



Maybe later baby?

A guide to relationships, sex
and fertility for young people
with cancer

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This booklet is a comprehensive and realistic guide for young adults who until now have not had to think about these matters.

**- Dr Mark Bowman,
Sydney IVF Medical Director**

This book provides important and timely information for young people who have undergone or are about to undergo treatment for cancer, and is proudly endorsed and supported by IVFAustralia and Melbourne IVF.

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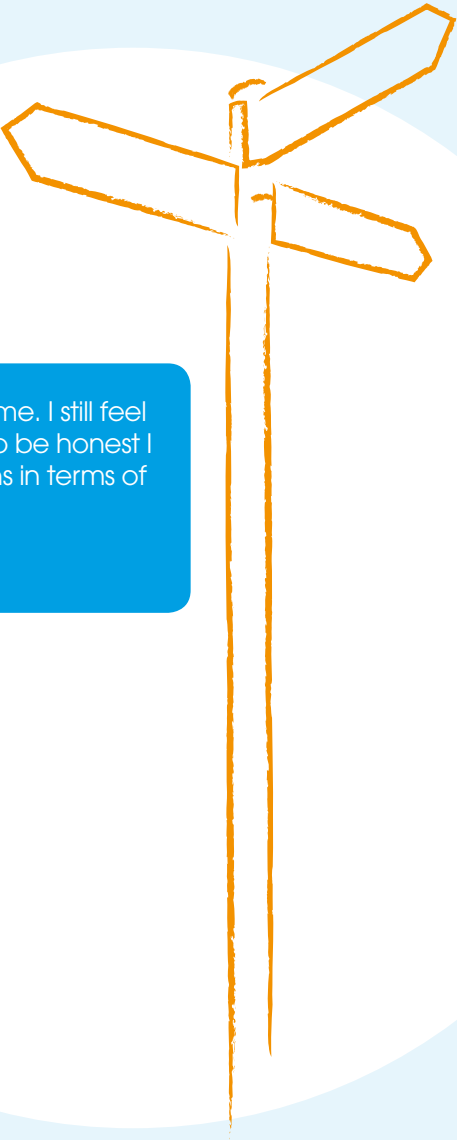
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This book is intended as a general introduction to the topic and should not be seen as a substitute for advice from doctors or other health professionals. All care is taken to ensure that the information contained here is accurate at the time of publication.

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"Cancer changed everything about me. I still feel the impact all these years later and to be honest I am still working out what this all means in terms of sex and fertility. "

Tristan, Hodgkin's Lymphoma.

Introduction

Whether you have just been diagnosed, are already having treatment or completed most of your treatment, you may worry about whether having treatment for cancer can impact the way you feel about your body (your body image), relationships, your ability to enjoy sex and have children in the future (your fertility). We are going to explain why, and talk about what you might be able to do to take action against these effects. Talking to someone in your cancer team before treatment begins is the best way to keep your options open. Some of the options we talk about might not be right for you, or available to you. We just want to inform you so you can ask the right questions.

Why we suggest you read this book.

If you're reading this book, you have either just been diagnosed with cancer or are currently undergoing treatment.

If you have just been diagnosed with cancer you are probably experiencing lots of different emotions all at once, and are most likely feeling confused, scared, lonely – or all of the above.

Cancer is the last thing anyone would invite into their lives but, like many things, it's not something you have much control over. Having the right kind of help and information can make a big difference. That's why we've written this book.

It has been written in collaboration with other young people diagnosed with cancer – so it's designed for real life. We hope the information in here will make it easier for you to talk about some of the difficult and sometimes awkward or embarrassing aspects of what you are going through.

You can either read it from cover to cover or just look at the sections you think are relevant to your situation right now. The main thing we want to do is give you access to as much information as possible so you have some answers to questions you may have about sex and fertility, which will in turn help you understand your choices and make decisions for the future.

Your fertility is not something you may be thinking about right now, but because you have recently been diagnosed with cancer it is something that you need to get your head around. If you are thinking "but I don't want kids anyway", remember that you might change your mind when you get older and your circumstances are different – so you need to keep your options open.

Throughout this book we encourage you to chat with your nurse or doctor about lots of the issues raised. If you have a different health professional who you know and trust – talk to them. We have stated doctor or nurse for reasons of simplicity only. Talk to whom you feel most comfortable with. They will be able to help you find the right answers.



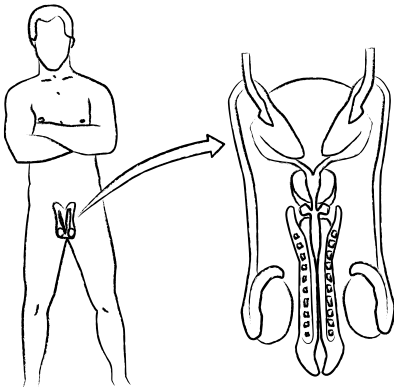
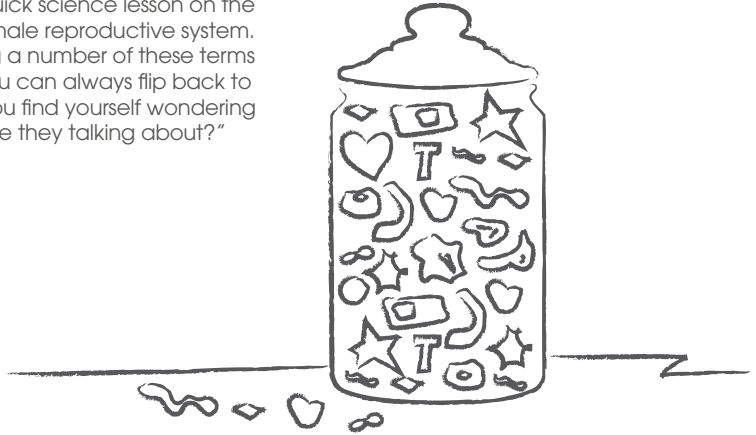
There is a list that describes many of the medical terms and words we use in bold on page 56.

Check it out if you are unsure of what any of them mean.

The basics

The bits and pieces: anatomy and physiology.

This is just a quick science lesson on the male and female reproductive system. We'll be using a number of these terms later on so you can always flip back to this page if you find yourself wondering "which bits are they talking about?"



Men.

The most important organs of the male reproductive system are the testes (or testicles). Men are born with two testes, and their main job is to produce sperm and the hormone testosterone.

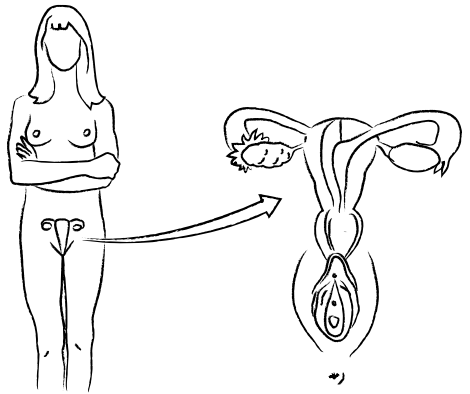
The testes ('balls') hang outside the body so that they stay cool, enabling them to produce sperm (it is a few degrees warmer inside than out). Sperm will undergo maturation in the testes and move through a tube called the epididymis. The function of the epididymis is to aid the storage and transport of sperm, as well as to facilitate sperm maturation. On this journey - this takes about 72 days - sperm become mature and are then able to fertilise an egg.

Women.

The main organs of the female reproductive system are the ovaries. Every woman has two ovaries, which have two functions – producing eggs (ova) and hormones (progesterone and oestrogen). All the other female reproductive organs are there to help the ovaries do their job. Women are born with a limited number of eggs (approximately 700,000) which may seem like a lot, but you don't get new ones as you get older. The number of eggs decreases each day until there are only a few left. When there are no more eggs left, menopause (the end of having your period) begins.

The ovary contains ovarian follicles in which the egg develops. Once it matures, the egg then moves into the fallopian tubes. The fallopian tubes are like funnels from the ovary to the uterus. They have little finger-like pipes that come from the ovary directly into the fallopian tubes and these are what catch the egg when it is released. This is called ovulation and every woman goes through this process approximately every 28 days.

The egg then takes about five days to travel down the tubes into the uterus. To have a child an egg needs to be fertilised by a sperm. If the egg is not fertilised, you will have a period. If the egg is fertilised, the embryo will attach to the wall of the uterus where it will continue to grow.



What is fertility and infertility?

Fertility.

For women, fertility is the ability to become pregnant. For men, fertility means making a woman pregnant or fathering a child. Some cancer treatments can impact your fertility.

Infertility.

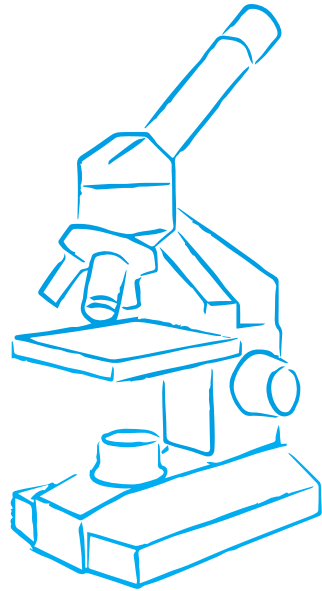
For women, there are a couple of factors that could be the cause of infertility, such as not having enough eggs, problems with hormone signalling between the brain and the ovaries, or damage to the uterus or fallopian tubes.

For men, infertility can be due to issues related to sperm production (not producing a high enough number of sperm or 'sperm count'), low sperm movement ('sperm motility') or abnormal sperm shape ('sperm morphology'). Sometimes there are issues related to sperm transport, such as blockage.

Infertility is something that affects members of the general population as well, not just people who have had cancer treatment. One in six couples in Australia experience infertility, so it is quite common.

Most young people who have had cancer will not have long term problems with fertility as the cancer or the treatment doesn't permanently damage their reproductive system. For people that have temporary damage to their fertility, their recovery rate

varies from person to person and may take some time. It is important to talk to your medical team as early as possible about the impact of cancer treatment on fertility. This will help you make well informed decisions about preserving your fertility and keeping as many options open for the future.



Infertility means having difficulty with getting pregnant. If there is difficulty with getting pregnant and staying pregnant then further investigation may be required. There are many treatments which will help you to have a baby and become a parent.

What is fertility preservation?

It can be difficult to predict the exact impact of cancer treatment on your future fertility. Fertility preservation is a way of maximising your chances of becoming pregnant in the future.

Preserving fertility in women.

Young women who have periods may be able to store fertilised eggs (embryos) or unfertilised eggs before treatment begins (see page 35 for fertility options before undergoing treatment).

Preserving fertility in men.

You may be referred to a fertility specialist to discuss your options of freezing and storing sperm before treatment begins (see page 22 for fertility options before undergoing treatment).

What if I haven't heard about fertility before?

You may not have heard much about fertility before now, especially if you are still at school or going to Uni or TAFE.

Having children may not be something you have thought a lot about either, but unfortunately being diagnosed with cancer often means that you have to grow up a bit faster than you had planned. This is an example of something that you need to think about sooner rather than later. Someone in your cancer team should discuss this with you. But you can also bring the topic up yourself.



The best thing you can do is to think about your sexuality and fertility and ask questions now. You might be just about to start treatment. If you can discuss it with your nurse or doctor it will make things a lot easier for you in the future.

"It's always good to have someone there at the appointments as well. There are things you miss, because you're just like zoned out, or you're freaked out. That person can fill you in on things you might have missed, or misunderstood. That really helps."

Shirley, Brain tumour.

How can changes to your fertility affect relationships, sex and sexuality?

You may have read that cancer treatment can cause changes to your ability to become pregnant and be starting to worry that all of these changes may affect your ability to have a satisfying intimate relationship, feel good about your body and enjoy sex now or in the future. The good news is that even if cancer has changed your reproductive system, you can usually still have healthy, happy relationships and enjoy sex. Because cancer can have physical as well as emotional side effects we cover this in more detail on page 51 for body image and rebuilding intimacy.

"I was just sitting in the doctor's rooms with my parents. The doctor just said 'we have your test results back and unfortunately you are sterile' rah rah rah. I sort of zoned out."

Ben, Leukaemia.

"The idea of discussing something sexual around my conservative parents made it incredibly difficult for me to understand what was going on in that department."

Nathan, Ewing's Sarcoma.

Talking about sex and fertility.

Sex and fertility is one of those topics that can make people feel embarrassed and uncomfortable. It can sometimes be difficult to talk to your partner (if you have one), friends or family about such personal stuff.

Many people just don't get that cancer can affect your ability to enjoy sex and/or your ability to have a child. Even those who do understand can find it challenging to talk about it with you as they don't want to cause you embarrassment or they don't know what to say. It's really important for you to find someone that you feel comfortable talking to so you get the information you need and you know your options.

"It was so good to be able to call my nurse who was amazing. Just to be able to explain my symptoms and hear if I was normal or not was helpful and made me feel so supported."

Hope, Hodgkin's Lymphoma.

FAQs

Men and women.

Can I still have sex during cancer treatment?

If you are undergoing cancer treatment you can still enjoy having sex. You will need to use barrier protection such as a condom to protect your partner from the effects of chemotherapy as well as to protect yourself from pregnancy and sexually transmitted infections. Please discuss the best type of barrier protection to use with a member of your treatment team. If you don't feel up to sex you can continue to be intimate with a partner. See page 51 for body image and rebuilding intimacy.

Will having sex make my cancer worse?

No. Having sex will not make your cancer worse. Nor can you give your partner cancer from having sex.

Can we kiss and touch during cancer treatment?

Kissing and touching while having cancer treatment is generally okay and something you may continue to enjoy. However, there are times during your treatment when your immune system is low when it is best to avoid exposing yourself to infections. Infections can be passed from person to person during kissing and touching so it's best to avoid close contact with people who have colds, coughs or cold sores on their mouth until your immune system is functioning optimally. Your nurses or doctor will be able to advise you more on that. See page 51 for body image and rebuilding intimacy.

Can I have oral sex during treatment?

Having oral sex while undergoing chemotherapy requires use of barrier protection such as condoms or dental dams (latex A4 size sheet that gets placed over vagina or penis). This ensures no chemotherapy is passed through fluids coming from your penis or vagina. Such protection is required for 48 hours after the end of your last dose of chemotherapy.

What if we get pregnant while I am undergoing chemo?

If you or your partner falls pregnant while undergoing treatment then you should talk to your doctor immediately about what to do. Their recommendation will be based on the treatment being given. It is very difficult to give an answer as it is a very individual situation depending on the person.

I am worried my cancer will come back if I decide to have a child.

It is hard to imagine the stresses of having a young child and becoming seriously ill. Your doctor may recommend that you wait a certain time period before starting a family as the risk of cancer recurrence is higher in the first couple of years after treatment. Talk to your doctor about when they think enough time has passed and the cancer is unlikely to return.

Can I pass cancer on to my children?

A number of studies have looked at the effects of cancer treatment on the children of those who have undergone such treatment. The research to date suggests there has been no risk identified to children who have been conceived naturally after cancer treatment. Studies have also shown there are no risks to

children born from eggs and sperm that may have been frozen.

There are however, a small number of people who have a 'faulty gene' that increases their risk of getting a certain type of cancer. Your doctor will be able to tell you if there is a chance you have a faulty gene that could be passed onto your children. If this is the case your doctor will recommend you speak to a genetic counsellor so you can make a well informed decision.

What if I am single?

The effect of cancer treatment on your fertility is the same regardless of whether you are in a relationship or single. If you do not have a partner it is still important to raise the topic of fertility before you start cancer treatment. Seeking the right information and support will help you make a well informed decision about the choices you have now or in the future.

What if I am gay, bisexual or transgender?

Your sexual preference or gender orientation does not exclude you from fertility options following a cancer diagnosis. It is the same for surrogacy, fostering and adoption. It is really important that you let your doctor or nurse know that your sexuality and fertility are important to you. You may find it hard to ask for professional advice if you are still 'coming out' or adjusting to your sexual orientation. You may feel more comfortable talking to one of the Helplines on page 54 before talking to your doctor.

How much do fertility treatments cost?

The public and private health systems in Australia have different costs for these procedures. You are best to chat with your health care provider about how much some of these procedures might cost and what the out of pocket expenses may be. If your cancer specialist refers you to a fertility specialist for an initial assessment, most of the assessment cost is covered by Medicare.



What if I don't ever want children?

Even if you don't think you will ever want to have children right now, you just can't tell how you might feel two, five or ten years or more down the track. It is best to give yourself as many options as you can – and storing sperm or eggs now will give you those options in the future.

Just for men

Cancer and its treatment can affect your sex life.

Everyone experiences confidence and body image issues at some time in their life, particularly as a teenager or young adult. Your cancer experience can change how your body looks, feels and works. Sometimes your sexual feelings can change as a result of your cancer treatment. Whether the changes are physical or emotional it's hard not to be affected by these changes. While dealing with unwanted changes can be really tough, it may help to remember that underneath all of the changes you are still you. The good news is that with time and support, confidence in your appearance and sexual feelings will return. Even if the cancer and its treatment have damaged your ability to have children, you can usually still enjoy relationships and sex after cancer. Remember that what your body goes through with treatment does not make you less of a man, despite the effects it may have on your body, functionality and interest in sex.

Physical effects.

You may not be able to get an erection ('hard on') if cancer and its treatment have damaged blood vessels and nerves to the pelvic area where your sex organs are located. Radiotherapy and surgery can sometimes cause this.

Surgery to remove a testicle doesn't

usually affect your sex life. It may lower the amount of testosterone your testes produce for a while. This can also happen if you have had radiotherapy to the testes (the 'balls') or if treatment affects your pituitary gland in the brain. This gland produces hormones that control the production of testosterone in the testes.

Low levels of testosterone can make you less interested in sex. It can also make it more difficult to get an erection. If you are having problems getting an erection it may sort itself out after a while. Your doctor may prescribe you testosterone. Or you can talk to your doctor about other treatments to help you have an erection.

"Cancer changed everything about me. To be honest I am still working out what this all means in terms of sex life and fertility."

Tristan,
Hodgkin's Lymphoma.

How does having cancer affect my fertility?

Not all cancer and cancer treatments affect your fertility, but some can, depending on a number of things. It is really important to know what the risks and the issues are before you start your treatment, so you know whether you need to make some decisions about 'preserving' your fertility.

You may not have this option before you start treatment because of your type of cancer, or there may be a rush to start treatment immediately. We want to provide you with some information so you can chat to your doctor or nurse about this as soon as possible, to find out what you can do.

We are going to be totally honest with you about this subject, so you may find some of the information on the following pages a bit difficult to read. Please, if you do start to become worried, go and talk to your nurse or doctor - or your parents or partner (if you have one) straight away. They will help to answer your questions and help you with some of your concerns.

"I think it should be a requirement for anyone diagnosed with cancer to have a session with a counsellor or psychologist or someone to discuss how it's making you feel. At the time I was being bombarded by people and thought I was managing okay. Now I know I wasn't!"

Bruce, Ewings Sarcoma.



Types of cancer that can affect fertility.

There are some cancers that could directly impact upon your fertility, but not all changes are permanent.

Testicular cancer.

Being unwell in any way can reduce the quality of sperm. Having testicular cancer may also mean that you have a low sperm count at the time of diagnosis. A low sperm count does not mean you are infertile.

Brain tumour.

If you have experienced a brain tumour, some reproductive hormones may be involved. This does not always mean you are infertile.

Hodgkin's lymphoma.

Because of the way the disease develops, having Hodgkin's lymphoma could mean that you have a low sperm count at diagnosis. A low sperm count does not mean you are infertile.

Cancer treatments and how they can affect sex and fertility.

Chemotherapy.

Chemotherapy or 'chemo' is the most common form of cancer treatment. Chemo uses drugs called cytotoxics to kill or slow the growth of cancer cells. Unfortunately while chemo can stop cancer cells growing and multiplying, it can affect normal, healthy cells in the process. Reproductive cells fit into this category, so this includes sperm. Having chemo may therefore impact upon sperm production. Chemo can also reduce your interest or desire in sex but with time, this will return.

The extent of the damage is determined by a number of different factors:

- Drug type.
- Dosage.
- Combination of medications.
- Your age at the time of your treatment.

With all of the things described above it is best to check with your doctor to see what the effect may be.



Before starting your treatment you should emphasise to your medical team that your fertility is important to you.

Radiotherapy.

Radiotherapy uses high energy x-rays, gamma rays or electrons to kill cancer cells in a specific part of the body. It creates shifts in the body's cells that destroy the cells' ability to grow and divide.

Radiotherapy only affects the cells and tissues within a specific area (unlike chemo, which affects the whole body). Normal, healthy cells are also more able to resist the radiation, which is why your body may recover from the effects of radiotherapy faster.

Radiation also kills rapidly dividing cells, such as reproductive cells, but is generally limited to those in a contained area. So this is why it can impact your fertility if you are having radiotherapy in that area.

The amount of damage that radiotherapy can do to your reproductive organs depends on a number of things:

- Dosage.
- Number of treatments (called fractions) required.
- Area of radiation.
- Your age at the time of your treatment.

Radiotherapy only affects the cells and tissues within a specific area (unlike chemo, which affects the whole body).

There are some procedures that may decrease the impact of pelvic radiotherapy on your fertility. Have a look at page 23 for a description of these options.

Abdominal or pelvic radiotherapy.

Having radiotherapy directly in your abdominal (stomach) or pelvic area may cause infertility. Pelvic radiotherapy may cause the sperm production process to be affected.

Some cancers that might require pelvic or abdominal radiotherapy include some rhabdomyosarcomas or germ cell tumours in the abdomen.



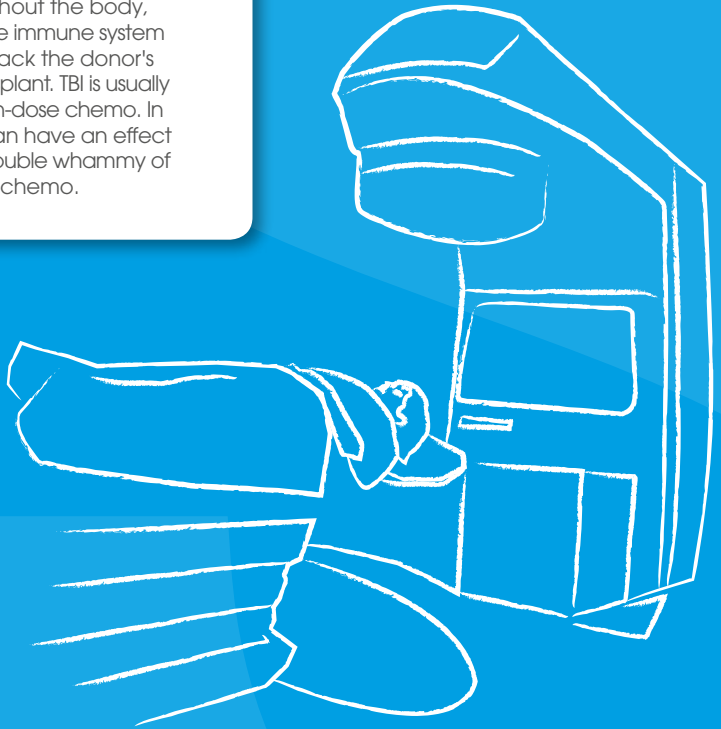
Radiotherapy to the brain.

Having radiotherapy to your brain can also cause problems with fertility. Why is that? It may seem strange that having radiotherapy to your brain could affect the way your reproductive system works, but your brain contains the pituitary gland which releases hormones that work on the reproductive system. These are the ones that make the testes work, produce sperm and affect your sex drive.

If you do have radiotherapy to the brain, then you may be able to take medication that replaces the hormones that the pituitary gland releases.

Total Body Irradiation (TBI).

Total body irradiation involves undergoing radiation to the whole body. This treatment is often given to people before having a bone marrow transplant. It destroys the cancer cells throughout the body, and also destroys the immune system so that it will not attack the donor's cells during the transplant. TBI is usually given alongside high-dose chemo. In combination, this can have an effect on fertility as it is a double whammy of both radiation and chemo.



TBI is usually given alongside high dose chemo. In combination, this can have an effect on fertility as it is a double whammy.

Medical Imaging.

As you are no doubt aware, you will have many tests before and during treatment, especially several types of medical imaging, including X-rays and Computed Tomography (CT) scans, as well as more involved scans such as PET (Position Emission Tomography) and nuclear medicine scans.

The tests mentioned all involve the use of ionising radiation, which causes levels of damage to cells within the body depending on the dose and scan type.

The benefit greatly outweighs the risk for the majority of these tests, but some precautions can be taken, particularly for the lower dose X-rays and some CT scans. The use of gonadal shielding for some X-rays and CT scans is available as long as the area of interest is away from the pelvis. For more involved scans such as PET this is not always possible as you are injected with a radioactive “tracer” to highlight areas of interest, so it is not possible to shield from these. The radiation used in medical imaging is slightly different to that used in radiotherapy and is generally less damaging.

The radiation dose of all of these tests is always closely monitored by the radiographers/medical imaging technologists conducting the scan and reduced wherever possible. It is, however, always worth asking your doctor if there is an alternative test that does not use ionising radiation (such as ultrasound or MRI) available that will show the same information.

Bone Marrow Transplant (BMT) and Stem Cell Transplant (SCT).

Having a transplant means that you will be given high dose chemotherapy and/or TBI. Therefore there is a significantly higher risk of infertility because of the reasons outlined under chemotherapy and radiotherapy above.

Surgery.

Having surgery to the reproductive organs, or to the organs in the surrounding areas may affect your ability to have a child. Some of the areas where you might have surgery are mentioned below:

- Penis.
- Testes.
- Prostate.
- Bladder.

It is best to chat with your doctor about what the impact of surgery may be on your reproductive organs and sex life.



Safe sex.

It is always strongly recommended to avoid getting someone pregnant during your cancer treatment. This is because damaged sperm can result in the baby not developing normally. It is advisable to use barrier methods of contraception during and after cancer treatment e.g. condoms or dental dams (for oral sex) which protect your partner from chemotherapy and you from sexually transmitted infections, which you don't need on top of everything you are going through. It is best to discuss it with your doctor or nurse in advance and ask them how long you need to use barrier contraception for.

What could happen once I have treatment?

While you are going through treatment it will be very difficult to tell what the impact may be on your sperm production. There may be effects on the number of sperm you have, or their ability to swim. These effects may be temporary during treatment, or permanent.

After you have finished treatment you can have your sperm tested to work out what the impact may have been.

There may be effects on the number of sperm you have and their ability to swim. These effects may be temporary during treatment, or permanent.

Fertility options before undergoing treatment.

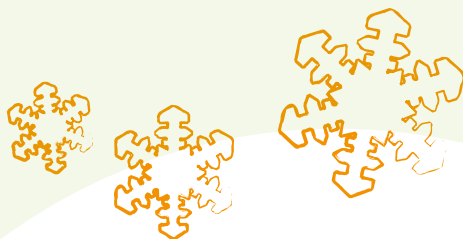
You may be feeling a little freaked out by now with all this information on fertility, and might be thinking – what am I supposed to do now?!?

This can be a really worrying time for you – but you do have a number of options that will help you to look after ‘the boys’ and to ensure you are giving yourself the best possible chance of having children in the future.

Your doctor (probably your oncologist or haematologist) will discuss the risk to your fertility before you start treatment. Depending when you start treatment, you may be referred to a fertility specialist before or after. Please just make sure that your doctor knows that your fertility and sex life is a priority for you.

We have outlined some of the available options on the next few pages. It is really important to know that not all of these options may be available to you or right for you. Some are very new techniques and are still in the early experimental stages (like testicular tissue freezing). We just want to outline the possibilities, but you need to talk to your doctor about what is appropriate.

Take your time to read through these, and take any questions you may have to your doctor or nurse (there is a notes section at the back of this booklet where you can write them all down). We have also created a list of questions (on page 25) which you could use.



Sperm freezing.

Sperm freezing involves making a sperm deposit and then having it frozen. If you have gone through puberty you generally go to a clinic (called an andrology clinic or an andrology lab), which could either be part of the hospital or a separate IVF/fertility clinic. If you are well enough, you may be able to do this at home and deliver your sample within an hour to the andrology clinic or lab.

You will be told step-by-step what to do by the staff there, and given as much time as you need. This can be a bit of an embarrassing or awkward situation for a lot of people (especially if you have to be taken there by your parents), but the doctors and nurses do this every day and will try to make you feel as comfortable as possible.

To give you some idea of what will happen, you will be required to masturbate (you may know this as ‘wanking’, ‘jerking off’ or ‘jacking off’) and ejaculate samples of your sperm for collection into a jar. You will probably be asked to give a couple of samples, generally three, but not all in one go. The reason for this is that your sperm might not be of high quality because of the cancer.

If time allows, you may be asked to wait 2-3 days between each collection to give the sperm time to build up again. This might not be possible though depending on your treatment protocol and how fast your doctor needs to start treatment.

Once you have a sample, the sperm will be frozen and stored for an annual fee. It is then clearly labelled with your details and stored in a large tank of liquid nitrogen where the temperature is maintained at -196°C . The storage tanks are not run on electricity or through machines, but work like thermos flasks.

It is important that you stay in contact with the sperm bank so that your yearly storage fees are paid and they know your contact details. In some States there is legislation that defines a maximum period of initial storage (usually ten years), after which you must reapply for your sperm to be stored. While this may not be a priority at diagnosis, it will be something you may have to encounter down the track.

If you are in a relationship your partner may be able to 'help' you produce a specimen if you find it hard to produce one by masturbation. You may be able to collect some sperm into a special condom during sex and bring it into the lab. This is NOT a normal condom, but one which is specially designed for this purpose.

Radiation shielding.

If the testes are close to where the radiation is directed (but they are not the target for radiation), then they can be shielded from the radiation beams by using protective coverings. This technique cannot completely reduce the level of radiation that your testes will receive, especially if your abdomen or pelvis is being irradiated, but it does provide some level of protection from radiation. Your doctor will probably still recommend that you freeze your sperm.

Other options.

There are other options that are only used in rare instances. They are only used for boys and men who are unable to produce a sperm sample by masturbation. These involve using a needle to remove some sperm from the testes (called testicular sperm extraction), usually with a local or light general anaesthetic.

Testicular tissue freezing is when testicular tissue is obtained through a biopsy and frozen for future use. This technique is in an experimental phase of development and is not readily available. At the time of editing this book, no human success rates have been reported using this technique.



Questions you may have...

There are a number of different questions you may have about the fertility options we have just explained. Make sure you talk to your doctor if you have questions that we don't answer here.

What will they do with my sperm samples if I no longer need or want them?

If you have returned to normal fertility or no longer want to use the sperm you have stored, then you should advise the clinic that you no longer wish to keep them. They can either have them destroyed or donated to research. They will generally have a protocol under which they will have the sperm destroyed.

What if my partner gets pregnant while I am undergoing chemo?

If your partner falls pregnant while you are undergoing treatment then you should talk to your doctor immediately about what to do. Their recommendation will be based on the treatment you are having. It is very difficult to give an answer as it is a very individual situation.

When I have sex, will I still ejaculate if I am infertile?

Yes, you will still ejaculate and produce semen even if you are infertile. You just won't have any sperm in your semen. Make sure you still use protection though, as just because you can't get someone pregnant doesn't mean that you aren't susceptible to sexually transmitted diseases.

I am nervous – what if I can't masturbate for a sample?

If you aren't able to masturbate for whatever reason, then your doctor might suggest a testicular sperm extraction as described on page 56.

Can I bank my sperm after starting treatment?

This is a bit of a difficult question as research has shown that sperm cells can be genetically damaged from chemotherapy and radiotherapy. You would be best to chat with your doctor, but this is why it is best to bank sperm before starting treatment.

How long can I store my sperm for?

Storage time has no impact on the quality or the outcome of the sperm. Many men have gone on to have children using this method – there have even been healthy babies born to men who stored their sperm for over 30 years. Some States do define a maximum period of storage, after which you will have to reapply for storage.

What happens when I want to have a baby?

You will need to have your sperm tested to see if you need to use the sperm that you stored. If you do need to use the sperm stored, there are a few ways in which your sperm can be used to fertilise an egg:

- Intrauterine Insemination (IUI)
- In Vitro Fertilisation (IVF)

Details about these procedures are described on page 22 of CanTeen's other resource '[Maybe Later Baby: A guide to relationships, sex and fertility for young people after cancer](http://www.canteen.org.au)'. You can download or order this book from www.canteen.org.au

What happens to my sperm if I die?

You can nominate what you would like to have done with your sperm. This could mean donating the stored sperm to research or having it destroyed. If you have a partner then you are able to legally sign over your sperm to your partner. The decision is totally up to you.

Questions to ask your doctor.

- What are the risks of infertility with my treatment plan?
- What can I do to preserve my fertility?
- How much time do I have before I start treatment?
- What happens if I delay treatment to bank sperm?
- What can I do during treatment to protect my fertility?
- Who do I need to talk to about my fertility options?
- Is it safe to have sex during my treatment?
- What can I do to enhance my desire for sex?
- How long do I need to use contraception for after my treatment finishes?
- Can you refer me to a sperm bank or fertility clinic?
- How do I know if I will be fertile after treatment?

Summary table of options.

Name	Definition	Medical status	Time required	Timing
For men				
Sperm freezing	Sperm deposited at sperm bank	Standard	Outpatient procedure	From puberty
Radiation shielding	Shielding the testes during radiation treatment	Standard	When treatment occurs	Before or after puberty
Testicular sperm extraction	Using a biopsy to take sperm from the testicular tissue	Standard	Outpatient procedure	After puberty

Now what? When treatment has finished.

The run through treatment may have changed you mentally and physically and you may be thinking ahead to the next step. There may be hundreds of questions running through your head - mostly about getting your life back on track and moving forward. You are probably feeling very different now compared with before you were diagnosed with cancer. Whether or not you can have children - and moving forward sexually - is something we can explain here. See page 47 for let's talk about feelings.



"As soon as they said you are sterile it hit me pretty hard. We talked about it a bit and in the end the doctor said we will speak about it when you want to know more."

Ben, Leukaemia.

Will my fertility ever return?

As we have described before, a lot of the treatments you may have had can change your ability to have children. This all depends on a number of factors such as when, where, what type, how much treatment you had and how old you were at the time. It can be very hard to predict what the impact may be as everyone's body is different and everyone's response to treatment is different.

You may return to your normal reproductive state within a couple of months of finishing treatment. To be on the safe side though, if you are going to have sex it is best to always use contraception and undergo testing so your fertility status is known. There are cases of young people who thought they were infertile, but their partners became pregnant because they hadn't tested their fertility status.

CanTeen has another resource for young people who have completed cancer treatment called '[Maybe Later Baby: A guide to relationships, sex and fertility for young people after cancer](#)'. You can download or order it from canteen.org.au



How do I know if my fertility has returned and can I have children?

It is hard to tell whether your treatment has had an impact on your fertility because you may be able to produce semen, but you will need to have it tested to determine the number and quality of sperm in the semen.

You will undergo some tests (yes – more tests) to determine what your fertility status is. Your GP, cancer or fertility specialist can order these tests. You may be told to wait a while for these tests (6-12 months) until your body settles back down to a more normal rhythm. This is so the tests can be more accurate.

"There's a huge possibility I will never be able to have children of my own and that hits."

Nathan, Ewing's Sarcoma.

Fertility testing.

A semen analysis is the most common test for men to undergo to determine their fertility status. It measures the amount of semen you produce and determines the number and quality of sperm in the sample.

In order to undertake a semen analysis you will need to provide a sample. In order to do this you will need to go to an andrology clinic or lab.

Your sample will then be taken into the lab for testing.

If you have no sperm in your sample, then your doctor may also want to consider a testicular biopsy to determine if there are any sperm remaining in the testicular tissue. Check out page 56 for a definition.

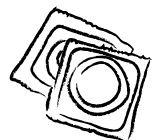
If there are no problems then you should be able to conceive 'naturally' (through unprotected sex). If your fertility is not back to normal, then your doctor will advise you of the next steps.

What happens when I want to have a baby?

When you are ready to have a child, the first thing you will need to do is determine your fertility status.

As we described before, this will answer questions such as "how likely is it that I can have children naturally?"

You should always use barrier contraception such as a condom, unless you are planning on starting a family. This will protect you from sexually transmitted infections. Even if you can't have children you still need to use contraception for this reason.



Just for women

Cancer and its treatment can affect your sex life.

Everyone experiences confidence and body image issues at some time in their life, particularly as a teenager and young adult. Your cancer experience can change how your body looks, feels and works. Sometimes your sexual feelings can change as a result of your cancer treatment. Whether the changes are physical or emotional it's hard not to be affected by these changes. While dealing with unwanted changes can be really tough, it may help to remember that underneath all of the changes you are still you. The good news is that with time and support, confidence in your appearance and sexual feelings will return. Even if the cancer and its treatment have damaged your ability to have children, you can usually still enjoy relationships and sex after cancer. In most situations you will still be able to have children.

If you have had surgery or radiotherapy to your pelvic area, having penetrative sex may initially feel uncomfortable. This may mean it takes you longer to feel aroused or reach an orgasm ('come').

"When I got home and tried to get on with my life that was when it really hit me. I kept thinking 'what's wrong with me?' I feel so different to all my friends and sometimes I feel really alone."

Rachael, Ovarian cancer.

It is a good idea to get some help in dealing with sexual changes. You may not feel in the mood for sex until you get adjusted to how you look and feel after cancer treatment.

Some cancer treatments can lower the female hormone called oestrogen. This can be temporary or permanent. Low oestrogen levels can cause vaginal dryness which can be treated with hormones, lubrication or hydrating gels used on the inside lining of your vagina. These can be bought at a pharmacist or supermarket or be prescribed by your GP. You can ask for products such as SYLK, Pjur, Hydra, Sliquid and Replens. None of these products contain hormones.

Sometimes it can feel embarrassing to talk about sex, but doctors and specialist nurses are used to dealing with these kinds of issues and can offer advice and support.

How does having cancer affect my fertility?

Not all cancer and cancer treatments affect your fertility. But it is really important to know what the risks and the issues are before you start your treatment, so you know whether you need to make some decisions about protecting your fertility.

You may not have this option before you start treatment because of your type of cancer. We want to provide you with some information so you can chat to your doctor or nurse about this as soon as possible, to find out if there is anything you can do.

We are going to be totally honest with you about this subject, so you may find some of the information on the following pages a bit difficult to read. Please, if you do start to become worried, go and talk to your nurse or doctor - or your parents or partner (if you have one) - straight away. They will help to answer your questions and help you with some of your concerns.



Cancer treatments and how they can affect fertility.

Chemotherapy.

Chemotherapy or 'chemo' is the most common form of cancer treatment. Chemo uses drugs called cytotoxins to kill or slow the growth of cancer cells. Unfortunately, while chemo can stop cancer cells growing and multiplying, it can also affect normal, healthy cells in the process. Reproductive cells fit into this category, so this includes eggs, and the hormone producing cells around the eggs.

The extent of the damage is determined by a number of different factors:

- Drug type.
- Dosage.
- Combination of medications.
- Your age at the time of your treatment.

With all of the things described above it is best to check with your doctor to see what the effect may be.



Before starting your treatment you should emphasise to your medical team that your fertility is important to you.

Contraception.

It is always strongly recommended to avoid becoming pregnant during cancer treatment. This is because damaged eggs can result in the baby not developing normally. So that you don't accidentally become pregnant during treatment, it is advisable to use barrier methods of contraception (e.g. condoms for penetration and dental dams for oral sex, which also protect you from sexually transmitted infections) during and after cancer treatment. It may also be appropriate to use a contraceptive pill or another form of contraception. It is best to discuss with your doctor or nurse in advance and ask them how long you are required to use barrier contraceptives.

Managing pregnancy during cancer treatment.

If your cancer is diagnosed when you are pregnant, your treatment options will depend on the stage of your pregnancy and the type and stage of cancer you have. Having a baby can be scary enough and adding cancer to the equation can be very confronting. Your doctor will provide you with the information and support you need to make the best decision for you.

Chemo can also have some late effects that may complicate any future pregnancy and delivery. You can find out more information about this in on page 14 of CanTeen's other resource '[Maybe Later Baby: A guide to relationships, sex and fertility for young people after cancer](#)'. You can download or order this book from canteen.org.au



Make sure you chat with your doctor when you begin to think about starting a family, to ensure that you have taken into account any special considerations.

Radiotherapy.

Radiotherapy (or 'radio') uses high-energy X-rays, gamma rays or electrons to kill cancer cells in a specific part of the body. It creates shifts in the body's cells that destroy the cells' ability to grow and divide.

Radiotherapy only affects the cells and tissues within a specific area (unlike Normal, healthy cells are also more able to resist the radiation, which is why your body may recover from the effects of radiotherapy faster.

Radiation also kills rapidly dividing cells, such as reproductive cells, but is generally limited to those in a contained area. So this is why it can impact your fertility if you are having radio in that area.

The amount of damage that radio can do to your reproductive organs depends on a number of things:

- Dosage.
- Number of treatments (called fractions) required.
- Area of radiation.
- Your age at the time of your treatment.

There are some procedures that may decrease the impact of pelvic radiotherapy on your fertility. Have a look at page 38 for a description of these options.

Abdominal or pelvic radiotherapy.

Having radiotherapy directly in your abdominal (stomach) or pelvic area can cause infertility.

Pelvic radiotherapy may cause damage to the ovaries so they can no longer produce eggs, or it may damage the uterus and cervix so being able to carry a baby may be difficult.

For some younger girls having radiotherapy to the uterus may mean that the uterus doesn't develop to the size it normally would, which again may make it difficult to carry a baby.

Some cancers that might require pelvic or abdominal radiotherapy include cervical cancer, ovarian cancer and some rhabdomyosarcomas or germ cell tumours in the abdomen.



Radiotherapy to the brain.

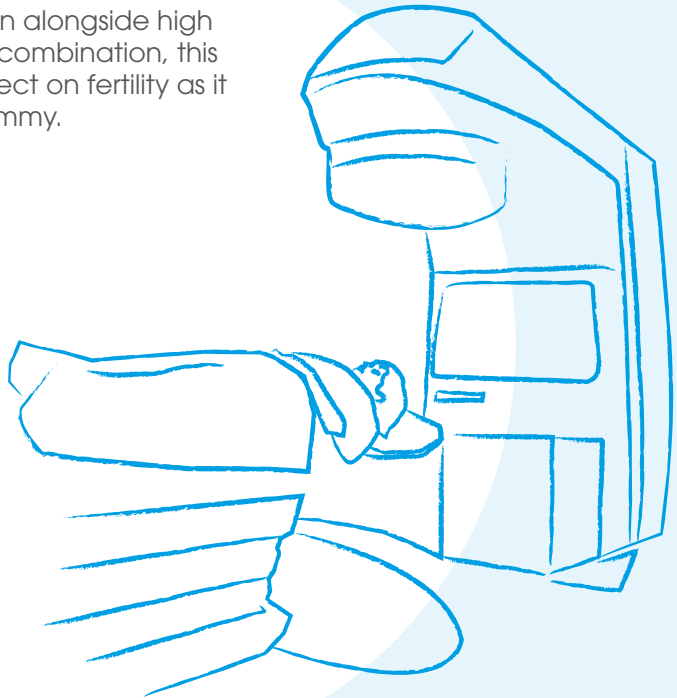
Having radiotherapy to your brain can also cause problems with fertility. Why is that? It may seem strange that having radiotherapy to your brain could affect the way your reproductive system works, but your brain contains the pituitary gland which releases hormones that work on the reproductive system. These are the ones that make the ovaries work and produce eggs.

If you do have radiotherapy to the brain, then you may be able to take medication that replaces the hormones that the pituitary gland releases.

Total Body Irradiation (TBI).

TBI involves undergoing radiation to the whole body. This treatment is often given to people prior to having a bone marrow transplant. It destroys the cancer cells throughout the body, and also destroys the immune system so that it will not attack the donor's cells during the transplant. TBI is usually given alongside high-dose chemo. In combination, this can have an effect on fertility as it is a double whammy.

TBI is usually given alongside high dose chemo. In combination, this can have an effect on fertility as it is a double whammy.



Medical imaging.

As you are no doubt aware, you will undergo many tests before and during treatment, especially several types of medical imaging, including X-rays and Computed Tomography (CT) scans, as well as more involved scans such as PET (Position Emission Tomography) and nuclear medicine scans. The tests mentioned all involve the use of ionising radiation, which causes levels of damage to cells within the body depending on the dose and scan type.

The benefit greatly outweighs the risk for the majority of these tests, but some precautions can be taken, particularly for the lower dose X-rays and some CT scans. The use of gonadal shielding for some X-rays and CT scans is available as long as the area of interest is away from the pelvis. For more involved scans such as PET this is not always possible as you are injected with a radioactive “tracer” to highlight areas of interest, so it is not possible to shield from these. The radiation used in Medical Imaging is slightly different to that used in radiotherapy and is generally less damaging.

The radiation dose of all of these tests is always closely monitored by the radiographers/medical imaging technologists conducting the scan, and reduced wherever possible. It is, however, always worth asking your doctor if there is an alternative test that does not use ionising radiation (such as ultrasound or MRI) available that will show the same information.

Hormone treatment.

Some cancers (such as breast cancer) use anti-hormone therapy as treatment. Some of the medications used will cause the ovaries to stop working, but this is usually only temporary and fertility will return once you stop taking the medication.

Bone Marrow Transplant (BMT) and Stem Cell Transplant (SCT).

Having a transplant means that you will be given high-dose chemotherapy and/or TBI. There is a higher risk of infertility due to the reasons outlined under chemotherapy and radiotherapy on pages 29 and 31.

Surgery.

Having surgery to the reproductive organs may affect your ability to conceive or carry a child. Some of the areas where you might have surgery that may affect your ability to become pregnant are:

- Ovaries.
- Cervix.
- Uterus and fallopian tubes.
- Vagina or vulva.

It is best to chat with your doctor about what the impact of surgery may be on your reproductive organs.

What could happen once I have treatment?

Temporary ovarian failure.

Some cancer treatments can lower the female hormone called oestrogen as a result of damage to the ovaries and eggs. This can be temporary or permanent. It is extremely common for periods to stop for a while during and after chemotherapy, even for up to two or three years. This is called temporary ovarian failure or temporary menopause. Usually the ovaries start to work again sometime later. However it is important to note that even after ovarian function returns, there is still a moderately high risk of developing ovarian failure, or menopause, a few years down the track, see this page for premature menopause. Often this occurs at a time when you would want to start trying to have a family. So you should talk to your doctor as early as possible about your future plans for a family.

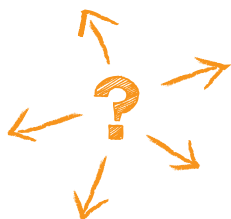
It can be confusing because having your period does not mean you are fertile and not having a period does not always mean you are infertile.

Early menopause.

Unfortunately your ovaries may stop working permanently resulting in what is known as premature ovarian failure or early (or premature) menopause. It is hard to predict in whom this would happen as treatment affects everyone differently.

This can also mean that you have fewer eggs left than you normally would due to possible damage by your cancer treatment. This puts you at risk of premature ovarian failure. Once this occurs you will have much greater difficulty in conceiving a child. Early menopause can be a devastating experience. For more information on coping with feelings related to early menopause see page 48.

We are not saying that this is the case for everyone who has chemo or radiotherapy. But it may happen for some people. On the next few pages are some of the options you may be able to access prior to starting treatment, so that if your fertility is impacted upon by your treatment, you may still be able to have a baby.



It can be confusing because having your period does not mean you are fertile and not having a period does not always mean you are infertile. See page 46 for fertility testing.

Fertility options before undergoing treatment.

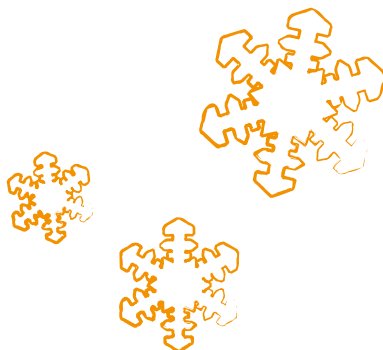
You may be feeling a little freaked out by now with all this information on fertility, and might be thinking-what am I supposed to do now?

This can be a really worrying time for you – but you do have a number of options that will help to ensure you are giving yourself the best possible chance of having children in the future.

Your doctor (probably your oncologist or haematologist) will discuss the risk to your fertility before you start treatment. Depending on when you start treatment, you may be referred to a fertility specialist before or after. Please just make sure that your doctor knows that your fertility is a priority for you.

We have outlined some of the available options below. It is really important to know that not all of these options may be available to you or right for you. Some are very new techniques and are still in the early experimental stages, and it is important to know that there are varied success rates of pregnancy with each of the options. We just want to outline the possibilities, but you need to talk to your doctor about what is appropriate.

Take your time to read through these, and take any questions you may have to your doctor or nurse (there is a notes section at the back of this booklet where you can write them all down). We have also created a list of questions (on page 42) which you could use.



Egg collecting and freezing

Mature eggs.

The aim of egg collection or harvesting is to collect eggs that can be frozen (called cryopreservation) and used at a later date. The process of collecting and freezing eggs takes about 10-14 days of hormone stimulation (through hormone injections). Eggs are collected through the vagina under ultrasound guidance and it generally takes 10-20 minutes. You are asleep for the procedure which is performed under sedation. Normally you would go home about an hour after the procedure.

Once the eggs are collected they are frozen and stored. Several thousand babies have been born across the world from mature eggs that have been frozen by either slow freezing or vitrification.

Embryo development and freezing.

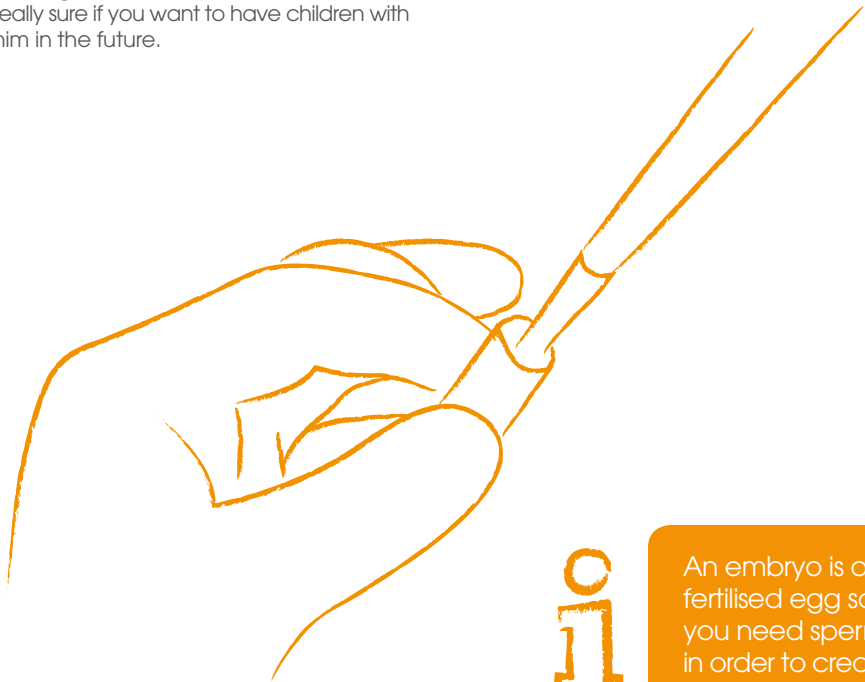
The process for developing and freezing embryos is quite similar to that of egg collecting and freezing – with one additional step. An embryo is a fertilised egg, so you need sperm in order to create an embryo.

Embryo freezing is a very successful form of treatment, but it's going to be less of an option for you the younger you are. This is because you are probably less likely to have a serious boyfriend or partner – or you might have a boyfriend but you're not really sure if you want to have children with him in the future.

Embryos are stored for your future use.

They can be stored for many years so it is important to stay in contact with the storage centre and keep them updated with your contact details. There is the need to reapply every ten years to continue to keep the embryos frozen and every twenty years to keep eggs frozen.

Once you decide to have a child, the frozen items are sent to your fertility specialist. Millions of babies have been born from frozen embryos.



An embryo is a fertilised egg so you need sperm in order to create an embryo.

Ovarian tissue freezing (ovarian cortex cryopreservation).

Taking a portion of your ovary and freezing it for the future is a technique that is becoming increasingly available although still considered experimental. There have only been some births worldwide so far using this technique.

It involves a small operation (called a laparoscopy) under a general anaesthetic to remove a portion from the outer part of an ovary. There are many immature eggs in this part of the ovary, which is then frozen.

The result of this procedure is that once you have completed your cancer treatment the ovarian portions can be transplanted back into your abdomen. The hope is that your ovary will start to function normally again.

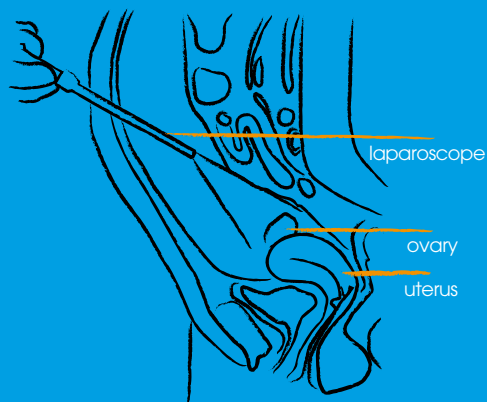


Diagram of the Laparoscopy operation.

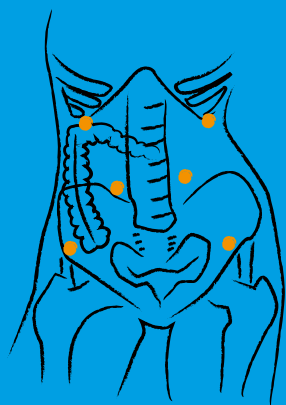


Diagram of ovary transposition.

Ovary transposition (oophoropexy).

Ovarian transposition is the surgical movement of one or both of the ovaries to another area in the body so that they are out of the field of radiation (normally 3 cm from the upper radiation field).

This may be performed for women who are having pelvic radiation. It does not protect you against the effects of chemo.

The ovaries are generally moved higher in the abdomen, sometimes up as high as the lowest ribs. See the diagram to the right for a picture of where the ovaries may be moved to.

Radiation shielding.

If the ovaries are close to where the radiation is directed (but they are not the target for radiation), then the ovaries can be shielded from the radiation beams by using protective coverings placed on your abdomen over your ovaries.

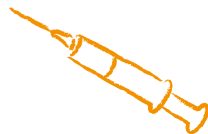
This technique does not guarantee that radiation will not affect your ovaries, particularly for radiotherapy focussed on the pelvis, but it does provide some level of protection from external radiation. Your doctor may still suggest undergoing ovarian transposition. Remember again, it does not protect your ovaries from chemo.



Ovarian function suppression using hormone therapies (GnRH analogues).

A method that might be offered to you to protect your fertility during treatment is the use of hormone therapy to slow down and stop the function of the ovaries. Given as a monthly injection, these hormones are usually started seven-ten days before cancer treatment starts and continue until the end of cancer treatment. This method may protect your ovaries during chemo as the hormones essentially cause a temporary shutdown of your ovaries, known as temporary menopause. Some large studies have suggested a definite benefit while others suggest it may not offer benefit in the short term. It is likely but not proven that these injections may protect the long term function of the ovaries.

A method that might be offered to you to protect your fertility during treatment is the use of hormone therapy to slow down and stop the function of the ovaries.



Questions you may have.

There are a number of different questions you may have about your sexuality and the fertility options we have just explained. Make sure you talk to your doctor if you have questions that we don't answer here.

How long can I freeze my eggs or an embryo?

As far as we know, you are able to freeze your eggs and/or an embryo for as long as needed until you decide to have a child. From a technical point of view there is no time barrier. But in most states, you are required to reapply for consent to the relevant authority for further storage every 10 years for embryos and 20 years for eggs or sperm. It's best to check with your fertility specialist.

How do I know if I can undergo...

Egg collection and freezing?

You should ask your doctor to refer you to a fertility specialist. There you can undergo an assessment and the doctor will discuss the various options for you to preserve your fertility. There may be reasons why egg freezing might not be an option for you:

1. You will have to delay treatment. This is so you can undergo the hormone injections to mature the eggs. This is something you will need to discuss with your doctor as you might not be able to hold off on treatment.
2. If you have a hormone-sensitive cancer then there is a very small possibility that the drugs used to mature the eggs may have some effect on the cancer cells. There is no demonstrated risk but it is an important point to discuss with your doctor. Most doctors would be happy for you to still have hormone stimulation for egg freezing, even if you have a hormone-sensitive cancer.

Talk with your doctor and if egg freezing isn't right for you, there might be some other measures you can take.

Embryo collection and freezing?

You will need to see whether you qualify for egg collection (see page 35). If you do, you will need to discuss creating an embryo with your partner.

What happens after I finish treatment?

Egg and embryo collection and freezing

Once you finish treatment you can think about what you might like to do with your eggs or your stored embryos. Having children may be a long way down the track though, so you might decide not to worry about it now and just think about it when the time comes. It is important to keep in contact with the storage centre so they regularly receive fees and updated contact details from you.

Ovarian tissue freezing.

Once you have finished treatment you can have the ovarian portions returned to your body, or they can remain frozen until you decide to have children.

Ovarian transposition.

Once treatment is completed the ovaries are surgically returned as close to their normal position as possible.

Use of GnRH analogues.

Once you have finished treatment you will generally stop the injections and hopefully within time your ovaries will start functioning again.

What happens when I want to have a baby?

Egg collection and freezing.

When the time does come that you want to have a child, your first step will be to undergo some testing to determine whether you need to use the eggs you have frozen. Your ovaries may have kick-started again after you finished treatment, and if they are producing eggs then you won't need to use frozen ones.

If, however, your ovaries aren't working, you will be able to have your eggs thawed and fertilised with your partner's sperm which he can deposit at a fertility clinic. An embryo can then be created through a process called in vitro fertilisation (IVF), which we have described in more detail on page 41.

If you don't have a partner, then you can use sperm that has been donated to the sperm bank by someone who is unknown to you or in some cases by a friend or extended family member. Donating sperm is something that has been happening for years and has allowed many people to have children. In Australia however there is a severe shortage of donated sperm and waiting lists at some clinics can be up to two years. This is mainly due to the fact that it is illegal in Australia to buy or sell any form of human tissue including sperm, and legislation now states that children born through donated egg and sperm have the right to know their genetic parent. This means that even in instances where sperm was donated anonymously, any subsequent children born have the right when they turn 18 years of age to contact their genetic father.



If you don't have a partner, then you can use sperm that has been donated to the sperm bank by someone who is unknown to you or in some cases by a friend or extended family member.

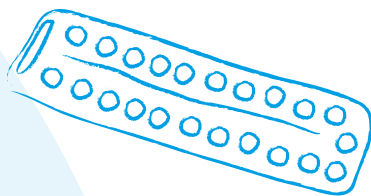
Embryo collection and freezing.

As is the case with egg collection and freezing your first step will be to undergo some testing to determine whether you do need to use the embryos that you have frozen. These tests will show if you are producing eggs and therefore can conceive naturally.

Ovarian tissue freezing.

When you are ready, you can have the portions of ovarian tissue thawed and put back in to either your abdomen, or your arm. Yep, your arm! Naturally you can't get pregnant in your arm, but what happens is that the ovarian portion, because it is back in an environment it knows, kicks back in and starts producing eggs again. You may also be given hormones to get the tissues to start working again.

This treatment is no longer considered experimental, as over 30 babies have been born. However it does require lots of testing and visits to your fertility specialist. With continued progress in this area of science, it may be an option you can undergo now, with the potential that the success rate is much higher when you want to have a baby in the future.



How do they fertilise the eggs?

Once you are ready, you will usually undergo IVF in an attempt to fertilise your eggs.

In Vitro Fertilisation (IVF) – is where the egg is fertilised with sperm in a laboratory, hence the term ‘test tube baby’, which you may have heard before. This process uses your eggs and the sperm from by your partner and attempts to develop an embryo by fertilising an egg.

Questions you may have:

There are a number of questions you may have about fertility options we have just explained. Make sure you talk to your doctor if you have any questions that we don’t answer here.

What will they do with my eggs if I no longer need or want them?

If you have returned to normal fertility or no longer want to use the eggs you have stored then you should advise the clinic that you no longer wish to keep them. They can either donate them (with your consent) or have them destroyed. However you may wish to keep them stored in case your fertility declines early. This is a common risk with chemotherapy.

Can taking the pill (OCP) during treatment protect my ovaries?

Taking the pill while you are undergoing treatment will generally not protect your ovaries from the effects of treatment. You might be advised to go on the pill by your doctor, but this is usually related to trying to minimise blood loss with periods.

What if I get pregnant while I am undergoing chemo?

If you fall pregnant while you are undergoing treatment then you should talk to your doctor immediately about what to do. Their recommendation will be based on the treatment you are having. It is very difficult to give an answer as it is a very individual situation.

What happens to my eggs if I die?

You can nominate what you would like to have done with your eggs. This might mean donating them to research or having them destroyed.

What happens to the embryos I have stored?

This is a really tricky question because the embryos don’t just belong to you they belong to your partner as well. This is guided by the laws in each state so you would be best to find out the legal situation from the clinic where you have stored your embryos. Generally before freezing embryos, your consent will outline your wishes in the event of death. This could mean either leaving the embryos to your partner or having them destroyed.

QUESTIONS TO ASK YOUR DOCTOR.

- What are the risks of infertility with my treatment plan?
- What can I do to preserve my fertility?
- How much time do I have before I start treatment?
- What happens if I delay treatment to stimulate eggs for collection?
- What can I do during treatment to protect my fertility?
- After my treatment is over, how long could it take for my periods to start again?
- Who do I need to talk to about my fertility options?
- Can you refer me to a fertility clinic?
- How do I know if I will be fertile after treatment?
- How much will these fertility treatments cost?
- What will my out of pocket expenses be?
- When should I have a fertility test?
- What can I do to enhance my desire for sex?
- What precautions should I take when having sex with my partner?



Summary table of options.

Name	Definition	Medical status	Time required	Timing
For women				
Egg collecting and freezing	Harvesting and freezing of mature and immature eggs	Standard	10-14 days of injections. Outpatient surgical procedure	After puberty
Embryo development and freezing	Harvesting of eggs utilising IVF to create an embryo and freezing the embryo for a later date	Standard	10-14 days of injections. Outpatient surgical procedure	After puberty
Ovarian tissue freezing	Freezing of a section of ovarian tissue for re-implantation after treatment is completed	More frequent success and becoming increasingly available	Outpatient surgical procedure	Before or after puberty
Ovary transposition	The surgical repositioning of the ovaries to a place in the abdomen outside of the radiation field	Standard	Surgical procedure	Before or after puberty
Radiation shielding	Shielding of the reproductive organs during radiation treatment	Standard	When treatment occurs	Before or after puberty
Ovarian function suppression using hormones	Using hormones to stop ovarian function during treatment	Not proven but likely to help	During treatment	After puberty

Now what? When treatment has finished.

You may have just finished treatment and be wondering "what happens now?" There may be hundreds of questions running through your head - mostly about getting your life back on track and moving forward. You are probably feeling very different now compared with before you were diagnosed with cancer.

Whether or not you can have children - and moving forward in a relationship or sexually - is something we can explain here.

There may be hundreds of questions running through your head - mostly about getting your life back on track and moving forward. See page 47 for let's talk about feelings.

Will my fertility ever return?

A lot of the treatments you may have had can affect your ability to have children. This will depend on a number of factors such as when, where, what type, how much treatment you had and how old you were at the time. It can be very hard to predict what the impact may be as everyone's response to treatment is different.

You may return to your normal reproductive state within a couple of months of finishing treatment. To be on the safe side, if you are going to have sex it is best to always use contraception and to undergo testing so your fertility status is known. There are quite a few cases of young people who thought they were infertile but who fell pregnant because they hadn't tested their fertility status. Not having a period does not always mean you are infertile.

REMEMBER: Your ovaries might take a while to function again. Your best option is to go and have testing done to see exactly what impact treatment has had on your fertility, as soon as you feel ready.



How do I know if I can still have children?

You will undergo some tests (yep – more tests) to determine what your fertility status is. These can be done by your GP, your cancer or fertility specialist. If you are anxious to know your fertility status after your treatment has finished you may be told to wait 6 – 12 months until your body settles back down to a more normal rhythm. This is so the results are more accurate.

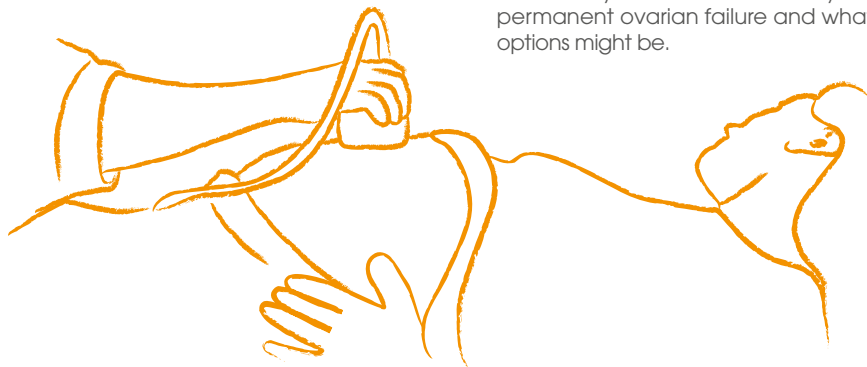
CanTeen has another resource for young people who have completed cancer treatment called 'Maybe Later Baby: A guide to relationships, sex and fertility for young people after cancer'. You can download or order it from www.canteen.org.au.

How do I know if my fertility has returned?

As we have explained before, after treatment you may be in temporary or permanent ovarian failure (see page 34 for more detail on what this is). The tricky part is that temporary ovarian failure can last quite a long time. There are some statistics that show that your period may not return for more than three years. You may eventually get your period again, at which point you know that your ovaries have started functioning again and are producing eggs. This doesn't necessarily mean you will be able to get pregnant easily, but it does indicate that things are working to some extent.

Even if your ability to have children hasn't been affected by your treatment, you should remember that some of your eggs might have been destroyed by the treatment. You may be okay to have a baby, but you might run the risk of developing premature ovarian failure. You may find yourself in a position where you need to consider fertility preservation options or having a family a little earlier than if you hadn't had cancer.

If your period doesn't return then you are best to make an appointment with your local fertility clinic to determine if you are in permanent ovarian failure and what your options might be.



Fertility testing.

When you visit a fertility clinic, you will undergo a series of tests.

Firstly, the doctor will take a thorough record of your menstrual history. They will ask whether your periods stopped during treatment (if you had begun puberty), and if they have re-started. If you are ovulating (releasing eggs), then the doctor will have a look at the timing of the cycles within which they are released.

You will also undergo a few blood tests to have a look at the hormone levels in your blood. There are a number of hormones that are essential for conception, so the levels of these hormones in your blood need to be determined.

Finally, you may undergo a physical examination. This might include an ultrasound of your ovaries and fallopian tubes and uterus to determine if there are any blockages or problems that might prevent you from conceiving or carrying a baby.

What happens when I want to have a baby?

When you are ready to have a child, the first thing you will need to do is determine your fertility status through fertility testing described on the pages before.

If you are unable to have a child naturally and you stored eggs prior to treatment then you may be able to use those.

It is best that you discuss any concerns with your oncologist or haematologist and your doctor or nurse at the fertility clinic.

Can I pass cancer on to my children?

A number of studies have looked at the effects of cancer treatment on the children of those who have undergone such treatment. In these studies there has been no risk identified to children who have been conceived naturally after cancer treatment. Studies have also shown there are no risks to children born from eggs and sperm that have been frozen.

There are however, a small number of people who have a 'faulty gene' that increases their risk of getting a certain type of cancer. Your doctor will be able to tell you if there is a chance you have a faulty gene that could be passed onto your children. If this is the case your doctor will recommend you speak to a genetic counsellor so you can make a well informed decision.

You should always use contraception unless you are planning on starting a family. This will protect you from sexually transmitted diseases and HIV/AIDS and your partner from the effects of chemotherapy. Even if you can't have children you still need to use contraception for this reason.



Psychological effects

Let's talk about feelings.

Undergoing treatment for cancer can have a huge impact on the way you think, feel and experience anything to do with your body, relationships, sex and having children. Everyone's reaction will be slightly different and may be influenced by your gender, culture and sexual orientation. How your family views these things can also shape how you think and feel. It is normal to feel anxious, frightened and even a bit lost. Many people who have been diagnosed with cancer do feel this way. For you, being younger than the person you typically hear about with cancer, there are heaps of other issues that you have to face - just being a teenager or young adult is hard enough without this as well!

It may take a while before you feel ready to think about relationships, sex or having children. Going through treatment is very tough and you might find yourself being really down and sad. You may also be trying to adjust to changes in your body and lifestyle and new priorities in your life. Some of these changes may come as a surprise to you.

Having to think about whether you might want to have children in the future doesn't make this any easier. You may also come across doctors that aren't really willing to talk about the impact cancer has had on your sexuality or fertility - and they can make you feel stupid or silly for asking. Make sure that you bring it up though. There are some people who believe that you should be treated at the expense of everything else, but now as people are surviving cancer more and more, long term side effects such as infertility are becoming more and more important to consider.

"Knowing I was infertile really got to me. I was okay about a lot of other things but not being able to have children really hit hard. I didn't even get a chance to know if I wanted children and then it was taken from me."

Nathan, Ewing's Sarcoma.

"I'm very relaxed about it. Not being able to have kids doesn't bother me anymore. I just say 'I can't have kids' and that keeps people quiet. No point trying to hide it."

Evan, Acute Lymphoblastic Leukaemia.

There may come a time in your future when you find yourself thinking about having children. Having taken some of the precautions we mentioned before will make your chances a lot higher than if you hadn't done anything at all. You may be scared of going to a clinic to have your fertility tested because you kind of don't want to know the answer. This is perfectly natural. Try having a chat to a friend or your parents or partner (if you have one) about how you feel - someone you can talk to about these sorts of things. They might be able to go to the clinic with you when you go for testing as moral support.

We've heard lots of young people say "I just want this whole thing to be over - no more surprises". But finding out about your fertility early on and knowing whether or not you can have a child naturally might actually help you to feel less in the dark about what is going on, rather than always thinking "what other surprises are waiting around the corner because I've had cancer?"



If you need someone to talk to, CanTeen provides a free and confidential counselling service. Support is available seven days a week, no matter where you live.

For more information, call 1800 835 932, visit canteen.org.au or email support@canteen.org.au

When you talk to your doctor, parents or partner about your fertility, you may find that they don't think it is as important as you do. Some other young people we spoke to said that they felt there was an expectation that fertility shouldn't be a concern for them, because they should be happy that they are alive and have completed treatment. This shouldn't be the case, and if someone is treating you like this you might need to explain to them what you are feeling, or let your counsellor know you are experiencing this reaction from other people.

The way you think and feel about having children may be directly affected by your cancer treatment and experience. Some studies have suggested that people who have had cancer may be reluctant to start a family, because of thoughts of premature death, or doubts about their ability to physically and emotionally raise children.

If you do find out in the end that you are unable to have children, either because the treatment destroyed your sperm, or because the interventions didn't work, then you may feel extreme sadness and grief. This is a totally normal reaction and people who have never had cancer but who are infertile may experience very similar feelings.

If you are experiencing early menopause way ahead of your peers this can feel lonely and isolating. You may feel friends and family are not interested in what you are going through physically and emotionally especially when they think you should just be grateful to be alive. Speaking to your doctor about managing the side effects of early menopause may be a helpful starting point to feeling like you are taking control. Reaching out to others who have been through a similar experience can be both affirming and empowering as you share practical strategies for managing early menopause.

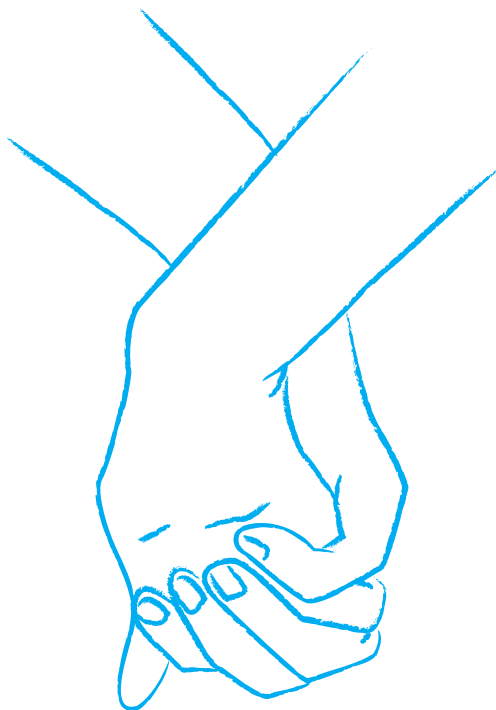
Partners.

Some people find going through something like this together strengthens their relationship and reinforces their commitment to each other. But living with cancer can place an enormous amount of pressure on everyone and problems can arise even between the most loving couples.

Young adults do not expect their partners to face a life-threatening disease. Like you, your partner is probably feeling scared, worried, angry, overwhelmed and confused.

They might even struggle more than you do. They will want to make things better for you and might feel helpless and frustrated when they can't make it all go away. With all the stresses of what is happening, you might not be communicating as well as you used to. Sometimes when you are close to someone you expect that they should be able to read your mind and know what you want. You might feel angry or upset if your partner doesn't know the best way to handle things.

All of these things can alter how you feel about your relationship and the intimacy you used to share. Hiding emotions creates distance between partners. It is normal that you and your partner will not always feel the same way. It's best to talk about your differences and respect their feelings without criticism or blame.



When to tell a new partner about cancer.

It can be difficult to tell people that you have had cancer or that you have had part of your body like a breast or testicle removed.

Deciding when to tell a partner is a very personal choice. Here are some tips:

- You may want to wait until you think the relationship could become serious before sharing the information.
- Pick a time to talk to your partner when you are both relaxed.
- Try practising what you want to say beforehand.
- You could tell them and show them any scars or physical changes before any sexual activity so you can both get used to how that makes you feel.
- Be honest about your concerns and encourage your new partner to be honest about theirs.

Talking to a partner about fertility.

Talking to a partner about being able or not being able to have children in the future might be one of the most difficult conversations you ever have.

Being uncertain about your ability to have children could directly affect any of the intimate relationships you may have. Not knowing may make you feel frustrated, scared and angry. If you have a partner then this may be a source of unspoken tension between the two of you. It might be best in this case to find out your fertility status as soon as you can. That way you might be able to make some decisions together about what the future holds for you.

Things that can help:

- Try to still talk about everyday things. You don't have to always talk about cancer.
- Do something special for each other and plan time together alone.
- Find ways to get your partner involved.
- Recall fun times together you have shared and ask yourselves – are we having fun yet?
- Being able to laugh together and cry together is what it is all about.

"He was my rock and still is. After all that we have been through I now know he genuinely loves me for who I am."

- Cassandra, Breast cancer.

Support for partners.

It can be difficult watching someone you love going through cancer. There may be times when your partner (and others) won't know what to say or do. Your partner may worry about saying the wrong thing or feel helpless because they can't make it better and they just want everything to go back to how it was before the cancer. Making sure your partner has lots of support can help you both keep on top of things. Encourage them to try and stay in touch with their friends and find someone to listen to how they are feeling. There is support available for your partner too. Let your partner know how much you care and be honest and upfront when you need some time out to recharge your own batteries. Many relationships grow stronger as you learn how to face the challenges together. There are many places to seek ongoing support via the internet sites listed on page 53.

CanTeen has written a resource called 'Wait... Did you Say 'Cancer'?!? A guide to supporting your partner when they have cancer' which can be downloaded or ordered at www.canteen.org.au

Body image and rebuilding intimacy.

You may experience changes in the way you feel about your body – both physically and emotionally. Some young people have said that they felt they had quite a negative body image as a result of their treatment – a bit like their body had let them down. If you are dealing with the prospect of infertility this might be something you find that you feel quite strongly. This may make it hard for you to connect with a partner, but talking things out with your partner or a counsellor are always a good option to help you deal with these feelings and emotions (remember that you can talk to a CanTeen counsellor if you want). Your interest and desire for sex may be lowered if hormones (such as testosterone and oestrogen) have been reduced by treatment. Loss of sexual interest, erection and orgasm difficulties can be caused by emotional as well as physical changes. The good news is that with time, practice and patience most people go on to have healthy and fulfilling sex lives after cancer.

"I have lost a lot of weight and I have lost all my features and especially my hair. My body image, self-esteem and confidence are shattered. It impacts how you view everything and I am trying to find myself now."

Hope, Hodgkin's Lymphoma.

Some strategies to enhance your sexual confidence may include:

- Setting aside time alone to explore what feels good.
- Let your partner know when you are ready for sex and if there are things you want changed.
- Start slowly and focus on cuddles and gentle massage to enhance your desire.
- Share any thoughts, fears or feelings you may have with your partner.
- Ask your partner how they are feeling.
- Don't forget to have some fun together!
- Prosthetic body parts can be quite intriguing to people who have not seen them before, and when you're ready, can become quite a talking point.
- Embrace your individuality and flaunt it.



What now?

After reading all of this information, you may be feeling shocked, a little scared and maybe a bit confused.

The next step you need to take is talk to your doctor as soon as you can so you can tell them that your fertility is a priority to you.

To the right is a list of places and websites where you can go to get more information. It might also be really helpful for you to read some stories of other people who have been in a similar situation. Under the list of internet resources you will find some links to these stories.

It might also be really helpful for you to read some stories of other people who have been in a similar situation.



Want to find out more?

Internet resources.

The internet is a great place to find more information about cancer and fertility. You could start by checking out some of these websites:

CanTeen

www.canteen.org.au

CanTeen provides an online support service where you can find out lots more information on living with cancer as a young person. You can also join an online community to connect with other young people, share experiences, join forums and blogs and generally support each other. You can also access online, email and phone counselling and find out more about the other programs and service that CanTeen provides.

Cancer Council

www.cancercouncil.com.au

This website has a list of information on all different cancers and treatments, and where to access support groups.

Fertile Hope

www.fertilehope.org

Fertile Hope is a US initiative dedicated to providing reproductive information, support and hope to cancer patients and survivors whose medical treatments present the risk of infertility.

Macmillan Cancer Support

www.macmillan.org.uk

This is a UK website that provides support for patients, carers, and families living with cancer. They have a section just for teens and young adults which is really easy to digest, from videos on how your blood works, to advice on how to deal with sex with a cancer diagnosis.

My Oncofertility

<http://www.myoncofertility.org/>

An informative website that provides reliable fertility facts and resources for people facing cancer.

Warwick Foundation

<http://twcf.org.au/>

Provides links to people who have been through a similar experience (both newly diagnosed and survivors) as well as emphasising practical strategies to thrive after cancer.



Talk to someone.

CanTeen Counselling Services.

1800 835 932

Kids Helpline.

1800 55 1800

LifeLine.

13 11 14

Cancer Council Helpline.

13 11 20

Australian fertility clinics.

There are a number of fertility clinics in Australia.

Go to www.access.org.au for a find a comprehensive directory to IVF Clinics accredited by the Reproductive Technology Accreditation Committee (RTAC) in Australia.

Sexual health and family planning clinics.

There are many family planning clinics in Australia.

Go to www.shfpa.org.au for a list of clinics throughout Australia.

Youth Cancer Services.

Youth Cancer Services are specialised treatment and support services for young people with cancer (aged 15-25, although this is flexible in some states). They are based in major hospitals throughout Australia. YCS services are staffed with expert doctors, nurses, social workers, psychologists and others experienced in working with young cancer patients. For more information about Youth Cancer Services and to find the service closest to you visit www.youthcancer.com.au

Foster care.

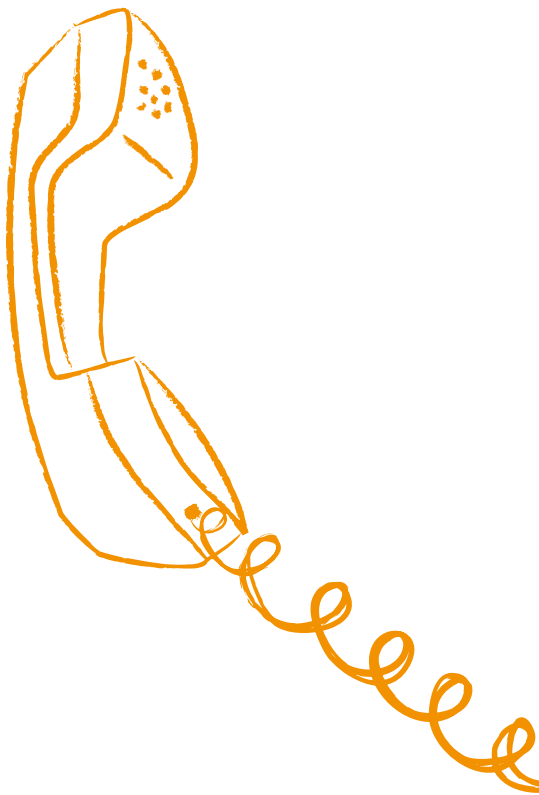
Australian Foster Care Association is a membership based voluntary organisation supporting and representing the voices of foster carers, their families and the children they care for throughout Australia.

www.fostercare.org.au

Surrogacy.

www.surrogacyaustralia.org

Supports Australians who are planning on, or who are already parents via surrogacy arrangements.



Recommended reading

Cancer and fertility: A guide for young adults – Fertile Hope.

There are 2 booklets in this series – one for young women and one for young men - both designed to provide information to young people who have just been diagnosed with cancer.

Childhood cancer and fertility: A guide for parents – Fertile Hope.

This booklet is designed for parents of children about to go through cancer treatment.

Relationships, sex and fertility for young people affected by cancer- Macmillan Cancer.

This resource is for teenagers or young adults who have or have had cancer. It gives information on relationships, sex life or fertility.

Cancer Council booklets.

The Cancer Council has a fantastic series of booklets on all types of cancer, treatments and anything else you may need to know. Check out their website for more information www.cancercouncil.com.au

Fertility after cancer: Cancer Council Australia.

A detailed and very comprehensive resource for adults with cancer. Focuses on informed decision making and explores the impact of infertility from a physical and psychological perspective. 2014 publication.



Can I still have children? Fertility options for young women having chemotherapy and radiotherapy.

This booklet provides information for women who are either just about to start treatment for cancer, or who have already undergone treatment. It is produced by Melbourne IVF and the Royal Hospital for Women, Melbourne.

Can I still have children? Fertility options for young men having chemotherapy and radiotherapy.

This booklet provides information for men who are either just about to start treatment for cancer, or who have already undergone treatment. It is produced by Melbourne IVF and the Royal Hospital for Women, Melbourne.

Medical jargon (your personal glossary)

Does it sometimes feel like everyone is speaking a foreign language? Medical terms and words can be a little out of this world, so we've put this page together to try and explain what some of them mean!

Anaesthetic: A drug given to a patient to stop him or her feeling pain during a procedure. It can be given as a local anaesthetic to numb the area or as a general anaesthetic to knock the person out.

Analgesic: A drug that relieves pain.

Aspiration: Removing fluid from the body with a needle.

Bilateral: On both sides.

Biopsy: The removal of a small sample of tissue from the body. This sample is then viewed under a microscope. A biopsy helps in the diagnosis of disease.

Blood: Circulates around the body through arteries and veins. It carries all different substances such as food, oxygen and chemicals to the body's cells, and helps to fight infection. Blood consists of white blood cells, red blood cells and platelets suspended in a liquid called plasma.

Bone Marrow: The soft, spongy area in the middle of bones where red and white blood cells and platelets are made.

Bone Marrow Transplant: This involves transfusing healthy bone marrow to replace bone marrow destroyed by high doses of chemotherapy.

Cancer: A general term for a large group of diseases that have

uncontrolled growth and spread of abnormal cells in the body.

Carcinoma: Cancer that forms in the tissue in the walls that line the body's organs.

Chemotherapy: The most common form of cancer treatment. 'Chemo' uses drugs called cytotoxics to kill or slow the growth of cancer cells.

Cervix: The lower, narrow portion of the uterus where it joins with the top end of the vagina.

Computed Tomography (CT) Scan: A type of scan utilising lots of x-rays to take slices of your body images. Often used in treatment planning. Scanning machine looks like a giant doughnut.

Cryopreservation: The freezing of eggs, sperm, embryos or ovarian or testicular tissue.

Cytotoxic Drugs: Drugs that are given that damage or kill off cancer cells.

Diagnosis: The identification of a person's disease.

Early Menopause: The start of menopause at an earlier age than normal.

Egg Freezing: Eggs are frozen for use at a later date.

Egg Harvesting: Eggs are collected through the vagina under ultrasound guidance.

Ejaculation: Expulsion of sperm during sex or masturbation.

Embryo Freezing: The fertilised egg (embryo) is frozen for use at a later date.

Epididymis: A collection of small tubes located at the back of each testicle.

External Beam Irradiation: Common form of radiation treatment.

Fallopian Tubes: The tube that lead from the ovaries to the uterus.

Fertility Preserving Interventions: Fertility preservation is a way of maximising your chances of becoming children in the future.

Fractions: The name given to each radiotherapy treatment.

Gamete: Egg or sperm.

Gonad: Ovary or testis.

Gonadal Toxicity: Damage to ovaries or testes, either temporary or permanent.

Haematology: A type of medicine that studies the blood.

Haematologist: A doctor who specialises in the treatment of disorders of the blood.

Hormone: A substance made by a gland that helps to regulate reproduction, metabolism and growth.

Hysterectomy: Removal of the uterus.

Intra Cytoplasmic Sperm Injection (ICSI - pronounced "eeksee"): Is an IVF procedure in which a single sperm is injected directly into an egg.

Intrauterine Insemination (IUI): Depositing sperm directly into the uterus to increase the chances of conceiving.

In Vitro Fertilisation (IVF): When an egg is fertilised with sperm in a laboratory.

In Vitro Maturation: This involves maturing eggs in the laboratory.

Laparoscopy: Small operation into the abdomen.

Leydig Cells: Cells found in the testicle that secrete testosterone.

Magnetic Resonance Imaging (MRI) Scan: A type of scan that creates slices of your body using magnets instead of harmful radiation. Scanning machine is large, with a narrow tunnel.

Masturbate: Self stimulation by touching genital area for sexual pleasure.

Medical/Diagnostic Imaging/Radiology: Tests, often scans, that create images of your body to help assess the extent of the cancer in your body, or to follow up during or after treatment.

Menopause: Cessation of periods either temporarily or permanently. Is a normal age-related process or can be associated with ovarian failure.

Menstruation: Having periods.

Nuclear Medicine: A type of scan that often, but not always, uses a radioactive injection to highlight areas of activity in your body, such as tumours.

Oestrogen: The primary female sex hormone.

Oncologist: A doctor specialising in the treatment of cancer.

Oocyte: Egg.

Oophrectomy: The removal of one (single) or both (bilateral) of the ovaries.

Ovarian Follicles: A cavity on the ovary that contains a maturing egg.

Ovarian Tissue Freezing: Involves taking a portion of ovarian tissue and freezing it for a later date.

Ovary: Organ which contains eggs and produces oestrogen and progesterone.

Ovulation: A phase of the menstrual cycle that involves the release of an egg from one of the ovaries.

Positron Emission Tomography (PET) Scan: Another type of scan that often uses a radioactive injection to highlight tumours.

Premature Ovarian Failure: When the ovaries stop functioning at an early age.

Progesterone: A hormone involved in the female menstrual cycle.

Pituitary Gland: A gland in the brain that secretes hormones.

Radiation: Energy in the form of waves that can injure and destroy cells, particularly cancer cells.

Radiotherapy: Use of high energy to kill cancer cells in a particular part of the body.

Semen: Fluid ejaculated from the penis. Contains sperm.

Sperm Freezing: A sperm sample is frozen for use at a later date.

Stem Cells: Immature cells found in the bone marrow from which blood cells are formed.

Stem Cell Transplant: Stem cells are taken from the blood prior to chemo, and then later returned after chemo.

Sterile: The inability to have children.

Testes: Organs which produce sperm and hormones including testosterone.

Testicular Tissue Freezing: When a piece of tissue is taken from the testicle and frozen for use at a later date.

Testicular Biopsy: A procedure in which a small piece of testicular tissue is removed, or sperm is removed directly from the epididymis.

Testosterone: The primary male sex hormone.

Total Body Irradiation: Radiotherapy of the whole body usually given prior to bone marrow transplants.

Toxicity: Harmful side effects caused by a drug.

Tumour: An abnormal growth in the body.

Ultrasound: A type of scan that uses sound waves instead of radiation to create an image. Can be used to look at your organs, or during pregnancy to see the foetus.

Uterus: The female organ where the foetus develops during pregnancy.

Vitrification: Flash freezing of eggs.

X-Rays: a type of radiation that is used to create 'shadows' of your body, especially bones and lungs. Also used in many other scans and therapies, such as CT scans and some Radiotherapies.

Notes

