

Self-care and support

During and after
melanoma

Looking after yourself

Maintaining a healthy lifestyle is important for both your physical and emotional wellbeing during and after melanoma treatment.

From being active and eating well to participating in activities you enjoy, it's time to put yourself at the top of your priority list!

Maintaining your follow-up visits

Be sure that you keep up to date with your scheduled follow-up visits and closely monitor your general health. Record details of your follow-up plan and appointments in the personal record section at the end of this Guide, from page 61.

Keeping active

Being physically active and exercising regularly is important for your physical health, your emotional wellbeing and your quality of life.

Try to be active most days of the week – every day if you can manage. In the beginning, start slowly and listen to your body. When you feel ready, work up to doing 30 minutes of aerobic activity on three or more days of the week.

This may include activities like walking, jogging, swimming or cycling. Aim to be working at a pace where you can talk but not sing.

Patient Information Brochures on Exercise

Melanoma Institute Australia has developed a series of helpful patient information brochures on exercising after neck, axillary and groin or pelvic dissection. If you have undergone a dissection procedure, you can download the relevant brochure/s from melanoma.org.au.



You should also incorporate two to three resistance exercise sessions during the week. This may include lifting weights or using your body weight as resistance in exercises such as squats, lunges and push-ups.

If you have had surgery, be mindful of your surgical site and move within the recommendations of your healthcare team. The aim is to reap the benefits of exercise without incurring injury.

Speak to your treatment team about referral to an accredited physiotherapist or exercise physiologist, who can help you set up an exercise program that suits your body and needs.

Eating well

Eating a fresh, nutritionally balanced diet can help you to maintain your energy and keep you feeling good during and after treatment for melanoma.

Choose fresh vegetables, fruit, nuts, lean meat, fish and non-processed foods. Drink 6 cups of water each day to keep hydrated.

Sometimes treatment can affect your appetite and change your relationship with food. It can be helpful to talk to a dietitian to help you stay nourished and strong.

You can find an accredited practising dietitian through the Dietitians Australia at daa.asn.au or on **1800 812 942**. The 'Find an accredited practising dietitian' button on the website allows users to search for dietitians with a specialty in cancer.

Resting and recuperating

You will need time to rest and heal following treatment for melanoma – especially if your treatment involved extensive surgery.

Be realistic about how much you can do immediately following your treatment. You may have good days and bad days. Don't push yourself to do too much, too soon, even if you feel well. Take your time to rest and recuperate so that you can get back to the things you enjoy the most without unnecessary setbacks.

**Nutrition and
Cancer**
Resource
available
from Cancer Council
cancercouncil.com.au
13 11 20



A good sleep routine is an essential element in your recuperation. Go to bed at the same time each night and wake up at the same time each day. Avoid caffeine and electronics, such as your phone, television or computer, close to bedtime. Instead, relax with a good book or some soft, calming music.

Doing activities that you enjoy

When you are feeling overwhelmed or stressed, it can be helpful to have something to look forward to. Making plans to do activities that you enjoy – like going out for a special meal or socialising with friends – can help to take your mind off things and make you feel more in control of your situation.

What are some of your favourite pastimes? Make a list and start planning!

Finding a 'new normal'

Being diagnosed with melanoma, and undergoing treatment, can be life changing. Once treatment is over, you may feel a sense of relief, but it can often be hard to simply return to 'normal' life.

Perhaps you have a new perspective on life or you're ready for a fresh start. No matter how you feel, it's ok to take time to find your 'new normal'. Here are some tips to help you along:

- **Recognise and accept that life may be different from now on.** There is no need to get 'back to normal' or to start new projects or activities. Do what feels right for you.
- **Think about what is most important in your life.** Do you love spending time with friends and family? Do you like to travel? Build a fulfilling life around what matters most.
- **Join a support group.** Speaking with others in similar situations can help you to feel more supported and optimistic about the future.
- **Channel your energy for good.** Volunteering, fundraising or taking part in a charity event are all great ways to help other people in need.
- **Always talk with your healthcare team** if you have any worries, sadness or low moods.

Your emotional wellbeing

Everyone deals with the diagnosis and treatment of melanoma differently. It is normal to feel a range of emotions during this time.

From worry and uncertainty about the future, to anger and guilt, these emotions can often be unpleasant or even overwhelming. Regardless of your experience, it is important to acknowledge how you feel, and if possible, talk about your feelings with someone. This is an integral part of looking after yourself.

In the following pages, we will explore some common emotions you may experience and provide some tips on how you can deal with them.



Worry

Being diagnosed with melanoma can be a frightening experience. It's normal to feel worried or afraid about what the future holds. You may feel worried about:

- treatment, side effects and feeling sick
- the impact of your diagnosis and treatment on your family
- keeping your job during treatment
- managing finances during treatment
- how your relationship with your partner, children, family and friends may change
- whether your family members may be at increased risk of melanoma (read more on page 50)
- what this diagnosis means for your future health.

Uncertainty about the future and feeling like you're not 'in control' of your health or situation is common.

One way you can manage this area of worry is being well-informed and well-prepared for what is to come. It's important to access information from reliable sources. We've listed some good examples on page 56.

Keep a notepad, or use the 'My notes and questions' pages at the end of this guide from page 75, to write down any questions you have for your healthcare team before and between your appointments. Talk with your team to learn as much as you can about your diagnosis and treatment options, so that you are actively involved in your treatment planning.

It can also help to plan how you will manage practical issues during and after your treatment. Think about who you can call on to help with things like cooking, shopping, cleaning and childcare during your treatment and recovery.

Fear of recurrence or progression

After you have been diagnosed or treated for melanoma, it's very common to worry that the melanoma will come back or spread. This worry is called 'fear of recurrence or progression'.

Fear of recurrence or progression is completely normal, but it can be distressing and unpleasant if not managed. Sometimes, this fear may stop you planning for the future or living your life to the fullest.

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People generally find this fear does improve over time. However, you may find you worry more at certain times, such as:

- around the time of medical check-ups, examinations or scans (this is also known as 'scanxiety')
- on special occasions like birthdays
- on anniversaries related to your diagnosis or treatment
- when you hear stories about other people who've been diagnosed with cancer
- when you notice a new sign or symptoms, such as skin changes or aches and pains.

If you are finding it difficult to manage your fear of recurrence or progression, or if it's affecting your daily life, it may be time to seek counselling. You can read more about psychological support and counselling on page 53.

Coping with the fear of recurrence

While nobody can control what the future holds, you can control how much fear of recurrence or progression affects your daily life. Here are a few ways to manage your concerns:

- **Join a support group** – Fear of recurrence or progression is the most common worry experienced by people after treatment for melanoma. It can be a big help to talk to other people who feel or have felt the same.
- **Know your risk for recurrence** – Talk with your healthcare team about your medical history and what that may tell you about the chances of melanoma coming back or progressing.
- **Be aware of symptoms** – It's important to be well informed about the signs and symptoms that may indicate a melanoma recurrence. But also, be mindful that checking your skin too often can be counterproductive! Frequent checking can make it harder to notice small changes in moles over time. It is usually recommended to check your skin monthly, at most. See page 30 for advice on how to conduct a self-examination.
- **Take control of your general health and wellbeing by making healthy choices** – Eat well, exercise regularly, be sun smart and avoid unhealthy habits such as smoking and excessive or frequent drinking.



Stress

Stress is the way your body reacts to a threatening or harmful situation. Being diagnosed with melanoma might be one of the most stressful things you will ever experience.

Stress can affect both your emotions and your body in very real ways. Some signs that you may be experiencing unhelpful stress include:

- becoming easily agitated
- feeling overwhelmed or out of control
- an inability to focus
- having tense muscles
- experiencing headaches
- having a rapid heartbeat
- trouble sleeping.

While stress is a completely normal reaction to your diagnosis, it can make it harder to cope with everyday life.

Prolonged or chronic stress may impact your everyday life, your ability to engage and enjoy activities and reduce your sense of wellbeing and vitality.

The good news is there are some easy things you can do to lower stress levels.

- **Exercise** – Regular, moderate-intensity exercise can be a big help to relax your body and clear your mind.
- **Mindfulness or meditation** – Practising mindfulness or meditation, even for just a few minutes at a time, can help you to feel calm and at peace. There's no one 'right' way to be mindful or meditate. You could attend a meditation class, download a meditation app on your phone or simply take a few minutes to yourself to sit comfortably and focus your thoughts.
- **Sleep well** – Sleep is an essential element in your recovery. Develop a sleep routine – go to bed at the same time each night and wake up at the same time each day. Avoid stimulants, like caffeine or screen time, within an hour of bedtime.
- **Write a journal** – Writing down the things that are causing you stress, preferably at the time you're aware of it, can be an effective way to release a lot of the tension.

Loss of identity

Sometimes, being diagnosed with melanoma can change the way you feel about yourself.

There are a number of reasons for this.

- You may find that your treatment and recovery affect the role you play in your family or at work. Changes in everyday arrangements can leave you feeling like you have lost a part of your identity.
- You may feel self-conscious about changes to your body or scars caused by your treatment. This can affect your confidence.
- You may find that you have a new perspective on life. Things that were important to you before your diagnosis may not feel as important now, and vice versa.

There are many ways to manage these feelings. But above all, it's important to allow yourself time to adjust. You have experienced a life-changing event. Be kind to yourself and take time to get to know the 'new you'!

Other ways to cope with a loss of your old identity include:

- **Join a support group** – Talking to other people who are feeling the same as you, to better understand your own experience and give you hope for the future.
- **Talk openly about your feelings** – Talk with your family and friends about how you are feeling. It can be hard for them to understand what you are experiencing. But letting them know how you feel can help them to support you.
- **Keep active** – Regular exercise can clear your mind and help you to feel in control of your body.
- **Seek psychological support** – If your feelings are continuing to cause you serious worry or concern, speak with your healthcare team about accessing a psychologist or counsellor. You can read more about psychological support and counselling on page 53.

Anger

Being diagnosed with melanoma might make you angry. It's an inconvenient disruption to your life plans and it's not uncommon to think, 'Why has this happened to me?'

Some people may feel anger over the way they were diagnosed. Perhaps you were misdiagnosed initially or experienced delays in diagnosis.

Feeling anger and hostility is unpleasant – it can make you physically tense and tired. So it's best to take some steps to not let anger build up.

It can help to talk through your feelings with someone you trust or channel your energy into a physical activity, like jogging or boxing.

Guilt

It's common for people with melanoma to experience feelings of guilt for various reasons. For example, you may feel guilty because:

- you blame yourself for past sun exposure that may have increased your risk of melanoma
- you could have noticed signs or symptoms, or acted on them, sooner
- you worry that you might be a burden to your family and carers
- you worry about not being able to fulfil your normal role in your family
- you worry about the financial strain that your treatment may cause

- you are concerned that you may have passed a specific faulty gene that causes an increased risk of melanoma to your children.

It's important to remember that melanoma is not your fault. Letting go of guilt, by sharing your feelings or joining a support group, is important for improving your emotional wellbeing.

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Genetics and melanoma

Melanomas themselves are not passed on from person to person but our risk of melanoma certainly is hereditary - it is affected by our genetic background. Rarely, a specific faulty gene that carries melanoma risk may be passed from one generation to the next. But for most people it is the combination of a lot of genetic differences that pushes our risk up or down: such as our different skin colours, the way we react to the sun, the number of moles, and other invisible effects of our genetic makeup.

Anxiety and depression

A melanoma diagnosis can have a huge impact on your life. It's normal to feel worried, stressed, sad and scared during this time.

Sometimes, these feelings are overwhelming and start to interfere with your daily life. If this sounds like you, you may be experiencing clinical anxiety or depression.

People diagnosed with melanoma are at higher risk of developing anxiety or depression and may require psychological support and treatment.

Know the warning signs

Signs of clinical anxiety

- Feeling agitated or on edge
- Trouble focusing and problem solving
- Trouble sleeping
- A need for constant reassurance
- Muscle tension, trembling or shaking
- Increased heart and breathing rate
- Sweaty palms
- Knots in the stomach
- Racing thoughts

Signs of clinical depression

- Feeling low, hopeless or flat for most of the day
- Losing pleasure or interest in things you used to enjoy
- Trouble sleeping, or sleeping too much
- A loss of appetite
- Difficulty concentrating
- Feeling an excessive amount of guilt
- Frequent thoughts of death or suicide

Talk to your healthcare team if you think you may have anxiety or depression. You are not alone.

There are programs, support groups and helplines that may be useful for you. You can read more about accessing psychological support on page 53.

Professionals such as psychologists or counsellors can provide you with strategies to help you cope with your situation.

Emotions and Cancer

Booklet available from Cancer Council



cancercouncil.com.au
13 11 20

Living Well After Cancer

Booklet available from Cancer Council



cancercouncil.com.au
13 11 20

Getting help and support

Everyone's experience with melanoma is different, and so are their supportive care needs. In this section, we explore a number of support services available to you.

Help from a psychologist or counsellor

Just like your GP, dermatologist, surgeon or nurse have helped to treat the physical symptoms of melanoma, a psychologist or counsellor can help you to manage your emotional health.

A **psychologist** is an expert in emotions, behaviour and thoughts. They can diagnose mental health illnesses and offer evidence-based strategies to help manage these issues. Psychologists are members of a regulated profession and require a formal registration to practise. However, they cannot prescribe medication.

A **counsellor** is someone who can listen to your issues and concerns and offer you strategies to deal with them. A counsellor does not require any formal qualifications to practise, although many counsellors do have recognised training.

If you are feeling anxious or depressed – or experiencing any other emotions that are having a negative impact on

your daily life or wellbeing – you may need to seek help from a psychologist or counsellor.

Someone in the healthcare team managing your melanoma treatment can put you in touch with a psychologist or counsellor who can provide tailored support for you. Alternatively, your GP can also help with directing you to one of these providers and may be able to advise you on eligibility for Medicare rebates for some of these services.

You can also:

- visit psychology.org.au to search for a psychologist in your area. The 'Find a psychologist' search function on the website allows users to search for a psychologist working in cancer support
- call the Cancer Council on **13 11 20** to find a psychologist specialising in cancer support in your area.

If you need immediate crisis support, call Lifeline on 13 11 14.

Help from a support group

While it is really helpful to have a network of family, friends and carers to lean on for support, sometimes you may prefer to speak about your experience with people in a similar situation. Face-to-face or online support groups can be a powerful way to share stories and information and learn from the experience of others.

Support groups are available for people with melanoma, their family and friends. Access to face-to-face support groups will differ depending on where you live.

Melanoma Institute Australia

melanoma.org.au

(02) 9911 7200

Melanoma Institute Australia support groups are run monthly in collaboration with Melanoma Patients Australia. Visit the website to find details on a group near you.

Melanoma Patients Australia

melanomapatients.org.au

1300 884 450

Melanoma Patients Australia (MPA) provides a range of support options throughout Australia, including:

- one-on-one telephone support where you can speak with a person who understands your experience and can provide you with helpful information

- peer-to-peer linkages where you can speak with another person who has had a similar experience to you
- face-to-face support groups in a number of locations
- a private Facebook support group: Melanoma Patients Australia Closed Support Group
- a telephone support group.

To access any of these support services, contact the MPA Support Line on 1300 884 450.

Skin Cancer Tasmania

skincancertasmania.org.au

0409 330 206

Skin Cancer Tasmania offers one-on-one and group support sessions in Tasmania.

Email info@skincancertas.org.au for more information.

MelanomaWA

melanomawa.org.au

(08) 9322 1908

MelanomaWA hold monthly meetings throughout Western Australia, and also offer one-on-one and peer-to-peer support.

Email wa@melanoma.org.au for more information.

Cancer Council

Cancer Councils throughout Australia offer a number of online and telephone support options.

Cancer Council Online Community onlinecommunity.cancerCouncil.com.au

This Cancer Council service is a moderated online community where you can ask questions and participate in groups, forums and blogs.

Cancer Council Helpline

13 11 20

Cancer Council provides a confidential telephone information and support service that anyone can call. This includes people recently diagnosed with cancer, those previously treated and living with cancer, their families, friends, carers, teachers, students and health professionals.

Cancer Connect

02 9334 1870 or 13 11 20

This Cancer Council service is a confidential telephone peer support service that connects someone who has cancer with a specially trained volunteer who has had a similar experience.

Melanoma Nurse Telehealth Service

A specialist melanoma nurse service is available to support patients in navigating the health system, accessing available services and making decisions regarding their health. This personalised telephone support service from Melanoma Patients Australia and supported by Melanoma Institute Australia is available to all melanoma patients and their carers.

Phone 1300 884 450 to book an appointment or visit melanomapatients.org.au to find out more.

Psychologists

Australian Psychological Society
psychology.org.au

1800 333 497

Lymphoedema

Australasian Lymphology Association
lymphoedema.org.au

1300 935 332

Exercise

Exercise and Sport Science Australia
essa.org.au

07 3171 3335

Nutrition

Dietitians Australia

daa.asn.au

1800 812 942

Finding information online

While the internet can be a helpful source of information it can also be overwhelming and inaccurate. Not all medical information available online is evidence-based – and it can be hard to tell the difference between fact and fiction.

To help, we've listed some useful websites that provide reliable melanoma information. But always remember to discuss any information from the internet with your healthcare team as they will be able to discuss it with you in terms of your individual circumstances.

General Australian websites:

Melanoma Institute Australia

melanoma.org.au

Melanoma Patients Australia

melanomapatients.org.au

Cancer Council Australia

cancer.org.au

Myths about cancer

iheard.com.au

eviQ Patient and Carers

eviq.org.au/patients-and-carers

International websites

Macmillan Cancer Support

macmillan.org.uk

US National Cancer Institute

cancer.gov

American Cancer Society

cancer.org

MD Anderson Cancer Center

mdanderson.org

Reliable written resources

Understanding Melanoma

This Cancer Council booklet is available online or you can order a copy by phoning the number below.

cancercouncil.com.au

13 11 20

A guide to understanding melanoma: A starting point for people in their journey with melanoma

Melanoma Patients Australia has made this booklet available online or you can contact them for a copy to be sent to you.

melanomapatients.org.au

1300 884 450

Your family and friends

Your diagnosis of melanoma can be overwhelming for your friends and family as well. They might not know what to say to you, or they may feel sad or worried for you.

In this section we'll explore how to talk about your diagnosis with your family and friends and how they can best support you during and after treatment.

Talking to your family and friends about your diagnosis

It's totally up to you how much or how little you want to share with them. When you feel ready to talk, the following tips may help you to have that conversation.

- Choose a quiet place and a time when you will not be interrupted.
- Be clear about your diagnosis. It is not helpful to avoid words like 'melanoma' or 'cancer'.
- Tell them slowly, using short and clear sentences. Give them time to take in what you are saying.

- Check they understand and do your best to answer any questions they may have.
- Understand that they may get upset and you may need to comfort them – even though you are the one with melanoma.
- Allow time for silence and thought.

Telling your loved ones that you have melanoma can be difficult. But it's an important first step in helping them to help you.

Talking to young children about your diagnosis

Parents and carers can find it challenging to talk about a melanoma diagnosis with their children, grandchildren or other young children in their life.

Most children will sense that something is happening. It's important to discuss your diagnosis with them so that they are not left to imagine the worst.

Helpful resources:

Talking to Kids About Cancer

Cancer Council has produced a comprehensive guide for talking to young children about your diagnosis. It outlines how to have this discussion in age appropriate ways.

cancercouncil.com.au

13 11 20

CanTeen

Information for young people between the ages of 12–25

canteen.org.au

1800 835 932

Ways your family and friends can help

You may find that your family and friends are keen to help you during and after your melanoma treatment. Sometimes it can be difficult to accept help from others – maybe you feel like you can handle it, or you want to maintain your privacy. But at some point, you may be very grateful for the offer. This extra help can make all the difference.

Try to be specific about the type of help you want or need when a friend or family member says, “What can I do to help?”. And remember, there will be times when you’re not sure what help you need. That’s ok. Allow your family and friends to offer something they can do for you.

Your family and friends can help by:

- attending medical appointments with you to take notes so that important information is not missed
- driving you to appointments, the shops or anywhere you need to go
- cooking meals for you and your family
- helping to look after your children.
- distracting you with enjoyable activities
- simply being around!



Information and support for carers

Carers play a vital and demanding role. It's common for carers to experience a range of emotions about their role – from worry about your loved one to frustration or stress about your situation.

If you are caring for someone with melanoma, it's important to look after yourself as well so that you're able to provide the best level of support you can.

Take time away from your caring duties to rest. The person you are caring for may also appreciate some time alone.

Information and support resources

Caring for someone with cancer

Booklet available from Cancer Council

cancercouncil.org.au

13 11 20

Cancer Council Telephone support group for carers

Cancer Council provides fortnightly phone groups:

- for people who are providing primary care for a family member, friend or loved one with a cancer diagnosis.

To register, call 13 11 20, 1300 755 632 or email tsg@nswcc.org.au.

Carers Australia

carersaustralia.com.au

1800 242 636

Access carer information, advisory and counselling services.

Young Carers Network

youngcarersnetwork.com.au

1800 242 636

Access information, support and financial aid services.