Radiotherapy.

Brain Treatment

Gliomas and Meningiomas

Health
Illawarra Shoalhaven
Local Health District

Illawarra & Shoalhaven Cancer Care Centres

The Illawarra and Shoalhaven Cancer Care Centres acknowledge the Traditional Owners of country throughout Australia and their connections to land, sea and community.

In this booklet

Radiotherapy consultation

Radiotherapy planning

Radiotherapy treatment

Managing side effects

After radiotherapy

Frequently asked questions

General information

This booklet will help you with your journey through radiation treatment. The information is general and may not always apply to you. Please talk with your treating team if you have any questions.

This document is a guide only and cannot cover every situation.

IMPORTANT PHONE NUMBERS

Illawarra
Cancer Care
Ph: 4222 5200

Shoalhaven
Cancer Care
Ph: 4428 7400

During your treatment contact your radiation oncologist or clinical nurse consultant if the following is not relieved by medication:

- Uncontrolled pain
- Fit or seizure (for example uncontrolled twitching of limbs)
- Loss of strength or feeling in face, arms or legs
- Loss of vision
- Speech problem
- Confusion
- Headache
- Vomiting.

Out of hours go to your nearest emergency department

Need an interpreter?

Professional interpreters are available if you need help to communicate in English, or if you are Deaf.

Our staff can also ask for an interpreter. The staff will book an interpreter for you.

Interpreter Services are free and confidential.

You can bring a family member or friend with you to the appointment. If you need help to communicate it should be through a professional interpreter.

You can also call the Translating and Interpreting Service on **1800 24 72 72** if you need to speak to us before an appointment.

Support services

There are a number of services available to help support both you and your family. Please ask staff for more information or a referral.

☐ **Counselling support for patients and carers affected by cancer**

- Access to social worker and/or psychologist.

☐ **Local community support for Aboriginal & Torres Strait Islander people**

- Support services and criteria vary across the local communities. Some services are Grand Pacific Health, Aboriginal Medical Services, and Waminda.

☐ **Legal and financial assistance**

- Cancer Council - 13 11 20 www.cancercouncil.com.au
- Can Assist - www.canassist.org.au
- Centrelink - apply online for payments such as JobSeeker, Disability Support Pension, Carer Payment or Carer Allowance.
- Advance Care Directive - www.health.nsw.gov.au/patients/acp/Pages/acd-form-info-book.aspx

☐ **Practical help in the home**

- My Aged Care 1800 200 422
- Carer Gateway 1800 422 737

☐ **Transport / Travel**

- There is community transport for those that have difficulty, at a small fee.
- Travel & accommodation subsidy (IPTAAS). If travelling more than 200km per week: www.iptaas.health.nsw.gov.au

☐ **Accommodation**

- For those who have difficulty getting to the cancer centre, we have on-site accommodation available at both centres.

☐ **Support for children**

- Camp Quality - support for children 0-15 years www.campquality.org.au
- CANTEEN - support for young people 12-24 years www.canteen.org.au

Each cancer centre may have extra information for you.

My radiotherapy care team

Radiation oncologist

Contact:

What they do:

A doctor who prescribes radiotherapy and organises your treatment.

Radiation oncology registrar

Contact:

What they do:

A doctor who is training to be an oncologist. They are always supervised by your radiation oncologist.

Clinical nurse consultant

Contact:

What they do:

A nurse with specialised knowledge of brain cancer who will help coordinate your care, provide information, referrals and support.

Radiation therapist

Contact: ______________________________

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What they do:

Specially trained to plan and deliver your treatment. They will also help support you through treatment.

Radiotherapy nurse

Contact: ______________________________

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What they do:

Specialise in caring for people having radiation therapy. They manage your side effects, and will help support you through treatment.

Radiation oncology medical physicist

Contact: ______________________________

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What they do:

Ensures that your treatment is delivered accurately and safely. You may see them at your planning appointment.

Psychologist

Contact:

What they do:

A specialist who provides counselling and support for you and your family.

Social worker

Contact:

What they do:

Provides counselling, support and information for you and your family. They can help with important conversations in planning for your future.

Dietitian

Contact:

What they do:

Advise and support you to maintain weight and nourishment when the treatment side effects make it harder to eat normally.

Your pathway

**The time could vary if you have other treatments to be coordinated.*

Clinic

Appointment to see your radiation oncologist

Waiting time between these appointments is approximately **1 to 2 weeks***

Planning appointment

Appointment to plan the radiotherapy

Waiting time between these appointments is approximately **1 to 2 weeks.** In this time your treatment plan is produced*

Treatment appointment

Course of treatment from 1 to 6 weeks

The follow-up visit with your radiation oncologist is approximately **6 weeks** after your treatment

After treatment follow-up visit

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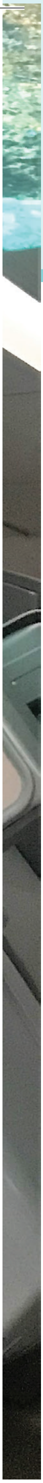


What is radiotherapy?

Radiotherapy uses x-ray beams to kill cancer cells.

A **linear accelerator** is a machine that delivers radiation to your body. It only gives radiation to the specific area that is being treated.

Your **radiation oncologist** will decide how much radiation you will receive and how many times you will receive it. Common short-term side effects.

When deciding this, they will take into account:

- Your age
- Your overall health, including any other medical conditions
- If you had surgery, the type of operation you had; and
- Details about your specific cancer. These include blood results, scans, the stage and exact location (site).

Sometimes, chemotherapy or antibody treatment is given during radiotherapy.

For these treatments you will see a medical oncologist who will discuss this with you.

Only the areas required to be treated will be affected by the radiation.

If relevant to you (female and childbearing age, the radiation oncologist will ask you if you are pregnant when you consent to treatment.

It is important to not get pregnant during treatment. If there is a chance you get pregnant, you will be asked to take a pregnancy test before the planning appointment and your treatment appointment.

Driving

When you are first diagnosed with a brain tumour, your doctor will probably advise you not to drive for a period of time. You probably won't be able to drive for some time after surgery and possibly after radiation therapy.

- If you have had seizures, you will need to be seizure free for a period of time before you are allowed to drive.
- If you stop taking your anticonvulsant medicines, you will also need to be seizure free for a period of time until you are allowed to drive.
- Before you start driving again, always check with your doctor. Laws in Australia require drivers to tell their driver licensing authority about any permanent or long-term illness or injury that is likely to affect their ability to drive.
- Your doctor can advise you if you should report your condition or if there are any temporary restrictions. The licensing authority may request information from your doctor to decide if you are medically fit to drive.

What side effects can the treatment cause?

Radiotherapy can cause both short- and long-term side effects.

Short-term side effects occur 10 to 14 days into your radiotherapy treatment. Long-term side effects can occur months to years after your treatment has finished.

Everybody reacts differently to the treatment and may not experience all side effects. You may get some side effects not listed here. **It is important to tell the staff about any side effects that worry you.**

It is important that you stop smoking during radiotherapy. Smoking can increase the chance of side effects of the treatment as well as reduce the chances of being cured from your cancer. If you would like more information please talk to a member of your health care team.

Common short-term side effects

Tiredness and lack of energy (fatigue)

You may:

- Feel very tired
- Have no energy
- Sleep a lot
- Not be able to do normal activities or things you enjoy.

Hair loss

Hair loss will be in the treatment area only and is often temporary. Hair should start to grow back in 8 to 12 weeks after radiotherapy has finished.

- Your hair may fall out in the path of the radiation beam
- This is usually temporary, but for some people it can be permanent.

Skin changes

Skin changes usually start to develop 2 to 3 weeks after the start of treatment. They usually begin to settle down about 2 to 4 weeks after treatment has finished.

- The skin on your scalp may become:
- Pink or red
- Dry, itchy and flaky.

Headache

You may get headaches due to radiation causing swelling in your brain.

Nausea and vomiting

You may feel sick (nausea) or be sick (vomit) from this treatment.

Ear problems

You may:

- Have ear aches
- Discharge from your ear
- Changes to your hearing
- Ringing in the ears.

Seizure

There is a small risk of having fits during this treatment.

Common short-term side effects continued

Worsening neurological symptoms

Radiation therapy can cause swelling of the brain and this can cause your existing symptoms to become worse. **Your Dexamethasone doses may need to be adjusted to reduce the swelling.**

These symptoms may include:

- Headache
- Nausea
- Weakness
- Altered sensation of the limbs
- Increase in seizures
- Visual, speech or memory problems.

Potential long-term side effects

Hair loss

Hair loss will be in the treatment area only and may be permanent.

Cognitive change

You may:

- Have difficulty concentrating
- Feel unusually disorganised or tired (lethargic)
- Have trouble with your memory.

Vision and eye changes

You may have:

- Cloudy, distorted or blurred vision
- Sensitivity to light
- A halo around bright lights
- Trouble seeing in the dark
- Eye pain or redness
- Dry, watery or gritty eyes
- Development of cataracts
- Reduced vision or blindness.

Hormone changes

Hormone changes due to radiation effecting the pituitary gland are uncommon, but can be serious.

You may have:

- Headaches
- Tiredness
- Dizziness or fainting
- A feeling of being hot or cold more easily
- Weight changes
- A deepened voice
- Irregular or absent periods
- Nausea and vomiting
- Muscle pain or weakness
- Changes in your mood or behaviour, such as decreased sex drive or irritability.

Tissue damage in your brain (radionecrosis)

Rarely, a mass of dead tissue forms at or near the site of the original cancer. If this occurs, it usually develops months to years after radiation is given. Surgery may be needed to remove the necrotic (dead) tissue

Developing a second cancer

There is a very small risk that you may develop a second cancer as a result of having radiotherapy. This may not happen until at least 10 years after treatment. Talk to your doctor if you have any concerns about the benefits and risks of radiotherapy.

Preparing for your planning appointment

Mask preparation

To keep you still during your treatment we will need to make a mask for you to have your treatment in. Some people feel anxious about this, especially those who feel they may be claustrophobic. If you feel this will be a problem for you, please discuss this with your radiation oncologist before your planning appointment. We may be able to help you. Relaxation, meditation techniques and some medications can help.

Dentures and hearing aids

At your planning and treatment appointments, we will ask you to remove dentures and hearing aids.

Beards and bulky facial hair

We may ask you to remove beards and bulky facial hair prior to your planning appointment. The mask needs to be firm throughout your treatment. Any hair removal during your treatment can make your mask loose which will not keep you still during your treatment.

Concurrent appointments

If you are having chemotherapy or antibody treatment with your radiotherapy you need to see your medical oncologist and your radiation oncologist before starting treatment. The start date of your radiotherapy and chemotherapy/antibody treatment will need to be coordinated to start at the same time.

Radiotherapy planning appointment

On this day we will give you information about the radiotherapy process. It is important to understand what is going to happen.

We will make equipment to keep you still, take a scan and mark the treatment area.

Please allow 1 to 2 hours for this appointment.

This appointment starts the planning process of your treatment.

Please feel free to ask questions.

Before or during this appointment you will be given a Patient Reported Measures survey. It will take 5 to 10 minutes to complete. The survey will ask you questions about your health and wellbeing. (More information on the next page).

An appointment card will be given to you. This will have your start date and treatment appointment times.

Identity check

Before we can start, please tell us:

- Your name
- Your date of birth
- What area on your body will be treated with radiotherapy.

This is a NSW Health requirement and helps us to identify you. It confirms we are treating the right person and part of your body. We will ask you this every day when you attend your radiotherapy treatment.

Patient Reported Measures Survey

What are Patient Reported Measures (PRMs)?

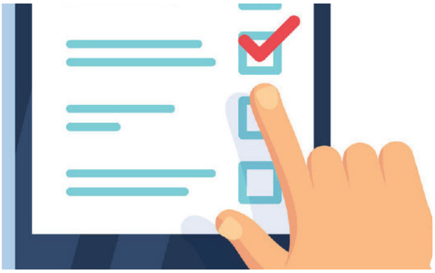
- PRMs are a way for you to tell your healthcare team about your general wellbeing and provide feedback about your care.
- As part of our standard practice, you will be asked to complete a survey with questions to help us identify any issues that may be causing you worry and distress.
- It is important to complete this survey as it will help your health care providers understand more about how you are feeling, and how your health and treatment might be impacting different parts of your life.
- Our aim is to deliver the best health care for you.

Do I have to complete a survey?

- No, surveys are not compulsory.
- If you don't complete a survey, you will still receive the best care available. However, completing a survey gives your healthcare team more information about what is important to you.

When will I be asked to do the survey?

- You will be asked to do the survey before or during your planning appointment and again during treatment.



During the planning appointment

Your radiation oncologist may want to give you an injection called contrast. This will help them see the area to be treated on the CT scan, we will talk to you about this on the day of your planning appointment.

There are 3 steps to the planning appointment:

1. Make equipment for your treatment
2. Take a CT scan of the treatment area
3. Mark treatment area on mask and take photos.

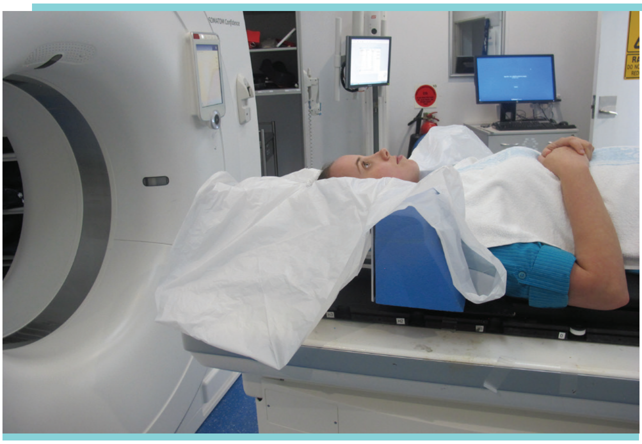
1. Equipment

Equipment for under your head:

We will use special foam under your head and neck or a pre-shaped headrest that will fit your neck.

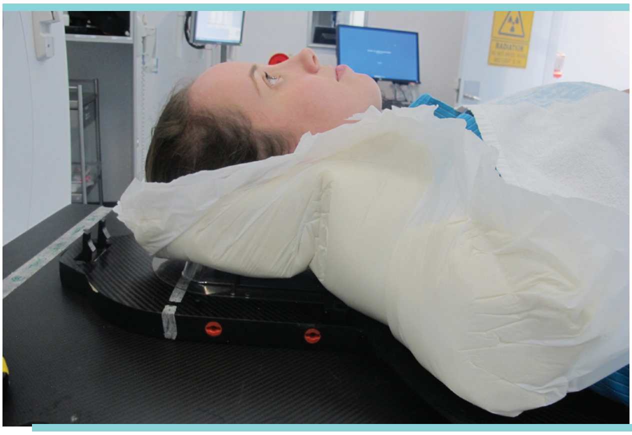
When we make the foam it will:

- Expand when you lie on it and then set to keep its shape
- Feel quite warm as it expands
- Not stick to your skin
- Sound very loud as it expands
- Cool as it moulds to your shape.



The foam will expand when you lie on it.

The foam will feel warm and sound loud when it expands



The foam sets to keep its shape.

Mask

We will make a mask for you to have your treatment in. The mask is made out of a special plastic material. We heat the mask to a warm temperature to make it soft so it is easy to mould to your face and neck. It has holes so you are able to breathe.

The mask is important to keep you still during treatment.

2. CT (computed tomography) scan

Texta and sticky markers will be placed on your mask before the CT scan. These help us to map out the treatment area and can be seen on the scan.

A CT scan will be taken of your head and neck area.

You will need to lie still and breathe normally during this scan.

The staff will leave the room while the scan is being performed.

This scan is used to plan your treatment.

Laying on the CT bed with mask

3. Marks on mask and photos

The area to be treated will be drawn on the mask after the CT scan. These marks will be used to put you in the same position on the treatment bed each day.

We will take photos of the way you are set up and the equipment that has been made for your treatment. This helps treatment staff set you up in the same position each day.

Radiotherapy planning

Your radiation team will create a plan for you between your planning appointment and the start of your treatment.

The CT (computed tomography) scan that was taken at your planning appointment is used to create the plan. It is designed specifically for you. This can take up to 2 weeks depending on how difficult the individual plan is.

Sometimes the start of treatment can be delayed due to the difficulty of the plan.

Many checks are completed to make sure we are going to be delivering the right treatment for you.

Radiotherapy team

Radiotherapy treatment

You will receive radiotherapy daily. You will be set up in the same position as your planning appointment. It will take 20 to 30 minutes for your treatment.

Treatment times

Treatment is usually 5 days a week, Monday to Friday.

You will be given a weekly list of appointment times, which you should check as they may change.

Treatment machines may need to be closed for maintenance. If you need treatment on those days, the staff will inform you.

Due to other patients receiving treatment. please inform the radiation therapists as soon as possible if you need to change an appointment or are running late.

Your first treatment appointment

On your first day, please come 15 minutes before your appointment time. Please see the nurses at the nurse’s desk before you sit down.

A radiation therapist will explain what will happen and answer any questions you may have.

Your first treatment is usually longer than your other appointments. This is because we need to check measurements from your planning appointment.

Please allow an hour on your first day. This will allow us to give you all the information you need and deliver your treatment.

Arriving in radiotherapy

Please check yourself in for your treatment. You do this by scanning the barcode on your appointment card at the nurse’s desk. If it is not your first treatment, once you have checked in you can take a seat in the waiting room.

A radiation therapist will come and get you when they are ready for you to have your treatment.

How long will my treatment take?

The time needed to deliver your treatment can be between 20 to 30 minutes.

The time in the treatment room includes:

- Getting you into the correct position
- Delivering your treatment
- Helping you in and out of the room.

In the treatment room

Before we can give you your treatment, you will be asked to tell us:

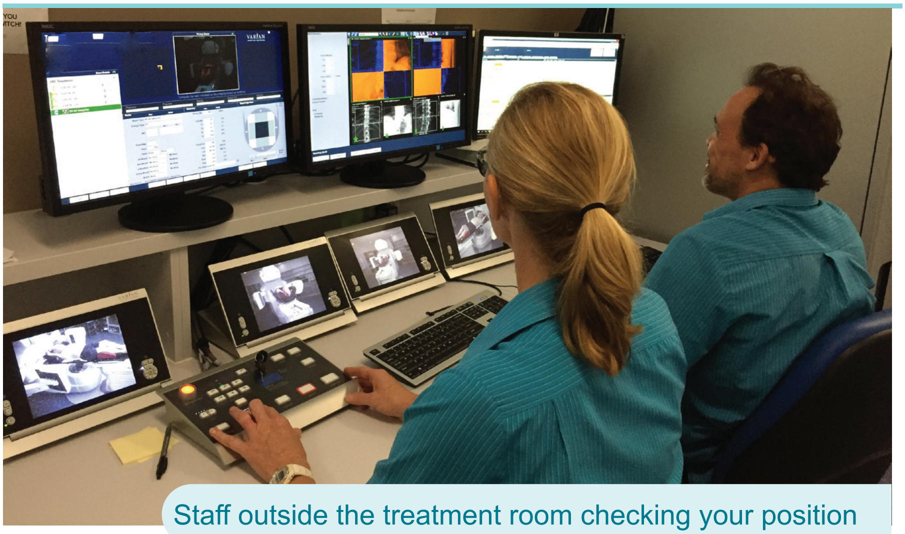
- Your name
- Your date of birth
- What area on your body will be treated with radiotherapy.

During your treatment you are able to listen to music. We can make a playlist for you, or you can bring in your own music if you like.

Once you are in position, the radiation therapists will leave the room.They will then start the treatment. We can see and hear you during the treatment (the room has television monitors and an intercom).

When the radiation therapist leaves the treatment room:

- You will be in the room by yourself for 5 to 10 minutes
- It is important to lie still during the treatment and breathe normally
- Parts of the machine will move into position to take x-rays. These x-rays are taken before we give you your treatment to make sure everything lines up and we are treating the correct area
- The treatment machine moves around you to give you your treatment, but it does not touch you
- You can alert us at any time by talking or raising your hand
- You will not be able to see or feel anything during the treatment, however you will hear a noise when the machine turns on.



Staff outside the treatment room checking your position

During your course of radiation treatment

All instructions given to you by the radiation staff need to be followed for every treatment.

Tell the radiation staff as soon as possible if you are not able to follow these instructions.

You will have x-rays taken throughout your treatment. This is to check the position of the treatment area. The x-rays are not used to check how treatment is working. Other measurements are also taken during your treatment. This is to check for any changes in your body shape.

It is important to try and maintain your weight during treatment. Any major changes in the shape and size of your body may change our calculations, which may require a new CT scan.

Every day during your treatment, the radiation team will check on your wellbeing. They will watch for side effects and any problems you may be having.

If you need more help, staff can arrange for you to see other staff in your radiotherapy care team.

You will not feel any effects from the treatment directly after the appointment.

Managing side effects during treatment

Side effects generally start 2 to 3 weeks into your treatment.

In most cases, these symptoms will settle 2 to 4 weeks after completing radiotherapy.

You may have already met a specialist nurse who cares for patients with brain tumours. This nurse is available for information and support before, during and after treatment.

If you have not already met this specialist nurse ask the staff in radiotherapy who can arrange this.

In some instances, you may be having chemotherapy at the same time as having radiotherapy. The specialist nurse and radiation therapy nurses are experienced in caring for patients who are receiving this treatment and will be able to help if you have questions.

Inform staff if you notice any of the following during your treatment:

- Headache
- Nausea
- Vomiting
- Fever
- Feeling unwell
- Become unstable on your feet
- Skin changes.

Fatigue/Tiredness

To help manage your tiredness during your treatment.

- Try some light exercise when you are feeling least tired during the day.
- Keep a diary to see what time of the day you are most tired.
- Listen to music/read books.
- Meditate or use relaxation exercises.
- Spread out and prioritise what you need to get done over the day.
- Allow others to help.
- Rest when you need to, but limit daytime naps to 45 minutes.

Headaches

You may get headaches from swelling in the brain.

It is important to alert your nurse at radiotherapy who will advise what medication to take. Your oncologist may prescribe a medication called dexamethasone in addition to pain relief.

Nausea and vomiting

You may feel sick or vomit during this treatment.

It is important to:

- Alert your nurse at radiotherapy who will advise what medication to take
- Maintain fluids.

Neurological Symptoms

You may get worsening

- Headache
- Stiff neck
- Confusion
- Difficulty concentrating
- Dizziness
- Drowsiness
- Fever
- Loss of consciousness
- Numbness or tingling
- Jerky movements.

Tell your doctor or nurse immediately, or go to your nearest hospital Emergency Department if these symptoms worsen and are not relieved by medication.

Hair Loss

In the area of treatment your hair may fall out. This can happen 2 to 3 weeks into treatment.

Ear problems

You may get earaches, discharge from your ear and changes to your hearing or ringing in your ear. Tell staff as soon as possible if you notice any changes to your hearing.

Skin

The skin on your scalp may become red, dry, more sensitive and possibly itchy.

Use a baby shampoo or mild unscented shampoo to wash your hair (e.g. Dove ®, Cetaphil ®).

You will also be given moisturising cream to apply daily to the treatment area.

Apply:

- After every treatment
- At bedtime
- As often as you like, but not within two hours of your next treatment.

If you are unsure of where and how much cream to apply, please talk to staff.

You will also need to follow the general skin care advice section on the following page during your radiation treatment.

Please do not use any other products on your skin in the treatment area without checking with your treating team first. Some products may make your skin reaction worse.

General skin care during your treatment

✓ Have a quick shower every day. Use warm, rather than hot water

✓ Gently pat dry the treatment area with a clean towel

✓ Start moistursing from the first day of treatment (do not apply any cream within 2 hours before your treatment)

✓ Protect yourself from the sun. Wear a hat and stay in the shade.

✗ Do not apply soap directly to the treatment area

✗ Do not apply any oils, colognes, lotions or talcum powders to the treatment area.

Notes

After radiotherapy

On your last day of treatment a follow-up appointment will be booked with your radiation oncologist in 4 to 6 weeks.

Any side effects that you have had during your treatment will start to improve around 2 weeks after your treatment has finished.

When treatment is completed, and you are no longer attending the cancer care centre, you are still able to contact us if you have concerns.

Make sure you have the contact phone number for your specialist nurse who is availble Monday to Friday during office hours for advice and support.

Last treatment

On completing your last treatment we will:

- Ensure you have cream to apply if required
- Tell you who to contact if you have any skin or other treatment related problems
- Make a follow-up appointment for you with your radiation oncologist.

After treatment

On completion of your treatment, side effects may get worse. It is important that you contact your treating team if you are concerned or have any questions.

Skin care after treatment

For the next four weeks, you need to continue to look after your skin.

Your skin changes can be worse about 10 to 14 days after treatment is finished. Your skin usually starts to improve after this time.

If the area is only dry, red or itchy, continue to apply cream several times a day until healed.

Any redness of the skin has usually improved 4 to 6 weeks after finishing your radiotherapy.

Fatigue

The tiredness you may have felt during treatment will improve after a few more weeks.

Vision and eye changes

If you have vision or eye changes protect your eyes from the weather by wearing sunglasses in the sun, or if it is windy.

Follow-up care appointments

Your first follow-up appointment with your radiation oncologist will 6 weeks after you finished your treatment. This will have been booked on your last day of treatment.

Your doctor may request scans prior to this appointment.

This appointment is important to make sure everything is going well and to answer any questions you may have.

During this appointment side effects that you may have had during your treatment will be discussed to ensure they are improving and being managed. Your skin should be healed. You should also have more energy.

If you have been having chemotherapy at the same time as radiotherapy you will have an appointment with your medical oncologist 3 to 4 weeks after completion of treatment.

At this time there maybe discussion about ongoing chemotherapy.

In some instances where you have received radiotherapy alone there may be discussion about commencing chemotherapy following radiotherapy.

Ongoing follow up care

After treatment, follow-up care is important for your long-term health.

Your follow-up care will depend on the type, stage of cancer and the treatment you had.

Follow-up care should be agreed between your radiation oncologists, general practitioner. any other health professionals involved in your care, and takes into consideration your preference.

In some cases, people will need ongoing hospital care for several years. In other cases, an arrangement with your general practitioner may be suitable.

Patient story

Kick-Off Event.

On the 8th August 2019 I had my first full body seizure in the middle of the night causing all my body muscles to fully tension and my mouth to froth, it lasted for approximately 30 seconds. Nothing like this had ever happened before. My wife phoned 000 mid seizure asking for help and thought I stopped breathing immediately following the seizure, I doubt she will ever forget this night. An ambulance soon came to collect me and in less than a day a brain tumour roughly the size of a mandarin was found and the recommendation for an operation received. How life can change in a day.

Head Op & Confirming The Grade Plus Type of Tumour.

On the 14th August I had my head operation and approximately 75% of the tumour was removed. The operation itself went well as my body function and cognitive abilities post operation seemed relatively good, the negative was some loss of memory – unfortunately many people's names were lost. The biggest difficulty encountered following the operation was the three and a half weeks taken to receive confirmation of the grade and type of brain tumour. Basically, knowing my life expectancy.

During this waiting period I received a phone call for an additional test of the tumour sample taken - It was extremely difficult not knowing the type of tumour which I had. Some friends and family were also thinking very differently to me at this time. They were so relieved and happy that the operation went well as I was alive, could talk, walk and think, yet all my thoughts and concerns were on my unknown future.

The meeting with my neurosurgeon after the 3 ½ week wait provided the results that I had a grade 2 astrocytoma tumour in my left temporal lobe and my life expectancy was 10+ years if it didn't change from a grade 2 tumour during this time. It was indicated that further treatment discussions would be conducted by Oncologists.

Post Diagnosis Thoughts & Emotions

Prior to having a seizure which kicked off the process of highlighting the brain tumour followed by the operation to remove as much tumour as possible and determine the type of tumour, I lived life with everything as managed and planned as possible. Every decision made at work was based on information, experience and very careful consideration. This was exactly the same at home as nothing was spontaneous, unplanned or unscheduled. At an age of 41 I had a lovely wife, two young kids, newly constructed house and an exciting job all of which I truly loved and greatly enjoyed. Much time and effort was placed into setting everything up for the future even thinking decades ahead.

Post the tumour diagnosis, my world turned completely upside down as the only certain event known for the future was leaving the world due to brain cancer. There was no certainty on anything else – radiation or chemo treatment side effects, cognitive abilities now and in the future, how long I would be able to work, how long I would be able to pay home loan repayments, would I even see my dear little kids reach the age of 10. This was very challenging and upsetting to say the least and wasn’t helping my situation in any way.

After a period of time, I understood that acting and feeling this way wouldn’t help my future whatever that may be. From that point onwards, I decided to make the most of family, friends, work – basically everything in life while I could, taking each day at a time. I would stop worrying about my complete list of unknowns and only planned to worry about them if and when they occurred. I wanted to move on loving life and making the most of absolutely everything for as long as I possibly could.

Radiotherapy

I went into radiotherapy looking to have fun and I really had a blast with the whole radiation medical team. During the 6 weeks of daily radiation, I tried to do something new with the medical staff and constantly changed purely to have fun. I started with quizzes asking the treatment staff questions about famous people who interestingly had either the same name or birthday as me (as I was required to indicate my name and DOB on each treatment day). I then started bringing my own music from the 50s, 60s, 70s, 80s through to very modern popular songs even using my own speaker, quizzing the staff on song title and artist. A competition was run with the radiation medical team asking how many treatment days it would take until I lost a golf ball sized amount of head hair on the left side of my head. Lastly, I asked them to sing for me during my last two treatments instead of me continually bringing songs in every treatment day. I really did have a fantastic time with the treatment team and they always went along with every weird treatment day idea that I had, one of the staff even sang for me on my second last day. Sometimes they would even be bopping to my treatment song playing from my speaker as I carried it into the treatment room on the day.

Fantastic assistance, recommendations and providing help with chasing information was also received from the Clinical Nurse Consultant throughout my entire time at Wollongong Hospital. She was able to provide great help with a range of varied questions that I had and just keeps on providing fantastic assistance.

The psychologist also really helped at different times during my treatments which also was brilliant. The great direction and advice they shared with me made me wish that somehow I had these discussions with them a very long time ago.

All the fun experiences and support mentioned above put aside, overall radiation treatment wasn’t easy. I’d often be tired, have headaches, stomach queasiness, have very low energy most days and sometimes be as dizzy as if I was drunk. I also noticed a dip in my memory and communication skills. I also never knew how I would feel each day, or even feel for half the day. I always had family at home and extra family members come and stay which really did help. Getting my mind off all the treatment effects by spending time with my family and friends plus all the daily and weekly fun with the radiation treatment plus help from the doctors, nurses and psychologist, made a massive difference for me.

Current Status

It is now 6 months from my starting seizure and operation, have finished all my radiation treatments, 6 weeks into chemo which will continue for almost a year, returned to work most days of the week and I’m moving on ahead! Neither the radiation or chemo treatments are easy but I am giving it everything that I have got to make the most of life and the future.

C.C. 18th Feb 2020.

Notes

Frequently asked questions

Will radiation therapy be painful?

While treatment is being delivered, you will not see or feel anything. The delivery of radiation is like having an X-ray or CT scan. You will hear the machine making a buzzing sound.

Will I be ‘radioactive’?

No, receiving radiotherapy will not leave you radioactive at any time. It is safe to be with family, children, friends and pregnant women.

Should I take medications and/or vitamins while receiving treatment?

It is important to tell your radiation oncologist all the medicines, supplements and vitamins you are currently taking. Continue to take your prescribed medicines as normal. Some vitamins or supplements could impact on the treatment.

Will I lose my hair?

Radiotherapy only effects the area being treated. You will only lose hair in this area. Please ask staff for more information specific to you.

Can I have a Covid-19, flu or tetanus vaccination?

Yes, it is safe to receive these while you are having your treatment.

Where can I park during treatment?

Free parking is available while you are having your treatment (not for doctors appointments).

Illawarra Cancer Care Centre: You can park in front of the centre, access by New Dapto Road.You will be provided with an access code to open the boomgate.

Shoalhaven Cancer Care Centre: You can park at the rear of the centre. Go to the boom gate, take a ticket and have it validated at the reception desk.

How long will treatment take?

The length (or course) of radiation is based on the specific plan designed for you by your doctor. Generally, you will be in and out of the centre within 30 to 60 minutes. Delays may occur on some days.

How much does my treatment cost?

For those eligible for Medicare, Medicare covers all costs for appointments with doctors, nurses and treatment.

Is there a problem if I missed a scheduled treatment?

Radiation treatment is small daily treatments to get the best outcome. Once treatment has started it is important that the rest are not delayed or missed. Sometimes medical reasons can cause a treatment to be delayed or missed. If this happens, your radiation oncologist will discuss this with you.

What should I wear to treatment?

Comfortable clothing.

Can I get the treatment area wet or go swimming during treatment?

Showering / swimming in salt water is fine. Swimming in chlorinated pools is not recommended. Pat the skin dry, do not rub it.

Resources

Online resources for additional information about your radiotherapy:

- The Illawarra Shoalhaven Cancer and Haematology Network (ISCaHN) http://www.islhd.health.nsw.gov.au/Cancer_Services/
- Targeting Cancer – www.targetingcancer.com.au
- Cancer Council – www.cancer.org.au/about-cancer/treatment/radiotherapy.html
- eviQ Cancer Treatments Online- www.eviq.org.au/eviQNavigationPatientsandCarers.aspx
- Beyond Five www.beyondfive.org.au/

Locally run programs

Look Good Feel Better – Free community service program designed to assist and manage the appearance related side effects of chemotherapy/ radiotherapy, call 1800 650 960.

CanConquer – Specialist allied health team providing targeted exercise and education for the patient pre, during and post cancer treatment. Please speak to your CNC to find out the referral process of attending CanConquer or call 02 4207 9999 (Illawarra).

Ask your clinical nurse consultant for more recommended information and resources

Cancer Council information

Cancer Council information centers are located on Level 2 at the Illawarra Cancer Care Centre and the main foyer at the Shoalhaven Cancer Care Centre.

There is a range of information and volunteers available to assist at both centres.

Notes

This information has been tested with Consumers

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If you would like to provide feedback on this booklet, please email ISLHD-ISCAHN@health.nsw.gov.au