Cancer Council

PRACTICAL SUPPORT fact sheet

Late Effects of Cancer Treatment

A guide for people who have finished cancer treatment

Some side effects of cancer treatment appear after treatment has finished. This fact sheet helps you understand late effects and how they can be managed.

What are late effects?

Some people have side effects from cancer treatment that begin months or years after treatment has finished. These are called late effects. Physical late effects may include tiredness (fatigue) or pain. Emotional late effects may include depression or anxiety. Late effects may last for a short or long time.

Late effects can be similar to long-term side effects, but long-term effects start during treatment and continue after it ends.

How common are late effects?

About 1 in 3 cancer survivors experience a late effect. A lot is already known about the late effects of established treatments such as chemotherapy and radiation therapy (radiotherapy). As new treatments are developed, researchers may also find that they cause late effects.

It's important to be aware of late effects, as getting help early can make them easier to manage. While the list of late effects (see pages 2–5) can seem alarming, you are unlikely to get them all and may not get any of them.

For most people, the benefits of treating the cancer far outweigh the risks of side effects and late effects. Talk to your cancer care team or general practitioner (GP) if you are worried about the risk of late effects, or think you may have a late effect.

Who is at risk of late effects?

Late effects can affect anyone who has had cancer treatment. Your chance of having late effects depends on a number of things, including:

- the type of cancer you had
- your age at diagnosis
- the type and amount of treatment you had
- your health and how active you are before, during and after treatment.

Your experience may be very different from someone else's, even if they had the same cancer and treatment. Some physical late effects are linked to certain treatments. Emotional effects, such as feeling anxious or depressed, can happen after any cancer treatment.

Your cancer care team can explain your risk of late effects. You can also ask if there are ways to lower your risk. They may suggest regular check-ups to look for signs of late effects.

A survivorship care plan can help you understand late effects and discuss them with your healthcare team (see page 7).

Physical late effects

Fatigue

Fatigue is the most common side effect of cancer treatment. It's linked to all cancer treatments and often occurs with other late effects, such as pain and sleep issues. Cancer-related fatigue can be short-term or last for many months or years.

Cancer-related fatigue makes you feel very tired and weak and it doesn't always go away with rest. Other symptoms include muscle aches, difficulty with daily tasks, low mood and irritability.

Fatigue can be caused by low red blood cell count (anaemia), hormone changes, reduced muscle strength or fitness, depression, side effects from medicines, nutrition issues, and effects from the cancer itself. These can often be managed by your GP and allied health professionals. Your GP may also refer you to a specialist or a late effects clinic, if available.

- See our *Understanding Fatigue and Cancer* fact sheet.

Sleep issues

Many people have trouble sleeping at some point in their lives – with or without cancer. But cancer and some treatments can cause sleep problems. You may find it hard to fall asleep, or you may wake up during the night or too early.

Sleep problems after cancer treatment can be linked with pain, anxiety or depression. Some medicines and hormonal changes can also affect sleep.

Your GP can suggest ways to improve your sleep. They may prescribe medicine if needed. They can also refer you to a counsellor or psychologist for help with anxiety or depression.

- Listen to our "Sleep and Cancer" episode of *The Thing About Cancer* podcast series.

If you had cancer treatment as a child or young adult, or if you received a stem cell transplant as a cancer treatment, you may have late effects that aren't covered in this fact sheet. Talk to your GP if you notice a new symptom.

When to talk to your doctor

See your GP or cancer care team if you have:

New symptoms

If you have a symptom listed in this fact sheet, see your GP or cancer care team as soon as possible. You don't need to wait for your next appointment. New symptoms can have many causes, but it's important to get them checked.

Pain that's not controlled

This might be new pain, or ongoing pain that's no longer controlled by pain medicine or treatment.

Trouble eating or sleeping

See your GP if these changes are new and last more than a few days.

"I experienced brain fog and fatigue after finishing my treatment. My doctors explained how common these issues are, which was really reassuring." ANTHEA

Nerve changes

Peripheral neuropathy is a nerve condition that affects the hands or feet. It can cause tingling or numbness, pain, or a burning feeling. Some chemotherapy drugs can damage nerves. So can some types of surgery, radiation therapy, and some newer drug therapies.

Peripheral neuropathy can start during cancer treatment, or in the months after treatment finishes. Your GP can help you manage some symptoms with exercises or medicines. They may also refer you to a pain specialist, physiotherapist, exercise physiologist, occupational therapist or psychologist for extra support.

- See our *Understanding Peripheral Neuropathy and Cancer* fact sheet.

Pain

You may feel different types of pain as a late effect of cancer treatment. Nerve damage, lymphoedema (see below), or scar tissue can cause pain. Some people feel pain in a body part that is no longer there (phantom pain).

How your pain is treated depends on the cause, as well as your general health. Your GP may prescribe pain medicine or refer you to a pain clinic. Physiotherapists and other allied health professionals can help improve your strength and movement.

- ▸ See our *Understanding Cancer Pain* booklet and listen to our "Managing Cancer Pain" episode of *The Thing About Cancer* podcast series.

Lymphoedema

Swelling caused by a build-up of lymph fluid under the skin is called lymphoedema. It can occur if lymph nodes are removed during surgery or damaged by radiation therapy. Lymphoedema can appear anywhere in the body but often affects an arm or leg.

Let your healthcare team know if you experience symptoms including swelling, aching, heaviness or tightness, reduced movement, and small dents in the skin (pitting). Lymphoedema can happen during or soon after treatment, or years later.

Early treatment is important to prevent lymphoedema from worsening. Treatment may involve compression, drainage and exercises from a specially trained occupational therapist, physiotherapist, or nurse.

- ▸ See our *Understanding Lymphoedema* fact sheet.

Heart conditions

Some cancer treatments can affect how your heart and blood vessels work. This can increase your risk of heart disease (cardiovascular disease) and heart conditions. Cancer treatments linked to heart conditions include some types of chemotherapy, targeted therapy, immunotherapy and radiation therapy to the chest.

Common heart conditions are heart inflammation (myocarditis), irregular heartbeats (arrhythmia) and damage to the heart muscle (cardiomyopathy). Some hormone therapies can also increase the risk of high blood pressure and cholesterol.

If you've had treatment that may affect your heart, ask your GP or cancer care team if you need regular check-ups to monitor your heart health.

Tell your GP or cancer care team immediately about symptoms such as:

- chest pain or tightness
- shortness of breath
- swelling in the legs
- fatigue or feeling dizzy.

If you have severe chest pain or shortness of breath, call Triple Zero (000).

- ▸ See our *Understanding Heart Health and Cancer* fact sheet.

Bone changes

Some cancer treatments can cause thinning of your bones and raise your risk of fractures (a condition called osteoporosis). Other risk factors for poor bone health include your age (being over 50), family history and low hormone levels (oestrogen for women and testosterone for men).

Your GP may arrange a scan to check your bone mineral density. They may also prescribe medicine or refer you to an exercise physiologist, physiotherapist or dietitian for support.

- ▸ Call Healthy Bones Australia on 1800 242 141 or visit healthybonesaustralia.org.au.

Why is my memory worse after cancer?

You may find it harder to focus, remember details or learn new information. These changes can happen before, during or after cancer treatment, and are sometimes called "chemo brain" or "brain fog".

The exact cause of these changes isn't known. They may be linked to cancer treatments or medicines. Other factors, including ageing, fatigue, hormone changes, stress, anxiety or depression, may play a part. Your GP can help you manage these changes, and may refer you to an occupational therapist or psychologist for extra support.

- ▸ See our *Understanding Changes in Thinking and Memory* fact sheet and listen to our "Brain Fog and Cancer" episode of *The Thing About Cancer* podcast series.

Bowel and bladder changes

Some cancer treatments can cause bowel and bladder problems. These are usually linked to radiation therapy to the pelvic area and some types of surgery. You may have trouble controlling your bowel or bladder (incontinence), difficulty passing bowel motions (constipation), or loose stools (diarrhoea).

See your GP or cancer care team if you notice blood in your stools (poo) or urine (wee), or if you need to go to the toilet more often. These changes may be signs of inflammation of the bowel (radiation proctitis) or bladder (cystitis) and should be checked by a doctor.

Most bowel and bladder problems can be managed. Your GP or cancer team can help by prescribing medicines, treatments, dietary changes and special exercises. You may be referred to specialists to help with ongoing problems.

▸ See our *Living Well After Cancer* booklet.

Hormonal changes

Different cancer treatments can affect the body's hormone system (endocrine system). This can lead to late effects, including:

- **Menopause** – The ovaries stop working and periods end. You may have hot flushes, night sweats, joint pain, trouble sleeping, dry or itchy skin, low sex drive, vaginal dryness, and anxiety.
- **Underactive thyroid** – The body makes too little thryoid hormone. This can cause weight gain, constipation, dry skin and feeling cold.
- **Overactive thyroid** – The body makes too much thyroid hormone. This can cause weight loss, tiredness, shaky hands and feeling too hot.
- **Weight gain** – Your general health, fatigue, mood, diet and activity levels can all affect your weight.

Your GP or cancer care team can help you manage these changes. They may prescribe medicines or suggest treatments to ease symptoms.

Changes to sex and intimacy

You may find sex difficult, painful or less enjoyable, and your interest in intimacy may drop. Cancer treatments like pelvic radiation therapy can lead to a loss of sensation, changes to the vagina and erection difficulties. Fatigue, pain, hormone changes, depression and anxiety can also contribute.

Speak with your GP about treatments, including medicines. A psychologist, counsellor or sex therapist can provide emotional support.

▸ See our *Sex, Intimacy and Cancer* booklet and listen to our "Sex and Cancer" episode of *The Thing About Cancer* podcast series.

Other late effects

Lung conditions – Some chemotherapy, targeted therapy, immunotherapy, and radiation therapy to the chest can damage the lungs. A rare but serious condition that can develop as a late effect is lung inflammation (pneumonitis). See your GP if you have shortness of breath, a cough, chest pain, or feel faint.

Teeth and mouth changes – Surgery or radiation therapy to the head and neck, and chemotherapy and other medicines, can affect your mouth and teeth. You may have mouth sores, tooth decay or trouble swallowing. Have regular dental check-ups. You may find it helpful to see a dietitian or speech pathologist.

Hearing loss – Radiation therapy to the head or neck and some chemotherapy drugs can affect hearing. You may have trouble hearing high sounds or notice ringing in your ears (tinnitus). An audiologist can test your hearing and suggest devices to help.

Vision changes – Some treatments increase the risk of cataracts. This can cause blurred or cloudy vision, double vision, light sensitivity, and trouble seeing at night. Have regular eye checks. An eye specialist can treat cataracts with surgery.

Am I more likely to get a different cancer now?

Rarely, people may develop a new cancer that is different from their first cancer. This is called a second cancer. The overall risk of a second cancer is low, but it can be slightly higher after some types of radiation therapy and chemotherapy. Other factors, such as age, family history and smoking, can also affect risk.

For most people, the benefits of treating the original cancer far outweigh the risk of developing a second cancer. Talk to your GP if you notice any new or ongoing symptoms that concern you.

Emotional late effects

Emotional late effects, such as depression and anxiety, can develop months or years after cancer treatment. Some people find it more difficult to cope after treatment has finished, even if they felt they were coping well at the time.

There are many reasons why emotional late effects happen. They can be linked to physical changes, fatigue, pain or other symptoms caused by cancer and its treatment, as well as changes to your relationships or your general health.

Fear of cancer coming back

You may worry that your late effects are signs that cancer has returned (recurrence). Many cancer survivors experience this fear, and it may come and go for many years.

This fear may be worse before follow-up appointments or while waiting for test results. This is sometimes called "scanxiety". It can also appear on birthdays or anniversaries of the date you were diagnosed, when you hear about other people having a cancer recurrence, or when you have symptoms like those when you were first diagnosed.

See your GP if you are worried about cancer returning. A counsellor or psychologist may be able to help you manage this fear.

▸ Listen to our "Managing Fear" episode of *The Thing About Cancer* podcast series.

Post-traumatic stress

You can experience post-traumatic stress after a cancer diagnosis or during treatment, but it can also happen after cancer treatment finishes. Symptoms of post-traumatic stress include:

- disturbing memories or nightmares
- avoiding people, places or events that remind you of cancer
- emotional distress when reminded of cancer
- always feeling "on alert" for danger.

If these symptoms happen for more than a few days or if they are stopping you from going to medical appointments or doing normal activities, talk to your GP. Treatment may include medicines or therapy provided by a psychologist or counsellor.

Complementary therapies are designed to be used alongside conventional medical treatments. Therapies such as acupuncture, massage and relaxation may decrease stress and anxiety and improve your mood. Talk to your doctor about any complementary therapies you are using or thinking about trying, as some may not be safe or evidence-based.

▸ See our *Understanding Complementary Therapies* booklet.

Depression and anxiety

Depression and anxiety are common after cancer treatment. Both conditions can affect your thoughts, physical health and behaviour – some of the symptoms are listed below. Talk to your GP if you are experiencing any of these symptoms.

Signs of depression

- Persistent sadness or low mood
- Loss of interest in activities
- Difficulty concentrating
- Fatigue or low energy
- Changes in sleep or appetite
- Neglecting responsibilities and self-care
- Thoughts of self-harm or suicide

Signs of anxiety

- Excessive worry or fear
- Racing thoughts
- Feeling overwhelmed
- Muscle tension or headaches
- Stomach upset, nausea or diarrhoea
- Tingling or numbness
- Changes in sleep

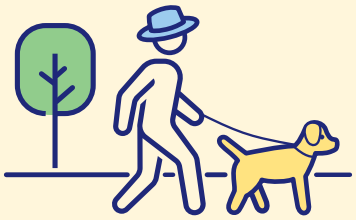
Treating these issues early may mean that you can avoid symptoms becoming worse. Treatment may include medicines or therapy provided by a psychologist, social worker or counsellor.

For information about coping with depression and anxiety, call Beyond Blue on 1300 22 4636 or visit beyondblue.org.au. If you are having intense thoughts about hurting yourself or others, call Lifeline 13 11 14. In an emergency, call Triple Zero (000).

▸ See our *Emotions and Cancer* booklet.

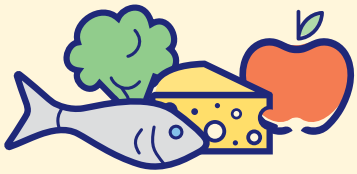
Ways to keep healthy with late effects

Move more



- Aim to be as physically active as you can. Any activity is better than none – even a walk around the block can have benefits.
- Talk to your GP about what exercise is safe for you, then start slowly and build up your activity gradually.
- Work towards doing 30 minutes of moderate-intensity exercise (e.g. brisk walking) on most days, and 3 balance and coordination sessions (e.g. tai chi) and 2 strength-training sessions (e.g. squats) a week.
- An exercise physiologist or physiotherapist can create an exercise program to meet your needs. Visit essa.org.au/find-aep or choose.physio/find-a-physio.

Eat well



- Enjoy a variety of foods from the 5 food groups – vegetables and legumes, fruit, breads and cereals, dairy (and alternatives) and lean meat (and alternatives).
- Limit sugary drinks, junk food and other processed foods high in saturated fat, salt and sugar.
- A dietitian can provide nutrition advice to meet your needs. Visit dietitiansaustralia.org.au to find a dietitian. Your GP can give you a referral.

Look after yourself and manage your mood

- Aim for about 7–8 hours of sleep each night.
- Pace your activities and rest when you need to.
- Talk to an occupational therapist (otaus.com.au/find-an-ot) about how to make daily tasks easier at home. Your GP or cancer care team can give you a referral.
- Try to focus on the present moment. Relaxation and meditation techniques may help. Listen to our *Finding Calm During Cancer* podcast series.
- Try cognitive behaviour therapy (CBT) and mindfulness-based stress reduction (MBSR). These can help with mood. Ask your GP what's available in your area.
- Write down your feelings or express yourself in painting, colouring, music or singing.
- Call Cancer Connect on 13 11 20 to connect with a support group, either over the phone or online.

Involve other people

- Tell your GP or cancer care team if you have new or worsening side effects. Do not wait until your next follow-up appointment.
- Ask your partner or a close family member or friend to come to your appointments with you.
- If household chores are becoming difficult, let family, friends or neighbours lend a hand. The Gather My Crew app can help you organise help from others.
- You may be eligible for services for help at home. Your local council or social worker can advise you on what is available. Some services are free, while others have a cost.
- Ask your employer whether they can make changes to support you at work.
- Call Cancer Connect on 13 11 20 to ask any questions about your situation. Qualified professionals can listen to your concerns, link you with local services and send you our free booklets.

Quit smoking and limit alcohol

- Aim to quit smoking and vaping and reduce or avoid alcohol, as these can worsen late effects.
- It's not always easy to quit smoking or vaping, but support is available. Call Quitline on 13 7848 or visit quit.org.au for advice.
- Talk to your doctor about nicotine replacement therapy or prescription medicines to help you quit.
- Download the My QuitBuddy app to help track your progress with quitting smoking, and download the Daybreak app to help track your drinking.
- Reduce your alcohol intake by choosing non-alcoholic drinks and having some regular alcohol-free days each week.

Care and support for late effects

Different health professionals can support your wellbeing if you have late effects. They can help you manage symptoms and monitor your general health.

If you have follow-up appointments

Your appointments may be with your cancer specialist, cancer nurse, GP, or a mix of these. A follow-up appointment is a good time to discuss your symptoms and possible late effects to watch for.

Your doctor or nurse may refer you to a range of allied health professionals to help you manage your symptoms. Psychologists, occupational therapists, physiotherapists, exercise physiologists and dietitians are all allied health professionals.

Write down any questions you have and bring the list to your appointments (see next page). You can also bring a family member or friend for support or to help listen and take notes. If you have a survivorship care plan, bring it with you (see below right).

If you notice any new symptoms or feel worried between appointments, contact your GP straightaway. You don't have to wait for your next check-up. It's important to speak up so your symptoms can be managed as soon as possible.

If you don't have follow-up appointments

If it has been at least 6 months since your last follow-up appointment, it's best to see your GP first. Your GP can:

- assess your symptoms
- prescribe medicines and suggest ways to help manage your symptoms
- give you a referral to your cancer specialist or an allied health professional
- create a chronic condition management plan or mental health treatment plan for you
- help you with next steps.

It's always useful to tell or remind your GP that you had cancer treatment, even many years later. If you have them, bring details of your cancer diagnosis and treatment (often called a treatment summary) or your survivorship care plan to your GP appointment.

The costs for seeing an allied health professional vary. Some hospitals and cancer centres have free services for patients. If your GP refers you as part of a chronic condition management plan or a mental health treatment plan, you may be eligible for a Medicare rebate for some visits. If you have private health insurance, your insurer may cover some of the costs.

If you live in a rural or regional area

Support is available if you travel long distances to get to doctors and support services. You can:

- get help with travel and accommodation services – call Cancer Connect on 13 11 20 for more information about practical support
- ask if telehealth can be used for any appointments to reduce your travel
- join a local cancer support group, where you can share experiences. You can call Cancer Connect on 13 11 20 to be linked with individuals and support groups by phone or online.

▸ See our *Life After Cancer: Rural and Regional Areas* fact sheet.

What is a survivorship care plan?

Some treatment centres give you a survivorship care plan when you finish cancer treatment. This plan can:

- summarise your cancer and the treatment you received
- set out a clear timetable for follow-up visits and screening tests, with contact details for your care team
- list symptoms to watch for and possible long-term or late side effects
- describe your medical, emotional and social needs after treatment, and how to manage them
- explain each team member's role and who to call if you feel worried
- suggest practical steps for a healthy lifestyle.

This plan helps you, your family and your healthcare team communicate. You can review and update it as your needs change over time. Ask your doctor or nurse to update it at appointments.

If you don't have a survivorship care plan, you can create your own and review it with your GP or cancer care team. Visit petermac.org/cancersurvivorship and search for "life after treatment resources".

Questions to ask your health professionals

This checklist may be helpful when thinking of questions to ask your GP or cancer care team.

- Am I at risk of getting any late effects and what can I do to prevent them?
- What symptoms or changes should I watch out for?
- Who should I contact if I develop new symptoms?
- Is this symptom related to my cancer treatment?
- What treatments are there for any late effects that I have?
- Am I eligible for a chronic condition management plan or mental health treatment plan?

Where to get help and information

Call Cancer Connect on 13 11 20 or visit the website for more information about cancer and health care. Qualified professionals can listen to your concerns, put you in touch with services and send you free copies of our booklets. You can also visit your local Cancer Council website.

Cancer Connect	cancerconnect.org.au
ACT	actcancer.org
NSW	cancercouncil.com.au
NT	cancer.org.au/nt
QLD	cancerqld.org.au
SA	cancersa.org.au
TAS	cancer.org.au/tas
VIC	cancervic.org.au
WA	cancerwa.asn.au
Australia	cancer.org.au

"I'm more aware of my own body and the need to get any changes checked out straightaway." SAM

Other useful websites

Cancer Council Online Community	cancercouncil.com.au/OC
Cancer Council podcasts	cancercouncil.com.au/podcasts
Australasian Lymphology Association	lymphoedema.org.au
Australian Association of Social Workers	aasw.asn.au
Australian Cancer Survivorship Centre	petermac.org/cancersurvivorship
Australian Physiotherapy Association	australian.physio
Carer Gateway	carergateway.gov.au
Dietitians Australia	dietitiansaustralia.org.au
Exercise & Sports Science Australia	essa.org.au
Heart Foundation	heartfoundation.org.au
Occupational Therapy Australia	otaus.com.au
Services Australia	servicesaustralia.gov.au

International

American Cancer Society (US)	cancer.org
Macmillan Cancer Support (UK)	macmillan.org.uk

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Note to reader
Always consult your doctor about matters that affect your health. This fact sheet is intended as a general introduction and is not a substitute for professional medical, legal or financial advice. Information about cancer is constantly being updated and revised by the medical and research communities. While all care is taken to ensure accuracy at the time of publication, Cancer Council Australia and its members exclude all liability for any injury, loss or damage incurred by use of or reliance on the information provided in this fact sheet.

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Cancer Council acknowledges Traditional Custodians of Country throughout Australia and recognises the continuing connection to lands, waters and communities. We pay our respects to Aboriginal and Torres Strait Islander cultures and to Elders past and present.

Cancer Council