Cancer, Fertility & Me

Helping you make the right decision for you

yorkshire cancer research

Contents

The Cancer, Fertility and Me decision aid booklet

Cancer treatments may affect fertility and the chances of becoming pregnant in the future.

Women with cancer asked for a booklet to help them think about the treatments which may help preserve their fertility, and prepare them to talk with their cancer care team and fertility care team, partner, family and friends about fertility preservation, before their cancer treatment starts.

This booklet was written by the Cancer, Fertility and Me (CFM) team to help women with cancer make decisions about fertility preservation before starting their cancer treatment. Yorkshire Cancer Research funded the development of this booklet.

The CFM team includes psychologists, decision scientists, researchers, children's and adult cancer and fertility doctors, specialist nurses, patient partners and local and national charity collaborators. Please see page 37 in this booklet for more detailed information about the CFM team and those involved in the making of this booklet.

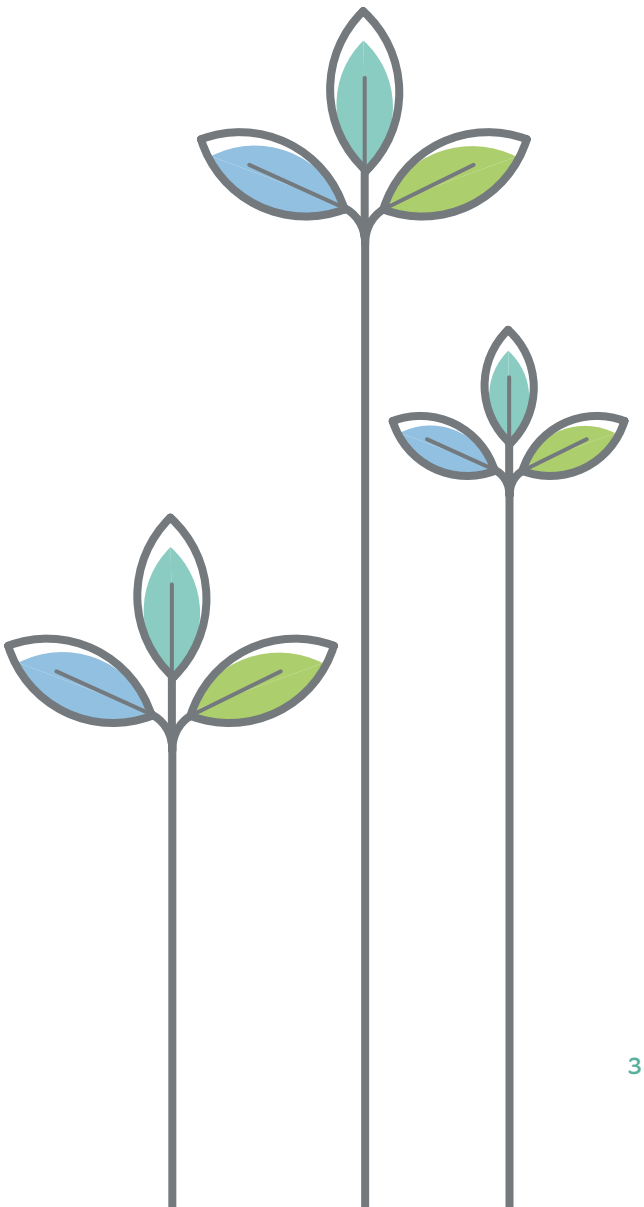
We hope this booklet will support you to know what options are available and help you make the best decision for you.

For an online version of this booklet please go to: www.cancerfertilityandme.org.uk

This patient decision aid accurately reflects recommendations in the NICE guidance on fertility problems and patient experience in adult NHS services. It also supports statements 4, 5 and 6 in the NICE quality standard for patient experience in adult NHS services, statement 7 in the quality standard for cancer services for children and young people, and statements 3 and 9 in the quality standard for fertility problems.

National Institute for Health and Care Excellence

July 2020



Disclaimer: Every effort has been made to provide accurate and complete information at the date of publication. However, errors can occur. If you have any questions, ask your cancer care team and fertility care team for more information (July 2020).

About this booklet

This booklet aims to help women with cancer make decisions about fertility preservation **before** starting their cancer treatment.

For some women, cancer treatments such as chemotherapy, radiotherapy, hormonal and surgical therapies may cause long-lasting fertility problems and may reduce the future chances of becoming pregnant. The ways in which cancer treatments affect fertility depends upon the type of cancer and the treatment you may have.

Fertility preservation treatments are ways of helping women with cancer have a higher chance of becoming pregnant and having a child in the future after their cancer treatment. Not all women that have cancer treatment will have a fertility problem in the future.

This booklet has information to help you:

- Understand more about how cancer treatments may cause fertility problems in women.
- Understand more about how women with cancer can preserve their fertility, **before** starting cancer treatment.
- Understand which options to preserve fertility may fit best into your life.
- Understand family planning decisions **during** and **after** cancer treatment.

This booklet may be helpful to you if:

- You have recently been diagnosed with cancer.
- You may want to become pregnant and try to have a child in the future after your cancer treatment has been completed.
- You would like more information to help you make a decision about fertility preservation.

This booklet highlights the importance of talking to your cancer care team and fertility care team **before** starting cancer treatment. It will help you consider what questions to ask and guide the conversations you may want to have with them.

Not all of the fertility preservation procedures described in this booklet are suitable for all women.

Not all women will be able to have the fertility preservation procedures described in this booklet at this current time.

Not all women who are treated for cancer will have a fertility problem in the future.

Some of the fertility preservation procedures described in this booklet may not be available at all fertility clinics.

Using this booklet to help you make your decision

Some women starting cancer treatment will know for sure whether or not they want to consider fertility preservation. Some women are uncertain about the fertility preservation decision and which option is best for them.

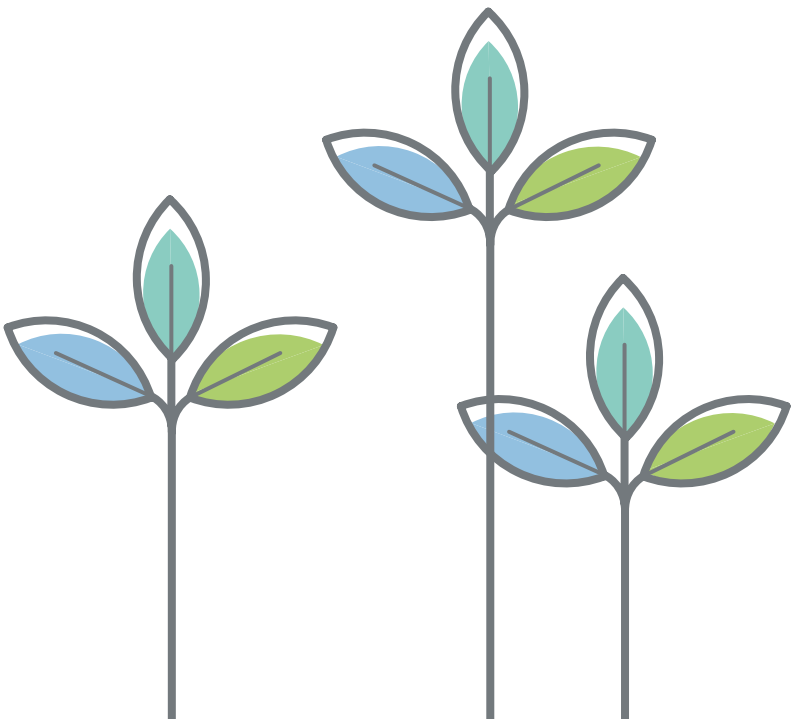
To support you to make this decision, the booklet has information to help you:

- Learn more about the different fertility preservation options.
- Think about whether fertility preservation may be an option for you.
- Think about what is important to your life now and in the future.
- Talk to your cancer care team and fertility care team whilst you make your decision.
- Discuss with your cancer care team and fertility care team the consequences and benefits of any decision you may make.

You can use this booklet in different ways. You may find it useful to read it a few times from beginning to end or to dip into sections. You may like to read it on your own or share it with your cancer care team and fertility care team, partner, family and friends whilst you are thinking about your decision.

There are prompts to help guide you through the booklet:

- **Content pages** list the chapters about cancer treatment, fertility problems, fertility preservation decisions and family planning with page numbers.
- **Decision pictures** make it clear what the fertility decisions are for women **before**, **during** and **after** cancer treatment.
- **Tables** describe the features of the fertility preservation options next to each other to help compare what is the same or different about each one.
- **Questions** that you may wish to ask your cancer care team and fertility care team.
- **My values questions** to help you think about which fertility preservation option fits best into your life at this time.
- **Writing spaces** to write down notes or questions important to you about your life, cancer diagnosis and future fertility.
- **Glossary** describes the meaning of the terms used to discuss cancer and its treatment, fertility and fertility preservation.



Introduction to cancer, fertility and the reproductive system

This section has information to help you understand how cancer treatment may affect fertility.

Cancer is the name given to diseases caused by the body's cells dividing without stopping, forming growths and moving into parts of the body where they are not needed. As a result people with cancer need to have treatments.

Cancer treatments aim to remove the cancer and prevent it from coming back. The main treatments for cancer are chemotherapy, radiotherapy, surgery, hormone therapy and targeted drug therapy. Many people will have two or more of these treatment options as part of their care.

Most cancer treatments have **side effects** caused by the treatments affecting healthy tissue. Many side effects last for a short time during and after treatment. Some side effects last longer and can affect a person's health for the rest of their life. In women, one of these side effects can be lowered fertility which means that a woman may not be able to get pregnant in the future.

Fertility means being able to get pregnant (conceive). The parts of a woman's body that are involved in fertility are called the 'reproductive system' (see **image 1**).

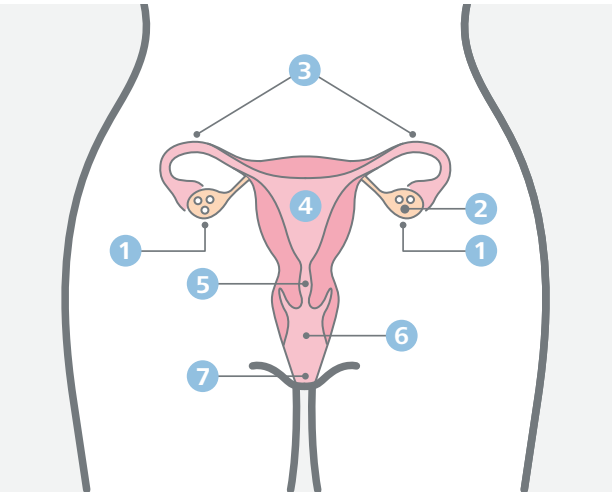
Cancer treatments can affect fertility by:

- Damaging or lowering the number of eggs stored in the ovaries.
- Damaging a part of the body that controls the fertility hormones.
- Damaging or removing a part of the female reproductive system.

The ways in which cancer treatments affect fertility depends upon the type of cancer and the treatment you may have.

Not all women that have cancer treatment will have a fertility problem in the future.

Image 1: The female reproductive system



The key parts of the reproductive system are:

1. **Ovaries** - these two organs sit on either side of the womb inside a woman's body between her hips (pelvis). The ovaries make the eggs and hormones needed to have a baby. These eggs travel down the fallopian tubes to the womb.
2. **Egg (oocyte)** - the female reproductive cell, which after fertilisation with sperm is capable of developing into a baby.
3. **Fallopian tubes** - the two tubes that connect each ovary to the womb (uterus) and this is where the egg is fertilised by the man's sperm.
4. **Womb (uterus)** - this sits inside the pelvis and is where the pregnancy develops.
5. **Cervix** - the opening to the womb which allows menstrual blood to leave the body (periods), and the woman to give birth.
6. **Vagina (birth canal)** - the opening between the lower part of the cervix and the outside of the body.
7. **Vulva** - the outside area of the vagina.

Introduction to cancer, fertility and the reproductive system

Women are born with a large number of eggs in their ovaries. Women cannot grow or make new eggs. The number of eggs a woman has at any point in time is known as her ovarian reserve.

The number of eggs a woman has is falling all the time. Before puberty this is because many of the eggs stop developing and are absorbed by the body.

When a woman reaches puberty, one egg is released each month from the ovary (called ovulation) and travels to the womb. The other eggs that began to mature during this cycle will break down and are also absorbed by the body.

Pregnancy occurs if the egg is fertilised by a sperm, and then implants in the womb. If a fertilised egg does not implant in the womb, the lining of the womb is shed and leaves the body. This results in bleeding known as menstruation or a period.

Age is one of the biggest things affecting the chance of getting pregnant. The number and quality of eggs lowers as women get older.

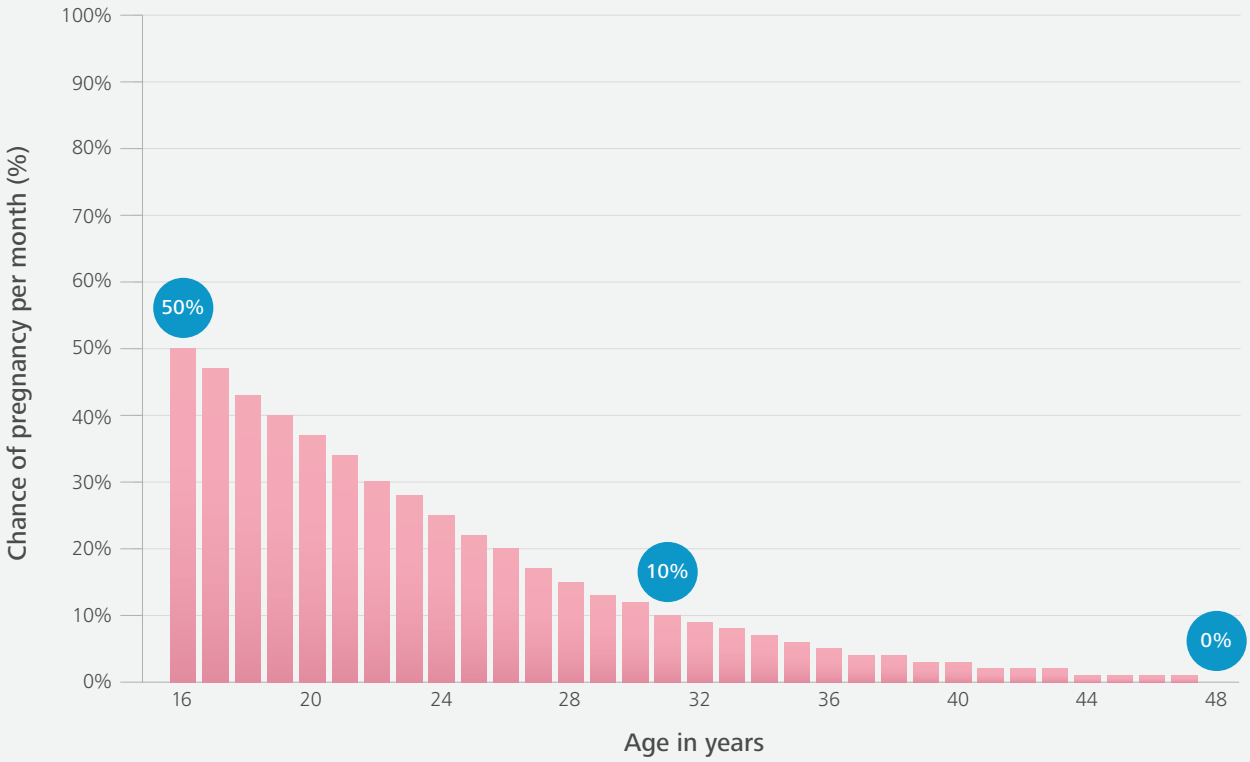
This fall in the number and quality of eggs lowers fertility and may make it harder to become pregnant. Eventually, there are so few eggs that women become infertile (unable to get pregnant), monthly menstrual periods stop, and the menopause begins. The menopause signals the natural end of a woman's reproductive years.

Female fertility may be different for each person. The exact age a women will no longer be able to have children can be different for each individual.

As **graph 1** (below) shows, a 22 year old woman has about a 30 in 100 chance (30%) of becoming pregnant every month that she attempts to conceive a child; whereas a 43 year old woman has about a 3 in 100 chance (3%) of becoming pregnant per month.

Most women reach the menopause by their mid-50s; they stop having periods and are unable to have children naturally.

Graph 1: How the chance of pregnancy gets less with age



Source: www.genea.com.au/my-fertility/i-need-help/female-trouble-conceiving/the-impact-of-age

Introduction to cancer, fertility and the reproductive system

Other than age, fertility in women can also be affected by:

- Problems in the womb. For example, fibroids.
- Diseases which cause scarring in the pelvic area. For example, pelvic inflammatory disease, endometriosis.
- Diseases which affect ovulation. For example, polycystic ovary syndrome.
- A low sperm count in the male partner.
- Medicines and treatments. For example, chemotherapy, radiotherapy, or surgery for cancer, some drugs to treat mental health illnesses and regular and long term use of non-steroidal anti-inflammatory drugs.
- Lifestyle. For example, being over or under weight, recreational drugs, alcohol and smoking.

On average, around 16 in 100 (16%) couples without cancer will have fertility problems. If having children in the future is important to you, talk to your cancer care team and fertility care team before starting cancer treatment.

Recommended source of information

NICE (National Institute for Health and Care Excellence) is an organisation that is separate from the NHS. They create guidelines by looking at the research carried out to treat illness and deliver care for healthcare professionals in England and Wales.

They have created guidelines on fertility preservation for women diagnosed with cancer (CG156- Fertility problems: assessment and treatment); and guidelines on fertility preservation for teenagers and young adults (QS55- Cancer services for children and young adults: fertility support).

For more information visit the NICE website: **www.nice.org.uk**

Use this space below to write down any notes or other questions you have about fertility and infertility:

How cancer treatments affect fertility

This section has more information about how cancer treatments may affect fertility.

The chance a woman gets a fertility problem from her cancer treatment depends on many things. These include her age, fertility and health before cancer, the type of cancer and the type of cancer treatment she has.

Because of the many things that can affect fertility, it is difficult to know for sure how a woman's fertility will be affected. Not all women that have cancer treatment will have a fertility problem in the future. It is difficult to know if the fertility problem will be long-lasting until after cancer treatment has been completed. We also cannot know for sure how long a woman will be fertile after cancer treatment.

For these reasons you may wish to talk about your chance of future fertility problems with your cancer care team and fertility care team before you begin your cancer treatment.

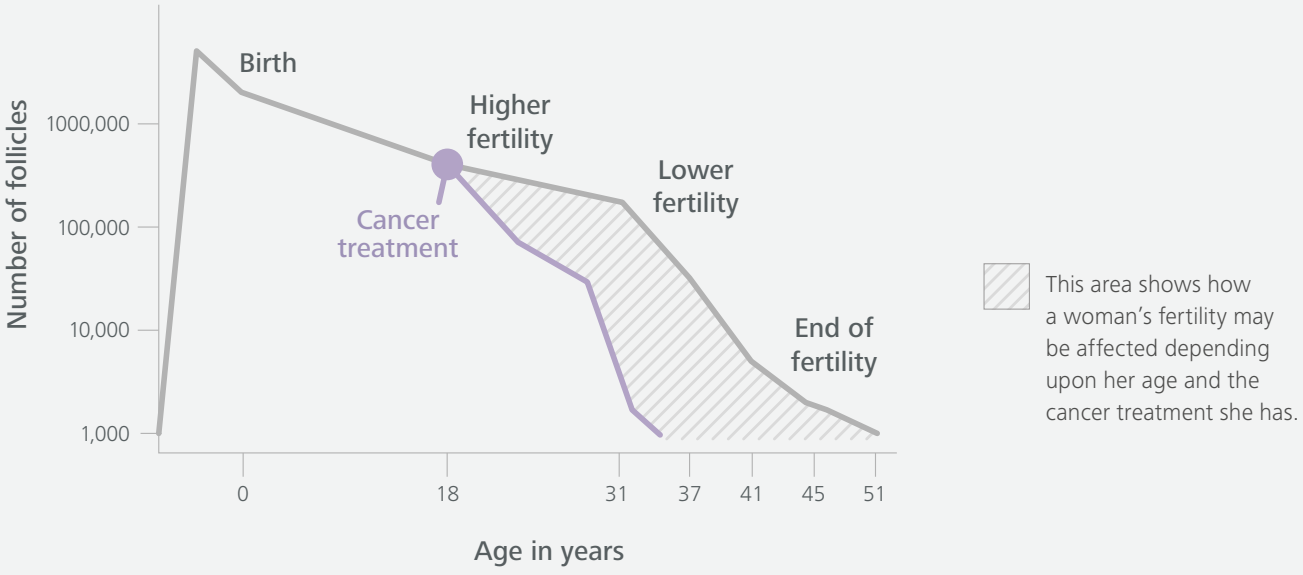
Both the cancer care team and fertility care team talk with women about their cancer type, cancer treatment and personal history. They try and work out how the cancer treatment may impact upon their fertility.

The main types of cancer treatments are chemotherapy, radiotherapy, surgery, hormonal therapy and targeted therapy and they all work in different ways. You will need to ask your cancer care team about what the chances of infertility are with each cancer treatment option you are offered.

Graph 2 (below) shows how cancer treatment can affect fertility. It shows how the number of eggs a woman has (her ovarian reserve) may be lowered after cancer treatment. The shaded area on the graph shows that a woman's fertility can be affected depending upon her age and the cancer treatment she has been given.

Fertility in women may fall anywhere within the shaded area. Talk to your cancer care team to find out more about how cancer treatment and your age may affect fertility for you.

Graph 2: How cancer treatment may affect women's fertility compared with the decline in women's fertility naturally



Source: http://oncofertility.northwestern.edu/resources assessing-ovarian-reserve-after-cancer-treatments

How cancer treatments affect fertility

Chemotherapy

Chemotherapy is the use of drugs to kill or slow the growth of cancer cells. It often causes side effects to healthy cells in the body and can affect a woman's fertility. This can damage the ovaries and lower the number of eggs (ovarian reserve).

The effect of chemotherapy upon fertility depends on:

- The type of drugs you will be given.
- The dose and for how long you take the drugs.
- The combination of drugs you will be given.
- Your age and previous fertility status.

Chemotherapy may damage a woman's ovaries and eggs. This can mean a woman's menstrual cycle often stops or becomes irregular during chemotherapy. This may be temporary or permanent.

Temporary: If the changes to the menstrual cycle are temporary then your periods will come back after cancer treatment. This could happen within a few months or may take up to a year or more. The younger you are when having chemotherapy treatment, and if you are under 35, the more likely it is that your periods will return. The number of years you are fertile might be lower. Even if your periods come back, this does not always mean you will be able to get pregnant.

Permanent: If the changes to the menstrual cycle are permanent this means your periods will not come back after cancer treatment, and the menopause starts. Women over 35 years old are more likely to be infertile after their cancer treatment.

Radiotherapy

Radiotherapy works by using high-energy rays (typically x-rays or similar) to kill or damage cancer cells in the area that is being treated. It can be given externally, through a machine directing invisible rays toward the body, or internally, through tiny radioactive implants in the body (brachytherapy). Whether or not radiotherapy affects fertility depends on its location (proximity to the ovaries, womb or brain) and dose.

- High doses of radiotherapy to the ovaries may destroy the remaining eggs inside and result in premature ovarian failure or early menopause.
- Treatment affecting the womb can cause future miscarriages, premature births and low-birth-weight infants.
- If radiotherapy is given to the brain, it may affect the pituitary gland. This could interfere with the hormone signals to use the eggs that remain in the ovary.

Women who get pregnant after treatment that exposed their womb to radiotherapy are much more likely to have miscarriages or premature births compared to those women who have not had radiotherapy to their womb.

Surgery

Surgery works by taking the cancer out of the body during an operation. Sometimes taking the cancer out means taking out the body part the cancer grew into. Women who need surgery to treat a cancer affecting the ovaries, cervix or womb may face problems with their fertility. The effect of the operation on fertility depends on the type of cancer you have.

- Some surgery in the abdomen may cause scarring in the fallopian tubes. This may block the eggs travelling to meet the sperm.
- Removal of the womb during a hysterectomy results in a woman being unable to carry a child.

- If the ovaries are surgically removed (oophorectomy), a woman cannot get pregnant using her own eggs, (unless ovarian tissue is frozen at the time of surgery).
- Some female reproductive organs may be removed during surgery. This is to treat other abdominal cancers, such as bladder cancer, which can spread in the abdomen.
- Surgery to the brain for brain tumours can cause damage to the pituitary gland. The pituitary gland produces the hormones involved in egg production. Women whose pituitary gland is damaged may not be able to make the signals that are needed to use the eggs that remain in her ovary.

Hormone therapy

Hormone therapy uses drugs to change how hormones work in the body. It is given to help lower the chance of the cancer coming back. It can also be used to treat a cancer that has returned after treatment or has spread.

Hormone therapy is given to women with cancers that are hormone sensitive or hormone dependent and this treatment can slow down or stop the growth of the cancer. This is by either a) lowering the levels of hormones in your body, or b) lowering the ability of cancer cells to respond to the hormones and stopping their growth. Hormone therapy is mostly used in breast cancer for a long period of time, between 5 and 10 years.

Some of these are the same hormones required for fertility, so treatment can affect your ability to get pregnant and have a baby.

Some common hormone therapies are Tamoxifen, Goserelin (Zoladex) or Leuprorelin (Prostap), Anastrozole (Arimidex), Letrozole (Femara) and Exemestane (Aromasin).

The above hormones can make your periods irregular or stop. They may start again a few months after you have finished taking it, as long as you haven't gone through the menopause naturally whilst taking the drug. Due to the length of time the hormones are taken for, it may be difficult to tell if you've started the menopause while taking them. It may only be when you finish taking the hormone treatments that you realise your menopause has started.

If part of your treatment involves hormone therapy, you will be advised not to get pregnant during treatment and for a while after. Some women may choose to take a break from their hormone therapy to have a baby. Talk to your cancer care team about this.

Targeted drug therapies

Targeted drug therapies (sometimes known as biological therapies) are new types of drugs to treat cancer. They are used to stimulate the immune system, control the growth of cancer cells or to overcome side effects of treatment.

As these are newer treatments, information about side effects for targeted drug therapies is still being studied, and it is not yet known exactly what effect they have on fertility.

There are lots of different targeted drug therapies available, used in many different cancers. The two main groups are:

- Monoclonal antibodies. These drugs attach themselves to cancer cells to prevent them from growing.
- Cancer growth inhibitors. These drugs block the chemical signals that help cancer cells grow.

Trastuzumab (Herceptin) and Pertuzumab (Perjeta) are monoclonal antibodies mostly used to treat some women with breast cancer. There is less information available about their effects on the reproductive system and the developing baby.

If part of your treatment involves targeted drug therapy, you will be advised not to get pregnant during cancer treatment and for a while after. Talk to your cancer care team about this.

How cancer treatments affect fertility

Other cancer treatments

Sometimes treating cancer can involve other treatments.

- **Blood and Marrow Transplantation (BMT)** can involve using chemotherapy, radiotherapy and antibody treatments followed by blood and bone marrow stem cell infusions.
- **Cellular therapies (such as CART cells)** are often combined with chemotherapy.

Most patients receiving BMT will have received chemotherapy and other treatments in the past, and fertility will have already been considered, but some patients will receive BMT as their first intensive treatment for their cancer.

These combined treatments can affect a woman's fertility. If fertility is affected by these treatments it is often permanent and means that you will not be able to become pregnant in the future.

You will need to have a pregnancy test before you begin these treatments and will be advised not to get pregnant whilst the treatments are in progress.

The following questions may help you talk with your cancer care team about the impact of your planned cancer treatment on your future fertility.

How might my planned cancer treatment affect my fertility in the future?

Is there a chance that my cancer treatment will affect any part of my reproductive system (for example, womb, ovaries, fallopian tubes, cervix)?

Are the effects of my cancer treatment on my fertility likely to be temporary or permanent?

How might my age, or other factors related to me, affect cancer related fertility?

When should I discuss fertility preservation and who can I talk with about this?

Use this space to write down any notes or other questions you have about cancer treatment and how it might affect your fertility:

The fertility preservation options

This section has information about the fertility preservation options for women with cancer **before** they start their cancer treatment.

You can choose:

- **No fertility preservation** - starting cancer treatment straight away.
- **Freezing** - methods of preserving eggs, embryos or ovarian tissue.
- **Ovarian suppression** - a method of protecting the ovaries during cancer treatment.
- **Specific Surgery** - fertility sparing surgery may be an option for some women.

Picture 1 (below) shows the fertility decisions for women to think about before starting cancer treatments. Not all of the procedures are available in every fertility clinic. Some are newer techniques and not yet proven to be successful with a large number of women. Your cancer care team and fertility care team can advise you further and discuss the options available to you.

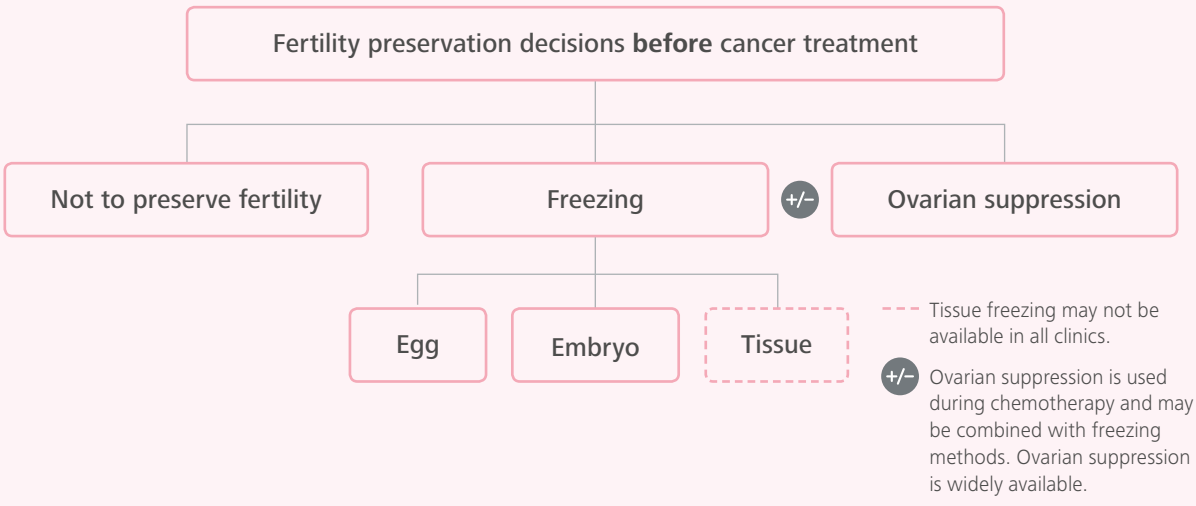
Not all women starting cancer treatment will need to consider these options. The opportunity to talk to someone and to become informed about your options can be of value. This could help you make the right decision for you and your personal situation.

Each fertility option has a different chance of success and no method works 100% of the time. The success rates for each procedure will be different for each woman. None of them can guarantee you will get pregnant and have a baby after cancer treatment.

The information that follows will look at each fertility preservation option in more detail. It explains the process and outlines the success and side effects associated with each procedure.

A **summary table** at the back of booklet compares the different fertility preservation options. It can be found on page 38.

Picture 1: Fertility preservation decisions **before** starting cancer treatment



No fertility preservation

This option means deciding not to have fertility preservation treatment before starting cancer treatment. Not all women starting cancer treatment will want to have treatment to preserve their fertility. Not all women will be able to have fertility preservation because of their cancer type and stage.

Who is it for?

Women who:

- Are prepared to 'wait and see' if their fertility returns naturally after cancer treatment.
- Are certain they have already completed their family.
- Are certain they do not wish to have a pregnancy after cancer treatment.
- Do not have fertility preservation options available to them. (For example, because of personal beliefs or the options may not be available at the local clinic).
- Have a fast growing cancer and need to start cancer treatment straight away.

It is often advised to wait for at least two years after completing cancer treatment before becoming pregnant. There may be more chance of the cancer coming back in the first two years after diagnosis. Waiting for this long may not be appropriate for every woman. If you are thinking about getting pregnant before this two-year period is up, talk to your cancer care team about this.

What does it involve?

There are no extra procedures. The treatment involves you continuing with your cancer treatment and using methods of contraception during treatment.

What is the chance of having a baby after cancer treatment?

The chance of having a baby in the future depends on how your ovaries have been affected by your cancer treatment. Some women get pregnant naturally after cancer treatment without fertility preservation. If treatment does cause the menopause, then it is unlikely natural pregnancy will happen.

Will this option affect the health of the baby?

No, the health of a baby in the future will not be affected.

Are there any side effects of not having fertility preservation?

You will not have any fertility treatment side effects.

Will this option delay the start of my cancer treatment?

No, this option will not delay the start of cancer treatment.

Will this option affect my chances of the cancer coming back?

If you choose not to have your fertility preserved, your cancer treatment will continue as planned. The chance of the cancer returning will not be affected.

You may find it useful to write down what you like about this option and what worries you about this option. These notes may help you talk about whether or not this option is best for you with your cancer care team and fertility care team, partner, family and friends:

What I like about this option	What worries me about this option
1.	1.
2.	2.
3.	3.
4.	4.

Freezing

There are three freezing options which may help preserve a woman's fertility:

1. Egg freezing
2. Embryo freezing
3. Ovarian tissue freezing

Eggs, embryos and ovarian tissues can be frozen and stored for many years. When the time is right, they can then be thawed and used for a pregnancy after cancer treatment has been completed.

Different methods of freezing are available to preserve eggs, embryos and ovarian tissue. Cryopreservation is a method of 'slow freezing'. Vitrification is a newer method of 'fast or flash freezing'. This method has been shown to improve the chance of eggs and embryos surviving the thawing process and make the pregnancy success rate higher.

Some women, if they have a male partner, may be able to freeze both eggs and embryos. They may have more fertility options available to them in the future after their cancer treatment.

Ovarian tissue freezing is a new method of fertility preservation. This could be another option for women with no male partner.

1 Egg freezing:

This option is when matured eggs are removed from the ovaries and frozen. This process is sometimes called 'egg banking'. When the woman is ready to become pregnant, the stored eggs are fertilised with sperm and put back into the womb.

Who is it for?

Women who want to preserve their fertility and who have gone through puberty, and who either:

- Do not have a partner.
- Do not want to use donor sperm.
- Do not want to choose embryo freezing because of their beliefs.
- Have time to go through a cycle of fertility treatment before starting cancer treatment.

For some women who have cancer in the pelvis, it may not be safe to carry out egg freezing because of the chance of spreading the cancer.

What does it involve?

You will need to have hormone injections to stimulate the ovaries (ovarian stimulation) for about 2 weeks. Eggs are then collected through a fine needle passed through the wall of your vagina up to the ovaries. This is done under sedation. You may be able to go home a few hours later.

As egg freezing only involves the woman, there is no need for partner consent to use the stored eggs in the future. Frozen eggs can be stored for 10 years. This can be raised by 10 year periods (up to 55 years in total) in some situations.

What is the chance of having a baby after egg freezing?

It is difficult to be certain how likely it is that egg freezing will result in a live birth. The number of cancer patients who have used frozen eggs is small. Most of the data comes from women without cancer who have used their own frozen eggs or donor frozen eggs to have a baby. Eggs that have been slow frozen or vitrified have also been included in this data.

The chance of having a baby after egg freezing depends on a number of factors. These are:

- Your age at the time the eggs are collected. Women who are younger than 35 years of age have a higher chance. Women over 35 years old will have a lower chance.

Egg freezing

- The number of eggs collected. Women who have more eggs collected have a higher chance.
- The fertility clinic where egg freezing has been carried out.
- The use of slow freezing or vitrification to freeze and store the eggs. Vitrification has a higher success rate.

Overall, if a woman under 35 has 10 eggs stored, these will give her a 4 in 10 (40%) chance of having a baby. Some women may not be able to freeze as many as 10 eggs, which will lower the chances of having a baby. You may also see success rates elsewhere that appear lower. However, these lower success rates may be based upon one cycle of IVF treatment using fewer frozen eggs.

For more information on national average success rates and the number of successful live births for each licensed fertility clinic visit the Human Fertilisation and Embryology Authority (HFEA) website **www.hfea.gov.uk**.

Will this option affect the health of the baby?

No, the data suggests that the health of a baby born using frozen eggs will not be affected.

Are there any side effects of the fertility treatment used in egg freezing?

The fertility drugs used to stimulate the ovaries can cause side effects, such as headaches, mood changes, hot flushes, and irritation of the skin. The fertility drugs may also cause the ovaries to over respond and this may lead to a condition called Ovarian Hyper-Stimulation Syndrome (OHSS). Once you start your treatment ask your fertility care team about the symptoms of this condition and how to contact them if you need to.

When the ovaries are stimulated to produce lots of eggs, the levels of the hormone oestrogen go up. This could be a risk in women who have an oestrogen sensitive breast cancer. These women can be given a drug called Letrozole (Femara). This lowers the levels of oestrogen in the blood stream.

At the time of egg collection there is a chance of bleeding, infection and puncture to the bowel but this is rare.

There may be a concern for women with pelvic cancers, where there could be a spill of cancer cells from the ovary into the abdomen following egg collection.

Will this option delay the start of my cancer treatment?

It takes around two weeks from the time of starting ovarian stimulation until the time of egg collection. The time before the start of stimulation can be different depending where a woman is in her menstrual cycle. Egg freezing may not be an option for women with cancers such as leukaemia, some lymphomas, and sarcomas as they may need immediate treatment. If you experience OHSS, this may cause a longer delay to the start of cancer treatment.

Will this option affect my chances of the cancer coming back?

There is no data to suggest that egg freezing affects the chances of cancers growing or coming back.

You may find it useful to write down what you like about this option and what worries you about this option. These notes may help you talk about whether or not this option is best for you with your cancer care team and fertility care team, partner, family and friends:

What I like about this option	What worries me about this option
1.	1.
2.	2.
3.	3.
4.	4.

Embryo freezing

2 Embryo freezing:

This option means that matured eggs are taken from a woman's ovary and fertilised with sperm through in-vitro fertilisation (IVF). This is done in a laboratory. The fertilised eggs (embryos) are then frozen and stored for future use. When a woman is ready to become pregnant the stored embryos are put back into the womb.

Who is it for?

Women who have gone through puberty, and:

- Have time to go through a cycle of fertility treatment before starting cancer treatment.
- Have a male partner, as it requires both eggs and sperm for the egg to be fertilised.

What does it involve?

You will need to have hormone injections to stimulate the ovaries (ovarian stimulation) for about 2 weeks. Eggs are then collected through a fine needle passed through the wall of your vagina up to the ovaries. This is done under sedation. You may be able to go home a few hours later.

If you are in a relationship and create and store an embryo with your male partner you will need the consent of your partner before the embryos can be used. This is important, because if you later split up, he may not want you to use the stored embryos. If you do not have a male partner, the use of donor sperm is an option. In this case, you do not need the consent of the donor to use the embryo in the future.

Frozen embryos can be stored for 10 years. This can be raised by 10 year periods (up to 55 years in total) in some situations.

What is the chance of having a baby after embryo freezing?

It is difficult to be certain how likely it is that embryo freezing will result in a live birth. The number of cancer patients who have used frozen embryos is small. Most of the data comes from women without cancer who have used a frozen embryo to have a baby.

This data shows the chance that embryo freezing will help a woman to have a baby after cancer treatment is around 30 in 100 (around 30%).

The chance of having a baby after embryo freezing depends on a number of factors. These are:

- Your age at the time the eggs are collected. Women who are younger than 35 years of age have a higher chance. This is around 40 in 100 (40%). Women over 35 years old will have a lower chance. This is around 20 in 100 (20%).
- The number of eggs collected.
- The number and quality of embryos frozen.
- The health of your partner's sperm.
- The fertility clinic where embryo freezing has been carried out.

For more information on national average success rates and the number of successful live births for each licensed fertility clinic visit the HFEA website **www.hfea.gov.uk**.

Will this option affect the health of the baby?

No, the data suggests that the health of a baby born using frozen embryos will not be affected.

Are there any side effects of the fertility treatment used in embryo freezing?

The fertility drugs used to stimulate egg production can cause side effects such as headaches, mood changes, hot flushes, and irritation of the skin. The fertility drugs may also cause the ovaries to over respond and this can lead to a condition called OHSS. Once you start your treatment it is advised that you ask your fertility care team about the symptoms of this condition and how to contact them if you need to.

When the ovaries are stimulated to produce lots of eggs, the levels of the hormone oestrogen go up. This could be a concern in women who have an oestrogen sensitive breast cancer. These women can be given a drug called Letrozole (Femara). This lowers the levels of oestrogen in the blood stream.

Embryo freezing

In an attempt to obtain egg cells there is a chance of bleeding, infection and puncture to the bowel, but this is rare.

There may be a concern for women with pelvic cancers, where there could be a spill of cancer cells from the ovary into the abdomen following egg collection.

If more than one embryo is replaced, there is a chance of multiple births (twins, triplets). All pregnancies have a risk of miscarriage, and ectopic pregnancy (a pregnancy outside of the womb).

IVF can be physically and emotionally draining, and pregnancy may not occur.

Will this option delay the start of my cancer treatment?

It takes around two weeks from the time of starting ovarian stimulation until the time of egg collection. The time before the start of stimulation can vary. It depends on things like where a woman is in her menstrual cycle. This option may not be suitable for women with cancers such as leukaemia, some lymphomas, and sarcomas as they may need immediate treatment. If you experience OHSS, this may cause a longer delay to the start of cancer treatment.

Will this option affect my chances of the cancer coming back?

There is no data to suggest that embryo freezing affects the chances of cancers growing or coming back.

You may find it useful to write down what you like about this option and what worries you about this option. These notes may help you talk about whether or not this option is best for you with your cancer care team and fertility care team, partner, family and friends:

What I like about this option	What worries me about this option
1.	1.
2.	2.
3.	3.
4.	4.

Ovarian tissue freezing

3 Ovarian tissue freezing:

Ovarian tissue which contains a large number of immature eggs is removed and frozen. After cancer treatment, the tissue can then be put back into the body to allow the eggs to develop. It is a newer method of fertility preservation and not available in all fertility clinics yet. It can be used immediately before and during chemotherapy.

Who is it for?

Women who wish to preserve their fertility and:

- Do not have time to freeze embryos or eggs.
- Who cannot use fertility drugs.

After the ovarian tissue is replaced, it can restore your normal hormone production and cycles, and may allow the chance of getting pregnant naturally.

It is also suitable for girls who have not reached puberty.

Careful consideration is required in women with a blood cancer such as leukaemia. This is because there is a chance of putting cancer cells back in the body with the frozen ovarian tissue.

What does it involve?

You will need to have keyhole surgery under a general anaesthetic. One ovary or part of an ovary will be removed so that the outer layer (the cortex) that contains the immature eggs, can be frozen. Women may go home the same day as the procedure.

As ovarian tissue freezing only involves the woman, there is no need for your partner or parents' consent to use the stored tissue in the future. Frozen ovarian tissue, can be stored for a maximum of 55 years.

What is the chance of having a baby after ovarian tissue freezing?

It is difficult to be certain how likely it is that ovarian tissue freezing will result in a live birth.

As this is a newer treatment, the number of cancer patients who have used their frozen tissue to have a baby is low. This data shows the chance that ovarian tissue freezing will help a woman to have a baby is around 30 in 100 (30%). For more information on national average success rates and the number of successful live births for each licensed fertility clinic visit the HFEA website **www.hfea.gov.uk**.

Will this option affect the health of the baby?

No, the data suggests that the health of a baby born using frozen ovarian tissue will not be affected.

Are there any side effects of the treatment used in ovarian tissue freezing?

There may be a chance of bleeding and infection and of damage to the bladder and bowel during the surgery to remove the ovarian tissue.

Will this option delay the start of my cancer treatment?

The procedure is mostly carried out during one day (with no overnight stay in hospital) and will not cause any delays to cancer treatment.

Will this option affect my chances of the cancer coming back?

In some types of cancer, such as leukaemia, there could be a chance of ovarian tissue being contaminated with cancer cells. There are no cases of a cancer coming back from the use of ovarian tissue.

You may find it useful to write down what you like about this option and what worries you about this option. These notes may help you talk about whether or not this option is best for you with your cancer care team and fertility care team, partner, family and friends:

What I like about this option	What worries me about this option
1.	1.
2.	2.
3.	3.
4.	4.

Ovarian suppression

Ovarian suppression:

This is an option to protect the ovaries during cancer treatment. It is a hormone treatment, in the form of injections. It works by temporarily 'switching off' oestrogen made by the ovary. This stops menstruation until after the cancer treatment has been completed. It is not clear whether it increases the chance of being able to have a baby after cancer treatment. Ovarian suppression can be used immediately before and during chemotherapy.

Who is it for?

Women who wish to preserve their fertility and:

- Have gone through puberty and are having chemotherapy.

What does it involve?

You will need to have monthly injections which stop the hormones that stimulate your ovaries. You may be offered Gonadotrophin-releasing hormone (GnRH) analogue treatment. This is a hormone treatment which may help preserve your fertility.

What is the chance of having a baby after ovarian suppression?

The chance of having a baby in the future depends on how your ovaries have been affected by your cancer treatment.

The evidence that it can protect the ovary against chemotherapy is only clear for women with breast cancer, and it may not be effective for women with other cancers. It is not clear how much it increases the chance of you being able to have a baby after treatment and it may be less effective than freezing techniques, so where those are possible, and future fertility is important to you, you should not choose ovarian suppression instead of freezing techniques.

Will this option affect the health of the baby?

No, the data suggests that the health of a baby born using ovarian supression will not be affected.

Are there any side effects of the treatment used in ovarian suppression?

This option means shutting down the ovaries for a short time. This can cause side effects common in menopause such as hot flushes, mood changes, difficulty sleeping, and vaginal dryness. These symptoms are temporary as ovarian suppression does not cause permanent menopause.

Will this option delay the start of my cancer treatment?

Hormone injections are mostly given monthly and will start around 2 weeks before cancer treatment. Once cancer treatment starts, the injections are given each month the whole time a woman is receiving chemotherapy.

Will this option affect my chances of the cancer coming back?

Studies have shown that ovarian suppression does not affect the chance of the cancer coming back.

You may find it useful to write down what you like about this option and what worries you about this option. These notes may help you talk about whether or not this option is best for you with your cancer care team and fertility care team, partner, family and friends:

What I like about this option	What worries me about this option
1.	1.
2.	2.
3.	3.
4.	4.

Fertility sparing procedures specific to certain cancers

If you have been diagnosed with cervical cancer, or are being treated with radiotherapy to the pelvis, there may be specific fertility preservation treatments available to you. These are provided by your cancer care team and may also help preserve your fertility. The cancer care team talk with women about having these fertility sparing procedures as part of their cancer treatment.

Trachelectomy

Trachelectomy is a surgical procedure to remove cancer from the cervix. The cervix, upper part of the vagina and lymph glands in the pelvis are taken out. The womb is left in place.

This may be an option if you have been diagnosed with early stage cervical cancer. The side effects can include bleeding and infection, blood clots in the veins (thrombosis). Surgical side effects can be a cut in your bowel or bladder causing further bladder problems, and problems with menstruation. This is a day surgery procedure, and does not cause any delays to cancer treatment.

The chance that a trachelectomy will help a woman to have a child after cancer treatment is not known. There is a chance of miscarriage and premature birth for women who become pregnant after the surgery. The baby will need to be delivered by Caesarean section (C-section). Studies have shown that a trachelectomy does not affect the chance of the cancer coming back.

Ovarian transposition

Ovarian transposition is a surgical procedure that moves the ovaries away from the field of the radiotherapy treatment. This may be an option if you are receiving radiotherapy treatment to the pelvis.

The side effects can include injury to internal organs. This is a day surgery procedure, and does not cause any delays to cancer treatment. The chance that ovarian transposition will help a woman to have a child after cancer treatment is not known. Studies have shown that ovarian transposition does not affect the chance of the cancer coming back. It does not protect the ovaries against the effects of chemotherapy.

Ovarian shielding

Ovarian shielding works by protecting the ovaries during radiotherapy treatment. This may be an option if you are receiving radiotherapy to the pelvis. During your radiation treatment, a protective cover is placed on the outside of the body, over the area of the ovaries.

You will be able to go home straight after the radiation treatment. The shielding does not delay cancer treatment. Although this may be offered to you, the data suggests that ovarian shielding gives poor protection of the ovaries during radiotherapy treatment.

The chances of having a child after cancer treatment is not known. It is not yet known whether ovarian shielding affects the chances of cancers growing or coming back. It does not protect the ovaries against the effects of chemotherapy.

Questions to ask your cancer care team and fertility care team

The following questions below may help you think about what is important to you about these fertility preservation options. Writing down your thoughts will help you talk with your cancer care team and fertility care team to plan your care **before** starting your cancer treatment.

Does my cancer type or treatment affect the type of fertility preservation option I can have?

Can I check if I am fertile before my cancer treatment starts?

Why should I make a fertility preservation decision right now?

Do I have time to undergo fertility preservation before starting cancer treatment?

Is there anything that can be done during cancer treatment to protect my fertility?

For how long is it safe to delay my cancer treatment?

Will having treatment to preserve my fertility delay my cancer treatment? If so, what effect could this have on my chance of recovering from cancer?

Will I have to pay for my fertility preservation treatment? Will I have to pay for storing and using my eggs, embryos or tissue in the future?

Use this space to write down any notes or other questions you have about fertility preservation:

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Financial costs associated with undergoing fertility preservation

NHS funding may be available, but the amount of funding and the criteria for treatment varies between Clinical Commissioning Groups (CCGs) and different regions.

NHS funding may not be available if either you or your partner already have children. If you are not eligible for NHS funded treatment, then you may self-fund treatment. Individual funding requests can be made to CCGs in exceptional circumstances.

Funding will be discussed during your consultation with your fertility care team. If NHS funding is available for fertility preservation, this does not guarantee that if or when you choose to use the frozen material to have a pregnancy that this will also be funded by the NHS.

For more information about the availability of fertility preservation procedures, please visit the HFEA website **www.hfea.gov.uk**.

Talking with your fertility care team about fertility preservation

The fertility care team carry out procedures known as fertility preservation for women who are diagnosed with cancer. The fertility care team can talk with you about your decision to have or not have fertility preservation procedures.

The fertility consultation depends on the clinic that you are attending, your cancer diagnosis and planned cancer treatment. The fertility care team will look at your medical history to make sure that fertility preservation treatment is appropriate. They will explain what is involved, success rates and the side effects of fertility treatment. If you need further tests, these will be done before fertility treatment starts. You will also have the chance to discuss the different fertility preservation options available at the clinic.

If you choose fertility preservation treatment, different tests will be carried out. These will include blood tests to measure hormone levels and other screening tests. The fertility care team will also discuss issues about consent to treatment as recommended by the HFEA.

Recommended source of information

The HFEA is the UK's independent regulator overseeing the use of gametes (eggs and sperm) and embryos in fertility treatment and research. There is advice on their website about how you can get the most out of your fertility consultations. You can do this by:

1) Asking questions.
2) Taking time out to think things through - there can be a lot of difficult issues to consider.
3) Remembering that the fertility care team are there to help you make the right choice for you.

The HFEA website **www.hfea.gov.uk** has more information about fertility clinics, fertility preservation treatments and fertility success rates in your area.

A member of your cancer care team will be able to refer you to a fertility clinic. They can ask them to fit you in as soon as possible to prevent any delays to your cancer treatment.

If you would like to be referred to a fertility clinic, there are some things to check. Tick one answer for each statement.

If your answer is no or unsure, you may want to ask your cancer care team to contact the fertility clinic on your behalf as soon as possible. The following questions on page 24 may help you prepare for the fertility consultation.

Tick one box for each statement	No	Unsure	Yes
Has a member of my cancer care team made a referral for me to a fertility clinic?	☐	☐	☐
Have I received an appointment to see the fertility care team?	☐	☐	☐

Questions to ask your fertility care team

The following questions may help you prepare for the fertility consultation:

I am not in a relationship but may want a child in future - what are my options?

How long will fertility preservation take and what will be the expected delay to starting my cancer treatment?

What are the chances of me being able to have my own children in the future?

Would using any fertility preservation option affect my chances of the cancer coming back?

Use this space to write down any notes or other questions you have about the referral process for fertility preservation:

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Talking about the fertility preservation decision with others

Some women find it helps to talk about their diagnosis of cancer, and fertility preservation, with others.

You may find it helpful to talk about issues such as:

- Making difficult decisions.
- Expressing your feelings to your loved ones.
- The impact of cancer and fertility on your relationships.
- Anxiety and stress.
- Moral, religious or ethical concerns.
- Coping with your cancer and fertility treatments.
- Ways you can manage your own feelings.

Finding the best support for you can mean you are able to cope better with your situation. This may help manage some of these emotional challenges. People choose different ways to help them feel supported. These could include:

- Finding out about all the options available.
- Keeping a diary or notes about your thoughts and reasons for your decisions.
- Thinking about who you might want to involve in your decision-making - a partner, family and friends or a nurse or doctor.
- Seeking counselling. This can be done either alone, with your partner or someone else close to you. Professional counsellors, who are not directly involved in your fertility or cancer care, may be available in the fertility and cancer clinics. Other counselling organisations which may be able to provide this dedicated counselling support have been listed on page 32.
- Talking to people who have been through similar experiences. There are support organisations available. We have listed some of these on page 32. You may also choose to speak to a member of your cancer care team and fertility care team.
- There may be times when you may not want to talk about fertility and cancer. If you are a private person, writing in a diary or expressing yourself creatively may be helpful.

Making my fertility preservation decision **before** starting cancer treatment

This section of the booklet aims to help you decide if you want to:

- Have fertility preservation treatment **before** starting cancer treatment, or
- Start cancer treatment without having fertility preservation treatment.

Some women know for certain whether or not they want to pursue fertility preservation. Other women find making this decision more difficult. There is no 'right' or 'wrong' decision. The decision depends on what is most important to you at this time. It depends on the plans you have for your life, after your cancer treatment.

Deciding to have, or not to have, fertility preservation **before** cancer treatment

To help you think about what is important to you now, look at the statements in the table below.

Give each one a value from 1 to 4, where

1 is **not** important to you,
2 is **slightly** important to you,
3 is **quite** important to you, and
4 is **very** important to you.

You can use the numbers more than once. Write down below the reasons for your answer.

You may find it helpful to complete this with your cancer care team and fertility care team, partner, family and friends.

What matters most to you?

1 not important, 2 slightly important, 3 quite important, 4 very important	
Starting cancer treatment straight away	1 2 3 4
Wanting to have my own biological child after my cancer treatment has been completed	1 2 3 4
Delaying the start of cancer treatment to have fertility preservation	1 2 3 4
Taking steps to preserve my fertility before cancer treatment	1 2 3 4
Waiting to see if my fertility comes back naturally after completing cancer treatment	1 2 3 4

Making my fertility preservation decision **before** starting cancer treatment

Deciding which fertility preservation option is best for me

In the previous sections, the fertility preservation decisions were described. These are:

- No fertility preservation
- Freezing
- Ovarian suppression

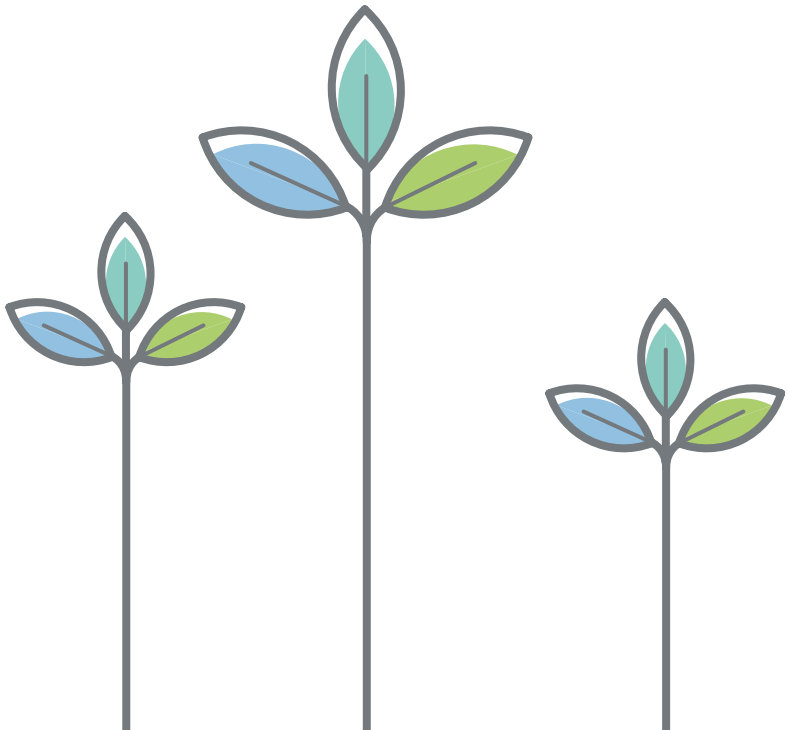
The **summary table** at the back of booklet compares the different fertility preservation options. It can be found on page 38.

Below is a list of the different fertility preservation options. Tick one response for each option.

Completing this task may help you think about which fertility preservation option best suits you and your lifestyle at this time. It might be helpful to talk about your choices with your cancer care team and fertility care team, partner, family and friends.

How likely are you to consider each of these fertility preservation treatment options?

	Definitely not	Maybe not	Unsure	Maybe	Definitely
No fertility preservation	☐	☐	☐	☐	☐
Egg freezing	☐	☐	☐	☐	☐
Embryo freezing	☐	☐	☐	☐	☐
Tissue freezing	☐	☐	☐	☐	☐
Ovarian suppression	☐	☐	☐	☐	☐



Other fertility decisions to consider

The focus of this booklet so far has been helping you to make the right fertility preservation decisions for you **before** starting cancer treatment. This section provides some more information about the other fertility decisions women may have to make **during** and **after** cancer treatment.

During cancer treatment:

These decisions may include what type of contraceptive option to use.

After cancer treatment and follow-up:

These decisions may include what type of contraceptive to use, what methods of fertility testing to have and planning for a future family.

Contraception **during** cancer treatment

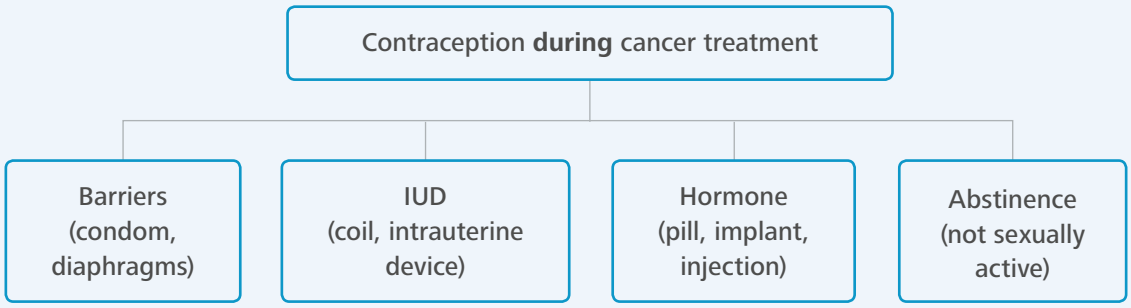
Women are strongly advised not to get pregnant whilst having cancer treatment. This is because cancer treatments can damage an unborn baby at the early stages of development. Even if your periods stop during treatment, this does not mean you cannot get pregnant.

If you are sexually active, you should use a reliable contraceptive method throughout your cancer treatment. **Picture 2** below shows the different types of contraception to consider.

It is recommended that women who are having hormone treatments, use non-hormonal methods of contraception. These include condoms, female condoms (Femidoms) and diaphragms. The contraceptive pill is less commonly advised for women with hormone sensitive cancers. This is because there is a chance that hormones in the contraceptive pill could stimulate any remaining cancer cells.

It is advised that you discuss these various methods of contraception with your cancer care team. They may refer you to a family planning clinic or your GP who can advise you further.

Picture 2: Contraception **during** cancer treatment



Other fertility decisions to consider

The following questions may help you talk with your cancer care team or GP about contraception:

What contraceptive would be best for me during my cancer treatment?

How long will I need to use this contraceptive for?

Do I need to use non-hormonal methods of contraception for my cancer type?

If I am not having a period during my cancer treatment, should I still use contraceptives?

Will it affect me or my unborn baby if I choose not to use contraception and get pregnant during my cancer treatment?

Use this space to write down any notes or other questions you have about contraception during cancer treatment:

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Family planning decisions **after** cancer treatment

For many women, deciding whether to try to get pregnant after a diagnosis of cancer is difficult. During this time, women make decisions about fertility management that best suit their lives. These include having tests to check fertility, choosing a contraceptive method and planning for a future family. This is shown in **picture 3** on the following page.

It is difficult to predict exactly how your fertility will be affected by cancer treatment. You can ask your cancer care team or GP to refer you to a fertility clinic. The fertility care team can check your fertility through a series of tests. These include blood tests to check your levels of a hormone or an ultrasound scan of the ovaries.

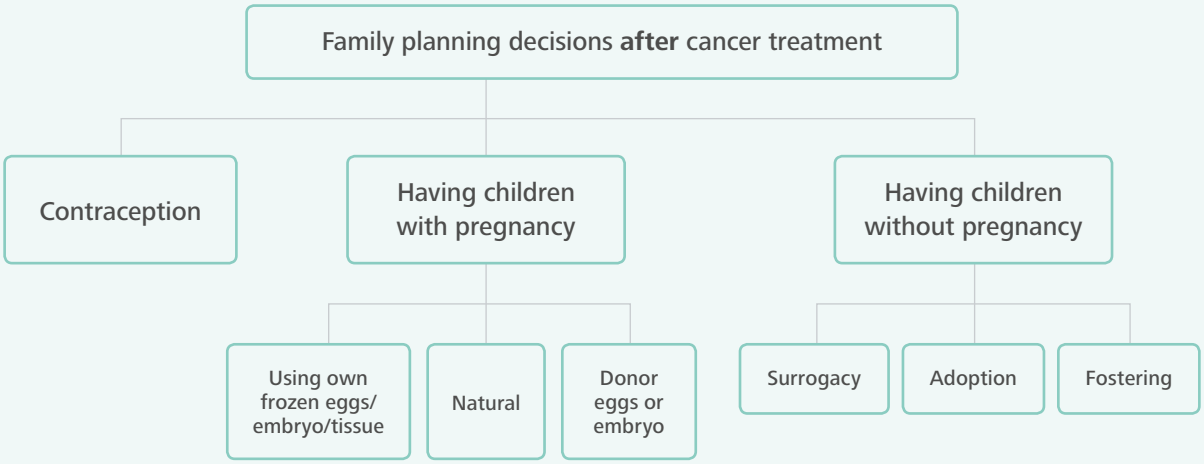
Some women may decide their family is complete or choose not to have any children after finishing cancer treatment. Your fertility may return naturally afterwards.

Not all women who have cancer treatment will have a fertility problem in the future. Even if your periods have not started again, you may still be producing eggs and could become pregnant. It is advised that you discuss methods of contraception with your cancer care team or GP. They can advise you on the options and the appropriate type of contraception for you. It is advised to wait for two years after completing your cancer treatment before trying for a baby.

There are no data to suggest that pregnancy affects the chances of a cancer coming back. There are no data to suggest that the health of children born after cancer treatment is affected. If you are thinking about getting pregnant, talk to your cancer care team.

Other fertility decisions to consider

Picture 3: Family planning decisions **after** cancer treatment



Not all women who have cancer treatment will have a fertility problem, and in fact most young women who want to have a baby after cancer treatment are able to do so. Some women may face permanent loss of fertility after cancer treatment. This can be upsetting and difficult to come to terms with. It might come at a time when a woman is planning to start a family or before a woman's family is complete.

If this is the case for you, you may find it helpful to seek professional counselling. This may be available in fertility services from someone who is not directly involved in your fertility treatment. Other organisations which may be able to provide this dedicated counselling support have been listed on page 32. As well as offering emotional support, they will be able to offer information on other options. These include surrogacy, adoption and fostering. They can advise on other methods of assisted pregnancies such as donor eggs and embryos or using your own saved eggs, embryos and ovarian tissue.

The HFEA website **www.hfea.gov.uk** has more information about egg or embryo donation and surrogacy.

The organisations listed on page 32 of this booklet include information and support for people interested in fostering and adoption.

Questions to ask your cancer care team or GP

The following questions may help you talk with your cancer care team or GP about family planning after cancer treatment:

How will I know if I am fertile after cancer treatment?

How long before I will know if I am fertile?

Are there any tests that I can take to check if I am still fertile after cancer treatment?

Would a future pregnancy affect the chances of the cancer coming back?

Assuming I can still have children, how long after treatment should I wait?

If I become pregnant after treatment for cancer, will my child have a higher chance of getting cancer?

If I didn't preserve my fertility before treatment, do I still have options?

Use this space to write down any notes or other questions you have about fertility concerns after cancer treatment:

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Summary

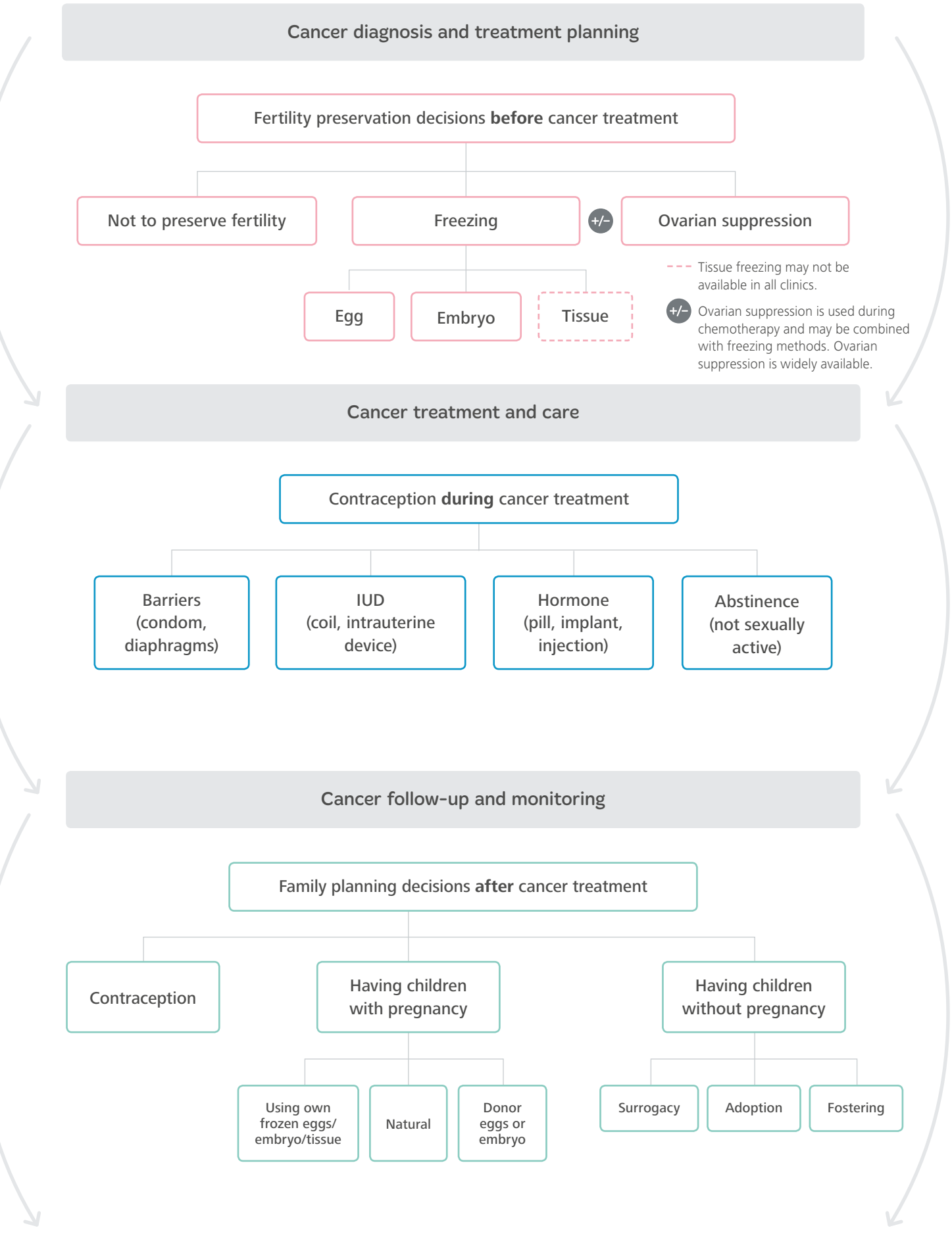
Women diagnosed with cancer are faced with making decisions about their fertility **before**, **during** and **after** their cancer treatment.

Picture 4 on the following page shows these fertility decisions, linking them to each stage of cancer treatment. At each stage, talk with your cancer care team and fertility care team, partner, family and friends. This will help you be informed and make the right decision for you.

The **summary table** at the back of booklet compares the different fertility preservation options. You can use this summary to help you think about the best decision for you. It can be found on page 39.

Finally, there may be other new and emerging fertility treatments that are in the early stages of research and development. For example, a womb transplant. Talk to your fertility care team about these.

Picture 4: Linking fertility options for women **before**, **during** and **after** cancer treatment



Other information and useful contacts

To help you make the right decision for you, below are some useful organisations, websites, forums and guidelines. These might help you to talk with other professionals and women who can provide support and have been through similar experiences to you.

General cancer support

Bloodwise
Tel: 0808 2080 888
www.bloodwise.org.uk

Breast Cancer Care
Helpline: 0808 800 6000
www.breastcancercare.org.uk

British Fertility Society
www.britishfertilitysociety.org.uk

CLIC Sargent (Young Lives vs Cancer)
Tel: 0300 330 0803
www.clicsargent.org.uk

Macmillan Cancer Support
Tel: 0808 808 0000
www.macmillan.org.uk

Teenage Cancer Trust
Tel: 020 7612 0370
www.teenagecancertrust.org

Yorkshire Cancer Research
Tel: 01423 501 269
www.yorkshirecancerresearch.org.uk

Fertility organisations

British Infertility Counselling Association
www.bica.net

Donor Conception Network
www.dcnetwork.org

The Daisy Network
www.daisynetwork.org.uk

Fertility Friends
www.fertilityfriends.co.uk

Fertility Network UK
Tel: 01424 732 361
www.fertilitynetworkuk.org

Fertility Preservation UK
www.britishfertilitysociety.org.uk/special-interest-groups/fertility-preservation-uk

Future Fertility Trust
www.futurefertilitytrustuk.org

Human Fertilisation and Embryology Authority
Tel: 020 7291 8200
www.hfea.gov.uk

National Gamete Donation Trust
www.ngdt.co.uk

Adoption and fostering

Adoption UK
Tel: 0844 848 7900
www.adoptionuk.org

Coram
corambaaf.org.uk

Counselling and emotional support

British Association for Counselling and Psychotherapy (BACP)
Tel: 01455 883 300
www.bacp.co.uk
itsgoodtotalk.org.uk

UK Council for Psychotherapy (UKCP)
Tel: 020 7014 9955
www.psychotherapy.org.uk

Youth Access
Tel: 020 8772 9900
www.youthaccess.org.uk

Guidelines to deliver services

National Institute for Health and Care Excellence (NICE)
www.nice.org.uk

Guidance:

- NICE (2013) Fertility problems: assessment and treatment [CG156]
- NICE (2014) Cancer services for children and young adults: fertility support [QS55]

Pathways:

- NICE (2016) Cryopreservation to preserve fertility in people diagnosed with cancer

Human Tissue Authority
www.hta.gov.uk

Human Fertilisation and Embryology Authority (HFEA)
www.hfea.gov.uk

Glossary

Abdomen - (tummy or belly) is the area below the chest and above the pelvis. It contains several organs such as the kidneys, liver and the stomach.

Adoption - To take on the legal responsibilities as parent of a child (that is not one's biological child).

Anastrozole (Arimidex) - Works by lowering oestrogen levels in postmenopausal women. This may slow the growth of certain types of breast tumours that need oestrogen to grow in the body.

Antipsychotic medication - A class of medicines used to treat psychosis and other mental and emotional conditions.

Assisted reproductive technologies (ART) - A group of procedures which help couples who are infertile to have a baby.

Blood Cancers - the name given to a group of cancers that develop when cells in the blood are not made properly. For example, leukaemia and lymphoma.

Brachytherapy - The treatment of cancer, by the insertion of radioactive implants directly into the tissue.

Breast cancer - A group of cancer cells (malignant tumour) that starts in the cells of the breast.

Caesarean section - A surgical operation for delivering a child by cutting through the wall of the mother's abdomen.

Cancer - A disease caused by an uncontrolled division of abnormal cells in a part of the body.

Cancer Growth Inhibitors - In order to grow and divide, cancer cells 'communicate' with each other using chemical signals. Cancer growth inhibitors are drugs that interfere with this process and so affect the cancer's ability to develop.

Cervical cancer - A type of cancer that occurs in the cells of the cervix - the lower part of the uterus that connects to the vagina

Cervix - The narrow neck-like passage forming the lower end of the womb.

Chemotherapy - The treatment of disease, especially cancer, using drugs that are destructive to malignant cells and tissues.

Clinical Commissioning Groups (CCG) - National Health Service (NHS) organisations set up by the Health and Social Care Act 2012 to organise the delivery of NHS services in England.

Clinical trial - A scientific test looking at how effective and safe a treatment agent (for example, medication) is.

Contraception - The use of different devices, sexual practices, techniques, chemicals, drugs or surgical procedures to purposely try to prevent pregnancy.

Cortex - Outer layer of the ovary.

Cryopreservation - A method of preserving eggs, embryos or tissue by slow freezing at very low temperatures.

Donor - The process when a fertile person provides (donates) one or several eggs/sperms to an infertile person.

Ectopic - An ectopic pregnancy is when a fertilised egg implants itself outside of the womb. This may be in one of the fallopian tubes.

Egg - A cell that is produced by the female reproductive organs and that combines with the males sperm in reproduction.

Egg freezing - A method where eggs are harvested from your ovaries, frozen unfertilised and stored for later use. This is also known as mature oocyte cryopreservation.

Embryo freezing - The process of preserving an embryo at below freezing (lower than zero) temperatures and stored for later use.

Endometriosis - A condition where tissue that behaves like the lining of the womb (the endometrium) is found outside the womb.

Exemestane (Aromasin) - A type of hormone therapy drug called an aromatase inhibitor and is used to treat breast cancer. It is only suitable for women who have had their menopause.

Glossary

Fallopian tubes - There are two fallopian tubes that transport the egg from the ovary to the womb (uterus).

Female reproductive system - Internal reproductive organs of the females, including the ovaries, fallopian tubes, womb (uterus) and vagina.

Fertility - Being able to have children.

Fibroids - Non-cancerous growths that develop in or around the womb.

Follicles - A small fluid filled sac in the ovaries that contains eggs. This is where eggs are formed and grow in size.

Fostering - To take care of a child. This may be for a limited time, without being the child's legal parent.

General anaesthetic - A combination of medicines to send you to sleep, so you're not aware of the surgery and do not move or feel pain while it is carried out.

Gonadotropin releasing hormone (GnRH) - A hormone triggers the brain to release other hormones that signal the ovaries to develop and release eggs.

Goserelin (Zoladex) - Zoladex is a brand name of medicines used in women to treat breast cancer or endometriosis. Goserelin over stimulates the body's own production of certain hormones, which causes production to shut down temporarily.

Gynaecological cancer - Cancer of the female reproductive tract, including the cervix, endometrium, fallopian tubes, ovaries, womb (uterus), and vagina.

HER-2 - HER-2 (human epidermal growth factor) is a protein that can affect the growth of some cancer cells. When there are higher levels of the HER-2 protein in a breast cancer, it is called HER2 positive breast cancer.

Hormone receptors - Can be 'positive' or 'negative' and describes whether the breast cancer will be stimulated to grow by oestrogen and/or progesterone.

Hormone sensitive - Certain cancers are called hormone sensitive or hormone dependent. Hormone therapy uses drugs that either stop the body producing hormones or prevent hormones from making the cancer cells grow and divide. Cancers that can be hormone sensitive include breast, prostate, womb and kidney cancers.

Hormone therapy - To slow or stop the growth of certain cancers (such as prostate and breast cancer). Hormones or other drugs may be given to block the body's natural hormones.

Human Fertilisation and Embryology Authority (HFEA) - The UK's independent regulator overseeing the use of gametes (male and female reproductive cells) and embryos in fertility treatment and research.

Hysterectomy - A surgical procedure to remove the womb (uterus). You'll no longer be able to get pregnant after the operation. If you haven't already gone through the menopause, you'll no longer have periods, regardless of your age.

Immature eggs - this is the name for the eggs which have not grown and developed in the ovaries.

Infertility - Not being able to get pregnant (conceive) naturally.

Intrauterine contraceptive device (IUD) - A device inserted into the womb (uterus) to prevent pregnancy (conception). The IUD can be a coil, loop, triangle, or T in shape made of plastic or metal.

In vitro fertilisation (IVF) - Fertilisation of an egg outside a woman's body by the addition of sperm to produce an embryo.

Letrozole (Femara) - A type of hormone therapy drug used to treat breast cancer in women who have had their menopause.

Leukaemia - Cancer of the blood cells.

Leuprorelin (Prostap) - Leuprolelin (Prostap) belongs to group of medicines called 'LHRH agonists'. These work by reducing hormone levels in the ovaries. It is given as an injection every one to three months.

Live birth - A birth at which a child is born alive.

Glossary

Lymph gland - Lymph nodes are small, bean-shaped glands throughout the body. They are part of the lymph system, which carries fluid (lymph fluid), nutrients, and waste material between the body tissues and the bloodstream. The lymph system is an important part of the immune system, the body's defense system against disease.

Lymphoma - A form of cancer that affects the immune system.

Mature eggs - There are tiny follicles inside the ovaries. Each ovarian follicle contains a single immature egg cell. Once a month, a few of the follicles will grow and develop the egg inside (mature) and one of the ovaries will release a single egg.

Menopause - The time in a woman's life when the menstrual cycle (periods) ends.

Menstruation/periods - The monthly cycle of changes in the ovaries and the lining of the womb (uterus), starting with the preparation of an egg for fertilisation. When the follicle of the prepared egg in the ovary breaks, it is released for fertilisation and ovulation occurs.

Miscarriage - If a pregnancy ends before the 24th week, it is known as a miscarriage.

National Institute for Health and Care Excellence (NICE) - Evidence-based guidance, advice and information services for health, public health and social care professionals.

Non-steroidal anti-inflammatory drugs (NSAIDs) - Medications mostly used to relieve pain, lower inflammation, and bring down a high temperature (fever).

Oestrogen - A general term for one type of female sex hormone that is secreted by the ovary and responsible for typical female sexual characteristics.

Oophorectomy - Surgical removal of one or both ovaries.

Ovarian hyper-stimulation syndrome (OHSS) - A serious side effect of fertility treatment, which may happen when having in vitro fertilisation.

Ovarian reserve - The number of eggs a woman has at any one point in time.

Ovarian shielding - A procedure done during radiation therapy in which a protective cover is placed on the outside of the body, over the area of the ovaries and other parts of the female reproductive system, to prevent damage from radiation therapy. This is a type of fertility preservation.

Ovarian stimulation - Hormone injections to temporarily raise the activity of the ovaries.

Ovarian suppression - The medical terms used to prevent the ovaries from producing oestrogen, either temporarily or permanently.

Ovarian transposition - A surgical procedure used to protect ovarian function before delivery of radiation therapy. It is performed in patients whose treatment includes pelvic radiotherapy as a part of management for Hodgkin's disease and other gynaecologic cancers.

Ovarian tissue freezing - An experimental method of fertility preservation in which the outer layer of an ovary, which contains a large number of immature eggs, is taken out of the body and frozen for future use.

Ovaries - A female reproductive organ in which eggs are produced.

Ovulation - A part of the female menstrual cycle whereby a mature ovarian follicle (part of the ovary) releases an egg. It is during this process that the egg travels down the fallopian tube where it may be met by a sperm and become fertilised.

Parametrial tissue - The fibrous tissue that separates the supravaginal portion of the cervix from the bladder.

Pelvic cancer - A type of cancer that occurs in the cells of the cervix (the lower part of the womb (uterus) that connects to the vagina).

Pelvic inflammatory disease - An infection of the female reproductive organs. It may occur when sexually transmitted bacteria spread from your vagina to your womb (uterus), fallopian tubes or ovaries.

Glossary

Pertuzumab (Perjeta) - a monoclonal antibody mostly used to treat some women with breast cancer.

Pituitary gland - The pituitary gland is a tiny organ, the size of a pea, found at the base of the brain. As the 'master gland' of the body, it makes or stores many different hormones.

Polycystic ovary syndrome (PCOS) - A common endocrine system disorder among women of reproductive age, which may have enlarged ovaries that contain small collections of fluid, called follicles.

Postpubertal - Occurring after puberty.

Pregnancy - The state of carrying a developing embryo or baby within the female body.

Puberty - The age at or period during which the body of a boy or girl matures and becomes capable of reproducing.

Radiotherapy - The treatment of disease, especially cancer, using X-rays or similar forms of radiation.

Recreational drugs - Recreational drugs are taken by people to alter their mood. Alcohol and tobacco are legal recreational drugs; heroin and cocaine are illegal recreational drugs.

Sarcoma - Cancerous (malignant) tumours of connective tissues.

Sedation - A combination of medicines to help you relax.

Sperm - A cell that is produced by the male reproductive organs and that combines with the female's egg in reproduction.

Stimulate - Drugs are used to stimulate development of multiple mature follicles and eggs in order to raise pregnancy rates with various infertility treatments.

Surrogacy - The practice by which a woman (called a surrogate mother) becomes pregnant and gives birth to a baby in order to give it to someone who cannot have children.

Tamoxifen - A drug often used as a hormone therapy treatment of breast cancer in women whose tumours are oestrogen receptor positive.

Targeted therapy - A type of treatment that uses drugs or other substances to identify and attack specific types of cancer cells with less harm to normal cells.

Thawed - To change from a frozen solid to a liquid by gradual warming.

Thrombosis - When a blood clot forms inside a blood vessel, blocking the flow of blood through the circulatory system.

Trachelectomy - A surgical removal of the uterine cervix. As the uterine body is preserved, this type of surgery is a fertility preserving procedure, and applicable in selected younger women with early cervical cancer.

Trastuzumab (Herceptin) - Is used to treat some types of breast cancer and stomach cancers following surgery and/or radiotherapy and chemotherapy to lower the chance of the cancer recurring.

Uterus (see womb) - The organ in the lower body of a woman where the baby is conceived and carried before the baby is born.

Vagina - The muscular tube leading from the external genitals to the cervix of the womb (uterus) in women.

Vitrification - A method of preserving eggs, embryos or tissue by fast freezing at very low temperatures.

Womb (see uterus) - The organ in the lower body of a woman where the baby is conceived and carried before the baby is born.

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The CFM research team is grateful to all the patients, user groups and health professionals who gave their time and expertise to support the development of this booklet.

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For a full list of the evidence we used to research and develop this booklet and readability levels please go to: www.leedsbeckett.ac.uk/cancerfertilityandme

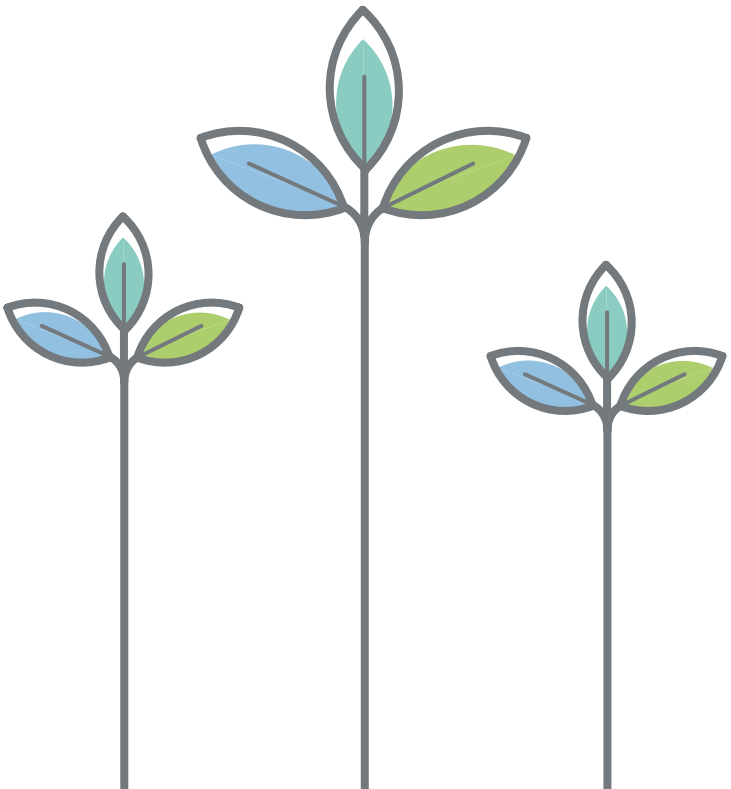
The development of the booklet was funded by Yorkshire Cancer Research. The CFM research team members do not stand to gain or lose with regards to the use of this resource.

The CFM team will continually review emerging evidence to ensure that accurate information is presented. The CFM team will update the resource annually, unless any new evidence emerges that warrants earlier updating. The next planned update will take place in September 2020.

For an online version of this booklet please go to: www.cancerfertilityandme.org.uk

Table 1: Summary of the fertility preservation options

	No Fertility Preservation	Egg Freezing	Embryo Freezing	Ovarian Tissue Freezing	Ovarian Suppression
Who it is for	Women who want to wait and see; already completed family; do not wish to have a pregnancy after cancer treatment; need to start cancer treatment straight away; do not have fertility preservation options available to them.	Women who do not have a partner; do not want to use donor sperm; do not choose embryo freezing because of their beliefs; have time to go through a cycle of fertility treatment before starting cancer treatment.	Women who have time to go through a cycle of fertility treatment before starting cancer treatment; women with a male partner as both eggs and sperm are needed for fertilisation.	Women who do not have time to freeze embryos or eggs; who cannot use fertility drugs; who prefer the possibility of natural conception later; girls who have not reached puberty.	Women undergoing chemotherapy; girls who have reached puberty.
Chance of having a baby	Variable. Depends on how your ovaries have been affected by your cancer treatment.	Variable. Women under 35 who store 10 eggs have approximately a 4 in 10 (40%) chance of having a baby. Women over 35 years old will have a lower chance.	Variable. The chance that embryo freezing will help a woman to have a child after cancer treatment is around 30 in 100 (around 30%). Women who are younger than 35 years of age have a higher chance. Women over 35 years old will have a lower chance.	Newer method of fertility preservation. Live birth rates of about 30 in 100 (30%) worldwide.	It is unclear if this method makes it more likely that you will be able to have a baby after treatment.
Effect on the health of baby	No effect.	No data to suggest health of baby will be affected.	No data to suggest health of baby will be affected.	No data to suggest health of baby will be affected.	No data to suggest health of baby will be affected.
Fertility treatment side effects	No fertility treatment side effects.	Headaches, mood changes, hot flushes, and irritation of the skin; levels of the hormone oestrogen go up (not safe for women who have an oestrogen sensitive breast cancer); chance of infection or bleeding; damage to other pelvic structures (not safe for women with pelvic cancer).	Headaches, mood changes, hot flushes, and irritation of the skin; levels of the hormone oestrogen go up (not safe for women who have an oestrogen sensitive breast cancer); chance of infection or bleeding; damage to other pelvic structures (not safe for women with pelvic cancer).	Involves surgery, so damage to bladder and bowel; chance of infection or bleeding. A chance of putting cancer cells back in the body with the frozen ovarian tissue (not safe for women with a blood cancer such as leukaemia).	Hot flushes; mood changes; difficulty sleeping; vaginal dryness.
Delay to start cancer treatment	No delay.	Two weeks.	Two weeks.	Likely to be none, or only a few days.	Likely to be none, or only a few days.
Effect on the cancer coming back	No effect.	No data to suggest this will affect the chances of the cancer coming back.	No data to suggest this will affect the chances of the cancer coming back.	No data to suggest this will affect the chances of the cancer coming back.	No effect.



For more information visit:
www.leedsbeckett.ac.uk/cancerfertilityandme

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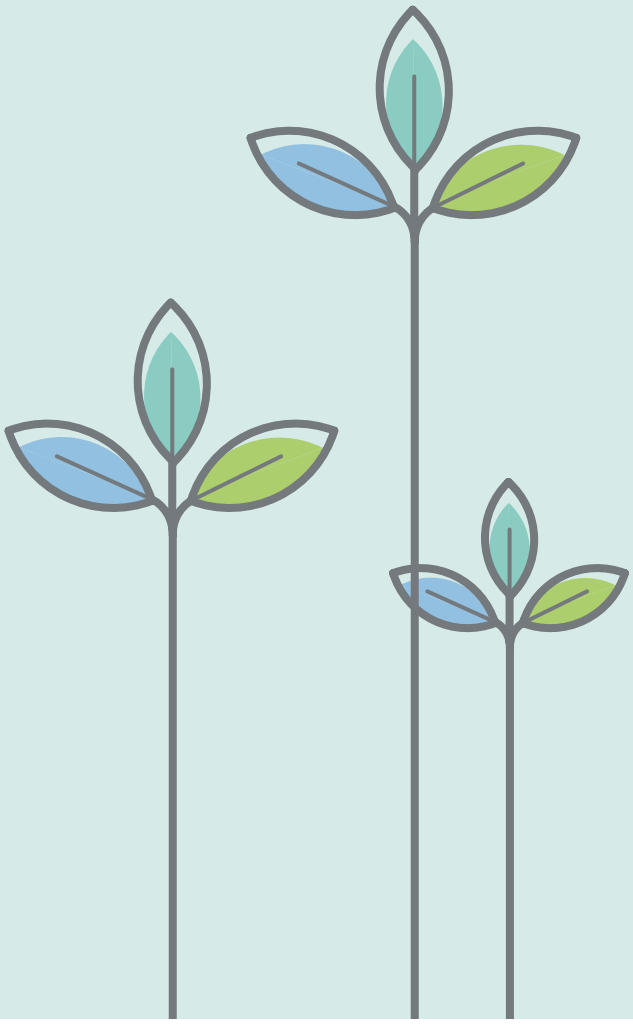

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