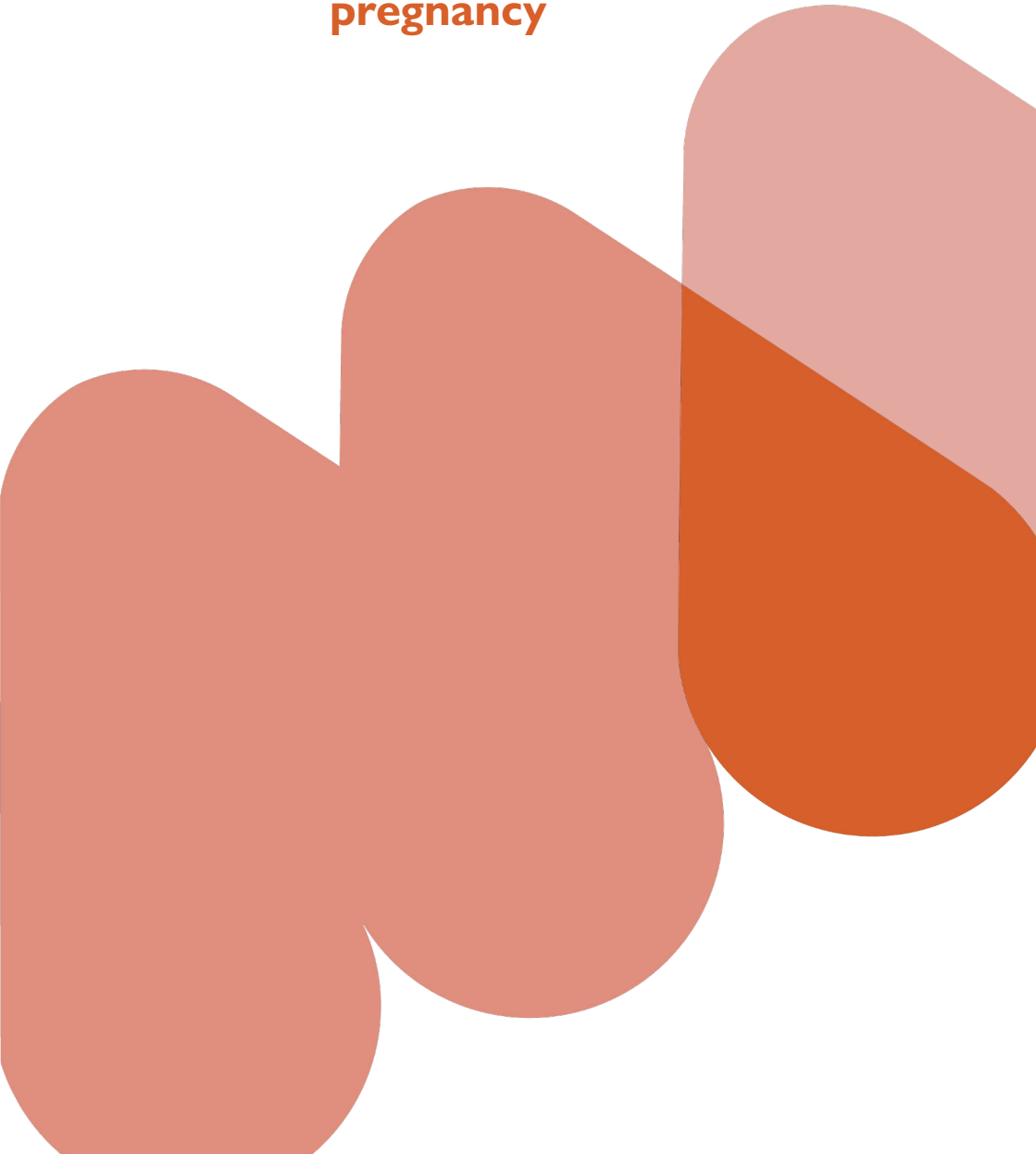
MISCARRIAGE ASSOCIATION

The knowledge to help

Ectopic pregnancy



Ectopic pregnancy can be a very distressing and frightening experience. This leaflet aims to explain what ectopic pregnancy is, to provide you with information and to answer some of the most common questions about both facts and feelings. We hope this will help at what can be a very difficult time.

What is an ectopic pregnancy?

An ectopic pregnancy is one that develops outside the main body of the womb. Around 1 in 90 pregnancies in the UK are ectopic and for some women[1], this can be a life-threatening condition.

In a healthy pregnancy, a sperm and egg meet in one of the two fallopian tubes which connect the ovaries to the uterus.

The fertilised egg moves from the tube down into the uterus, where the pregnancy grows and develops.
If this does not happen, the fertilised egg may implant and start to develop outside the uterus, leading to an ectopic pregnancy.

Most often an ectopic pregnancy will develop in a fallopian tube. It can be a life-threatening situation because as the pregnancy gets bigger it can burst (rupture), causing severe pain and internal bleeding.

Sadly there is no way of moving or transferring the pregnancy to the right place in the uterus and the pregnancy cannot survive.

Rarely, (in around 5% of cases) an ectopic pregnancy can be found somewhere other than the tube. These types of ectopic pregnancy include:

- an **interstitial ectopic**: the pregnancy implants in the top corner of the uterus near the Fallopian tube
- a **cervical ectopic**: the pregnancy implants in the cervix (the neck of the womb)
- a **scar ectopic**: the pregnancy implants in the scar from a previous Caesarean section
- a **cornual ectopic:** the pregnancy implants in a corner of the uterus which itself has not formed normally
- a **heterotopic pregnancy**: a twin pregnancy where one is in the correct place but one is ectopic
- an **ovarian ectopic**: the pregnancy implants in an ovary
- an **abdominal pregnancy**: the pregnancy implants somewhere within the abdomen

These are all rare conditions with individualised treatment.

This leaflet focuses mainly on tubal ectopic pregnancy, though some information is still relevant for non-tubal ectopics.

[1] *We often use the words 'woman' and 'women' in this leaflet, but we recognise that the person who has had the physical loss may not identify as such.*

Why does it happen?

We don't always know why an ectopic pregnancy has occurred, but there are some known causes and risk factors.

A fertilised egg normally takes two or three days to travel down the fallopian tube to the womb. It implants there between six and seven days after fertilisation.

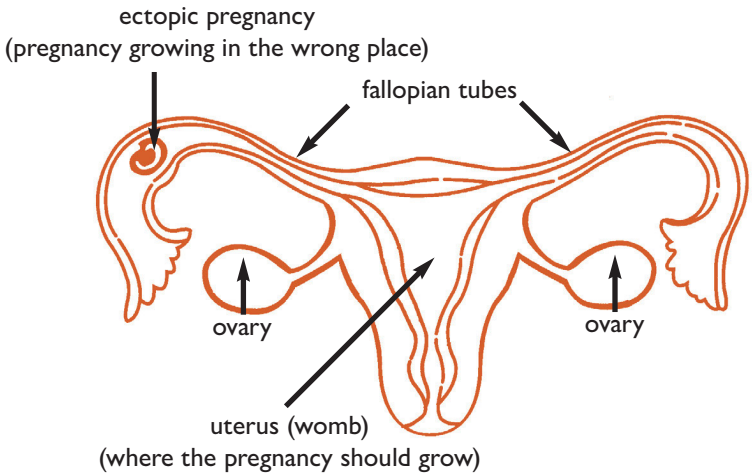
With a tubal ectopic pregnancy, however, the fertilised egg's journey is slowed down and it implants itself before it reaches the womb. There are several things that can make it more difficult for the egg to pass through the tube, including damage to the tiny hairs that help it travel towards the womb. The causes include:

- A previous ectopic pregnancy
- Infection in the uterus, fallopian tubes or ovaries, especially if they develop into pelvic inflammatory disease (PID). Chlamydia is one example.
- Surgery on the fallopian tubes, perhaps for a previous ectopic pregnancy or for sterilisation (or to reverse sterilisation).
- Becoming pregnant as a result of assisted conception, i.e. in vitro fertilisation (IVF) or intracytoplasmic sperm injection (ICSI). Even an IVF pregnancy can be ectopic.
- Falling pregnant while you still have an intrauterine device (IUD/coil) or while you were still on the progesterone-only contraceptive pill.
- If you smoke: smokers tend to have an increased level of a protein in their fallopian tubes that can slow the progress of the fertilised egg.

There is also a higher risk of ectopic pregnancy amongst women over the age of 35.

Many women who have an ectopic pregnancy, however, have no known risk factors.

> **"The scan showed that the baby was in the tube instead of the womb. I asked if it could be moved but was told it was impossible."**



What are the symptoms of an ectopic pregnancy?

Ectopic pregnancy can be very difficult to diagnose as sometimes there are no obvious symptoms. You may experience some or all of the symptoms listed below and these often begin around 6 weeks of pregnancy.

Symptoms can include:

- **Irregular vaginal bleeding** Bleeding that is different from your normal period. It may be constant but light over a number of weeks or you may have a brown discharge or spotting. Occasionally, some women think they may have had a light period and then they start bleeding again 10-14 days later and do not realise that they are pregnant
- **Pain low in your abdomen**, perhaps just on one side. It might start suddenly or develop gradually and it can be constant and severe.
- **Shoulder-tip pain** This kind of pain will be very different to any pain you have felt before and often comes with other symptoms such as vaginal bleeding and abdominal pain.
- **Bowel or bladder problems** You may have diarrhoea and perhaps vomiting; or pain when opening your bowels or passing urine.
- **Collapse** You may feel lightheaded, dizzy and/or faint. You may have a feeling that something is very wrong. You might look very pale, have a racing pulse and feel sick.
- **No symptoms** You may have no symptoms at all.

If you are or could possibly be pregnant now and are feeling unwell with any of the symptoms on this page, please seek medical attention urgently.

How is an ectopic pregnancy diagnosed?

Ectopic pregnancy can be very difficult to diagnose. The symptoms can be mistaken for gastro-enteritis, irritable bowel syndrome, miscarriage or even appendicitis.

In hospital, unless you are extremely unwell, the first steps are usually:

- **A medical history** You will be asked about your symptoms, pregnancy history and your previous medical history
- **A pregnancy test** (urine and/or blood)
- **An ultrasound scan**

You are most likely to have a transvaginal (internal) scan, as this provides the clearest picture in early pregnancy. It will not damage your pregnancy. The scan could show:

1. A pregnancy that is developing normally in the womb. You probably won't need further treatment unless your symptoms continue or get worse.
2. A pregnancy that seems to be failing or has died. You will probably be offered an appointment for another scan or options for treating a miscarriage
3. An empty womb. This finding is called a pregnancy of unknown location (PUL) and you will need further tests.

4. A pregnancy developing outside the womb – an ectopic pregnancy. This often can't be seen in the first weeks of pregnancy, but might be seen later.

• Blood tests

These are to measure levels of the pregnancy hormone ßhCG in your blood. In early pregnancy, the levels should double roughly every 48 hours. After a miscarriage, they drop quite quickly. If they rise slowly, or stay around the same level over this time, this can mean a pregnancy is failing or is an ectopic pregnancy. Some units also measure the level of the hormone progesterone in the blood. This can sometimes help to show if the pregnancy is failing or growing without having to repeat the hCG after 48 hours.

Blood tests alone cannot tell where the pregnancy is developing, but they can help doctors monitor patients who might have a growing ectopic pregnancy.

• Laparoscopy

This investigation is done under general anaesthetic. A tiny camera is passed through a small cut in your abdomen so that your fallopian tubes and internal organs can be seen directly. If it is clear that there is a tubal pregnancy, it will usually be removed at the same time.

> **"I did not have any of the typical symptoms and only minimal pain but had I not pushed for blood tests, there is little doubt that the ectopic would have ruptured."**

How is a tubal ectopic pregnancy managed (treated)?

If you are very unwell, the only safe option may be an urgent operation to confirm the diagnosis and to stop internal bleeding.

In most cases, though, there may be several options, depending on your condition, the scan report and any additional blood tests, and you should have time to discuss these with your doctor. We describe these treatments over the next few pages.

Conservative or expectant management

This is sometimes described as "watchful waiting". It means that you don't have any active treatment, but are checked regularly to make sure that the ectopic pregnancy is ending naturally.

You might be offered this treatment if:

- you are well (you have a normal pulse and blood pressure and little or no pain).
- there is no sign on the ultrasound scan that the tube has ruptured.
- your ßhCG levels are relatively low and
- during monitoring these levels continue to fall.

If you do have conservative management, you will need repeated visits to hospital to have your pregnancy hormone levels checked. Until your results are back to normal, there is still a risk that your tube might rupture.

During this time it is important to think of who you would contact in an emergency for support if you became unwell. It is also important not to have sexual intercourse as this can increase the risk of rupture, and to avoid alcohol as it may complicate the situation if you become unwell.

Medical management

Sometimes an ectopic pregnancy can be treated with drugs that stop the development of the pregnancy and allow it to be re-absorbed by the body. This may be offered if:

- you are well (you have a normal pulse and blood pressure and little or no pain)
- there is no sign on the ultrasound scan that the tube has ruptured
- you have a small ectopic pregnancy with no heartbeat
- your ßhCG levels are relatively low

The drug that is most often used is methotrexate and it is usually injected into a muscle. Methotrexate is a drug that is used for many conditions to stop the growth of rapidly dividing cells. It can cause abnormalities in a developing baby so it can only be given when the diagnosis of ectopic pregnancy is certain.

> **I was able to have methotrexate as the ectopic was caught quite early. The injection was fine and I had no side-effects, but I needed two lots of treatment and repeated blood tests before the pregnancy was over.**

Medical management isn't suitable for everyone, and especially not if:

- your pregnancy hormone levels are very high
- you have other medical problems that mean you should not use methotrexate (for example, kidney failure)

The advantage of medical management is that if it is successful (which it is in 90% of cases), you avoid having an operation and probably won't need to stay in hospital. If it is unsuccessful, you may still need to have an operation.

After the injection you will need regular blood tests to measure your hormone levels and check that they are falling.

The blood tests are usually done at the start of treatment, days 4 and 7 after treatment; then weekly after that until they are normal. This can take 4 to 6 weeks, depending on the level at the beginning.

About 15% of women will need a second injection and a smaller number may need surgery.

Until your hormone levels are back to normal, it is important not to have sexual intercourse as this can increase the risk of rupture, and to avoid alcohol as it may complicate the situation if you become unwell.

Some women have mild side-effects from the treatment, such as mouth ulcers, abdominal pain, nausea or skin rashes. You are also more at risk of sunburn and a small amount of hair loss.

If you have medical treatment, you will be advised to wait three months before trying for another pregnancy. This is because the drug can be harmful to an early pregnancy by reducing the amount of folic acid in your system.

It is important to make sure the drug is out of your system before you get pregnant again.

Once your hormone levels are back to normal, it is also advisable to restart your folic acid if you plan to try again.

> **"I'm glad I avoided surgery but the treatment made me very sick and I was absolutely exhausted for about two weeks."**

Surgical management

(under general anaesthetic).

This is the recommended treatment if:

- you are acutely unwell, with severe pain or internal bleeding
- there is a live ectopic pregnancy
- your hormone level is very high
- the diagnosis is uncertain

The advantage of surgical management is that it is a relatively quick treatment that does not usually require repeated hospital visits and blood tests. It may also be the treatment that you prefer when you compare it with the other options. However, it is not usually offered if your hormone levels are very low unless there are other medical reasons to do so.

In most hospitals, the operation is done by laparoscopy (key-hole surgery). This involves making two or three small cuts to the abdomen so that a camera can directly show the ectopic pregnancy and allow access for the instruments used to remove it.

Laparoscopic (key-hole) surgery shortens the length of time you need to stay in hospital and you will recover physically more quickly than after open surgery.

But this might not be possible, because, for example:

- you are too unwell or
- you have had previous abdominal surgery or
- you are very overweight or
- the doctor operating is more skilled and experienced at performing open rather than key-hole surgery.

In this case, you will have an operation which leaves a scar along the pubic hair line (bikini line).

In either operation, the doctor looks carefully at the fallopian tubes and other pelvic organs. This might give an idea of what caused the ectopic pregnancy, though this isn't always clear. It might also help your doctor advise you about a future pregnancy.

If this is your first ectopic pregnancy, your doctor will advise removing the affected tube completely, with the pregnancy tissue inside. This is called a **salpingectomy**.

If you have damaged tubes, however, or had a previous ectopic – and especially if you have already had one tube removed – there might be another option. It might be possible to remove the ectopic pregnancy from the remaining tube, and leave the tube behind. This is called a **salpingotomy**.

The advantage of this second option is that you will still have at least one tube left. The disadvantages are that:

- it increases the risk that not all the pregnancy tissue is removed, and
- you will need additional follow-up checks to check your hormone levels, and
- there is a higher risk of a future tubal pregnancy

Sadly for some women a further ectopic pregnancy will result in the loss of both fallopian tubes. This can have a huge emotional impact and the only option for a future pregnancy would be through IVF (*in vitro* fertilisation).

For further information, advice and support on the availability of this treatment it is best to see your GP.

> **"It was like a double loss. I lost my baby and I lost one of my tubes. It felt like the end of the world.**

How is a non-tubal ectopic pregnancy managed?

The management of non-tubal pregnancies depends on where the pregnancy has implanted and whether or not it is still alive. Each case needs to be considered separately, but most are managed **surgically**.

You might find it helpful to read the patient guidance from the Royal College of Obstetricians and Gynaecologists:
https://www.rcog.org.uk/for-the-public/browse-our-patient-information/ectopic-pregnancy-patient-information/

You may also find the resources from the Ectopic Pregnancy Trust helpful:
https://ectopic.org.uk/ectopic-pregnancy-leaflets

After the treatment

If you have surgical management, any tissue removed will be examined under the microscope to confirm that it was an ectopic pregnancy. That tissue is usually then disposed of by the hospital, in accordance with their sensitive disposal policy. If you prefer to take the remains of your pregnancy home to bury or to make your own arrangements, you can ask for them to be returned to you.

How long does it take to recover?

Recovering from an ectopic pregnancy is different for everyone. You might also find that you recover physically quite quickly, but that your feelings about what has happened stay with you for longer.

Physical recovery: your body

When can I go back to work or my usual routine?

Once you are home from hospital, you'll probably need to take things easy for at least a few days, whatever treatment you have had. If possible, it is best to return to work only when you feel ready both physically and emotionally. Your GP will be able to provide you with a certificate (a "fit note") for work.

After surgical management

After key-hole surgery, you should recover physically after about two weeks. If you have open surgery it is likely to be up to six weeks.

You should get a period about 4 to 6 weeks after your treatment, but this can take longer, particularly if your usual cycle is longer than 4 weeks.

After medical management

You will need to wait for the results of your blood test on day 7 after treatment. If the results show that the hormone level is falling and the pregnancy is resolving, you can start to return to your normal routine.

You may still have bleeding for some time, and it is best to wear pads rather than tampons to reduce the risk of infection.

Your period will not start until at least 4 weeks after your hormones have reached very low levels.

When is it OK to start having sex again?

This very much depends on how you are feeling after the ectopic pregnancy and what treatment you have had.

After surgery, it is safe to have sexual intercourse once any bleeding and discharge have stopped. After conservative and medical management it is advisable to wait until your levels are returning to normal.

You may want to wait longer, though, especially if you are feeling very tired and/or you are still sore or in pain. You might also be worried about the possibility of getting pregnant again (see page 13).

Emotional recovery: your feelings

Are my feelings normal?

Everyone is different, but many women say that ectopic pregnancy is a very upsetting and frightening experience, even if they weren't planning to have a baby.

There is no right or wrong way to feel and you'll probably find that you have lots of ups and downs in the days, weeks and months after your loss.

You may have felt – or you might still feel – one or more of the following:

Shock

Perhaps you didn't know you were pregnant until your ectopic was diagnosed. You had to cope with finding out you were pregnant and that it couldn't survive all at the same time.

You might have been treated as an emergency, with everything happening very quickly. You might have been very frightened, especially if you knew your life was at risk. You may still be replaying those feelings of shock and fear in your mind.

Perhaps you are shocked by thoughts about what might have happened – such as "What if I hadn't been diagnosed in time?".
This can be true for your partner too.

You may feel very anxious – about what happened or about all sorts of things. And you may have difficulty sleeping. If this becomes a real problem for you, then it is probably a good idea to talk to your GP.

Loss and grief

You may feel very sad for the loss of your baby, and for the hopes and dreams you had for her or him. Those feelings might be very strong and last longer than you expect.

It can be very difficult, especially if other people don't understand that.

You may find it helps to talk to other people who have had an ectopic pregnancy (see page 15).

> **"Everyone tells me how lucky I am to be alive. But I've lost my baby and I just feel so empty."**

Feeling "in limbo"

If you have been treated with methotrexate or are waiting for the ectopic to resolve naturally, you may feel in a kind of "limbo" for several weeks.

It can be very upsetting to have to go back to the hospital for repeated blood tests until your hormone levels are back to normal.

If you have been advised to wait some months before trying again, you might feel that it is even harder to recover and to begin to move forward.

Guilt and blame

You might wonder whether you are somehow to blame for what has happened. It's normal to want to try and make sense of what happened and to feel frustrated when there are no clear answers. It's important to remember that an ectopic pregnancy is not your fault.

As we have mentioned earlier in this leaflet there are some factors that may increase your likelihood of having an ectopic pregnancy, however we still do not understand fully why it happens to some women and not others.

Anger

Going through a traumatic experience can leave you feeling angry, this might be because of what happened and all that you went through or because others around you don't seem to understand how you feel. Everything can feel very out of control, and this can leave you feeling on edge.

Research has shown that 40-50% of people have some symptoms of post-traumatic stress after an ectopic pregnancy. You might relive some of your experience through nightmares or flashbacks this can make you feel anxious or irritable. These symptoms often gradually fade away in the first few weeks afterwards, but if they persist or impact your daily life do see your GP.

You might want to talk this through with someone whom you feel you can trust (see page 15).

Your partner

The experience of ectopic pregnancy can put a real strain on a relationship. It might bring you and your partner closer together but you might find that they don't seem to understand how you feel and don't react in the way you want or expect.

You may feel differently about what has happened. Your partner may focus on your health, especially if they saw you in pain and distress and perhaps felt powerless to help.

Partners sometimes think they need to be strong and supportive, rather than show any feelings of loss, sadness or anxiety.

It may just be that you deal with things or express yourselves differently and this can lead to misunderstandings, anger and hurt, especially at a vulnerable time.

You or your partner may find it helpful to read our leaflet *Partners Too.*

It may be that you do not have a partner, and feel very alone. You might need extra support at this time.

> **"Vicki was terribly upset and having a lot of pain too. I wanted to rescue her or take away the pain, and I couldn't do a damn thing except watch her cry."**

Anxiety about the future

You may worry about whether you'll be able to get pregnant again. Or you might be frightened that if you do become pregnant, you might have another ectopic pregnancy. You may wonder whether you should try again, or whether you even want to.

We provide some information about this in the next section. It may also be helpful to discuss your questions and concerns with your doctor.

If you had surgery for the ectopic pregnancy, your doctor should be able to tell you about the condition of your womb, tube(s) and ovaries and how this might affect your future fertility – particularly if there is any obvious damage to the other tube.

If you had problems getting pregnant this time, you may want to ask if you can see a specialist before trying again.

Getting support

Many women who have had an ectopic pregnancy – and their partners too – find that it can help to talk to someone who understands what they are going through. This may be a friend or relative, or perhaps a bereavement nurse, midwife or counsellor.

You may prefer to talk to someone you don't know personally, perhaps by phone or by using an online support forum. See page 15 for some suggestions.

Thinking about about the future

What about future pregnancies?

The chances of having a healthy pregnancy are still good after treatment for an ectopic, even if your tube is removed.

You will ovulate (release an egg) as before, probably once a month. And even if you have just one fallopian tube, it's possible to get pregnant even when you ovulate on the opposite side.

65% of women will fall pregnant within the first 18 months, 85% within two years, while some will need help to do so (e.g. fertility treatment) and others will decide not to try again.

What are the chances that I'll have another ectopic pregnancy?

The overall chance of you having another ectopic is between 7% and 10% – so at most, 1 in 10. This will depend on the kind of treatment that you had and the health of your remaining tube or tubes.

If you had surgical treatment but the tube was not removed (salpingotomy), the risk of another ectopic is slightly higher, at around 15%.

When one fallopian tube is damaged (because of infection or scarring, for example), there is a higher chance than normal that the other tube may be damaged too.

This means that:

- the chance of getting pregnant is less than normal
- there is an increased risk of another ectopic pregnancy if you do become pregnant.

The chance of having another **non-tubal ectopic pregnancy** is very low, but if it was a cornual pregnancy and this was managed surgically, there may be other concerns in the next pregnancy. It is important to discuss this with your doctor at your followup appointment.

When is it best to try for another pregnancy?

This will depend on the type of ectopic pregnancy you have and the treatment you receive.

There is no clear guidance on how long you should wait before trying again after an ectopic pregnancy and clinical opinion varies. The NHS advises waiting until you have had two periods before trying again. After medical treatment, you will be advised to wait at least three months.

You might want to get pregnant again as soon as possible or you may find the thought of another pregnancy very frightening. You and your partner are the best judges of when – or whether – to try again.

What about contraception?

If you don't want to get pregnant, you may want to talk to your doctor or family planning clinic about what kind of contraception is best for you and what to avoid.

Will I need special care in my next pregnancy?

The most important thing in your next pregnancy is to find out early if it is developing in the right place. So once you have a positive pregnancy test, it is best to consult your GP or Early Pregnancy Unit so that they can arrange an early scan for you.

It is not usually helpful to have a scan before six weeks as it can be too early to confirm where the pregnancy is developing. However, if you have pain or bleeding, it is best to go to your local EPU for assessment even if it is before six weeks.

If you see a GP or hospital doctor who doesn't know your history, it is important to tell them about your ectopic pregnancy so they understand that an early scan is important. It is helpful to tell them or the person scanning you which fallopian tube was affected and/or removed.

It is also essential to talk to your doctor if you might be pregnant and have any symptoms that might mean another ectopic: a late period, bleeding that is different from usual or any of the other symptoms listed on page 5.

If you are pregnant and an early scan shows a developing pregnancy in the womb, then you are unlikely to need any further special care or tests. You'll be booked in for routine scans at around 12 and 20 weeks.

Finally:

The experience of ectopic pregnancy can be extremely distressing. You may feel very relieved to be alive and free of pain, yet still feel deeply sad at the loss of your baby and anxious about the future.

Whatever your feelings and anxieties, you don't have to bear them alone. We hope that reading this leaflet has been of some help and that you can use some of the resources opposite to help on your journey to recovery.

> **"Just talking to people that understand what I've been through and how I'm feeling makes me feel like I'm not alone."**

Information and support

The Miscarriage Association offers support and information through a staffed helpline: phone, live chat, email and direct messaging; online and inperson support groups, an online forum and private Facebook groups.
Tel: 01924 200799
www.miscarriageassociation.org.uk

Ectopic Pregnancy Trust
provides information and support on ectopic pregnancy.
Helpline: 020 7733 2653
www.ectopic.org.uk

For advice on symptoms, it is best to call your GP, out-of-hours service or the NHS 111 helpline (0845 4647 in Wales).

If you suspect an ectopic pregnancy, seek help immediately from your GP, your nearest Early Pregnancy Unit, or Accident & Emergency Department.

For a list of Early Pregnancy Units, see www.aepu.org.uk (Association of Early Pregnancy Units)

Useful reading

NICE guideline (NG126)
Ectopic pregnancy and miscarriage: diagnosis and initial management.
National Institute for Health and Care Excellence, August 2023.
www.nice.org.uk/guidance/ng126

Royal College of Obstetrics and Gynaecology
Ectopic Pregnancy Patient Information
https://www.rcog.org.uk/for-the-public/browse-our-patient-information/ectopic-pregnancy-patient-information/

Other leaflets from the Miscarriage Association:
Looking after your mental health during and after pregnancy loss
Partners Too
Pregnancy loss and infertility
When the trying stops

Thanks

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Need to talk to someone who understands?

Call on 01924 200799.
Email us at info@miscarriageassociation.org.uk
Start a live chat via our website: miscarriageassociation.org.uk

Monday, Tuesday and Thursday: 9am - 4pm.
Wednesday and Friday: 9am - 8pm.

MISCARRIAGE ASSOCIATION

The knowledge to help

The Miscarriage Association

T: 01924 200799

E: info@miscarriageassociation.org.uk

W: www.miscarriageassociation.org.uk

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