Cancer treatment side effects

A guide for Aboriginal Health Workers
Introduction

As an Aboriginal Health Worker, you play an important role in supporting Aboriginal people with cancer throughout their cancer treatment.

This work can sometimes be challenging because of the complex medical terminology involved, and the different side effects that patients can experience during treatment.

This booklet has been developed in collaboration with Aboriginal Health Workers to provide important and practical information to help you support your patients during their cancer treatment.

The booklet will help you to:

- understand safety issues for patients having chemotherapy
- recognise some of the most common side effects of cancer treatment
- understand how to manage these side effects
- educate your patients about how to manage side effects
- know when to seek help (call a doctor or other healthcare professional)
- understand the effects of cancer on your patients’ social and emotional wellbeing.

Important

This booklet is to be used as a resource only. It does not replace advice provided by a medical doctor or nurse experienced in cancer care. If in doubt, always check with your patient’s treating doctor or GP.
Acknowledgements

We gratefully acknowledge the input of everyone who contributed to this booklet, particularly the generous contributions of all Aboriginal people who collaborated with the Cancer Institute NSW. Special thanks go to Denise Morgan-Bulled, Jillian Owen, Michelle Hutchison, Bronwyn McClure, Alison Simpson, Virginia Lovell, Charmaine Bell, Sharan Nicholson-Rogers, Gail Garvey, Valda Murray, Robyn Sharman, Gail Daylight, Margaret Broadbent, Kristine Falzon.

We also acknowledge the contributions of all Cancer Institute NSW staff involved in this project; in particular, Catherine Johnson, eviQ content author; and Sally Crawshaw, Aboriginal program coordinator.

Aboriginal artwork by Jilalga Murray

“This work depicts a story of great health professionals doing great work in Aboriginal communities. It focuses on the strong working relationships between Aboriginal Health Workers, cancer sufferers and their families.

At the top and base of the artwork, there are organic pathways flowing across the piece; this section represents the body—bones, muscles, veins, arteries, etc. These flow, much like cancer flows, through the body, affecting different parts along the way.

The pathway at the top and bottom of the piece features small purple circular shapes, which depict the travels and the journey that Aboriginal Health Workers take with patients—step by step, moving through the processes with them.

The use of black is imperative to the work. Cancer is a hard and harsh reality in our communities and in our families; it must not be taken lightly. The black symbolises the pain, sadness and hard times felt by cancer sufferers and those affected around them. It also pays respect and acknowledges those since passed.

Central to the artwork are large graphic elements which symbolise the nurturing and enveloping support of the Aboriginal Health Worker. The amount portrays the acknowledgement of the most common side effects experienced by people receiving cancer treatment.

The repetitive small circular motifs featured throughout the whole work, seem to radiate from the middle, and symbolise all cancers. These seem to have layers which are more obvious than others, which are much like the symptoms and effects of sufferers where, some are more obvious than others. It is commonly known to start small and then it grows, and grows; this is my representation.

The background and base of the artwork carries circular motifs with segments which seem to ‘reach out’. These symbolise Aboriginal Health Workers, other medical professionals, patients and families, all reaching out to help, assist, care and support each other for the journey, and for the fight for a better life.”

– Jilalga Murray

This booklet has been developed in consultation with Menzies School of Health Research. Special thanks to Associate Professor Gail Garvey and Dr Belinda Thewes for contributing content about managing the effects of cancer on social and emotional wellbeing.
Contents

The treating team

Chemotherapy safety
Safety at home for patients on chemotherapy

Cancer treatment side effects
About cancer treatment side effects
High temperature (febrile neutropenia)
Pins and needles in the hands or feet (peripheral neuropathy)
Feeling sick (nausea and vomiting)
Feeling tired (fatigue)
Hair loss (alopecia)
‘Got the runs’/runny poo (diarrhoea)
Hard poo (constipation)
Mouth side effects

The effects of cancer on social and emotional wellbeing
Social and emotional issues related to cancer

Useful contacts

Bibliography

Glossary

Useful phone numbers
The treating team

The treating team is the group of health professionals involved in a patient’s cancer journey. It is sometimes also called a multidisciplinary team.

Not all treating teams are the same. The health professionals in a patient’s treating team will depend on what type of cancer the patient has, and what treatment they are getting.

Treating teams can include:
- doctors (including medical oncologists, radiation oncologists, surgeons and general practitioners)
- nurses (including cancer care coordinators)
- physiotherapists
- pharmacists
- radiation therapists
- speech pathologists
- dietitians.

The glossary on page 57 provides more information about these different types of health professionals.

Important

If you have further questions about the side effects of treatment, or if your patient’s side effects are getting worse, speak to a doctor or nurse from their treating team.

Quick tip

If you know the name of the chemotherapy treatment that your patient is having, you can look this up on eviQ to find out what specific side effects to look out for.

Visit www.eviQ.org.au
Chemotherapy safety
Safety at home for patients on chemotherapy

Chemotherapy (pronounced kee-mo-ther-a-pee) is a cancer treatment that uses drugs or medicines to kill cancer cells. It is sometimes just called ‘chemo’.

Patients can have chemotherapy in different ways.

- Intravenous (IV) chemotherapy is given into the patient’s vein, and goes straight into their blood.
- Oral chemotherapy is given by mouth, as tablets, capsules or liquids that the patient swallows.

There are important safety measures that you should take while caring for patients who are having chemotherapy.

You also need to educate your patients, and their families and carers, about safety.

This section explains:

- how to protect yourself, and your patients’ families and carers, from chemotherapy drugs
- how to support patients who are taking oral chemotherapy at home
- what equipment you may need, like gloves and spill kits.

Bush medicine

Bush medicine could cause problems for patients having cancer treatment.

Your patient should check with their doctor before using bush medicine.
Safety information for all chemotherapy patients

Chemotherapy drugs kill cancer cells but can also damage normal cells.

Each time your patient has chemotherapy, it can take up to seven days for the chemotherapy drugs to leave the body.

During these seven days, chemotherapy drugs can be in the patient’s body fluids or waste products, including:

- blood
- urine (wee)
- vomit (spew)
- saliva (spit)
- semen
- vaginal secretions
- sweat
- stool/faeces (poo).

If you accidentally touch any of these fluids, some of the chemotherapy drug could get into your body through your skin.

You, and your patient’s family and carers, need to take special care to stay safe for the first seven days after each chemotherapy treatment. The information on the next pages explains how to do this.

Important

Women who are pregnant or breastfeeding should not touch:

- chemotherapy medication
- body fluids (wee, vomit, etc.) of someone having chemotherapy
- any bedding, clothing, or cleaning cloths with the above body fluids on them.
Educate your patient

About cleaning up spills

• If there is a spill of any body fluids (e.g. poo, wee, spew), put on rubber gloves and use a disposable cloth to clean up the spill straight away.

• Place the cloth in a plastic bag and tie it closed; then place that plastic bag into another plastic bag and tie it closed—this is called ‘double-bagging’.

• The plastic bag can then be placed in the normal household rubbish.

• Towels, linen or clothing that have body fluids on them should be machine washed separately in a hot or cold wash, on the longest washing cycle. They can then be dried outside.

• If there is a spill of body fluids on a bench top or floor, wear rubber gloves and wash it off with lots of water and detergent.

About feeling sick and vomiting

• It is a good idea to keep a plastic bowl or bag (without holes in it) handy for this.

• A bowl used for vomiting, should not be used for anything else.

• Wash the bowl out after each use.

• Throw it away at the end of the chemotherapy treatment.

About going to the toilet

• After going to the toilet, close the lid, and flush the toilet on full flush. This is so that fluids from the toilet don’t splash out.

• Men should sit down when using the toilet so there is no splashing.

About having sex

Your patient and their partner should always wear condoms when having sex in the first seven days after chemotherapy treatment. This is because low amounts of chemotherapy drugs may be passed in the semen or vaginal secretions.
Safety information for patients taking oral chemotherapy at home

You may need to care for patients taking oral chemotherapy at home. The patient may have to take tablets, capsules or liquid medicine. The information below explains how to do this safely.

Make sure your patient knows how to take their oral chemotherapy drugs

- Most patients will have a written plan, telling them when to take their tablets. It’s a good idea for you to go through this with them to make sure they have understood this information.
- Make sure the patient knows they must take the oral chemotherapy exactly as their doctor or pharmacist has told them to. This includes taking it on the right day, at the right time, and with or without food, as directed.

Check that your patient knows how to store their oral chemotherapy drugs safely

It is important that your patient:
- keeps the chemotherapy drugs in their original packaging
- stores any chemotherapy drugs (tablets or liquids) as the doctor or pharmacist tells them to
- stores them safely away from children or animals.
Educate your patient

How to handle oral chemotherapy drugs safely

Your patient:
- Your patient can handle the oral chemotherapy drugs because the treatment is for them.
- After taking the drugs, they should wash their hands before touching anything else.

You, and the patient’s family or carers
- You, and the patient’s family or carers, should never touch chemotherapy medicine with your bare hands.
- This is because some of the chemotherapy drug could be absorbed into your body through your skin.
- Sometimes you, or someone else, will need to touch chemotherapy drugs to help the patient to take them.
- You should always wear a pair of rubber gloves to touch or handle chemotherapy drugs.
- Wash your hands after taking off the gloves.

How to take oral chemotherapy drugs safely

Your patient should:
- take the chemotherapy exactly as directed by their doctor or pharmacist (e.g. this may be with food or on an empty stomach)—it will say on the medicine label on the bottle
- swallow the chemotherapy tablets or capsules whole—never crush, cut, chew or bite tablets, and do not open capsules
- wash their hands after handling the chemotherapy tablet or capsule.

Note: If the patient cannot swallow the tablets, talk to the doctor straight away.
Important things to know

What if my patient vomits after taking the chemotherapy?

- If your patient vomits straight after taking a dose of oral chemotherapy, they should not take a replacement dose but contact the treatment team for further advice.
- If they have been given anti-sickness tablets to stop nausea and vomiting, they should take this medicine as the doctor or pharmacist has instructed, even if they do not feel sick.
- If they have taken the anti-sickness medication and it does not stop them from vomiting, speak with the doctor about what to do.
- Make a note to tell the doctor or nurse from the treatment team about any missed or vomited doses.

What if my patient forgets to take their chemotherapy tablets?

- If your patient forgets to take a chemotherapy dose, they should take the next dose at the normal time, as prescribed.
- Refer to the eviQ patient information sheet that they may have been given for further information. If the patient is unsure about what to do, speak with the doctor or clinic staff on the next working day.

What if my patient has finished chemotherapy treatment but has some tablets left?

Leftover chemotherapy capsules or tablets should be returned to the cancer clinic or pharmacy.

Important

If your patient is having chemotherapy treatment in hospital, they may see nursing staff wearing protective equipment. This is necessary for some types of chemotherapy administration. It is nothing to be frightened of.
Useful equipment

Gloves

The best gloves to use are nitrile gloves, which are made from synthetic rubber and are resistant to chemotherapy.

If you or your patient don’t have nitrile gloves, you can use:

• two pairs of disposable gloves, or
• a thick pair of rubber gloves that can be bought from the supermarket.

Whichever gloves you use, they should only be used for cleaning up spills (see page 8), or for handling chemotherapy medication (see page 10).

Home-made spill kit

If your patient does not have a spill kit provided by the hospital, it is a good idea for them to keep a kit at home to clean up spills. It should include:

• incontinence pad/’inco sheet’ or disposable cloths
• gloves
• plastic apron
• vomit bag/bowl
• plastic bags.

Important

• Be careful when removing gloves.
• Do not touch the outside of the gloves with your bare hands.
• Wash your hands after removing gloves.
• If using re-useable gloves, these gloves should be stored separately in a sealed plastic bag and thrown away at the end of treatment.
Cancer treatment side effects
About cancer treatment side effects

Cancer treatments like chemotherapy and radiotherapy kill cancer cells but can also damage normal cells. This can cause side effects for the patient.

Not everyone having cancer treatment will have side effects, but most people experience some.

This section describes some of the most common side effects of cancer treatment. It explains:

- how to identify and manage these side effects
- how to educate your patients about managing their symptoms
- when to call the doctor.

Remember, the information in this booklet does not replace advice provided by a medical doctor or nurse experienced in cancer care.

Important
Call the doctor straight away (even if it is a weekend or evening) if your patient has:

- chest pain
- temperature of 38°C or above
- chills, shivers, shakes
- pain, burning, blood in urine (wee)
- shortness of breath
- diarrhoea that won’t stop
- vomiting that won’t stop
- drowsiness and confusion.

If you are unable to contact a doctor for advice, the patient should go to ‘Emergency’ at their nearest hospital for assessment.

* not corrected by putting on a jumper.

Bush medicine

Bush medicine could cause problems for patients having cancer treatment. Your patient should check with their doctor before using bush medicine.
High temperature (febrile neutropenia)

What is neutropenia?
• Neutropenia (pronounced new-tro-pee-nee-ah) is when a patient has low levels of neutrophils.
• Neutrophils (pronounced new-tro-fils) are white blood cells, which help to fight infection.

Why does it happen?
• Chemotherapy can temporarily stop the body making white blood cells.
• The numbers of neutrophils in the patient’s blood can drop, causing neutropenia.

Why is it a problem?
• Neutropenia increases the risk of infection.

What is febrile neutropenia?
• Febrile neutropenia (pronounced feb-riyl new-tro-pee-nee-ah) is when a patient has a high temperature (over 38°C) and low levels of neutrophils (neutropenia).
• Febrile neutropenia is also known as neutropenic fever or neutropenic sepsis.

Why is it a problem?
• Febrile neutropenia is a sign that the patient may have an infection.
• This can be very serious.

Warning
Febrile neutropenia can kill a person quickly. You should call the doctor or an ambulance if the patient is having chemotherapy treatment and they have:
• a temperature of 38°C or higher (even if the patient feels well)
• shivers, shakes or chills;* or begins to feel unwell.

* not corrected by putting on a jumper.
What are the signs and symptoms of febrile neutropenia?

- The main sign of febrile neutropenia is a high temperature of 38°C or more.
- Other symptoms may include:
  - feeling unwell
  - dizziness or fainting (these can be signs of low blood pressure)
  - shivers, chills or shakes*
  - confusion (not talking sense, being muddled)
  - difficulty passing urine (peeing) or a burning sensation when peeing
  - diarrhoea (the runs)
  - shortness of breath (difficulty breathing)
  - sore throat
  - pain, redness or swelling around an infusion device or port (where chemotherapy is given intravenously).

* not corrected by putting on a jumper.

Important

The patient might not have all of these symptoms.

- They can have a high temperature without any other symptoms.
- They could have a normal or low temperature with some or all of the other symptoms.

If in doubt, ALWAYS call the doctor straight away.
What to do if you think your patient has febrile neutropenia

Check the patient’s temperature and keep a record of it.

If the patient is:
- having chemotherapy treatment
- and
- has a temperature of 38°C or more

Call an ambulance to get the patient to a hospital as quickly as possible.

When the patient arrives at the hospital, it is important to tell the Emergency Department staff:
- the patient has cancer and is having chemotherapy treatment
- the name of the chemotherapy treatment (if known)
- the date of their last treatment (if known)
- the patient’s most recent temperature
- any other symptoms the patient has
- any drug allergies the patient has (especially to antibiotics).
Educate your patient

Infections can be dangerous for patients on chemotherapy.

How do infections happen?

Infections are caused by germs, including bacteria, viruses and fungi. Germs can get into a patient’s body in different ways, such as:

- through the mouth from things they touch or eat
- through the skin if it is damaged
- through the air by breathing them in.

Everyone has germs that live in their body; for example, on their skin and in their gut. These germs do not usually cause infections in healthy people, but they can cause them in people having cancer treatment. This is one of the most common ways that cancer patients get infections.

Other ways that patients can get infections are from other people with illnesses like colds or stomach bugs, and from things that carry germs like animal poo, or food that is not cooked properly.

Make sure your patient knows:

- how to check their own temperature
- who to contact if their temperature is above 38°C.
Talk to your patients about ways to reduce their risk of infection

How to stop infection getting in through the mouth

- Keep hands clean, and always wash them after using the toilet.
- Keep the mouth clean (see ‘mouth care’ on page 38).
- Wash hands before cooking or eating.
- Wash (or peel) all fruits and vegetables before eating.
- Don’t share drinking glasses or cutlery with anyone else.
- Don’t share toothbrushes with anyone else.
- Don’t eat raw meat and fish (and some fresh cheeses), as these may contain bacteria that can cause infection.

How to stop infection getting in through the skin

- Clean any cuts, scrapes, sores or stings straight away, using warm water, soap and antiseptic.
- Try not to squeeze or scratch pimples.
- Wear gloves when cleaning to stop germs getting into any cuts.
- Wear gloves and shoes when gardening to reduce the chance of getting scratches, scrapes, or insect bites that could get infected.

How to avoid infection spread through the air

- Stay away from people who are sick, especially if they are coughing or sneezing.
- Stay away from crowded places.
- Keep away from any garden compost as this contains germs that cause disease.
- Keep away from house renovations as some of the dust can carry germs.

How to keep away from germs

- Keep away from people who are sick with any illness you can catch.
- Don’t touch or clean up any pet or animal poo or clean fish tanks or bird cages.
- Try not to do gardening or have contact with soil. If this is not possible, wear gloves and boots when gardening.
Pins and needles in hands or feet (peripheral neuropathy)

What is peripheral neuropathy?
Peripheral neuropathy (pronounced puh-rif-er-al new-ro-path-ee) is a change in feeling in a person’s hands and feet.

Why does it happen?
• It happens when there is damage to the nerves of the hands or feet.
• Nerve damage can be caused by some diseases, including diabetes and kidney disease.
• It can also be caused by some cancer treatments.
• Some chemotherapy drugs can cause peripheral nerve damage (in the hands and feet).
• Radiation therapy can also cause nerve damage, but it may take several years for symptoms to appear if caused by radiotherapy treatment.

Why is it a problem?
Peripheral neuropathy can be very painful for some patients. It can also make it difficult for patients to feel certain things with their hands and feet, including:
• pain
• temperature
• the position of their hands and feet.
This means that patients can injure themselves, for example by:
• cutting or burning themselves
• tripping or falling over.
What are the symptoms?

- Patients complain of changes in feelings or sensations in the hands and/or feet. These can be different for everyone, but may include:
  - tingling, burning or pins and needles
  - heaviness in the hands and/or feet
  - weakness in the hands and/or feet
  - a warming or burning sensation when touching something cold
  - not being able to feel if something is hot
  - discomfort or pain in the hands or feet
  - difficulty buttoning a shirt or picking up a coin from a flat surface.

- Symptoms may develop during cancer treatment or shortly after. They may also continue after treatment. Check with the treating team for further advice.

- Neuropathies can affect other parts of the body and cause symptoms like:
  - ringing in the ears or difficulty hearing
  - constipation (for more information see page 32).

How is it treated?

- How peripheral neuropathy is treated depends on the patient’s symptoms and what caused the neuropathy.

- The patient’s doctor will work to diagnose the cause of the neuropathy and help to manage the symptoms.

- Many people recover fully from peripheral neuropathy over time, usually in a few months to years.

- Sometimes the condition is more difficult to treat and may require long-term pain management.

What to do if your patient has peripheral neuropathy

Phone the hospital/unit where the patient goes for treatment to report any new symptoms. They will then be able to:

- assess the patient’s symptoms and provide advice about what to do
- assess whether changes need to be made to the treatment plan
- arrange for the patient to see members of the treatment team as necessary.
Educate your patient

Peripheral neuropathy can be uncomfortable for your patient. They could also injure themselves because of the neuropathy. Talk to your patient about the following.

How to stay comfortable
- Wear comfortable cotton socks.
- Wear gloves and warm socks in cold weather as this will help with blood circulation.
- Keep feet loosely covered in bed to allow good circulation (restricted circulation can also cause pins and needles).
- Don’t wear tight-fitting shoes, as these can worsen pins and needles.

How to stop trips and falls
- Take care when walking around.
- Keep a light on in the room when moving around.
- Remove or secure rugs.
- Avoid slippery wet floors.
- Get up slowly.
- Wear shoes that fit properly.

How to stop injuries
- Take care cutting food and opening jars so they don’t cut themselves.
- Wear boots and gloves when working in the garden to avoid bug bites, scratches or cuts to the skin.
- Test the temperature of water with their elbow to make sure it isn’t too hot before having baths or showers, or washing up.
- Use oven gloves and pot holders in the kitchen, so they don’t burn themselves accidentally.

Other things they should know
- Report any new symptoms.
- Make sure that any injuries (like cuts) are assessed and treated quickly by a nurse or doctor, to reduce the risk of infection.
- Don’t drink grog (alcohol) as this can affect feeling in the hands and feet.
Feeling sick (nausea and vomiting)

What is nausea and vomiting?
- Nausea (pronounced naw-zee-ah) is feeling sick, like you are going to throw up.
- Vomiting is being sick (spewing or throwing up).
- Nausea and vomiting are common side effects of cancer treatment.

Why does it happen?
- Nausea and vomiting can be caused by:
  - cancer
  - chemotherapy
  - radiation to some areas of the body
  - medicines
  - food smells and other smells (like some perfumes)
  - going to hospital.
- Not everyone receiving cancer treatment will feel sick.
- If people do feel sick, it will usually only last one to four days.

Stop it before it starts
- Preventing nausea is really important, as it is more difficult to stop it once it starts.
- Your patient’s doctor will prescribe the patient some anti-sickness medicine to help control the nausea and stop them from being sick.
- It is very important that the patient takes this medicine at the times the doctor prescribes (e.g. half an hour before food or chemotherapy).
- Your patient should take their anti-sickness medicine even if they do not feel sick, as this medicine helps to prevent nausea and vomiting.

Call the doctor if:
- the patient’s anti-sickness medicine is not working
- the patient is unable to keep food or drink down without vomiting
- there is blood in the patient’s vomit
- the patient has diarrhoea or cramping with the nausea.
Educate your patient

Nausea and vomiting is a problem for many patients on cancer treatment. There are a few things they can try that might help them to feel better. Have a yarn to your patient about the following things that might help with nausea.

**Taking their anti-sickness medicine**
- Remind your patient to take their anti-sickness medicine as prescribed, even if they don’t feel sick at the time.

**What to drink**
- Sip on fluids throughout the day to prevent becoming too dry in the mouth or dehydrated. This is very important for patients who are vomiting.
- Don’t drink grog (alcohol) as this can make the nausea worse.

**What to eat**
- Try food that is cold or room temperature. This may be easier to eat as it doesn’t smell as strongly as hot food.
- Eat dry starchy foods like crackers, plain rice or toast, as these are less likely to cause nausea.
- Avoid fried, spicy or very sweet foods as these can make nausea worse.
- Eat small amounts more often—sometimes an empty stomach can make the nausea worse.
- Avoid lying down for 30 to 60 minutes after eating to help digestion.

**Making meals**
- Stay away from the kitchen when food is being prepared if the smell of food makes them feel sick.
- Ask friends and family to help with preparing food.

**Other things that can help**
- Get fresh air by opening a window or using a fan. This will help move the air and remove smells.
- Take regular gentle exercise, such as going for a walk.

**Important**

Medicines should not be shared. They should only be taken by the person that the doctor prescribed them for.
Feeling tired (fatigue)

What is fatigue?
Fatigue (pronounced fah-teeg) is extreme tiredness that doesn’t get better with sleep or rest.

Fatigue is one of the most common side effects of cancer treatment.

Why does it happen?
There are many things that can cause fatigue, such as:
- the cancer itself
- pain
- low red blood cells (anaemia)
- changes in how the body works
- side effects of having cancer treatment
- travelling for treatment
- being worried or anxious
- depression
- trouble sleeping
- some medications
- not eating enough
- not drinking enough water
- not being active.

Some patients experiencing fatigue may worry that the cancer has come back. Fatigue does not necessarily mean that the cancer has come back.

What to do if your patient has fatigue

You should tell the treating team if:
- the tiredness is making the patient sleep most of the time
- they are unable to look after themselves properly (e.g. they fall asleep eating and drinking)
- the patient feels like they cannot cope.
Educate your patient

Talk to your patient about:

- fatigue—what it is and why they may be getting it
- how to reduce their stress levels
- the importance of relaxation/meditation/spiritual practices
- the potential benefit of gentle exercise—see the ‘tips for getting active’ on page 49.

Encourage your patient to:

- get some help at home (with cooking and cleaning)
- save energy for things they enjoy
- eat a balanced diet, including plenty of fruit and vegetables
- maintain energy by eating more frequent, smaller meals or snacks throughout the day.

Tips to help improve sleep:

- Avoid stimulants, like alcohol (grog) or caffeine, in the late afternoon or evening.
- Try to go to bed and get up at the same time each day.
- Take short naps or rest periods during the day (but take them early enough in the day so they don’t interfere with nighttime sleep).
- Mix periods of activity with periods of rest.

Important

Identifying the cause of fatigue can help to work out the best way to deal with it.
Hair loss (alopecia)

What is alopecia?
Alopecia (al-o-pee-sha) is the medical term for hair loss.

With alopecia, some or all of the patient’s hair can fall out.

Why does it happen?
• Some cancer treatments can damage the cells that make hair grow.
• Hair loss can be a side effect of chemotherapy or radiation therapy.

What will happen?
• Not everyone who has these cancer treatments will lose their hair.

• If the treatment does cause alopecia, the hair usually starts to fall out two to three weeks after the first dose of chemotherapy, and three to four weeks after starting radiotherapy treatment.
• How much hair a person loses depends on the chemotherapy drug dose, and/or strength and site of radiation therapy.
• Some patients on chemotherapy can lose all of the hair on their head and body. Others may get thinning or patchy hair loss.
• Patients having radiation therapy alone will only lose hair on the part of the body being treated.
• Patients who lose their eyelashes may get sore eyes and have an increased risk of eye infections.

Will the hair grow back?
• The hair may start to grow back three to six months after the treatment is finished.
• It can grow back a different colour and texture (e.g. curly instead of straight).
• For patients who have a high dose of radiation, their hair may never grow back in the area that has been treated.
Educate your patient

Patients get upset when they lose their hair. Here are some ways that you can help your patient to prepare for and manage this side effect. Talk to your patient about the following.

**Before the hair loss starts:**

- prepare their family and friends (particularly children) by telling them that the treatment may cause hair loss
- keep the hair style short if they are likely to have hair loss
- cut the hair using clippers, or visit a hairdresser who can cut it safely, if it starts to fall out in large amounts.

**After the hair has fallen out:**

- moisturise their scalp twice daily with a simple non-perfumed moisturiser (such as sorbolene cream) to reduce dryness
- patients having radiation therapy should check with their treating team about when to apply moisturiser (e.g. don’t apply it for two to three hours prior to treatment)
- wear a hat, scarf or wig to protect them from feeling cold (most treatment centres have information about these products)
- protect the scalp from sun damage by wearing a hat/scarf if outside, as well as applying sunscreen (factor 30+).

**There may be other special support your patient needs**

**Eye care**

- Some chemotherapy can cause the patient’s eyelashes to fall out.
- Speak to the treating team about how to educate your patient about eye care, to reduce the likelihood of eye soreness and infections.

**Body image**

Hair loss can change the way a person feels about themselves. This is called ‘body image’. Refer to ‘The effects of cancer on social and emotional wellbeing’ on page 43 for more information about how to help your patient with body image.
Got the runs’/runny poo (diarrhoea)

What is diarrhoea?
- Diarrhoea (pronounced diy-uh-ree-uh) is when the poo (stool) becomes runny, and the patient needs to go to the toilet more often.
- The patient may also have tummy pain, cramps and bloating (feeling like their tummy is full of wind). Some patients might feel like they want to vomit.

Why does it happen?
There are many things that can cause diarrhoea, such as:
- medicines
- cancer
- chemotherapy
- radiation therapy to the tummy
- other problems with the tummy
- infection, such as gastroenteritis (‘gastro’).

Why is it a problem?
- The body absorbs (takes in) water and many other things from what we eat and drink. When a patient has diarrhoea, they can lose a lot of water from the body. This can make them dehydrated (not have enough water in the body).
- They can also lose nutrients, vitamins and minerals. All of these things are needed for the body to work properly.
- Potassium is one of the minerals the body needs. Patients with diarrhoea can have low potassium levels. This can cause symptoms such as:
  - numbness or tingling in the hands and feet
  - feeling sick or vomiting
  - palpitations (feeling that the heart is racing, thumping or skipping beats)
  - cramps in the tummy or bloating.
- Low potassium can also cause low blood pressure, which might make the patient:
  - feel dizzy
  - cause them to faint (pass out temporarily)
  - cause them to become muddled or confused (not talking sense).
What to do if your patient has diarrhoea

Speak to a nurse or doctor about medications that may help.

You should call the doctor if the patient:

- has bleeding from their bottom, or there is blood in the poo
- has a temperature above 38°C
- is going to the toilet (passing diarrhoea) five or more times a day
- has diarrhoea that is getting worse
- is vomiting or unable to drink water
- has very dry skin and tongue
- has a headache or dizziness, or they are confused (muddled, not talking sense)
- has bad tummy pain, or their tummy looks bigger and rounder than normal.

Important

Some chemotherapy drugs can cause severe diarrhoea which can be life threatening.

If your patient has severe diarrhoea or any of the symptoms on this page, contact the doctor urgently or call an ambulance to take them to the hospital emergency department.
Educate your patient

There are things you can do to help your patient manage diarrhoea. Severe diarrhoea can be dangerous for your patient so you need to educate them about when to get help. Have a yarn to your patient about the following.

How to stop dehydration (not enough water in the body)

- Sip water regularly throughout the day.
- Try to drink about 8–10 cups (or two litres) per day.
- Some patients may be fluid restricted and should check with their doctor how much they can drink.

What to eat if they have diarrhoea

- Eat smaller meals more often to make digesting food easier.
- Eat foods that the tummy can digest more easily, such as
  - bananas
  - rice
  - noodles
  - white bread
  - skinned chicken
  - white fish.

Don’t eat or drink things that can upset the tummy or make diarrhoea worse, like:

- grog (alcohol),
- milky or fizzy drinks (fizzy drinks can make the feeling of bloating worse too)
- spicy or fatty/greasy foods
- raw vegetables and fruit (until the diarrhoea has stopped)
- diet foods containing artificial sugars (e.g. diet drinks, some muesli bars, some high protein bars).

When they should get help

Call the doctor if:

- their temperature is 38°C or above
- they feel unwell
- they have any of the symptoms on page (30).

Important

If the patient gets diarrhoea while having oral chemotherapy, they should not take any further doses of chemotherapy until they have seen the doctor.
Hard poo (constipation)

What is it?
• Constipation is when someone has trouble pushing a hard, dry poo (stool) out of the back passage (bowel).
• Importantly, everyone poos different amounts. Some people can poo up to three times a day and others can poo once every three days—both of these are normal.

Why does it happen?
• Constipation can be caused by some medications, cancer treatments or cancer itself.
• Hard poo can get worse if the patient:
  • has a diet low in fibre (not eating enough fruit and vegetables)—two serves of fruit and five serves of vegetables per day are usually recommended
  • takes certain medications—some types of chemotherapy and anti-sickness medicines can cause constipation that won’t be fixed by diet (in this case, tell the treating team so that medications can be prescribed to help)
  • not drinking enough water
  • experiencing other diseases that affect the tummy (abdomen)
  • not moving or exercising as much as they once did.

What to do if your patient has constipation

You should call the doctor if the patient:
• has not pooed for more than three days (they may need medicine to soften the poo to help it to pass)
• has problems passing urine (wee), or is passing urine more frequently
• has pain
• has any blood in their poo
• has liquid poo but hasn’t had a ‘normal’ poo for three days or more—this can be a sign of ‘overflow diarrhoea’ as the liquid poo passes around the poo blocking the bowel (constipation).
Educate your patient

There are things you can do to help your patient manage constipation. Talk to them about the following.

**Drinking enough water**

Drink about 8–10 cups (about two litres) of water or cordial per day, unless they are restricted to drinking a certain amount of fluid by their doctor.

**Eating a healthy diet**

- Eat more fibre to keep the bowel clean and working well:
  - Fibre is in fresh fruit (like pears and kiwi fruit) and vegetables (such as carrots and peas).
  - Nuts, seeds and grainy breads, brown rice and cereals are also high in fibre.
  - Different beans are good fibre to mix into stews and soups.
  - Baked beans, kidney beans and green beans also have a lot of fibre.
  - Fibre helps the poo to move through the body.

**Exercising**

- Do some gentle exercise every day, such as going for a walk.
- Any exercise will help the poo move through the body.

If these measures do not work, tell the treating team so they can consider prescribing other medications to help.

**Important**

Encourage your patient to go to the toilet the first time they feel they need to poo. Don’t put it off.
Mouth side effects

What are mouth side effects?
The most common mouth side effects from cancer treatment are:
• mucositis
• xerostomia
• changes to taste and smell.

Mouth side effects can occur in patients having chemotherapy, and patients having radiation therapy to the head and neck area.

Why do they happen?
Cancer treatments can damage cells in the patient’s mouth, and this can cause side effects.

Why are they a problem?
• Mucositis can increase a patient’s risk of getting infection through their mouth. This can be dangerous for patients on cancer treatments as their bodies cannot always fight infection properly.
• Mucositis can be painful or uncomfortable for the patient and stop them eating and drinking properly.
• Changes in taste and smell can make it difficult for patients to eat and enjoy food.

What can you do to help?
The next pages explain:
• the symptoms of mucositis and xerostomia
• how to educate your patients about mouth care
• the symptoms of taste and smell changes
• how to help your patient manage these.
Sore mouth and throat (mucositis)

What is mucositis?
- Mucositis (pronounced mew-koh-site-us) is the medical term for painful swelling and ulceration of the lining of the gut (gastro-intestinal tract).
- Patients usually get ulcers and soreness in the mouth and throat, but this can happen anywhere along the gut, from the mouth to the bowel.

Why does it happen?
- Mucositis happens when cancer treatments cause inflammation (swelling) in the lining of the mouth and other parts of the gut.
- Mucositis can be caused by chemotherapy and/or radiation therapy.
  - Radiotherapy can cause mucositis but only at the site where the radiotherapy is given.
  - Chemotherapy can cause mucositis anywhere.
  - Having both of these treatments increases the risk and severity of mucositis.
- Mucositis usually starts during the first week after chemotherapy, and about two weeks after starting radiation therapy.
  - It can start sooner in patients having both radiotherapy and chemotherapy.
  - Mucositis can come and go with chemotherapy cycles—it will heal with time and care.

Why is it a problem?
- Mucositis can be very painful and stop the patient from eating and drinking properly.
- Mucositis makes it easier for infections to get into the body through the mouth and other parts of the gut.
- Patients can get serious infections because of mucositis.

Important
Patients should have their teeth checked by a dentist before they start cancer treatment.
What are the symptoms of mucositis in the mouth?

- Pain (particularly when eating and drinking)
- Redness
- Mouth sores/ulcers
- Bleeding in the mouth
- Burning feeling
- Trouble swallowing
- Pain or difficulty wearing dentures
- Thick or no saliva (spit)
- Sensitivity to hot, cold, salty, spicy (curry) or acidic foods and drinks (like tomatoes and fruit juice)

What to do if your patient has mucositis

**Call the doctor if the patient:**

- has a fever of 38°C or more
- has uncontrolled pain
- has trouble swallowing
- coughs a lot when eating or drinking
- is unable to eat or drink
- has difficulty opening their mouth
- is bleeding from the mouth
- has white spots appear in the mouth or on the tongue.

**Medication may be needed to treat these problems.**

---

**Important**

- Mucositis often causes sores in the mouth or throat.
- Chemotherapy can reduce the body’s ability to fight infection, so a sore in the mouth can sometimes turn into an infection in the mouth.
- There is a higher risk of infection from mucositis in patients who have:
  - chemotherapy and radiation therapy to the head and neck area
  - treatment for blood cancers (leukaemia, lymphoma, myeloma).
Educate your patient

Mucositis can increase the risk of infection for patients having cancer treatment. It can also be very painful for patients. Advise your patient on how to do the following.

**Keep their mouth healthy**
- See a dentist before and after their course of treatment.
- Perform mouth care after meals, smoking and before bed (see ‘mouth care’ on page 38).

**Manage mucositis pain**
- Take their pain medicine as prescribed, particularly before meals.
- Eat soft moist foods that are at room temperature (e.g. food can be easier to swallow if gravy or sauce is added).
- Put food through a blender or liquidiser to make it easier to swallow.
- Don’t have acidic foods and drinks like tomatoes and fruit juices.
- Don’t eat crunchy and spicy foods as these might make the soreness worse.
- Speak to a dietitian who can help them decide what foods are good for them to eat during mucositis.
- Take out dentures when not eating—they can make the patient’s mouth sore.

**Important**
Teach your patient to check their mouth at least once per day (see ‘check inside the mouth’ on page 38).
Mouth care

It is important that your patient looks after their mouth during treatment. Encourage your patient to start mouth care at the beginning of treatment.

Protect the mouth

- Stop smoking.
- Keep the mouth and lips moist with lip balm.
- Sip water often and/or suck on ice chips.

Clean the mouth and teeth

Brush the teeth and tongue gently after each meal and at bedtime

- Use a toothbrush with soft bristles or an electric toothbrush. Replace the toothbrush or toothbrush head regularly to reduce the risk of infection.
- Use a mild toothpaste (like Biotene or Sensodyne). It should contain fluoride and should not have peroxide or tartar control. Ask your dentist or pharmacist for more information.
- Rinse the mouth after eating, brushing, flossing, smoking and before bed. Use:
  - a quarter teaspoon of salt to one glass of water; or
  - a quarter teaspoon of sodium bicarbonate (baking soda) to one glass of water; or
  - an alcohol-free mouthwash recommended by the hospital or dentist.
- Don’t use mouthwash that contains alcohol, as this can sting, irritate and dry out the mouth.

Check inside the mouth daily

- Sit in front of a mirror and use a small torch or a bright light to look in the mouth.
- Look for any sores, ulcers, pimples, red areas, white patches, or bleeding. Tell the treating team of any changes.

Important

- Patients who usually floss their teeth can continue to do this but only if there is no bleeding when they floss.
- If there is bleeding when flossing, stop flossing! This can cause an infection in the mouth or in the bloodstream, which can be serious.
- Patients who have never flossed should not start during treatment.
Dry mouth (xerostomia)

What is xerostomia?
• Xerostomia (pronounced zeer-oh-stomee-ah) is a medical term for dryness in the mouth.
• Some medications or radiotherapy treatment can cause a dry mouth.

Why is it a problem?
• Saliva (spit) is important for keeping the mouth healthy. Patients who don’t have enough saliva can get dental decay (holes in the teeth).

How long does it last?
• Xerostomia caused by chemotherapy usually gets better a few weeks to months after the end of treatment.
• Xerostomia caused by radiotherapy to the head and neck can last for months after treatment, and can be permanent in some patients.

What are the signs and symptoms?
• Thick or rope-like saliva (spit)
• Not as much saliva as normal
• A sticky or dry feeling in the mouth
• Difficulty chewing, tasting and swallowing
• Difficulty talking, as the tongue can get stuck to the inside of the mouth.

Educate your patient

Regular mouth care is very important for patients with xerostomia. Remind them to:
• use regular mouth care (see page 38)
• report any new spots/ulcers or lumps in the mouth
• report any pain
• try artificial saliva and oral moisturisers
• sip water regularly to moisten the mouth
• eat foods that are easier to swallow, such as soups, gravies and mashed vegetables.
• not drink grog (alcohol).

If your patient is still having problems, refer them to a dentist or speech pathologist who can advise them on how to manage their xerostomia.
Changes to taste and smell

What is it?
A change in taste and smell is a common side effect during or after cancer treatment.

Why does it happen?
• Cancer treatments can cause changes to:
  • the sense of taste
  • the sense of smell
  • the sense of touch (food texture)
  • or a combination of these.

• Changes in taste and smell can occur in patients having chemotherapy or radiotherapy to the head and neck area.

• Changes for patients on chemotherapy:
  • can occur from the first chemotherapy treatment
  • can change with treatment cycles
  • are usually temporary, but can be long-lasting for some patients
  • usually return to normal within two to three months of finishing treatment.

• Changes for patients having radiation therapy to the head and neck:
  • can affect how food tastes, as well as the patient’s sense of smell
  • can sometimes be long-term or permanent.

Why is it a problem?
• Changes in taste and smell can affect how food tastes to the patient.
• This can affect the patient’s appetite and enjoyment of food.
• Changes to the flavour of food are different for each patient
• Changes can be unexpected and quite frustrating for patients
• It may take some time for patients to be able to go back to enjoying foods that they go off during treatment.

What are the signs and symptoms?
• Reduced taste or no taste from food.
• Metallic or bad taste in the mouth.
• Food can taste like ‘cardboard’ or ‘leather’.
• Sensitivity to sweet or bitter foods, so foods taste too sweet, sour, salty or bitter.
• Sensitivity to smells (some might make your patient feel sick).
• Going off favourite foods, or not wanting certain foods or drinks.
• Losing appetite (not feeling hungry), because food doesn’t taste like it used to.
Educate your patient

Changes in taste and smell can stop your patient from enjoying food. In some cases, it may stop them from eating properly.

There are no cures for taste or smell problems, but you can tell your patient that they will probably get better when their treatment is finished.

Have a yarn to your patient about things they can try for common problems

<table>
<thead>
<tr>
<th>Food has no taste</th>
<th>Use seasonings, like fresh herbs, lemon, lime, ginger, garlic, soy sauce, honey, chilli, pepper pickles or sauces.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Foods they used to like taste bad</td>
<td>Try other foods, including things they didn’t like before. If they used to like sweet foods more than savoury, they might find they now like savoury foods better.</td>
</tr>
<tr>
<td>Foods with strong flavours taste bad</td>
<td>Avoid spicy or hot foods, and eat less chilli, spices, carbonated drinks, mints or chewing gum. Choose foods with less strong flavours.</td>
</tr>
<tr>
<td>Sweet foods taste bad</td>
<td>Try plain breakfast cereals with less added sugar, like porridge, bran flakes or weetbix.</td>
</tr>
<tr>
<td>Food tastes too salty</td>
<td>Use lower salt alternatives, and don’t add salt to food.</td>
</tr>
<tr>
<td>Some smells make them feel sick</td>
<td>Avoid smells from cooked food by having foods at cold or room temperature. Changes in taste and smell can occur after a chemotherapy treatment cycle or at times of nausea so patients should take their anti-sickness medicines as prescribed.</td>
</tr>
<tr>
<td>They don’t want to eat meat</td>
<td>It is common to go off meat during treatment. Eat eggs, nuts, dairy foods, baked beans, kidney beans, lentils or chickpeas to replace protein in the diet.</td>
</tr>
</tbody>
</table>
Some foods taste bitter or metallic, or the patient has a bitter taste in the mouth

- Try to avoid the foods that taste bitter.
- Try refreshing food or liquids to disguise the taste.
- Sometimes a bad taste in the mouth can be because of an unhealthy or dry mouth. Try rinsing the sensation away, or blocking the nose to see if this helps.
- Having a glass of water with meals may help.

Other things they should do

- Take care of their mouth often (see section on mouth care on page 38).
- Cut down or stop smoking. Speak to them about how they might do this using the various quit support services available (see page 53).
- Speak to a dietitian if they are finding it difficult to eat and drink and maintain a healthy weight.
The effects of cancer on social and emotional wellbeing
Social and emotional issues related to cancer

What are social and emotional issues related to cancer?

Cancer and cancer treatments can cause physical problems for patients, like hair loss, or nausea and vomiting.

They can also cause social and emotional issues. These are problems that affect how a patient feels, or how they relate to their family and community. They are also sometimes called psychological problems.

Common reactions to cancer

People with cancer (and those close to them) can experience a range of feelings during their cancer journey. These can include:

- anger
- sadness
- fear
- feeling out of control
- feeling that there is nothing they can do to help themselves or their situation.

These feelings are very common around the time of diagnosis, or when there are changes in the course of cancer treatment.

Negative feelings related to cancer often come and go. They usually improve with time as the person gets used to their cancer diagnosis and treatment, and learns to cope with the stress of having cancer.
Why do they happen?

There are certain things that may make people more likely to have social and emotional issues during cancer treatment. These include the following.

**Individual factors**
- Younger age
- Being female
- Single, divorced, widowed
- Living alone
- Having young children
- Money problems
- Having relationship problems
- Lots of previous stressful life events or past trauma
- History of problems with alcohol or other drugs

**Cancer factors**
- Having cancer that has spread to other parts of the body (advanced disease).
- Having a limited life-expectancy (poor prognosis).
- Experiencing a number of treatment-related side effects.
- Having multiple side effects which affect their ability to do things they would normally do.
- Lymphoedema (swelling from having lymph nodes removed or treated).
- Frequent or severe pain.
- Extreme or long-lasting tiredness (fatigue).
- Issues relating to body image—a person’s thoughts and/or feelings about his or her body (see page 51).

**Physical factors**

Cancer treatments, such as chemotherapy, radiotherapy and hormonal treatments can have direct physical effects on the patient. Some of these can cause psychological problems or make them worse.

Physical side-effects that can make social and emotional problems worse can include:
- feeling exhausted (fatigue)
- feeling sick in the stomach (nausea) and vomiting
- pain
- fertility problems (e.g. being unable to have children)
- sexual problems (see page 51)
- hormonal changes and menopausal symptoms
- problems with sleep.
Why are social and emotional issues a problem?

Social and emotional issues can be difficult for patients to understand and talk about. They can also lead to other problems, like depression and anxiety.

Signs that a patient may have anxiety:

- Feeling fearful, scared or on edge a lot of the time.
- Avoiding certain people or places due to fears.
- Needing constant reassurance from others.
- Sweating, shaking, or tingling.*
- Breathing difficulties or tightness in the chest.*
- Increased use of grog (alcohol) or other drugs.

Signs that a patient may be depressed:

- Feeling sad, empty, hopeless or tearful most of the day on most days.
- Losing interest or pleasure in things that usually make the person happy.
- Appetite and/or weight changes.*
- Avoiding friends, family or going out
- Sleep problems.*
- Feeling very tired and not wanting to get out of bed.*
- Feeling worthless, guilty or like they are being a burden to others.
- Feeling that life is not worth living.
- Being very critical of themselves.
- Having thoughts or plans of hurting themselves or ending their life.
- Increased use of grog (alcohol) or other drugs.

* Note: There may also be physical reasons directly related to cancer or its treatment for these symptoms.

Useful resource

Researchers from the Menzies School of Health Research have developed a short questionnaire designed to help cancer health professionals identify and meet the needs of Aboriginal cancer patients.

This tested (validated) questionnaire has been developed together with Aboriginal cancer patients. It is available free of charge for health professionals to use.

For further information about this questionnaire, go to:

www.menzies.edu.au/supportivecaretool and click on the ‘resources’ tab.
What to do if you think your patient needs help

When to seek professional help
Depression and anxiety are different from normal feelings of sadness and fear because, these feelings are very strong and/or they happen a lot of the time for a long time (usually more than two weeks).

It is common for depression and anxiety to happen at the same time and your patient may need referral to an appropriate service or healthcare professional for treatment.

Who can help your patient?
The types of health professionals that can help cancer patients with social and emotional issues are:

- health workers
- social workers
- psychologists or psychiatrists
- doctors (GP, oncologist)
- specialist cancer care nurses (such as clinical nurse specialist)
- cancer care coordinator.

Find out what services are available in your local area and how to refer to them.

Discussing referral with your patient
If you, the patient, or their carers, are concerned about psychological issues, it is worthwhile encouraging them to seek specialist help.

You can simply begin a conversation with the patient, to find out how they are feeling.
Educate your patient*

Things that can help people to cope with feelings associated with cancer include:

- talking to supportive friends, family and health professionals
- gathering information from health professionals to understand their cancer better
- planning enjoyable activities
- trying to keep doing normal activities
- taking care of themselves by eating and sleeping well
- doing little things that might make them feel better (e.g. having a bath, dressing nicely or wearing makeup)
- faith, prayer or spirituality
- getting involved in a support group, or meeting other Aboriginal people who are also living with cancer.

Ways to find help and healing

- Seek help to strengthen their spirit.
- Keep in touch with people.
- See a doctor, health worker or counsellor.
- Talk kindly to themselves.
- Talk to someone they know and trust.
- Avoid using alcohol and drugs to feel better.

There are other people that can provide help and support too, like family, friends and the community.

Family and friends can:

- listen and provide support
- keep the family spirit strong
- help the person to find healing
- spend time together
- organise family activities.

Communities can provide:

- traditional or spiritual healing
- links and support with other families
- community education and activities
- cultural and traditional activities.

* Information provided in this section has been sourced from www.beyondblue.org.au
Other things you can talk to your patient about

Tips for getting active

- Physical exercise, such as walking, swimming, dancing, playing golf or going to the gym can help social and emotional wellbeing by:
  • relieving the tension in muscles
  • relaxing the mind
  • providing distraction from negative thoughts and worries.
- Do some physical exercise every day, even if it’s just going for a walk.
  • Keep it simple and enjoyable.
  • Increase activity levels gradually.
  • Start by planning simple daily activities, such as shopping, driving, gardening, writing emails or completing simple household tasks.
  • Completing these activities can increase self-confidence and build the motivation needed to take on more energetic activities.
  • Plan activities that are enjoyable, interesting, relaxing or satisfying.
  • These activities are important in helping to overcome depression and anxiety.
  • At first, they may not feel as enjoyable as before, but with persistence, the pleasure should eventually return.

- Take part in activities with family members and close friends.
  • Accept social invitations.
  • Keeping connected with people helps increase levels of wellbeing, confidence and opportunities to participate in activities.
  • Planning a routine can help.
  • Make sure some form of exercise is scheduled in for each day.
  • Try to stick to the plan as closely as possible, but be flexible.

Download the Keeping Active fact sheet from www.beyondblue.org.au
Tips for getting a good night’s sleep

- Depression and anxiety can disrupt sleep patterns. It is important to try to restore a regular sleep pattern to make a full recovery.
- Try to get up at about the same time each morning.
- To prevent worrying about things during the night, set aside some time for problem-solving during the day.
- Avoid drinking caffeine after 4pm and try not to drink more than two cups of caffeine-type drinks each day (e.g. coffee, strong tea, cola or energy drinks).
- Avoid using alcohol to help with sleep. When alcohol is broken down in the body, it causes people to sleep less deeply and to wake more frequently.
- Allow time to wind down before going to bed. Stop any activities at least 30 minutes before bedtime and do something relaxing.

Download the Sleeping Well fact sheet from www.beyondblue.org.au

Reducing alcohol and other drugs

- It’s a good move to reduce the use of alcohol and other drugs as these can cause long-term problems and make it much harder to recover.
- It’s also a good idea to avoid stimulants, including:
  - excessive amounts of caffeine
  - any kind of amphetamine (speed, ecstasy, ice)—these can worsen symptoms of depression and anxiety.

Download the Reducing alcohol and other drugs fact sheet from www.beyondblue.org.au

Cultural, social and practical issues associated with cancer

Cancer is also associated with many social and practical issues, such as:

- money problems related to the cost of treatment
- travel and accommodation issues
- access to practical support
- Aboriginal people with cancer have many social and practical needs that they might need support with.
- They may find it helpful to speak with and Aboriginal Health Worker about their cancer treatment.
Body image and sexuality

Cancer can affect a person’s ability to be intimate in both physical and emotional ways.

Changes to body image

Body image is how a person feels about their body. Having cancer and cancer treatment can affect a person’s body image. This can be because of:

- cancer symptoms
- scarring or body changes after surgery
- treatment side effects (like weight changes)
- hair loss or skin changes
- fertility problems (that make it hard to get pregnant or father a child).

Every person having cancer treatment changes in different ways. Some changes, like hair loss, can be seen by other people. Other changes only the patient will notice.

When a person’s body image changes, it can affect how they relate to other people. This can sometimes put a strain on relationships with people close to them, particularly their partner.

Changes to sex life

It is common for people to have problems with sex during cancer treatment.

This can be because of:

- physical changes from the cancer or its treatment
- feeling tired and unwell during treatment
- changes in body image.

These problems often improve when the cancer treatment is finished.

Your patient and their partner may need to find new ways to show that they care about each other. This can include touching, holding, hugging and cuddling.

How to support your patient

Encourage your patient to tell the doctor or nurse if they are having problems with their body image or sex life. There may be treatments that can help.
Useful contacts

**eviQ Cancer Treatments Online**

**Telephone:** (02) 8374 3670  
**www.eviq.org.au/Home.aspx**

evIQ is a free online resource delivered by the Cancer Institute NSW.

It provides evidenced-based cancer treatment advice and protocols, and patient information about cancer treatments.

**beyondblue**

**Telephone:** 1300 22 4636  
**www.beyondblue.org.au**

**Webchat:** [www.beyondblue.org.au/get-support/get-immediate-support#chat](http://www.beyondblue.org.au/get-support/get-immediate-support#chat)

This organisation aims to achieve an Australian community that understands depression and anxiety, empowering all Australians, at any life-stage, to seek help.

It provides specific resources for Aboriginal and/or Torres Strait Islander people.

Other useful contacts for emotional support:

- **Lifeline:** 13 11 14
- **Suicide Call Back Service:** 1300 659 467

**Useful websites related to Aboriginal people with cancer:**

- **National Indigenous Cancer Network**  
  www.cancerinfonet.org.au
- **HealthInfo Net**  
  www.healthinfonet.ecu.edu.au/chronic-conditions/cancer/resources/

**Cancer Council Australia**

**Helpline:** 13 11 20  
**www.cancer.org.au**

The Cancer Council Australia website provides links to the state and territory Cancer Council websites.

Visit your local Cancer Council website for general information about cancer, or to find out what resources and support are available for patients, families or carers (e.g. counselling services or support groups).
**CanTeen**
**Telephone:** 1800 226 833 (free call)
**www.canteen.org.au**

This website provides support services to young people aged 12–24 living with cancer, including young people who have an immediate family member with cancer. This website has links to upcoming support programs in each state and territory.

**Quitnow**
**www.quitnow.gov.au**

This is a quit smoking online support resource from the Australian Government. It contains information specific to Indigenous communities.

**iCanQuit.com.au**

This website provides online resources to help your patients to quit smoking, including local directories of quit smoking support and fact sheets.

Download a free Quit Kit at: **www.icanquit.com.au/further-resources**

**Quitline**
**Telephone:** 13 7848 (13 QUIT)

Quitline provides a free, confidential and individually-tailored service to assist people through the process of quitting smoking. Quitline advisors are professionals with specialist training to assist smokers to quit. Aboriginal Quitline advisors are available. Quitline also offers a call-back service.

---

**Prescriptions**

Aboriginal and Torres Strait Islander people of any age who have an existing chronic disease (or who are at risk of chronic disease) may be eligible to access the Close the Gap PBS Co-payment Measure.

This may mean that they do not have to pay for their PBS prescriptions or they can get them at a reduced rate. Patients need to register either at a GP practice or Aboriginal Medical Service to receive this benefit.

For further information, visit: **www.medicareaustralia.gov.au/provider/pbs/prescriber/closing-the-gap.jsp**

**Email:** PBS-Indigenous@health.gov.au  
**Call:** (02) 6289 2409* (CTG PBS Co-payment Measure)  
**132 290** (claiming information)

* Call charges apply. This information was correct at the time of publishing.*
Bibliography


## Glossary

<table>
<thead>
<tr>
<th>Word</th>
<th>Meaning</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Adjuvant</strong></td>
<td>This describes treatment given in addition to primary (first) treatment; often surgery. Adjuvant treatment can include chemotherapy, radiotherapy, hormonal and targeted therapies.</td>
</tr>
<tr>
<td><strong>Alopecia</strong></td>
<td>Hair loss.</td>
</tr>
<tr>
<td><strong>Anaemia</strong></td>
<td>A low red blood cell count.</td>
</tr>
<tr>
<td><strong>Antineoplastic</strong></td>
<td>Anti-cancer.</td>
</tr>
<tr>
<td><strong>Body image</strong></td>
<td>A person’s thoughts and/or feelings about his or her body (i.e. its form, size, shape, and the way it fits with society’s views of ‘normal’ appearance).</td>
</tr>
<tr>
<td><strong>Cancer care coordinator</strong></td>
<td>A health professional who helps to coordinate the care of patients with cancer.</td>
</tr>
<tr>
<td><strong>Chemotherapy/chemo</strong></td>
<td>Cancer treatment using drugs.</td>
</tr>
<tr>
<td><strong>Complementary and alternative medicines (CAM)</strong></td>
<td>Treatments used instead of conventional treatment, like bush medicine or homeopathy.</td>
</tr>
<tr>
<td><strong>Cytotoxic</strong></td>
<td>Kills cancers and can be harmful to normal cells.</td>
</tr>
<tr>
<td><strong>Diarrhoea</strong></td>
<td>Runny stools (poo).</td>
</tr>
<tr>
<td><strong>Dietitian</strong></td>
<td>A health professional who is an expert in nutrition or dietetics.</td>
</tr>
<tr>
<td><strong>Dizziness</strong></td>
<td>A feeling of unsteadiness, wooziness and light-headedness.</td>
</tr>
<tr>
<td><strong>Double-bagging</strong></td>
<td>A safe way to dispose of hazardous waste, where the waste is placed into one bag, sealed, then placed into another bag and sealed.</td>
</tr>
<tr>
<td><strong>Fatigue</strong></td>
<td>Extreme tiredness or exhaustion, which is not relieved by rest.</td>
</tr>
<tr>
<td><strong>Febrile neutropenia</strong></td>
<td>A high fever (sometimes with other signs of infection) while the person has an abnormally low white blood cell count. It can be a side effect of chemotherapy treatment and is <strong>life-threatening</strong> if not recognised and treated early.</td>
</tr>
<tr>
<td><strong>Haemoglobin</strong></td>
<td>How the red blood cells are measured. When the red blood cells are low, it’s called anaemia.</td>
</tr>
<tr>
<td><strong>Haematologist</strong></td>
<td>A doctor who specialises in treating blood conditions, including blood cancers.</td>
</tr>
<tr>
<td><strong>Infection</strong></td>
<td>When germs, like bacteria or viruses, enter the body and cause illness.</td>
</tr>
<tr>
<td><strong>Intravenous infusion</strong></td>
<td>A method of putting fluids, including drugs, into a vein through a cannula (needle), central venous access device (CVAD) or port.</td>
</tr>
<tr>
<td><strong>Medical oncologist</strong></td>
<td>A doctor who specialises in treating cancer using chemotherapy.</td>
</tr>
<tr>
<td><strong>Lymphoedema</strong></td>
<td>Swelling that results from lymph nodes being removed or treated.</td>
</tr>
<tr>
<td><strong>Metastatic cancer</strong></td>
<td>Cancer that has spread from the original cancer site to another site in the body.</td>
</tr>
<tr>
<td><strong>Mucositis</strong></td>
<td>Painful inflammation and ulceration, of the lining of the mouth, throat and digestive tract.</td>
</tr>
<tr>
<td><strong>Multidisciplinary team/treating team</strong></td>
<td>A team of health professionals who plan and manage the treatment of cancer patients.</td>
</tr>
<tr>
<td><strong>Nausea</strong></td>
<td>Feeling sick like you are going to vomit (spew).</td>
</tr>
<tr>
<td><strong>Neoadjuvant</strong></td>
<td>Describes treatment given before primary (first) treatment (e.g. a woman may receive neoadjuvant chemotherapy for breast cancer to shrink the tumour before she has surgery).</td>
</tr>
<tr>
<td><strong>Neutrophils</strong></td>
<td>A type of white blood cell that helps to fight infection.</td>
</tr>
<tr>
<td><strong>Palliative care</strong></td>
<td>Care that focuses on relieving and preventing suffering. It can be used for those undergoing treatment for curable illnesses and those living with chronic diseases, as well as patients nearing the end of life.</td>
</tr>
<tr>
<td><strong>Palliative care team</strong></td>
<td>A team of experts who specialise in relieving or preventing suffering. They can often manage pain, nausea and other symptoms effectively.</td>
</tr>
<tr>
<td><strong>Peripheral neuropathy</strong></td>
<td>Damage to the nerves of hands and feet, which can cause tingling, pain or numbness.</td>
</tr>
<tr>
<td><strong>Pharmacist</strong></td>
<td>A healthcare professional who focus on the effective and safe use of medicines.</td>
</tr>
<tr>
<td><strong>Radiation therapist</strong></td>
<td>Plans and gives radiation treatments to patients.</td>
</tr>
<tr>
<td><strong>Radiation oncologist</strong></td>
<td>A doctor who specialises in treating cancer using radiotherapy.</td>
</tr>
<tr>
<td><strong>Radiotherapy or radiation therapy</strong></td>
<td>Cancer treatment using x-rays to a particular area of the body.</td>
</tr>
<tr>
<td><strong>Social worker</strong></td>
<td>A healthcare professional who can provide practical support, counselling, information and emotional support to individuals, families and communities. They can help with problems such as homelessness, domestic violence, and alcohol and drug addiction. They can help with Centrelink entitlements, and generally assist with financial matters if required.</td>
</tr>
<tr>
<td>-------------------</td>
<td>---------------------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td><strong>Speech pathologist</strong></td>
<td>A health professional trained to assess and treat people who have a communication disability. They can also help people who have difficulties swallowing food and drink.</td>
</tr>
<tr>
<td><strong>Targeted therapies</strong></td>
<td>Drugs that stop the growth of particular types of cancer cells. Also known as biological therapies.</td>
</tr>
<tr>
<td><strong>Tinnitus</strong></td>
<td>Ringing, swishing, buzzing or humming noises in the ears, when there is no physical noise present. It can be caused by many things, including wax in the ears and some chemotherapy drugs.</td>
</tr>
<tr>
<td><strong>Vomiting</strong></td>
<td>Throwing up/spewing.</td>
</tr>
<tr>
<td><strong>Xerostomia</strong></td>
<td>Dry mouth caused by lack of saliva. It can be caused by radiotherapy treatment to the mouth.</td>
</tr>
</tbody>
</table>
# Useful phone numbers

<table>
<thead>
<tr>
<th>Place</th>
<th>Phone number</th>
<th>Contact person</th>
</tr>
</thead>
<tbody>
<tr>
<td>Aboriginal Medical Service (AMS)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aboriginal Liaison Officer (ALO)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aboriginal Health Worker (AHW)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Cancer care coordinator</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Emergency Department</td>
<td></td>
<td></td>
</tr>
<tr>
<td>General practitioner (GP)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Occupational therapist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oncologist (doctor)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oncology Day Unit</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oncology nurse</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Oncology ward</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Palliative care doctor</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pharmacist – community</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Pharmacist – hospital</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Radiation oncologist (doctor)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social worker</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Speech pathologist</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Support worker</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>