Cancer - what to expect
Information for Aboriginal and Torres Strait Islander people who have cancer

This information explains what to expect before, during and after your cancer treatment, and tells you about the care you should be offered. Your carer, family and community might also find this information helpful.

There are also guides that tell you what to expect for your type of cancer. You can find guides about different cancer types at www.cancerpathways.org.au
If you have cancer, it is important that you have all the information and support you need about your treatment. Starting treatment as early as possible and completing it gives you the best chance of getting better.

**Seeing the doctor**

If you want to see either a male or female doctor, ask if this is possible. It may help if you write down questions and take them with you to your appointment. You can ask the doctor or someone in your cancer care team to explain anything you don’t understand.

You can take family or other people to support you at your appointments and tests, or ask if an Aboriginal and/or Torres Strait Islander Health Worker, Health Practitioner or Liaison Officer can be there.

**Talk to the doctor about:**

- any new or unusual changes in your body
- how you are feeling
- whether you are in any pain
- any other health problems you have
- whether anyone in your family has or had cancer
- any other problems that are worrying you.

Your doctor will work with a team of specialists and nurses that understand cancer. Your personal information will be kept private and only shared with health professionals involved in your care. A member of your team should know about Aboriginal and Torres Strait Islander culture and help you get support. You may also have a care coordinator to help with appointments and keeping everything on track. You might find it helpful to write important information down. You can also ask your doctor to write down information that you want to remember.
Your doctor and team members will talk with you about your needs, answer your questions and tell you where to get information and support.

You can ask for information that makes sense to you, and get support for:

- physical symptoms, such as pain, feeling sick or feeling tired
- emotional needs, like fear, sadness and anger
- practical needs, like help with transport and costs of your care
- information needs, to help you understand more about what may happen.

Your doctor can connect you with other services and health professionals to make sure you stay as well as you can.

**Having tests**

Your doctor or specialist will tell you if you need tests and where to go to have them.

If you need help getting to your appointment to see the specialist or to have tests, talk to your doctor or Aboriginal and/or Torres Strait Islander Health Worker, Health Practitioner or Liaison Officer. They can help organise transport for you.

Ask the doctor, Aboriginal and/or Torres Strait Islander Health Worker, Health Practitioner or Liaison Officer:

- Why do I need this test?
- Where do I have it?
- How will I get there?
- What happens during the test?
- Can someone come with me?
- Will it cost me money?
- What will the test tell me?
- When will I know the results?

**What happens next?**

Your doctor or specialist will get your test results and talk to you about them.

Someone from your cancer care team should make sure you have the information and support you need.
Having treatment

Your team will look at your test results and explain what they mean. They will talk to you about your treatment options and the aim of your treatment. Your team will help you to choose treatment that is the best for you.

Before deciding on treatment, you can talk to your family and other people in your community, or ask for a second opinion from another doctor.

It is really important that you complete your treatment.

Your team might talk to you about taking part in a clinical trial. A clinical trial is used to test a new treatment, or to see if a treatment works better than another. If you are in a clinical trial, you will have the best current treatment or a new treatment. You can say yes or no to taking part in a clinical trial – you can ask questions to find out as much as you can to help you decide if it is right for you.

Let your team know about any traditional medicine or bush medicine you are using or thinking about trying. Your team can help you decide how it will work with your treatment.

There can be costs for your cancer care, as well as for things like accommodation and travel. There is support available to help make things easier for you. Talk to your doctor or the social worker at the hospital about the support you can get.

For more information about practical support services visit www.cancer council.com.au/get-support/practical-support-services

You can ask your team:

• what treatment you are having
• why you are having it
• what will happen
• what it will do to your body
• how long it will take
• if there are any costs
• what are the advantages and disadvantages
• how it might make you feel (side-effects), and what you can do to feel as well as possible

• how any traditional medicine or bush medicine will work with your treatment
• what to expect afterwards.
After your treatment

After your treatment is finished, your doctor should give you a treatment summary. It will tell you:

- the tests you had to diagnose your cancer, and the results of these tests
- the treatment you had, and when you had it
- the support services and other treatment plans you received.

Your doctor will tell you what happens next, including:

- when to come back for a check-up
- whether you need to have any tests before your check-up
- how to manage any side-effects you have
- what signs to look out for if the cancer comes back or gets worse
- how to get help if you need it
- what you can do to stay healthy.

Side effects

Some people get side effects during and after their treatment and they can make you feel unwell. You might have side effects straight away, not at all, or a long time after your treatment. Ask your doctor what side effects are common, so you know what to expect.

You can talk to your doctor about your side effects or visit www.cancervic.org.au/about-cancer/survivors/long-term-side-effects

Palliative care

Palliative care can help you to feel well during your treatment. It is not only used at the end of life - it is for people at any age who have a serious illness. Palliative care can help with pain relief, to reduce your symptoms and to improve your quality of life. It can also help with emotional, social, spiritual and cultural concerns.

You can talk to your doctor about the type of palliative care that is best for you or visit www.palliativecare.org.au or http://dyingtotalk.org.au/aboriginal-torres-strait-islander-discussion-starter

Advance care plan

Your team might work with you to make an advance care plan. If you become very sick, your family and Health Worker may need to make decisions for you. An advance care plan is a way of setting out your wishes and making sure everyone knows what you want in future medical care.

You can talk to your doctor about making an advance care plan together or visit www.advancecareplanning.org.au

It is important to stay well after cancer and have regular check-ups, because sometimes cancer can come back after treatment.

Talk to your doctor if you’re worried about cancer coming back. They can give you information, support and a check-up.
Support

You can ask for information and support at any time. Talk to someone from your cancer care team if you need help with transport or accommodation. If you need someone to travel with you, you can ask a member of your team if this is possible. You can tell them if you have family or community responsibilities that make it hard for you to be away from home to see if they can make it easier for you.

You can ask your doctor about finding a cancer support group. Some of these are online or can be via telephone. It can help knowing that there are other people who understand what you are going through. Your friends and family can talk to a support group for carers.

There are a lot of things to think about when you have cancer.
A lot of information and support is available. It is important that you do what is right for you.
You can work with your team to make sure you have the best care.

Further information and support

Cancer Australia
For information and resources for Aboriginal and Torres Strait Islander people affected by cancer, visit canceraustralia.gov.au/affected-cancer/atsi/resources-people

Cancer Council
For information and support call Cancer Council on 13 11 20
Nurses can answer your questions about cancer, explain what will happen during your cancer care and link you to support groups and other community resources

Cancer Council Online Community
To connect with others in a supportive online community for people affected by cancer, visit onlinecommunity.cancercouncil.com.au

Carers Australia
For support and advice for carers, call the Carers Association on 1800 242 636

National Indigenous Cancer Network
For information about cancer, and resources and links to help Aboriginal and Torres Strait Islander people affected by cancer, visit www.nican.info

This work is available at canceraustralia.gov.au and www.cancerpathways.org.au