



Fertility-related choices

**A decision aid for younger women
with early breast cancer**

Fertility-related choices

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ABOUT THIS BOOKLET

This is a booklet for young women who have recently been diagnosed with early breast cancer. As chemotherapy and hormonal therapy 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,
- 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 of 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 53 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 51 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.

The major factor that affects which fertility options are available to you is whether you have a male partner with whom you want to have children. The most successful fertility treatments, such as In Vitro Fertilisation (IVF) require you to have a male partner.

This decision can be difficult. Many people feel better about their choices with careful decision-making. For some, a written record of what matters most to them helps when making the decision.

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 CANCER
Wait & see	Depends on age & treatment	No delay	Not applicable	No cost	No	No impact
IVF	25-60% per IVF cycle (dependant on the woman's age)	2-6 wks per cycle	Widely available (over 350,000)	Costly	Yes	Very little is known*
Egg freezing	15-60%** per cycle	2-6 wks per cycle	At some clinics (over 1000)	Costly	No	Very little is known*
Ovarian tissue freezing	Several live births reported worldwide	Short delay	Experimental (over 10 - 5 from IVF, 6 naturally)	Costly	No	Very little is known*
Ovarian suppression	Most women resume their periods but there is little data about pregnancies	No delay	Only available through a clinical trial or by prescription	Costly (unless in a trial)	No	Experimental - very little is known*
Adoption	N/A	N/A	Widely available - but often a long & difficult process	Costly	No	No impact
Egg and embryo donation	Egg: 30-50% Embryo: 25-60% per cycle	No delay	At some clinics	Costly	Only for egg donation	Very little is known*

* Key negative impact on cancer: high dose hormones may impact on cancer and options may cause cancer treatment delays

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

Some background information



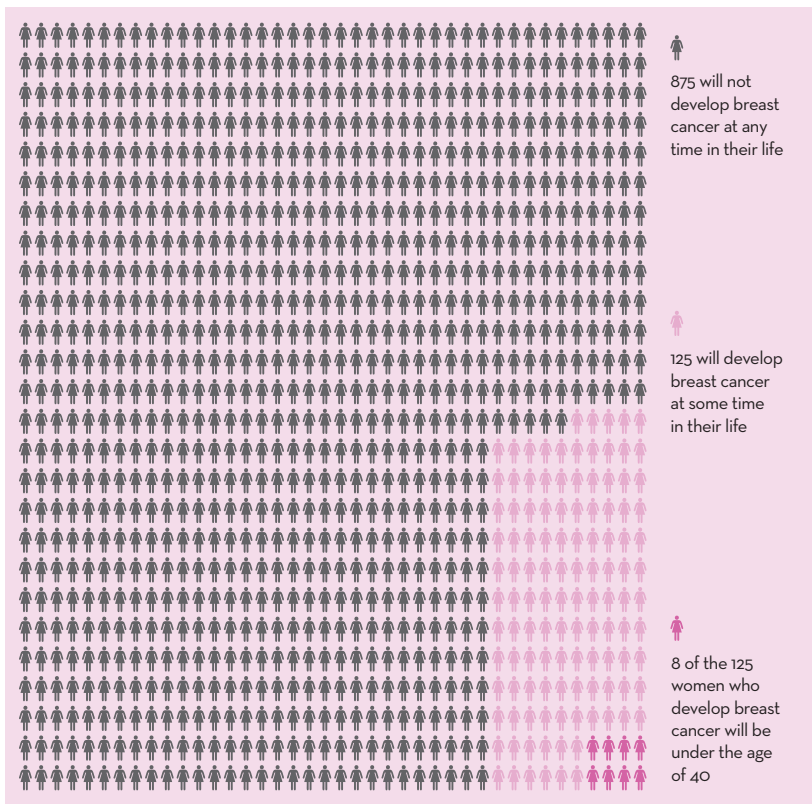
SOME BACKGROUND INFORMATION

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 hormonal 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 15-20% 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.
- Hormonal (endocrine) therapy. An anti-oestrogen is often given to women with hormone sensitive cancers and significantly reduces the chance of the cancer returning. Hormonal therapy is given for a long time (up to 5 years and sometimes longer). This is different to Hormone Replacement Therapy (HRT), which is used to treat symptoms of menopause.

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 a child; 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.

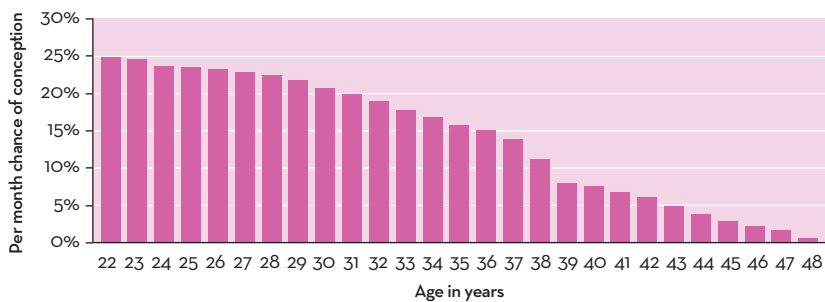


Figure from: <http://www.sydneyivf.com>

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.



The effect 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 your 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 the ovaries stop producing the hormones oestrogen and progesterone, which are needed for normal periods. In this case, periods stop permanently and natural pregnancy is very unlikely. This may be either:
 - Premature menopause - menopause in women aged less than 40 years.
 - Early menopause - menopause in women aged between 40–50 years.

Between 8%–80% of women aged 40 years or less may become menopausal as a result of cancer treatment, depending on the treatment that is 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 17 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.



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.

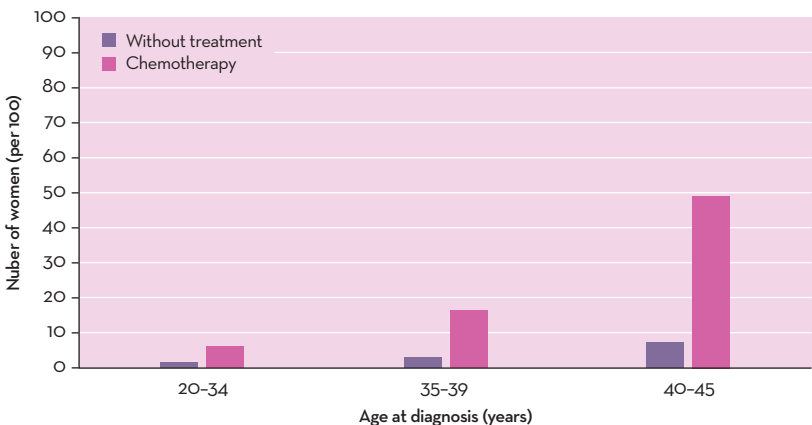
Chemotherapy can lead to:

- Early menopause.
- Temporary menopause (amenorrhoea). Periods may stop for up to a year or more after chemotherapy.

The graph below shows the chances of menopause during the first year after diagnosis without cancer treatment, and with chemotherapy only.

The figures on this graph are average figures for all chemotherapies and therefore provide a rough guide.

Estimated number of women who became menopausal (depending on their age at diagnosis) and the effect of chemotherapy



Data from Goodwin P et al. Journal of Clinical Oncology 1999; 17 (8): 2365-70 and Sukumvanich P et al. Cancer 2010; 116: 3102-11.



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.

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 on your fertility, as age is the main factor that affects female fertility. 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 use of chemotherapy. Please talk to your oncologist about this. It might be helpful to ask him/her what chance there is of your cancer returning within the next 2-3 years. This might help you decide what is best for you and for your family. The risks of recurrence depend on many factors including the size of your tumour, the grade, and whether any lymph nodes were affected.

Trastuzumab (Herceptin)

Herceptin is usually administered for up to 1 year, little is known but it does not appear to affect 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 whilst taking Herceptin.

Hormonal (endocrine) therapy

Many 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. Hormonal therapy is advised for most women who have this type of breast cancer and aims to block the effects of oestrogen in the body. One of the drugs that is commonly used is called tamoxifen. Tamoxifen is an “anti-oestrogen” and can halve the risk of the cancer coming back if taken for 5 years. Pregnancy should be avoided when taking hormonal therapy. Stopping this treatment early, before the recommended 5 years, could affect the chances of your cancer coming back in the future. If you decide to try for a pregnancy during this time you should discuss the risks of stopping tamoxifen with your oncologist.

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

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 how the cancer treatment has affected your fertility. In some cases, blood tests may be helpful. 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 30).

Pregnancy during breast cancer treatment

Rarely, breast cancer is diagnosed during pregnancy. If this should happen to you, your treatment options will depend on the advancement of your pregnancy and the stage of your cancer. Breast surgery does not appear to be unsafe during pregnancy. However, there is a slight increase in the chance of miscarriage during early pregnancy.

Radiotherapy is not safe for the baby, and it is usually possible to wait until the baby is born before starting radiotherapy.

Chemotherapy can be used after the first 12 weeks of pregnancy. This is only advised in cases where it is essential for the mother's health. The risks and benefits of treatment need to be discussed before deciding to start treatment. Some women diagnosed in early pregnancy may decide to terminate their pregnancy so that chemotherapy can start immediately. For others, the right decision might be to wait until after the baby is born to start chemotherapy. It is advisable to discuss these options with your oncologist.

Pregnancy after breast cancer

Women are often advised to wait 2-3 years after diagnosis before trying for a pregnancy, as this is a high risk time for recurrence. 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 in part be because they have tumours with a better prognosis.

However it should be noted 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.

As we do not know the number of women who try to fall pregnant, this low number may be due to there being only a small number of women actually trying to become pregnant.

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.

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 hormonal 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 birth control 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 birth control which are safe include barrier contraceptives (like condoms and diaphragms), and intra-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 who are on tamoxifen are advised not to breastfeed, you may wish to discuss this with your oncologist.



Fertility-related information



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. 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 21 to 32.

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 usually still 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 (e.g. do you need to have a will in place) 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. 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. If this is not possible, you may want to speak with your oncologist about delaying your cancer treatment further.

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) work. 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.

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 may be possible for you to act before chemotherapy starts. This can help improve your chances of having a child in the future.

A major factor that can affect which fertility treatments are available to you is whether you have a current male partner with whom you wish to have children

Fertility treatments where you need to have a male partner (such as IVF) are the ones that most likely to be successful.

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 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 30) or
- b donation of an embryo from another couple, or an egg from another woman (explained in more detail on page 30).

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

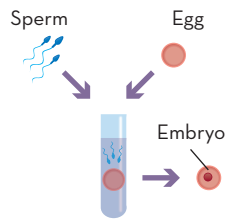
During the menstrual cycle 5-20 eggs develop but only one matures. For fertilisation to occur, an egg must be mature. IVF aims to stimulate more eggs to grow and mature and to collect as many mature eggs as possible. To do this, women are given hormones to stimulate the ovaries. This then allows all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

2 Egg collection

Egg collection is a minor surgical procedure performed under a local 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.



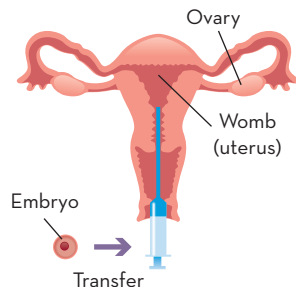
4 Embryo culture and freezing

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.



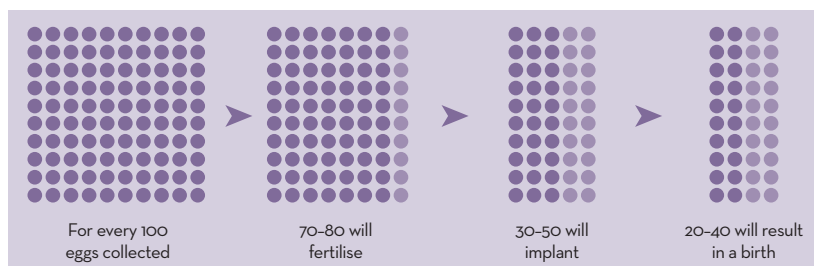
The success rates of IVF vary between labs. The success rate is also linked to the age of the woman being treated.

In women aged 40 years or younger, more than half (70-80%) of the eggs collected for IVF will fertilise. This proportion can vary and there are some situations where no eggs are fertilised.

On average, couples can expect that around 30-50% of the embryos will successfully implant into the womb.

Unfortunately, not all of these pregnancies will continue to term and some women will miscarry. The chances of having a healthy baby in any one IVF cycle are only 20-40% (regardless of whether the woman has had breast cancer treatment).

Generally:



IVF may involve the use of high dose hormones. These hormones might also stimulate the breast cancer. We do not yet know whether IVF increases the chances of breast cancers growing or coming back. To avoid exposure to hormones, “natural cycle IVF” may be an option. Here, the single egg that matures in a normal menstrual cycle is collected (before chemotherapy) and mixed with the partner’s sperm to see if fertilisation occurs. Whilst this avoids the use of high dose hormones, success rates with natural cycle IVF are much lower, at around 20% (or 2 in 10) per cycle. New ovarian stimulation regimens (using tamoxifen, clomiphene or aromatase inhibitors) are currently being developed to try and prevent high oestrogen levels during IVF. Ask your fertility specialist about this.

Will this delay my treatment?

IVF will cause a delay in cancer treatment of at least 2 to 6 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 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 many fertility clinics and some larger hospitals in Australia. There is a list of accredited fertility clinics on the Fertility Society Australia website (details on page 53).

What are the costs involved?

Again, this will vary from state to state, and may depend on whether you already have children. IVF can be very costly (thousands of dollars), with different fertility clinics charging different amounts. 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?

It is possible that you do not have a male partner and do not have access to sperm. In this case, you may wish to consider the use of donor sperm. Australian states have different laws about the use of donor sperm. There is often a long waiting period particularly for single women. Check with your fertility specialist about what options are available to you.

Another 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.

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:

- Multiple pregnancy - up to 20% of the pregnancies resulting from IVF are twins or triplets. This is largely due to the transfer of more than one embryo into the uterus. Most clinics will recommend the transfer of only one embryo to reduce the risk of multiple pregnancies. Multiple pregnancies carries an increased risk for both mother and child.
- Medication related side-effects - women have reported experiencing various side effects. For more information visit: <http://www.hfea.gov.uk/>
- Complications of the egg collection - there is a small risk of complication. For more information visit: <http://www.hfea.gov.uk/>

Long-term effects of IVF:

- Effects on your baby - children conceived by IVF are slightly more at risk of premature birth and birth abnormalities. For more information visit: <http://www.hfea.gov.uk/>
- Effects on your own health - the long-term effects of IVF on a woman's health are still unclear.

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.

Most breast cancers depend on hormones to grow. Many fertility treatments, including IVF, involve the use of high dose hormones to stimulate the ovaries to produce eggs. These hormones may make breast cancer cells grow more quickly or to return.

There are some new treatments available that may reduce the need for high dose hormones in IVF. New studies have found that some drugs used to treat breast cancer (such as tamoxifen or letrozole) may also be used to stimulate ovulation for fertility treatment. Discuss this further with your fertility specialist.

2 A delay in breast cancer treatment for at least 2 to 6 weeks (see page 24).

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 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. The chances of pregnancy are very variable at 15% to 60% per cycle. In a regular stimulated cycle, between 5 and 15 eggs are usually collected.

Like IVF, there will be a delay in cancer treatment of between 2 to 6 weeks to allow for the stimulation of the ovaries and collection of eggs (see Steps 1 and 2 on pages 21-22). Egg freezing also requires the storage of the eggs over a period of time. Thus, you would need to think about the length of time the eggs will be stored and the costs involved.

This is still an experimental technique, and some clinics may not be able to offer this approach.

Breast cancer is potentially affected by ovarian stimulation required for egg freezing in the same manner as IVF (see page 21). 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 25).



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. 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 only very few live births using this technique in cancer patients have been reported.

Storage of ovarian tissue has similar implications to egg freezing (see page 27). There is also concern that implantation of the stored tissue may increase the risk of transmitting cancer cells back into the body. It is also important to note that removing some of the ovary will decrease the number of eggs you have, should your fertility return after treatment, and thus may also reduce your fertility.

Fertility options during treatment

Ovarian suppression

Ovarian suppression is another experimental treatment. 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. Some scientists think that by stopping the eggs from growing, it will protect them from the harmful effects of chemotherapy. It is not yet known whether this treatment is effective at protecting the ovaries from the effects of chemotherapy.

This treatment 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

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 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: <http://www.dfc.sa.gov.au/pub/default.aspx?tabid=199>

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 be 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 25).



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 4 of this booklet.



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 45-50.

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 columns labelled 'personal importance'. 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’:

Personal Importance (*****)	PROs	CONs	Personal Importance (*****)
	No delay in my cancer treatment	High risk of infertility following treatment	
	I won't need to be exposed to fertility hormones	If I become infertile I can't have children that are genetically related to me	
	No cost	Chance of early menopause	
	I can think about my fertility later	I may regret my decision	
	My fertility may return	If I become infertile I may never have children	
	If I become infertile I can still consider adoption, egg or embryo donation	No guarantee of future children may affect my relationship with my partner	

At this point in time, are you leaning towards waiting or not?
(Please tick the box that is closest to how you feel)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am leaning towards waiting		I am not sure yet		I am NOT leaning towards waiting

The pros and cons of IVF:

Personal Importance (*****)	PROs	CONs	Personal Importance (*****)
	Usually easily available	Delay in cancer treatment might affect my cancer	
	Generally good success rates (depending on age and other factors)	I need a committed partner to provide sperm	
	Results in stored embryos in case of infertility	I would not consider donor sperm or there is none available	
	If I become infertile, I can still have children genetically related to me	Exposure to hormones might affect my cancer	
	I want to look back after cancer treatment and know that I gave it a go	Costly	
	I have a partner who I would like to have children with	There may be a need to discard stored embryos	
	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?
(Please tick the box that is closest to how you feel)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am leaning towards IVF		I am not sure yet		I am NOT leaning towards IVF

The pros and cons of egg freezing:

Personal Importance (*****)	PROs	CONs	Personal Importance (*****)
	No delay in my cancer treatment	High risk of infertility following treatment	
	No cost	If I become infertile I can't have children that are genetically related to me	
	I can think about my fertility later	Chance of early menopause	
	My fertility may return	I may regret my decision	
	If I become infertile I can still consider adoption, egg or embryo donation	If I become infertile I may never have children	
		Reduced chance of children may affect my relationship with my partner	

At this point in time, are you leaning towards egg freezing or not?
(Please tick the box that is closest to how you feel)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am leaning towards egg freezing		I am not sure yet		I am NOT leaning towards egg freezing

The pros and cons of ovarian tissue freezing:

Personal Importance (*****)	PROs	CONs	Personal Importance (*****)
	May cause only a minor delay in my cancer treatment	Extremely low chance of pregnancy	
	I do not currently have a male partner or access to a sperm donor	A minor delay in cancer treatment might affect my cancer	
	I can fertilise my eggs with a future partner's sperm	Surgical procedure	
	No hormones needed	Not widely available	
	I want to look back after cancer treatment and know that I gave it a go	Costly	
	Insurance against possible future infertility	Exposure to hormones (when proceeding with IVF later) might affect my cancer	

At this point in time, are you leaning towardsovarian tissue freezing or not?
(Please tick the box that is closest to how you feel)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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:

Personal Importance (*****)	PROs	CONs	Personal Importance (*****)
	No delay in my cancer treatment	Experimental procedure – effectiveness is not established	
	Less invasive than some of the other assisted reproductive technologies	Impact on my cancer treatment is unknown	
	I will be able to participate in a clinical trial and thus potentially help research	Impact on chemotherapy unknown	
	I want to look back after cancer treatment and know that I gave it a go	Potentially costly if not given as part of a clinical trial	
	If it works, I can have children genetically related to me		

At this point in time, are you leaning towards ovarian suppression or not?
(Please tick the box that is closest to how you feel)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I am leaning towards ovarian suppression		I am not sure yet		I am NOT leaning towards ovarian suppression

The pros and cons of adoption:

Personal Importance (*****)	PROs	CONs	Personal Importance (*****)
	No delay in my cancer treatment	Long waiting period	
	If I carry a gene fault that increases the chances of breast cancer, the child will not inherit it from me	The child is not genetically related to either my partner or me and the genetic history of the child may be unknown	
	I would be able to give a child needing a family a good home	Costly	
		May not be possible to access	
		I may need to look overseas to adopt as it is very difficult in Australia	
		I may not be eligible to adopt	

At this point in time, are you leaning towards adoption or not?
(Please tick the box that is closest to how you feel)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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:

Personal Importance (*****)	PROs	CONs	Personal Importance (*****)
	No delay in my cancer treatment	There may be an additional cost for a stimulated 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 will not be genetically related to me	
	I can decide later about whether to have children	Difficult to find an egg donor	
	The child will be genetically related to my partner	Exposure to hormones might affect my cancer	
	I will not need to be exposed to hormones before my cancer treatment		

At this point in time, are you leaning towards using a donated egg or not?
(Please tick the box that is closest to how you feel)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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:

Personal Importance (*****)	PROs	CONs	Personal Importance (*****)
	No delay in my cancer treatment	Some cost implications	
	If I carry a gene fault that increases the chances of breast cancer, the child will not inherit it from me	Not genetically related to either me or my partner	
	I can decide later whether or not I want to have children	Donated embryos may not be available to me	
		Exposure to hormones might affect my cancer	

At this point in time, are you leaning towards using a donated embryo or not? (Please tick the box that is closest to how you feel)

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
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

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

Wait and see

<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leaning towards		Not sure yet		NOT leaning towards

IVF

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Leaning towards		Not sure yet		NOT leaning towards

Egg freezing

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Leaning towards		Not sure yet		NOT leaning towards

Ovarian tissue freezing

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Leaning towards		Not sure yet		NOT leaning towards

Ovarian suppression

<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Leaning towards		Not sure yet		NOT leaning towards

Adoption

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Leaning towards		Not sure yet		NOT leaning towards

Egg donation

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Leaning towards		Not sure yet		NOT leaning towards

Embryo donation

<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>
Leaning towards		Not sure yet		NOT leaning towards

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.

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.

Hormonal (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.

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

<http://www.fertilitysociety.com.au>

Clinical practice guidelines for the management and support of younger women with breast cancer:

Ph: 02 9357 9400

<http://canceraustralia.nbooc.org.au/>

Helpful organisations

Cancer Australia

Ph: 02 9357 9400

<http://canceraustralia.nbooc.org.au/>

Breast Cancer Network Australia

Ph: 1800 500 258

<http://www.bcna.org.au>

McGrath Foundation

Ph: 02 8962 6100

www.mcgrathfoundation.com.au

Fertile Hope

<http://www.fertilehope.org>

ACCESS – Australia's National Infertility Network

Ph: 1800 888 896

www.access.org.au

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?

[illegible]

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*together we can make a difference**



The information in this booklet is correct at the time of publication. However, as research is ongoing, the booklet will be updated as required.

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