Fertility-related choices

A decision aid for younger women with early breast cancer

Breast Cancer Network Australia

About us

Breast Cancer Network Australia (BCNA) is the peak national organisation for Australians affected by breast cancer. We provide a range of free resources for women with breast cancer, including the *My Journey Kit* for women newly diagnosed with early breast cancer and *Hope & Hurdles* for women with secondary breast cancer. BCNA's free quarterly magazine *The Beacon* includes stories from women with breast cancer, as well as information on a wide range of breast cancer issues.

BCNA's partners and sponsors raise much needed funds to ensure we can continue to support people affected by breast cancer.

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About this booklet

This is a booklet for young women who have recently been diagnosed with early breast cancer. As cancer treatment may decrease fertility and reduce the chance of having children in the future, we hope that the information provided here will help you decide which, if any, of the available fertility options are of interest to you.

This booklet may be helpful if you:

- have recently been diagnosed with early breast cancer, and
- are still of reproductive age (having regular periods and no menopausal symptoms), and
- are thinking of starting a family or having more children in the future.

This booklet contains information about cancer treatment, how it can affect your fertility, and fertility options to consider. There are also some worksheets to help you think about these issues. With these worksheets are examples from other women who have faced these decisions.

Please note that this booklet does not replace talking to your health professionals. Some of the fertility options described are not suitable for all women. Also, some options may not be available at all centres.

Your religious and moral beliefs may affect the decision you are making. Some of the issues discussed may or may not fit in with these beliefs.

We encourage you to share this booklet with your partner and/or support person who may also wish to attend doctors' appointments with you. Page 62 has a list of support services available for both of you.

This booklet contains some technical language. If you are not sure what a word means, have a look at page 59 for a definition.

Overview

If fertility is important to you, talk to your oncologist and a fertility specialist before your cancer treatment starts. Your oncologist can give you an idea of how your cancer treatment may affect your fertility. The fertility specialist can explain which treatments are available and may be able to arrange treatment before your cancer therapy starts. For many women, the fertility options after breast cancer treatment are very limited.

This decision can be difficult. Many people feel better about their choices after reviewing all the options and making a careful and considered decision. For some, a written record of what matters most to them helps when making the decision. It is also very helpful to talk to your health care team about your situation even if you choose not to have fertility treatment.

This booklet describes the different fertility options available. This is to help you consider the pros and cons and work out which fertility treatment, if any, is best suited to your situation.

Summary of fertility options

	PREGNANCY RATE	DELAY	AVAILABILITY (births worldwide)	COST	REQUIRES SPERM	IMPACT ON BREAST CANCER
Wait & see	Depends on age & treatment	No delay	Not applicable	No cost	No	No impact
IVF	10-40% per egg collected 20-60% per embryo transferred****	2-4 wks per cycle	Widely available (over 350,000)	Has some costs***	Yes	Very little is known*
Egg freezing	10-40% per egg collected 20-60% per embryo transferred****	2-4 wks per cycle	At some clinics (over 1000)	Has some costs***	No	Very little is known*
Ovarian tissue freezing	Several live births reported worldwide	Short delay	Experimental (very few)	May have some costs***	No	Very little is known*
Ovarian suppression	Most women resume their periods but there is little data about pregnancies	No delay	Available by prescription	May have some costs***	No	Very little is known* – small benefit for oestrogen negative breast cancer
Adoption	N/A	N/A	Widely available - but often a long & difficult process	Costly	No	No impact
Egg and embryo donation	Egg: 10-40% per egg collected Embryo: 20-60% per embryo transferred****	No delay	At some clinics	Costly***	Only for egg donation	Very little is known*

* Key negative impact on breast cancer: theoretically, high dose hormones may impact on breast cancer and may cause cancer treatment delays

** Recently greater success has been achieved with experimental methods in some centres

*** Clinics can bulk bill some procedures, talk to your fertility clinic about options

**** Success rates will vary depending on female age at egg collection

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My notes

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SECTION 1

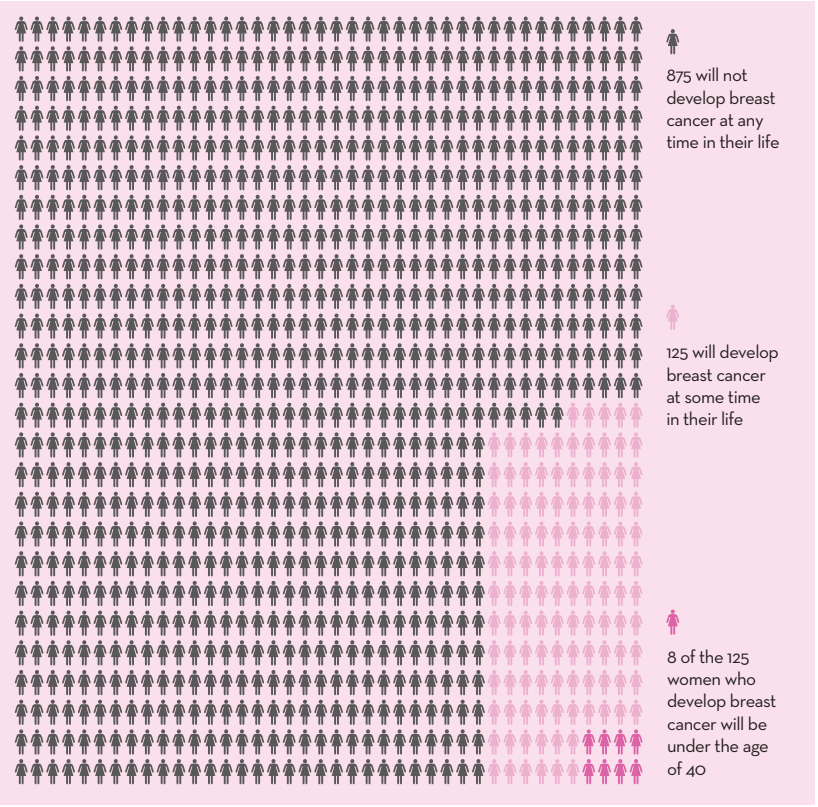
SOME BACKGROUND INFORMATION

Facts about breast cancer

About 125 out of every 1000 Australian women will develop breast cancer at some time in their lives. Of these 125 women who develop breast cancer, 8 will be under the age of 40. This is shown in the diagram below.

Being diagnosed with breast cancer can interfere with your plans for having a family.

On average, in any group of 1000 Australian women:



Breast cancer treatment

Being diagnosed with breast cancer is a major life event. This requires many decisions about treatment including surgery, radiotherapy, chemotherapy and hormone (endocrine) therapy. It is likely that chemotherapy for breast cancer will reduce your fertility. Some of the options to increase the chance of becoming pregnant require action before chemotherapy starts.

There are lots of different ways to treat breast cancer. The choice of treatment depends on the type and stage of the cancer, whether or not it is hormone sensitive, and your age.

Generally, treatment for early breast cancer involves one or more of the following:

- Removal of the lump (lumpectomy) or whole breast (mastectomy) through surgery.
- **Radiation therapy after surgery.** This is where high energy x-rays (in controlled doses) are used to destroy any cancer cells left in the breast.
- **Chemotherapy.** This is used to destroy any cancerous cells that might be elsewhere in the body.
- **Herceptin.** About 15% of breast cancers have increased copies of a gene called HER2. This gene makes a protein that speeds up the growth of cancer cells. Cancers with this gene are potentially more aggressive cancers. Herceptin is an antibody therapy to help fight these types of cancer. Herceptin lowers the chance of the cancer coming back and is administered usually at 3 week intervals for 1 year.
- **Hormone therapy**. An anti-oestrogen is often given to women with hormone sensitive cancers and significantly reduces the chance of the cancer returning. Hormone therapy is given for a long time (at least 5 years and sometimes 10 years). This is different to Hormone Replacement Therapy (HRT), which is used to treat symptoms of menopause.

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- **Ovarian suppression.** Some pre-menopausal women will be given drugs to halt the function of their ovaries at the same time as hormone therapy. Together, these drugs will stop the body producing oestrogen. This combination has been shown to reduce the chance of the cancer returning in certain women.

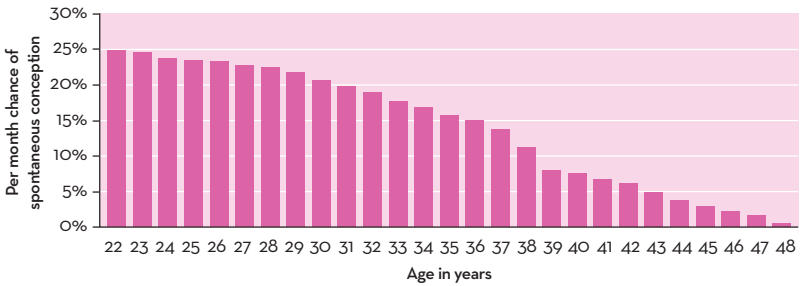
It is important to remember that breast cancer treatment may be different for each person. The effects of treatment are also different for each person.

Female fertility

Women are born with about 2 million undeveloped eggs in their ovaries. When a woman reaches puberty, she has about 200,000 left. Each month, about 5-20 eggs begin to mature. This means that as a woman gets older, she has fewer and fewer eggs. Usually, only one egg is released each month (ovulation) and travels to the womb (also called the uterus). The other eggs that began to mature during this cycle will break down and be absorbed by the body. Pregnancy occurs if the egg is fertilised by a sperm, and then implants in the womb.

As the number of eggs in the ovaries decreases, this causes a reduction in fertility. With increasing age egg quality also reduces. This fall in the number and quality of eggs as women grow older leads to a reduction in female fertility. As the graph on the next page shows, a 22-year-old woman has about a 1 in 4 chance of becoming pregnant every month that she attempts to conceive; whereas a 43-year-old woman has about a 1 in 20 chance of becoming pregnant per month. The exact age at which a woman can no longer become pregnant varies. Due to poorer egg quality, older women are more likely to miscarry than younger women and also to have fetal abnormalities such as Down syndrome.

Aside from age, there are other things which contribute to fertility. These include smoking, being over- or under-weight or having medical conditions like fibroids, endometriosis, or pelvic infection. One in six couples have trouble falling pregnant. In about one third these, sperm problems (male infertility) play a part.



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The effects of cancer treatment on fertility

The main goal of breast cancer treatment is to prevent the cancer from coming back and to improve survival. Unfortunately cancer treatment may also affect fertility by causing:

- Temporary menopause (amenorrhoea) – This is when periods stop for some time. Periods may come back, which may mean fertility has returned. However, this does not necessarily mean that it will be easy to fall pregnant.
- Permanent menopause – This is when periods stop permanently and natural pregnancy is very unlikely.

The chance of becoming menopausal depends on your age and the treatment you are given.

If having children in the future is important to you, it may be useful to consider your fertility options while considering your cancer treatment options. Fertility treatments aim to improve your chances of having a child in the future (see page 23 for fertility information).

You can usually delay starting your chemotherapy for a few weeks to think about fertility. Generally, putting off treatment for a short while won't change how effective the cancer treatment is. This gives you some time to talk about any concerns and get information that is relevant to you. You should discuss this with your oncologist and a fertility specialist.

Surgery & radiotherapy

The first step in treating cancer is usually to remove the cancer surgically. This can be either a lumpectomy or mastectomy. This is often followed by radiation of the breast or breast area. Surgery and radiation of the breast area will not reduce your fertility.

Chemotherapy

You, like many women, may be advised to have chemotherapy after surgery. Chemotherapy uses drugs to destroy cancer cells that may have spread through the body.

Chemotherapy may also affect your fertility by damaging the ovaries and eggs. Women are born with a fixed number of eggs and are unable to make any more. So if chemotherapy destroys or damages these eggs, you will not be able to replace them. The effect of chemotherapy on your fertility depends on your age and the drugs used. Younger women are more likely to have eggs left in their ovaries after cancer treatment.

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This may mean that you can become pregnant easily. However, even if regular periods return, some women may still have trouble becoming pregnant. Women who are older already have fewer eggs, so by the end of treatment, they may have very few or no eggs left.

Chemotherapy can lead to:

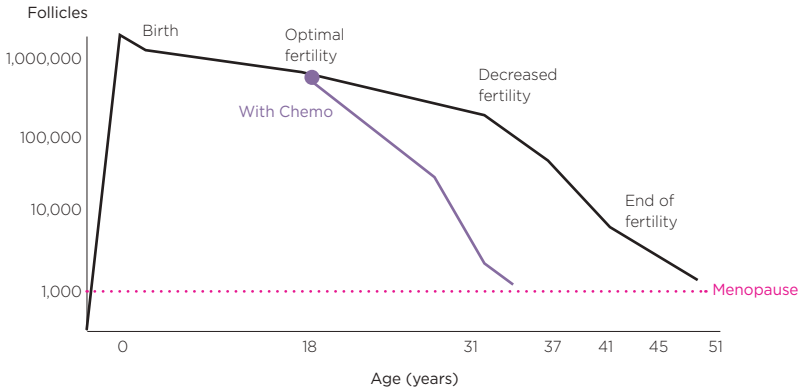
- Premature permanent menopause - when periods don't return after chemotherapy
- Temporary menopause - periods may stop for a year or more after chemotherapy
- Early onset (permanent) menopause - even if periods return after treatment, menopause happens 5-7 years earlier than if there had been no chemotherapy.

The graph below shows the natural decline of ovarian reserve (black line) and the impact of chemotherapy on fertility (purple line).

Menopause is reached when the number of follicles (potential eggs) drops below a certain point. Chemotherapy reduces the number of follicles a woman has, which means that menopause is more likely to occur at an earlier age than it would without chemotherapy.

Natural decline of ovarian reserve

Image reproduced with permission from www.myoncofertility.org



For example, the graph shows that for women who are diagnosed with breast cancer when they are 35, about 30 out of 100 women who have chemotherapy will become menopausal. But for women who are 25, only about 5 out of 100 women will become menopausal. However, even the 25 year old woman may have earlier onset of menopause.

There are lots of different types of drugs used in chemotherapy. The type of drug that is used, and how long cancer treatment lasts, can change how much the treatment impacts on fertility. The type of chemotherapy you are offered will be the one that has the best chance of stopping your type of cancer from coming back. If you have any concerns or would like more information about whether your periods will stop when you have chemotherapy, you may wish to talk to your oncologist.

Women are often advised to delay pregnancy for at least two years after they are diagnosed with breast cancer. This delay might also impact your fertility, as the chances of becoming pregnant decline with increasing age. However, you may choose to try and become pregnant within that time if there is no good reason for you to delay. There doesn't appear to be an increased risk of miscarriage or fetal malformations due to previous use of chemotherapy. Please talk to your oncologist about this. It might be helpful to ask what chance there is of your cancer returning. This might help you decide what is best for you and for your family.

Trastuzumab (Herceptin)

Herceptin is usually administered for up to 1 year, and it is not thought to reduce fertility. If your tumour has extra copies of the HER2 gene, Herceptin helps to lower the chance of your cancer coming back. The effects of Herceptin on a pregnancy are also unknown; however, pregnancy should be avoided while taking Herceptin.

Hormone (endocrine) therapy (e.g. tamoxifen)

Most breast cancers are dependent on the ovarian hormones oestrogen and progesterone which can stimulate growth of cancer cells. These are called hormone receptor positive breast cancers. Hormone therapy is advised for most women who have this type of breast cancer and aims to block the effects of oestrogen in the body. Commonly used drugs that aim to block oestrogen include tamoxifen, aromatase inhibitors such as exemestane, and GnRH agonists such as zoladex.

Tamoxifen is an "anti-oestrogen" and can halve the risk of the cancer coming back if taken for 5 - 10 years. Women taking tamoxifen should use contraception, but hormonal contraception should not be used. Zoladex is an injectable hormonal treatment that suppresses the ovaries and brings on temporary menopause. This may be given at the same time as tamoxifen, and has been shown in certain women to further reduce the risk of the cancer returning. It is contraceptive and menstrual periods will stop temporarily while on zoladex.

Recent research has also shown the combination of an Aromatase Inhibitor with a GnRH agonist will further reduce the risk of the cancer returning in certain pre-menopausal women and this should be discussed with your oncologist.

Hormone therapies for cancer treatment do not appear to cause infertility. However, because hormone therapy may be continued for 5 - 10 years or more, fertility will naturally fall during this time. In general, the older a woman is when she starts endocrine therapy, the lower her fertility will be by the time she finishes her treatment because of the delay.

It may also be possible to have 'time out' from hormone treatment to try to have a baby. Although we do not currently have any evidence to show this is a safe thing to do, it is being looked at in an international study. If you wish to try and get pregnant during this time you should discuss the implications of stopping hormone therapy with your oncologist. You may also wish to talk to your doctor about the new research in this area and consider participating in a clinical trial.

The risks of infertility vary depending on which drugs are used, and how long they are taken. You will need to ask your doctor what the risks of infertility are with each treatment option you are offered.

After cancer treatment

After you have finished your treatment, there is no 100% reliable way to find out whether it is now possible for you to become pregnant. In some cases, blood tests may provide important information. It may be helpful to see a fertility specialist to talk about fertility tests. If your periods stop for more than a year after you finish cancer treatment this probably means you are menopausal. It is also important to note that even if your periods return after chemotherapy it is still likely that menopause will occur at an earlier age than may have happened if you had not had chemotherapy. After menopause the chance of falling pregnant is extremely unlikely, even after fertility treatment (unless you have access to, and decide to use, donated eggs – see page 37).

Pregnancy after breast cancer

Often women are advised to wait a couple of years before becoming pregnant after their breast cancer diagnosis. The waiting time will vary depending on the type of breast cancer.

Some women decide not to wait and to try for a baby within this time. If you do become pregnant after breast cancer, studies so far are reassuring that pregnancy does not increase the risk of the cancer returning or decrease your chances of survival. In fact, some women who choose to become pregnant during this time seem to fare better. However, this may be because they have tumours with a better prognosis.

It should be noted, however, that generally very few women become pregnant after breast cancer (about 5% of women under 45 years old). The main reasons for this are:

- a loss of fertility, or
- choosing to avoid pregnancy.

If you are thinking about having a baby after breast cancer, you are advised to talk to your doctor about the chance of the cancer returning, and how this might affect your children and family.

As mentioned earlier, there is a large international study that is looking at the impact of taking time out from cancer treatment to try for a baby. You may wish to talk to your doctor about this study.

You may also be worried that any child you have may have breast cancer as an adult. In most cases (about 95%), breast cancer does not run in families. However, if breast cancer does run in your family because of a faulty gene, then your children may be at increased risk of developing breast and other cancers. If you are worried about breast cancer running in your family, ask your doctor for a referral for genetic counselling at a family cancer clinic.

Contraception

Women are advised to avoid falling pregnant while having treatment for cancer. Chemotherapy and hormone therapies may cause your periods to become irregular or to stop. However, this does not necessarily mean that you cannot fall pregnant. It is recommended that contraception should be used during this time. In most cases, women who have had breast cancer are advised not to use hormonal contraception (such as 'the pill', injections or implants). Other forms of contraception which are safe include barrier contraceptives (like condoms and diaphragms), and inter-uterine devices (IUDs). Discuss your contraceptive options after breast cancer with your oncologist, family doctor or a family planning clinic.

Breastfeeding

The type of cancer treatment you are receiving will probably affect whether or not you can breastfeed during or after treatment. During chemotherapy, breastfeeding is not recommended as the drugs can be passed to the baby. During radiotherapy, breastfeeding is safe if you feed the baby from the untreated breast only. Women taking tamoxifen are advised not to breastfeed, you may wish to discuss this with your oncologist.

My notes

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SECTION 2

FERTILITY-RELATED INFORMATION

Your oncologist can give you an idea of how different cancer treatments may affect your fertility. This will help you decide which treatments are best for you. The fertility specialist can discuss with you the options available to you. Your cancer and fertility health professionals should work closely together.

Assisted reproductive technologies

Assisted Reproductive Technologies (ART) are treatments that help couples who are unable to have a baby naturally to have a child. One of these techniques is called In Vitro Fertilisation, or IVF. IVF brings eggs and sperm together in a laboratory to help a couple become pregnant. IVF can also be used prior to chemotherapy to allow embryos to be created and stored for future pregnancy. Another option is to freeze eggs to be used at a later time. These technologies are available through fertility clinics. Clinics offer counselling and support before and during the process of ART. These technologies are described in detail on pages 28 to 38.

Different states have different laws

It is important to be aware that the laws about fertility treatment are different in each state in Australia. Consent from both partners may be required for treatments like IVF. Check with your doctor to see if the options discussed in this booklet are available to you.

Differences between fertility clinics

The fertility treatments described in this booklet might not be available at all fertility clinics. Ask your clinic to see if it offers the methods you are interested in.

Availability of techniques

While reading this booklet, it is important to remember that ARTs include fairly new techniques. Some of the options described in this booklet are still being developed and are not yet proven to be successful amongst a large number of women. There are often new treatments being looked at through clinical trials. If you would like to know about what clinical trials are available and suitable for you, ask your oncologist.

Finances

Fertility treatment can be expensive. Medicare and private health insurance sometimes cover some of the costs. However, there is sometimes an out-of-pocket cost. Ask clinics for pricing (including appointments, procedures, hospital stays, ongoing storage costs etc) and check the reimbursements available for each item.

Storage of biological material

Some ART treatments produce eggs or embryos which can be frozen and stored for attempts at future pregnancy. Ovarian tissue can also be removed and frozen. You may need to consider the cost of storage and how long you may wish to store them. You also need to consider what will happen to the stored materials if something happens to either you or your partner or if the relationship breaks up. If you are able to have children naturally, you might no longer require the stored material. In this case a decision must be made about the stored material, and legally this may require permission from both partners (in the case of embryos). Your clinic can tell you what the options are.

Appointments with a fertility clinic

When making an appointment with a fertility clinic, you may want to ask your doctor or Breast Care Nurse to contact the fertility clinic on your behalf. They can ask the clinic to fit you in as soon as possible to minimise any potential delays. You may also want to ask about whether the fertility clinic has particular experience in helping cancer patients.

If possible, you should try to schedule your fertility appointment before your next period.

This is because many fertility treatments begin on the first day of your period. Also, if you are on hormonal contraception, continue taking this until you have seen a fertility doctor.

What we know and don't know...

The area of breast cancer and fertility is rapidly changing, and with time we will gain a better understanding. However, at the moment there are still many "unknowns" regarding fertility treatments in breast cancer patients

We don't know the number of women who wish to have a child after breast cancer, or what their outcome is. There is no clear answer to the effects of fertility treatment on the risk of cancer recurrence. It has not been established whether complementary and alternative therapies (in other words, medicines that are not thought of as standard care) protect fertility, nor has their safety been established in breast cancer patients. There is no evidence to indicate that being hormone receptor positive or negative will have any implications for future pregnancies. We do not know whether fertility treatments affect the chances of breast cancer recurrence or new cancers.

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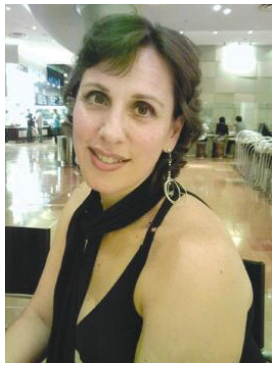
Physical and emotional issues



For most women fertility treatment has a physical and emotional impact. Many of the treatment options may require extra blood tests or medical procedures (in addition to the cancer treatment you are receiving). The fertility treatment process can also be very emotional, partly because of the hormonal changes and also the uncertainty regarding the success of treatment. Also, sometimes IVF cycles are started but then need to be cancelled which can be frustrating for everyone.

Fertility options before treatment

It is usually possible for you to act before chemotherapy starts, if appropriate. This can help improve your chances of having a child in the future.

The possible fertility options for women facing cancer treatment are described below.

Wait and see

What is this?

You may choose to go ahead with your cancer treatment and 'wait and see' if your fertility returns when your treatment is over.

What does this mean for your future fertility?

The outcome of the 'wait and see' option on future fertility depends on your fertility level and your partner's fertility level before you start treatment and how much your ovaries have been affected by chemotherapy. Different chemotherapies have different chances of damaging the ovaries and causing menopause. Choosing this option means accepting those chances. If cancer treatment does cause menopause, then natural pregnancy is very

unlikely to occur. In this case, you (and your partner) may opt for living without children. However, there are still some options for parenting. These include:

a) adoption or fostering (explained in more detail on page 36) or

b) donation of an embryo from another couple, or an egg from another woman (explained in more detail on page 37).

In Vitro Fertilisation (IVF)

What is this?

IVF involves removing eggs from a woman's ovary, and then fertilising them with sperm. This is done in a laboratory. The fertilised eggs (now called 'embryos') are then either transferred back into the woman's womb, or are frozen and stored for future use.

The process of IVF involves five steps:

1 Ovarian stimulation

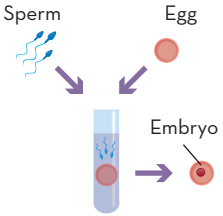
During the menstrual cycle 5-20 eggs develop but only one matures. For fertilisation to occur, an egg must be mature. IVF aims to stimulate more eggs to grow and mature and to collect as many mature eggs as possible. To do this, women are given hormones to stimulate the ovaries. This then allows all the developing eggs to mature.

2 Egg collection

Egg collection is a minor surgical procedure performed under sedation or a light general anaesthetic. It involves the insertion of an ultrasound probe into the vagina to identify the fluid filled cysts (follicles) in the ovary which contain mature eggs. These eggs are then collected using a special suction device.

3 Insemination and fertilisation

The eggs are then examined in a laboratory under a microscope. The best quality eggs are selected and put into a special liquid that prepares them for fertilisation. The sperm is also tested for quality. The sperm is then put together with the eggs to allow fertilisation. In some situations where there are problems with the sperm, one sperm can be injected directly into the egg. This is called Intracytoplasmic Sperm Injection or ICSI. Not all eggs need to be fertilised, you might choose to make some embryos to freeze and keep some eggs (see section on egg freezing, page 32).



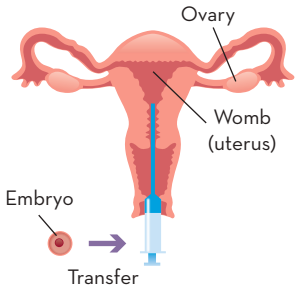
4 Embryo culture and freezing

The embryo develops for 2–5 days in a dish with a special solution designed to help them grow. Embryos can be transferred into the uterus to try and achieve pregnancy. This can be done either straight away or the embryos can be frozen and then thawed in the future before transfer to the uterus or womb. This is the usual approach for women about to start chemotherapy for breast cancer

5 Embryo transfer – after cancer treatment

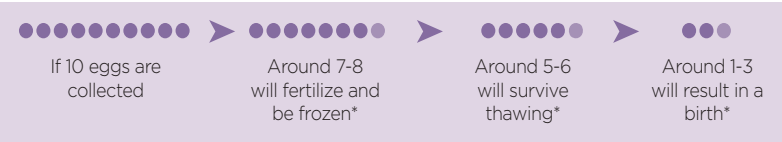
When a couple decide to have the embryos put into the uterus, it is likely that the woman will need to take more hormones.

Although it is easy to freeze embryos, not all of them survive the freezing process.



The success rate of IVF is linked to the age of the woman being treated. In women aged 40 years or younger, around 5-15 eggs will be collected. More than half (70-80%) of the eggs collected for IVF will fertilise and be frozen. Around 65-70% of these will survive thawing and be transferred to the womb. Of these, 20-60% will result in a baby. These proportions will vary depending on the number of eggs collected and the quality of the eggs.

So, for example:



*These proportions will vary depending on the number of eggs collected and the quality of the eggs

IVF may involve the use of high dose hormones. These hormones might also stimulate the breast cancer. There is no research showing that IVF increases the chances of breast cancers growing or coming back. However, to avoid exposure to high levels of hormones, new ovarian stimulation regimens have been developed to try and prevent high oestrogen levels during IVF. Ask your fertility specialist about this.

Will this delay my treatment?

IVF may delay cancer treatment (i.e. chemotherapy) by at least 2 weeks. If you are considering IVF, it is important to talk about the possible consequences of delaying treatment with your breast surgeon and/or oncologist. In most cases, delaying cancer treatment by several weeks is unlikely to affect your prognosis. In addition, IVF cycles may be cancelled in up to 10% of cases, which may mean deciding whether to further delay chemotherapy to go ahead with IVF.

Where can I access this option?

IVF is available at clinics in Australia. There is a list of accredited fertility clinics on the Fertility Society Australia website (details on page 62).

What are the costs involved?

Costs can vary. Not only are there the costs of consultations and treatments to think about, but also the costs of storing embryos (centres may have a yearly fee). Contact the clinic nearest to you for cost estimates, and check the reimbursements available from Medicare and your health fund.

Are there any legal issues?

A potential legal issue is access to your embryos in the future. Unless donor sperm is used, the embryos legally belong to both you and your partner. As such, permission from both you and your partner is required for the embryos to be used. You will need to plan for future possibilities in your relationship (like separation, illness, natural conception) and what will happen to unused embryos. You may want to consider using some of the eggs collected to create embryos and leaving some as eggs to freeze.

Are there any side-effects?

The process of IVF can be physically and emotionally draining which may be something you want to consider when deciding whether or not to proceed with IVF.

Serious side-effects from treatment are uncommon. There are, however, some problems that (rarely) may lead to complications:

- Medication-related side effects – Overall, fertility drugs are generally safe and any side effects are usually quite minor. These can include: mood swings, headaches, nausea, hot flushes, abdominal discomfort and bloating, among others. The type of symptoms will depend on the drugs used. In rare cases some women may have a serious reaction to the drugs. Fertility clinics will closely monitor patients for side effects and treat any problems. Your doctor can give you more information about possible medication-related side effects.
- Complications of the egg collection - there is a small risk of bleeding or infection.

Long-term effects of IVF:

- Effects on your baby – children conceived by IVF are slightly more at risk of premature birth and birth abnormalities.
- Effects on your own health – the long-term effects of IVF on a woman's health are still unclear. However, from what we know so far, there is no increase in risk of your cancer returning.

For more information you may want to have a look at the document "Possible health effects of IVF" available from the Victorian Assisted Reproductive Treatment Authority (www.varta.org.au).

What is the effect on breast cancer?

Very little is known about the short- and long-term effects of IVF treatment on the future course of breast cancer.

Breast cancer may potentially be affected by:

1 High dose hormones used in IVF.

   The evidence is limited, but so far it does not appear that IVF increases the risk of breast cancer returning.

   There are some new treatments available that may reduce the need for high dose hormones in IVF. You may wish to discuss this further with your fertility specialist.

2 A delay in breast cancer treatment for at least 2 weeks (see page 30).

Discuss these issues with your oncologist and fertility specialist.

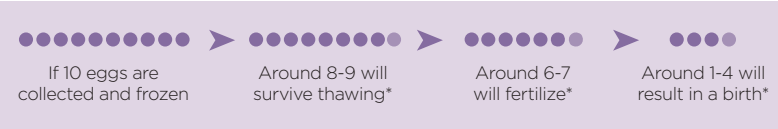
Egg freezing (cryopreservation)

What is this?

This involves the freezing of unfertilised mature eggs. This may be an option if you are not in a position to create embryos with a long-term male partner. Freezing of eggs allows the option of fertilisation later on with a future partner's sperm or sperm donor. The process is similar to that of IVF. Your ovaries are stimulated with hormones to form mature eggs that are collected and frozen. These eggs are then later thawed and fertilised before being implanted. The only difference is that the eggs are not fertilised prior to freezing.

Pregnancy rates using frozen eggs are improving with current rates approaching those of traditional IVF. In a regular stimulated cycle, between 5 and 15 eggs are usually collected. Around 80-90% of eggs will survive thawing. Around 70-80% of these will fertilise and be transferred to the womb. Of these, 20-60% will result in a baby. These proportions will vary depending on the number of eggs collected and their quality.

So, for example:



*These proportions will vary depending on the number of eggs collected and the quality of the eggs

Like IVF, there may be a delay in cancer treatment of at least 2 weeks to allow for the stimulation of the ovaries and collection of eggs (see Steps 1 and 2 on page 28). Egg freezing also requires the storage of the eggs. Thus, you would need to think about the length of time the eggs will be stored and the costs involved.

Breast cancer is potentially affected by ovarian stimulation required for egg freezing in the same manner as IVF (see page 28). You might wish to talk about the availability of egg freezing with your fertility specialist. Also, talk to your oncologist about any impact this treatment might have on your cancer treatment.

The side-effects and impact on breast cancer are similar to those of IVF (see page 31).

Ovarian tissue freezing (cryopreservation)

Techniques for achieving pregnancy from ovarian-tissue freezing are still being developed.

This involves an operation to remove some ovarian tissue. In younger women, this tissue is likely to contain a large number of immature eggs. After it has been removed, the tissue is frozen until needed. When it is needed, the tissue is then thawed and transplanted back into the woman. It is hoped that new blood vessels will grow and the transplanted tissue will produce hormones and ripen the eggs. If this happens, the IVF process may be used to mature, collect and fertilise the eggs. In the future, it may also be possible to mature this ovarian tissue in the laboratory to produce mature eggs for IVF. This is still a very new procedure and is considered experimental.

Storage of ovarian tissue has similar implications to egg freezing (see page 32). There is also concern that implantation of the stored tissue may increase the risk of transmitting cancer cells back into the body. There is also a theory that removing some of the ovary may reduce your fertility should it return naturally after cancer treatment.

Fertility options during treatment

Ovarian suppression

Ovarian suppression during chemotherapy for a hormone receptor negative breast cancer may help protect the ovaries and thus improve the chances of remaining fertile. This fertility treatment involves a particular type of drug (GnRHa – Gonadotropin Releasing Hormone analog) such as zoladex or goserelin. This drug blocks the hormones that signal the ovaries to develop and release eggs.

New research has shown that in pre-menopausal women with oestrogen-receptor negative breast cancer, use of a GnRHa (e.g. zoladex) in combination with chemotherapy protects fertility. Using a GnRHa while on chemotherapy may also reduce the chance of the cancer returning and improve chance of survival in this group of women.

Ovarian suppression does not delay cancer treatment. However, it may be costly and the benefits and risks are not yet fully understood.

Dealing with infertility after treatment

Some women may choose to investigate fertility treatment, such as IVF, after their cancer treatment. However, because of the effects of cancer treatment on fertility, the chance of success is lower than if you freeze eggs or embryos before cancer treatment.

If you are unable to have a baby after breast cancer treatment, you and your partner may decide to live without children. However, if you still wish to experience parenting, there are other options available.

Adoption

Adoption is a legal process that creates a parent-child relationship between people who are not related by blood. The adopted child has all the rights of a child who was born naturally to the adoptive parents. Adoption can be a difficult, lengthy and costly process. The process can differ between states and territories.

People who have a history of cancer are not necessarily excluded from adoption. The criteria may vary between states and countries. However, all applicants must declare their health status, and agencies may talk about your health in detail with your doctors. This is to determine the risk of the cancer coming back, and how this might impact on your ability to look after a child.

The following website has a list of places you could contact to ask about adoption in Australia:
https://www.dcp.wa.gov.au/FosteringandAdoption/AdoptionAndHomeForLife/Pages/AllAboutAdoption.aspx

Egg and embryo donation

What is egg donation?

If you are unable to have a baby, even after fertility treatment, you may wish to think about using eggs donated by another woman. The egg donor undergoes the IVF process described earlier. The difference is that the donor egg is fertilised with your partner's sperm and implanted into your womb. Children born as a result of this method would not be genetically related to you, the birth mother. The egg donor may be known to you or anonymous. The egg donor should ideally be under the age of 35 and have completed her family. You will also be given hormones to prepare your womb before the embryo is put into your womb. It can be very difficult to find an egg donor.

What is embryo donation?

In this case, you would receive an embryo from another couple. Embryos are usually donated by a couple who have been through the IVF process and have excess embryos. Again, you would be given hormones to prepare your womb for the embryo. A child born from a donated embryo is not genetically related to you or your partner.

What are the implications of egg or embryo donation?

These options are available once cancer treatment is over and you want to start a family. They do not require a delay in cancer treatment. The cost of egg donation is usually higher than IVF as you may need to cover the cost of a stimulated cycle for the donor.

Hormone treatment to prepare the womb for the embryo is not as high dose as that used for IVF. However, it is still unknown whether it is safe to use these hormones after breast cancer. You are advised to talk about this with your oncologist.

There are important psychological, practical and legal issues involved with these kinds of treatments. A woman should only go ahead after careful thought and counselling.

Are there any legal issues?

By law, the woman who gives birth to the baby is considered the mother of the baby, not the egg donor. Different states and clinics may have different laws and guidelines about these procedures.

The side-effects and impact on breast cancer are similar to those of IVF (see page 31).

Surrogacy

Surrogacy is an option if you do not wish to or cannot carry a child in your womb. In this process, eggs are collected and fertilised (IVF procedure). This time the embryo is placed in the surrogate's womb, rather than your own womb. The child is genetically related to the couple and does not biologically belong to the surrogate. Surrogacy laws in Australia vary from state to state. Check with your local IVF clinic or legal advisor for the current surrogacy legislation in your state or territory.

You can find a summary table of most of the fertility options discussed in this section on page 6 of this booklet.

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MY PERSONAL WORKSHEET

There may be lots of reasons why different fertility options may seem right for you. Part of making a good decision is to consider all the pros and cons of a fertility option at the same time. The worksheets on the following pages are designed to help you to put all the facts together and consider what is important to you. There are two example worksheets filled out by women in similar situations on pages 52-57.

Step 1: Clarify the decision

Try to put the decisions you face into words.

For example: *Do I want to conserve my fertility?*
If so, which fertility method is the best one for my situation?

What are your reasons for making this decision?

Step 2: Compare the options

a. What am I comparing?

In the following pages are some tables that relate to each fertility option. At the top of each table is a question you are asked to consider.

b. What I know

The following pages list most of the pros and cons associated with each fertility option. If there are any other pros and cons you can think of, just add them to the table.

c. What is important to me?

Show how important each pro and con is to you by writing zero to five stars (*****) in the column provided. If a pro or con is not at all important to you, then give it zero stars.

d. How sure I feel

Using the scale at the bottom of each table, tick the box that reflects how you feel about this fertility option. The option with the pros that are most important to you is probably the right option for you. Avoid the option with the cons that are most important to you.

For a tough decision like this, people rarely feel completely sure. With careful decision-making, many people feel better about and more comfortable with their choices. Many people are also glad they made a written record of what mattered most to them when making the decision.

The pros and cons of 'wait and see':

Use the side columns to mark personal importance to you using one to five stars (*****)

(*****)	PROs	CONs	(*****)
	I won't need to delay my cancer treatment	There is a high risk of infertility following treatment	
	I will not be exposed to hormones before my cancer treatment	If I become infertile I won't be able to have children that are genetically related to me	
	This won't cost me anything	There's a high chance of early menopause following treatment	
	I can think about my fertility later	I may regret my decision not to preserve my fertility	
	If my fertility returns, I won't have had unnecessary treatment	If I become infertile I may never have children	
	Even if I become infertile I still have other options like adoption and egg or embryo donation	Not being able to have children may affect my relationship with my partner	

At this point in time, are you leaning towards waiting or not?
(Mark the position on the line that is closest to how you feel)

I am leaning towards waiting | I am not sure yet | I am NOT leaning towards waiting

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The pros and cons of IVF:

Use the side columns to mark personal importance to you using one to five stars (*****)

(*****)	PROs	CONs	(*****)
	This option is usually easily available	The delay in cancer treatment might affect my cancer	
	Generally, this will give me a good chance of having a baby later (depending on age and other factors)	I need a committed partner to provide sperm	
	This will give me stored embryos in case of infertility	I would need to consider donor sperm (or there is none available)	
	If I become infertile, I can still have children genetically related to me	The exposure to hormones might affect my cancer	
	I want to look back after cancer treatment and know that I gave it a go	This can be costly	
	This will increase the chances that I can have a child with my current partner	I'm not comfortable with having to discard stored embryos (if I don't need, or can't store, them)	
	This is a sort of 'insurance' against possible future infertility	Future access to embryos needs both my and my current partner's consent	

At this point in time, are you leaning towards IVF or not?
(Mark the position on the line that is closest to how you feel)

I am leaning towards IVF | I am not sure yet | I am NOT leaning towards IVF

The pros and cons of egg freezing:

Use the side columns to mark personal importance to you using one to five stars (*****)

(*****)	PROs	CONs	(*****)
	This needs only a slight delay in my cancer treatment	This may involve the use of high dose hormones which may affect my cancer	
	This may increase my chances of having children in the future	There is no guarantee that I will have a baby (success depends on the number and quality of eggs collected)	
	I can think about my fertility later	This can be costly	
	Children born from frozen eggs will be genetically related to me	I am not comfortable with having to discard frozen eggs	
	I can fertilise my eggs with a future partner's sperm	This is a minor surgical procedure requiring sedation	
	I will be able to look back after cancer treatment and know that I gave it a go		
	This is a sort of 'insurance' against possible future infertility		

At this point in time, are you leaning towards egg freezing or not? (Mark the position on the line that is closest to how you feel)

I am leaning towards egg freezing | I am not sure yet | I am NOT leaning towards egg freezing

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The pros and cons of ovarian tissue freezing:

Use the side columns to mark personal importance to you using one to five stars (*****)

(*****)	PROs	CONs	(*****)
	This may need only a minor delay in my cancer treatment	At the moment, this has an extremely low chance of pregnancy	
	I do not need a male partner or access to a sperm donor to do this	The minor delay in cancer treatment might affect my cancer	
	I can try to make embryos with a future partner's sperm	This is a surgical procedure	
	I will not be exposed to hormones before my cancer treatment	This is not widely available	
	I will be able to look back after cancer treatment and know that I gave it a go	This can be costly	
	This is a sort of 'insurance' against possible future infertility	The exposure to hormones (when proceeding with IVF later) might affect my cancer	

At this point in time, are you leaning towards ovarian tissue freezing or not? (Mark the position on the line that is closest to how you feel)

I am leaning towards ovarian tissue freezing | I am not sure yet | I am NOT leaning towards ovarian tissue freezing

The pros and cons of ovarian suppression:

Use the side columns to mark personal importance to you using one to five stars (*****)

(*****)	PROs	CONs	(*****)
	This won't delay my cancer treatment	This is an experimental procedure – effectiveness is not proven	
	This is less invasive than some of the other assisted reproductive techniques	As I have oestrogen-positive breast cancer, it is not known if this will protect my fertility	
	As I have oestrogen-negative breast cancer, this will protect my fertility	As I have oestrogen-positive breast cancer, the effect on chemotherapy is unknown	
	I will be able to look back after cancer treatment and know that I gave it a go	This is not part of standard care so there may be additional costs	
	If it works, I can have children genetically related to me		
	As I have oestrogen-negative breast cancer, this may reduce my risk of cancer returning and improve my chances of survival		

At this point in time, are you leaning towards ovarian suppression or not?
(Mark the position on the line that is closest to how you feel)

I am leaning towards ovarian suppression		I am not sure yet		I am NOT leaning towards ovarian suppression

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The pros and cons of adoption:

Use the side columns to mark personal importance to you using one to five stars (*****)

(*****)	PROs	CONs	(*****)
	This won't delay my cancer treatment	There are usually waiting periods	
	If I carry a gene fault that increases the chances of breast cancer, the child will not inherit it from me	The child will not be genetically related to either me or my partner and the genetic history of the child may be unknown	
	I would be able to give a child needing a family a good home	This can be costly	
	I will not be exposed to hormones before my cancer treatment	I may not be able to access this option	
		I may need to look overseas to adopt as it can be very difficult in Australia	
		I may not be eligible to adopt	

At this point in time, are you leaning towards adoption or not?
(Mark the position on the line that is closest to how you feel)

I am leaning towards adoption		I am not sure yet		I am NOT leaning towards adoption

The pros and cons of using a donated egg:

Use the side columns to mark personal importance to you using one to five stars (*****)

(*****)	PROs	CONs	(*****)
	This won't delay my cancer treatment	There may be an additional cost for a simulated donor cycle	
	If I carry a gene fault that increases the chances of breast cancer, the child will not inherit it from me	The child might not be genetically related to me (unless the egg comes from a relative)	
	I can decide later whether or not to have children	It can be difficult to find an egg donor	
	The child will be genetically related to my partner	Exposure to hormones (when I decide to try to become pregnant) might affect my cancer	
	I will not be exposed to hormones before my cancer treatment		

At this point in time, are you leaning towards using a donated egg or not? (Mark the position on the line that is closest to how you feel)

I am leaning towards using a donated egg		I am not sure yet		I am NOT leaning towards using a donated egg

The pros and cons of using a donated embryo:

Use the side columns to mark personal importance to you using one to five stars (*****)

(*****)	PROs	CONs	(*****)
	This won't delay my cancer treatment	There may be some costs	
	If I carry a gene fault that increases the chances of breast cancer, the child will not inherit it from me	The child will not be genetically related to me or my partner (unless the embryo comes from a relative)	
	I can decide later whether or not to have children	Donated embryos may not be available to me	
	I will not be exposed to hormones before my cancer treatment	Exposure to hormones (when I decide to try to become pregnant) might affect my cancer	

At this point in time, are you leaning towards using a donated embryo or not? (Mark the position on the line that is closest to how you feel)

I am leaning towards using a donated embryo		I am not sure yet		I am NOT leaning towards using a donated embryo

Step 3: Compare how I feel about different options

Copy your response for each option into this 'balance sheet' to help clarify your overall 'leaning' towards a choice of fertility option.

Personal Values Clarification Balance Sheet

Wait and see

Leaning towards | Not sure yet | NOT leaning towards

IVF

Leaning towards | Not sure yet | NOT leaning towards

Egg freezing

Leaning towards | Not sure yet | NOT leaning towards

Ovarian tissue freezing

Leaning towards | Not sure yet | NOT leaning towards

Ovarian suppression

Leaning towards | Not sure yet | NOT leaning towards

Adoption

Leaning towards | Not sure yet | NOT leaning towards

Egg donation

Leaning towards | Not sure yet | NOT leaning towards

Embryo donation

Leaning towards | Not sure yet | NOT leaning towards

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Step 4: Determine your decision

Which of the options is most suited to your situation?

Step 5: Plan the next steps

List what you need to do before you make this decision.

If conserving your fertility is important to you, speak to your oncologist and a fertility specialist. There is a list of places to get more information at the end of this booklet.

OTHER PEOPLE LIKE ME

Jenny's Story

Jenny is 29 and has been diagnosed with oestrogen receptor positive (cancer that responds to the hormone oestrogen) early breast cancer. She is very concerned about the effects of chemotherapy on her ability to have children in the future. She is not in a committed relationship, and does not want to use her current partner's sperm or donor sperm. She doesn't want to delay her cancer treatment, and is not really comfortable with exposing her body to the hormones of fertility treatments. She is also concerned about the costs of treatment. However, she would prefer that any future children be genetically related to her.

Step 1: Clarify the decision

I am deciding if I want to conserve my fertility and which fertility conservation method, should I choose to use one, is best suited to me.

Step 2 and 3: Weigh and compare different options

Personal Values Clarification Balance Sheet

	Leaning towards		Not sure yet		NOT leaning towards
Wait and see	✔				
IVF				✔	
Egg freezing				✔	
Ovarian tissue freezing					✔
Ovarian suppression		✔			
Adoption				✔	
Egg donation				✔	
Embryo donation				✔	

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Step 4: Determine your decision

looking at the balance sheet above, I am leaning towards the wait and see option and maybe ovarian suppression.

Step 5: Plan the next steps

I will speak to my doctors about the options mentioned and questions raised in this booklet and what treatments they advise.

Natalie's Story

Natalie is 36 and has been diagnosed with early breast cancer. She has two children from a previous relationship and is now in a committed relationship with another partner. Her current partner has no children of his own and adores her children. However, prior to her diagnosis they had discussed having a baby. She and her husband are keen to have a backup plan in case she becomes infertile. They are not very concerned about potential costs.

Step 1: Clarify the decision

I am deciding if I want to conserve my fertility and which fertility conservation method, should I choose to use one, is best suited to me.

Step 2 and 3: Weigh and compare how I feel.

Personal Values Clarification Balance Sheet

Wait and see

Leaning towards		Not sure yet		NOT leaning towards
				✔

IVF

Leaning towards		Not sure yet		NOT leaning towards
✔				

Egg freezing

Leaning towards		Not sure yet		NOT leaning towards
				✔

Ovarian tissue freezing

Leaning towards		Not sure yet		NOT leaning towards
			✔	

Ovarian suppression

Leaning towards		Not sure yet		NOT leaning towards
		✔		

Adoption

Leaning towards		Not sure yet		NOT leaning towards
		✔		

Egg donation

Leaning towards		Not sure yet		NOT leaning towards
			✔	

Embryo donation

Leaning towards		Not sure yet		NOT leaning towards
			✔	

Step 4: Determine your decision

Looking at my balance sheet, I am leaning towards IVF.

Step 5: Plan the next steps

I will ask my partner to read this booklet so that we can discuss my options. We will speak to my doctors about the options mentioned and questions raised in this booklet (e.g. will a delay in treatment impact my cancer) and what treatments they advise. We will also ask to be referred to a fertility specialist to further explore our options.

My notes

SOME WORDS USED IN THIS BOOKLET

Some of the words that are used in this booklet are defined below. You may want to read this page to help you understand the information provided in the booklet.

Amenorrhoea – stopping or absence of periods.

Assisted Reproductive Technologies (ART) – a group of procedures which help couples who are infertile to have a baby.

Cryopreservation – a method of preserving eggs, embryos or tissue by freezing at very low temperatures.

Clinical trial – a scientific test looking at how effective and safe a therapeutic agent (e.g. medication) is.

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

Hormone (endocrine) therapy – treatments that change a person's hormone levels.

Hormone receptors – on the cancer that may be 'positive' or 'negative' and describes whether the breast cancer will be stimulated to grow by oestrogen and/or progesterone.

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

Menopause – the time in a woman's life when the menstrual cycle (i.e. periods) ends.

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

Ovarian suppression – stopping of ovarian function.

Ovarian stimulation – to temporarily increase the activity of the ovaries.

Progesterone – a female sex hormone that prepares the womb for implantation of the embryo, maintains pregnancy and promotes production of breast milk. Progesterone is part of a group of hormones called progestogens.

Tamoxifen – an antagonist (a drug that opposes/counteracts the effects of oestrogen); it is used in the treatment of breast cancer in women whose tumours are oestrogen receptor positive.

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WHERE TO GO FROM HERE?

Sources of extra information

Listed below are some good sources of extra information and support about fertility-related choices for women with early breast cancer.

A list of Reproductive Technology Accreditation Committee (RTAC) – accredited Fertility Units can be found at the Fertility Society of Australia
Ph: 03 9645 6359
www.fertilitysociety.com.au

Clinical practice guidelines for the management and support of younger women with breast cancer:
Ph: 1800 624 973
www.canceraustralia.gov.au

Helpful organisations

Cancer Australia
Ph: 1800 624 973
www.canceraustralia.gov.au

Breast Cancer Network Australia
Ph: 1800 500 258
www.bcna.org.au

LIVESTRONG Fertility
www.livestrong.org/we-can-help/fertility-services

ACCESS – Australia's National Infertility Network
Ph: 1800 888 896
www.access.org.au

Breast Cancer Network Australia

Questions to ask your doctors

When making decisions about your fertility, you may wish to consider the following fertility-related questions. These questions may help you decide about the treatment of your breast cancer. You might want the answers to some of the questions straight away, while some may become important later on. Some questions might not matter to you at all. You can either ask these questions directly, or use them as a guide to put together your own questions.

1. Am I currently fertile?
2. What should I be doing about contraception?
3. What is the likely future course and outcome of my breast cancer?
4. If I become infertile, does it happen straight away?
5. Am I going to be able to fall pregnant after treatment?
6. For how long will I have to wait after treatment before I can check whether I am still fertile?
7. What are the statistics about my chances of becoming pregnant?
8. Would a future pregnancy influence my prognosis (chances of cancer coming back)?
9. How can I conserve my fertility?
10. Do I have time to I delay cancer treatment to undergo fertility treatment?
11. Are fertility drugs safe for me? How would fertility treatment impact on the future course of my cancer?
12. If I don't have a committed partner, where can I access sperm?
13. How much does each type of fertility treatment option cost?

14 What will happen to any embryos/eggs that aren't used?

15 What do I need to know if I want to consider not using my own eggs?

16 What are the risks and benefits of having a child after breast cancer?

17 What has happened to other breast cancer survivors who have decided to have children?

18 Are there any health concerns for children I might have in the future as a result of my treatment?

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

20 Are there any clinical trials which I may be eligible to take part in?

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