

CANCER & FERTILITY

MATE PUKUPUKU ME TE MATAHUA

Before, During and After Treatment
i Mua, i te Wā, me Muri i te Maimoatanga



INFORMATION

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

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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.

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Whāia te mātauranga hei
oranga mō koutou:

Seek knowledge for the
sake of your wellbeing.

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

Q: What happens at a fertility specialist appointment?

A: At this appointment the fertility specialist will discuss your options and your results from your semen 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: 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.’



TICK
HERE

Checklist

PAGE

<input checked="" type="checkbox"/>	I received this booklet on cancer and fertility	
Before Treatment		
<input type="checkbox"/>	I have talked with my doctor/nurse about my fertility risks	6
<input type="checkbox"/>	I have decided whether or not I will bank sperm	7
<input type="checkbox"/>	I have banked sperm	
<input type="checkbox"/>	- Before banking sperm I have read the 'Tips for Sperm Banking'	8
<input type="checkbox"/>	- I banked sperm more than once (time permitting)	8
<input type="checkbox"/>	- I received a copy of my consent form and sperm analysis from the fertility clinic	9
During Treatment		
<input type="checkbox"/>	I'm having radiation to my pelvic region and my doctor has told me about radiation shielding	11
<input type="checkbox"/>	I have talked to a doctor/nurse about contraceptive use during treatment	12
After Treatment		
<input type="checkbox"/>	I have talked to a doctor/nurse about my fertility, now that my treatment has finished	13
<input type="checkbox"/>	I have been offered the opportunity to have my sperm/ semen tested now that I'm one year after treatment	13
<input type="checkbox"/>	Someone has explained that I should always consider myself potentially fertile and contraceptive use has been discussed with me	15
<input type="checkbox"/>	I am thinking about becoming a parent and know what I need to do and what reproductive assistance I am entitled to	16-18
Other considerations (if applicable)		
<input type="checkbox"/>	I have updated my contact details with the fertility clinic where I stored sperm	10
<input type="checkbox"/>	I have had the opportunity to talk to a professional (nurse, counsellor, fertility support group) about my fertility worries	6 & 14-15
<input type="checkbox"/>	I have renewed my storage on my stored sperm (9.5 years after first stored)	10

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

My Keyworker is: _____
Contact details: _____

Q: I have low sperm count/am infertile and do have banked sperm. Can I still be a parent?

A: If you have banked sperm or have a low sperm count assisted reproduction may be an option for you.

For those with a female partner:

The fertility doctor can use your sperm alongside eggs from your partner in a process called In-Vitro Fertilisation (IVF) to try to create a pregnancy.

For those with a male partner:

If you and your partner want to father a child with your biological material then you will need to



undertake the process of finding an egg donor and/or surrogate. The fertility doctor can then use your sperm alongside eggs from your donor/surrogate in a process called IVF to try to create a pregnancy.

Tip Make sure you have done a recent semen analysis and required tests before your fertility clinic appointment.

Q: I'm infertile and don't have banked sperm. 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 sperm (using sperm donated by someone else) being used for IVF.

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.

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

Your first step should be to complete a semen analysis and blood tests to check for HIV, Hepatitis B and C, and VDRL/TPHA, if you have not already done so. You will need recent results - done within the last 12 months.

The semen analysis results will indicate your current fertility status. Discuss them with your GP, specialist or at a fertility specialist appointment.

I have a normal sperm count

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

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.

I have a low sperm count or I am infertile

Q: What if my semen analysis shows I have no sperm or a low sperm count?

A: Your GP 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, and is open to people with either a male or female partner as part of government funding for infertile couples.



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 (either permanently or temporarily):

1. No treatment-related effect on your sperm
2. Lower sperm count and sperm quality
3. A loss of sperm production.

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.

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.

Males do not start to produce sperm until they enter puberty (around 11-14

years old), and then usually they will keep producing it for the rest of their lives. However, cancer treatment can damage your sperm production. This means you may stop producing sperm, or produce less sperm. This can reduce your chances of having biological children.

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.

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.

Your partner may also experience some feelings of sadness about infertility. Encourage them to think of places they can get support, such as friends, whānau, 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 and Contraception

Even if your initial semen analysis results indicate low fertility or infertility, your sperm production can return. If you are going to have sex with female partner/s it is best to **always assume you are fertile and use some form of contraception.** There are plenty of situations where young people have thought they were infertile, haven't used contraception and this has then resulted in a pregnancy.



If you **have** stored sperm - consultation and semen analysis at a fertility clinic - publicly funded (free)

If you stored sperm prior to treatment you will need to contact the fertility provider where your sperm is stored and say "I have sperm banked with you and I would like to make an appointment to come in and talk about it". At this appointment they will

arrange for you to produce a sample for a semen analysis. This will be the same process as when you banked your sperm. For those with stored sperm, the after-treatment fertility appointment and semen analysis is publicly funded. Please note if you are found to be fertile your stored sperm will be discarded unless you choose to privately fund the ongoing storage of your sperm.

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.

Q: If I am infertile will I still be able to ejaculate (cum)?

A: Yes, you will still be able to ejaculate as you will still have semen; however the semen won't carry sperm.

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. A counsellor or health professional may be able to help you think of ways to bring infertility up with a partner and what clear information you can tell them to help them understand.

Fertility Preservation

Before Treatment: Sperm Banking

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.

Please note: you may not always have the option of banking sperm 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 prior to starting treatment to improve the chances of having biological children in the future?

A: **Yes.** You may be able to freeze your sperm before treatment so it can be used at a later stage. This is called sperm banking and is when you bank your sperm with a fertility provider and have it frozen for future use. Your banked sperm will be stored with a fertility provider until you want to use it in the future.

If you don't already have children and have started puberty both the consultation with a fertility specialist and sperm banking are publicly funded (free).



Semen is the fluid that carries your sperm. It is also called cum. Sperm is the male reproductive cell. Sometimes people use these terms interchangeably, but they are different.

Q: What does sperm banking involve?

A: You give a sample of your sperm by masturbating (jacking off/wanking) and ejaculating (cumming) into a plastic container. This will either be at the hospital, in a private room in the fertility clinic, or you may be able to do this at home if you can get the sample to the clinic within one hour.

In rare instances, if you are unable to provide a sperm sample by masturbation, there may be the option of surgical sperm collection (testicular biopsy or testicular aspiration) to obtain your sperm. This will be done under general or local anaesthetic.

'Even though it was embarrassing it's worth doing it'

Q: What if I'm nervous or embarrassed?

A: It is totally normal to feel nervous or awkward about giving a sperm sample. Remember, the doctors and nurses are used to this, so they will understand if you're feeling this way. Also, remember heaps of people in your situation have banked sperm.

'The person who talked to us about it was really informative, explained everything to us and told us everything to do with it. And that helped a lot, also to make it not so awkward.'

Q: What if I can't get an erection?

A: Your ability to masturbate and produce a sample can be impacted by your age, type of cancer, or how unwell and tired you are. If this happens to you then you may be asked to come back to provide a sample on another day, if time allows.



Sperm banking

1. It is important to have a private space where you feel comfortable to do your sample (e.g. having a lock on the door at home, or you'll be given a private room at a clinic)
2. Do not spit or use moisturiser, lubricant or any other cream or lotions, because this can kill the sperm
3. You only need to ejaculate ('cum') once into the container. This will only appear as a small amount in the container, which is totally fine
4. Make sure you get all the semen/cum in the container including the first part that comes out, as this contains the most sperm
5. Wash your penis and hands before doing the sample
6. You might find it helpful to use some visual material (e.g. magazines, websites) or assistance from your partner
7. To get the best sample, try not to have sex and/or masturbate for three days before giving your sample
8. You may be asked to do a second bank on another day, if time allows.

Finishing Treatment

If sperm production is to return this usually happens in the first few months to two years after treatment; however it is possible for fertility to return years later than this.

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 produce a small number of sperm, and for others treatment will have made them infertile. We cannot predict which young people will experience issues with fertility during and following treatment.

Whatever your results, health professionals can discuss these and your options with you.

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

- Your GP (family doctor)
- Your cancer specialist/surgeon
- 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.

Testing my fertility - when and how

It is advised that you wait at least one year after treatment completion to have your semen tested.

Semen analysis involves producing a sample of semen (cum) to be tested to see if it contains sperm. The process for producing the sample is the same as described in the previous sections: 'What does sperm banking involve?' and 'Tips: Sperm Banking'.

If you have not stored sperm - semen analysis at a community lab - publicly funded (free)

If you did not store sperm prior to treatment your GP can give you a form to have your semen tested at a community lab. This is a free service, but requires you produce your sample somewhere else (e.g. at home) and bring it to the lab within one hour. There are specific labs to undertake this and they are only open certain hours, so make sure you check which lab you're supposed to go to and what its opening hours are.

Another option is to get a referral to a fertility clinic through your specialist or Late Effects team. This referral will be for semen analysis only and does not include a consultation. If you have already been discharged from Late Effects, you can still contact them for advice and possibly a referral.

Contraceptive Use During Treatment

Unsafe to get someone pregnant

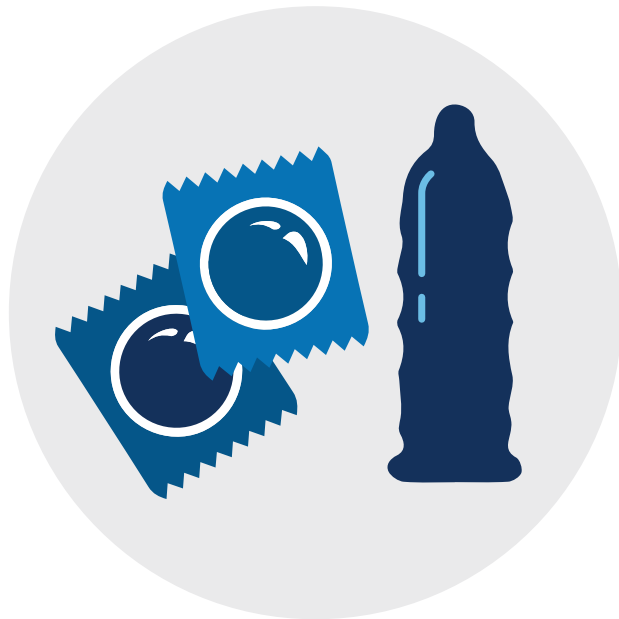
It is important to continue to use contraception during treatment to prevent unplanned pregnancies and sexually transmitted infections.

Sometimes the drugs you are given for treatment can damage sperm and increase the chance of abnormalities in a baby who is conceived during this time. Depending on your type of cancer and treatment, these effects may last for 12 months after treatment finishes. Ask your doctor or nurse how long after treatment you should be careful to not get someone pregnant.

Exposure to chemotherapy

While you are undergoing chemotherapy, condom use is advised to protect your sexual partner/s from chemotherapy exposure from your bodily fluids.

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



Testing

Once you have provided a sample your semen will be examined for health and quantity (sperm count).

You will also be required to undertake a blood test for HIV, Hepatitis B and C, and VDRL/TPHA. This ensures the correct storage of your sperm within the facility.

You will be sent a copy of these results.

Q: What if my results show poor health and quantity of sperm?

A: Being tired and unwell can impact your ability to produce a good sample. If no sperm is present in your sample you will be given the opportunity to be referred to a fertility specialist (funded). If the quality or sperm count is low you will be encouraged to bank again, if time allows.

Consent form

You will need to sign a consent form providing your permission to store your sperm.

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

- if something should happen to you who may use your sperm?
- who is a secondary contact person the 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 sperm is stored.

Tip Take along contact details (name, phone number, address) for your secondary contact person when you go to bank sperm.

'The person that told me about sperm banking explained it to me really well and why I needed to do it. So that if I couldn't have babies, I would have a backup and would have a chance of having babies.'

Sperm storage

If sperm is present the sample will be frozen in liquid nitrogen and will be fully labelled with your name and details.

If you meet the criteria, storage is free for up to 10 years. After 10 years, or if you have kids already, you will need to pay for storage yourself. The cost of storing sperm differs slightly between providers but is currently approximately \$300 for one year. If you find out after treatment that your fertility *hasn't* been affected by treatment then you can choose to keep your pre-treatment sperm frozen, but you will have to pay for the storage.

The standard initial storage period for sperm 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 sperm will be able to assist you with this application. It is believed that correctly stored sperm can be stored indefinitely and still used successfully.

You need to notify the clinic storing your sperm if your contact details change (phone number, address). This ensures they can get in contact with you for the guaranteed continuation of your storage.

Tip If you banked sperm - record the details here:

First sperm bank date:
(if applicable)

I banked my sperm at:

Clinic contact number:

Date to re-apply for storage:
(9.5 years after bank date)



Fertility Preservation During Treatment: Radiation Shielding

If you are having radiation to your testicles or to your pelvic area, special shields can be placed over one or both of your testicles to lower the risk of fertility damage.



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 (through banking sperm or radiation shielding) you are giving yourself options for the future. You never know how you or a potential future partner might feel later on about having children. It is really important to seriously consider your 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.