

Maybe later baby?

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



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We acknowledge the contribution of Members and staff from CanTeen in developing this resource.

We thank the reviewers of this book:

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Edition 2: Dr Antoinette Anazodo, Assoc Prof Kate Stern, Dr Shlomi Barak, Assoc Prof Pandora Patterson, Lachlan Korvin, Dr Claire Wakefield, Bronwyn Kilby, Janine MacDonald, Erin Griffiths and Kerry Kalcher.

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The development and production of the booklet could not have been made possible without the financial support of the GHD Foundation and Sydney IVF.

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 treatment for cancer and is proudly endorsed and supported by IVFAustralia and Melbourne IVF.

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The direct quotes used throughout this booklet represent the real experiences of people interviewed for the study: The construction and experience of fertility in the context of cancer: patient, partner and health professional perspectives, an Australian Research Council Linkage Grant, LP110200153. This was funded research in conjunction with University of Western Sydney, Cancer Council New South Wales, National Breast Cancer Foundation and CanTeen.

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.

Foreword

"This book is a wonderful resource to have on hand after treatment and the initial hardships cancer throws at you. Even now, years post treatment I am still living with cancer and I reflect on my life and what is next for me. Fertility was not the first thing I thought about when diagnosed at 19, as I was worried about the cosmetic effects and to a more serious note, my chances of survival and relapse. It is only recentlyat 23 that I have wanted information on what my options are in relation to having kids. This resource covers the issues I have been unsure about and I can read it in the comfort of my bedroom without the stress or embarrassment of talking to a range of people to weigh up my options. I am now confident in making my choices regarding fertility whichwill ultimately affect my future and give my life direction."

Chris Bond.

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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 just finished cancer treatment, or it was many years ago, you may worry about whether this will have had any impact on your ability to enjoy sex and have children in the future (your fertility). Your treatment may also have had an impact on how you feel about your body (your body image) and your relationships.

Why you need to read this book. The aim of this book is to give you information about your sexuality and fertility after cancer, so that when you start to think about relationships and having a family in the future, you will already know what your fertility status is and what your options are. Hopefully all this will mean that there are fewer surprises down the track.



If you have just been diagnosed with cancer and are about to start treatment, then read our other book 'Maybe Later Baby: A guide to relationships, sex and fertility for young people with cancer.' If you have already had treatment for cancer - then continue on from here.



Returning to "ordinary" life after having cancer could mean that you have new things to think about and some of those could be your body image, relationships, sexuality and fertility. For both women and men, having treatment for cancer may affect all those things. We are going to explain why and talk about what you can do to determine your fertility status. Talking to a doctor (preferably your treating doctor but this may not be possible) or fertility specialist about the options that are available to you helps you feel like you are taking control. Understanding what you know (and don't know) is a good place to start.

This book has been written in collaboration with 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 the sometimes difficult, awkward or embarrassing aspects of what you are feeling.

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.

There is a list that describes many of the medical terms and words we use in bold on page 45.

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

Throughout this book we mention and encourage you to chat with your nurse or doctor about the issues raised. If you have a different health care professional whom you know and trust-talk to them. We have stated doctor or nurse just to keep things simple, but you should talk to whomever you feel most comfortable with. They will be able to help you find the right answers.

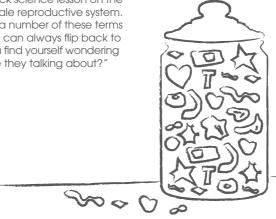
"After treatment is harder than going through treatment itself. Your body image, self-esteem and confidence all impact the way you view everything in life and I'm still trying to find myself now."

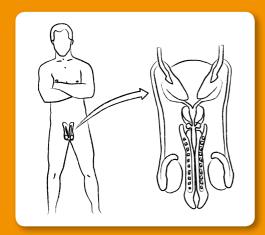
Hope, Hodgkin's Lymphoma.

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.

and their main job is to produce sperm

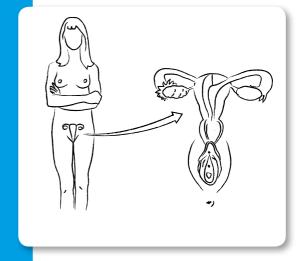
body so that they stay cool, enabling them to produce sperm (it is a few and move through a tube called the epididymis. The function of the epididymis is to aid the storage and transport of sperm, as well as to facilitate sperm and are then able to fertilise an egg.

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?

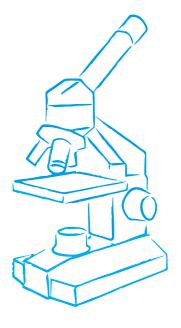
What is fertility and infertility.

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.

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. Currently one in six couples in Australia experience infertility, so it is quite common.



If you are infertile it doesn't necessarily mean that you can't become a parent. It means that there are difficulties with getting pregnant that you need to seek help for. Usually with that help, you will be successful, but there are also other ways to become a parent such as using donor eggs, donor sperm, a surrogate, fostering and adoption.

Why haven't I 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. If you were very young when you were diagnosed, your doctor may not have discussed this term with you. There may still be ways to preserve your fertility now, so you have more options when you are ready to have a baby. If this is something you want to find out more about, chatting to the doctors that treated you at the time is probably the best option. They may refer you to a fertility specialist.

Having children may not be something you have thought a lot about, but having cancer may have meant that you had to grow up a bit faster than you had planned and this is an example of something that you also need to think about sooner rather than later.

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 understand your options.

Unfortunately, your fertility may not have been talked about when you were diagnosed and treated for cancer. We are going to be pretty upfront here: your cancer treatment may have affected your ability to have children biologically. To what extent we can't tell you and in order to work this out you will have to go and have fertility testing done at a fertility clinic.

"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. I would have liked open and honest discussions with the doctor."

Nathan, Ewing's Sarcoma.

"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. I sort of zoned out."

Ben, Leukaemia.

FAQs

You probably have a million and one questions running through your head. We have the answers to some frequently asked questions below.

Why wasn't I given the option of fertility interventions?

Depending on when and where you had your treatment, there may have been a few reasons why you didn't get the option of fertility intervention. You may have been too young, they may not have been available where you live, or you may have had to start treatment straight away. There might still be ways to preserve your fertility now, so you have more options when you are ready to have a baby. If this is something you want to find out more about, chatting to the doctors that treated you is probably the best option. They may refer you to a fertility specialist so that they can help you work out what your options are.

I am really angry at my doctor that I wasn't told about this before my treatment! What can I do?

Your first reaction might be anger or frustration at your medical team because you didn't know about your options. Like we said above, there may have been many reasons why you didn't have fertility interventions. Our advice to you is to find out what the actual reason was from your doctors and then deal with the situation from there. Seeking support from a counsellor may help you cope and process this information.

Will having sex make the cancer come back?

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

Will sex hurt or feel the same after cancer treatment?

It usually takes time and plenty of practice to feel comfortable and confident with having sex after cancer. Many people prefer to take it slowly and find out what feels good, or not so good, while they are alone so when they are ready, they can then tell their partner how they feel. Others focus on hugging, kissing and intimate touching until they feel the desire for sex. Everyone is different so do what feels right to you. See page 35 for body image and rebuilding intimacy.

Can I still have sex if I am infertile?

Even if you are unable to have a baby, you can still have sex. You will need to take precautions and use contraception to prevent sexually transmitted infections.

What if I am gay, bisexual or transgender?

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 a priority for 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 before you speak to your doctor on page 38.



Is it possible to adopt or foster a child if you have a history of cancer? This can depend on the adoption or fostering agency. Some may require you to be cancer free for a number of years before starting the process.

What is the difference between premature ovarian failure and infertility?

Premature ovarian failure is a cause of infertility and occurs because you stop producing eggs a long time before the natural age of menopause. Premature ovarian failure can be temporary or permanent, however infertility is permanent. See page 24 for temporary ovarian failure or early menopause.

How long can sperm, eggs, embryos and ovarian tissue be frozen for?

Eggs, embryos and ovarian tissue can be frozen indefinitely, however because these techniques haven't been around for years and years it can be hard to know exactly how long they can be stored for. Frozen sperm stored for 30 years has been known to produce healthy babies.

If I get my period back after treatment, does that mean that I am fertile?

If your period starts again after you finish treatment, then it is a good sign that your body may be getting back to normal. This usually happens after about six months. However, just because you have your period doesn't necessarily mean that you can have children. There are many women who have their period, yet are unable to have children (and no - they haven't all had cancer). Even if your periods resume, you still may have trouble conceiving a child. See page 24 for temporary ovarian failure or early menopause.

What if I am still producing semendoes that mean that I am fertile?

Even though you may be producing semen, it does not necessarily mean that you are producing sperm. The only way you will be able to know is if you have fertility testing (a semen analysis) – or if your partner falls pregnant!

What is surrogacy?

Surrogacy involves having another woman (a surrogate mother) carry your child and give birth on your behalf. The surrogate's full intention is to hand over the child after the birth. Surrogacy can be done using either your eggs (fertilised with your partner's sperm) or the surrogate's eggs (using your partner's sperm to fertilise her eggs) although this second option is very uncommon in Australia.

How much do fertility treatments cost?

The public and private health systems in Australia has different costs for these procedures (some are free through the public health system). Medicare will cover most of the cost of speaking to a fertility expert for your initial assessment. This way you can ask how much some of the fertility procedures might cost and what your out of pocket expenses may be. A cancer specialist or your GP can organise all the tests you need done before you go to the fertility specialist and can refer you to the specialist.

If I am able to have a child, how long should I wait to conceive after cancer?

This depends on a number of things. You are best to chat to your doctor as they may have different reasons for telling you to wait to have a family.

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

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 vour 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.

Can I pass cancer on to my children?

Research studies have looked at the effects of cancer treatment on the children of those who have undergone such treatment. 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 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 know your options – and make the final decision when you are ready.



I am really upset about having to deal with infertility and changes to my body. Where can I go to get help?

Although the best people to talk to about your feelings generally tend to be your family and friends, sometimes it might be too much for them, so we would also recommend that you talk to a counsellor about how you feel. CanTeen offers a free and confidential counselling service (visit canteen.org.au or call 1800 835 932) and we have also listed websites on page 42 which you might like to check out. This could be a starting point for where to get help. You may also find it helpful to talk to someone who has been through a similar experience. See page 43.

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 has having cancer affected my fertility?

Not all cancers and cancer treatments affect your fertility, but some can. The dose, type, location and your age at the time of your treatment may have had an impact.

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 partner (if you have one) or parents - straight away. They will help to answer your questions and alleviate some of your concerns. You can also call a CanTeen counsellor on 1800 835 932. See page 30 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.

Types of cancer that can affect fertility.

Being diagnosed with some of the cancers listed below may have directly impacted upon your fertility.

Testicular cancer.

Having testicular cancer could mean that you had a low sperm count at the time of diagnosis.

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.



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

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.

Radiation also kills rapidly dividing cells such as reproductive cells, but is generally limited to those in a contained area. This is why it can have impacted upon your fertility if you had radiotherapy in your reproductive region.

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.

Abdominal or pelvic radiotherapy.

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

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 did have radiotherapy to the brain, then you may already be taking medication that replaces the hormones that the pituitary aland releases.

Total Body Irradiation (TBI).

TBI involves having radiation to the whole body. You may have undergone TBI if you had a bone marrow 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 could have had an effect on your fertility as it is a double whammy.

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.





What could have happened as a result of my treatment?

Now that we have talked about the impact the treatment may have had, it is good to know exactly what it may have done to your testes and hence your sperm.

After treatment, depending on all the factors we described, you may have developed a low or non-existent sperm count. This means that there may not be many sperm in each semen sample.

Another thing that may have happened is that your sperm may not be very good 'swimmers' anymore. So you still produce sperm, but they just move a little slower.

We are not saying that this is the case for everyone who had chemo, radiotherapy or surgery. But for some people it may be. On the next few pages we have listed some of the options that you have in order to have a baby - once you know what your fertility status is.

"I have talked to them in the clinic and I know I need to do a fertility test when I have the guts to go in."

Shaun, 19, Testicular Cancer.

Options after having treatment.

You may be feeling a little freaked out by now with all this information on fertility. We realise that this can be a really worrying time for you – but taking it all in slowly and working out what your situation is will be the best way to deal with all of this.

Your first priority should be to determine whether you had any fertility preserving interventions before you had treatment. Fertility preserving interventions can include sperm freezing or testicular tissue freezing. Check out page 40 for a definition of these terms. You may have been quite young when you had cancer so you may not remember whether you had any fertility intervention. If this is the case, then it would be best to ask your parents or doctor as they will probably know. Depending on how old you were when you had treatment, you may or may not have needed any fertility intervention.

If you did undergo fertility preservation, then your parents or doctor will know where your sperm or tissues are being stored and will be able to put you in contact with the right people. They will then be able to outline what steps you will need to take in order to have a baby. We have described the different techniques available to you on page 25.



If you didn't undergo any preservation interventions, then your first step should be to go to a fertility testing clinic (sometimes called andrology centre or clinic) and find out whether you will be able to conceive naturally, or whether you may need some help. We have listed the details of a directory of clinics you can call on page 38. You will probably need a referral from your GP for the clinic.

At this time it could also be a good idea to talk to a fertility counsellor or specialist. Your GP or the fertility clinic can refer you to someone. They will be available to talk you through your thoughts and feelings surrounding your options and will give you some tips for coping with any anxiety or stress that you might be feeling. Don't hesitate to ask for help in dealing with your feelings.

Also, take any questions you have to your GP.

How do I know if I can still have children?

Fertility testing for men.

A semen analysis is the most common fertility test men can have. It measures the amount of semen you produce and determines the number and quality of sperm in the sample.

In order to have a semen analysis you will need to go to a clinic (called an andrology clinic or an andrology lab) and provide a sample.

You will be told step-by-step what to do by the staff there and given as much time as you need. 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. Your sample will then be taken into the lab for testing. You may also be able to have sex and collect the sperm sample. You need to use a special condom the fertility centre will provide for you.

If you have no sperm in your ejaculation, or if you cannot ejaculate for a medical reason, then your doctor may also consider a testicular biopsy to determine if there are any viable sperm left in the testicular tissue. Having had cancer we are pretty sure that you already know what a biopsy is, but if you don't, check out page 40 for a definition.

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

Nathan, Ewing's Sarcoma.



A semen analysis is the most common fertility test men can have. It measures the amount of semen you produce and determines the number and quality of sperm in the sample.

After fertility testing.

If you can have children naturally.

If your fertility tests indicate that you are able to have children by 'natural' means, i.e. through having unprotected sex, then until the time comes when you want to have a baby you will need to use contraception.

Establishing a fit and healthy lifestyle can increase your chances of getting pregnant naturally. Some suggestions on how to prepare for having a baby are:

- Eat a healthy balanced diet.
- Keep your weight within the recommended range for your height.
- Have sex regularly (e.g. twothree times a week).
- Stop smoking and doing recreational drugs.
- Don't drink alcohol.
- Check with your doctor about any medications you and your partner are on to assess if they are absolutely necessary.

If you need a bit of help (called assisted reproductive technology – ART).

The next stages depend on whether you had your sperm frozen before cancer treatment or the quality of your sperm now treatment has ended. Your results may show that you need help or assistance to have a baby using donor egg or sperm. There are a couple of methods that fertility clinics use. They are called Assisted Reproductive Technology (ART) and involve a few different procedures.

1. In Vitro Fertilisation (IVF).

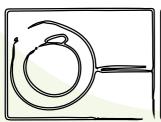
In Vitro Fertilisation (IVF) is the process whereby your partner's eggs will be fertilised with your sperm (or donor sperm) in a laboratory, hence the term 'test tube baby'.

2. Intracytoplasmic Sperm Injection. (ICSI pronounced "eeksee")

ICSI is an IVF procedure in which a single sperm is injected directly into an egg. This technique is generally used when there is only a small sperm sample, or not many sperm in each sample. The sperm is then selected based on its shape and ability to swim.

3. Intrauterine Insemination (IUI).

This involves depositing sperm directly into the uterus to increase the chances of conceiving. This technique may be used if your sperm count is slightly reduced or if they aren't very good swimmers.







If you cannot have children naturally. Unfortunately having cancer treatment can cause sterility, which means you are not able to father a child. Being unable to have children can be a very difficult thing to deal with – especially after going through cancer and treatment. If you are in this situation, we would suggest that you talk to someone about how you feel. See page 30 for let's talk about feelings. A fertility clinic will be able to refer you to a specialist fertility counsellor. You can do this alone or with your partner.

We also want to make it clear that not being able to conceive a child does not mean that you can't be a parent. There are options available which mean that you can still be a father. These include:

Donor sperm: If you are no longer producing sperm, then your partner may be able to get pregnant using sperm donated from another man. This can be from someone you know or from an unknown donor. Sperm donations are in severe shortage, so there may be a waiting list. 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 though donated sperm (and embryos) have the right to know their instances when the sperm was donated anonymously, any children born have the right to contact their genetic father when they turn 18. Alternatively you may be able to use a donor embryo.

"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.

Adoption: Adoption is when a child is placed into the care of a person who didn't give birth to them. There is a process which you will have to undergo to determine your suitability for adoption, prior to having a child placed in your care.

Fostering: Fostering a child is when you take responsibility for a child, but do not legally have parental status. There are many more opportunities to foster a child than adopt one and it can be an extremely rewarding and meaningful experience.

Surrogacy: Involves having another woman (a surrogate mother) carry your child and give birth on behalf of you and your partner. The surrogate's full intention is to hand over the child after the birth. Surrogacy can be done using either your partner's eggs (fertilised with your sperm) or the surrogate's eggs (using your sperm to fertilise her eggs) although this second option is very uncommon in Australia.

Legislation regarding adoption, fostering and donor sperm is different in each state throughout Australia. Check with your local IVF clinic or legal advisor for the current legislation in your state or territory.

Not having a child.

Many people live happy lives without children. Some people decide they do not want to have fertility treatment or adopt or foster a child. Others find that it hasn't been the right time in their life - or that they have the right partner to consider being a parent. We are all different and the important thing is that you feel you have the right information and support to make the best decision for you.

What if I am gay, bisexual or transgender?

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 38 before talking to your doctor.

We are all different and the important thing is that you feel you have the right information and support to make the best decision for you.



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 may have changed how your body looks, feels and works. Your desire or interest in sex may also have changed. Whether the changes are physical or emotional it's hard not to be affected by them. While dealing with unwanted changes can be really tough, it may help to remember that underneath it all, you are still you. The good news is that with time and support, confidence in your appearance and sexual feelings are likely to return. See page 30 for let's talk about feelings. Even if the cancer and its treatment have damaged your ability to have children, you can usually still enjoy relationships and sex after cancer.

Some cancer treatments can lower the female hormone called oestrogen. This can be temporary or permanent. This is called temporary ovarian failure or temporary menopause see page 24.

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 prescribed by your GP. You can ask for lubrication products such as SYLK, Pjur, Hydra, Sliquid and Replens (a vaginal moisturiser). None of these products contain hormones. They are designed for relieving discomfort.

If you had surgery or radiotherapy to your pelvic area, having penetrative sex may have initially felt uncomfortable. If this has happened to you, it may take longer to feel groused or reach an orgasm ('come'). 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 treatment has ended. 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 practical advice and support to help you move forward after cancer.

"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?' and I still even now, feel so different to all my friends."

Rachael, Ovarian Cancer.

How has having cancer affected my fertility?

Not all cancer and cancer treatments affect your fertility, but some - depending on the dose, type, location, how old you were and the way the body reacts - may have had an impact.

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. 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 alleviate some of your concerns. You can also call a CanTeen counsellor on 1800 835 932. See let's talk about feelings on page 30.



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 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 these things described above it is best to check with your doctor to understand the impact your treatment might have had.

"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.

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 40 for a description of these options.

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

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. You may have undergone TBI if you had a bone marrow 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 could have had an effect on your fertility as it is a double whammy.

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

Undergoing a transplant probably meant that you had high-dose chemotherapy and/or TBI. There is a higher risk of infertility due to the reasons outlined under chemotherapy and radiotherapy above.

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 had surgery are:

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

It is best to speak with your doctor about what the impact of surgery may have been on your reproductive organs.



What could have happened as a result of my treatment?

Temporary ovarian failure.

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 your ovarian function returns, there is still a moderately high risk of developing ovarian failure/menopause a few years down the track, often at a time when you would want to start trying to have a family. Once this occurs you will have much greater difficulty in conceiving a child.

What is early menopause?

Whilst you may regain ovarian function after your cancer treatment and start having your periods again, you will have fewer eggs left than you normally would. This puts you at risk of going into early menopause (sometimes called premature menopause). Once you start menopause you may be unable to conceive a child. Early menopause can be a devastating experience so we'd recommend talking to a counsellor. For more information on coping with feelings related to early menopause see page 30.

We are not saying that this is the case for everyone who had chemo, radiotherapy or surgery. But for some people it may be. On the next few pages we have listed some of the options that you may be able to access in order to have a baby once you know what your fertility status is.

If you do want to have children, you may need to consider having them earlier than you might have planned just in case you go into early menopause.



Options after having treatment.

You may be feeling a little freaked out by now with all this information on fertility. We realise that this can be a really worrying time for you - taking it in slowly and working out what your situation is will be the best way to deal with all of this

Your first priority should be to determine whether you had any fertility preserving interventions before you had treatment. Fertility preserving interventions can include egg freezing, embryo freezing and ovarian tissue freezing. Check out page 40 for a definition of these terms.

You may have been quite young when you had cancer so you may not remember whether you had any fertility preservation interventions. You would be best to ask your parents or doctor as they will probably know.

If you did undergo fertility preservation, then your parents or doctor will know where your eggs or tissues are being stored and will be able to put you in contact with the right people. They will then be able to outline what steps you will need to take in order to have a baby.

Also, take any questions you have to your GP.

If you didn't undergo any preservation interventions, then your first step should be to see your GP who can perform some initial fertility tests (such as hormone levels). Or, they can recommend you consult a fertility specialist who can perform more tests to see if you will be able to have a baby naturally, or whether you may need some help. We have li sted a website on page 37 where you can get information about your nearest clinic.

You will probably need a referral from your GP for the clinic. It would be best to chat to your GP about any concerns you might have and they can refer you to the best clinic for you. We would also recommend you find someone such as a fertility counsellor to talk to about this. They will be available to discuss your thoughts and feelings surrounding your options with you and give you some tips for coping with any anxiety or stress that you might be feeling. See page 30 for let's talk about feelings.

"My doctor brought out a sheet of paper explaining all my fertility options and that definitely helped. It was good to see it on paper and know it wasn't the end. I had options."

Hope, Hodgkin's Lymphoma.





How do i know if i can still have children?

Fertility testing for women.

When you visit a fertility clinic, you will have a series of tests. They usually involve a doctor taking a history, some blood tests and a full physical examination.

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 cycle within which they are released.

You will also have 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 being able to conceive and the levels of the hormones in your blood need to be worked out.

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

After fertility testing.

If you can have children naturally.

If your fertility tests indicate that you are able to have children by 'natural' means, i.e. through having unprotected sex, then until the time comes when you want to have a baby you will need to use contraception.

It is possible that your treatment may have caused long term damage that may complicate any future pregnancy and delivery. You should make sure you ask your doctor whether there are any risks involved in you having a baby.

Establishing a fit and healthy lifestyle can increase your chances of getting pregnant naturally. Some suggestions on how to prepare for a pregnancy are:

- Eat a healthy balanced diet.
- Keep your weight within the recommended range for your height.
- Have sex regularly (e.g. two-three times a week).
- Don't smoke or do recreational drugs.
- Don't drink alcohol.
- Check with your doctor to see if any medications you and your partner are on are absolutely necessary.

REMEMBER: Even if you are producing eggs naturally, because of your treatment you may be at risk of developing early menopause, where your body runs out of eggs. Make sure you take this into consideration. You may need to plan to have your family sooner rather than later.

If you need a bit of help (called assisted reproductive technology - ART).

Your results may show that you need help or assistance to have a baby. There are a couple of methods that fertility clinics use in order to help women get pregnant. They are called Assisted Reproductive Technology (ART) and involve a few different procedures.

1. In Vitro Fertilisation (IVF)

In Vitro Fertilisation (IVF) is the process in which your eggs will be fertilised with sperm in a laboratory, sometimes called a 'test tube baby'. Your eggs will be collected through a process called **egg** harvesting and will then be fertilised with sperm donated by your partner.

2. Intrauterine Insemination (IUI)

This involves depositing sperm directly into the uterus to increase the chances of conceiving. You will need to have injections for a couple of weeks and monitor when your body releases the egg for the right time to have this procedure done.

There are a couple of methods that fertility clinics use in order to help women get pregnant. They are called Assisted Reproductive Technology (ART) and involve a few different procedures.

If you cannot have children naturally...

Unfortunately having cancer treatment can cause infertility. Being unable to have children can be a very difficult thing to deal with – especially after going through cancer and treatment. If you are in this situation, we would suggest that you talk to someone about how you feel. A fertility clinic will be able to refer you to a specialist fertility counsellor. You can do this alone or with your partner (if you have one).

We also want to emphasise that not being able to conceive a child does not mean that you can't be a parent. There are options available which mean that you can still be a mother. These include:

Surrogacy: Involves having another woman (a surrogate mother) carry your child and give birth on your behalf. The surrogate's full intention is to hand over the child after the birth. Surrogacy can be done using either your eggs (fertilised with your partner's sperm) or the surrogate's eggs (using your partner's sperm to fertilise her eggs) although this second option is very uncommon in Australia.

Donor eggs or embryos: If you are no longer producing eggs, then you may be able to get pregnant using an egg donated from another woman. Alternatively you can use a donor embryo.

Adoption: Adoption is when a child is placed into the care of a person who didn't give birth to them. There is a process which you will have to undergo to determine your suitability for adoption prior to having a child placed in your care.

Fostering: Fostering a child is when you take responsibility for a child, but do not legally have parental status. There are many more opportunities to foster a child than adopt one and it can be an extremely rewarding and meaningful experience.

Legislation regarding adoption, fostering and donor sperm is different in each state throughout Australia. Check with your local IVF clinic or legal advisor for the current legislation in your state or territory.



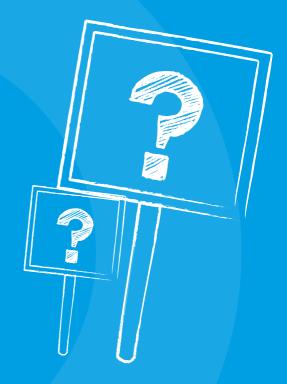
Not having a child.

Many people live happy lives without children. Some people decide they do not want to have fertility treatment or adopt or foster a child. Others find that there just hasn't been the right time in their life - or they haven't found the right partner to consider being a parent. We are all different and the important thing is that you feel you have the right information and support to make the best decision for you.

What if i am gay, bisexual or transgender?

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 38 before talking to your doctor.

We are all different and the important thing is that you feel you have the right information and support to make the best decision for you.



Psychological effects

Let's talk about feelings.

Whilst you were having cancer treatment you probably had to deal with many different and difficult thoughts and feelings. Even after finishing treatment, you may still be dealing with lots of emotions that relate to the way cancer has impacted upon your life. This can happen for quite a long time after treatment. Going through cancer can have a long term impact not only physically, but on the way you think and feel. Some of these feelings will relate to 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. The way you feel can also influence how you

"It forced me to think of something that I didn't even feel ready to look at. I wasn't in the right head space or position to think about whether I someday wanted to be a parent."

Roberta, Breast Cancer,

"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 bide it"

Evan, Acute Lymphoblastic Leukaemia

Reading this book may have been confronting for you, particularly if sexuality and fertility weren't discussed prior to you undergoing treatment, or if you had treatment when you were really young. Facing the prospect of adjusting to your changed body, embarking on an intimate relationship or facing potential infertility may feel like adding insult to injury after what you have already been through.

If these topics were not discussed before you had treatment, you may feel upset or angry that you weren't told everything or given any options. It is perfectly okay to feel this way. We know that this can have a big impact on what you thought your future would look like.

At times you may find it difficult to pinpoint what it is you are actually feeling or understand why. The main thing to remember is there is no right or wrong way to feel. You might not be naturally comfortable with sharing your feelings and sometimes you hope that if you just ignore them they will go away (guess what? ... They don't). Feelings are not good or bad, they are just feelings. Even if you keep them hidden or try and ignore them, they will still be there.

"I still don't feel like my old self and that's probably the worst part of my cancer experience."

Lily, Hodgkin's Lymphoma.

The problem is that when things get bottled up they need to get out somehow and this can lead to behaviour that is not safe, angry outbursts or having a bit of a meltdown. As hard as it might be, finding ways to express what you are feeling is really important in helping you deal with the stress of all you have been through.

Feelings about your attractiveness to other people can be shaped by your cancer experience. This can make it difficult to feel excited about sex after cancer, or even just being in a relationship. Talking to someone you trust can help you make sense of it all and ease the load. Connecting with someone who has been through a similar experience can help you feel less alone. You may be able to get some practical advice about adjusting to your changed body (see page 38 for information on CanTeen). Doing regular exercise (ask your doctor or nurse for tips on pacing yourself) and learning meditation are also ways to help restore your energy and confidence.

Throughout this book we have encouraged you to talk to your doctor, your nurse, your parents or partner (if you have one). We do know though that sometimes the reactions some people have had from their doctors, nurses, partners or parents when they went to talk about their fertility were difficult to take.

Some people mentioned that their fertility wasn't seen as a priority to them and that there was an expectation that they should just be happy to be alive and have completed treatment.

This isn't a very fair response and if someone is treating you like this, as tricky as it may be, you might need to explain to them what you are feeling. It can sometimes be hard for people to understand what you have been through.

The way you think and feel about having children may also be directly affected by your cancer treatment and experience. 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. Even if you are able to have children after your treatment, you may still feel this way, but try to remember that it is okay to have these feelings.

The process of undergoing fertility testing and finding out your results may leave you with feelings of sadness and grief. This is a totally normal reaction whatever the outcome of your tests. Feeling down and upset by what has happened to you is okay too. Again though, you are best to find someone who you can talk to about your feelings.



REMEMBER – you don't have to deal with all of this information alone. There are people out there you can talk to!

EARLY MENOPAUSE.

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 are relieved your cancer treatment is over and think you should be just celebrating that. Speaking to your doctor or nurse 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 car be both affirming and empowering as you sarrly menopause.

The only advice we can give you is that you should try and talk to someone who can help you deal with what you are going through.

The longer I was in menopause the more I worried it was going to be forever. Dealing with the side effects of menopause is so annoying and it makes me feel older than my mother. I didn't expect that!"

Joy, Breast Cancer.

Talking to a partner.

Some people find going through something like cancer together strengthens their relationship and reinforces their commitment to each other. But life after 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 have faced a life-threatening disease. Long after your treatment has finished, your partner may still feel scared, worried, angry, overwhelmed and confused about all you have been through.

Partners can struggle more than you do. It is hard watching someone you love trying to pick up the pieces after cancer. 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 you have gone through, 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.

"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.



CanTeen has written a resource called 'Walt.. 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

Talking to a partner about fertility.

Talking to a partner about being able to 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 or sexual 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.

If you already know your fertility status, then as difficult as it may be you should talk to your partner about your fertility status if and when your relationship is serious. Having a professional counsellor to help guide you through how to approach this conversation will help make it a lot easier for you.

Support for partners.

It can be difficult knowing someone you love has been 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 erase that part of your life. They may be sensitive to your reaction to the news you have had cancer or could have challenges having a child. Open and honest communication is a good way to keep you both on track for a positive relationship. Let your partner know how much you care and be honest and upfront to help them understand what you have been through and how this affects your relationship today. There is support available for your partner too. Talking to another person who has been through a similar experience (as a partner) or seeking professional advice can really help your partner work through what has happened and how to deal it. 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 37.

"If I didn't have a partner it probably would have been embarrassing having to explain I only have one testicle. How do you weave that into a conversation?"

Christian, Testicular Cancer.

Body image and rebuilding intimacy after cancer.

You may also experience changes in the way you feel about your body both physically and emotionally. Some young people have said that 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 possibility of infertility this might be something you find you feel quite strongly. This may make it hard for you to connect with a partner, but talking things through with your partner or a counsellor is always an option to help you deal with these feelings and emotions. 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.

"The one question that everyone asks me is what your sex life is like. And I just say it's just like any other relationship."

Shaun,

19, Testicular Cancer.

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, confused, upset - or even quite normal. There may be a huge mix of emotions running around inside of you.

The next step you need to take (when you are ready) is to go and find some more information.

There is a list of places and websites on the next few pages where you can go to get more information on relationships, sex and fertility (including fertility clinics).

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

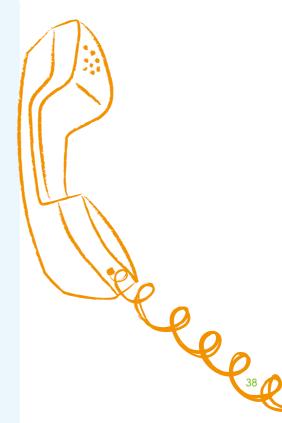
Foster care.

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

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 vaaina.

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 agerelated 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 taking 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

