Fertility for girls, women, and people recorded female at birth

Lymphoma Australia Nurse hotline: 1800 953 081 nurse@lymphoma.org.au

We recognise some people identify differently to the sex recorded at birth. For the purposes of discussing your fertility, please use the fertility fact sheet that aligns with the sex recorded for you at birth.

If you have not yet reached menopause, your fertility can be affected by lymphoma treatments. Even children who have not yet reached puberty can have problems with fertility later in life. This brochure will discuss what you need to know before you start treatment, and things to consider after treatment.

What is fertility?

Fertility is your ability to reproduce by getting pregnant, and carrying a pregnancy to term to give birth to a live baby. In order to do this, you need a functioning reproductive system.

Your reproductive system includes specific hormones and organs that allow your body to mature and release healthy eggs, transport the eggs to your womb and maintain a strong, nutrient rich environment in your womb to carry the baby.

Many treatments for lymphoma can affect your fertility and make it harder, or impossible to get pregnant without medical assistance.

There are some things that can be done to try to protect your fertility. It is

important that these be done BEFORE YOU START TREATMENT.

If there was/is no time for fertility preservation before starting treatment, there is still help available to improve your chances of having children.

Ask your doctor "Will my treatment affect my fertility?" And, "What can be done to protect it?".

Your reproductive system

Your reproductive system includes your:

 Ovaries – You have two ovaries and when you are born, your ovaries are full with immature eggs (ova). You are born with all the eggs that you will ever have and do not make new eggs during your lifetime.

Once you reach puberty, your body starts recruiting cohorts of eggs to mature and be released, but on average, only one egg reaches maturity and is released (during ovulation) each month until you reach menopause. The number of eggs your body recruits each month depends on your age and your ovarian reserve.

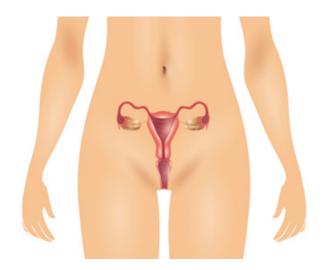


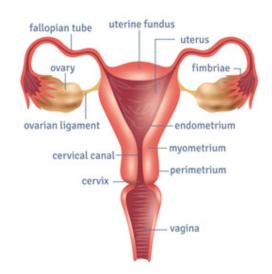
Ovaries are sometimes called gonads, which is the medical name for sex organs that contain cells for reproduction.

- Fimbriae small brush like structures at the end of your fallopian tubes near your ovaries, that capture the egg from your ovary and move it into your fallopian tubes.
- Fallopian tubes A tube like structure joining your ovaries to your womb. The sole purpose of the fallopian tubes is to transport the egg from your ovary to your womb.

Each month when you release an egg, it travels from your ovaries, through your fallopian tubes to your womb (also called uterus).

- Uterus An organ where an unborn baby develops and lives until birth. The lining of your uterus is lined each month with nutrient rich blood which either supports a developing baby, or is shed through your vagina during a menstrual period each month. The uterus is comprised of three layers: the endometrium, the myometrium and the perimetrium.
- Cervix your cervix is located at the top of your vagina and makes up the opening to your uterus.
- Vagina the passage a penis enters when having sex for reproduction (or pleasure).





Hormones

Hormones are chemicals we naturally produce to help our bodies develop, grow and reproduce (make babies). Our pituitary gland is a gland in our brains that releases chemicals so our body knows what hormones to make and release into our bloodstream.

Luteinising Hormone

Luteinising Hormone (LH) is produced by our pituitary gland in our brain and released into our bloodstream. It stimulates your ovaries and adrenal gland



gland to make hormones called oestrogen and progesterone.

If your lymphoma is in your brain, or you have had other treatments that change the way your pituitary gland works, you may not produce enough LH which will result in you producing less oestrogen.

Oestrogen and Progesterone

Oestrogen and progesterone are needed to develop and maintain secondary sexual characteristics and fertility including:

- Development of breasts and widening of your hips.
- · Growing pubic and underarm hair.
- Lining your uterus with nutrient rich blood each month, or maintain it during pregnancy.
- Maturing and releasing an egg each month from puberty to menopause (except during pregnancy).
- Onset of and ongoing monthly periods
 if you are not pregnant.
- Lubricating your vagina for selfcleaning and in response to sexual arousal.
- Maintaining a pregnancy.

Testosterone

A small amount of testosterone is also produced by your ovaries. Most of it turns into oestrogen, the rest is involved in keeping your body strong and healthy.

Other functions of Hormones

As well as the functions written above, healthy levels of oestrogen and testosterone are needed for:

 Bone and muscle development and strength

- Mood, behaviour and emotional regulation
- Maintaining a healthy heart
- Fat distribution how and where you carry fat in your body (for example on your waist, tummy or thighs).

Why does treatment affect my fertility?

Different treatments can affect your fertility in different ways.

Chemotherapy

Some chemotherapies are gonadal toxic, which means they can affect your ovaries (gonads). Gonadotoxic chemotherapy often results in premature ovarian failure and infertility.

Eggs stored within the ovary are vulnerable to damage caused by chemotherapy, which affects rapidly dividing cells like that of the ovary.

The risk of infertility varies substantially between patients. The effect it has on you will depend on several factors including:

- Your age when having treatment.
- The type of chemotherapy you have.
- The dose and how long chemotherapy goes for.

Monoclonal antibodies

Some monoclonal antibodies, especially immune checkpoint inhibitors such as pembrolizumab or nivolumab can affect your ability to produce hormones.

When your hormone levels are affected, your fertility is affected. This can be a temporary or permanent change, but does not happen to everyone. There is no way to tell if your hormones will be



will be permanently affected by these medicines.

Radiation therapy

Radiation to your abdomen or genital area can cause scar tissue, and affect your adrenal glands or ovaries from producing hormones needed for fertility. Radiation to your ovaries can permanently reduce your ovarian reserve.

It may also cause scarring to your fallopian tubes, stopping an egg reaching your womb; or it can affect your womb which may make it more difficult to get pregnant and carry a baby.

Surgery

If you have lymphoma in your uterus or reproductive tract that needs to be removed surgically, it can affect your fertility through scar tissue, or the removal of your ovaries or uterus.

Can I get pregnant during treatment?

Treatments may make it harder to get pregnant. However, in some cases a natural pregnancy may still happen, so you will likely need to take precautions to avoid pregnancy.

Talk to your doctor about when the best time to plan a pregnancy will be. In some cases, you may need to wait up to 2 years after you finish treatment before becoming pregnant.

You should not get pregnant during treatment for lymphoma unless you have spoken to your doctor about the risks to you, your partner and your unborn baby. Many treatments for lymphoma can

affect your eggs (ova), and your ability to produce a nourishing environment for an unborn baby to grow.

This puts your baby at risk of deformities, miscarriage and stillbirth. The biggest risk to the baby is in the first 12 weeks of pregnancy when all the cells that make the baby are being developed.

If an unexpected pregnancy happens while you are having treatment, let you doctor know as soon as you suspect you are pregnant

You may also like to visit our webpage Pregnancy and Lymphoma - https://www.lymphoma.org.au/lymphoma/

How is fertility affected after treatment?

Depending on the type of treatment you had:

- Your body may no longer produce enough of the hormones needed for you to recruit immature eggs, or mature to a point that they are able to be released and fertilised to make a baby.
- You have no remaining eggs within your ovaries. This could lead to ovarian insufficiency or early menopause.
- You may no longer be able to produce enough hormones to maintain a pregnancy.
- Your reproductive organs may have been damaged, removed or scarred, making it difficult or impossible for the egg to travel from your ovary to your womb.



 Your uterus or cervix may not be healthy enough to maintain a pregnancy.

Is this effect permanent?

In some cases, the effect on your fertility may be permanent, meaning you will never be able to naturally get pregnant. For some people though, fertility may recover, but how long this takes is different for everyone.

Early Menopause and Ovarian Insufficiency

Treatments can result in early menopause or ovarian insufficiency. Menopause and ovarian insufficiency are covered in more detail on our website, or call our nurses for more information.

https://www.lymphoma.org.au/ lymphoma/side-effects-of-treatment/ early-menopause-and-ovarianinsufficiency/

Ask your doctor:

- How will my treatment affect my fertility, and will the change be permanent or temporary?
- What can be done to protect my fertility?
- When can we plan to have a baby?

How can I protect my fertility so I can still have babies?

There are several options that may be available to you that may help protect your fertility.

The right option for you will depend on

several factors including:

- how old you are
- if you have reached, or gone through puberty
- the urgency of your treatment
- ability to get fertility appointments before treatment needs to start.

There are both public and private services available for urgent fertility preservations, ask your doctor about them.

Freezing eggs, embryo's or ovarian tissue

The Sony foundation has a program called You Can Fertility. This service is free for people 13-30 years of age to store eggs, embryos (fertilised eggs), or ovarian tissue to help with pregnancy later in life. Their contact details are at the end of this brochure under Other resources.

Storing eggs

Eggs may be stored if you have already reached puberty or are an adult. You will be given daily hormone injections to help mature more eggs than you normally would so they can be collected and frozen.

Storing an embryo

An embryo may be stored if you have a partner or sperm donor who can provide sperm to fertilise your eggs. The eggs and sperm are then collected from you both and joined together in a laboratory to make an embryo (a fertilised egg). This is then frozen and stored until you want to get pregnant. The embryo can be transferred into your uterus when you want to get pregnant.



Storing ovarian tissue

Ovarian tissue is usually stored for younger children who have not yet reached puberty. It may also be an option if you need to start treatment before your eggs can be matured, collected, frozen and stored.

This is done during a surgical procedure where a piece of ovary is removed through keyhole surgery) and then frozen and stored. After you finish treatment, if you suffer premature menopause the ovarian tissue can be transplanted back into your body, allowing you to have eggs collected, frozen and stored after your treatment.

Other options to store or preserve eggs/ sperm, embryos and other tissue

If you don't meet the criteria for Sony Foundations program, you can still store your eggs, embryos or ovarian tissue. There is usually a yearly fee which will differ depending on where it is stored. **Talk to your doctor** about options and costs involved if you cannot use the Sony foundation.

Medicine to protect your fertility

You may be able to have medicine that helps protect your ovaries during treatment. This medicine is a hormone that temporarily shuts your ovaries down so treatment has less harmful effects on them. After treatment ends, you will stop hormone treatments and your ovaries may start working again.

Hormone treatments for fertility preservation are not effective for young children.

Ask your doctor what options you have to protect your fertility before you start treatment.

Can I get pregnant after treatment if I haven't had fertility preservation?

Most lymphoma treatments can make it harder to get pregnant later in life. However, pregnancy can sometimes still happen naturally. This may happen whether you have had fertility preservation or not.

If you do not want to get pregnant, you should take precautions to prevent pregnancy after treatment.

How do I know if I can get pregnant?

For some people, fertility improves soon after treatment, and for others it may improve years after treatment. A reassuring measure is the return of your menstrual cycles. For some patients though, pregnancy will only be possible through other means, such as using your stored, eggs, embryos, or ovarian tissue.

Are there tests to check my fertility?

To check if you may be able to get pregnant naturally, talk to your general practitioner (GP or local doctor). They can arrange tests to check your hormone levels, reproductive system and your ovarian reserve. However, results of these tests can change over time.

Your GP can also refer you to a fertility specialist if needed for more tests or treatment options to help you get pregnant.



Getting pregnant

Natural pregnancy

A natural pregnancy is when an egg is fertilised by sperm through vaginal sex. In rarer cases, a pregnancy may occur even if you haven't vaginal sex but sperm is released near the opening of your vagina.



A natural pregnancy may still occur after treatment, but this will depend on your treatment, your age, where in your body the lymphoma was, and any other underlying conditions.

You will need an egg to mature and be released by your ovaries, and travel through your fallopian tubes to your womb (uterus). The egg is usually fertilised either in the fallopian tubes or uterus.

You also need to produce enough hormones, and have a healthy womb to maintain a pregnancy.

Some people can have difficulty having sex during and after treatments for lymphoma. Some things that can affect your ability to have sex include:

- a low sex drive (libido)
- difficulty reaching an orgasm
- vaginal dyrness making sex painful

Talk to your doctor if you have any difficulty having sex. This side-effect is just as important as any other side-effect of cancer treatments, so they need to know.

Depending on what is causing your changes in sexual function there could be treatments or medicine that can help.

For more information on sex, sexuality and intimacy please see our website <u>here.</u>

Other ways to get pregnant:

In-vitro Fertilisation (IVF)

If you had time to collect and store eggs or ovarian tissue to help preserve your fertility, you may be able to fall pregnant with IVF. Talk to your doctor about how long after treatment you should wait before trying.

Donor eggs

IVF treatment may still be an option for you by using eggs donated by somebody else. This may be an option if you didn't have time to preserve your eggs or ovarian tissue before starting treatment.



Who may be involved in your fertility care

Different types of specialist doctors can help you with fertility. You can also ask your doctor to refer you to a fertility clinic for expert fertility care.

Fertility Counsellors

Facing fertility challenges after treatment can be emotionally and physically challenging. Specialist Fertility counselling is available through most fertility clinics and can include Psychologists, Psychotherapists and Social workers.

| Specialist | What they help with |
|---------------|--|
| Gynaecologist | Treating conditions of your reproductive system and breasts. They can check your fertility and give advice on the best way to get pregnant, or avoid pregnancy if you do not want to get pregnant. |
| | They can also help if you have any difficulties or pain during sex. |

| Specialist | What they help with |
|------------------|---|
| Endocrinologist | Treating conditions of your reproductive system. They can check your fertility and treat conditions that may cause hormone imbalances. |
| Fertility Doctor | A fertility doctor may be involved in your care if you and your partner need help getting pregnant through IVF using your own, or a donor's eggs. |
| | They can also help if you have hormone imbalances affecting your fertility, or need genetic testing. |
| Obstetrician | An obstetrician is a doctor with extra training and a special interest in caring for you and your baby during and just after pregnancy. |



What if pregnancy is not an option?

There are many ways to start a family, and if getting pregnant is not possible because of your cancer treatments, there are still options available.

Surrogacy

Surrogacy is when somebody else carries a baby in their womb for you. In some cases, your and your partners eggs and/or sperm can be used, or a donors eggs and/or sperm can be used. The surrogate carries the baby in their body during pregnancy but is not legally considered the baby's parent.

There are different laws around surrogacy across Australia. If you are interested in finding out more, talk to your doctor or ask to be referred to a fertility doctor.

Adoption

Adoption is when biological parents cannot, or choose not to raise a child as their own. The child is then adopted by another couple or single person to raise as their own child. The adopted parent/s are legal parents.



Children of any age, including babies and teenagers can be adopted.

You may be able to adopt a child born in Australia or overseas. To learn more about adoption in your state see the links below.

Victoria

https://www.vic.gov.au/adopt-child-victoria

New South Wales

https://www.facs.nsw.gov.au/families/adoption/adopting-a-child/want-to-adopt

Australian Capital Territory

https://www.communityservices.act.gov.au/childrenand-families/adoption-kinship-and-foster-care/ adoptions/adopting-a-child-from-the-act

Queensland

https://www.qld.gov.au/community/caring-child/adoption

Northern Territory

https://nt.gov.au/community/child-protection-and-care/adoption/introduction

Western Australia

https://www.wa.gov.au/organisation/department-of-communities/adoption

South Australia

https://www.sa.gov.au/topics/family-and-community/parenting/adoption

Tasmania

https://www.decyp.tas.gov.au/safe-children/adoptions-and-permanency/about-adoption-in-tasmania/

Foster care

Foster care may be an option for you. Foster care can include short- and longterm care of children who need a safe and loving home.

In some cases, foster care can lead to adoption if suitable.



What if I don't want to get pregnant.

Talk to your doctor about your fertility if you do not want a pregnancy.

You should always use barrier protection (such as condoms or dams) when you have sex with someone outside of a committed monogamous (one partner only) relationship, to avoid risk of sexually transmitted diseases or infections.

However, even if you are in a monogamous relationship, you may still need to use some sort of protection to prevent an unwanted pregnancy.

Ask your doctor to check your fertility to find out if you need to take extra precautions. There are many different choices of contraceptives, so ask your doctor to explain the choices you have for your circumstances.

What if I am already pregnant when I am diagnosed with lymphoma?

Being diagnosed with lymphoma while you are already pregnant is challenging. And it is not fair! But unfortunately, it does happen. In many cases you may still be able to keep your baby, and have treatment, however there are extra things to consider.

Please see our webpage <u>Pregnancy and Lymphoma</u> for more information or call our nurse on 1800 953 081.

Other resources

youcanfertility

 Sony foundation You Can Fertility program https://www.sonyfoundation.org/ Early Menopause and ovarian insufficiency

https://www.lymphoma.org.au/ lymphoma/side-effects-of-treatment/ early-menopause-and-ovarianinsufficiency/

- Pregnancy and lymphoma
 https://www.lymphoma.org.au/
 lymphoma/
 lymphoma/
- Sex, sexuality and intimacy
 https://www.lymphoma.org.au/
 lymphoma/side-effects-of-treatment/
 sex-sexuality-and-intimacy/

Summary

- Lymphoma treatments can have a temporary or permanent effect on your fertility.
- Treatment can affect your fertility causing hormonal changes or damage to your reproductive organs.
- If there is time before treatment starts, you may be able to have procedures to help increase your chances of a successful pregnancy in the future.
- Some medicines may help preserve your fertility.
- Natural pregnancy can still happen for some people who have had treatments.
- If you do not want to get pregnant, talk to your doctor about having fertility tests done, and how to prevent an unwanted pregnancy.
- You may need extra help to get pregnant through IVF.



- Other options to start a family include surrogacy, adoption and fostering.
- Talk to your doctor about your options and referrals to the above specialist.
- You are not alone; our Lymphoma
 Care Nurses are here to help. Call our
 nurses on 1800 953 081 Mon-Fri 9am 4:30pm Eastern Standard Time.

Resources and support

Lymphoma Australia offers a wide range of resources and support for people living with lymphoma or CLL, and their carers. How to access our resources:

- Visit our website <u>www.lymphoma.org.au</u> for more information.
- Phone our Lymphoma Care Nurse Hotline on 1800 953 081.
- Email our Lymphoma Care Nurses nurse@lymphoma.org.au
- Booklet: Understanding Non-Hodgkin Lymphoma (NHL)
- Downloadable information: Visit our website, or give us a call if you would like some more information on a variety topics related to lymphoma
- Join our Facebook page
 <u>Lymphoma Down Under</u> (make sure you complete all the membership questions when you join).

Cancer Council offers a range of services, including free counselling, to support people affected by cancer, including patients, families and friends. Services may be different depending on where you live. You can contact them at www.cancer.org.au or by phone on 13 11 20.

Medicare Australia: Check with your GP

if you are eligible for a Mental Health Treatment Plan (MHTP). This plan is funded by Medicare and can provide you with up to 10 sessions with a registered psychologist. More information can be found <u>here</u>.

WeCan is an Australian supportive care website to help find the information, resources and support services you may need following a diagnosis of cancer. You can visit their website at www.wecan.org.au.

Canteen provides support for young people aged 12-25 years who have cancer, or, who have a parent with cancer. Find out more at their website here at www.canteen.org.au.

Disclaimer: Lymphoma Australia has taken every precaution to make sure the information in this document is accurate and up-to-date. However, this information is intended for educational purposes only and does not substitute for medical advice. If you have any concerns about your health or wellbeing, please contact your treating team.



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