement                      | NBM  | nil by mouth                       | TIS      | Tackling Indigenous Smoking            |
|       |   | NCSR | National Cancer Screening Register | UV       | ultraviolet                            |
|       |   | NGO  | non government organisations       | WA       | Western Australia                      |
|       |   | NSW  | New South Wales                    |          |  |
|       |   | NT   | Northern Territory                 |          |  |



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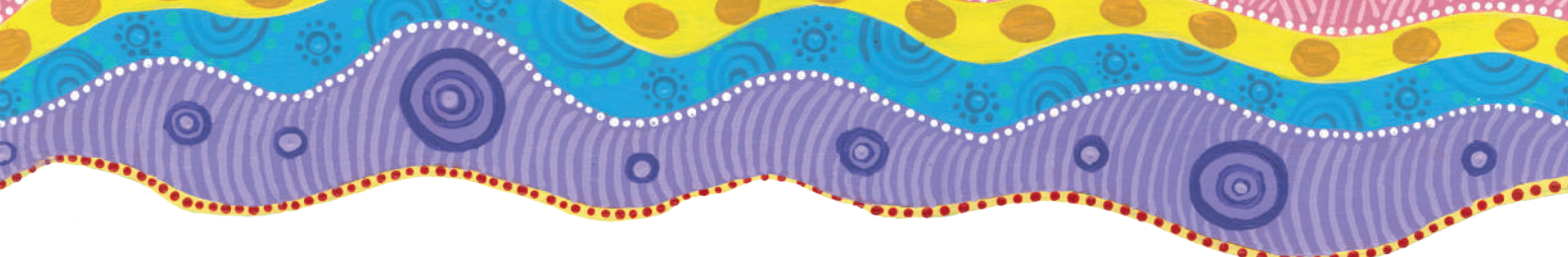
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# Ngununggula

## *Walking and Working Together*

This heartfelt and wise book is inspired by the deep experience of cancer care workers. And contains powerful stories from Aboriginal people on a cancer journey.

*Ngununggula - walking and working together* is a manual by and for health professionals supporting Aboriginal people with cancer.

It is written for Aboriginal Health Workers and other health professionals working in Aboriginal Community Controlled Health Organisations, hospitals and non-government organisations, so they can support Aboriginal people with (or around) cancer.

The Illawarra Aboriginal Medical Service Cancer Care Team and medical writer Dr Janelle Trees developed the book as part of a collaboration with the Aboriginal Health and Medical Research Council, the University of Sydney, Menzies School of Health Research, Coordinare and the University of Wollongong, funded by Cancer Australia.

*Check this book out! It's cultural, spiritual, and full of down-to-earth info. Health professionals, healers, clients, and their families will find treasure here.*

– Dr Janelle Trees, Dhanggati,  
interviewer and co-author.