

The Miscarriage Association



Acknowledging Pregnancy Loss

Late miscarriage the experience of second trimester loss

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We are sorry you have had a miscarriage. Whether it happened recently or some time ago, you are likely to have found it very distressing. You may have unanswered questions about what has happened and what might happen in the future. You may have had support from family and friends or you might feel very much alone.

We hope that this leaflet will help and that by giving you information, we can also offer you some comfort.

Late miscarriage: what do we mean?

This leaflet is about miscarriages between 14 and 24 weeks of pregnancy.

It does not cover losses which happen at 24 weeks or later, since the law defines these as stillbirths. And it does not cover 'missed miscarriages', where the baby dies before 14 weeks. If your baby died before 14 weeks, even if the actual miscarriage happened later, please ask for our leaflet *We are sorry that you have had a miscarriage*.

Sadly, miscarriages before 24 weeks are not officially recorded by the Registrar. This is because 24 weeks gestation is the legal age of viability – the stage at which a baby is thought to stand a good chance of survival if born alive.

For some people, hearing their 23-week loss called a miscarriage adds to their distress. Jayne felt it was unfair:

She was a perfect, tiny little baby – but officially she never existed. She didn't even have a birth or death certificate. How can someone decide she was never a person?

Other terms and definitions

As well as 'late miscarriage' and 'late loss', other terms you might hear are:

Second trimester or mid-trimester loss This means a miscarriage between 14 and 24 weeks of pregnancy. Doctors divide pregnancy into three stages: the first trimester is up to 13 weeks; the second, or middle, trimester is from 14 to 24 weeks; the third trimester is from the start of the 25th week of pregnancy onwards.

Intra-uterine death (IUD) This term may be used when it is clear, usually from a scan, that the baby has died in the womb. It tends to be used from 24 weeks onwards.

Neo-natal death This is the term used for a baby born alive at any stage of pregnancy, who dies within 4 weeks of the birth. The baby's birth and death will be recorded by the Registrar.

Causes of late miscarriage

Miscarriage is more common than many people think. Around one in five pregnancies ends before 24 weeks.

Most miscarriages happen in the first trimester – that is, in the first 12 or 13 weeks of pregnancy. It is less usual to miscarry between 14 and 24 weeks, although some of the causes may be the same. Unlike in first trimester losses, a cause is found in over half of pregnancies lost after 13 weeks.

Abnormalities in the baby which may lead to miscarriage

Most miscarriages, at whatever stage, are the loss of a pregnancy which is in some way abnormal. Abnormalities include:

Chromosome problems

Examples of chromosome problems are Down's Syndrome, Edwards' Syndrome and Turner's Syndrome. These are usually one-off abnormalities, although they can sometimes be the result of an unusual arrangement of one, or both, of the parents' chromosomes.

When a baby dies in the second trimester, it is possible to examine the baby's chromosomes – the karyotype – from samples taken from the placenta and umbilical cord. If it is necessary to examine the parents' chromosomes as well, this can be done from a blood sample. With the information obtained from the karyotype, a geneticist can tell you what the risk is of a similar problem occurring in another pregnancy.

Amniocentesis is usually offered during pregnancy if it is thought that there is an increased risk of a chromosome abnormality in the baby. A very fine needle is passed through the mother's abdomen into the pregnancy sac so that fluid from around the baby can be withdrawn and analysed. Unfortunately this procedure carries a 1 in 100 risk of miscarriage, which may occur soon after the procedure or much later.

Genetic problems

The chromosomes carry our genes. We all have many thousands of genes; we also all have some abnormal genes. Sometimes these genes can cause

fatal conditions. An example of a genetic problem is cystic fibrosis.

Genetic problems are more likely to cause early miscarriage, in the first trimester. But if a genetic cause is suspected for a late miscarriage, it might be possible to test for the specific gene, if it is known. You may also be offered an appointment with a clinical geneticist who will be able to discuss the risks of a similar problem occurring in a future pregnancy.

Structural problems

Examples of structural problems are spina bifida and congenital heart defects. These problems may be identified during pregnancy on an ultrasound scan, but sometimes they are only discovered after the baby is born.

If your baby is found to have such a problem, you should be offered the opportunity to find out more about the chances of this happening again in a future pregnancy. If your baby had spina bifida, you may be advised to take high doses of folic acid in your next pregnancy, to reduce the risk of it occurring again.

Other causes of late miscarriage

Anatomical problems

1 in 25 women has an unusually shaped womb (uterus). In most cases this does not increase the risk of miscarriage. So even if you do have an unusually shaped womb, it may not have been the cause of your miscarriage. However, in some women who have a womb that is partly divided in two (an arcuate uterus), the risk of loss in mid-pregnancy is greater.

A weak cervix ('cervical incompetence') can cause a late miscarriage. Throughout pregnancy, the cervix (the neck of the womb) should be tightly closed. If it is weak, it may open as the baby grows bigger. You are more likely to have a weak cervix if you have had surgery for abnormal cervical cells, or surgical treatment for a previous miscarriage or termination of pregnancy. But often the cause of a weak cervix is unknown. It can be treated by putting a strengthening stitch in the cervix. This is usually done under general anaesthetic at 13 or 14 weeks of pregnancy.

Infection

Infections can cause a mid-trimester miscarriage, either by infecting the baby or by infecting the amniotic fluid.

Infections directly affecting the baby

Organisms that can infect the baby include parvovirus, cytomegalovirus (CMV), and toxoplasmosis. These infections can cause the baby to die in the womb. They do not usually recur in later pregnancies.

Infection of the amniotic fluid

Some infections, such as bacterial vaginosis, are thought to increase the risk of going into labour early. If this happens before 24 weeks, the baby is usually not developed enough to survive.

Infection can also cause a leak in the amniotic sac. The amniotic sac is the bag of fluid in which the baby floats inside the womb. The fluid is vitally important for the normal development of the baby's lungs, so a leak can cause serious problems. It can also cause infection inside the womb, which can cause labour to start too early.

Antiphospholipid Syndrome (APS)

Antiphospholipid antibodies are formed in the body after many different illnesses. Anybody who has had a variety of illnesses may have antiphospholipid antibodies in their bloodstream without knowing it. If these antibodies are found in a woman who has had repeated miscarriages, this is known as antiphospholipid syndrome.

Antiphospholipid antibodies are found by doing a blood test. They can be transient (that is, they can come and go), so a diagnosis of antiphospholipid syndrome should not be made unless the antibodies are found in a second blood sample taken at least six to eight weeks after the first.

If your miscarriage is thought to be because of antiphospholipid syndrome, there is a high risk of problems in a future pregnancy. It may be possible to prevent this by treatment with low-dose aspirin, starting before conception. Your doctor may also recommend that you have heparin injections, starting early in pregnancy.

How miscarriage happens

A miscarriage may be spontaneous, or labour may have to be induced.

Spontaneous miscarriage

A spontaneous miscarriage begins naturally. Most women feel uncomfortable and/or have labour pains. Sometimes the waters around the

baby break, sometimes they stay intact until the baby is born.

A spontaneous miscarriage can happen quickly. In many cases the neck of the womb is too far dilated to stop the miscarriage happening.

Silent miscarriage

You may have had no sign that anything was wrong with your pregnancy, but an ultrasound scan showed your baby had died. This is likely to have been a great shock.

When a baby dies in the womb in mid-pregnancy, and is not miscarried naturally, labour has to be induced – that is, started artificially – to deliver the baby. Procedures vary from hospital to hospital, but in every case staff should explain clearly what your choices are and what is likely to happen.

Finding a reason

Most women and their partners want to know the reason for their miscarriage, and after a late miscarriage, most hospitals offer some investigations – although these may not provide clear answers.

If a baby miscarries after 14 weeks, it is usually developed enough for a post mortem examination to be carried out. ('Post mortem' means after 'death'.) A post mortem is also called an autopsy.

A post mortem examination can provide valuable information about your baby, your pregnancy, and your own health. It can also provide information which will help your doctor to care for you in a future pregnancy.

A post mortem can:

- identify a cause or causes of miscarriage and death
- identify structural abnormalities
- identify the presence of chronic intrauterine disease
- provide information about the progress of the pregnancy, and especially the baby's growth and development
- provide information about the placenta and maternal health problems.

A post mortem also confirms the baby's sex. It can be difficult to be certain at delivery if a very tiny baby is a boy or a girl. Some parents are distressed

to find that the post mortem shows their baby to be a different sex from what was originally thought.

A post mortem does not always provide a reason for a miscarriage. Even after the most careful and detailed examination, a specific cause of death may not be found. For some parents this is sad and frustrating, but if you are considering another pregnancy, it can also be helpful to know that your baby was normal and there was no obvious cause for the miscarriage.

Making a decision

Parents are likely to be asked to give written consent for the post mortem examination of babies of less than 24 weeks.

To help you decide whether or not you want a post mortem examination of your baby, your hospital should provide you with as much information as you need, and it is important that you have the chance to talk about it with a knowledgeable professional and to ask questions.

You do not have to feel rushed into making a decision. You may need time as well as clear information to help you reach a decision, and a delay of up to several days will not significantly affect the findings.

If you decide not to have a post mortem examination, you can still ask for the placenta to be examined. An examination of the placenta can provide information which may be helpful when making decisions about a future pregnancy.

The examination

If you agree to your baby having a post mortem examination, it will be carried out by a pathologist, a doctor specialising in the study of disease and causes of death. In some areas, a specialist paediatric pathologist will carry out the examination. Your baby may have to be transferred to another hospital for the examination, but your hospital should tell you about this and when your baby will be returned.

A post mortem involves examining the baby carefully and thoroughly for signs of possible problems, both externally and internally. Small samples of tissue are taken from each organ and are looked at under a microscope. This will show the pathologist if the tissues were developing normally or not. Sometimes special investigations are also needed, such as photographs, x-rays, bacteriology and virology to look for infections, and karyotyping to study the baby's chromosomes.

Sometimes it is only possible to examine an organ after fixation. Fixation involves placing the organ in a chemical called formalin for a few days to help firm the tissues. You will be asked about whether you want this to be done, and you will need to think about what you wish to happen to the organs and tissues after examination. It is important to talk this over and ask any questions you may have. The organs can be returned to the body after examination, but this may delay the funeral.

The post-mortem examination takes up to several hours to perform. Afterwards, the incisions made to examine the baby internally will be repaired where possible and, if you wish, your baby can be wrapped or dressed to hide any marks. It is possible to see your baby again afterwards if you wish. You can talk this through with the pathologist or other staff.

After the post mortem, the tissue removed at the post mortem will be examined in a laboratory. This can take some time and it may be several weeks before you can be given results. Your consultant will probably invite you to a follow-up appointment to discuss the results, or the results may be sent to your GP, who will talk about them with you. (See also *Follow up*, page 13)

After the miscarriage

Many couples wonder what happens to their baby, or the remains of their pregnancy, after they miscarry. What happens will depend the stage at which your baby died and the policy of your hospital.

Babies who are stillborn, or who are born alive and then die, must by law be buried or cremated. The hospital may arrange this for parents, or parents may prefer to make arrangements themselves.

When a baby is miscarried before 24 weeks, there is no legal requirement to bury or cremate the body and hospital services vary. Most hospitals offer a simple funeral and burial or cremation for babies who die late in pregnancy but they may have different definitions of 'late' miscarriage. For example, some hospitals only offer this service for babies miscarried after, say, 16 weeks of pregnancy. Other hospitals offer burial or cremation for all babies that miscarry, regardless of the timing of the loss. Some hospitals offer collective burial or cremation where a number of babies are buried or cremated together.

The hospital staff should take time to explain to you what the hospital offers and should also give you written information. They should give you time to consider what you would like to do. You may feel too shocked to be able to make a decision right away – this is, after all, a decision you probably never

expected to have to make. You may want to ask staff to keep your baby, or his or her remains, until you are ready to decide. They should also understand if you feel you cannot make a decision at all.

You have the right to make your own arrangements for a funeral and/or burial or cremation if you prefer. You may wish to consult a funeral director or a minister of your own faith if you have one. The hospital chaplain may also be a good source of information, advice and support, whether or not you have any religious beliefs.

If you wish to bury your baby's body or remains yourself, you can do so, whether you miscarried in hospital or at home. There are guidelines about how and where this can be done and you can get more information from The Miscarriage Association or from SANDS (see page 14). You may need to make your wishes very clear to hospital staff or your GP as they may not be aware that this is legal.

Marking your loss

Whether or not you have a funeral for your baby, you may feel you want to find other ways to acknowledge his or her brief existence.

It may be important to you to name your baby. If you do not know whether your baby was a boy or a girl, you could choose a name that could be given to either.

Some parents gather mementos in an album or a special box – for example, a scan photo, photos taken during pregnancy, a hospital bracelet, letters or cards, and maybe a toy or clothes that they had made or bought for their baby. Some hospitals offer to make hand or footprints of babies miscarried late in pregnancy and may put them in a special memorial card.

Other parents mark their loss in other ways, perhaps planting a bush or tree, making a donation to charity, or creating something else in their baby's memory. Liz miscarried at 22 weeks:

As a permanent marker that Michael was here, we named a star in loving memory of him. The name is registered permanently. This makes us feel that he will never be forgotten.¹

Your hospital may have a book of remembrance and if you wish you can enter your baby's name and the date of your miscarriage. Some hospitals hold regular remembrance services for babies who died during pregnancy or around birth.

¹ To find out more, contact the International Star Registry on 020 7684 4444; www.international-star-registry.org

Certificates

The Registrar does not currently provide death certificates for babies miscarried before 24 weeks of pregnancy, but it may be possible to have a certificate from the hospital. This would note your baby's name, if you have given one, the date of the miscarriage and maybe some other details.

If your hospital does not provide certificates, you could ask whether they would sign one which you provide. The Miscarriage Association and SANDS both provide outlines you can use.

Recovering

Your body

Following your miscarriage, you are likely to have some bleeding and possibly period-like pain, and this may continue for several weeks. If the bleeding or pain increases or you have a discharge that looks or smells offensive, or if you are worried about any other physical symptoms, ask for advice from your hospital or GP. They will be able to tell you whether your symptoms are normal and whether you need any further treatment. Your GP can also give you a sickness certificate if you need one for work.

In some areas, a midwife will visit you at home and check your progress. If you don't want anyone to visit you, then try to have regular contact with your GP so that he or she can check your body is returning to normal.

Your breasts will naturally produce milk and this can be very distressing. A good, supporting bra can help you feel more comfortable. If your breasts are painful, you might want to take a mild pain-killer such as paracetamol. If you have a lot of pain and discomfort, talk to your midwife, GP or the hospital staff. They may be able to give you tablets to reduce the production of milk. You can also buy breast pads at the chemist or supermarket to soak up any leaking milk.

You may feel very tired for quite a long time after your miscarriage. Your body needs time to recover from labour and maybe also from infection or treatment. If you are producing milk, that can be tiring too. Despite being tired, you may find it hard to sleep.

Emotional distress can be exhausting too, and can affect how you feel physically. Tracy miscarried twins at 20 weeks:

I felt tired all the time and didn't want to get out of bed. I felt that a part of me had died with my babies, that a part of me was missing. I had a constant pain in my chest and a heavy feeling all over.

Your body may get back to its pre-pregnancy state quite quickly, or it may take longer, especially if your loss was late in pregnancy. People have very different feelings about how they look. Some women are upset when they still look pregnant and are relieved when they get back to their normal shape and fit their ordinary clothes again. Others feel that returning to their pre-pregnancy shape is somehow forgetting or betraying their baby. They don't want to let go of the look and feel of pregnancy.

Try to give yourself time to recover. Sometimes the demands of home and work make that difficult. You might even feel that the sooner you get back to your usual routine, the quicker you'll feel better. That might work – but it might not. Pushing yourself (or being pushed) to get back to normal as quickly as possible may actually slow down your recovery. It may help to talk to someone who understands – perhaps someone else who has been through late miscarriage or a bereavement counsellor.

Your feelings

For those of us who have undergone the trauma and complex feelings following miscarriage, a little of that pain remains in a corner of one's heart forever.

Barbara Dickson, singer and actress

Feelings after a miscarriage vary from person to person and there are no rights or wrongs. Feelings of grief and loss are very common, but people express how they feel in different ways. For example, some people cry, maybe a lot of the time; others don't, either because it doesn't feel natural to cry or because they are anxious that if they do, they won't be able to stop.

Returning home from hospital without your baby can be hard. If you have bought baby clothes and equipment, or decorated a room, it can be painful to see them – although you may also find it comforting:

My husband put all the baby things away out of sight, before I came home. He thought they'd upset me. I got the littlest baby-gro out and just held it and I cried and cried. It was sort of comforting in a way.

You may feel angry – with the hospital staff or your GP, or when you see other pregnant women or couples with small babies. You may feel bitter because of the unfairness of it all. Some women blame themselves, or blame their partner.

Clare miscarried several days after having an amniocentesis. She felt guilty about having had the test, especially when the results showed her baby was normal. She was also angry with her doctors:

I was told that the chances of miscarriage were very small – about one per cent . . . The doctors make this test seem so routine.

Some people find it hard to talk about what happened or how they feel. Others want to talk all the time, going over what happened again and again. It can sometimes be hard to find people who are willing to listen, and you may feel very lonely. Sometimes family and friends say the wrong thing, try to cheer you up, or just avoid talking about what has happened altogether:

I needed others to acknowledge my babies, that they existed, that I was a mother.

You may find you continue to grieve for your baby for much longer than you, or other people, expect. You may feel you will never recover. For many people, it is not so much a matter of getting over their loss as learning to live with it – and this can take time.

Your partner may also have sad and difficult feelings to cope with. Although he has not gone through the physical changes of pregnancy or miscarriage, he is likely to be grieving for the loss of your baby. He may have had to put his feelings on hold while supporting you, and he too may feel exhausted. One bereaved father remembered:

That first evening at home, contacting relatives and friends to break the news, was heartbreaking. Telling people over and over again made it all seem so much more real and I have never felt so alone.

A miscarriage can bring a couple closer, but it can also put strain on a relationship, especially if one partner feels that the other is moving on too quickly or if they have different wishes or feelings. It may be helpful to read the Miscarriage Association leaflet *Men and Miscarriage*.

If you already have a child or children who knew you were pregnant, they may be affected by the miscarriage too. They may seem anxious and may be more dependent for a time. Some parents find their children go through a phase of being naughty – and this can be hard to handle, especially if you are feeling low. It may help to talk to a teacher, health visitor or counsellor about this.

Most people find their feelings of grief and loss do ease over time. There are likely to be good days and bad days and some particularly difficult times,

such as the baby's due date or the anniversary of the miscarriage. For some people, feeling better makes them feel guilty, as though they are betraying their baby. It is important to know that it is normal to return to everyday activities, and that enjoying a TV programme, or laughing at a joke, does not mean you have forgotten your baby.

Do remember there are people who can offer support whenever you feel you need it. The Miscarriage Association has a helpline and a national network of support volunteers who have experienced miscarriage themselves. We can also refer you to other organisations (see page 14). A number of hospitals now have a specialist bereavement midwife or nurse whom you can talk to, and some GP practices are able to provide counselling.

Follow up

Different hospitals and community health services offer different kinds of follow up after a miscarriage.

If you miscarry in hospital, you may be offered an appointment with the consultant. This appointment is an opportunity to get the results of any investigations, get answers to questions about the cause of the loss, find out about any treatment that might be available and/or about preventing another miscarriage in the future. You may have a lot of questions you want to ask and it will help if you write them down beforehand so you can make the most of the appointment. You may not get answers to all the questions you have. Sometimes the answers simply aren't known. Sometimes, unfortunately, the appointment is rushed or the doctor is not well prepared. It may help to talk to your GP, who may be able to find out more for you.

Whether you miscarried in hospital or at home, you may prefer to receive follow-up care from your GP, especially if you already have a good relationship with him or her. You can see your GP to talk about the miscarriage, and you may also want to talk about care before and during a future pregnancy. If you are not happy with your GP's care, this may be the time to consider changing so you can feel more confident in a future pregnancy.

Another pregnancy

Deciding whether or not to try again can be difficult. It may be something you don't want to think about for some time, or it may be all you can think about. For some women, there is an overwhelming urge to be pregnant

again as soon as possible. This is not necessarily to replace the baby they have lost – most women feel this would be impossible – but it may answer a physical as well as an emotional need, as Tracy remembers:

I had so much love to give but no outlet for it – I needed a baby to hold.

Other women cannot consider another pregnancy, at least for some time. This may be because of fear of another loss, or it may be that even thinking about having another baby feels disloyal to the baby they have lost. These feelings may change over time, and you do not have to make a decision immediately.

It is crucial to find good care and emotional support in a future pregnancy. You are likely to feel anxious throughout the pregnancy, especially as you approach the time when your last baby died. Others close to you, including children, may share some of this anxiety too. Making sure that you have good medical care and the support of people who understand your needs can make a real difference.

Sources of support

If you would like further support and/or information, the following organisations are there to help:

The Miscarriage Association

c/o Clayton Hospital, Northgate, Wakefield WF1 3JS.

Tel: 01924 200799

email: info@miscarriageassociation.org.uk

www.miscarriageassociation.org.uk

Offers support and information on pregnancy loss through a staffed helpline, telephone support volunteers, support groups and a range of leaflets. We may be able to provide additional information on some aspects of late miscarriage.

SANDS (Stillbirth and Neonatal Death Society)

28 Portland Place, London W1N 4DE.

Tel: 020 7436 5881 www.uk-sands.org

Offers support and information on stillbirth and neonatal death through local support groups, publications and a helpline.

British Association for Counselling and Psychotherapy

BACP House, Unit 15 St John's Business Park, Lutterworth, Leics LE17 4HB
Tel: 0870 443 5252 www.bacp.co.uk

Maintains a register of qualified counsellors and can help you find a counsellor in your area.

Relate

Herbert Gray College, Little Church Street, Rugby CV21 3AP
Tel: 0845 456 1310 www.relate.org.uk

Offers counselling for couples or individual partners with relationship problems

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