AYA CANCER NETWORK AOTEAROA
ADVANCING CANCER CARE FOR 12-24 YEAR OLDS

Appendix Neuroendocrine Tumours in Adolescents & Young Adults (AYAs)

If you've recently been told that a neuroendocrine tumour (NET) was found in your appendix, this has likely come as a surprise – especially if you thought you were just being treated for appendicitis.

The good news is that appendiceal NETs are usually found early and have an excellent prognosis. For most people, especially when the tumour is small and completely removed, the risk of recurrence (it returning) is very low. Many people do not need any further treatment.

But hearing the words 'cancer' or 'tumour' can still come as a shock and bring up a range of emotions and questions. This is completely understandable.

The AYA Cancer Network Aotearoa has put together this guide to explain what might happen next, what to be aware of, and where to go for more information and support.

What is an appendiceal NET?

An appendiceal neuroendocrine tumour (NET) is a rare type of cancer that starts in specialised hormone-producing cells in the appendix. Although it is the most common tumour found in the appendix, it is still uncommon overall.

Most appendiceal NETs are small, slow-growing, and found early.

NETs can develop in different parts of the body, but this information sheet is about NETs that start in the appendix.

Why did I develop an appendiceal NET?

It's natural to wonder why this has happened.

The exact cause of appendiceal NETs is not well understood. In most cases, they happen randomly. There is nothing you did to cause this.

Many appendiceal NETs are very small and may not cause symptoms, so they are often found **incidentally** (which means by chance) when the appendix is removed and tested.

How was my appendiceal neuroendocrine tumour found?

For most young people, an appendiceal NET is found after surgery for appendicitis.

When your appendix is removed, it is routinely sent to a laboratory for testing. This is called a pathology test. A specialist doctor (a pathologist) examines the tissue under a microscope to check for anything unexpected.

In many cases, this is how an appendiceal NET is discovered. You may not have had any symptoms from the tumour itself, and it may not have been visible during surgery.

What did the pathology show?

Your healthcare team will explain what your pathology results show and what they mean for you.

These results include details such as the size of the tumour, where it was located in the appendix, and whether it was completely removed.

Because NETs are rare, your care may be discussed at a multidisciplinary team (MDT/MDM) meeting. You can ask your healthcare team whether your results have been reviewed by a NET specialist team if you would like reassurance.

Tip

It's always okay to ask your healthcare team questions if they use any medical terms or explanations that you are unsure of.

What treatment will I need?

For most people, the only treatment needed is an appendicectomy (removal of the appendix).

The appendix is not essential, and removing it is unlikely to cause any ongoing health problems. It won't affect what you can eat or drink.

When the tumour is small and completely removed, the risk of recurrence (it coming back) is very low and no further treatment is usually needed. This can feel surprising, but many appendiceal NETs are slow growing and are often completely removed with the appendix.

Key message: Most appendiceal NETs in young people are small, grow slowly and stay within the appendix. This means they usually have an excellent prognosis.

Helpful support and information

Neuroendocrine Cancer New Zealand: Provides Information and support for people with NETs. Visit **www.neuroendocrinecancer.org.nz** If you have questions or would like support from a specialist nurse, you can email: **support@neuroendocrinecancer.org.nz**

Cancer Society: Provides a range of emotional wellbeing resources to those aged over 18. Resources include free counselling sessions, webinars and online talks, and online support groups. Visit **www.cancer.org.nz** or phone **0800 226 237**.

Canteen Aotearoa: Offers online and face-to-face support services for young people aged 12–24 who are affected by cancer. They provide free individual support sessions and therapy, and organise regular peer support events. Visit **www.canteen.org.nz** or phone **0800 2268 336.**

AYA Cancer Network Aotearoa: Our website offers Information and resources for Adolescents and Young Adults with cancer, including guides and links to help you find support services across Aotearoa. Visit **www.ayacancernetwork.org.nz/**

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What will happen next?

Most people recover well after an appendicectomy and can return to their usual activities after a short recovery period. Your healthcare team can guide you on when it is safe to return to things like sport, study, or work.

Many people will not need ongoing follow-up or treatment after their appendix has been removed. If any further treatment is recommended, your team will explain why this is needed and what it involves.

What do I talk about during appointments?

Appointments are your opportunity to understand your results and feel more confident about your plan. It can help to write down any questions you have beforehand.

You might want to ask:

- What did my pathology results show?
- How big was the tumour?
- Was it completely removed?
- Do I need any further treatment or follow-up?
- Has my case been reviewed by a specialist team?
- What symptoms should I look out for?
- Who can I contact if I have questions or concerns?

Your healthcare team will let you know if there are any symptoms to look out for, but for most appendiceal NETs in young people, the risk of problems is very low.

You are welcome to bring a support person with you to your appointment. If anything is unclear, it is always okay to ask for it to be explained again in a different way.

Questions I want to ask

Who can I talk to?

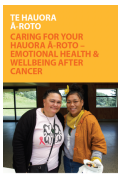
Being told you have cancer, even one with a very good prognosis, can still have an emotional impact. Some people feel worried or overwhelmed, while others don't feel very concerned at all. Both are completely normal.

Support is available if you feel you need it. You may find it helpful to start by talking to a trusted friend or family member. Sharing how you're feeling can help them understand how to support you.

If you would like additional support, you can also talk to your GP or a member of your healthcare team. They can help connect you with further support if needed, such as a trained counsellor or psychologist, either through your healthcare team or organisations like Canteen or the Cancer Society.

'Talking about your experience with loved ones and letting them know how you feel is a great way of dealing with your feelings.'
– Young person with cancer

Check out our publication 'Caring for Your Emotional Health and Wellbeing After Cancer'. It provides advice on managing any fears and worries you might have.



This resource was developed for young people who have had cancer treatment, but some of the information and tools (such as relaxation exercises and ways to manage stress) may still be helpful.

You can find this (and many other resources) at **www.ayacancernetwork.org.nz**

Where can I learn more?



For more general information about neuroendocrine tumours (NETs), you can download the Neuroendocrine Cancer New Zealand Patient Guide by visiting www.neuroendocrinecancer.org.nz

Please note that this guide covers all types of NETs, including more complex cases, so some of the information may not be relevant to appendix NETs.

Checklist	Yes	No
I understand what an appendiceal NET is	○	○
I've had the opportunity to ask any questions that I have	○	○
I understand what my pathology results showed	○	○
I know the size of my tumour and whether it was completely removed	○	○
I understand what follow-up or treatment (if any) I need	○	○
I know who to contact if I have any questions or concerns	○	○
I am aware of the resources and support services available to me	○	○