



Advanced Melanoma/ Tonapuku maukaha o te kiri



This information sheet will help you understand an advanced melanoma diagnosis, the type of treatment you might have, and about living with advanced melanoma.

Melanoma is the most serious of the three common forms of skin cancer. Occasionally, melanoma starts in other parts of the body also. Advanced melanoma of the skin is cancer that has spread beyond the original primary cancer in the skin.

He matepukupuku ō te kiri te tonapuku, a, koinei te matepukupuku taumaha rawa atu ō ngā momo matepukupuku ō te kiri e toru (ko te basal cell carcinoma me te squamous carcinoma ērā atu). Ko te matepukupuku kua rauroha ki tua atu ō te matepukupuku matua i roto i te kiri. I tēnei pukapuka iti, ka ako koe i ngā āhuetanga e pā ana ki tonapuku maukaha.

Understanding advanced melanoma

Advanced melanoma means that your melanoma has spread from where it first started to another part (or parts) of

your body.

The different stages of melanoma take into account how thick the original melanoma was. It also considers if it was ulcerated or not, and whether it has spread to other parts of the body. Advanced melanoma relates to stages three and four.

Advanced melanoma is diagnosed when your melanoma has spread from where it first started to another part (or parts) of your body.

Melanoma can spread to almost any part of your body, but it is most likely to spread to one or more of the following places: skin (away from your original melanoma), lymph nodes, lungs, liver, bones or brain.

How is melanoma diagnosed

The first sign of melanoma is usually the appearance of a new spot or a change in an existing freckle or mole. The change may be in size, shape and/or colour and is normally noticed over several weeks or months rather than days.

If your GP suspects you have advanced melanoma you will be referred to a hospital doctor who may recommend some further tests. This waiting period can be an anxious time and it may help to talk things over with someone.

Advanced melanoma means your melanoma is unlikely to be cured. However, in recent years new treatments that are more effective have been developed. These new treatments can lead to remission that may last for many months and possibly years.

Treatment for advanced melanoma of the skin

Your treatment team will advise you on the best treatment for your advanced melanoma. Treatments may include surgery, radiation treatment, targeted therapies, immunotherapy, chemotherapy and palliative care.



Treatment through surgery

Surgery can be used to assess and remove lymph nodes, help control the growth of advanced melanoma, help relieve symptoms, and treat melanoma that has spread.

Radiation treatment

Radiation treatment uses radiation to kill melanoma cells. The radiation can be precisely targeted to melanoma sites in your body.

Treatment is carefully planned to do as little harm as possible to your normal body tissue. It may be given to shrink the tumour or to reduce the likelihood of the cancer returning to the area being treated. It can also be used to relieve symptoms such as pain or swelling. A potential side effect of radiation to lymph nodes is lymphoedema.

Targeted treatments

Targeted treatments aim to stop melanoma cells growing by targeting changes (mutations) in the genes of the cells. These changes may be either on the surface of the cell or on the growth pathway inside the cell.

Targeted treatments work for specific gene changes, such as changes to a gene called BRAF, present in about 50 percent of all melanomas. Changes in this gene lead to the production of a changed BRAF protein, which helps melanoma to grow.

Treatments that aim to target this change and stop the melanoma cells growing and dividing are called BRAF inhibitors. Examples of BRAF inhibitor drugs are Tafinlar (Dabrafenib) and Zelboraf (Vemurafenib).

Immunotherapy

Immunotherapy boosts your body's own immune system to fight cancer. Advanced melanoma can produce a substance that turns off a type of white cell (called a T-cell) so that the T-cell can no longer fight off the melanoma. The medications Keytruda (Pembrolizumab) and Opdivo (Nivolumab) are treatments that allow the T-cell to stay active (turned on) to fight melanoma cells.

The side effects of targeted treatments and immunotherapy can depend on the type of treatment you are having. Funded immunotherapy and targeted treatments are only available when certain criteria are met. **(See the chart in the Advanced Melanoma booklet available from the Cancer Society).**

“The doctors gave me six months. I’ve had Pembrolizumab and I’m going strong 18 months later. I’m feeling really good.”

Chemotherapy

Chemotherapy uses special anti-cancer medications that destroy all cancer cells while doing the least possible damage to normal cells.

The medications work by stopping cancer cells growing and reproducing. Chemotherapy can be given before or after surgery and is usually given by injecting the medication into a vein (IV treatment). There are other ways of having chemotherapy, including tablets.

Chemotherapy is occasionally used as palliative treatment for melanoma that cannot be treated by other methods.

Some medications used in chemotherapy can cause side effects. The side effects are specific to the chemotherapy medications used. They may include an increased risk of infection, feeling sick (nauseous), vomiting, feeling unwell and tired, and some thinning or loss of hair from your body and head. Generally these side effects are temporary.

Talk to your treatment team about how to manage them. If you develop a fever (a temperature of 38 degrees Celsius or over), or you feel unwell even with a normal temperature, don't wait to see what happens. Phone your cancer treatment team or hospital immediately for advice.

Taking part in a clinical trial

There are many new and emerging treatments for advanced melanoma. There may be clinical trials available that you could join. Clinical trials are a vital part of the search to find better treatments for cancer, to test new and modified treatments, and to see if they are better than existing treatment. The decision to take part in a clinical trial is yours. If you are asked to take part in a clinical trial, make sure that you fully understand the reasons for the trial and what it means for your treatment.

Palliative Care

Palliative care focuses on improving quality of life—it is not just about care at the end of life. Care can be offered in a hospital, a rest home, at home, or in a hospice. It is a good idea to ask for palliative care early. Early rather than waiting until they become difficult to manage can help to reduce stress for both you and your family/whānau. In general, palliative care services are free. You may like to get information on advance care planning on the website www.advancecareplanning.org.nz.

How to look after yourself following treatment

Regular checkups

Following your treatment you will need to have regular check-ups. As well as a physical examination of your skin,

an important part of each check-up will be an examination of your lymph nodes. Lymph nodes can get enlarged if you are unwell with a cold or flu, or it may mean that cancer cells have spread to the area. It is important that any changes in your lymph nodes are checked by your GP.

Your GP should examine your entire skin surface under a good light using a dermoscope. If they do not use a dermoscope, ask them to recommend someone in their general practice who does.

Melanoma New Zealand has a list of accredited skin check providers around New Zealand on its website

www.melanoma.org.nz/melanoma/skin-check-providers.

It is important that you be shown how to check your own skin and that you do it regularly. If you notice any changes in your skin or in your general health, contact your GP.

Changes in appearance after surgery

Some scars may affect your appearance, depending on their size and location. People cope with changes in appearance in different ways.

Some feel self-conscious, while others are not concerned. If you are finding it difficult to adjust to any change, it is important to seek support early.

Talk to your treatment team, someone close to you, or a counsellor. You can call the Cancer Information Helpline 0800 CANCER(226 237) for information about support available in your area.

Protecting your skin

Exposure to UV radiation from the sun causes permanent skin damage. Levels of UV radiation in New Zealand are high. If you have melanoma it is especially important to protect your skin all year round.

Living with advanced melanoma

A diagnosis of advanced melanoma can cause physical and emotional strain. Eating well, exercising and relaxing may help to reduce stress and improve wellbeing. Addressing changes in your emotions and relationships early on is important.

When you are diagnosed with advanced melanoma you may be faced with difficult decisions and emotions. This is a good time to talk to a counsellor or seek support from your local Cancer Society. You have access to trained interpreters and cultural advocates should you need them.

Lymphoedema

Lymphoedema is a potential side effect of lymph node removal and radiation treatment to lymph nodes. To reduce the risk of lymphoedema, keep your skin clean and well moisturised. Avoid damage to the skin in the affected areas, especially sunburn, insect bites, blood tests and injections, and treat cuts or grazes with antiseptic.

Lymphoedema can be managed with a specialised programme of exercise, massage and skin care and a properly fitted support garment or bandage. You may wish to see a lymphoedema therapist if this is available in your area.

Other side effects

There may be other side effects related to melanoma and its treatment. Cancer-related fatigue is one of the most common side effects. You may also experience changes to your eating habits and you may experience pain. There are resources available on www.cancernz.org.nz to help you manage these.

You may have changes in your employment

If you can no longer work you may have to negotiate leave, talk to your bank about a mortgage holiday, or visit Work and Income to see if you are eligible for income support. planning on the website

Suggested websites and information

You can find out more information in our booklet: Advanced melanoma of the skin-Tonapuku maukaha o te kiri available from the Cancer Society.

The Cancer Society's website (www.cancernz.org.nz) has information on your local Cancer Society as well as other information you may find helpful. You may also find useful information on one of these websites:

- Melanoma New Zealand (NZ) www.melanoma.org.nz
- Melanoma Institute Australia www.melanoma.org.au
- Macmillan Cancer Support UK www.macmillan.org.uk
- Cancer Council Australia www.cancer.org.au
- Health Promotion Agency www.hpa.org.nz
- American Cancer Society www.cancer.org

For more information or support call our Cancer Information Helpline 0800 CANCER (226 237) to speak with our specialist information staff or visit your local Cancer Society office.