



## Section Seven: Living well with a brain tumour

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Te noho ora me te puku roro

### Key points:

- Finding ways to focus positively on your body – such as eating well, starting a new exercise programme, and making positive lifestyle changes – can help you live well with a brain tumour.
- If possible, try to avoid going back to work too soon after treatment.
- A counsellor can help you to talk about your feelings on the impacts a cancer diagnosis can have.
- Hospitals throughout New Zealand have trained health workers available to support your spiritual, cultural, and advocacy needs.
- Talk to your GP or whānau doctor, or your local Cancer Society, about the support services available for you and your family.
- If you are caring for someone with a brain tumour, it is important to get some support for yourself. Talk to your GP or whānau doctor or phone 0800 CANCER to talk to our information nurses about coping strategies.

## Ngā kōrero matua:

- Rapua ngā huarahi ki te arotau pai i tō tinana - pērā ki te kai pai, te tīmata i tētahi hōtaka korikori hou, me te whakamahi panoni pai ki tō toioranga - tērā ka āwhina i a koe ki te noho ora me te puku roro.
- Mēnā ka taea, kua noa iho e tere hoki ki te mahi whai muri i ō maimoatanga.
- Tērā pea mā tētahi kaitautāwhi koe e āwhina ki te kōrero mō ōu kāre ā-roto e pā ana ki ngā papātanga ka puta nā runga i tētahi whakataua kua pā te matepukupuku.
- Kua whai kaimahi ngā hōhipera huri noa i te motu, i ngā kaimahi hauora kua whakangungutia ki te tautoko ōu hiahiatanga wairua, hiahiatanga ahurea, hiahiatanga whaitaua.
- Kōrero ki tō GP, tō rata ā-whānau, tō Kāhui Matepukupuku ā-rohe rānei mō ngā ratonga tautoko e wātea ana mōu me tō whānau.
- Mehemea kei te tiaki koe i tētahi tangata kua pāngia ki te puku roro, he mea nui kia whai tautoko koe mōu ake. Kōrero ki tō GP, ki tō rata ā-whānau, me waea rānei ki: 0800 CANCER ki te kōrero ki ā mātou tapuhi mōhiohio e pā ana ki ngā rautaki whakapakari.

## Adjusting to change

You may have many adjustments to make, such as not driving, changing the work you do, or giving up work. You may have to hand over tasks you used to do easily to others at work or within your whānau.

Finding ways to focus positively on your body — such as eating well, starting a new exercise programme like yoga, and making positive lifestyle changes — can help you live well with a brain tumour.



You can find more information on living well with cancer on our website: [cancer.org.nz/living-with-cancer](https://cancer.org.nz/living-with-cancer)

## Keeping active

Keeping active will help you maintain a healthy weight and reduce stress and tiredness. It will also help to keep your bones strong and your heart healthy.

It is important to start any new activity slowly and build up gradually. It can be hard to exercise after treatment for a brain tumour, especially if the tumour has affected your movement, balance, or eyesight. However, exercise can give you many benefits. The most important thing is to find what works best for you.

Maybe you could try exercising in a few short sessions throughout the day rather than a long single session.

Walking is usually easy to build into your daily routine, or you may choose other activities like yoga or tai chi, which can help rebuild balance, muscle, and bone strength.



For more information on keeping active, see the Cancer Society's *Keeping Active with Cancer* booklet, available on our website: [cancer.org.nz/cancer/living-with-cancer/being-active](https://cancer.org.nz/cancer/living-with-cancer/being-active)

## Returning to work

Depending on the type of tumour you have, and any ongoing effects you are experiencing, you may find it hard to return to work after treatment. If possible, postpone going back to work too soon. Or, if you need to go back earlier than you would like, consider speaking to your employer about the possibility of making some changes to your work schedule. You might be able to work reduced hours, take regular short breaks, or have lighter duties.



You can find more information on returning to work on our website: [www.cancer.org.nz/cancer/living-with-cancer/life-after-cancer-treatment/working-after-your-treatment-is-over](https://www.cancer.org.nz/cancer/living-with-cancer/life-after-cancer-treatment/working-after-your-treatment-is-over)

If your job involves using machinery, you may not be able to return to this type of work. We recommend that you discuss this with your treatment team if you think it might apply to you.

Talk to your doctor about services that can assist you with returning to work, such as a referral to a social worker or occupational therapist.



There are employment services that specialise in helping people with health needs or disabilities to find work. Examples are Workbridge ([www.workbridge.co.nz](https://www.workbridge.co.nz)) and ChoicesNZ ([www.choicesnz.org.nz](https://www.choicesnz.org.nz)).

## Financial and legal support

### Financial support – benefits and entitlements

If you are unable to work for a period of time because of the effects of a brain tumour, you and/or your carer may be entitled to receive income support from the Ministry of Social Development – Work and Income.

Depending on your situation, financial help may be available. Talk to a social worker, Work and Income, or Senior Services if you are 65 and over, to find out about the types of support you may be able to receive.



You can find more information on returning to work on financial support on our website: [cancer.org.nz/supporting-you/financial-impacts-of-cancer/financial-assistance-and-benefits](https://cancer.org.nz/supporting-you/financial-impacts-of-cancer/financial-assistance-and-benefits)



The Cancer Society has partnered with Sorted NZ to produce a life guide to help navigate finances during a difficult time. The guide is available here: <https://sorted.org.nz/seriousdiagnosis>

## Talking to your bank

If you have a mortgage or other financial commitments, talk to your bank as soon as possible about how they can support you if you are unable to work for a period of time.



You can visit these pages for more information:

- Applying for KiwiSaver hardship withdrawal: <https://sorted.org.nz/must-reads/applying-for-kiwisaver-hardship/>
- Cancer Society/Sorted NZ financial and legal guide: <https://sorted.org.nz/seriousdiagnosis>

## Personal insurance benefits

It is also a good idea to check your personal insurance policies, as you may be eligible for an early payment. Speak to your insurance agent to find out if you are covered.

## Power of attorney

A power of attorney is a legal document giving one person the power to act for another person. There are two types of power of attorney.

- An Ordinary Power of Attorney
- An Enduring Power of Attorney (EPA)

It is a good idea to have your advance care planning (see page 34) done before you choose who you will give your powers of attorney to. A person cannot act on your behalf if they do not know what your wishes are. The person (or people) you choose should be someone you trust, a member of your whānau, or a friend.

Ordinary Power of Attorney	Enduring Power of Attorney
This is used when you are still able to manage your own affairs.	There are two types of EPA. <ul style="list-style-type: none"> <li>• Property.</li> <li>• Personal care and welfare.</li> </ul> You must set them up while you are able to manage your own affairs.
The person you choose to act on your behalf has the power to act on specific issues only (such as managing your bank account while you are overseas).	<b>Property</b> - authority can start immediately. You can nominate more than one person to manage your property.
You can have one or more people acting on your behalf	<b>Personal care and welfare</b> - the person you nominate can only act on your behalf when you are no longer able to make decisions for yourself. You can only nominate one person for personal care and welfare.



For more information, visit these websites.

- Community Law ([www.communitylaw.org.nz](http://www.communitylaw.org.nz))
- Citizens Advice Bureau (<https://www.cab.org.nz/article/BK00001276>)

## Finding support

For some people, meeting others who are in similar situations can help decrease feelings of anxiety, isolation, or fear. Support groups and online forums offer you the opportunity to share your experiences and learn different ways of dealing with problems.



The Cancer Society offers support groups that you may find helpful.

You can phone the Cancer Information Helpline (0800 CANCER 226 237) for further information.

Brain Tumour Support New Zealand has a service called Support Friends: [www.braintumoursupport.org.nz/support-friends](http://www.braintumoursupport.org.nz/support-friends)

Check out the online booklet Behaviour and Personality Change for information and coping tips: <https://brainstrust.org.uk/wp-content/uploads/2020/01/bpc-resource.pdf>

## Counselling

A counsellor can help you to talk about your thoughts and feelings after a diagnosis of a brain tumour. Counselling can be very useful to help you and your whānau understand feelings and develop coping strategies. To find a counsellor, talk to your GP or whānau doctor, your local Cancer Society, or your treatment team.



You can find more information on counselling on our website: [cancer.org.nz/emotions-and-cancer](https://cancer.org.nz/emotions-and-cancer)

## Cultural and spiritual support

Hospitals throughout Aotearoa New Zealand have trained health workers available to support your spiritual, cultural, and advocacy needs. They may include Māori and Pacific health workers who will work with you and your whānau.

Hospital chaplains are available to offer support through prayer and quiet reflection. Community-based health workers at your local marae and Pacific health services may also be good sources of support.



You can find more information on cultural and spiritual support on our website: [cancer.org.nz/spirituality-and-cancer](https://cancer.org.nz/spirituality-and-cancer)

## How whānau can help

As a friend or whānau member of someone diagnosed with a brain tumour, you are learning to cope with your own feelings and emotions. You may want to help but not know what to do. Here are some suggestions that may be useful.

- Learn about brain tumours and their treatment. This will help you understand what the person you are supporting is coping with.
- Be thoughtful about offering advice. Listening while they talk or just being there with them are good ways to show your care.
- Talk about your feelings together and be honest about what worries you.
- Offer to go to appointments with them. You can be there for support, to take notes or, when appropriate, to take part in the discussions.
- Respect that your whānau member or friend may want to talk to their treatment team alone.



The Cancer Society offers a range of resources to support you. For more information on how whānau can help, see the Cancer Society's Supporting Someone with Cancer booklet, available on our website: [cancer.org.nz/supporting-someone-with-cancer](https://cancer.org.nz/supporting-someone-with-cancer)

We also have an online tool – Support Crew – to help you coordinate offers of help such as meals, childcare, and cleaning. You can also use it as a secure online channel to send updates to whānau members and friends. This is free to use.



For more information: [www.supportcrew.co.nz](http://www.supportcrew.co.nz)

## Caring for someone with a brain tumour

Supporting or caring for someone with a brain tumour can be challenging and tiring, and you may have to take on different roles within your whānau that are new to you. There are community organisations and services that can support you and your whānau. You could:

- try to get a good understanding of support services you can access for help. Local hospitals and hospices across New Zealand offer different services. Your GP or whānau doctor, practice nurse, or local Cancer Society can help guide you.
- check what extra services are available in your area, such as help with driving to treatment and medical appointments, online shopping (delivered or click and collect), gardening, and childcare.
- keep a ‘to do’ list, such as for lawn mowing, shopping, and cleaning. That way, when others offer help, you already have a list of things they could do. Check out the Support Crew service or ask a friend to do this for you.



For more information: [www.supportcrew.co.nz](http://www.supportcrew.co.nz)

- suggest things that friends can do to give you a break, such as a coffee date, seeing a movie, going for a walk, or simply spending time together.



Find out how others manage in this situation – talk to other supporters, contact Carers New Zealand ([www.carers.net.nz](http://www.carers.net.nz)), Cancer Connect and Cancer Chat (<https://www.cancer.org.nz/supporting-you/how-we-can-help/connecting-with-people-with-similar-cancer-experiences>), and Brain Tumour Support NZ Support Friends ([www.braintumoursupport.org.nz/support-friends](http://www.braintumoursupport.org.nz/support-friends))



Check out the online booklet *Behaviour and Personality Change* for information and coping tips: [www.brainstrust.org.uk/wp-content/uploads/2020/01/bpc-resource.pdf](http://www.brainstrust.org.uk/wp-content/uploads/2020/01/bpc-resource.pdf)

- get some support for yourself. Counselling can be very useful to help you understand your feelings and develop coping strategies.
- talk to your GP or whānau doctor if you are feeling overwhelmed – it is important not to forget about your own health needs. Keep up your usual health checks, screening programmes, and vaccinations.



Read *A Guide for Carers* ([www.msd.govt.nz/documents/what-we-can-do/community/carers/a-guide-for-carers-spreads.pdf](http://www.msd.govt.nz/documents/what-we-can-do/community/carers/a-guide-for-carers-spreads.pdf)). It has some good information on the help available for people who care for and support whānau with health conditions.

## Taking a break

If you need to take a break from caring, talk to your GP or whānau doctor about respite care.

If you are eligible, they can refer you to a Needs Assessment and Service Coordination (NASC) service. The NASC service will help you apply for funding for respite care and find the respite options that will work best for you.



You can find more information on respite care on the Ministry of Health website: [www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/respite/respite-supports-and-services](http://www.health.govt.nz/your-health/services-and-support/disability-services/types-disability-support/respite/respite-supports-and-services)

## Questions you may wish to ask

When you hear you have a brain tumour, you and your whānau may have many questions. Here is a list of questions you may want to ask to help you make the most of your time with your doctor.

**Let your doctor know if there are things you do not want to be told.**

- What type of brain tumour do I have?
- What grade is it?
- What scans do I need?
- What treatment do you advise for my brain tumour and why?
- Are there any private treatments available that you would advise for my cancer, and why?
- Are there other treatment choices for me?
- Are there any clinical trials that I could be eligible for?
- What are the risks and possible side effects of each treatment?
- Will I have to stay in hospital, or will I be treated as an outpatient?
- How long will the treatment take?
- How much will it affect what I can do?
- How much will the treatment cost?
- If I need further treatment, what will it be like and when will it begin?
- How often will my check-ups be and what will they involve?
- Are there any problems I should watch out for?
- If I choose not to have treatment either now or in the future, what services are available to help me?
- When can I return to work?
- When can I drive again?
- Will the treatment affect my sexual relationships?
- Is my cancer hereditary (passed on by my parents)?
- Is the treatment attempting to cure the brain tumour or not?
- What is my prognosis (future outlook)?
- I would like to have a second opinion. Can you refer me to someone else?

**If there are answers you do not understand, feel comfortable saying:**

- “Can you explain that again?”
- “I am not sure what you mean” or
- “Could you draw a diagram or write it down?”



For more information, see the Cancer Society’s *Questions You May Wish to Ask* booklet, which has general questions and spaces in which you or your doctor can write answers. You can also phone the Cancer Information Helpline (0800 **CANCER 226 237**) for further information or visit our website: [cancer.org.nz/questions-to-ask](https://cancer.org.nz/questions-to-ask)