

# Understanding Advanced Melanoma



*A guide to stage III and  
IV melanoma*

**Melanoma**  
New Zealand





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# ABOUT THIS BOOKLET

More than anything else, we want you to know that you are not alone; that there is help and support for you both through Melanoma New Zealand, your medical team and district health board, and other organisations whose role is to help you and your family through your cancer diagnosis and treatment, and life beyond.

Receiving a diagnosis of melanoma can be frightening. You'll probably have many questions about melanoma and what will happen next. This booklet is designed to answer some of the questions you may have about your diagnosis, treatment, and living with stage III and IV melanoma.

Just remember that treatment options are evolving all the time, and outcomes for melanoma patients are improving as a result.

We can't tell you what the best treatment will be for you; this is something you have to work out with the team of health professionals caring for you. However, we can help you understand some of what you will experience from the time you are diagnosed, some of the terminology that you will hear, some of the tests and treatment options that may be offered to you, and some of the issues you may face through this period of your life.

At the end of the booklet we give you some useful resources and links where you can get more information, support or help.

We also encourage you to share this booklet with your whānau/family and friends to help them understand what stage III or IV melanoma means for you, and so they have a better idea of how they might be able to support you.

## Melanoma NZ

Melanoma New Zealand is a registered charitable trust devoted to issues relating to melanoma and:

- provides information about all aspects of melanoma;
- promotes regular skin checks for early detection;
- advocates to increase access to high quality clinical care.

For more information

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# CONTENTS

Stage III & IV Melanoma	3
Diagnosis	6
Waiting for Results	10
What You Should Ask	11
Treatment Options	14
Are Clinical Trials for You?	22
Coping with Side-Effects	24
Lymphoedema	27
Complementary Therapies	28
Talking to Your Family	30
The Impact of Melanoma on your life	32
Your Work Life	39
Support for Family	40
Advance Care Planning	41
Legal Issues	44
Financial Assistance	46
Resources	47
Glossary	49
Index	52

# STAGE III & IV MELANOMA

## About Melanoma

Melanoma is a type of skin cancer that develops from pigment producing cells in the skin, called melanocytes, which are the cells responsible for the colour of our skin, eyes and hair.

When these cells grow uncontrollably it results in melanoma. Melanoma can be more serious than other types of skin cancer (basal cell carcinoma or squamous cell carcinoma); it can progress quickly and can be life-threatening:

## What is Stage III and Stage IV Melanoma?

Stage III and Stage IV melanoma is also sometimes called advanced melanoma, or secondary melanoma. This is when the melanoma has grown beyond the skin and has either spread to your lymphatic system – that is, melanoma cells can be found in your lymph nodes (stage III melanoma) – or has spread beyond the regional lymph nodes to other parts of your body (stage IV or metastatic melanoma).

When the cancer spreads or metastasises to other parts of the body, away from the original site, the cells still have the characteristics of a melanoma even though they may now be growing somewhere else. The most common sites of melanoma metastases are in vital organs (liver, lungs, abdominal organs and the brain), bone, soft tissues (skin, subcutaneous tissues) and distant lymph nodes (lymph nodes beyond those closest to the primary tumour).

## Melanoma in New Zealand

- Over 4000 people are diagnosed with either melanoma *in situ* or invasive melanoma every year in New Zealand – that's about 13 people every day.
- It accounts for nearly 80% of all skin cancer deaths.
- Over 300 New Zealanders die of melanoma every year.
- New Zealand has one of the highest melanoma incidence rates in the world.
- 70% of melanoma cases occur in people aged 50 years and older.
- Melanoma rarely occurs in children.
- Although Māori and Pacific people have a lower chance of getting melanoma, they often have thicker, more serious melanomas.
- Death rates are higher among men.

## Signs and Symptoms

If you have been previously diagnosed with an early stage melanoma, symptoms of advanced melanoma may develop years later. Some people may notice a change to a mole or freckle or some other change in what was normal-looking skin.

Other people with stage III or IV melanoma experience few or no symptoms. Sometimes people can be diagnosed with stage III or IV melanoma, even if there have been no signs of early melanoma, such as an abnormal mole or changes to the skin.

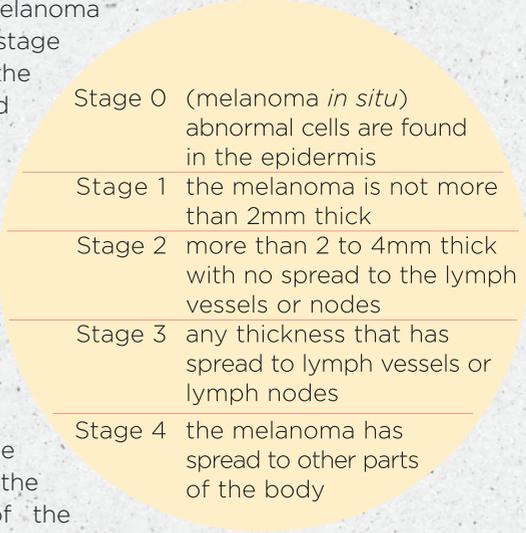
What you experience will depend on where the melanoma has spread to.

If your melanoma has spread you may not experience definitive symptoms, but may generally feel unwell. Some people feel very tired or lose weight. Many symptoms people experience can be caused by other conditions, such as colds, the flu and other infections, injuries and muscle strains, not just a progression of the cancer, so it is important to see your doctor with any persistent symptom if you have previously had melanoma.

## Staging

When you are diagnosed with melanoma your cancer will be “staged”. The stage is determined by the thickness of the cancer, the Breslow thickness, and whether or not it has spread to your lymph nodes and other parts of your body (metastases).

How far advanced the melanoma is when it is diagnosed strongly influences your prognosis. For people who are treated early, when melanoma affects only the superficial layers of the skin, the prognosis is excellent and the disease is often curable. Once the cancer spreads to other parts of the body, melanoma can be difficult to treat.



Stage 0	(melanoma <i>in situ</i> ) abnormal cells are found in the epidermis
Stage 1	the melanoma is not more than 2mm thick
Stage 2	more than 2 to 4mm thick with no spread to the lymph vessels or nodes
Stage 3	any thickness that has spread to lymph vessels or lymph nodes
Stage 4	the melanoma has spread to other parts of the body

## Understanding Staging

There are different ways in which melanoma is described and the “codes” used might be confusing and hard to understand. However, you need to understand your diagnosis and how far your melanoma has spread in order to make informed decisions about your treatment and care. So it is important to have some understanding of what staging is and what it means for you.

When you have a biopsy or when your melanoma is surgically removed it will be investigated in a medical laboratory and your doctor will be sent a histology report. In that report the characteristics of your melanoma will be described; it will be staged and given a TNM classification where T is the primary tumour, N is regional lymph nodes and M is distant metastasis.

### Stage IIIA no distant spread

**T1A-4A, N1A OR N2A, M0**

Spread to between one and three lymph nodes near your original melanoma - is found only when viewed under the microscope.

### Stage IIIB

**T1B-4B, N1A OR N2A, M0**

Melanoma is ulcerated and has spread to between one and three lymph nodes near your original melanoma - is found only when viewed under the microscope.

**T1A-4A, N1B OR N2B, M0**

Spread to between one and three lymph nodes near your original melanoma and nodes enlarged. Not ulcerated.

**T1A/B-4A/B, N2C, M0**

Spread to skin lymphatic channels around the original tumour, but the nodes do not contain melanoma. May or may not be ulcerated.

### Stage IIIC

**T1B-4B, N1B OR N2B, M0**

Spread to between one and three lymph nodes near your original melanoma and nodes enlarged. Ulcerated.

**ANY T, N3, M0**

Spread to four or more nearby lymph nodes, to nearby lymph nodes that are clumped together, or it has spread to skin lymphatic channels around the original tumour and to nearby lymph nodes and nodes enlarged. May or may not be ulcerated.

### Stage IV

**ANY T, ANY N, M1**

Spread beyond the original area of skin and nearby lymph nodes to other organs such as the lung, liver, or brain, or to distant areas of the skin or lymph nodes.

# DIAGNOSING STAGE III & IV MELANOMA

If you have had a previous early melanoma diagnosis, you will have ongoing check-ups after your treatment. Whether your GP or specialist picks up changes that you have been unaware of (e.g. a new change in a mole or freckle or change to previously normal skin), or you present to your GP or specialist with other symptoms, the tests that your doctor orders will depend on the signs and symptoms that you have.

## Fine Needle Aspiration

If your doctor suspects that your melanoma has spread to your lymph nodes you may have a fine needle aspiration (FNA) biopsy (the needle might be guided by ultrasound). The needle is smaller than the needle used for a blood test; very small pieces of the lymph node are removed with the needle and then examined under a microscope.

FNA biopsies are not as invasive as some other types of biopsies, but they may not always collect enough of a sample to tell if a suspicious area is melanoma. In these cases, a more invasive type of biopsy may be needed.

## Blood Tests

Blood tests may be taken to check your general health – perhaps to rule out other possible causes of your symptoms, such as infection. They may include a blood count to check on blood cells, and tests to check how well your liver and kidneys are working.

You may have heard about the LDH blood test. LDH is a blood test that measures the amount of lactate dehydrogenase, an enzyme, in your blood. LDH is measured to check for tissue damage in areas such as your heart, liver, kidney, skeletal muscle, brain, and lungs; tissue damage that the spread of melanoma can cause.

LDH is not used in New Zealand to diagnose stage III and IV melanoma but you may have this blood test after imaging tests (see next page) and/or a biopsy, and



once you have been diagnosed, because it can sometimes help your oncology team to decide on the treatment plan or monitor your progress.

## **Sentinel Lymph Node Biopsy**

The most common place for melanoma cells to spread to is the lymph nodes, so your doctor will test them first.

If you have already been diagnosed with melanoma, you may have already had a sentinel lymph node biopsy (SLNB), when your primary tumour was surgically removed. A sentinel lymph node is the very first lymph node to which lymph from the cancer site is likely to drain.

SLNB involves surgically removing the whole the sentinel lymph node or nodes, which are examined under a microscope. To find this lymph node, a radioactive tracer is injected into the site of the melanoma.

If there are no melanoma cells in the sentinel nodes, no more lymph node surgery is needed because it is unlikely the melanoma would have spread beyond this point. If melanoma cells are found in the sentinel node, further discussion is required with your specialist.

A negative sentinel lymph node biopsy indicates a lower risk that the cancer has spread than if the biopsy shows cancer cells. However, a negative SLNB does not mean you don't have, or won't develop advanced melanoma, and a positive SLNB doesn't necessarily mean you will, but does identify a higher risk group.

If your SLNB is positive, or if you are returning with symptoms that suggest that your cancer may have spread, you will have further tests. Which tests you have will depend on the symptoms you have.

## **Ultrasound**

Ultrasound uses sound waves to create a picture of tissues inside your body and can help diagnose metastases in the liver or lymph nodes, or may be used to guide needles in an FNA biopsy (see previous page).

## **Chest X-rays**

Chest x-rays may be ordered if you have symptoms affecting your breathing and lungs, to check whether the cancer has spread to your lungs.

## **CT Scans**

A CT – or computerised tomography – scan is a series of detailed cross-sectional x-rays that build up a three-dimensional view of your body. This type of scan can show the detail in soft tissues, such as your internal organs. For



example, a CT scan can show if any of your lymph nodes are enlarged or if organs, such as your lungs or liver, have suspicious spots, which might be caused by the melanoma having spread.

A CT scan may involve a drink or injection of dye or contrast agent that will allow certain areas to be seen more clearly. Iodine and barium are the two dyes commonly used in CT scanning.

## MRI

MRI (or magnetic resonance imaging) scans use radiofrequency waves, powerful magnets and a computer to create detailed images of parts of your body. They are useful for looking at your brain and spinal cord, and these scans are primarily used to determine if melanoma has spread to your brain.

MRI can distinguish between normal and diseased tissue to precisely pinpoint cancerous cells, so it is useful for determining if the melanoma has metastasised. MRI offers greater contrast between the soft tissues of your body than a CT scan does, so this is why it is used more often for imaging the brain, spine, muscle, connective tissue and the inside of bones.

Like with the CT scan, MRIs can require a contrast dye to be injected into a vein before the scan. Because of the powerful magnets that are used you may not be able to have an MRI if you have a pacemaker, or certain types of metal surgical clips, pins or screws. Like other forms of imaging, an MRI is not painful, but some people find it claustrophobic.



## Bone Scan

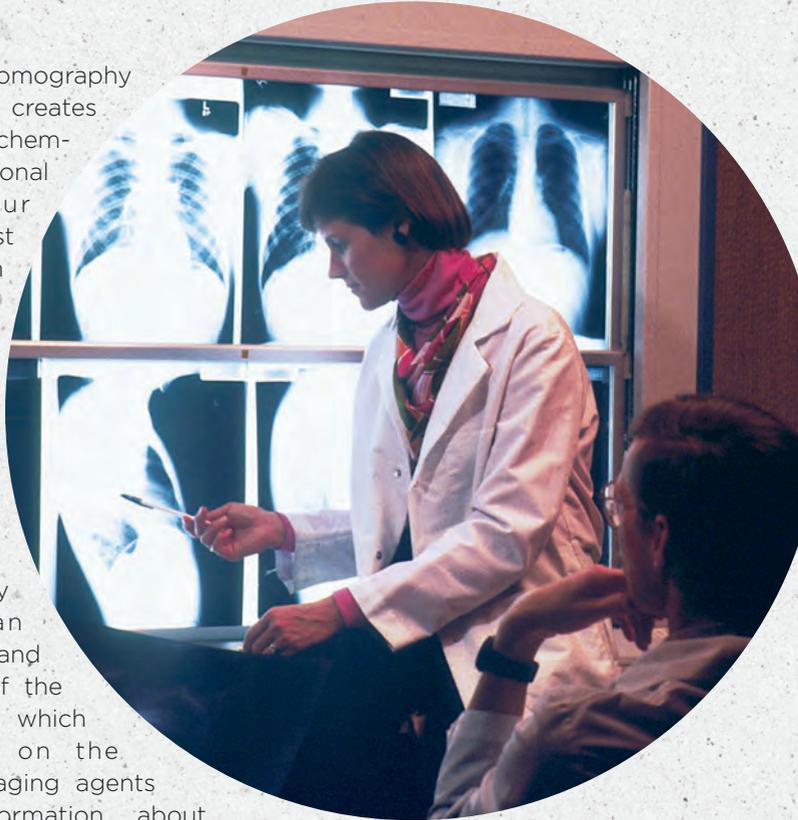
A bone scan is occasionally used if your doctor suspects that your melanoma has spread to your bones. A small amount of radioactive material is injected into a vein, where it travels through your bloodstream to your bones. Abnormal areas of bone absorb more radioactivity than normal or healthy bone, and show up on the scanner.

Bone scans can't always tell whether an abnormal area of bone is caused by cancer or another condition, such as arthritis, so sometimes you will need to have further scans such as CT or MRI scans.

## PET Scan

Positron emission tomography (PET) scanning creates images that show chemical or other functional changes in your body's tissues. Most commonly with cancer, PET uses a slightly radioactive form of sugar (called FDG) to measure the metabolic activity of the cells in your body. Areas where there is cancer are usually more active than surrounding tissue, and so absorb more of the radioactive sugar, which then shows up on the scanner. Other imaging agents can provide information about the level of oxygen in a particular tissue, the formation of new blood vessels, the presence of bone growth, or whether tumour cells are actively dividing and growing.

In some cancer centres, CT and PET scans can be done by a single machine, and this procedure is increasingly more available.



# WAITING FOR RESULTS

It can be a very difficult time waiting for test results, and it can take from a few days to a couple of weeks for your test results to be ready. If you have already had a previous melanoma diagnosis you will be familiar with the anxiety that this wait can cause.

It is normal to feel anxious and apprehensive, or frightened about what your test results will tell you, and what they may mean for your future. You may fluctuate between feeling that the news will be bad, and feelings of disbelief or denial; that you couldn't possibly have cancer or a cancer recurrence. You may feel restless and worried, and have a tendency to repeatedly consider the worst case scenario.

It is really helpful if you have someone you can talk to – your partner, a family/whānau member or close friend. Melanoma New Zealand can provide support for you during this time. In addition, each district health board (DHB) has its own support services (psychology and social work) available for people being tested and treated for cancer.



# WHAT YOU SHOULD ASK

## Talking with your Doctors and Health Care Team

Asking questions about your diagnosis and your treatment will help you feel more in control of what happens to you, more involved in your care, and will also make the decision making process easier.

You may have a lot of questions for your doctor and clinical team, but often those questions might occur to you over a period of time. You may find it helpful to write down your questions so that you don't have to remember them at your appointments, or forget to ask an important question. It can also be very helpful to take a support person - a family/whānau member or close friend - with you to appointments. He or she may think of question you haven't thought of or remember questions you might have forgotten.

Sometimes you get a lot of information, in a short space of time at appointments, so you might want to write down the answers to your questions. Likewise, having someone there to support you will help; they can write things down for you and may remember things you have been told and later forget.

You might even want to record your discussions with your doctors, with their consent, to listen to later.

It can be difficult to remember everything, take everything in or understand the significance of everything you are told. If you don't remember the answer to a question, or don't understand what you have been told, you can ask more questions or for better or simpler explanations. This is an important part of understanding what is happening and an important part of you making informed decisions about your care and treatment.

Ask your doctors to write down anything you don't understand, or terminology you are not familiar with. You can even ask them to draw you a diagram if that will help you understand what they are telling you.

Your doctors must obtain your informed consent before treatment is started. To be able to give them informed consent you must understand what the treatment is, what it means for you, how it is expected to work, and what the risks, benefits, side-effects and alternatives are.



## Important Questions to Ask

### *Before Diagnosis*

- Why am I having these tests?
- What will the tests involve?
- When do I get the results?
- Can I bring someone with me when I get the results?

### *At Diagnosis*

- What is my stage of melanoma and what does that mean?
- Has my melanoma spread and if so, where to?
- Who will be part of the multi-disciplinary or clinical team looking after me?
- Do I need any further tests or scans before my treatment?

### *Discussing Treatment*

- When will my treatment start?
- What will happen if I delay my treatment so I can fully explore my options before making a decision?
- Are there any alternative surgeries/medical treatments<sup>†</sup> that could be considered besides the one you are offering or suggesting?
- What is your rationale for the prescribed treatment?
- Is the treatment you are suggesting recommended in the *Clinical Practice Guidelines for the Management of Melanoma in Australia and New Zealand*, and if not, what is your rationale for the treatment you are suggesting?
- Should I consider getting a second opinion if the surgery/treatment is complex or controversial?
- Which treatments are funded and can I be treated in the private sector with an unfunded drug and be treated at the same time in the public sector with a funded drug?
- Would there be different treatment options if I were treated privately?
- Should I consider enrolling in a clinical trial and if so what trials are there available for my prognosis and stage of cancer? (see also Are Clinical Trials for You? on page 22)
- Are clinical trials the only option for my stage of melanoma?
- Is this treatment aimed at helping me live longer or controlling my symptoms?\*
- What are the risks and side-effects of treatment?
- Will the treatment cause me a lot of pain, and if so how will we deal with that?

- Can I have a family/whānau member or friend with me while I'm having the treatment?
- Is there anything I can do to help me cope with the effects of treatment?†
- What would happen if I decided to stop my treatment at any point?
- What do you expect will happen if I choose not to have some or all of the treatment you are suggesting?
- What happens if the treatment you are suggesting doesn't control my cancer; if I don't go into remission?
- How will I know if the treatment has worked?



### *After Treatment*

- What is my prognosis and what are my chances of remission?
- What are the long-term effects of the cancer and its treatment?
- How can I reduce the risk of the cancer coming back?
- What symptoms should I watch for?
- What type of follow-up will I need after treatment?
- Who do I contact if I have a problem in between follow-up appointments?
- How will we know if the cancer has come back? What would my options be if that happens?
- What support services are available for me and my family/whānau?

\* For questions you may want to ask about palliative and end of life care if you have stage IV melanoma, see the section on Advance Care Planning on page 41.

† For questions you may want to ask about complementary and alternative therapies for treatment or alleviating the effects of treatment or for improving the quality of your life living with cancer see the section on Complementary Therapies on page 28.

# TREATMENT OPTIONS

Cancer treatments are changing all the time and treatment for each different cancer, and different stages of the same cancer, vary depending on what your clinical team believes will work best for you. More frequently doctors can offer targeted treatments.

Ongoing research gives us more information on which treatments work best for different types and characteristics of cancer, including melanoma. So the treatment plan worked out for you might be different to the treatment plan for someone else with melanoma.

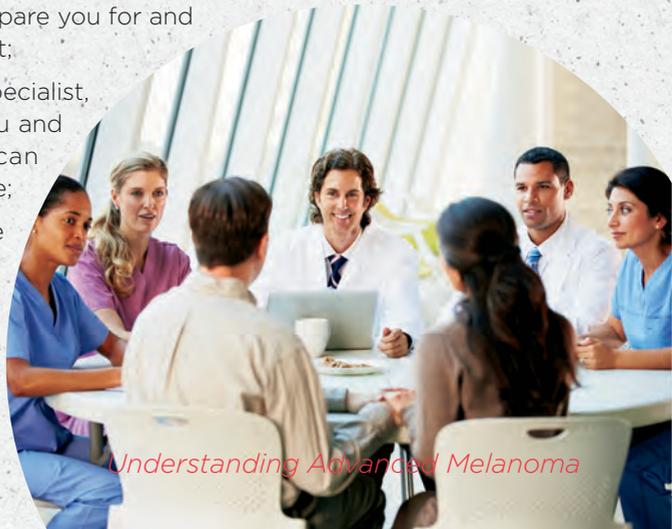
However, there are still broad categories of treatment types which you are likely to be offered.

## Planning Your Treatment

You will be cared for by a team of health care professionals known as a Multidisciplinary Care Team (MDT). Exactly who will be involved in your treatment depends on the characteristics of your melanoma and what your prognosis is, and the best treatment for you.

Your Multidisciplinary Care Team is likely to include:

- a general surgeon/surgical oncologist;
- a plastic surgeon;
- a medical oncologist (specialises in cancer treatment using medications; they are responsible for prescribing any chemotherapy and other treatment options, such as targeted therapies);
- a radiation oncologist, who specialises in radiation treatment;
- a dermatologist (skin disease specialist);
- radiation therapists, who prepare you for and give your radiation treatment;
- a melanoma clinical nurse specialist, who provides support to you and your family/whānau and can help to co-ordinate your care;
- radiologists, who analyse x-rays and scans;
- your GP, who is responsible for your general health and referral for specialist treatment;



# Your Clinical Nurse Specialist

Your melanoma clinical nurse specialist (CNS) will be an important point of contact for you. This role has evolved to improve your experience as a melanoma patient. Key aspects of the CNS role are patient support, care, co-ordination and management of complex needs.

Your CNS will provide you with a single point of contact throughout your journey; has close links within your multidisciplinary team and can refer you to other professionals if needed. CNSs offer:

## *Resources:*

- Patient information resources.
- Fertility advice and referral.
- Informal discussion and clarification for you and your family/whānau.
- Ensuring you are informed and can make decisions about your care (see Important Questions to Ask on page 12).

## *Complex Symptom Management*

- Lymphoedema referral (see Lymphoedema on page 27).
- Palliative care input - inpatient team and community hospice (see Palliative Treatment for Advanced Cancer on page 21).
- Managing medication toxicities (see Coping with Side-Effects on page 24).
- Phone triage and acute assessment.

## *Patient Advocate and Supportive Care*

- End of life goals of care.
- Advance care planning (see Advance Care Planning on page 41).
- Transport issues.
- Cancer support - psychosocial referral and input for you and your family/whānau.
- Cancer Society of New Zealand liaison nurses.
- Specific input from cultural support services.



- pathologists, who advise on the type and extent of the cancer.

Depending on how far your melanoma has spread and which organs it has spread to, you might also have:

- a physiotherapist, who helps treat your body so you can cope with the physical effects caused by the cancer, surgery and treatment;
- an occupational therapist, who helps you with everyday tasks like bathing, dressing and cooking;
- a pharmacist, who gives advice on medication;
- a dietitian, who gives advice on nutrition;
- psychologist and social worker;
- palliative care doctors and nurses, who work closely with your GP and other doctors to provide supportive and palliative care so you can cope better with the effects of cancer at home and in hospital.

Once melanoma has spread to other parts of your body, the main focus of treatment is to control the cancer and help you live longer. Treatment may improve or reduce your symptoms and your quality of life. Controlling your cancer may mean shrinking the size of the tumour or stopping it from growing.

You may have treatment for a finite course (such as with radiotherapy) or a number of cycles of drug treatment, and then have some further scans done to see if the treatment is having the expected effect on the tumour/s. If the treatment is working you will continue with it, but if it is not helping, or if the side-effects outweigh the benefits of the treatment, your doctor will discuss other treatment options with you.

## Treatment for Stage III and IV Melanoma

Treatments for advanced melanoma include surgery, radiotherapy, chemotherapy and targeted treatment. Your treatment plan may include one or more of these therapies, depending on the stage of the disease, and where your melanoma has spread to.

### Surgery

#### *Lymph Node Dissection*

If you have stage III melanoma in which the spread is limited to lymph nodes and vessels, you might have a lymph node dissection. This is surgery that is done under a general anaesthetic and you will probably be in hospital for a few days. The operation you have will depend on where the lymph nodes are, but essentially your surgeon will remove the affected lymph nodes and vessels. For example, if your primary melanoma tumour is on your leg, your surgeon would

remove the nodes in the groin region on that side of your body, which is where melanoma cells would most likely travel to first.

Lymph node dissection (or removal) can lead to a condition called lymphoedema, in which you develop swelling in your affected limbs or part of the body near where the lymph nodes were. This is because the lymph nodes and vessels help drain lymph fluid from around your body and when they have been removed that drainage is compromised (for more on lymphoedema see page 27).

### *Other Surgery*

If your melanoma has spread to the skin in other parts of your body and caused new lumps or tumours to develop, and particularly if these lumps bleed or cause you discomfort, they can be surgically removed. If the tumour is large enough, you may need a skin graft to replace the skin that is removed.

Generally, surgery in advanced melanoma is used to control the growth of the secondary tumour or tumours and prolong survival, or to alleviate symptoms you may be experiencing. If you have a single melanoma metastases in another part of your body, for example your lungs or liver, your surgeon may recommend surgery to remove it.

Whether or not brain metastases can be operated on will depend on the size of the tumour and the brains structures involved. You will be referred to a specialist neurosurgeon so he or she can decide whether surgery is possible.

If your melanoma has spread more widely to other organs in the body, surgery may not be an option and other medical treatment, such as chemotherapy, radiotherapy and targeted treatments are used to treat or control your cancer.

Increasingly, surgery for advanced melanoma is being delayed until after other treatments have been used, to see whether those therapies are effective or might shrink your tumours.

## **Radiotherapy**

Radiotherapy or radiation therapy uses ionising radiation – a more intense radiation than is used in other medical x-rays, such as for broken bones – to destroy cancer cells. It is very carefully targeted at the tumour so that it causes the least possible damage to surrounding tissue. It is usually given as a series of short treatments every day



for one to five weeks, but may also be given in a single dose in some situations. In stage III melanoma, radiation therapy may be used after surgery has removed enlarged lymph nodes to decrease the chance of the cancer coming back in the nodes. In more advanced melanoma, it is used to reduce pain and improve other symptoms that you might be experiencing.

The exact amount, or dose, of radiation you have, how often and for how long you have it will depend on what the aim of the treatment is and where your melanoma has spread to.

Generally, radiotherapy is not used to treat melanoma on your skin unless surgery is not an option for some reason. However, radiation can be used to reduce the size of skin nodules or lymph nodes and reduce symptoms that they cause, such as pain.

Sometimes, you might have radiation after surgery in the area where your lymph nodes were removed, especially if many of the nodes contained cancer cells. This is used to decrease the likelihood of the cancer coming back in the lymph nodes in the area.

Radiation is most often used in metastatic melanoma if your cancer has spread to your bones or brain, and is used specifically to relieve symptoms associated with melanoma spread. When radiation is used like this it is called palliative radiation; that is, it is not designed to cure your cancer, but may help shrink the tumours or slow their growth, relieve symptoms especially pain, and may help you live longer.

A special type of radiotherapy, called stereotactic radiosurgery (SRS) is sometimes used for melanoma that has spread to your brain. There is no actual surgery, despite the name, but high doses of radiation are aimed very precisely at the tumours. This is particularly important as it limits the potential damage to healthy brain cells.

As with any treatment, radiotherapy can cause side-effects, and these can include:

- fatigue;
- nausea (if radiation is aimed at the abdomen);
- sunburn-like skin problems;
- changes in skin colour;
- hair loss where the radiation enters the body.

If you have radiotherapy for brain tumours it can cause memory loss, headaches, confusion or difficulty thinking clearly and reduced libido. However, these side-effects are often more minor than the symptoms caused by the tumour.

## More Recent Treatment Developments

Surgery, radiotherapy and chemotherapy are long standing approaches to cancer treatment and have been used for decades. However, in the last ten to 15 years, as we have learned more about the complexities of cancer, the medical research world has increasingly been developing biological treatments.

We know that some traditional treatments work very well for some people, moderately well for others, and not well at all for some people. Targeted treatments are “tailor made” for specific cancer characteristics. The type of targeted treatment that may suit one cancer patient, might not work at all in another. This is an ever-changing area of cancer treatment research and as a result, there are new drugs becoming available all the time. These drugs are not cures for metastatic (stage IV) melanoma but may help you live a lot longer than if you relied on just traditional treatments.

For example, in about 40% of all melanomas patients, the cancer cells have changes in the BRAF gene. If this gene change is found in your cancer, you might be a suitable candidate for drugs such as vemurafenib (Zelboraf), dabrafenib (Tafinlar), trametinib (Mekinist), and cobimetinib (Cotellic).

Another gene change may occur in the C-KIT gene; if you have this genetic variant you might benefit from drugs such as imatinib (Gleevec) and nilotinib (Tasigna),

Immunotherapy stimulates a cancer patient’s immune system to fight the melanoma, and effectively “take the brakes off” in the immune system. While this can have a beneficial effect because your immune system fights the melanoma more vigorously, it can also cause your immune system to attack other parts of your body, which can cause serious or even life-threatening problems in the lungs, intestines, liver, glands, kidneys, or other organs. Side-effects of these drugs can include fatigue, coughing, nausea, itching, skin rash, decreased appetite, constipation, joint pain, and diarrhoea.

One class of immunotherapy drugs are called checkpoint inhibitors, such as pembrolizumab (Keytruda), nivolumab (Opdivo), and ipilimumab (Yervoy). These drugs have been shown to help some people with advanced melanoma live longer.

## Chemotherapy

When people are told they have cancer, chemotherapy is probably the first treatment they associate with their diagnosis. However, with stage III and IV melanoma it is often not the preferred option as it is not as effective as it is for other types of cancer, and other treatment options, such as targeted therapy or immunotherapy, are more effective.

Chemotherapy can help a small number of people with stage IV melanoma – usually it is used to relieve symptoms for some patients; your tumours may shrink for a while under chemotherapy but will eventually start growing again.

If you have advanced melanoma that is confined to your arms or legs, you might have regional chemotherapy called isolated limb infusion (ILI) using the drugs melphalan and actinomycin-D. The blood flow of your affected limb is separated from the rest of the body, and a high dose of chemotherapy is circulated through the limb for a short period of time. This limited type of chemotherapy means that the adverse impacts are limited to only the affected limb, reducing side-effects in the rest of your body.

Chemotherapy can cause a range of side-effects depending on the type and dose of drugs. Except in ILI where only a limited part of your body is involved, chemotherapy affects your whole body. Because chemotherapy targets cells that are rapidly dividing, it affects not only your cancer cells but rapidly dividing healthy cells, such as hair follicles, and the lining of your stomach and other mucous membranes, and bone marrow. Side-effects can include:

- hair loss,
- mouth sores,
- loss of appetite,
- nausea and vomiting,
- diarrhoea or constipation,
- increased risk of infection (from having too few white blood cells),
- bruising or bleeding (from having too few platelets),
- fatigue (from having too few red blood cells).

Usually the side-effects subside when your treatment stops but some chemotherapy drugs can have longer term effects, such as nerve damage (peripheral neuropathy) that can cause numbness, pain, burning or tingling, and heat/cold sensitivity, particularly in your hands or feet.

Depending on why you are having chemotherapy, and what the expected benefits are, if you are experiencing severe side-effects that impact on your quality of life, you and your oncologist may decide to reduce your dose, or stop or postpone chemotherapy treatment.



## Palliative Treatment for Advanced Cancer

You may get to the point with advanced or stage IV melanoma, that your treatment may no longer control your cancer. If this happens, the aim of treatment is to give you as much quality of life for as long as possible, rather than trying to shrink the cancer. Treatment will be aimed at reducing troubling and distressing symptoms and keeping you pain-free.

Palliative care is the treatment that you receive to help you live well with incurable cancer. It is not just for end of life care, but any stage of advanced melanoma.

Your palliative care team is a team of specialist doctors and nurses who help to maintain your quality of life and keep you comfortable by managing symptoms, such as pain, nausea, breathlessness or fatigue. Palliative care is provided in hospitals, at home and in hospice. Sometimes people go to hospice for short periods of a few days in order to get specific symptoms, such as pain, under control before returning home. In this way, symptoms can be addressed without you having to change your life style too much or permanently leave your home if your wish is to stay there.

Pain is often the symptom that people fear the most, but not all people with advanced cancer experience severe pain, or it may not happen for some time. Your experience will depend on where your melanoma has spread to and how big the tumour has grown. If you need medication to help control pain, it may take a little time to find what works for you and what dose you need.

There are many ways to manage pain, including:

- pain-relieving drugs like paracetamol, codeine, and morphine;
- pain-relieving procedures, such as 'nerve block' and 'vertebroplasty'; and
- treating the cause of the pain with chemotherapy, surgery, and radiation treatment, alone or together.

You may have a range of different drugs over time and your palliative care team can advise you what pain treatment might work best for you at different stages.

### Sativex

You may have heard about "medicinal cannabis" (cannabis-based products). Although its use has been controversial in the past, Sativex has been approved for use in New Zealand and some cancer patients find it is of significant benefit in palliative care. At the time that this booklet was written, Sativex was the only cannabis-based medicine with consent (approval) for distribution in New Zealand. To be prescribed Sativex for off-label use (such as for cancer) a GP can apply following the recommendation of a specialist.

# ARE CLINICAL TRIALS FOR YOU?

You may have heard about clinical trials and want to know if they are an option you should consider. Clinical trials of new treatments – usually drugs, but they can also include new surgical procedures and other treatments – are carried out all over the world in an effort to find new and better treatments for cancer. A new treatment may offer a greater chance of a cure, longer disease free survival, or longer survival with metastatic cancer, or it may mean fewer side-effects and less loss of quality of life.

Sometimes clinical trials investigate new combinations of existing drugs or trial existing drugs on different cancers or different cancer stages. Sometimes clinical trials may not involve cancer treatment drugs so much as drugs that help you manage side-effects.

The more advanced your melanoma is the less likely it is that an existing treatment will be able to cure it. However, because new treatments are being developed all the time, a clinical trial might give you access to an effective treatment that you might not otherwise be able to get, either because it is not yet licensed or because it is not funded.

Even if you are approached about participating in a clinical trial, it is entirely voluntary. It is important that you find out as much as possible about the trial and read the patient information sheet (PIS) carefully. This will tell you what the clinical trial is about, what will happen to you and what you are expected to do, including things like pre-trial tests, whether or not it is a placebo controlled

## Benefits:

- access to the most up-to-date drugs and treatment;
- treated by leading medical experts with cutting edge medical facilities;
- closer and more comprehensive monitoring;
- an opportunity to take an active role in your care;
- can be important for rare or difficult to treat conditions;
- future patients may benefit from what is learned.

## *There are three<sup>†</sup> different phases of clinical trials:*

- Phase I: these are first in human trials – the first time that a new drug or procedure is tried in a small group of often healthy people (but also sometimes patients) – are for finding out how safe a treatment is and the approximate dosing range.
- Phase II: these are trials undertaken with larger groups of people with the disease that the study medication is designed to treat. These trials are done to better measure the safety and side-effects, and to see whether the drug has a positive effect in patients, and to work out what the best dosage is.

trial\* and if it is randomised, and how much follow-up there is. Another important issue for you to consider is what compensation you might receive if you suffer an adverse event arising from your participation in the trial.

While there are disadvantages and risks in participating in a clinical trial there are also benefits. You need to discuss these carefully with your oncology team and weigh up the risks and benefits before making an informed decision. Make sure you get answers to all your questions.

### Risks:

- the treatment may not do what the researchers hoped and you may not receive any therapeutic benefit;
- you may be randomised to have the placebo and not get the trial treatment;
- you will have more tests, and more frequent visits to hospital/clinics;
- you may suffer from side effects and adverse events caused by the treatment;
- participants in research funded by pharmaceutical companies are not covered by ACC and are reliant on those companies compensating them in the event of injury;
  - you may not be able to continue to get the treatment after the trial has ended.

If you decide that clinical trials are something you would like to be considered for, your participation will depend on what clinical trials are being run at the time, and if you are eligible for those trials. Many trials have very strict eligibility criteria because of the design of the trial or what the researchers are trying to find out.

\*some trials include a placebo, in which some of the participants receive “dummy” treatment. In most of these trials, participants are randomised to receive treatment or the placebo and neither you nor the researcher’s know what you have received until the end of the trial. Sometimes those getting the placebo are offered the active treatment at end if it has been found to be effective and safe.

- Phase III: these are much larger trials often involving hundreds or thousands of people and in several countries. The aim with these trials is to compare the therapeutic benefit of the drug with the current treatment, if there is one, and to find out if the treatment works, and how long the effects last. They also help establish how common any side-effects are, and any possible long-term problems that could develop.

† you may also hear about phase 4 trials but these are “post-licensure” trials that are carried out after the drug is licenced for use and can help identify rare side-effects not previously identified as well as establishing how the drug is received by the public.

# COPING WITH SIDE-EFFECTS

All medical treatments have side-effects and adverse events associated with them. Your experience will vary, as drugs and treatments tend to have different effects on different people even when certain side-effects are very common across all patients.

Some side-effects are minor, localised, and transient or fleeting, while others may be severe, systemic (involve your whole body) and ongoing.

While some degree of side-effects will be expected with your treatment you should make sure to find out from your doctors or clinical nurse specialist (CNS) what you can expect, which side-effects are common, how you can alleviate or cope with them and when you should talk to your doctor or CNS. If you experience any symptom that is unexpected, unusually persistent or unresponsive to efforts to alleviate it, or that causes you significant discomfort, pain or debilitation, you should contact your CNS or doctor as soon as possible so that a serious adverse reaction can be ruled out, or dealt with. There are some side-effects that you should not try to manage on your own and should report them immediately to your oncologist or CNS. If you are unsure what symptoms should be reported immediately, discuss this with your team and report anything you are unsure about.

Common side-effects of your treatment may include: nausea, pain, fatigue, and changes in eating habits or poor appetite.

## Fatigue

Fatigue and tiredness is a common side-effect of both treatment and living with melanoma. It can be both profound and persistent or constant. Other side-effects and symptoms, such as nausea or pain, poor appetite or low levels of red blood cells, can exacerbate your fatigue and be debilitating. Additionally, you may find that you are not sleeping as well as you usually do.

To help deal with fatigue, conserve energy as much as possible for the most important or essential activities you must take part in, or if it is possible the most enjoyable activities. Energy levels are usually highest in the morning so try to schedule activities for then, allowing you to rest in the afternoon, or to do less demanding things then.

Ensure that your diet is as good as it can be, even if you are suffering from changed eating habits or nausea, and ensure you are getting plenty of high quality protein. Protein is vital for repair of tissues and for maintaining muscle mass and tone.

Other things you can do include:

- Ensuring family/whānau, friends and/or colleagues understand your limitations.
- Exercise as best you can; even short walks in the fresh air can be invigorating and energising as long as you don't overdo things.
- Rest and take naps when you can.
- Some complementary therapies, including mindfulness and relaxation techniques, can help to manage fatigue and improve energy.

If you have tried a number of methods for managing your fatigue and are still finding it difficult to cope, talk to your doctors or CNS and ask for advice.

## Pain

Although pain may be a side-effect of cancer treatment, depending on the treatment you are having, the cancer itself is often the cause of pain.

What your doctors will advise for the control of pain will depend on its severity, how often you experience pain and what is causing it. Sometimes chemotherapy and radiotherapy are used to relieve and control pain, even if there is no cancer-control benefit from these treatments.

Your doctor may prescribe you oral painkillers and will often recommend that you take these on a regular basis to prevent pain from escalating to a level at which it might be harder to get under control. If you have advanced cancer, and are receiving palliative care, your doctors or the Hospice staff may recommend that you be admitted to Hospice for a few days to get your pain medication and dosage sorted out and your pain under control.

A more recent treatment for pain is the use of Sativex (see page 21). Some cancer patients find that it has the added benefit of improving their appetite (see Changes to Eating Habits on the next page).

## Nausea

Nausea and vomiting can be a common side-effect of both treatment and the progression of your cancer, depending where in your body it has spread to. For many people this can be effectively treated by anti-emetic (anti-nausea/anti-vomiting) drugs. Sometimes adjustments to your diet may help, as does drinking dry ginger ale or ginger tea, taking ginger tablets and eating plain biscuits or crackers. Relaxation and mindfulness/mediation may also help.

For those with nausea that does not respond to anti-emetics, research has shown that acupuncture and acupressure may be particularly safe and effective, and can also be used in conjunction with other treatments.

## Changes to Eating Habits

A range of factors associated with both treatment and living with cancer may impact on your eating habits. One of the side-effects of treatment may be changes to your sense of taste and smell. Some treatments can also cause difficulty with swallowing, or reduce your appetite. Feeling sick or being in pain can also leave you less than enthusiastic about food.



Maintaining a healthy diet is important to provide the fuel your body needs not just for daily activities and energy, but to help your body repair and recover from treatment. To manage changes to your eating habits and diet, try some of these things:

- Eat smaller amounts of nutrient dense food more often.
- Choose foods that you enjoy and leave the ones that don't appeal.
- Maintain your fluid intake, including water; soups and broths will also assist with nutrition.
- Drink protein drinks or smoothies, which may be more appealing or easier to consume and digest.
- Avoiding foods that are fatty, spicy and sugary.

If you are still struggling with eating adequate nutritious food talk to a dietitian to see if they have workable solutions for you.

## Important Issues with Newer Treatments

While it is important to talk to your CNS or doctors about any side-effects you are experiencing, it is especially important if you are on one of the newer drugs as some can have serious side-effects.

You should always tell any other healthcare professionals that you might see if you are on drugs to treat your melanoma. If you have any symptoms or side-effects while you are on these drugs you should contact your oncologist or CNS immediately, and you should not try to manage the side-effects yourself. You may be able to continue treatment if your side-effects are treated early, so it is very important to report any you may be experiencing to your CNS or oncologist as soon as possible.

# LYMPHOEDEMA

If melanoma has spread to your lymph nodes in the groin or under the arm, and you have had either surgery or radiation to the lymph nodes, you may develop a condition called lymphoedema.

Excess fluid from your body's tissues is drained through your lymphatic system – a network of very fine vessels. Lymphatic fluid carries dead cells, cancer cells, viruses, bacteria and other waste, which is filtered out by the lymph nodes, which also contain white blood cells (lymphocytes) to help fight infection. The filtered fluid eventually returns to the bloodstream near the heart. There are lymph nodes all around your body, including your armpit, groin, abdomen, chest and neck.

Secondary lymphoedema may occur after cancer treatment when the lymph nodes are damaged or removed. The risk is higher the more lymph nodes you have removed or if you have both surgery and radiation. However, most people who have surgery or radiation to their lymph nodes don't develop lymphoedema.

If you develop lymphoedema, fluid will collect in the tissues under your skin in your arm or leg causing it to swell up. Symptoms can also include:

- a feeling of heaviness, tightness or fullness in the limb; and/or
- ache, pain or tension in the limb or body part.

Lymphoedema can develop weeks, months or years after your cancer treatment. You can reduce your risk of developing it by:

- Looking after your skin, especially in the at risk limb.
- Keeping your skin clean and well moisturised.
- Avoiding damage to that limb (e.g. sunburn, insect bites, blood tests, injections) and treat cuts or grazes with antiseptic. Don't have your blood pressure tested on an at risk limb.
- Avoiding extreme heat or cold.
- Wearing a compression bandage if flying, and using a bag with wheels.
- Maintaining a healthy weight as being overweight can increase risk.
- Staying active with regular gentle exercise.
- Avoiding lifting heavy items with the at risk limb.

Lymphoedema is not curable but can be managed and controlled. Treatment can include massage, compression, skin care and exercise. If you develop lymphoedema you may want to see a lymphoedema therapist. The New Zealand Lymphoedema Therapist Group is a nationwide group specialising in the treatment of patients with lymphoedema. There are also exercise programmes designed for cancer patients that help reduce the risk of and manage lymphoedema.

# COMPLEMENTARY THERAPIES

Complementary therapies – sometimes called complementary and alternative therapies (CAM) or holistic therapies – are increasingly being used by cancer patients. These are therapies that sit outside conventional medicine and range from herbal medicine to massage, yoga and mindfulness.

It is not in the scope of this book to recommend an alternative approach to treatment of melanoma, and Melanoma New Zealand recommends conventional medical treatment for melanoma. However, complementary therapies increasingly have a role in helping people cope with and manage the symptoms and effects of their cancer, to lessen or cope with any side-effects of treatment they are having, to boost their overall health and immunity and to improve their quality of life both during treatment and while living with melanoma.

In this sense, the emphasis is on “complementary”; therapies you may choose to use alongside your conventional treatment. If you are considering taking supplements or herbal medicines you should tell your oncology team in case any of them might interact with chemotherapy or other drugs you are taking as part of your treatment.

Increasingly, CAM practitioners have advanced qualifications, much experience working with cancer patients, and can offer

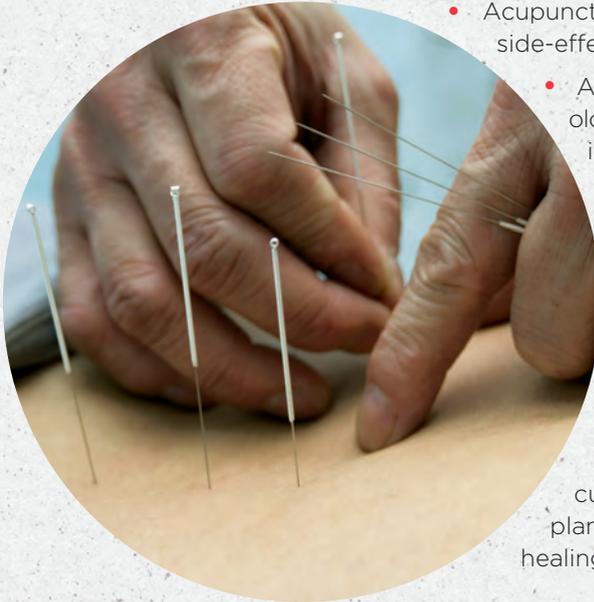


useful treatment programmes that will complement your conventional treatment and improve your well-being and quality of life.

Just as not all conventional medicine works all the time for everyone, not all complementary therapies work all the time for everyone. You will need to do your own research, get advice from a registered complementary practitioner and find things that work for your particular circumstances and needs. Many hospitals, doctors and hospices offer or recommend complementary therapies alongside your conventional care.

You may want to consider:

- Nutritional advice to keep your body as healthy as possible and help it become stronger and more resilient.
- Herbal medicine to cope with side-effects of treatment or symptoms you experience, such as loss of appetite.



- Acupuncture for pain, nausea, and treatment side-effects.
- Aromatherapy, massage, Reiki, reflexology, mindfulness/meditation, visualisation or guided imagery techniques to help you cope with pain, stress, anxiety, sleep concerns and loss of quality of life.
- Art and music therapy for improving quality of life, helping you to express your feelings and coping with anxiety.
- Traditional Māori healing such as rongoā Māori, romiromi or mirimiri – customary remedies based on native plants, massage therapy and spiritual healing.

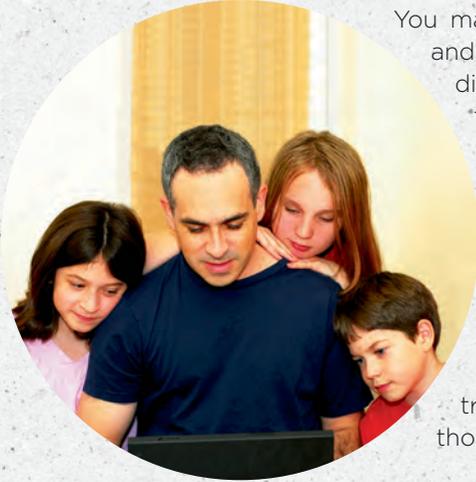
Nutrition is particularly important but it can be difficult to ensure you are meeting your body's nutritional needs for coping with both illness and the effects of treatment when both of these can impact on your appetite, cause nausea, a dry mouth and indigestion, or pain, and some foods may not taste the same any more.

You may need nutritional supplements if you are struggling to eat well, but adequate nutrition is important to help with repairing your body, giving you energy, allowing you to exercise and helping you cope physically and mentally with treatment.



# TALKING TO YOUR FAMILY/WHANAU

Telling family/whānau and friends about their diagnosis is something that many cancer patients find very difficult. How you approach this is very individual and will depend if you have children to tell, and how old they are, and the sorts of relationships within your family/whānau and circle of friends.



You may find it hard to talk about your diagnosis and prognosis, especially if you have been diagnosed with advanced melanoma and your future is uncertain. Sometimes your friends and family/whānau may not know what to say to you or how to support you. They may have difficulty with their own feelings, which may be similar to your own: sadness, anger, fear, guilt and uncertainty. Some cancer patients find that, not only are they coping with their own feelings about their diagnosis, treatment and life with cancer, but trying to manage the feelings and concerns of those closest to them as well.

## Talking to Young Children and Teenagers

You may find it difficult to tell your children or grandchildren, and what you tell them and how will depend on their ages. It is best to be honest with them, tell them that you have been diagnosed with cancer, or that a previous cancer has come back or spread. Tell them sooner rather than later; you don't want them to find out from outside the family/whānau, and perhaps get the wrong information.

Tell your children as simply and gently as possible what has happened. Keep your explanations simple. Try to anticipate questions that they may have and work out how you plan to answer them; and don't tell them more than they need or want to know. If you let them know that they can ask questions, they will ask for more information if they need it.



It is helpful to reassure younger children that there is nothing that they did that caused the cancer. It is better to reassure them early in case they keep feelings of guilt and blame to themselves. Similarly, they may worry that cancer is contagious, or that everyone dies from it, or that the other parent will get it, too.

If treatment is likely to offer good control of your melanoma it's important to tell them that. However, if your melanoma is advanced, and your treatment is more about managing your symptoms, you can sensitively prepare them for your death. You may find this very difficult to do and you might need support from family/whānau, friends and health professionals to do this in a way that helps you and your children.

Teenagers may be particularly difficult to tell because adolescence is time of change and emotional upheaval for many teens. The same things apply to telling teenagers as for younger children but they may find it harder to talk to you about what is happening. They may need to seek support from others and you can encourage them to talk to someone close who can support them, such as other family/whānau members, or family friends.



## Talking to Adult Children

Although your children have grown up, they are still your children and you may have as much difficulty telling them of your diagnosis as you would with younger children.

If this is the first time you have experienced a major health issue, it could be that your children have never perceived you as being vulnerable. They may have difficulty coping with the inevitable transition from being cared for by their parent/s to feeling that they have to take on a caring or nurturing role with them.



If you don't have a spouse or partner, and depending on your prognosis, you may need to ask your adult children to be involved in your advanced care plan or to take on the role of Enduring Power of Attorney (see chapters on Advance Care Planning on page 41 and Legal Issues on page 44). Chose a good time to talk to them about this and let them know that this is an important way in which they can support you.

# THE IMPACT OF MELANOMA ON YOUR LIFE

It is normal for people receiving a cancer diagnosis to experience a range of emotions: fear, anger, guilt and blame; feeling alone; and concern for how other people in your life will cope with your diagnosis. These feelings may be particularly strong if your cancer has metastasised and your long term prognosis is not very positive; people often worry about their future, the future of their loved ones and about dying. Other feelings that cancer patients commonly report include disbelief that this is happening to them, sadness, despair and a sense of feeling overwhelmed.

Some cancer patients who have a second diagnosis can experience a sense of betrayal; that their body has let them down again, especially if they have done all that they could to avoid a recurrence, such as making health and lifestyle changes.

If you are diagnosed with stage IV melanoma, you may receive a distressing prognosis and have many end of life concerns, preparations and considerations.

It is important to work through all your emotions in your own time and at a pace that feels right for you. However, help is available if you need it.

## COPING WITH DIAGNOSIS

Every person has a different way of coping with their diagnosis. Irrespective of the initial feelings that you have about your diagnosis, many people find that over time these emotions become easier to cope with. However, at the beginning it can be hard to think of anything but the cancer, and you may feel like your diagnosis and treatment have taken over your life.

Some people find that the best thing to do is carry on with life as normally as they can, continuing with as many of their normal activities as possible, staying in touch with family/whānau and friends and keeping as normal a routine as treatment allows. However, some people decide - or need - to reprioritise their lives. This may mean spending more time with family/whānau or friends, changing their lifestyle, or taking up a relaxing or self-focused hobby or activity, a new physical activity that makes allowances for changes to their bodies and capabilities, or perhaps a much longed for holiday or trip.

Allow yourself time to adjust to this new life or period in your life, in which your body is undergoing changes. Treat yourself with compassion and kindness. It may be that this is the first time in your adult life when you have put yourself first; accept that for you this is the right thing to do, at least for now.

Talk with other cancer patients, people who have been through or are living with the same issues and concerns that you have. As well as learning new ways of coping and living with your disease, this will help you to feel less alone.

Many people who have lived with cancer report that humour has many positive benefits. While there will no doubt be many times that laughter has never seemed so far away or less appropriate, it has many positive benefits on both the mind and body and can help you relax at a difficult time.

Ask for and accept help, even if it is just with simple things. Treatment may be energy-sapping and you may not be able to keep up a previous busy schedule, so ask friends and family/whānau to support you and help out so that you can put your energy into healing and staying as well as you can.

## HOW YOU MAY FEEL AND REACT

Common reactions include fear and anxiety, anger, avoidance, guilt and blame, sadness, feeling alone, and feeling overwhelmed. You may have body image concerns, and possibly anxiety or depression.

New treatments for melanoma can mean that even those people with incurable metastatic cancer live well for many years. It is important that you have ways to cope with negative emotions so you can enjoy your life as much as possible.

### Things that may help you to cope

- talking to supportive friends, family/whānau and health professionals, or a trained counsellor;
- gathering information from health professionals to understand your melanoma better;
- taking care of yourself by eating and sleeping well;
- doing little things that might make you feel better (e.g. having a bath, dressing nicely or wearing make-up);
- faith, prayer or spirituality, art or music therapy, or yoga;
- planning enjoyable activities;
  - trying to keep doing normal activities;
  - getting involved in a support group, or meeting other people who are also living with cancer.

## Fear and Anxiety

It is entirely normal to feel frightened about your melanoma and what the time ahead has in store for you. You may experience fear about the treatment you are having, and the impacts that this is having on your life, and fears for your future.

It is important to discuss your fears with your doctors or clinical nurse specialist so that you have a good understanding of what you can expect from your treatment and possible side-effects; you may be fearful of side-effects that may not eventuate. More information about what the future holds for you might alleviate your anxiety or help you come to terms with what is likely to happen to you:

- Talk to your oncology team and establish if your fears are realistic or unfounded, and what you can do to reduce the impact of the treatment or the melanoma on your life.
- Talk to a trusted family/whānau member or friend, or someone from a patient support group; sharing your worries may help you deal with them and these people can offer comfort, support and practical assistance that can make your anxieties about the future easier to cope with.
- Speak with a counsellor who has experience with helping cancer patients.

## Anger

Anger is a common emotion ranging from “why me” feelings and questions, to anger at having your life potentially cut short, anger that you are forced to undergo stressful tests and treatments, or anger that you might miss out on watching your children grow up and reach various milestones.

While anger is an entirely natural and legitimate emotion to experience, it is important that you express your anger in healthy ways, rather than keeping the anger bottled up or using drugs and alcohol to deal with it. Anger need not be a negative emotion and may give you the energy, strength and resolve to overcome the challenges you will face in the weeks or months ahead.

## Avoidance

Some people like to know the bare minimum about their cancer. Limiting the amount of information is a useful and adaptive coping strategy for some people. It is as valid to not want to talk about your melanoma as it is to want to talk about it, and your needs may change over time. In the immediate aftermath of your diagnosis, when you are focused on treatment, it may be that you need to put your energy into just getting through this period.

If you want to keep talk of treatment and your prognosis to a minimum, you need to let your friends and family/whānau know, and let them know how they

can support you in other ways. Likewise, you can also tell your GP or oncology team that there are things that you would prefer not to know. However, keep in mind that you need to know enough about your situation and the treatment being offered to you to make the best and most informed decision possible. This also applies if you have to make decisions about continuing with treatment, or changing to another course of treatment.

## **Guilt**

Many cancer patients feel a certain amount of guilt at times. It is natural to want to find reasons for developing cancer, or if this is not your first diagnosis, why the cancer has returned. Many people feel guilty about the impact their diagnosis has on other people. Some people look for things they have or haven't done, and while this can be useful if it means changing poor habits and improving your lifestyle, it is not helpful or healthy to feel guilt for what has happened to you. No-one asks to have cancer.

The reality is that, while we know what many of the risk factors are for melanoma, like other cancers it is a complex disease and it's impossible to know exactly what has caused your cancer. Instead of trying to find answers to "why?" try to focus on looking after yourself and getting the help and support you need.

## **Feeling Alone**

Many cancer patients feel alone; if you feel like you are the only person you know with melanoma, there are support groups where you will find other people at various stages of their journey with this disease. While no two individuals' experience is identical, many people you meet in support groups will have had similar experiences and will understand what you are going through. Sometimes just finding other people near-by who have had melanoma is enough to stop you feeling so much like you are on this journey by yourself.

## **Physical Changes**

Having cancer, in particular if the treatment results in changes to how your body looks or functions, can lead you to experience negative feelings about your body image. These might include negative feelings associated with: your looks, such as hair-loss, and changes in your skin quality and appearance; with how well your body works, such as fatigue and loss of energy or strength; and, impacts on your sex life, including libido and your sense of desirability.

Changes in your appearance, such as having a melanoma removed from a visible part of your body, scarring or skin grafts, may be hard to come to terms with. A small number of people develop lymphoedema, and this can lead to feelings of embarrassment, and affect the way that they feel about themselves and how their body looks.

Some changes may be transient – your hair will grow back, or the fatigue will ease as you recover from or your body gets used to the effects of treatment. But, some people may need to get used to a new way of living and functioning in their bodies.

Not all effects are negative. You may find a new appreciation for the strength of your body and its ability to cope with the cancer and treatment. With a shift in personal priorities you may develop a greater clarity about meaning in life and your personal goals. While no one wishes to experience cancer, many people who have had or live with cancer report benefits and gifts that they had not imagined.

If you are struggling to come to terms with the changes in the appearance or functionality of your body, talk with your oncology team or your clinical nurse specialist, your GP or a trained counsellor.

## Anxiety or Depression

It is normal to feel sad, worried or fearful about advanced melanoma, treatment and your prognosis. But if your feelings of sadness and fear are very strong or persistent, and don't resolve within a couple of weeks you may have depression and need more help to overcome this.

\* Keep in mind that these symptoms might also be a result of your treatment not just anxiety or depression.

## Signs of Anxiety

- feeling fearful, scared or on edge a lot of the time;
- feeling tense or "wound up", restless and worried;
- avoiding certain people or places due to fears;
- needing constant reassurance from others;
- breathing difficulties or tightness in the chest\*;
- increased use of alcohol or other drugs;
- sweating, shaking, or tingling\*;
- having difficulty sleeping.

## Stress Management

Dealing with cancer is enormously stressful and managing stress effectively is an important aspect of caring for yourself. We know that stress has negative impacts on the immune system, and when dealing with cancer and having treatment you need to have your immune system working as well as possible. However, there are things you can do for yourself to help manage and reduce stress.

If you are having treatment, try to avoid scheduling conflicts. Use a diary or your calendar on your phone or computer to keep track of appointments. Don't schedule too many activities for the same day or week, especially on days you have treatment that may leave you feeling unwell or tired. If managing your schedule is exhausting, ask someone you trust to help review your appointments.

## Signs of Depression

- feeling sad, empty, hopeless or tearful most of the day on most days;
- losing interest or pleasure in things that usually make you happy;
- withdrawal from others, avoiding friends and family/whānau or going out;
- appetite and/or weight changes\*;
- feeling very tired and not wanting to get out of bed\*;
- feeling worthless, guilty or like you are being a burden to others;
- feeling that life is not worth living;
- having thoughts or plans of hurting yourself or ending your life;
  - increased use of alcohol or other drugs;
  - being very critical of yourself;
  - sleep problems\*.

Know your own limitations and don't take on too much. You might be used to "doing everything" but this time is about you, and the healing you need to do, so learn to say no. Cancer is life changing and you need to focus on the things that matter most. Prioritise! Work out what are the most important things for you to do each day or each week, and concentrate your efforts on those things. It is okay to let less important things slip.

Ask for help from family/whānau and friends, and colleagues if you can. Many people will be happy to step in and help where they can, so think about particular tasks you need help with beforehand, and before you desperately need help.

Work out what the things are that you can control, and can influence, and don't get stressed about the things you have no control over. Sometimes you can reduce your stress levels by just accepting that there are some things you can't control and understand that all you can control is how you react to those things.

## Nutrition and Physical Activity

There are things that you can do that will not only improve your health but reduce your stress through feeling more relaxed and feeling less anxious. It is important to eat well, exercise and spend time outdoors.

Maintaining a healthy diet and getting enough rest will give you more energy to deal with both the cancer treatment and other stressors in your life. Healthy eating doesn't just support your body's physical health at a time when you need it most, but also your mental health. If you are unsure of the best nutritional approach to suit your circumstances, consider talking to a nutritionist experienced with working with those living with cancer or going through treatment.

Moderate exercise is again important not only for our physical health but mental health as well. Many people report a greater sense of well-being when they get regular exercise. In addition, many people who suffer with depression find that it is easier to manage their depression when they get regular exercise. Even a short walk a few days a week is beneficial.

Try to consider sleep as a part of your nutrition plan. Sleep is a vital part of not only the healing process but for general physical and mental health. If the effects of your treatment or cancer are interfering with your sleep, talk to your oncology team about ways to manage your sleep needs and ensure you are getting seven or more hours of quality sleep every 24 hours.

## Support From Melanoma New Zealand

Melanoma New Zealand offers a range of support to people with melanoma and their families, carers and supporters. Our Melanoma Information Advisor is ready to help you interpret information and clarify your understanding of melanoma. While your best source of information about your situation will always be your own clinical team, the Melanoma Information Advisor is happy to listen to you, explain terminology or concepts, and provide support, and contacts for other services.

You can contact the Melanoma Information Advisor on freephone 0800 463 526 or at [education@melanoma.org.nz](mailto:education@melanoma.org.nz).

Melanoma New Zealand also runs some melanoma meetings. Melanoma meetings are for people affected by melanoma, either personally or through a family/whānau member or friend. They are an informal opportunity to talk and share information. People who attend the meetings support the work of Melanoma New Zealand and recognise the importance of raising awareness and it provides an opportunity to meet other patients (or family members) with a similar diagnosis.

To find a meeting, contact Melanoma New Zealand's Educator on 09 449 2342 or email [education@melanoma.org.nz](mailto:education@melanoma.org.nz).

# YOUR WORK LIFE

## The Impact on Your Job

You may need to take time off work at various times during the period leading up to your diagnosis and for treatment. For some people, their treatment programme may be such that they have to take an extended period of time away from work. If you are in this situation, when you go back to work, or if you go back to work at all will be a very individual decision. It may depend on the type of work you do (for example, if it is very physically demanding and you no longer have the strength or energy to continue), your age at diagnosis, your prognosis and the effects of treatment on your well-being and ability to work.

For many people getting back into a normal routine is an important part of recovering from treatment and living with a chronic illness. However, if full-time work is not possible owing to fatigue issues or other health reasons, talk to your employer about part-time possibilities.

For some people, recovery and healing from cancer treatment can take a long time and it may be many months before you feel able to return to work.

## Talking to Colleagues

You will need to think about how much and who you want to tell among your work colleagues. It is likely that your absences for tests and treatments will be noticed and you may feel the need to control what people at your work place are told, rather than allowing the grapevine to swing into gear.

If you have to take an extended period of time off, or regularly attend appointments and treatments, you may need to advise your immediate boss or someone in human resources. Different workplaces will need different amounts of information and some may need a medical certificate to fulfil sick leave requirements.

Beyond what you must tell your employer, it is up to you who you tell and what you tell them. You could start by talking to someone you trust or are close to; they may be able to help you decide how much you say and who you tell.

While many co-workers will be supportive, others may not know how to react or what to say to you; some may even avoid you so that they don't need to think or talk about cancer. Some people don't know what to do or say when someone close to them is diagnosed with cancer or has a recurrence. Remember that the focus should be on you, not supporting those around you.



# SUPPORT FOR FAMILY/WHĀNAU

Most of this booklet is about and your needs as you undertake treatment for, and live with, advanced melanoma. However, many people find that their families/whānau need support too.

As a first step, you could give your family/whānau members this booklet to read. This would help them understand some of the things that you face from your diagnosis, through treatment to living with cancer. Many of the feelings that they will experience may be similar to what you may experience – anxiety, fear, sadness, anger, uncertainty about the future.

They may find it difficult to know what to say to you or how to discuss your illness or treatment or things you may be experiencing, such as side-effects. Those closest to you may feel powerless about their inability to help you or to “fix” things, and may worry about how your cancer is going to affect their lives and those of the rest of the family/whānau.

Just as you might like to speak to a counsellor about your fears, worries and feelings, they may need that support too. The Cancer Society of New Zealand can put you in touch with organisations and people who can support your family/whānau.



# ADVANCE CARE PLANNING

Many people with advanced cancer find it difficult to discuss their end of life care, and avoid talking about death and dying, either because they find it upsetting, or those close to them do. However, if your melanoma has progressed to an advanced stage and your treatment is palliative or will be in the near future, planning your advanced care and for what will happen when you die can give you a sense of control and relief.



Advanced care planning enables you to tell your family/whānau, friends and your medical team what is important to you, how and where you would like to die and what medical procedures or treatment you will want in the last stages of your life. If you were to become too ill to clearly communicate what you want and need, it can be a relief knowing that you have made those plans in advance.

Advance care planning can include:

- making a decision to stop treatment;
- explaining to family/whānau and friends what you want from the end of your life;
- writing or updating your will (see Wills on page 44);
- assigning enduring power of attorney (see Enduring Power of Attorney on page 45);
- how much medical care and intervention you want to have at the end of your life;
- if you prefer to be pain-free even if that means not remaining lucid or becoming unconscious, or tolerating a certain amount of pain in order to stay conscious and lucid;

- deciding where you want to die – in hospice or at home;
- planning your funeral.

While your family/whānau and friends may not want to talk about the end of your life and your death, planning your end of life in advance can be a huge gift to them. They will know what you want and need for the end of your life and know how they can fulfil your wishes. Your advance planning can take a burden away from them and allow you and them to enjoy what time you have left.

## Stopping Treatment

If you have advanced or stage IV melanoma your treatment will be focussed on controlling your cancer for as long as possible and giving you the best quality of life. For many people, there comes a time when the impact of treatment may be significantly reducing your quality of life. You may ask if continuing treatment is worth it.

You will need to talk to your oncology team and discuss your options, then weigh up the benefits of treatment against the side-effects. You may make an informed decision to discontinue active treatment and have only palliative care that will maintain your best quality of life for a shorter time.

Your family/whānau and friends may feel unhappy about your decision, so be prepared to explain to them that the quality of what time you have left is important. You may need counselling or support during this process.

## Hospice

Hospice is a philosophy of care for people near the end of their lives. It offers a unique whole person approach – which means physical, spiritual, emotional and social needs are equally important. A multidisciplinary team provides care for the person who is dying and their families and friends, both before and after their death.

While some people may see hospice as a place that people go to die – and some do choose to die in hospice – the majority of people are cared for in their homes.

*While every hospice is different, the services offered are likely to include:*

- medical and nursing care,
- pain and symptom control,
- rehabilitation,
- therapies, including physiotherapy and complementary therapies,
- spiritual support,
- practical and financial advice,
- bereavement care.

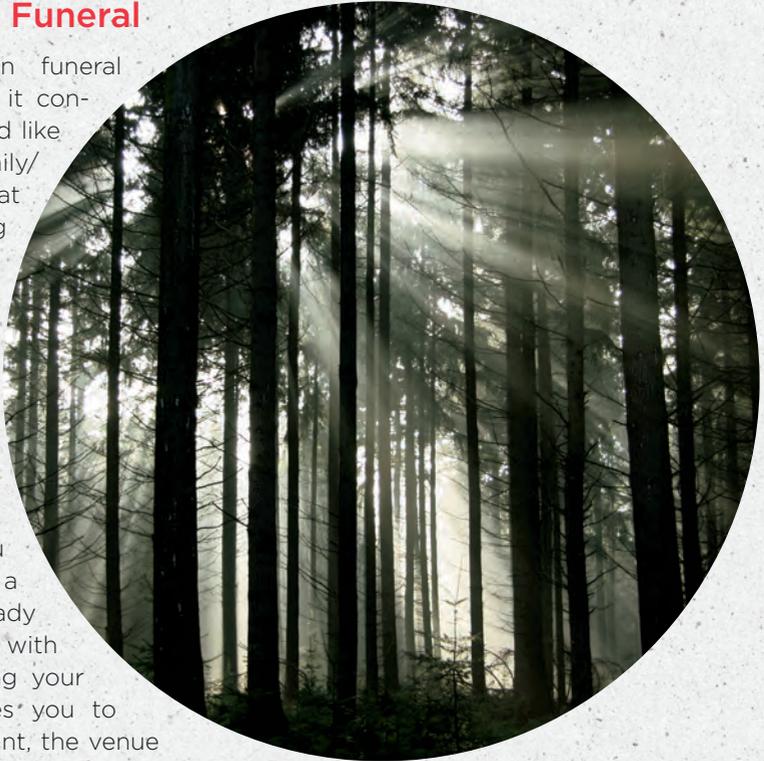
Hospice aims to help people make the most of their lives; to live every moment in whatever way is important to them. Every effort is made to ensure that you are as pain-free and as comfortable as possible.

You may go to hospice to get your pain or other symptoms under control, or to give your family/whānau or carers some respite before you return home. For those who don't wish to die at home, they may be admitted to hospice for their final days.

## Planning Your Funeral

Planning your own funeral allows you to have it conducted as you would like and lets your family/whānau know what you want. Planning your funeral enables your spiritual values and beliefs to be acknowledged. You can select your favourite music or hymns, readings or poems, and choose who is to conduct the service. If you don't belong to a church or don't already have a relationship with a celebrant, planning your own funeral enables you to choose your celebrant, the venue and the type of service it is to be, as well as enabling the celebrant to get to know you and what is important to you.

Again, this can be a gift to those closest to you. They will have less to do in the days immediately after your death when their grief is most raw, and if you involve them in part of the process they will know that your funeral will be a celebration and acknowledgement of all that is important to you.



# LEGAL ISSUES

As you come to terms with your advanced melanoma diagnosis, treatment and living with melanoma, legal issues may be the last thing on your mind. However, your legal rights and responsibilities and those of the people around you are another thing you should consider.

First, your rights as a patient are protected under the New Zealand Code of Health and Disability Services Consumers' Rights 1996. This act establishes the rights of consumers, and the obligations and duties of providers (that is, your medical and other health care providers) to comply with the Code.

Under The Code (Right 7(5)), every consumer may use an advance directive regarding their treatment. This includes the right to refuse treatment at any point if you so wish. You may choose to set out your wishes regarding medical care in an Advanced Care Plan (see page 41). However, advance directives do not need to be formal written documents, and they can include any treatments, not just life-sustaining treatments.

An advance directive must meet certain criteria, including that you must be competent at the time you make the directive; and any decision to refuse treatment you must make freely, without undue influence, or limiting pressure, from anyone else.

Outside of your rights as a patient and health consumer, the main legal issues you will need to consider are your will and enduring power of attorney.

## Wills

It is important to make a will so that when you die your property, assets and personal effects go to the people you wish to have them. A will ensures that your wishes are carried out after your death; it doesn't just cover how your possessions will be divided up and who will get them, but things like how you would like your funeral to be carried out, how any dependent children will be provided for.

You can write a will at any time. Your will should include the following types of information:

- the name of the the executor of your will;
- whether you want to be buried or cremated, whether you want to donate parts of your body for medical or scientific research, and how you would like your funeral to be carried out;



- the name of the person or people you have appointed as guardians for any dependent children;
- instructions for how you want your money and other assets to be distributed.

To be legally valid, your will needs to be:

- in writing,
- witnessed by two people who are not beneficiaries of the will,
- signed by the witnesses, in your presence, and
- signed by you.

## Enduring Power of Attorney

Enduring Power of Attorney (EPOA) is a power that you assign to someone you trust to make decisions on your behalf if you are in a position in which you are unable to make such decisions.

There are two types of EPOA:

- Property, which covers your money and assets and can come into effect before you lose mental capacity, and you may have more than one EPOA for property.
- Personal care and welfare, which covers your health, accommodation and associated care decisions, and comes into effect only if a medical professional or the Family Court decides you have become 'mentally incapable'. You can only appoint one attorney for your personal care and welfare.



It is important to set up EPOAs sooner rather than later as it needs to be done when you are still mentally capable. An EPOA means only your attorney/s can make decisions about your life and/or your possessions, such as your house, money and belongings.

Your attorney can be anyone you trust to understand and respect your wishes and feelings, and is usually a friend or family/whānau member or a colleague. It is important that your care and welfare EPOA knows what is in your advance care plan, particularly relating to future treatment options.

# FINANCIAL ASSISTANCE

A cancer diagnosis can be financially devastating, especially if you are the main earner and you have to give up work or reduce to part time hours. There are also costs associated with treatment. You may live some distance away from a cancer treatment centre and have to travel long way for each appointment or temporarily live nearer to where you are receiving treatment. The Cancer Society of New Zealand operates accommodation for cancer patients having to travel away from home for treatment.

If you have to travel long way to get to appointments and to receive treatment you may qualify for financial help with that.

If you have to give up work, even if only temporarily, you should make an appointment to see Work and Income to see what financial assistance might be available to you. It is important that you contact them as soon as possible as there may be a stand down period during which you won't receive any benefit.

Your eligibility for assistance will depend on your circumstances, such as whether you have a partner who is earning, or you have any other source of income.

If you have to reduce your hours or stop work for a while, and have a job to go back to, you may be entitled to the Jobseeker Support benefit.

If your cancer prevents you from working for two years or more you may be eligible for the Supported Living Payment. It may also apply if you have a life expectancy of less than two years and can't regularly work 15 hours or more a week.

Even if you are not eligible for a benefit you may be able to get other assistance, such as help with mortgage or rent costs (Accommodation Supplement) and childcare costs (Childcare and/or OSCAR Subsidy). You may also be eligible for help with prescription costs.

Even if you have not previously qualified, you may also now be eligible to get a Community Services Card, which will assist with the costs of your health care.

# RESOURCES

## General Melanoma Information

Melanoma New Zealand	<a href="http://www.melanoma.org.nz">www.melanoma.org.nz</a>
Cancer Society of New Zealand	<a href="http://www.cancernz.org.nz">www.cancernz.org.nz</a>
New Zealand Dermatological Society (DermNet)	<a href="http://www.nzdsi.org/index.aspx">www.nzdsi.org/index.aspx</a>
Melanoma Unit	<a href="http://www.nzmu.co.nz/">www.nzmu.co.nz/</a>

## Support

Melanoma New Zealand	<a href="http://www.melanoma.org.nz">www.melanoma.org.nz</a>
Cancer Society of New Zealand	<a href="http://www.cancernz.org.nz">www.cancernz.org.nz</a>
Northern Cancer Network	<a href="http://www.northerncancernetwork.org.nz">www.northerncancernetwork.org.nz</a>
Midland Cancer Network	<a href="http://www.midlandcancernetwork.org.nz">www.midlandcancernetwork.org.nz</a>
Central Cancer Network	<a href="http://www.centralcancernetwork.org.nz">www.centralcancernetwork.org.nz</a>
Southern Cancer Network	<a href="http://www.sialliance.health.nz/our-priorities/southern-cancer-network">www.sialliance.health.nz/our-priorities/southern-cancer-network</a>

## Melanoma Treatment

Clinical Practice Guidelines for the Management of Melanoma in Australia & NZ  
[www.health.govt.nz/system/files/documents/publications/melanoma-guideline-nov08-v2.pdf](http://www.health.govt.nz/system/files/documents/publications/melanoma-guideline-nov08-v2.pdf)

Standards of Service Provision for Melanoma Patients in New Zealand  
<http://www.health.govt.nz/our-work/diseases-and-conditions/cancer-programme/faster-cancer-treatment-programme/national-tumour-standards>

## Clinical Trials

Australian New Zealand Clinical Trials Registry	<a href="http://www.anzctr.org.au">www.anzctr.org.au</a>
Clinical Trials	<a href="http://clinicaltrials.health.nz">http://clinicaltrials.health.nz</a>
ClinicalTrials.gov	<a href="http://www.clinicaltrials.gov">www.clinicaltrials.gov</a>
Australia and New Zealand Melanoma Trials Group	<a href="http://www.anzmtg.org">www.anzmtg.org</a>
Cancer Trials New Zealand	<a href="http://www.cancertrialsnz.ac.nz">www.cancertrialsnz.ac.nz</a>

## Lymphoedema

Lymphoedema NZ	<a href="http://www.lymphoedemanz.org.nz/">www.lymphoedemanz.org.nz/</a>
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The website of New Zealand lymphoedema therapists, with lots of information on lymphoedema, resources and links, and how to find a therapist.

Cancer Society of New Zealand	<a href="http://www.cancernz.org.nz">www.cancernz.org.nz</a>
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Living with Lymphoedema – a resource written for people with lymphoedema.

## Books

*Coping With Lymphedema* by Joan Swirsky and Diane Sackett Nannery, available on Amazon.com

## Supporting Children

### Skylight

Skylight is a New Zealand not for profit trust that enables children, young people, their family/whānau and friends to navigate through times of trauma, loss and grief.

[www.skylight.org.nz](http://www.skylight.org.nz)

### RipRap

A website especially for teenagers who have a parent with cancer.

[www.riprap.org.uk](http://www.riprap.org.uk)

### Cancer Care

Helping children when a family member has cancer: [www.cancercare.org/publications/22-helping-children\\_when\\_a\\_family\\_member\\_has\\_cancer](http://www.cancercare.org/publications/22-helping-children_when_a_family_member_has_cancer)

[www.cancercare.org](http://www.cancercare.org)

## Financial Assistance

### Work and Income

[www.workandincome.govt.nz/eligibility/lost-job/health-condition.html#null](http://www.workandincome.govt.nz/eligibility/lost-job/health-condition.html#null)

## Health and Wellbeing

### Healthline

0800 611 116 for free, for advice from trained registered nurses

### Gawler Foundation

<https://gawler.org>

### Health Navigator

[www.everybody.co.nz](http://www.everybody.co.nz)

## Advance Care Planning

### Advance Care Planning

[www.advancecareplanning.org.nz](http://www.advancecareplanning.org.nz)

## Hospice

### Hospice New Zealand

[www.hospice.org.nz](http://www.hospice.org.nz)

## Legal Issues

### Public Trust – Wills and EPOAs

[www.publictrust.co.nz](http://www.publictrust.co.nz)

## Community Services

### CanTeen

People aged between 13 and 24 who have been diagnosed with melanoma or any other cancer can contact CanTeen for support. Call 0800 226 8336 or visit the Canteen website.

[www.canteen.org.nz](http://www.canteen.org.nz)

### Look Good, Feel Better

Look Good Feel Better is a free service for women undergoing treatment for any form of cancer. Free makeover workshops are available to restore appearance confidence during and after treatment. Ph 0800 865 432 or visit the Look Good, Feel Better website.

[www.lgfb.co.nz](http://www.lgfb.co.nz)

### Pinc and Steel Cancer Rehabilitation Programme

Offer a range of exercise and physiotherapy programmes, which are designed to help people of all ages recovering from any type of cancer surgery or cancer treatments.

[www.pincandsteel.com](http://www.pincandsteel.com)

## International

### Melanoma Institute Australia

[www.melanoma.org.au](http://www.melanoma.org.au)

### Melanoma Research Foundation

[www.melanoma.org](http://www.melanoma.org)

### Melanoma International Foundation

[www.melanomainternational.org](http://www.melanomainternational.org)

# GLOSSARY

**Adjuvant therapy** Supportive or additional treatment given to kill undetected cancer cells that may remain in the body after surgery, and may include chemotherapy, radiotherapy and new drugs, such as Keytruda or Opdivo.

**Advance Care Planning** Making decisions about the care you would want to receive if you become unable to speak for yourself. It may also include things like Enduring Power of Attorney and funeral plans.

**Advance Directive** Also known as living will, an advance directive is instructions that you provide for your future medical care and treatment in the event that you become you become unable to speak for yourself.

**Alternative therapies** Therapies or treatments that are outside conventional medical practices, also referred to as complementary and alternative (CAM), natural or holistic therapies.

**Anaemia** A condition in which there are fewer blood cells than normal.

**Anaesthetic** A drug that causes numbness or loss of feeling in an area (local), a region (spinal or epidural) or all (general) of the body.

**Analgesia or analgesic** Painkillers; prescription or over the counter drugs.

**Anti-emetic** A drug used to control nausea or vomiting.

**Benign** Not cancer – does not invade nearby tissues or spread to other parts of the body.

**Biological therapy** Treatment that can help the immune system fight disease more effectively. This form of treatment often involves the use of biological response modifiers. Also called immunotherapy or biotherapy.

**Biopsy** The removal of a sample of tissue for examination under a microscope to check for cancer cells.

**Breslow Thickness** The thickness in millimeters between the upper layer of the epidermis and the deepest point of tumour penetration. Breslow thickness is related to the five-year survival rate after surgical removal of the tumour.

**Clinical Nurse Specialist (also melanoma clinical nurse specialist)** A specialist nurse, who provides support to you and your family/whānau and can help to co-ordinate your care.

**Chemotherapy** Treatment with anti-cancer drugs. It may be administered through an IV or orally.

**Clinical trials** Medical research studies conducted with volunteers. Each study is designed to answer scientific questions and to find better ways to prevent or treat cancer.

**Complementary therapies** Treatments or therapies that are used alongside conventional medical treatment and often used by patients

to improve quality of life or to reduce the impact of side-effects from conventional treatment.

**Dermatologist** A doctor who specialises in diagnosing and treating skin problems.

**Enduring Power of Attorney (EPOA/EPA)** A legal authorisation to act on someone else's behalf in legal and financial (property), or medical and well-being (personal care) matters, which can continue in force after the person granting it loses mental capacity. Property EPOA can come into effect at any time, but Personal Care EPOA only after a person is no longer competent to make such medical and well-being decisions for him or herself.

**Haemoglobin** The iron-containing pigment in the red blood cells, which carries oxygen around the body.

**Hospice** A facility providing care for the sick or terminally ill; a philosophy of care aimed helping people with incurable conditions make the most of their lives, including maintain comfort and quality of life.

**Immune system** The body's front line of defence against invading bacterial infections, viruses and allergens. White blood cells (lymphocytes) are stimulated to create antibodies to defend the body against foreign invaders. Lymph nodes are an important part of the immune system and there is good evidence that the immune system acts against cancer cells.

**Infusion** A chemotherapy technique that may be used when melanoma occurs on an arm or leg. The flow of blood to and from the limb is stopped for a while with a tourniquet, and anti-cancer drugs are put directly into the blood of the limb. This allows the patient to receive a high dose of drugs in the area where the melanoma occurred.

**Local therapy** Treatment that affects a tumour and the tissue close to it.

**Lymph** The almost colourless fluid that travels through the lymphatic system and carries cells that help fight infection and disease.

**Lymph nodes** Small, bean-shaped structures along the network of lymphatic vessels. They store special cells that can trap bacteria or cancer cells travelling in lymph. Clusters of lymph nodes are found in the armpits, groin, neck, chest, and abdomen.

**Lymphatic system** The system of structures that move lymph around the body.

**Lymphoedema** A condition in which excess fluid collects in tissue and causes swelling. It may occur in the arm or leg after lymph vessels or lymph nodes in the underarm or groin are removed.

**Malignant** Cancerous; can invade nearby tissue and spread to other parts of the body.

**Melanin** A skin pigment (substance that gives the skin its colour). Dark-skinned people have more melanin than light-skinned people.

**Melanocytes** Cells in the skin that produce and contain the melanin.

**Metastasis** The spread of cancer from one part of the body to another. Cells in the metastatic (second) tumour are like those in the original (primary) tumour. The plural of metastasis is metastases.

**Multidisciplinary care** A team approach by health care practitioners to your cancer care

**Oncologist** A doctor who specialises in treating cancer.

**Palliative care** Treatment given to optimise quality of life, attending to physical, psychosocial, spiritual and cultural needs when the cancer is incurable and treatment is no longer controlling it.

**Pathologist** A doctor who identifies diseases by studying cells and tissues under a microscope.

**Plastic surgeon** A surgeon who specialises in reconstructive, skin or cosmetic surgery.

**Portocath** A small medical device surgically implanted under the skin, and which allows delivery of drugs for people who require frequent IV drug administration such as chemotherapy.

**Prognosis** The probable outcome or course of a disease; the chance of recovery.

**Radiation therapy (also radiotherapy)** Treatment with high-energy rays from x-rays or other sources to kill cancer cells.

**Remission** Disappearance of the signs and symptoms of disease. When this happens the disease is said to be “in remission”. A remission can be temporary or permanent.

**Sentinel Nodes** The first few lymph nodes in the lymphatic system into which a tumour drains and to which tumour cells are most likely to spread.

**Skin graft** Skin that is moved from one part of the body to another.

**Surgical Oncologist** A surgeon trained in the principles of cancer biology, cancer surgery and treatments, and often with a special interest in melanoma or other specific cancers.

**Systemic treatment** Treatment using substances that travel through the bloodstream, reaching and affecting cancer cells all over the body.

**Targeted therapies** A newer generation of cancer drugs that prevent the growth of specific types of cancer cells.

**Tumour** An abnormal mass of tissue.

**Wide Excision** Wide excision is a surgical procedure to remove the tumour with a margin of normal, healthy tissue. This procedure is commonly performed on skin cancers, including melanoma, and in breast cancer surgery, but can be used on any area of the body.

## Index

- Advance directive 44
- Advanced care planning 41-43, 45, 48
- Anxiety 10, 29, 33, 34, 36, 40
- Bereavement care 42
- Biological treatment (see targeted treatment)
- Blood tests 6, 27
- Body image 33, 35
- Bone 3, 9
- Bone scan 9
- Brain 3, 5, 6, 8, 17, 18
- Breslow Thickness 4
- Chemotherapy 14, 16, 17, 19-20, 21, 25, 28
- Clinical nurse specialist 14, 15, 24, 34, 36
- Clinical trials 12, 22-23, 47
- Complementary and alternative therapies (CAM) 25, 28-29, 42
- Coping with diagnosis 30, 32
- Counsellor 33, 34, 36, 40
- CT scans 7-8, 9
- Depression 33, 36-37, 38
- Dermatologist 14
- Diagnosis 1, 5, 6, 10, 11, 12, 30-31, 32-33, 39, 40, 44, 46
- Diet/nutrition 16, 24, 25, 26, 29, 38
- District health board (DHB) 1, 10
- Emotions 32-37
- Employment 39, 46, 48
- Enduring power of attorney 31, 41, 44, 45
- Fatigue 18, 19, 20, 21, 24-25, 35, 36, 39
- Fear 21, 30, 32-34, 36, 40
- Feeling alone 1, 32, 33, 35
- Feeling overwhelmed 32, 33
- Financial assistance 42, 46, 48
- Fine needle aspiration 6
- Guilt 30-31, 32-33, 35, 37
- Health care team 1, 7, 11-12, 14-16, 23, 24, 28, 34, 35, 36, 38, 41, 42
- Hospice 15, 21, 25, 29, 42-43, 48
- Immunotherapy 19
- Isolated limb infusion (ILI) 20
- Legal issues 31, 44-45, 48
- Libido 18, 35
- Liver 3, 5, 6, 7, 8, 17, 19
- Lungs 3, 6, 7, 8, 17, 19
- Lymph node dissection 16-17, 27
- Lymph nodes 3, 4, 5, 6, 7, 8, 16, 18, 27
- Lymphatic system 3, 5, 27
- Lymphoedema 15, 17, 27, 35, 48
- Medicinal cannabis (see Sativex)
- Melanoma New Zealand 1, 10, 28, 38, 47
- Metastases, metastatic melanoma 3, 4, 5, 7, 8, 17, 18, 19, 22, 32, 33
- MRI 8, 9
- Multidisciplinary care team 12, 14, 15, 42
- Nausea 18, 19, 20, 21, 24, 25, 29
- Cancer Society of New Zealand 15, 40, 46, 47
- Oncologist 14, 20, 24, 26
- Pain 18, 20, 21, 24, 25, 27, 29, 41-43
- Palliative care 15, 16, 18, 21, 25, 41, 42
- PET scan 9
- Physical activity 25, 27, 29, 32, 38
- Planning your funeral 42, 43, 44
- Primary tumour 3, 5, 7, 16
- Prognosis 4, 12, 13, 14, 30-31, 32, 34, 36, 39
- Radiation therapists/radiologist/  
radiotherapy 14, 16, 17-18, 19, 21, 25, 27
- Remission 13
- Risks 11, 23
- Sadness 30, 32, 33, 36, 40
- Sativex 21, 25
- Sentinel lymph node biopsy 7
- Side-effects 11, 12, 13, 16, 18-20, 22-23, 24-26, 28-29, 34, 39, 40, 42
- Sleep 24, 29, 33, 36-37, 38
- Staging 3-5
- Stopping treatment 42
- Stress management 36-37
- Support groups/services 1, 10, 13, 15, 33, 34, 35, 38, 40, 47-48
- Surgery 7, 12, 16-17, 21, 27
- Symptoms 4, 6, 7, 13, 16, 17-18, 20, 21, 28-29, 43
- Targeted treatment 14, 16, 17
- Telling family/friends/collagues 30-31, 39
- Test results 10, 12
- Treatment 1, 5, 11-13, 14-21, 22-23, 26, 28-29, 32-33, 39, 41-42, 44, 45, 47
- Ultrasound 6, 7
- Wills 41, 44-45, 48
- Work (see employment)

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# Understanding Advanced Melanoma

More than anything else, we want you to know that you are not alone; that there is help and support for you both through Melanoma New Zealand, your medical team and district health board, and other organisations whose role is to help you and your family through your cancer diagnosis and treatment, and life beyond.

Receiving a diagnosis of melanoma can be frightening. You'll probably have many questions about melanoma and what will happen next. This booklet is designed to answer some of the questions you may have about your diagnosis, treatment, and living with stage III and IV melanoma, including:

- Diagnosis
- What You Should Ask
- Treatment Options
- Clinical Trials
- Complementary Therapies
- Coping with Side-Effects
- Lymphoedema
- Talking to Your Family
- Your Work Life
- Financial Assistance
- Advance Care Plans



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