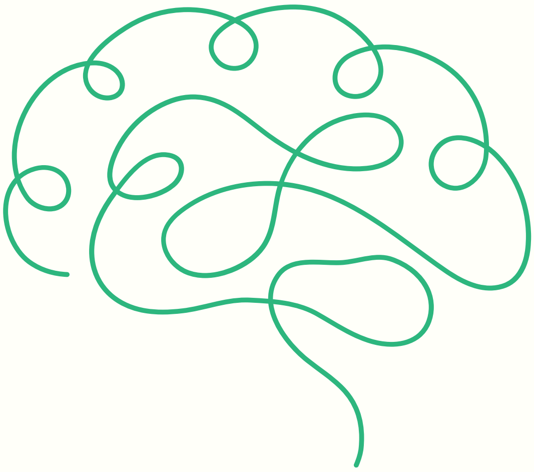
**Care Plus**
Best care for people with cancer

# What now?

## After the diagnosis of a brain tumour



Workbook One
Resources for your ongoing support and care

## About Workbook One

### What now?
After the diagnosis of a brain tumour

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### Acknowledgements

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This workbook has been developed by the Neuro-Oncology team at St Vincent's Hospital Melbourne. It includes recommended information resources that have been collated from selected sources. These resources have been reproduced for educational purposes only. The publishers of each resource are duly acknowledged at the bottom of each page, but include the Cancer Institute NSW, the Cancer Council Victoria, Cancer Council WA and the Brain Tumour Alliance Australia Information (BTAI).

The authors would like to acknowledge the members of the Care Plus Brain project advisory group and investigators who reviewed and updated this workbook, with specific mention of: Prof Jennifer Philip, Chair of Palliative Medicine; Dr Anna Collins, Research Fellow; Jane Staker, Neuro-oncology Nurse Coordinator; Kylee Bellingham, study coordinator.

### Note to reader

Always consult your doctor for specific advice that is right for you. This workbook is intended as a general introduction and should not be seen as a substitute for your health professional's advice. However, you may wish to discuss issues raised in this booklet with them. All care is taken to ensure the information in this workbook is accurate at the time of publication.

## Table of Contents

# What now?

## After the diagnosis of a brain tumour

You’re receiving this information because you, or someone you love, has recently been diagnosed with a brain tumour.

You’re probably feeling overwhelmed, shocked, and maybe even wondering “What now?”. It is normal to feel worried, or angry, or unsure of what choices you need to make about treatment. It is okay to feel confused about what needs to happen next.

We are here to help guide you and answer any questions you may have. There is lots of information available, and it can be difficult to understand or know what’s important – so we have included some basic things which we think might be useful at this early stage – and will give you some more along the way.

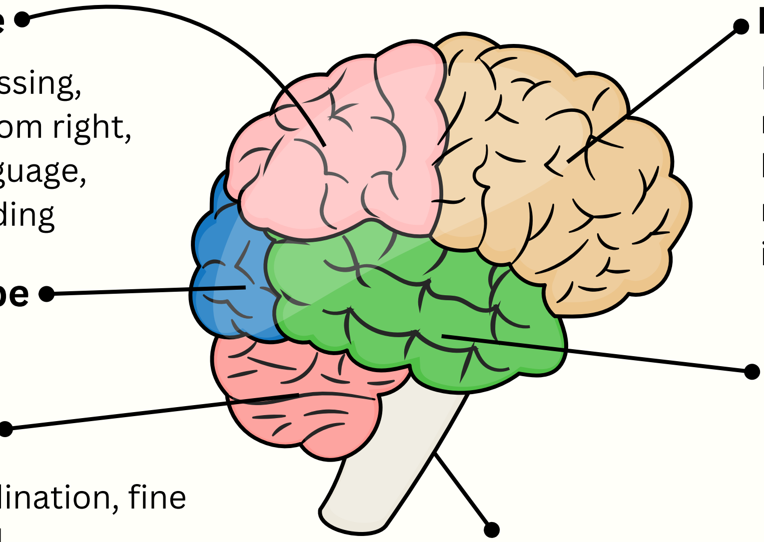
This workbook is just one aspect to the support you will be provided. We encourage you to use this to keep notes, write down appointment times and contact numbers, and any questions that you have. You may also find it helpful to bring this workbook along when you meet with your doctors. You, and your family can play an active role in looking after your health and wellbeing, and we hope this workbook will help you do so.

# Understanding My Brain

## How does the brain work?

*Each area of our brain controls particular functions in our body – so people with a brain tumour can sometimes have difficulties with those functions that are controlled by the part of the brain where your tumour is located. It can be useful to understand what functions might be affected, so you can tell your doctors if you notice anything different. Some people won't notice any changes, some may notice only subtle things, and for others, changes may be more obvious. Sometimes you may not notice any change – but a friend draws your attention to something they have noticed, which may take you by surprise.*

### The Brain



**Parietal lobe**

Sensory processing, knowing left from right, reasoning, language, sensation, reading

**Occipital lobe**

Vision

**Cerebellum**

Balance, coordination, fine muscle control

**Frontal lobe**

Movement, mood, reasoning, personality, behaviour, planning, memory, initiative, inhibition, judgement

**Temporal lobe**

Speech, hearing, behaviour, vision, memory, emotions

**Brain stem**

Breathing, blood pressure, heartbeat, swallowing

# My Tumour Information

## What type of tumour do I have?

*There are different types of brain tumours and different grades which describe how quickly the tumour might grow – it is useful to know which type you have so you can access the right information.*

**Date of my diagnosis:** ______________________________

**Name of my brain tumour:** ______________________________

**Grade:** ______________________________

**Other information:**

**Methylation:** ______________________________

**IDH status:** ______________________________

**Where my tumour is:** ______________________________

**Everyday activities controlled by this area of the brain:**

______________________________

______________________________

## Key Terms

**Malignant tumour:** cancerous tumours which rapidly grow and destroy or invade our normal tissue.

**Primary brain tumour:** tumour which starts in the brain.

**High-grade:** tumours which grow more quickly.

**Low-grade:** tumours which grow more slowly.

**Recurrence:** tumours which have grown back after treatment. Tumours can come back in the same area as the original tumour, or in a new area.

**Glioma:** tumours which are formed from glial tissue—including tumours called astrocytomas, oligodendrogliomas, ependymomas, and mixed gliomas.

**Astrocytoma:** the most common type of glioma tumours, which are divided into four grades.
The two high-grade tumours include:

- Grade III—Anaplastic Astrocytoma
- Grade IV—Glioblastoma multiforme (sometimes known as GBM)

# Meet the Brain Tumour Team

*These are the people in your care team who will look after you at different stages throughout your illness. You may meet some, or all of them, depending on what you need, but it’s useful to understand how they might help you. Your treating team will make recommendations on your tumour type.*

## Your core care team

**Neuro-oncology Nurse Coordinator:** specialises in the coordination of treatment, education, resources, and support for brain tumour patients and their families, and liaises between your doctors in the hospital and your local area.

**Neuro-surgeon:** A surgeon that may assist in your diagnosis, treatment planning, and the surgical removal of your tumour.

**Radiation Oncologist:** A cancer specialist that administers radiation therapy (a treatment which uses radiation to stop cancer cells from dividing).

**Medical Oncologist:** A cancer specialist that administers chemotherapy (chemical drugs which are used to kill cancer cells).

**Palliative Care:** A specialist team who can help to manage particular symptoms and provide assistance in the home, care and support for people with a terminal illness, including care at the end of life.

**Care Plus Team:** Adds an extra layer of support to your care alongside your treatment. They can monitor your symptoms and make sure you and your carers have the support needed.

## Other important people

**Social worker:** Provides counselling, resources and education, and assists you to access appropriate health care, legal advice and financial assistance.

**Physiotherapist:** Helps patients to improve their physical functioning and mobility after illness to limit permanent disability and relieve pain.

**Speech Pathologist:** Provides strategies to help patients communicate well after treatment and assists with language or swallowing difficulties.

**Dietician:** Provides dietary advice for people who experience weight changes or develop diabetes because of certain medications.
Occupational Therapist: Assists with everyday functioning, including advice on equipment available to promote safety and help with mobility.

**Psycho-oncologist:** A doctor who specialises in helping patients with cancer and their families adjust to the diagnosis and cope effectively by providing support, coping strategies, and insight into behaviour patterns.

**Neurologist:** A specialist who studies how brain functions impact a person’s behaviour and abilities, has expertise in seizure management.

**Clinical Trials Coordinator:** A research professional who coordinates particular clinical trials, which investigate the effectiveness of new treatments.

# My Care Team

*You will probably meet many people at the hospital who are part of your care team – record the names of your particular doctors and other health care professionals who you might like to remember later.*

*Remember that you won’t always need everyone listed, but if you do, they are available to help you. Sometimes people will access services closer to their home instead of at the hospital, so some of your care team below may be in your local area.*

| Role | Name | Details |
|---|---|---|
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |

# Important Contact Numbers

## Who do I contact if I have questions?

*It may not always be possible for you to speak with your doctors in between hospital appointments. However, the Neuro-Oncology Nurse Coordinator is available to provide general support and guidance or refer you to someone who may be able to help answer your questions.*

### 1. Neuro-Oncology Nurse Coordinator

**For general support or guidance:**

**Ph:** ____________________________________________

### 2. Hospital Switchboard

**To speak with the Neuro-surgical or Oncology Registrar on call:**

**Ph:** ____________________________________________

### 3. Your local GP

**For any non-urgent medical concerns or support and guidance:**

**Ph:** ____________________________________________

### 4. Cancer Centre

**Location of your oncology treatment:**

**Ph:** ____________________________________________

### 5. Care Plus

**Extra support for both you and the people caring for you:**

**Ph:** ____________________________________________

**IN THE EVENT OF AN EMERGENCY**

**Please call 000 or contact your local emergency department**

# Frequently Asked Questions

## After treatment for a brain tumour

*The pages that follow provide some answers to questions which other people with a brain tumour have had after treatment. Remember, you can also discuss these questions with your health care professional if you're unsure about this information.*

**Frequently Asked Questions**

- What is a seizure and what do I do if one occurs?
- What is Dexamethasone and what are the side effects?
- Am I allowed to drive?
- Where can I seek help for legal and financial concerns?
- Where can I get information about clinical trials?

**Brain Tumours Online**

It is easy to search the internet for information about brain cancer but not all sites are reputable, reliable or current.
A key Australian internet resource, Brain Tumours Online which has been co-designed by patients, carers and health care professionals to provide reliable information, tools, and a supportive community for Australians affected by brain tumours.

**https://braintumoursonline.org**

# Seizures

## Managing seizures

A brain tumour or its treatment can sometimes cause seizures (fits or convulsions). A seizure is a disruption to the normal patterns of electrical impulses in the brain. There are 2 main groups of seizures:

**Generalised seizures –** These occur when all of the brain is affected, and typically involve the whole body. The most common type is called a tonic-clonic seizure (previously known as a grand mal seizure).

A seizure often starts with a loss of consciousness. The person's muscles may stiffen, their limbs may jerk rhythmically, and their breathing may be shallow for up to 2 minutes. They may bite their tongue, and lose bladder and bowel control.

**Focal seizures –** Also called partial seizures, these occur when only one area (lobe) of the brain is affected. Focal seizures affect one part of the body, such as an arm or leg.

Symptoms of focal seizures depend on the area of the brain involved. They may include twitching; jerking; tingling or numbness; not being able to speak; and changes in vision or hearing, strange tastes or smells, or a feeling of deja vu. Focal seizures may also cause a brief loss of consciousness, changes in mood, and memory loss just before, during and after the seizure.

## Ways to prevent seizures

Seizures can often be prevented with anticonvulsant medicines (also called anti-epileptic or anti-seizure medicines) – see page 50. Feeling overstimulated or very tired can also increase your risk of having a seizure. Try to get 6–8 hours sleep each night. Drinking less alcohol may also help.

# Seizures

## How to help someone having a seizure

- Remain calm and stay with the person while they are having a seizure. Refer to their Seizure Management Plan (see last tip in this list), if they have one.
- Do not hold them down or put anything in their mouth.
- Protect the person from injury (e.g. move hazards, lower them to the floor if possible, loosen their clothing, cushion their head and shoulders).
- Call Triple Zero (000) for an ambulance if it is the first seizure the person has had; if the person is injured; if there was food or fluid in the person’s mouth; if the seizure lasts longer than 5 minutes; or if you are unsure of what to do.
- Time how long the seizure lasts so you can tell the paramedics.
- Watch the person until they have recovered, or the ambulance arrives.
- If the seizure occurs while the person is in a wheelchair or car, support their head and leave them safely strapped in their seat until the seizure is over. Afterwards, remove the person from their seat, if possible. Roll them onto their side if there is food, fluid or vomit in their mouth.
- Explain to the person what has occurred. In many cases, people are confused after a seizure.
- Allow the person to rest afterwards as most seizures are exhausting.
- For detailed information and an online tool for creating a Seizure Management Plan, contact Epilepsy Action Australia on 1300 37 45 37 or visit epilepsy.org.au.

# Seizures

## Anticonvulsant medicines

Different types of anticonvulsant drugs are used to prevent seizures. You may need to have blood tests while you are taking anticonvulsants. This is to check whether the dose is working and how your liver is coping with the medicine.

Side effects of anticonvulsant drugs vary, but they may include tiredness, gum problems, shakes (tremors), nausea, vomiting, weight changes, depression, irritability and aggression.

If you are allergic to the medicine, you may get a rash. Tell your treatment team if you have any skin changes or other side effects. Your doctor can adjust the dose or try another anticonvulsant. Do not stop taking the medicine or change the dose without your doctor's advice.

*If you take anticonvulsants, you may need to avoid some foods. Check with your doctor before taking any herbal medicine, as it can change how some anticonvulsants work. Ask your doctor or pharmacist about potential interactions and foods to avoid.*

*The information in this section has been sourced from pages 48-50 of the Cancer Council NSW Understanding Brain Tumours Booklet.*

*The full booklet can be accessed via:*
*https://www.cancer.org.au/assets/pdf/understanding-brain-tumour-booklet*

## Brain Tumour Australia Information

# © FACT SHEET 19

# Dexamethasone

### Dexamethasone described here as DEX

is a drug that is used to treat the swelling or oedema of the tissue that can occur in the brain due to the presence of the tumour and the treatments given for the tumour. This swelling can cause discomfort and increase other symptoms because it increases the overall pressure inside the skull. This is called intra-cranial pressure (ICP). Sometimes other steroid medications (such as prednisone) are used instead of **DEX**

### About Dexamethasone

- Comes from a group of medications (drugs) known as ‘steroids’ or ‘corticosteroids’.
- Usually the human body produces its own supply of steroids from a part of the body called the adrenal gland. However, when steroids are taken as medication, the body accommodates by slowing down making its own supply.

***When reducing/ceasing DEX your treating specialist will reduce the dose gradually to allow your body to resume producing its natural supply of steroids. This is known as tapering.***

### How does it work?

- Reduces the amount of fluid found in the irregular blood vessels of the tumour.
- Leads to a reduction of the swollen area (oedema) of the normal tissue.

### When may Dexamethasone be prescribed?

- Prior to surgery to reduce swelling in the normal tissue surrounding the tumour.
- During & after surgery to reduce swelling associated with the surgical procedure. The use of **DEX** at this time helps reduce the damage by decreasing the flow of fluid across the damaged normal blood vessels.
- To improve symptoms such as headaches, nausea, vomiting or other tumour related symptoms.
- **DEX** may also be used to reduce the swelling that Radiation Therapy as a treatment may cause.

### Taking Dexamethasone

It is important to remember the following:

- Never discontinue steroid medication abruptly.
- Follow the medication plan in order to stimulate your body to produce its normal production of steroids.
- Follow your doctors instructions on `tapering’ (reducing) the medication.
- Sometimes it is necessary to stay on **DEX** for an indefinite period because the body can no longer produce adequate amounts of its own steroids.
- Stomach upsets may occur when taking **DEX** because of the effect on the lining of the stomach
- Your doctor may advise taking the medication with milk or food to reduce the incidents of discomfort
- Other medications may be prescribed to assist your comfort level eg. antacid medication.
- Ensure that **DEX** is not taken to late in the afternoon or at evening as this can affect sleep and agitation
- If problems occur discuss them with your treatment team and discover what other options are available.

***Remember to provide your doctor with a list of other medications that you take to assist in monitoring your treatment.***

### Side Effects of Dexamethasone

- Your immune system may be affected when taking **DEX** so report all changes to regular function to your doctor
- Purchasing a thermometer will assist with monitoring changes in body temperature. If concerned report these changes to your doctor .
- Sore throats and mouths (‘Thrush’ or candida) may occur.
- Fluid retention may occur in feet, face or hands.
- Sometimes one may notice a weakness in the lower limbs and shoulders when walking up stairs, moving from sitting to standing or stretching eg. hanging washing on the line.
- Changes to sleep patterns, moods and behaviours should also be discussed with your doctor.
- Weight gain may occur due to an increase in appetite (**DEX** induced weight gain). Weight gained is usually lost after medication is ceased.
- Changes to facial appearance may occur (‘a moon faced appearance’ - **DEX** induced).
- Blood levels for diabetes may have to be monitored due to an increased level of blood sugar when taking **DEX**

Fact sheet sourced from https://btaa.org.au/sites/default/files/2019-04/FS19.pdf

# Driving

*We understand that receiving a brain tumour diagnosis can be overwhelming, and you may have many concerns about how it will affect your daily life. One common worry is whether you'll be able to continue driving. This is a natural and valid concern, as driving often represents independence and freedom.*

*It is important to know that driving regulations can differ between Australian states and territories, and the advice you receive may depend on your specific situation. In general, you would be advised not to drive for a period of time following a seizure and after brain surgery. Your care team is there to support you through this process and help you navigate these considerations with care and understanding.*

**Brain** Tumours Online is a valuable resource with plenty of information about driving with a brain tumour. For more information: https://braintumoursonline.org/

**Hint**: *Use the 'search' function to find information about driving.*

In Victoria, Transport Victoria offers assessments to review one's fitness to drive.

**For more information:** https://transport.vic.gov.au/Registration-and-licensing/Licences/Medical-conditions-and-reviews

Some people find accessing an Occupational Therapist independently of Transport Victoria can be a useful process to assessing one's ability to continue driving. Speak to your doctor about whether a driving review is right for you.

# Financial and Legal Concerns

*A cancer diagnosis is a difficult time for both the person with cancer and their loved ones. Families of people with a brain tumour often have to make medical, financial, and legal decisions. There are many supports available to help you and your family navigate treatment, ongoing care, financial, and legal concerns.*

## Medical, legal, and financial decisions

Many people want to make their own medical and financial decisions throughout their treatment.

If your illness makes it difficult for you to make your own decisions, either temporarily or permanently, you can appoint a trusted person who knows your preferences to act on your behalf. You should think about who this trusted person might be for you, and consider asking them to be your Medical Treatment Decision Maker (MTDM).

A Power of Attorney is a legal process that allows you to nominate someone you trust to make specific financial or property decisions for you if you are unable to do so yourself. This document allows you to specify conditions and instructions to be followed.

The following web links provide further information about the different types of decision making:

**Medical treatment decision maker (MTDM):**
https://www.publicadvocate.vic.gov.au/your-rights/your-healthcare/appointing-a-medical-treatment-decision-maker

**Enduring power of attorney (financial and property decision):**
https://www.publicadvocate.vic.gov.au/your-rights/enduring-power-of-attorney/making-a-power-of-attorney

**Advance Care Planning:** This allows you to plan for future medical and personal care should you no longer be able to make decisions for yourself. An Advance Care Directive outlines your values and wishes for future care, to ensure decisions are made in your best interest.
For more information: https://www.health.vic.gov.au/end-of-life-care/advance-care-planning

**Will**: A will is a legal document outlining what will happen to your assets and dependents after you die. For information: https://service.vic.gov.au/find-services/personal/make-a-will

## Financial Support

A lot of people worry about finances after a cancer diagnosis. There is support available to help you access financial benefits and support. Some of these may be helpful now, and others may be helpful in planning for the future.

**For help with carer payments:**
https://www.servicesaustralia.gov.au/carer-payment

**For help with disability support:**
https://www.servicesaustralia.gov.au/disability-support-pension

**For help accessing your superannuation early:**
https://www.ato.gov.au/individuals-and-families/super-for-individuals-and-families/super/withdrawing-and-using-your-super/early-access-to-super/access-on-compassionate-grounds

**The following groups might be helpful in navigating financial support options for you and your carers:**

**National Advocacy Service:**
This service is a collaboration between Peace of Mind Foundation and Cure Brain Cancer Foundation that directly assists families with accessing support services including the National Disability Insurance Scheme (NDIS), Centrelink and other government programs.
https://www.peaceofmindfoundation.org.au/services-resources-1
https://www.curebraincancer.org.au/support-information

**Cancer Council:**
Cancer Council offers a Legal Support Program providing free legal support for wills, powers of attorney, and medical treatment decision makers to eligible Victorians with advanced cancer.
https://www.cancervic.org.au/get-support/legal-and-financial

**Carer Gateway:**
An Australian Government program providing free services and support for carers https://www.carergateway.gov.au

**Social Worker:**
Your treating team may include a social worker who can guide you through the assistance available to you.

# Cancer clinical trials

## What are cancer clinical trials?

A cancer clinical trial is a research study with participants which provides essential information about important issues in the management of patients with cancer, most commonly the effects of different treatments. Clinical trials may not only improve the health outcomes for the volunteers who participate, but may also improve treatment for people who develop cancer in the future.

**In cancer research, clinical trials can answer questions about how to:**

- prevent cancer, e.g. using diet, exercise or drugs
- determine any genetic predisposition to cancer
- detect cancer earlier, e.g. screening methods
- diagnose cancer, e.g. new technologies
- treat cancer using different protocols, or combinations of new drugs
- control symptoms or side effects e.g. complementary therapies or conventional medications
- enhance quality of life, e.g. evaluate ways to improve this during and after treatment

## Why do we need clinical trials?

Results produced in trials can help people with cancer in the future and participating in a trial may also provide a direct benefit to the participants in that trial. Clinical trials are often used to prove the effectiveness of new treatments.

Advancements in treatments are the result of clinical research which is the basis on which a new medication or protocol is developed.

Clinical trials can tell us if the new treatment is more effective than the current standard treatment, and determine any risks and side effects of that treatment.

## How do cancer clinical trials help people with cancer?

**Cancer clinical trials may help in the following ways:**

- The treatment you receive on a clinical trial will be the best available treatment, or treatment that may prove to be even better than the current standard treatment for the disease (the researchers will not know this for sure, which is why the trial is being done).
- You will receive extra personalised care and monitoring from the research nurses and treating doctors because their treatments, tests and follow-up procedures must abide by strict protocols and guidelines.
- You may gain extra information about your cancer and treatment.
- Your health may be improved after receiving treatment

## How does a cancer clinical trial work?

Clinical trials are designed after lengthy research in the laboratory where researchers investigate the effect of treatments on cancer cells in humans and in animals.

Different studies are designed to test a range of different treatments including:

- drugs or vaccines
- combinations of treatments
- new methods of delivering radiation or performing surgery

A study protocol plan is prepared which includes key information about the reason for the study, specific eligibility requirements and further information about the treatment(s) involved in the study. There are very strict ethical requirements that need to be adhered to before a trial protocol will be approved by an independent ethics committee.

## What are the phases of cancer clinical trials?

Clinical trials involve a series of testing of new treatments and are split into various phases. These phases are designed to ensure the treatment is safe, effective and also to determine whether it works better than the standard treatment. Each phase is represented below.

| | |
|---|---|
| **PHASE 1** | Shows that a new treatment is safe amongst a small group of people approximately 15-30 people. |
| **PHASE 2** | Provides more information on how the treatment works and its safety rating. This data is collected on a larger group of people. |
| **PHASE 3** | The aim is to compare the new treatment with the standard treatment. |
| **PHASE 4** | For the purposes of monitoring progress for a longer term, once the intervention has been marketed. |

## Who can participate in a cancer clinical trial?

Cancer clinical trials have strict guidelines or criteria that determine a patient's eligibility. The aim of inclusion and exclusion criteria is to ensure that participants have as many of the same characteristics as possible, thereby producing more reliable and comparable results. Examples of important characteristics include type and stage of the cancer, previous treatments and other medical issues.

## Are there risks?

Like all medical interventions, clinical trials do have some risks such as:

- **Side effects** - a person may experience none, some or all of the side effects, which may be mild, moderate or severe.
- **No guarantee** - it is unknown if taking part in the study will result in an improvement in your condition and it cannot be guaranteed whether you will receive any benefits. You may have a positive response, may remain the same or even get worse.
- **Added commitment** - a trial may require extra time and attention compared to the standard treatment, including extra visits to the hospital. Participating also requires taking in a lot of information and paperwork.

Talk to your doctor about the risks and side effects of being on a cancer clinical trial.

## What cancer clinical trials are available in WA?

Cancer research and clinical trials are quickly evolving and the list of cancer clinical trials available in WA can change frequently.

You can find out information about current trials that may be suitable for you in several ways:

- **Speaking to your consultant or medical team** - your doctor may be able to advise you of any trials for which you are eligible.
- **ClinTrial Refer** - available in both website and App versions this includes trials from a wide range of cancer treatment areas including: chemotherapy, radiotherapy, surgical procedures and preventive measures.
- **Australian Cancer Trials** - housed on the Cancer Australia website, this page provides information on the latest clinical trials in cancer care, including trials that are currently recruiting new participants.
- **Cancer Trials WA** - designed to connect patients and healthcare providers to clinical trials that are currently open for recruitment in Western Australia.

Not all trials are run in every centre or hospital. You may have to travel to a different location to participate.

## Frequently Asked Questions

### Do all trials find better treatments?

No, not in all cases. The trial may conclude that the treatment being tested is not better than the current standard treatment, or they may result in side effects which will be worse than the standard treatment.

### How long will a study last?

This depends on the study. Firstly, the recruitment phase can take months or years to establish the right number of participants. The length of each study will vary, but often it takes years or even decades. However, as a participant you may only be involved for a short period of this time, e.g. you may be required a few times a week or possibly for a once off visit for only a couple of hours. Sometimes studies will require participants to be surveyed for some time.

### Are clinical trials only appropriate for people who have already tried all of their other standard treatment options?

No. You are able to consider looking into clinical trials at various stages during your care, from diagnosis and beyond.

### Are clinical trials safe?

Participants are protected in many ways when they take part in a clinical trial and the treatments are tested in a laboratory before they are given to people. They usually commence testing on humans (who undergo monitored surveillance) first in phase 1 trials. In all cases the trial plan is reviewed by both a scientific panel as well as an ethics committee before its final approval.

### How much does it cost to participate?

Participation in a trial is free for Australian residents and citizens. Some associated costs such as travel might be encountered, especially for regional participants.
For regional participants, it may be worth discussing financial support with a social worker.

### Can I leave a clinical trial?

Yes. If you decide that you no longer want to participate you can stop (withdraw) at any time, for any reason.
Withdrawal will not affect your future care, and you will be returned to receiving the standard treatment for your type of cancer.

### Further information

For further information contact Cancer Council's information and support line on **13 11 20** or speak with your doctor or medical team.

*This information has been sourced from pages 1-3 of the Cancer Council WA Clinical Trials Fact Sheet.*
*This fact sheet can be accessed here:*
*https://cancerwa.asn.au/assets/public/2023/10/WACOG-Clinical-Trials-Fact-Sheet.pdf*

# Recommended Resources

## Where can I find more information?

*The following websites are reliable if you would like to seek more information yourself at this time. General internet browsing is not recommended. You will also be given additional information as needed.*

### Australian resources

**Brain Tumours Online:** https://braintumoursonline.org/

**Cancer Council**: https://www.cancer.org.au/

**Peace of Mind:** https://www.peaceofmindfoundation.org.au/

**Cure Brain Cancer Foundation:** https://www.curebraincancer.org.au

**Brain Tumour Charity**: https://www.thebraintumourcharity.org/

**Carers Gateway:** https://www.carergateway.gov.au/

### International resources:

**Brain Charity UK**: https://www.thebraincharity.org.uk/

### Resources for Clinical Trials:

**Cancer Council Victoria:** https://www.cancervic.org.au/cancer-information/treatments/clinical-trials/clinical-trials-explained.html

**Cancer Council Western Australia:**
https://cancerwa.asn.au/research/clinical-trials/

***Scan the QR code for a list of the above links via the Care Plus website*** *www.careplusau.org*

# So, what now?

*It is likely that the next few months are going to be busy: you'll probably spend a lot of time hearing what treatments are available, making decisions about what is right for you, and then planning for treatment. We'll check in frequently to see how you're doing, but until then here's a few things to keep in mind.*

- **Before you leave hospital ask:**
    - *Who is my contact person?*
    - *Who will be coordinating my treatment and appointments?*
    - *How can they be contacted?*

- **Write things down:** use the following workbook pages to help you keep track of everything. There will be lots to learn, so write everything down: appointment times, doctors, medication.
- **Bring someone along to appointments with you:** when possible, try to bring someone along with you to appointments. It can be useful to have another person in the room, as there can be a lot to remember by yourself.
- **If you're not sure, ask:** if you have worries or are confused, try to speak to people who can help. Remember that the staff at the hospital are happy to help—even if they seem busy. That's what they're there for, and it's okay to ask for help. Some common questions we have covered within this workbook include:
    - *Who can I contact when I leave the hospital?*
    - *What do I do in an emergency situation?*
    - *Am I suitable for a clinical trial?*

# My Appointment Schedule

*Before you leave the hospital, it is helpful to record your next follow-up appointment, so you have a plan and know that the doctors will continue to check-in and monitor how you are going. It can be helpful to note which hospital department you will attend at each visit.*

| Date | Hospital Dept | Place | Time | Attended (Y/N) |
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| Date | Hospital Dept | Place | Time | Attended (Y/N) |
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