**Fertility Preservation for Adolescent and Young Adults with Cancer**

Cancer in adolescents and young adults (AYA) are uncommon. About 1200aged 15 to 25 years are given a cancer diagnosis each year in Australia and New Zealand. Although many are curable, cancer and its treatment can have several difficult side effects for this age group. This may include problems with the ability to have children (‘fertility’). These changes can last for a short time, or may be permanent.

This fact sheet answers some common questions about this topic and suggests ways to try and preserve fertility for AYA with cancer. Knowing what can be done helps you make informed decisions about minimising fertility problems.

The information in this factsheet does not replace talking to your doctors or nurses. It aims to act as a tool to help you prepare questions you can ask your healthcare team about your individual situation.

**Finding out your fertility might be affected**

Being given a cancer diagnosis as an AYA usually comes as a huge shock. Having to cope with cancer and its treatment can be very challenging. Being young should be a time full of new experiences, fun, friends and the freedom to discover who you are and what you want do. Cancer is the last thing you would choose to bring into your life.

Your family and friends will support you through this difficult time as much as possible. Your medical team will also take time to discuss your cancer and its treatment with you. Talking about how your treatment may affect your sexual health and future fertility will be part of the discussion. Many AYA patients may not have thought about having children yet. But it is important to find out if your cancer and its treatment will affect your fertility.

In AYA males some cancers can directly cause a reduction in sperm count or sperm quality which may reduce your chances of fathering a child. Treatment can further reduce sperm count and its quality. Many men will still be able to father a child naturally despite a lowered sperm count.

In many female AYA’s, fertility will often return after treatment finishes. But for some the damage to their eggs or hormones may mean they will have problems with fertility after treatment finishes.

**Your feelings about infertility**

Finding out you may not be able to have children naturally may cause a mixture of feelings.

Some AYA patients may not want to think about this right now. You already have enough to worry about with your treatment and possible side effects such as sickness, hair loss, pain and other changes to your body and lifestyle.

Others may be very shocked, angry and upset by the news they might not be able to have children. This is normal and it is important you are able to express your feelings to someone you trust. You may find it difficult to do this with your parents, doctors, nurses or close friends. There are trained counsellors who you can speak with confidentially on the phone, online or face to face with if you think it will help. Our *help and support section* [LINK to this: **Where to get further help and information**] gives you further information.

**Your parents’ feelings**

Parents worry about their children, especially when they are not well. No matter how old you are, they will usually want to know what is going on in your life. They will always want the best for you and want to help where they can. Having a child diagnosed with cancer is devastating. Parent’s worries increase dramatically when this happens and they will share many of the same fears you have. AYA often do not want their parents to worry or ask too many questions. You may want privacy and independence. Most parents will respect this but will still want to be involved in your care and decision making process as much as possible. If you are under 18 your parents will need to still consent to having certain procedures done.

Many young adults won’t feel the need to have their parents present at medical appointments to discuss fertility issues. However, the younger adolescent (15 to 19) may not be so sure. Some adolescents will want their parents to ask the questions whilst others may feel awkward with this and want to do it alone. There is no ‘right’ way. A lot will depend on your relationship with your parents. Most parents will want to help as much as they can so if possible, share your feelings with them. They may help you make the best decisions for you about preserving your fertility.

**When should I ask my doctor about my fertility?**

Not all AYA’s having cancer treatment will end up infertile. Many will go on to conceive a child naturally, even if it takes time after your treatment finishes. However, it is important to ask your doctor about your risk of infertility and preservation options **before** treatment begins. If necessary, your cancer specialist can refer you to a fertility specialist. These are doctors who have expert knowledge about how to preserve fertility.

Some AYA’s may find it difficult to ask about infertility but your options will be more limited if you wait until after your treatment starts. Your medical team will be sensitive to your concerns and want to help you. See *Questions to ask your doctor* [LINK to **Questions for your doctor**].

**How cancer and its treatment affect your fertility**

Surgery, radiotherapy and chemotherapy can all affect fertility. Hormone therapy, stem cell, cord and bone marrow transplants may also lessen your chances of having children.

The fertility problems may be temporary (up to about 5 years after your treatment finishes). However, for some, the damage will be permanent, meaning you may not ever be able to have children naturally. The level your fertility is affected will depend on:

* your age and whether or not you have gone through puberty;
* the type of cancer you have;
* how much treatment you have;
* the area being treated;
* how many treatments are used together.

It is important if you are sexually active that you do not conceive during your cancer treatment. Your doctor will be able to advise you about contraception if necessary.

Cancer and its treatment may affect both male and female AYA’s ability to conceive a child naturally. In females this may happen because of:

* a decrease in number of eggs which cannot be replaced in females;
* decrease in production of sex hormones;
* the removal of a part or all reproductive organs (e.g. cervix, hysterectomy or oophorectomy but cancers needing this type of treatment are rare in AYA).

In male patients, cancer treatment may affect the ability to have children by:

* decreasing the amount of sperm you make or stopping its production;
* lessening the quality of your sperm;
* changing the genetic make-up of your sperm;
* reducing or stopping production of semen which is used to help your sperm move from one place to another – this will change the ability of sperm to effectively travel up the woman’s fallopian tubes to fertilise her eggs;
* some surgical procedures for cancer treatment may damage the tubes carrying sperm from the testis to the penis, and the nerves necessary for normal ejaculation or erections (the types of cancers needing this surgery are very rare in AYA).

In the older AYA patients there may also be changes in the emotional and physical desire to have sex due to side effects of treatment (e.g. tiredness, or altered body image).

**Which cancer treatments affect fertility?**

**Chemotherapy**

Chemotherapy is the use of medications to kill or slow the growth of cancer cells. Some of these drugs can affect both male and female fertility. But it will depend on which drugs are used as well as the dose and length of time they are given.

As well as destroying cancer cells, chemotherapy also attacks normal cells causing possible damage to the cells involved in reproduction.

In AYA males the cells in the lining of tubes in the testis where sperm is produced can be damaged. Chemotherapy can temporarily or permanently destroy developing sperm production. Sperm production may slow down or stop during and after chemotherapy but eventually return. This may happen for up to 10 years after treatment. However, most commonly sperm production returns in the first two to three years after treatment finishes.

For females who have gone through puberty, ovarian function usually stops during chemotherapy but often returns after cancer treatment. However, there is still a very high risk ovarian failure and menopause will develop a few years after treatment finishes. This is often at the time when the young female adult wants to start having a family. For females who have not yet gone through puberty chemotherapy may damage your developing reproductive organs and prevent your eggs maturing normally.

Your doctor will discuss with you in detail about the drugs you are having and their specific fertility related side effects. They will be able to inform you about the risks your cancer and its treatment will have on permanently impairing your fertility. They can also discuss fertility preservation options and refer you to appropriate specialists for help and support.

**Radiotherapy**

This is treatment using high energy waves similar to X-rays which kills or slows the growth of cancer cells.

In male patients, radiation can decrease sperm production and change the sperm’s ability to move quickly or freely. These effects can be permanent or less commonly the sperm may recover after treatment finishes. Giving radiotherapy directly near or around the testes can damage sperm production. This is because as well as killing cancer cells it will also kill the stem cells that produce sperm. It may also have a harmful effect on the production of the male hormone testosterone. Some childhood blood cancers are treated with radiotherapy directly to the testes. Young men with tumours around the groin may need to have radiotherapy to this area. This will affect the remaining healthy testis.

Radiation given directly to or near the ovaries as well as near the vagina can cause damage. It may result in temporary or permanent infertility in AYA females. .

Radiotherapy to the brain for brain tumours can cause damage to the pituitary gland. This gland in the brain plays an important role in fertility. In females it sends messages to the ovaries to make sex hormones involved in egg production. In males it sends messages to the testes to make sex hormones involved in sperm production. It is possible to use medical treatment to replace the affected hormones and restore normal function.

**Surgery**

AYA males who have testicular cancer may face problems with infertility. Surgery to remove pelvic lymph nodes can also affect fertility. Lymph nodes are part of the immune system. They are found all over the body and play an important role in helping the body remove bacteria and other harmful agents such as cancer cells.

Removing lymph nodes from the pelvic area can damage nerves necessary to ejaculate semen out through the penis. Instead, semen is propelled back up into the bladder. Doctors call this ‘retrograde ejaculation’. This type of surgery is sometimes necessary for men with testicular cancer and bowel cancer.

Adolescent females and young adult women who need surgery to treat cancers affecting the ovaries, cervix or uterus may face problems with infertility. The types of cancers requiring surgery to these organs is rare in AYA females.

Removing the uterus (hysterectomy) will mean a female won’t be able to carry a child. If your ovaries are taken out (oophorectomy) you will no longer be able to produce eggs for fertilisation. Removing the cervix (trachelectomy) will also affect your ability to carry a child. Your doctor may be able to do ovarian tissue sparing surgery for your cancer. But this is not always possible. If any of these operations are necessary your doctor will discuss what it may mean for you.

**Stem cell, cord and bone marrow transplants**

These terms are used to describe a treatment that happens in three steps:

* step one: collection of stem cells either from the bone marrow, peripheral blood or from umbilical cord blood
* step two: giving high doses of chemotherapy and possibly radiotherapy (known as conditioning treatment)
* step three: infusing the stem cells back into the patient to make sure the bone marrow recovers and keeps making healthy blood cells

This type of treatment is mainly used for AYA patients with leukaemia and lymphoma. The drugs used and the very high doses of chemotherapy and radiotherapy greatly increase a person’s risk of infertility. If you need a transplant as part of your cancer treatment your doctor will talk to you in detail about it.

**What fertility preservation options are available to AYA patients?**

Several factors affect the AYA’s options for preserving their fertility before and after cancer treatment. These include age, prognosis, sexual maturity and cultural and religious beliefs.

Your cancer specialist and/or fertility specialist will be able to discuss options most suitable for your situation. The effectiveness of each preservation method varies and not all options will work for every person. It is important to understand that no method can guarantee a 100% success rate. Some AYA’s find it helpful to speak with a fertility counsellor along with their specialist doctors to help make the right decision. They will be able to discuss any risks involved with each option.

Non-invasive methods include:

* trying to reduce the impact of chemotherapy on fertility
* protecting/shielding the testis/ovaries during radiotherapy if the cancer is in another part of the body

Your doctor may recommend methods which involve detailed discussion, a lot of thought and written consent on your behalf. We discuss these in the next few paragraphs. For more information go to the *further help and support* [LINK to **Further help and support**].

**Preservation methods in AYA males**

**Sperm banking (sperm cryopreservation)**

This is a well-established method of preserving fertility for men who have gone through puberty. It involves collecting sperm ejaculated by masturbation and freezing semen for future use. Sperm can be frozen indefinitely without deterioration in quality. During cancer treatment, sperm quality can be impaired due to stress and being unwell. It is always best to freeze several samples if possible in order to maximise the opportunities for future fertility. Even if the sperm count is low, future fertility is still likely with the assistance of fertility treatment.

The process of collecting the samples through masturbation may cause anxiety and embarrassment for some AYA males. This is normal and your medical team will be used to dealing with this situation in a sensitive and professional manner. They will want to support you in any way they can. The specimen can be obtained either privately in the hospital, laboratory or sometimes at home. For more information read *What is involved in sperm banking [LINK to* **What is involved in sperm banking***].*

**Sperm aspiration/testicular tissue**

This method is for young men and sexually mature males who are not able to produce a masturbated sample due to stress or illness.

The procedure involves having a local or general anaesthetic and removing a small amount of testicular tissue with a needle. A doctor will examine this tissue under a microscope to find mature sperm, immature sperm or tubules

There is a small risk of bruising, bleeding or infection with the process of testicular biopsy. There is also a very small risk associated with having a general anaesthetic. Please discuss the risks with your doctor.

**Sperm stem cell storage in immature males**

In young males, mature sperm are unlikely to be found. There is research going on into whether sperm stem cells or testicular tissue itself may be frozen and used years later to restore fertility. The hope is mature sperm can develop either within the tissue or from the immature sperm. It can then be used to fertilise an egg later in life. This procedure is not available in many hospitals/fertility centres and to date has not produced any live births. You will need to ask your doctor whether this is an option for you.

**After treatment is over**

After treatment is over, many AYA males will recover the ability to make sperm again. They will go on to conceive their own children either naturally or using their stored sperm. For those who have had sperm stored, these can be used for intrauterine insemination or to fertilise a woman’s egg in the laboratory as part of an IVF treatment. Ask your specialist to discuss these procedures with you. You may also want to have your sperm analysed to find out if you are fertile.

**Preservation methods in AYA females**

**Embryo banking/freezing (embryo cryopreservation)**

Most people will be familiar with the term ‘in vitro fertilisation’ (IVF). This is what embryo banking is. It is the most successful way to preserve your fertility. It involves taking fertility drugs and then having your eggs collected by a short surgical procedure. The eggs are fertilised with a partner’s sperm in a laboratory to create embryos. The embryos are then frozen and kept until you are ready to have a child. This method is only suitable for AYA’s who have gone through puberty.

Embryo banking does have some drawbacks such as the need for donor or partner sperm which has ethical and legal implications. There may be religious and cultural beliefs that prevent this method of fertility preservation.

**Egg banking/freezing (oocyte cryopreservation)**

This means freezing eggs on their own; they are not fertilised with sperm before freezing happens. The process also involves taking fertility drugs to stimulate egg production and then having the eggs collected. This method is good for AYA females who do not have a partner yet or wish to keep their options open. This method is only suitable for AYA females who have gone through puberty.

Eggs and embryos can be frozen for many years. However, some storage facilities will have a set time for storing eggs and embryos, unless you advise otherwise or pay to store them longer. It is important to ask how long a facility will keep an individual’s frozen eggs/embryos. Egg storage for many years can be less complicated than storying embryos for a long time. This is because of the ethical and legal issues related to storing embryos for an indefinite period of time.

**Ovarian tissue banking/freezing**

This procedure involves surgically removing a small piece of your ovarian tissue and then freezing it. It is possible to do this in both pre pubertal and pubertal girls. If treatment is with high dose chemotherapy/bone marrow transplant then the whole ovary may be removed. It is then transplanted back after your treatment, if there is permanent ovarian failure Sometimes this is the only procedure available if you need to start cancer treatment quickly or if you have not gone through puberty. Although women have conceived and had babies after cancer treatment using this method, and it is no longer considered experimental, it cannot yet be considered to be a guarantee of future fertility.

**Surgery to protect your ovaries from radiotherapy**

This is called ‘ovarian transposition’. It involves having an operation to move one or both of your ovaries to another part of your body during your radiotherapy treatment. It allows protection of your ovaries during radiotherapy. The ovaries may later be put back into place once the treatment is over. The operation is called an oophoropexy. Success rates depend on how far the ovary can be moved away from the radiotherapy site.

**Medical Therapy to suppress ovarian function**

This involves taking medications to protect the ovaries during treatment. It is only suitable for girls who have gone through puberty. However it may not be protective when extremely high doses of chemotherapy are used prior to bone marrow transplant

**After treatment is over**

After treatment is over many AYA female’s menstrual cycle will return to normal. Many will go on to conceive their own children, either naturally or using their banked eggs or embryos. However for many AYA females who have had chemotherapy, long term ovarian function will be reduced. They will go through early menopause, often five to seven years earlier than would be otherwise expected.

After treatment finishes you may also want to have your fertility status analysed to find out if you are fertile [LINK to the fact sheet **How will I know if my fertility has been affected after cancer?**]

**Questions for your doctor**

Raising the topic about fertility can be difficult but it is important you do. These questions may help you begin the conversation with your doctor:

* How will my cancer treatment affect my chances of having a child in the future?
* Do all chemotherapy drugs affect fertility?
* Who can I talk to about my treatment and the possible fertility side effects of treatment?
* Can you recommend a fertility specialist I can talk to?
* What options do I have to preserve my fertility?
* I would like to freeze sperm/eggs/embryos. Is this an option for me? Could you please give me more information?
* Do the methods used to preserve fertility guarantee I will be able to father/mother a child in the future?
* Where can I find support for coping with fertility issues?
* Who can I contact if I need help talking with my spouse or partner about fertility issues?
* How will I know if I am fertile after cancer treatment?

For parents of adolescents you may like to read our fact sheet *Preserving fertility in children with cancer*. It has questions to ask when deciding the best approach to fertility perseveration for your son/daughter

**Where to get further help and information**

This fact sheet has only provided you with an overview of fertility issues for AYA with cancer. It is important you find out as much as you can so as you can make an informed decision. For more detailed information please refer to our other factsheets and the following resources:

* Fertility After Cancer. A guide for people with cancer, family and friends. First published June 2014. © Cancer Council Australia 2014.
* The COSA wiki guidelines online at <http://wiki.cancer.org.au/australia/COSA:AYA_cancer_fertility_preservation>
* Sperm banking factsheet [LINK]
* Having a baby after cancer treatment fact sheet [LINK]
* The Clinical Oncologial Society of Australia (COSA) has guidelines for health professionals who are discussing fertility issues with young people who have cancer. You can view these at wiki.cancer.org.au – type ‘fertility’ in the search box.
* CanTeen’s resource, Maybe Later Baby, is written specifically for a young audience. It provides reliable information about cancer and fertility. You can download or order a copy of this booklet at [www.nowwhat.org.au](http://www.nowwhat.org.au).

You may also like to call a Cancer Helpline service:

* Australia 13 11 20
* New Zealand call 0800 **226 237**

Both these help lines will allow you to have a confidential conversation with an experienced cancer nurse.