INFORMATION

AYA keyworker contacts and further information go to: ayacancernetwork.org.nz

AYA Cancer Network Aotearoa @NZayacancer ayacancernetwork

AYA Adolescent and Young Adult Cancer Services

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

CANCER & FERTILITY

MATE PUKUPUKU ME TE MATAHUA

Before, During and After Treatment

i Mua, i te Wā, me Muri i te Maimoatanga

AYA Adolescent and Young Adult Cancer Services

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

Please note:

This booklet is designed to introduce you to the topic of fertility and cancer treatment and to outline some of your options. If you want to know more, ask your AYA Keyworker, health professional or fertility specialist for additional information.

This information is current at the time of publication but fertility 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.

Thanks
to the AYA Cancer Consumer Advisory group for their role in helping to develop this resource

Whāia te mātauranga hei oranga mō koutou:

Seek knowledge for the sake of your wellbeing.

A: If you have frozen ovarian tissue from before treatment: the fertility doctor will discuss/explore possibilities with you to transplant your ovarian tissue back with the hope that it may function again and eggs can be retrieved.

Tip If you already have children you may not qualify for funded reproductive assistance. Talk to your doctor/nurse/specialist about your options.

Q: I'm infertile and I don't have frozen biological tissue. Can I still be a parent?

A: You may want to consider whether assisted reproduction, fostering and/or adoption could be options for you.

Assisted reproduction may involve donor eggs or embryos (using an egg or embryo donated by someone else) being used for IVF, or surrogacy.

Being a foster caregiver is when you take responsibility for a child but do not have legal parental status. Sometimes fostering a child might be in a short term capacity and sometimes it is long term or permanent.

Adoption is when you have the parental rights and responsibilities legally transferred from the birth parent/s to you. There are different kinds of adoption including open adoption, private adoption or adopting a stepchild.

Q: What are the criteria for reproductive assistance?

A: There are criteria that you and your partner may need to meet to be eligible for funded assistance for reproduction in New Zealand. Given you have had cancer you will likely fulfil this criteria. However, some regions include considerations such as weight range, not having smoked or abused alcohol/drugs in the last 3 months and whether you already have children. The fertility service will discuss these with you in detail.

If you and/or your partner do not meet the criteria you can still seek reproductive assistance from a fertility specialist, but you will need to fund this yourself.

Tip There are various options for having a baby regardless of your relationship status and/or your sexual orientation. Talk to your fertility specialist about these.

As a young person, being diagnosed with cancer means you will face some difficult decisions.

One of these may be thinking about whether you want to have children one day.

We know this is important because young people tell us it is. The quotes in this booklet are all from young people, like you.

'Even if you don't believe you should do it then, it may be important to you later. So you should have the opportunity.'

Checklist

TICK HERE		PAGE
☑	I received this booklet on cancer and fertility	
	Before Treatment	
○	I have talked with my doctor/nurse about my fertility risks	6
○	I have been offered an appointment with a fertility specialist to discuss my fertility preservation options	7
○	I have decided whether or not I will undertake fertility preservation	7-8
○	I have preserved: eggs embryos ovarian tissue other (circle which)	
○	- I received a copy of my consent form and results of my preservation from the fertility clinic	8 & 9
	During Treatment	
○	If I'm having radiation to my pelvic region, my doctor has told me about ovarian shielding and ovarian transposition	10
○	I have talked to a doctor/nurse about contraceptive use and ovarian suppression drugs during treatment	11
	After Treatment	
○	I have talked to a doctor/nurse about my fertility, now that my treatment has finished	12-13
○	I completed my after treatment fertility tests before the fertility specialist appointment	12
○	I have had an appointment with a fertility specialist to discuss: - my fertility status - further fertility preservation options	17-18
○	I have read the 'Symptoms of Premature Menopause' and will talk to my doctor if I experience these	12-13
○	Someone has explained to me that I should always consider myself potentially fertile and contraceptive use has been discussed with me	15
○	I am thinking about becoming a parent and know what I need to do and what reproductive assistance I am entitled to	15-18
	Other considerations (if applicable)	
○	I have updated my contact details with the fertility clinic where I stored biological tissue	9
○	I have had the opportunity to talk to a professional (nurse, counsellor, fertility support group) about my fertility worries	6 & 14-15
○	I have renewed my storage on my stored biological tissue (9.5 years after first stored)	9

If I have any more questions I can ask my AYA Keyworker

My Keyworker is:.....

Contact details:.....

Q: What happens at a fertility specialist appointment?

A: At this appointment the fertility specialist will discuss your options and your results from your fertility analysis and blood tests. This is a publicly funded consultation if you meet the criteria.

Fertility clinics funded for fertility preservation are located throughout New Zealand:

Fertility Associates (nationwide)
Repromed (Auckland)
Fertility Plus (Auckland)

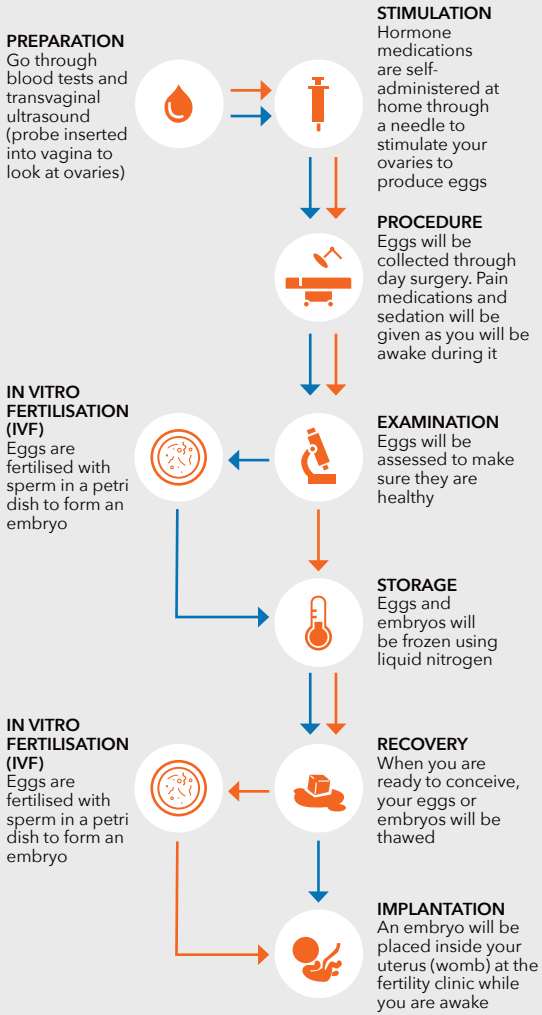
Q: I'm infertile or have reduced fertility and I <u>do have</u> frozen biological tissue. Can I still be a parent?

A: If you have frozen eggs or embryos from before treatment: the quality of these will be assessed and assisted reproduction may be an option for you. In-Vitro Fertilisation (IVF) is the only option clinics can use in this situation to try and create a pregnancy.

IVF increases chances of pregnancy through fertilisation, embryo development, and implantation. IVF works by using a combination of medicines and surgical procedures to help sperm fertilise an egg, and help the fertilised egg implant in your uterus.

What happens at the fertility clinic for eggs and embryo preservation and use?

→ Egg Preservation → Embryo Preservation



Source: adapted from Fertility Preservation pamphlet, Princess Margaret Cancer Centre.

considerations that may need to be taken into account in planning a family as a result of cancer treatment. For example, if you've had anthracycline chemotherapy there may be increased risk to your heart during pregnancy, so close monitoring may be required.

If you have not become pregnant after 12 months of trying, it is wise to seek fertility support to get both you and your partner assessed.

Tip Make sure your maternity care team are aware that you've had cancer in the past and the treatment you had. You may need specialist care during pregnancy.

Q: Can I pass cancer on to my child?

A: Many cancer survivors have healthy children after cancer. The birth defect rate in children of survivors is similar to the rate in the general population (if conceived more than 12 months after treatment completion). They also do not appear to be at higher risk for getting cancer, unless the parent's cancer is a genetic and inherited type. Talk to your doctor to find out if your cancer is genetic.

My fertility tests indicate I am infertile or have reduced fertility

Q: What if my fertility tests show I have no eggs or a low egg supply (i.e. infertile or reduced fertility)?

A: If you have not been referred prior, your GP, a Family Planning doctor or specialist will need to make a referral to your local/regional fertility service for a consultation. At this appointment the fertility specialist will discuss your potential options. This is a publicly funded consultation if you meet the criteria.

Tip Make sure you have done your tests before your fertility clinic appointment.

Infertility (not being able to have your own biological children) or reduced fertility could be one of your long term side effects from treatment.

As a result of treatment one of the following will happen:

1. No treatment-related effect on your eggs
2. Fewer healthy eggs left
3. No healthy eggs left.

This booklet will help you understand your fertility risks and parenthood options. It covers things to consider before, during and after treatment. It also covers your fertility options as well as coping with infertility.

You can read the whole booklet now, or just read the parts that give information on the stage you are at - before, during or after treatment. The checklist on page 4 can guide you.

Your best fertility preservation options exist **before treatment**. However, there are some options available during treatment.

Hearing you have cancer changes your life. Educating yourself about the risks involved allows you to make the best decisions for your future.

Treatment-Related Fertility Risks

It is important to talk to your doctor or nurse about your specific treatment-based fertility risks.

Cancer and its treatments (chemotherapy, radiotherapy, surgery) can affect your ability to have biological children. Infertility risk is different for everybody and will depend on the type of cancer and treatments you have.

Females are born with all the eggs they will ever have. This means that if some eggs are damaged or destroyed by cancer treatment (i.e. chemotherapy or radiotherapy) they cannot be replaced because no new eggs will develop. This loss of eggs can reduce your chances of having biological children. Surgery or radiotherapy to your reproductive organs, pelvic area, or pituitary gland can be another risk to your fertility as this may damage your eggs or make carrying a baby difficult.

If your doctor believes you are at risk of infertility as a result of treatment (no matter how small this chance may be) they should discuss this risk with you.

'For a young girl diagnosed with cancer it is really important to tell her in the beginning how her fertility may be affected.'

Tip

Ask your doctor to mark on the below Fertility Risk Scale where they perceive your risk to be.

Fertility Risk Scale: What is my risk of being infertile?

High	Medium	Low
(More than 80%)		(Less than 20%)

◯ Risk unknown (tick if applicable)

Infertility and Emotions

Finding out that your treatment could impact your fertility may make you feel sad, worried, or angry. If you have a partner they may also have these feelings. Support is available. It is a good idea to talk to someone who can help you with what you're going through – friends, whānau, a partner, a counsellor or a specialist.

Fertility and Contraception

Even with reduced fertility, there is still a chance you could get pregnant if you are having unprotected sex with a male partner/s so, unless you have been told otherwise, it is best to **always assume you are fertile and use some form of contraception**. There are situations where young women have thought they were infertile, haven't used contraception and this has then resulted in a pregnancy.

'One day I went to the doctors not feeling well and found out I was pregnant again. Even the doctor there was shocked because of the way they had put it out that I was not going to have kids again. Contraception? Didn't think I needed it.'

What happens when I'm ready to be a Parent?

Your first step should be to complete fertility tests, such as blood tests and/or ultrasound, if you have not already done so. You will need recent results - done within the last 12 months. These results will indicate your current fertility status. Discuss them with your GP, specialist or at a fertility specialist appointment.

My fertility tests indicate I am fertile

Many cancer survivors have children after treatment. Before you decide to have your children, you should talk to your doctor about how long you should wait after finishing treatment. The normal suggestion is 12 months after treatment has completed.

If you are planning on becoming pregnant it is important to discuss with your specialist any additional

What Happens if I'm Infertile?

If your tests show you are infertile your doctor or a fertility specialist will discuss your options with you. Finding out you have fertility issues can leave you with feelings of sadness and grief. It is a good idea to talk to someone who can help you with what you're going through – friends, whānau, a partner, a counsellor or a specialist. Sometimes talking to others who have been through similar experiences can help.

- All fertility clinics are required to have counselling services available. These counsellors know the importance of offering support and will help you learn coping strategies and build resilience for your journey. The cost of counselling services may be covered if you meet the criteria.
- Fertility New Zealand is a charity that organises support groups for people experiencing fertility issues or facing infertility. **fertilitynz.org.nz**
- Your local cancer support services (through the hospital or cancer charities) may provide psychological services or be able to connect you with someone who does.

Talking to a partner about infertility

Going through cancer can be life changing and can sometimes bring complications to relationships you are in during or after treatment. Support is available. A counsellor or health professional may be able to help you think of ways to bring this up with a partner and what clear information you can tell them to help them understand. Your partner may also experience some feelings of sadness about infertility. Encourage them to think of places they can get support, such as friends, family, and fertility support groups.

If your partner was there during treatment they may have some idea of what your long term fertility impacts will be. Talking with them and sharing your emotions together is an important part of having a respectful and intimate relationship.

Deciding what to tell a new partner about your cancer treatment and fertility is a personal choice. You may want to wait a while before sharing information, but it is good in the long term to be honest about your concerns and not feel like infertility is something you need to feel secretive or ashamed about.

Fertility Preservation

Before Treatment

It is an important and expected part of your cancer care that you are provided with the opportunity to discuss your options for fertility preservation prior to starting treatment. Your cancer treatment team should organise this for you.

Please note: you may not always have the option of fertility preservation before starting treatment as this will depend on how well you are, your type of cancer, and how soon treatment needs to begin. However, it is important to be informed about any risks to your fertility.

Q: Is there anything I can do before starting treatment to improve the chances of having biological children in the future?

A: Yes. You may be able to freeze your eggs or embryos (a fertilised egg in the early stages of development) before treatment so that they can be used a later stage.

If freezing eggs or embryos is not an option for you the specialist may discuss the option of freezing ovarian tissue (before treatment) or the administration of ovarian suppression (GnRH analogues) drugs (during treatment) where available and appropriate for your situation. Freezing ovarian tissue is not currently funded for all (i.e. you may have to pay for it yourself).

Tip A fertility specialist is the best person to discuss these things with – they will know all the latest options and processes.

Fertility preservation options in more detail

There are several options that may be available for young people before treatment (p.8) or during treatment (p.10). Together with a fertility specialist you can find out which of the following options are available and right for you. This may depend on your age and situation. Some of these processes are publicly funded and some you would need to fund yourself. Some of the procedures may take place at a fertility clinic and some at the hospital where you are receiving treatment.

Egg freezing (Oocyte cryopreservation) – publicly funded if you don't have children*

This involves collecting and freezing some of your eggs until you are ready to use them. The process usually requires hormonal stimulation to mature the eggs. This process takes 10 to 14 days.

When you are ready to try to get pregnant, the eggs are thawed and can be fertilised with your partner's or donor sperm to create embryos.

Embryo freezing (Embryo cryopreservation) – publicly funded if you don't have children*

Embryo freezing requires sperm, so is an option if you are in a relationship with a male partner and he is willing to use his sperm, or if you have donor sperm. The process usually requires hormonal stimulation to mature your eggs. Your eggs are then collected and fertilised with the sperm. The embryos are frozen until you are ready to use them. This process takes 10 to 14 days.

When you are ready to try to have a baby, the embryos are thawed and placed into your uterus (womb) or into a surrogate (another person who carries the baby for you).

Check out the flowchart on p.17.
It helps explain these processes.

* There are criteria that you may need to meet to be eligible for funded egg or embryo freezing. One is that you don't already have children, but some regions in New Zealand also have considerations such as weight range, or not having smoked or abused alcohol/drugs in the last 3 months. Talk to the fertility clinic about their criteria.

Tip Egg freezing can be a simpler option for young people. Using frozen embryos requires the permission of both partners. This can be complicated if you are no longer with that partner in the future.

Egg and Embryo Testing

If you freeze eggs or embryos these will be tested for number and quality and you will receive a copy of these results.

Ovarian tissue freezing (Ovarian cryopreservation) - self-funded

Ovarian tissue freezing is not currently publicly funded. However, for those treated at one of the two child cancer centres there may be funding available to contribute to this procedure. It is a technique that is still considered experimental in New Zealand. It may be an option if you do not have a lot of time, cannot have hormonal stimulation, or have not yet started periods.

Ovarian tissue freezing is a surgical procedure that involves removing a small bit of tissue from your ovary and then freezing it. A fertility specialist will discuss with you that in the future it may be possible to transplant your ovarian tissue back into your body with the hope that the ovary starts functioning again and eggs can be collected.

common. It can also be called temporary menopause. Although your periods return, you are at higher risk of going into premature menopause a few years later.

Premature menopause

Menopause is when your ovaries have no more functioning eggs to release, and you don't get your period anymore – signalling the end of your ability to have a biological child. Premature menopause is when this happens before you are 40 years old, it can also be called early, primary or premature ovarian failure. If you are experiencing any of the symptoms of premature menopause listed below please discuss this with your health care team. They might refer you to a specialist such as a gynaecologist. The specialist can help you by advising you on ways to manage your symptoms and reduce discomfort such as through medication (e.g. hormone replacement therapy), supplements, diet and exercise.

Symptoms of premature menopause can include:

- Vaginal dryness
- Loss of interest in sex
- Suddenly feeling hot (sometimes called hot flashes/flushes)
- Discomfort/soreness during sex
- Sore/tender breasts
- Fatigue
- Irregular periods

Q: If I am at risk of premature ovarian failure can I do anything now to preserve my fertility?

A: If your tests show you are at risk of premature menopause you should consult with a fertility specialist to explore and consider any fertility preservation options that may be available to you, including starting a family earlier than you may have planned.

Tip Having a period return may or may not signal fertility. The best thing is to talk to a health professional and have some tests done so you know what your fertility status currently is and what can be done to support you.

There are a number of people you can discuss this with to start with:

- Your GP (family doctor)
- Your specialist
- Family Planning doctor
- Fertility specialist
- AYA Keyworker
- Late Effects Team (LEAP) (if you're under LEAP)

These people can either help you find out about your fertility or refer you to someone who can. Some regions have dedicated fully funded fertility services – your AYA Keyworker will know.

Q: What happens when I see a doctor about my fertility?

A:
- They will take a history of your periods (menstrual history) - when they started, how long they last, how long between periods, whether they are regular or irregular, and whether you are having any menopausal symptoms
- They will ask about your current medication use (contraception, hormone replacement, or medication to assist sexual functioning)
- They will talk to you about your sexual health and function
- They may ask about your relationship status, any relationship concerns you have and how you are feeling (psychological state)
- They will run some tests. These are to help show what your after-treatment fertility status might now be. Depending on where these tests are undertaken there may be a charge for them.

After-Treatment Fertility Tests

AMH: a blood test to determine ovarian reserves (an estimate of how many eggs you have remaining in your ovaries)

Ultrasound: to examine your ovaries

Hormonal blood tests: to check hormone levels, done at specific times in your menstrual cycle

Blood tests for viruses: to check for HIV, Hepatitis B and C, and syphilis.

Temporary ovarian failure and premature menopause

Some women may go into temporary ovarian failure or premature menopause. It can be hard to predict who this will happen to as treatment affects everyone differently.

Temporary ovarian failure

This is when your periods stop for a while during and after chemotherapy, even for up to two or three years, and then the ovaries start to work again. This is referred to as temporary ovarian failure and it is extremely

Consent form – for egg, embryo and ovarian tissue freezing

You will need to sign a consent form providing your permission to store biological tissue (eggs/embryos/ ovarian tissue) at the fertility clinic.

The consent form also outlines things you may need to consider like:

- if something should happen to you who may use your biological tissue?
- who is a secondary contact person the fertility clinic can get in touch with if they lose contact with you? When deciding on your secondary contact think of someone (like a parent or adult relative) who is unlikely to move around in the next 10 years.

You will be given a copy of your consent form and you can request a change to the details you have provided at any time by contacting the clinic where your biological tissue is stored.

Tip **Take along contact details (name, phone number, address) for your secondary contact person when you go to the fertility clinic.**

Storage – for egg, embryo and ovarian tissue freezing

If your fertility preservation is successful your biological tissue will be frozen, labelled with your name and stored.

If you meet the criteria, storage is free for up to 10 years. After 10 years, if you have kids already, or if you are storing ovarian tissue, you will need to pay for storage yourself. The cost of storing eggs and embryos differs slightly between providers, but is currently approximately $300 for one year. Storing ovarian tissue is approximately $600 per year.

The standard initial storage period for biological tissue in New Zealand is 10 years. To extend this you need to apply for approval from an ethics committee. This process needs to be completed six months before the expiry date. The fertility provider storing your tissue will be able to assist you with this application.

Keeping your contact details (phone and address) updated ensures the clinic can get in contact with you for the guaranteed continuation of your storage.

Tip **If you stored eggs, embryos or ovarian tissue - record the details here:**

I stored eggs / embryos / ovarian tissue (circle)

Stored at (name of clinic):

Clinic contact number:

Date stored:

Date to re-apply for storage: (9.5 years after first stored)

Tip If you want to store your frozen biological material for longer than 10 years you need to start the process of applying for this extension 6 months before the expiry date of storage.

During Treatment

Ovarian suppression drugs (GnRH analogues) during chemotherapy – publicly funded

This is a drug that can be given to suppress your period (menstruation) and slow down or stop the function of the ovaries. This is done to reduce the effects of chemotherapy on ovarian function. There are conflicting opinions on the effectiveness of this on your fertility (ranging from definite benefits to no benefit). Because of this uncertainty it is not routinely offered if other options are available.

Ovarian shielding and ovarian transposition – publicly funded

These are options if you are receiving radiotherapy to the pelvic region as part of your cancer treatment. Ovarian shielding is where the ovaries can be shielded from radiation beams by using protective coverings placed on your stomach. Ovarian transposition is where ovaries are surgically moved to another area in the body. These methods are designed to minimise the radiation to your ovaries. By decreasing the amount of radiation, you can lower the risk of damage to your ovaries and your eggs.

Is Fertility Preservation for me?

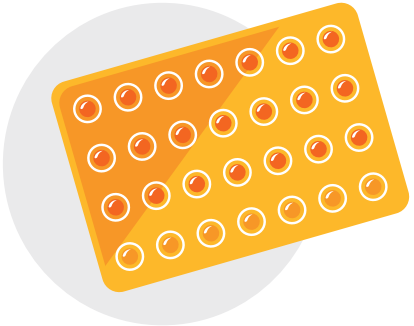
Q: What if I have never thought of wanting children in the future or I am single?

A: By preserving your fertility you are giving yourself options for the future. Although you might not want children now or in the future you could change your mind. You never know how you or a potential future partner might feel later on about having children. It is really important to seriously consider and explore your fertility preservation options.

Q: What if I identify as LGBTQ+?

A: All young people with cancer have the right to good fertility information and an opportunity to preserve their fertility. If you feel uncomfortable discussing any of this with your cancer treatment team, or want additional support, services like Rainbow Youth or Gender Minorities Aotearoa can provide this.

Contraceptive Use During Treatment



Unsafe to get pregnant

It is important to continue to use contraception during treatment to prevent unplanned pregnancies and sexually transmitted infections. The drugs you are given for treatment can increase the risk of miscarriage and birth defects for children conceived during treatment. These effects may last for 12 months after treatment finishes.

Hormonal based contraception (i.e. the Pill, the injection, implant)

It is not always suitable to continue on hormonal based contraception such as the Pill, the injection (Depo Provera), or other contraceptives (IUD or rods) during treatment. They can be less effective and have an increased risk of side effects. Talk to your doctor or nurse about your current contraception and whether it is suitable.

Tip Also check out the AYA Cancer Network Aotearoa's booklet **Young People, Cancer and Sex.**

Finishing Treatment

Q: How do I know if I'm fertile?

A: You may experience permanent or temporary infertility as a result of treatment. For some young people their fertility will not have been affected, for others, they might only have a small number of eggs left, indicating the likelihood of premature menopause, for others, treatment will have made them infertile.

You should get your fertility checked 12 months after you have finished treatment - even if you don't plan on having children. Knowing your fertility status means you and your doctor can explore ways of managing this. Whatever your results, health professionals can discuss these and your options with you.