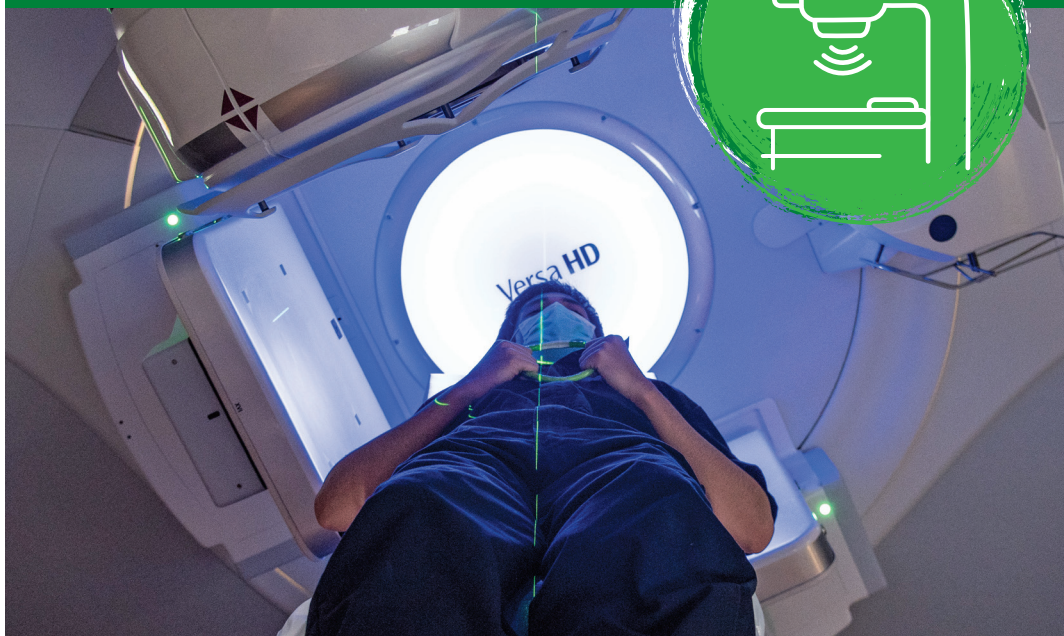


HAUMANU IRARUKE RADIATION TREATMENT

He aratohu mā te taiohi
A guide for young people



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Kia ora, nau mai haere mai.

Finding out you have cancer can be a big shock, leaving you with lots of questions and wondering what will happen next.

It can be overwhelming and difficult to take everything in. Often it's easier to make decisions and feel more in control when you know what to expect. We hope this information will help. It has been written by young people like you and cancer experts to give you all the information you will need.

You can read it all in one go, or just dip into different sections when you need to - whatever works for you.

*Whāia te mātauranga hei oranga mōu
Seek knowledge for the sake of your wellbeing.*

My NHI is:

My planned course of treatment is:

My radiation team includes:

My Radiation Oncologist is:

Treatment machine:

Radiation checklist

There are a few points that you may want to consider before you start your treatment.

Run through this list to see that you can check off the following. If you are still unsure, please talk to your medical team.

ANSWERED

Questions

I know what to expect from my radiation treatment

I know how many sessions I will have

I have given consent to start the radiation planning and treatment

I know what part of my body is being treated and the side effects I can expect

My radiation team has talked to me about safe sex and contraception options best for me

I have received the AYA cancer and fertility booklet

I have had the opportunity to see a fertility specialist and discuss options if relevant

If I have to travel for treatment, my travel and accommodation has been organised

Need more information or questions I still have are:

If I have questions or worries during treatment the best person to discuss these with is:

What is cancer?

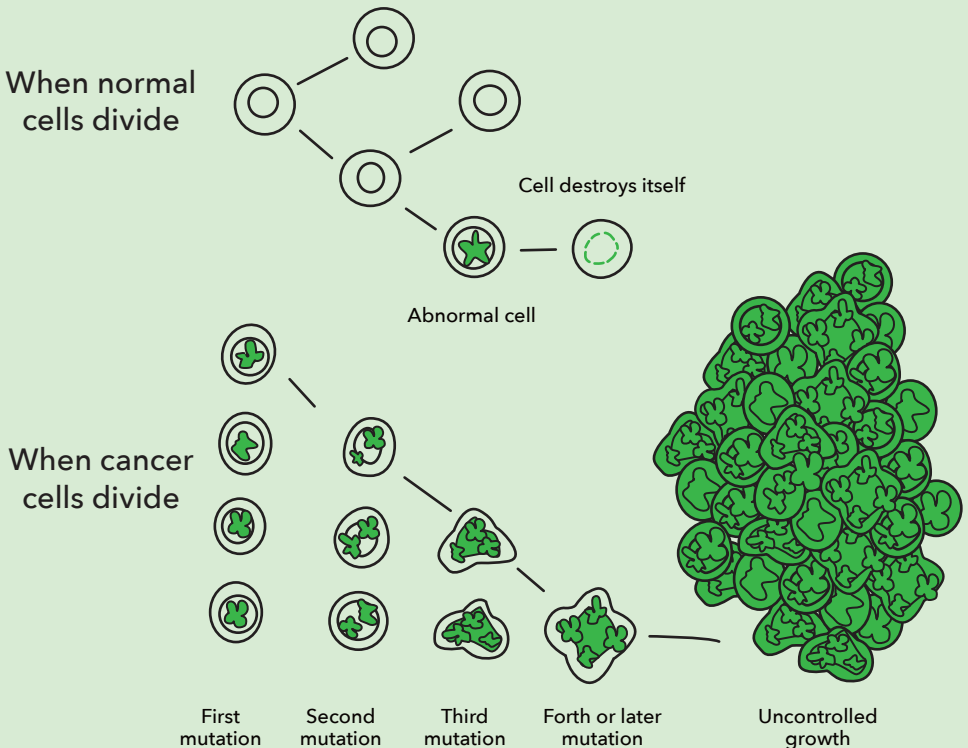
Your body is made up of millions of healthy cells. There are different types, each with their own unique structure and function.

Throughout your life, your cells continue to divide and make copies of themselves. These new cells help you grow or they replace older cells. However, if something goes wrong

when the cells are dividing, an abnormal cell may be produced. When this happens, the cell usually destroys itself.

But, sometimes, abnormal cells continue to divide, producing more abnormal cells. In some cases, they divide and grow faster than normal cells. This is cancer.

When normal cells become cancer cells



How does radiation therapy work?

Radiation therapy uses controlled doses of high-energy X-rays to destroy the cancer cells while trying to do as little harm as possible to your normal cells. It damages the cancer cells at their very core: their DNA. Eventually, by giving a little bit of radiation every day, the cancer cells get really shaken up and stop growing or attacking normal healthy cells. This means that the cancer cells shrink away or die.

Your normal healthy cells are smart: they can repair themselves while cancer cells can't.

Often you will have a number of treatments given over days. This is to give a little bit of radiation each day to attack the cancer cells, while giving your normal healthy cells time to recover between the treatments.

One benefit of radiation is that it's like having an X-ray. It's not painful and will only last a few minutes.


Why is radiation therapy used?

There are many reasons and ways to use radiation as part of your cancer treatment.

Another is it will only affect the area of the body being treated.

Unfortunately, side effects still happen as normal cells get in the way of the radiation beam and get irritated or inflamed in the process. This will only be in the area that is being treated.

This can be a lot to take in, but all of this will be discussed when you first meet your radiation doctor, known as a Radiation Oncologist, including what side effects to expect.



Your normal healthy cells are smart: they can repair themselves while cancer cells can't.

It could be used:

- To cure
- To control or to shrink the cancer
- To relieve symptoms
- In combination with other treatments like chemotherapy or surgery.



What will my treatments look like?

External Radiation Therapy

Radiation treatments are normally given as a series of short, daily treatment sessions called a fraction. Treatments can be given Monday-Friday. How many sessions you have will depend on:

- Where the cancer is
- What kind of cancer you have
- What other treatments you are having.

The number of treatments could be as little as one or two but it's more common to have many treatments over a span of 4 to 6 weeks.

Each daily session is only usually 15-20 minutes from walking into the treatment room to walking out and is totally pain free!

'The machine itself did not worry me but the mask I had to wear while receiving treatment was a bit daunting and claustrophobic at first, but I brought my own music for the team to play to take my mind off it. The sessions were only 15 minutes so I often reminded myself I only need to wear it for a very minimal period of my day.'

Young person





How will my treatments be delivered?

Radiation is delivered using a machine called a linear accelerator or LINAC for short.

It delivers beams of radiation that shine down onto your body, kind of like a light. The x-ray beams are shaped to you and can be delivered as the machine moves around you. Your treatments will be tailored specifically to you.

Where will I have my treatments?

These machines are highly specialised and because of this, there are only a handful of radiation treatment centres around Aotearoa.

If you don't live near a treatment centre, you may have to travel and be away from home for a number of weeks. If this is the case, your AYA key worker and radiation team will help organise travel and accommodation for you. You can always bring a support person with you.

If you have to travel for treatment

Think about bringing activities and things from home that you enjoy doing in your spare time. This could be reading books, devices, games, craft, music... the list is endless.

It's also a good idea to bring comforting things like your favourite pillow or blanket, or pictures from home. If the city is new to you, talk to your team about fun and free activities to do in the city.

Travelling for treatment can also be a good chance to connect with other young people.



Check out the AYA Cancer Network Website to search all the different organisations out there that can support you before, during and after your treatment eg Canteen and Leukemia and Blood Cancer (LBC).

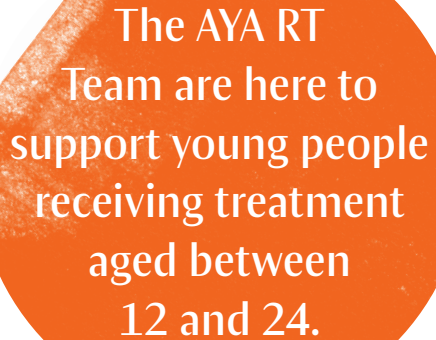
'The LBC service have been the best thing because they have helped me meet others going through the same thing of a similar age, helped me with petrol... supported me through work...'

Young person

'I tried to treat my time away from home as a holiday in a new city. I enjoyed going for walks through Hagley Park and exploring the surrounding city. I was given weekends off from the radiation treatment so my radiation therapists would often let me book an early Friday appointment and a late Monday appointment so I had more time to go home for the weekend if I wanted to.'

Young person

Your support - the AYA RT Team



The AYA RT
Team are here to
support young people
receiving treatment
aged between
12 and 24.

YOUNG PEOPLE
LIKE YOURSELF
DESERVE TO HAVE
YOUR OWN TEAM
WHO ARE THERE
JUST FOR YOU!

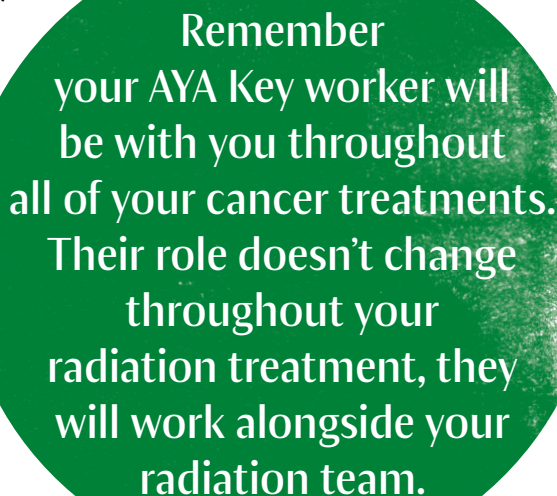
It's widely recognised young people have different needs compared to children and older adults, so this team are trained to guide you through the treatment path and to educate you and your whānau.

They are here to offer you support and assistance during treatment.

Your team could include:

- **RT AYA Champion:** A key 'go to' person during radiation treatment. They are there to help guide you throughout treatment and to connect you to the right people. They will check in and catch up with you as often or as little as you want them to.
- **Radiation Oncologists (doctor):** These are the doctors who will oversee your radiation therapy.
- **Radiation Therapists:** These are people who actually give you the radiation and will help you with anything that comes up during the course of the treatment.

- **Radiation Nurses:** They are there to undertake health assessments, give medications, and review you if needed throughout your treatment.
- **Other health care professionals:** You may work with a number of other health care professionals while undergoing radiation therapy such as a dietician, physiotherapist, psychologist, or social worker. They are an important part of the team and are there to ensure that your physical, emotional, spiritual, cultural and social needs are met.



**Remember
your AYA Key worker will
be with you throughout
all of your cancer treatments.
Their role doesn't change
throughout your
radiation treatment, they
will work alongside your
radiation team.**

TIME LINE

The following is a guide of the different appointments you will need during your radiation treatment.

Radiation Oncology First Specialist appointment (FSA)

The first appointment to discuss your treatment, side effects, risks and benefits

CT Planning

A CT and planning session to design your treatment

Mold Room or Radiology

Extra appointments might be needed to make special equipment or extra diagnostic scans like MRI or PET needed for planning. Not everyone will have these appointments

Finish

Radiation is completed. Talk with your team about what's next

Doctor Reviews

During and after your treatment you will be reviewed by a doctor to monitor and manage your side effects

Treatment

Attending daily session of your treatment

What appointments will I need to go to?

Radiation Oncology First Specialist Appointment (FSA)

When you first come to the Radiation Oncology department you will meet with a Radiation Oncologist. At this appointment they will discuss:

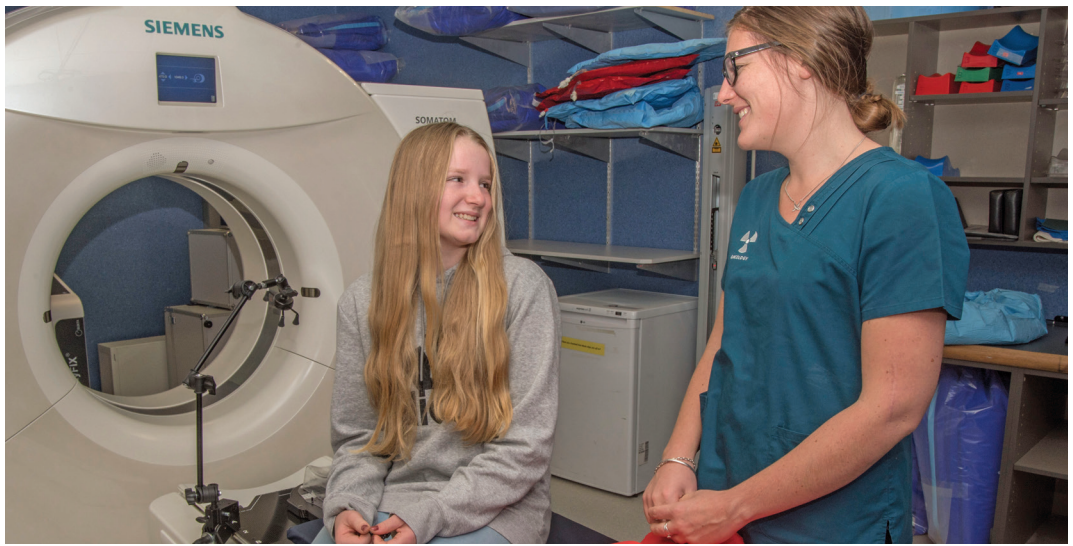
- What radiation is
- Why you might need it
- How many treatment sessions you will need
- The risks and benefits of treatment

- Any side effects that might occur during and after treatment, and what can be done to help you through.

At this appointment the doctor will ask you lots of questions to help build a picture of your health and what's important to you. These sessions can be long so it can be a good idea to bring a support person, whānau or your AYA Key worker.



Notes



Computed Tomography (CT) Simulation/ Planning Scan

A part of getting ready for radiation is a planning session. This involves a CT scan that will be used to personalise the delivery of your radiation therapy.

At this appointment the RT's (Radiation Therapists) will gather all the information that they will need to design your treatments. They will be figuring out what position you will be in for your treatment. They may need to make special equipment for you to use for your treatments, or they may need to give you small tattoo dots. The tattoos are the size of a small freckle. Both of these things help to get you in the right position each time you come for treatment.

Your job for the scan is to keep nice and still. Again, it won't hurt and the RT's will keep talking to you and explain what is happening.



You can bring in a device that has your favourite music that we can play in the background. You can also bring a support person, whānau or your key worker to this appointment.



Treatment Equipment

To ensure you are in the same position for each treatment session, you may need to have some special equipment made especially for you.

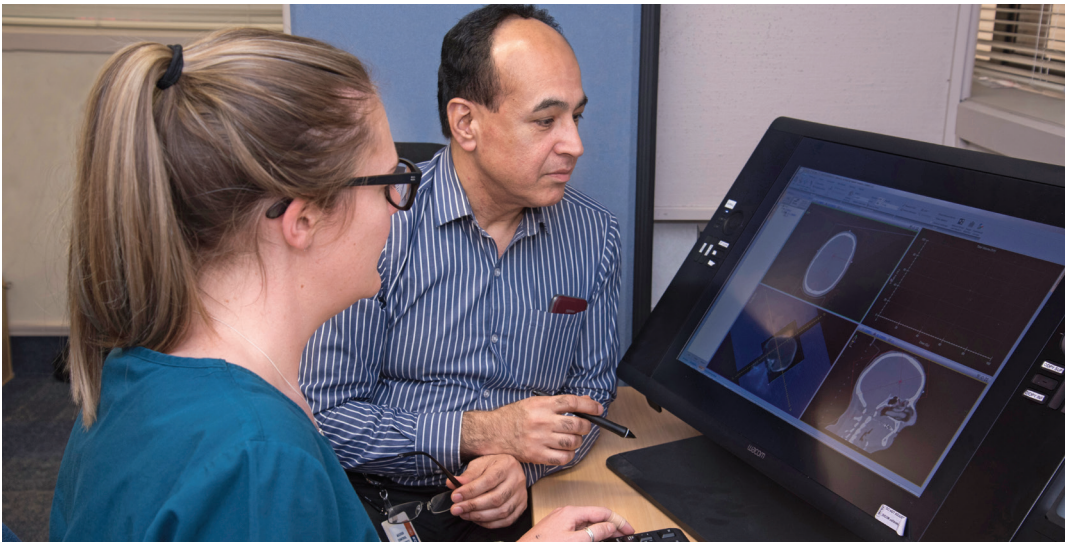
This could be a special cushion that is vacuum-formed to fit your body.

If you are having radiation around your head or neck, it is likely that you'll need a special type of mask moulded to you. This is clicked into the treatment bed to make sure that you are in the perfect position and to help keep you still. This mask is yours to keep after you have finished.

Don't worry, your team will talk to you about what this equipment could be and exactly what to expect. Here are some pictures that show some of the equipment used.

Don't worry,
your team will talk
to you about what
this equipment
could be and exactly
what to expect.





Treatment Planning

There will often be a few weeks between your CT planning session and actually starting your radiation treatment.

During this time your team will be busy designing your treatments on their fancy computers. You won't have any radiation appointments but we will be busy getting everything ready for you.

Daily Treatments

At these appointments you may need to get changed into a special gown or trousers so that the RT's can get to the area being treated or to see your tattoo dots. Depending on the treatment area, you may be able keep your own clothes on, so make them loose like sweatpants and t-shirt. We don't like metal in our treatment areas, so avoiding zips is really helpful if you don't want to change. The more comfortable you are the better!!



First Day

On your first day of treatment, you will spend time with the team going through what to expect. It can be a good idea to bring a support person with you and to write down any worries or questions that you or your whānau may have.

When you're good to go, the RTs will take you into the treatment room. They often have the lights dark and have special lasers that shine around the room. They help the RT's align you into your treatment position. Your only job is to keep nice and still.

It is okay to feel nervous about treatment; the idea of radiation can be daunting. However your team are there to support you the whole way through.

When you are in the perfect position your team will leave the room to start the treatment. They are always watching you on TV cameras, plus they can hear you and can talk to you on their microphones.

Often you will see the same team and get to know them. Before long, treatment will feel more routine and less scary.

Take home message:

The treatment doesn't hurt and all you have to do is keep nice and still.

Other than seeing the machine moving around you and it making a buzzing sound, that's it!

Tip

Tips to help you relax:

- Bring a support person with you
- Make a music playlist with your favourite music
- If you want, the team can talk to you through a microphone the whole time
- Your treatment is surprisingly quick. Often sessions will only be 15-20 minutes long
- Depending on where your treatment is, you could bring a stress ball to squeeze to take you mind off things.



Wellbeing During Treatment

Your whole team wants to make sure we look after all of your wellbeing, not just deliver your treatments.

If there are important things going on in your life, we want to know about them! We know that life carries on outside of treatment so sing out if you have important school, work or whānau commitments. We will try our best to ensure that you can keep your normal daily rhythms.

We are also eager to know about you and your identity. If you have any cultural or spiritual considerations we would love to know about them. This could be saying a Karakia or blessing the room prior to treatment, it could be telling the team what pronoun you identify with. Take home message: what is important to you is important to us, so let us know as we plan your treatments.

'I went for daily walks through the nearby gardens to stay active, and often went on little day adventures with my mum who stayed with me while away. I would often go for visits to Canteen to socialise and keep me busy.'

Young person

On Treatment Review

During treatment you will see many people from doctors, nurses, dietitians and a whole lot more.

The team will be monitoring your progress, help to manage any side effects you are experiencing, and to answer any questions that you and your whānau have.

Finishing Treatment

Some young people find finishing treatment hard.

This is because you go from seeing your team and having people to answer all of your questions daily, to then returning home to find a new normal. Another factor is that your side effects will continue, and in fact be at their worse a week to 10 days after your last day of radiation, and then take some time to heal.

In time you will be provided with a treatment summary and plan moving forward. Your radiation oncologist will be working closely with other team members caring for you. Usually you will head back for a follow up appointment 4-6 weeks after your treatment is completed.

A few good questions to ask before your treatment finishes are:

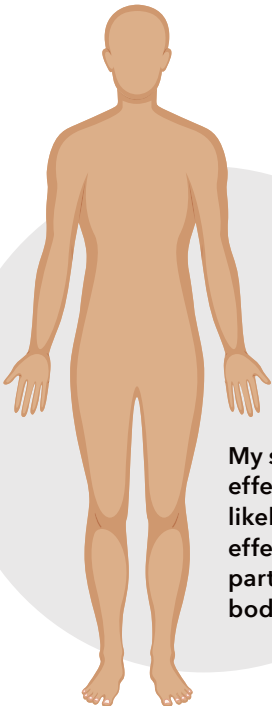
- **What happens next?**
- **If I can't manage my side effects or need new supplies or prescriptions, who do I contact?**
- **Will I have any more treatments or hospital appointments?**
- **Will I need any more tests? (eg bloods or scans)**
- **What are the best ways to look after my hauora, health and wellbeing?**
- **Do I need to be on any surveillance (future monitoring) programmes?**
- **If I have any worries or concerns, who is the best person to contact?**



What side effects can I expect?

Side effects occur because the radiation has to pass through normal cells to get to the cancer. Side effects can happen during treatment (called acute reactions), or a long time after (called late reactions). Your oncologist will cover both in depth before you start.

For the side effects that happen during treatment, most will ease four to six weeks after you finish radiation. Everyone is different. What side effects you experience will depend on what part of your body is treated, how much radiation is given, and what other treatments or medications you are on. This will be discussed with you before you start.



My side effects are likely to effect this part of my body

Some side effects that young people comment on during treatment are:

- Tiredness
- Feeling sick (mainly if your abdomen or brain is being treated)
- A change in appetite
- Hair loss – but this only happens to the area that’s being treated, not all over like chemo
- Skin changes (dry, flaky, red, itchy or sometimes sore skin).

‘I felt totally normal for the first few weeks, but in my last week I was shattered and definitely had to ditch school early or sleep a lot.’

Young person

Your team will give you more specific information on exactly what you can expect when you first meet with them.

Let your team know if you notice any symptoms and they can help you manage them.

Complimentary medicines and traditional medicines.

We understand that there may be many other forms of treatment, skin creams/topical agents, or medicines that are important to you, your whānau, and culture.

It is important that you tell us if you are taking, applying or ingesting anything alongside your treatments. This is because of the way that radiation interacts with medicines and in some cases, it can make your side effects worse, or affect how the radiation works.

If you are taking something that isn't prescribed, talk with your doctor to come up a plan to support your entire hauora wellbeing.



Things I need to check are safe to keep taking or doing during treatment: (e.g. vitamin C, kava, Aloe Vera creams, healing teas, etc.)

Sex and fertility

Because you are young, safe sexual practises and fertility will be discussed.

It is important that anyone having radiation practises safe sex (uses contraceptives/protection).

There are two reasons for this:

1. To prevent unplanned pregnancies. We know that radiation can cause harm to an unborn child, and if testis are treated it can cause sperm to be damaged, leading to birth abnormalities.
2. To stop sexually transmitted infections. Often during treatments your immunity is lower, putting you at greater risk of harm from an STI.

If you need help getting contraception or think there is a chance you could be pregnant, please discuss this with your team.

We know that there is so much more to sex and fertility than what is written here. There's two extra books for that!



If your team hasn't given you these booklets, check out the AYA Cancer Network's website for more information and resources written for you!

- I have received the booklet on Cancer and Fertility
- I have received the 'Young People, Cancer & Sex' information

With regards to fertility, some people's treatment can affect their ability to have a baby in the future. This doesn't happen to everyone, but if it is a risk for you it will be discussed before you start treatment, as well as ways to help protect your future fertility.



Notes

Common questions

Q: Am I safe to be around other people/ Will I be radioactive?

A: If you are having external radiation therapy it is gone from the body as soon as the machine stops. No part of your body becomes radioactive so you are safe to be around others.

Q: Will I lose my hair?

A: Radiation therapy is a targeted treatment. This means it only affects the area of the body the treatment is aimed at. Unless the treatment is targeted to an area where hair grows, like your scalp, face or groin area, you will not lose your hair. For example, if you are having treatment to your brain, unlike chemotherapy, you won't lose all of your hair.

You will only loose hair in patchy parts where the radiation goes. Often this is around your scar and this won't happen until the very end of your treatment. Sometimes hair loss can be permanent in patches. Your team will talk with you and give you lots of information if this is likely to happen.

Q: Should I continue to take regular medications?

A: Please continue to take all regular medications unless told otherwise. It is helpful to bring in a list of all the medications you are taking so a copy can be kept on your file.



Q: Will I notice or feel anything during treatment?

A: Short answer, no. The treatment doesn't hurt. You will only hear the buzzing sound of the machine and see the machine moving around you. Sometimes young people who have treatment to their brain say they smell something funny, like a metallic smell. This is nothing to worry about; it is the oxygen in the room turning into ozone that young people's senses sometimes pick up. Let us know if the smell is too much. We have some tricks up our sleeve to help with this.

Q: Can I work or should I restrict activities?

A: As long as you feel up to it, it is okay to continue with normal activities. You may become more tired than usual and notice changes in your body as a result of the radiation. Your Radiation Oncologist will discuss this with you each week when they see you in the Review Clinic. They can organise letters for your work, school, university or to your whānau, especially if you need to get out of the dishes!



Notes

Questions you might like to ask

It is helpful to make a note of any questions that you still have and discuss them with your oncology doctor or oncology nurse.

Here's a list of questions to spark korero with your doctor. Use the spaces below or over the page, to jot down any answers or any further questions you may have.

- 1 Are there any other treatments I can have instead?
- 2 What are the advantages/disadvantages of radiation?
- 3 Can I have a second opinion?
- 4 Which part of my body will be treated?
- 5 How long will each treatment take and how many sessions will I have to have?

1

2

3

4

5

6 Will I be able to carry on with my normal life when I am not at the hospital?

7 If I can have the treatment privately, how much will it cost?

8 Do I have to change what I eat or how I exercise during treatment?

9 What side effects can I expect from my treatment?

10 How long after my treatment ends will it take for the side effects to go away?

6

7

8

9

10



Notes

Glossary

Radiation Oncologist: Doctors who specialises in the delivery of radiation who will create a treatment plan, oversee your treatment and address any questions or side effects you may have.

Radiation Therapist: Specially trained people that plan and deliver your Radiation Therapy.

On Treatment Review Clinic (OTR): a weekly appointment where you will see a Doctor to address any questions or concerns that you have with your treatment.

Nurse: You may see a nurse to help with any side effects.

Computed Tomography (CT): A machine that takes x-ray pictures of your body that will be used to plan your Radiation Therapy.

Linear Accelerator: A machine that creates radiation from electricity for radiation treatment.



Please note:

This booklet is designed to introduce you to the topic of radiation treatment and to outline some of your options. If you want to know more, ask your AYA Keyworker, radiation therapist or radiation Oncologist for additional information.

This information is current at the time of publication but medicine is an area that is frequently changing. The AYA Cancer Network Aotearoa will endeavour to keep this publication updated, but please be aware that some of this information may change over time.

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INFORMATION

For further information go to: ayacancernetwork.org.nz

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