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

Non-malignant brain and spinal cord tumours in Adolescents & Young Adults (AYAs)

If you have recently been told that you have a tumour in your brain or spine, even one that is non-malignant (not cancer), this can still come as a real shock.

You may have been given a diagnosis with a long or unfamiliar name, such as juvenile pilocytic astrocytoma, craniopharyngioma, pituitary adenoma, or vestibular schwannoma. Many young people have never heard these words before, and it is very normal to feel confused, scared, or unsure what it all means.

The good news is that many of these central nervous system (CNS) tumours are slow-growing and may not need intensive treatment. Some are removed with surgery. Others are monitored over time with scans and clinic appointments.

Even so, it is completely normal to feel uncertain, worried, or unsure what this means for you.

The AYA Cancer Network Aotearoa has put together this guide to explain what might happen next, what some common words mean, and where to go for information and support.

What is a non-malignant CNS tumour?

A non-malignant CNS tumour is a growth in the brain or spinal cord that is not cancer. You might also hear these tumours described as benign or low-grade. While these terms all mean that the tumour is not cancer, but they don't always mean it is harmless.

Because the brain and spinal cord control how your body works, even a non-malignant tumour can cause symptoms depending on where it is located.

What symptoms might it cause?

Symptoms vary depending on where the tumour is in the brain or spinal cord. Some people may have symptoms such as headaches, changes in vision, seizures, or difficulties with balance or thinking. Others may have very few symptoms, and the tumour may have been an incidental finding (found during tests for something else).

Your healthcare team will explain how your specific tumour may affect you.

How is it diagnosed?

Non-malignant CNS tumours are usually diagnosed using imaging scans such as an MRI or CT scan.

Sometimes, a sample of the tumour (biopsy) is taken or the tumour is removed during surgery and examined in more detail. This helps your healthcare team understand the exact type of tumour and plan your care.

It's natural to wonder why this has happened. In most cases, the exact cause of non-malignant CNS tumours is not known. They usually develop by chance, and there is nothing you did to cause this.

What treatment will I need?

For many people, treatment may include surgery to remove all or part of the tumour. Other treatments, such as radiotherapy, may sometimes be recommended.

For some people, treatment may not be needed. Instead, the tumour may be monitored with regular scans. This is sometimes called "watch and wait" or "active monitoring".

This can feel surprising, but for tumours that are slow growing or not causing symptoms, monitoring may be the safest and most appropriate approach. Some tumours may never need treatment.

Your care plan will be tailored to you, and your healthcare team will explain what is recommended and why.

What happens next?

After your diagnosis or treatment, you may have follow-up appointments to monitor your recovery and keep an eye on the tumour.

Your follow-up plan will depend on your specific tumour and situation, and your specialist team will guide you on what to expect.

This may include regular scans and check-ups.

Waiting for scan results can sometimes feel uncertain, and some people may find this stressful. If this is the case for you, it can help to talk to someone you trust or a member of your care team.

Tip

It's important to attend any follow-up appointments and scans. If a time doesn't suit because of school, work, or other commitments, let your healthcare team know — they may be able to offer an alternative.

Helpful support and information

Brain Tumour Support NZ: Provide nformation and support for people with brain tumours and their whānau, including support kits, online support groups, events, advocacy, practical advice and patient guides.. Visit **www.braintumoursupport.org.nz** or phone hone **027 292 3337.**

Canteen Aotearoa: Offer a range of online and face-to-face support services for young people aged 12 – 24 who are affected by cancer. This support extends to AYAs with non-malignant CNS tumours. They provide free individual support sessions 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 can I expect as I recover?

Recovery may take time, depending on your treatment and how the tumour has affected you. Give yourself time to recover, both physically and emotionally.

Most people are able to return to their usual activities over time, although things may look a bit different at first.

You may need some support when returning to school, study, or work. This could include flexible hours if you are feeling fatigued, time off for appointments, or temporary adjustments while you recover. Your care team can help guide these conversations if needed.

You may also have questions about things like driving, drinking alcohol, or returning to sport. Your care team can give advice on what is safe for you.

Tip ***It's okay if your energy levels or concentration aren't back to where they were straight away – rest, sleep, and gradually building up your activity can help.***

What do I talk about during a follow-up appointment?

Appointments are your opportunity to understand your diagnosis and feel confident about your plan.

It's important to tell your care team about any physical or emotional challenges you're experiencing. This is your chance to talk about any symptoms or concerns and ask questions.

You might want to ask questions such as:

- What type of tumour do I have?
- What did my scan or test results show?
- What is the plan for my treatment or monitoring?
- How often will I need scans or follow-up?
- Who will be responsible for my follow-up care, and how will I be contacted about appointments or results?
- What symptoms should I look out for?
- How might this affect my daily life (e.g. study, work, sport, or driving)?
- Who can I contact if I have questions or concerns?

It can be helpful to write down your questions and bring a support person with you.

Tip ***It's always OK to ask your care team questions if they use any medical terms or explanations that you are unsure of.***

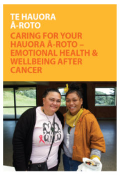
Other questions I want to ask

Who can I talk to?

Being told you have a tumour in your brain or spinal cord can feel overwhelming. Some people feel worried or anxious, while others don't feel very concerned – both are completely normal.

Support is available if you need it. Try talking to a trusted friend or family member. Sharing how you're feeling can help them understand how to support you. Or you can seek support from a trained counsellor or psychologist either through your healthcare team or an organisation such as Canteen .

> *'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 brain tumour-specific information and support in New Zealand, Brain Tumour Support NZ provides a range of patient resources, including there patient guide: Living Well With a Brain Tumour. This guide covers topics such as support services, driving, returning to work, counselling, practical questions to ask your healthcare team, and adjusting to life after diagnosis. **www.braintumoursupport.org.nz**

Checklist	Yes	No
I understand what a non-malignant CNS tumour is and the type of tumour I have	○	○
I understand what treatment, follow-up or scans (if any) I need	○	○
I know who will be responsible for my follow-up care and how I'll hear about appointments or results	○	○
I know what symptoms I should look out for	○	○
I understand what to expect as I recover and how to get support if I need it	○	○
I know who to contact if I have questions or concerns	○	○
I know where to go for more information and support	○	○

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AYA Adolescent and Young Adult Cancer Services