Neuroendocrine tumours

Your guide to best cancer care

About this guide

Being told you have a neuroendocrine tumour (NET) or could have a NET can be overwhelming. A lot can happen quickly, and you might have lots of questions. This resource can help to guide you and your family and friends through this experience.

Information and support

Cancer Council: For information and support, call Cancer Council on **13 11 20** to talk to an experienced health professional or visit **www.cancer.org.au**.

NeuroEndocrine Cancer Australia: For information or to talk to a cancer nurse, call **1300 287 363** or visit **www.neuroendocrine.org.au**.

Translating and Interpreting Service (TIS): If you need a translator, call TIS on **13 14 50** or visit **www.tisnational.gov.au**.

Initial tests and referral

Symptoms

Your general practitioner (GP) should do a check-up to see if they can find what is making you unwell. They will ask you about any symptoms you might be having such as abdominal pain, bloating, flushing, feeling tired, diarrhoea (even while not eating), wheezing, rapid heartbeat and unexplained weight loss.

Initial tests you may have

Physical check. Your GP will check your stomach and listen to your heart and lungs.

Blood test. A sample of your blood will be taken. Tests will include full blood count, liver function and tumour markers.

Ultrasound. Sound waves are used to make a detailed picture of the area being investigated.

Computed tomography (CT) scan. Computers and x-rays are used to make a detailed picture of the area being investigated.

Chest x-ray. An x-ray takes a picture of the chest.

You may have additional tests to these.

Referrals

If your GP has concerns, you will be referred to a medical oncologist, gastroenterologist or respiratory physician at a public hospital or in private practice for more tests. Medical oncologists, gastroenterologists and respiratory physicians are specialists who are highly trained in treating NETs.

You can bring a family member or friend with you to your appointments.

Timeframes

You should be referred to an appropriate specialist **within one week** of completing initial investigations.

If you haven't been referred within this time, follow up with your GP.

Questions you might want to ask

- Can I choose whether I go to a public hospital or private practice?
- Can I choose the specialist I see?
- How much will appointments cost me?

Diagnosis, grading and staging

Depending on the site of investigation, you may have one or more of the following tests to see what is causing your symptoms and if you have a NET. This process of working out if you have a medical problem is called making a **diagnosis**.

Colonoscopy. A small camera on a tube is put into your bottom to check your large bowel. Your specialist or GP will tell you what you need to do to prepare for this test. You will have sedative medicine or a general anaesthetic (you will be put to sleep) so you cannot feel it.

Endoscopy. A small camera is inserted down your throat and into your digestive tract. You will have sedative medicine or a general anaesthetic (you will be put to sleep) so you cannot feel it.

Bronchoscopy. A small camera is inserted in your nose or mouth down to your airways. You will have sedative medicine or a general anaesthetic (you will be put to sleep) so you cannot feel it.

Blood tests. Further samples of blood are taken to check specific biomarkers and hormones depending on the symptoms you are experiencing.

If the procedure(s) shows cancer, the specialist will do more tests to see exactly where the cancer is in your body, and if it has spread. This is called **staging**. Staging helps to work out the best treatment for you.

You might have one test or a mix of tests:

Biopsy. A sample of tissue is taken to check under the microscope. This will give the **grading** (type of tissue) of the tumour. Grading also helps to work out the best treatment for you.

Genetic testing. Some subtypes of cancer suggest an underlying inherited susceptibility.

Your specialist might send you for a **CT scan.**

Magnetic resonance imaging (MRI). A scan where a powerful magnet and radio waves are used to make a detailed picture of the body.

Positron emission tomography/ computed tomography (PET/CT) - Ga68 and/or FDG PET. A small amount of radioactive material is injected and your whole body is scanned to show where the cancer is.

Timeframes

Results should be available **within two weeks** from when you have the tests.

Questions you might want to ask

- What is a neuroendocrine tumour?
- What tests will I have?
- How much will tests/appointments cost?
- Where should I be treated? Do I have a choice?
- What grade is my cancer?
- What stage is my cancer?
- Has my diagnosis been discussed at a multidisciplinary meeting?
- What support services are available to me?

Treatment

There are several ways to treat NETs. Your specialist will talk to you about your treatment options.

You will be treated by a team of experts, and you may need more than one treatment type to get the best results. The team will work with you and your family or carer to plan your treatment.

You might have one treatment or a mix of treatments:

Surgery is where the cancer is cut out. Some tumours can be completely removed. In other cases only some of the tumour can be removed, which can reduce symptoms.

Active surveillance / watch and wait may be suitable for some people who have no symptoms or problems.

Radiation therapy uses x-rays to kill cancer cells and stop the cancer growing. It is used to treat metastases such as in the bone.

Peptide receptor radionuclide therapy (PRRT) is a radiopharmaceutical treatment used to control symptoms and growth of the tumour.

Somatostatin analogues (SSAs) are injections given monthly to reduce symptoms or control growth of the tumour. It is a common treatment for people with NETs.

Chemotherapy uses drugs to kill cancer cells and stop the cancer growing. Chemotherapy might be used before or after surgery. Chemotherapy might be used alone, or with radiation therapy.

Targeted therapy uses drugs to attack specific features of cancer cells and stop the cancer growing. It may be used to treat some advanced NETs.

Liver-directed therapy uses heat or chemicals to kill the cancer. It is used to directly treat cancer that has spread to the liver. Treatment types include radiation, chemotherapy and ablation.

Immunotherapy is a type of cancer treatment that helps the body's immune system to fight the cancer. It is currently being studied in NETs.

For more information visit

www.cancer.org.au/cancer-information/treatment

www.neuroendocrine.org.au/information-booklets.

Supportive care (treatment or services that support you through a cancer experience) are also available.

Timeframes

Treatment should start **within four weeks** of agreeing to your treatment plan.

You can ask your GP for a referral to another specialist for a second opinion.

Clinical trials

You may be offered to take part in a clinical trial. Clinical trials are used to test whether new treatments are safe and work better than current treatments. Many people with cancer are now living longer, with a better quality of life, because of clinical trials.

For more information visit **www.australiancancertrials.gov.au**.

Complementary therapies

Speak to your healthcare team about any complementary therapies (including dietary supplements like vitamins) you use or would like to use. Something as common as vitamins might not work well with your treatment.

Questions you might want to ask

- What treatment do you recommend?
- Where will I have to go to have treatment?
- What will treatment cost and how much of the cost will I have to pay myself?
- What activities/exercise will help me during and after treatment?
- Can I still work?
- How will the treatment affect my day-to-day life?
- Who are the people in my team and who is my main contact person?
- What side effects could I have from treatment?
- Who do I contact if I am feeling unwell or have any questions?
- Will treatment affect my ability to have a child?

Decisions about cost

You may have to pay for some appointments, tests, medications, accommodation, travel or parking.

Speak with your GP, specialist or private health insurer (if you have one) to understand what is covered and what your out-of-pocket costs may be.

If you have concerns about costs talk to your healthcare team or a social worker about:

- being bulk-billed or being treated in the public system
- help with accommodation during treatment
- the possible financial impact of your treatment.

You can call Cancer Council on **13 11 20** to speak to a health professional about financial support.

For more information about costs, visit **www.cancer.org.au/support-and-services/practical-and-financial-assistance** and **www.cancer.org.au/support-and-services/practical-and-financial-assistance/what-will-i-have-to-pay-for-treatment**.

Recovery

Cancer treatment can cause physical and emotional changes.

Follow-up care plan

Your healthcare team will work with you to make a plan for you and your GP. This plan will explain:

- who your main contact person is after treatment
- how often you should have check-ups and what tests this will include
- understanding and dealing with side effects of treatment
- how to get help quickly if you think the cancer has returned or is worse.

Many people worry that the cancer will return. Your specialist and healthcare team will talk with you about your needs and can refer you to other health professionals and community support services.

Other information you may get:

- signs and symptoms to look out for if the cancer returns
- late effects of treatment and the specialists you may need to see
- how to make healthy lifestyle choices to give you the best chance of recovery and staying well.

For more information visit

www.cancer.org.au/cancer-information/after-a-diagnosis/after-cancer-treatment.

www.neuroendocrine.org.au/treatment-wellness-care-plan/.

Questions you might want to ask

- Who should I contact if I am feeling unwell?
- What can I do to be as healthy as possible?
- Where can I get more help?

Living with recurrent or advanced cancer

If cancer returns

Sometimes NETs can come back during or after treatment. It can come back in the same place or can appear somewhere different in your body.

If cancer returns, you may be referred to the specialist or the hospital where you were first treated, or to a different specialist.

Treatment will depend on how far the cancer has spread, how fast-growing it might be and the symptoms you are experiencing.

Questions you might want to ask

- Where is the cancer and has it spread?
- What are my treatment options?
- What are the chances that the treatment will work this time?
- Is there a clinical trial available?
- Where else can I get support?

Advance care planning

Your GP or healthcare team may talk with you, your family and carer about your future treatment and medical needs.

Advance care directive

Sometimes known as a living will, an advance care directive is a legally binding document that you prepare to let your family and healthcare team know about the treatment and care you might want or not want in case you become too unwell to make those decisions yourself. For more information visit **www.advancecareplanning.org.au**.

Palliative care

Your specialist may refer you to palliative care services, but this doesn't always mean end-of-life care. Today people can be referred to these services much earlier if they're living with cancer or if their cancer returns. Palliative care can help you to live as well as you can including managing pain and symptoms. This care may be at home, in a hospital or at another location you choose.

Speak to your GP or specialist or visit **www.palliativecare.org.au**.

Making treatment decisions

You may decide not to have treatment at all, or to only have some treatment to reduce pain and discomfort. You may want to discuss your decision with your healthcare team, GP, family and carer.

For more information visit **www.cancer.org.au/cancer-information/treatment/advanced-cancer-treatment**.

Questions you might want to ask

- What can you do to reduce my symptoms?
- What extra support can I get if my family and friends care for me at home?
- Can you help me to talk to my family about what is happening?
- What support is available for my family or carer?
- Can I be referred to a community support service?

Published in June 2022.
This resource is based on information from the optimal care pathway for people with neuroendocrine tumours (1st edition), available at www.cancer.org.au/OCP.

Australian Government
Cancer Australia
Cancer Council