

PATIENT GUIDE

# What to ask your specialist

This Patient Guide provides details of many questions that might be relevant to you. It is unlikely that all of these questions will be important to you. You can use this Patient Guide to help you to think about and prepare the questions that are most relevant to you.

## Prior to your appointment

- You may wish to read the [Optimal Care Pathway](#) for Melanoma to understand what you can expect at each stage of your treatment.
- Make a list of all the things you want to know as they come to your mind and be prepared to take this list with you to your appointment.
- Identify someone who can come to the appointment with you. It is normal to lose focus when you are given lots of new information and having a second set of ears is very helpful, as well as having someone for extra support.
- Double check your appointment time and the location of the appointment if you haven't been there before. Check how long it will take to travel to your appointment and allow extra time to prevent rushing (which can cause unnecessary stress).
- Call ahead to find out about parking location and cost, or nearest bus stop, train station.

- Have a folder or envelope to place your appointment card, referral letter and any other referral forms, or test requests you may be given.
- Make a list of the medications and doses you currently take to give to the doctor or pharmacist.
- Call ahead to request an interpreter if you speak a language other than English.

## **On the day**

- Have something to eat before you go, unless advised against this for a procedure.
- Take a bottle of water or cold drink with you and some snacks in case you are there longer than expected.
- Be prepared that you may have to wait longer than your appointment time, especially if the clinic is busy. If possible, take something with you that can help you to relax and fill in time, such as a book, music, headphones, crochet, knitting, iPad (ensure it is charged).
- Double check you have your Medicare card details and/or health insurance details with you.

## **At the appointment sample questions to ask**

Not all of these questions will be relevant for you.

### **Diagnosis**

- What type of melanoma do I have?
- What is the stage of the melanoma? What does the stage mean for my treatment?
- Has the melanoma spread? If so, where has it spread? How fast is it growing?
- Are the latest tests and treatments for this type of melanoma available in my local hospital?
- Who makes the decision about my diagnosis and treatment?
- Is my case discussed by a group of specialists (Multidisciplinary Team Meeting) to decide the best treatment? [See Melanoma Patients Australia's Patient Guide – Understanding the Multidisciplinary Team \(MDT\) and the Multidisciplinary Team Meeting \(MDM\).](#)
- Will I have access to a social worker, psychologist or dietician, or will I need to arrange support myself?
- Do you have a support nurse who will be there for me and my family throughout my treatment?

### **Test I may require**

- What will this test involve?
- What is the estimated out-of-pocket cost of the test?
- What will the test results tell us?

- What are the benefits and risks of having this test? Will the results affect the type of treatment I'm offered?

## **Treatment and costs**

- What treatment do you recommend?
- What is the aim of the treatment?
- Are there other treatments that might work? If not, why not?
- How often will I have treatment?
- How long will treatment take?
- Will I have to stay in hospital?
- Are there any out-of-pocket expenses not covered by Medicare or my private health cover?
- Is there a way the cost can be reduced if I can't afford it?
- Will I have only one treatment or will I also have other treatments?
- How long do I have to make a decision about my treatment?
- If I am thinking of getting a second opinion, how do I do this?
- If I don't have the treatment, what should I expect?
- How will I know if the treatment is working?
- What if this treatment does not work?
- How often will I require blood tests?
- Who do I call if I am unwell? Do you have a contact to call out of hours and at weekends?
- Should I keep taking my current medications?
- Can I keep taking my nutritional supplements?
- Does the treatment affect my ability to have children in the future?
- Is there a possibility my cancer is genetic and runs in my family? Should I see a genetic specialist?
- Can I still work during my treatment?
- Can I still get pregnant when having treatment?
- How often will I need to have check-ups after treatment finishes?
- Who should I go to for the check-up appointments?
- If the cancer returns, how will I know? What treatments could I have?
- What do I still need to know?
- What organisations and peer support groups exist to provide information and support me?
- Will you keep my GP informed?
- What role will my GP play in my care?

## **Clinical trials**

- What does taking part in a clinical trial mean?
- Are there any clinical trials or research studies I could join?
- What are the benefits and risks of these trials?
- Can I see the Participants Information and Consent Form to help me decide?
- What are my obligations if I join a clinical trial?

## Side effects

- What are the risks and possible side effects of each treatment?
- How can these be managed?
- Will the side effects improve or have lasting effects?
- Is there any side effect that I should particularly look out for?
- Are there any complementary therapies that might help me?
- Can I have the flu, COVID-19 or other vaccines?

## If advanced cancer is diagnosed

- What's the best I can hope for by having treatment?
- Are there new treatments I can try?
- Is the treatment going to improve my chance of survival?
- What treatments can relieve my symptoms?
- Who will be responsible for my medical care?
- What help can my family and/or friends get if they care for me at home?
- What is palliative care?
- Can I have palliative care at home? How do I get it?
- Can you help me talk to my family about what is happening?

## After the appointment

- Document any important information and keep in a folder.
- Read over any material provided to you.
- Note date and time of your next appointment in your diary or phone.
- Keep important contact numbers in a visible, easy-to-remember place i.e., fridge.
- Seek clarification if there is anything you are unsure about via your medical team or Melanoma Patients Australia.
- Share important information with those who will be supporting you, so that they also know what to do and what to expect.

## Next Steps After the Appointment

- Allow time to reflect on the appointment, don't expect to remember everything.
- If someone went with you, ask them to summarise what they recall from the appointment.
- Call the Melanoma Support Line 1300 88 44 50 if you would like to talk to someone.

- If you need further explanation or have more questions call the Melanoma Patients Australia Telehealth Nurse.
- Share any concerns with a trusted family member or friend, or connect with Melanoma Patients Australia Support Programs, such as the Peer Support Program, a Support Group or the Melanoma Patients Australia Facebook Group.

### **Connecting with Melanoma Patients Australia Support Programs**

Melanoma Support Line 1300 88 44 50

Connect with other patients through [Melanoma Patients Peer Support Programs](#) via the website

Connect with Melanoma Patients Australia [Melanoma Telehealth Nurse](#) via the website

The information contained in this resource is intended to be a guide. Every patient is different and will have different experiences, the information contained in this resource will not apply to all patients. This information is not aimed specifically to an individual and it is therefore important that patients always consult their specialist doctor or other medical professional (e.g., General Practitioner) about any specific matters affecting their individual treatment and care. The information in this guide is not intended to replace medical information or substitute the formal professional advice or your supportive care team. Melanoma Patients Australia exclude all liability for any injury, loss or damager incurred by using or relying on the information provided in this resource.

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