16 The loss of your baby

Some women may have to cope with miscarriage, ectopic pregnancy, stillbirth or neonatal death (death shortly after birth). This chapter explains why some of these things may happen.

Help and support

If your baby dies during pregnancy or shortly after birth, you will need both information and support. Each Trust has a bereavement coordinator and bereavement midwife who can support you and also put you in touch with other people and organisations who can help you. More information can also be found on your Trust website by searching for 'bereavement support'.

Talk to the people close to you about how you feel, and to your midwife, doctor or health visitor about what has happened and why. Sometimes it is easier to talk to someone who is not a family member or friend, such as the health professionals mentioned above.

There are also a number of voluntary organisations that offer support and information. These are often run by bereaved parents. It can be very helpful to talk to another parent who has been through a similar experience.

The following organisations may help:

The **Ectopic Pregnancy Trust** (www.ectopic.org.uk) offers support and information for parents who have had an ectopic pregnancy. They have a helpline on 020 7733 2653 and can put you in touch with other people who have had an ectopic pregnancy.

The **Miscarriage Association** (www.miscarriageassociation.org.uk) can give you information and put you in touch with other parents who have experienced a miscarriage. You can call their helpline on 01924 200 799.

Sands (www.sands.org.uk) can put you in touch with other parents who have had a late miscarriage, stillbirth or neonatal death. They also have an online community at www.sands.community/login and a parents' telephone helpline on 0808 164 3332.

Ectopic pregnancy

After fertilisation, the egg should move down into the uterus to develop. Sometimes it gets stuck in the fallopian tube and begins to grow there. This is called an ectopic or tubal pregnancy. Rarely, the egg can become stuck elsewhere, such as the ovary or the cervix. The fertilised egg cannot develop properly and your health may be at serious risk if the pregnancy continues. The egg has to be removed. This can be done through an operation or with medicines.

Ectopic pregnancy can be caused by damage in the fallopian tube, possibly as a result of an infection. Previous abdominal surgery and previous ectopic pregnancy can also increase the risk. The warning signs start soon after a missed period.

These are:

- severe pain on one side, low down in the abdomen;
- vaginal bleeding or a brown watery discharge;
- pain in your shoulders;
- feeling dizzy or faint;
- pain when you have a bowel movement.

If you have any of these symptoms and you might be pregnant – even if you have not had a positive pregnancy test – you should see your doctor immediately.

Some women have no obvious signs or symptoms at all and an ectopic pregnancy may sometimes be mistaken for irritable bowel syndrome, food poisoning or even appendicitis.

Afterwards

You almost certainly will feel a strong sense of loss and it is important to give yourself time to grieve. An ectopic pregnancy involves abdominal surgery or treatment with powerful medicines. It may affect your chances of becoming pregnant again.

It may be helpful to talk to your doctor to discuss the possible causes and whether your chances of conceiving a baby have been affected.

Miscarriage

If a pregnancy ends before the 24th week, it is known as a miscarriage. Miscarriages are quite common in the first three months of pregnancy. At least one in six confirmed pregnancies end this way. Many early miscarriages (before 14 weeks) happen because there is something wrong with the development of the baby. There can be other causes, such as hormone or blood-clotting problems. A later miscarriage may be due to an infection, problems in the placenta, or the cervix being weak and opening too early in the pregnancy.

A miscarriage in the first few weeks may start like a period, with spotting or bleeding and mild cramps or backache. The pain and bleeding may get worse and there can be heavy bleeding, blood clots and quite severe cramping pains. With a later miscarriage, you may go through an early labour. If you bleed

or begin to have pains at any stage of pregnancy, you should contact your GP or midwife. You could also contact your local early pregnancy unit. If you are more than six or seven weeks pregnant, you may be referred for an ultrasound scan to see if your baby has a heartbeat and is developing normally. Sometimes the bleeding stops by itself and your pregnancy will carry on quite normally.

Some women find out that their baby has died only when they have a routine scan. If they have had no pain or bleeding, this can come as a terrible shock, especially if the scan shows that the baby died days or weeks before. This is sometimes called a missed or silent miscarriage.

Treatment for miscarriage

Sometimes it is preferable to wait and let the miscarriage happen naturally, but there are three ways of actively managing a miscarriage:

- **Medicine.** You may be offered tablets or pessaries to start the process of miscarriage.
- **Operation.** If you have been pregnant for less than 14 weeks, your doctor may advise an operation called an ERPC (evacuation of retained products of conception). It is done under anaesthetic. The cervix is gently widened and the contents of your uterus are removed by suction.
- **Induced labour.** If your baby dies after about 14 weeks, you may go into labour. If this doesn't happen, you will be offered tablets that start labour. Although some women would prefer not to go through labour, this is safer for you than an operation to remove the baby. You will be cared for and supported throughout the labour and the birth of your baby.

Afterwards

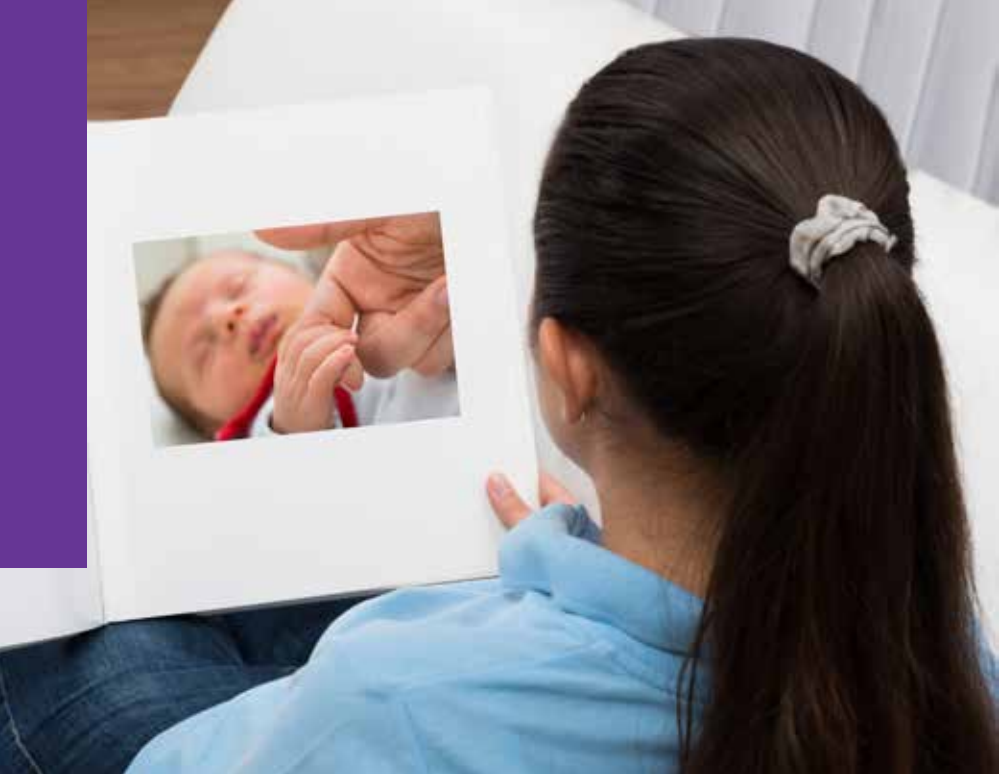
One early miscarriage is unlikely to affect your chances of having a baby in the future. If you have three or more early miscarriages in a row, you should be referred to a specialist for further investigations. However, sometimes no clear cause can be found.

Both women and men find it difficult to come to terms with a miscarriage at any stage. You will almost certainly feel a sense of loss. You will need time to grieve over the lost baby just as you would over the death of

anyone close to you, especially if the miscarriage has happened later in your pregnancy. You may feel shocked, distressed, angry, or just numb. You may feel guilty, wondering whether your miscarriage was caused by anything you did or did not do. It is important to know that, whatever the cause, miscarriage is never anyone's fault. If a miscarriage is going to happen, there is very little that anyone can do to stop it.

Some people find having something to remember their baby by helps. In an early loss, this may be a copy of a scan picture. If you have a late miscarriage, you may be able to see and hold your baby if you wish. You might also be able to take photographs, footprints and handprints as a keepsake. Some hospitals offer parents a certificate to commemorate their baby. This is done because there is no formal registration of a baby who dies before 24 weeks of pregnancy.

Try to talk about your feelings with your partner and those close to you. You might also want to contact the Miscarriage Association or SANDS (see page 179).



Stillbirth and neonatal death

In the UK around 3,000 babies are stillborn every year. This means that the pregnancy has lasted for 24 weeks or more and the baby is dead when it is born. About 1,300 babies also die shortly after birth.

Sometimes a baby dies in the uterus (an intra-uterine death or IUD) but labour does not start spontaneously. If this happens, you will be given medicines to induce the labour. This is the safest way of delivering the baby. It also means that you and your partner can see and hold the baby at birth if you want to.

Following a stillbirth or in the event of a baby dying in the first month of life, a form called a perinatal death notification (PDN) is completed by a health professional. Information is collected about mothers and babies from pregnancy through to birth and the early newborn period. The form, which is anonymised (it contains no information that could identify individuals), is then sent to a national surveillance programme which is run by a consortium called MBRRACE-UK. MBRRACE-UK conducts a national perinatal mortality surveillance programme and topic specific confidential enquiries. This work, which is jointly funded by the UK Departments of Heath, brings together the information and learning associated with every stillbirth and neonatal death and develops recommendations to improve the care provided to women, babies and families during pregnancy, childbirth and the newborn period.

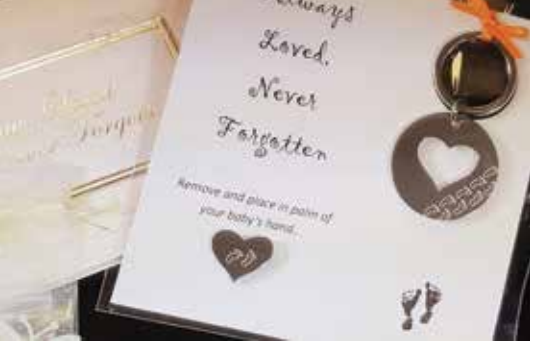
Further information on the work of MBRRACE-UK/NIMACH can be obtained by contacting the NIMACH office on 028 9536 3481 or at pha.site/mbrrace-uk

It is devastating to experience a stillbirth or neonatal death.

You and your partner are likely to experience a range of emotions that come and go unpredictably. These can include disbelief, anger, guilt and grief. Some women think they can hear their baby crying, and it is not uncommon for mothers to think that they can still feel their baby kicking inside. The grief is usually most intense in the early months after the loss. Some parents find helpful to create memories of their baby, for example they may see and hold their baby and give their baby a name. You may want to have a photograph of your baby and to keep some mementos, such as a lock of hair, hand and footprints or the baby's shawl. All this can help you and your family to remember your baby as a real person and may, in time, help you to live with your loss. You may also find it helpful to talk to your GP, community midwife or health visitor or to other parents who have lost a baby. SANDS can put you in touch with other parents who can offer support and information (see page 179).

Post-mortems

One of the first questions you are likely to ask is why your baby died. A post-mortem examination can help to provide some answers, although sometimes no clear cause is found. A post-mortem



may, however, provide other information that could be helpful for future pregnancies and may rule out certain causes. If it is thought that a post-mortem could be helpful, a senior doctor or midwife will discuss this with you and explain the possible benefits.

If you decide to have a full or partial post-mortem, you will be asked to sign a consent form. When the post-mortem report is available, you will be offered an appointment with a consultant who can explain the results to you and also what these might mean for a future pregnancy.

For those parents who choose to have a post-mortem on their baby, this will be carried out in Alderhay Women's and Children's Trust.

For those parents who choose not to have a post-mortem, other tests including genetic testing and testing your placenta may provide important answers as to why your baby died.

Multiple births

The loss of one baby from a multiple pregnancy is very difficult for any parent. Grieving for the baby who has died while caring for and celebrating the life of the surviving baby brings very mixed and complex emotions. Often the surviving baby is premature and in a neonatal unit, causing additional concern. For further information and support, contact Twins Trust (www.twinstrust.org). Staff in the neonatal unit will support you through this difficult time.

Saying goodbye to your baby

A funeral or some other way of saying goodbye can be a very important part of coping with your loss, however early it happens.

If your baby dies before 24 weeks, your midwife will provide you with information and the hospital may offer to arrange for a cremation or burial, possibly together with other babies who have died in pregnancy. If you prefer to take your baby home or to make your own arrangements, you can do that. You may need some form of certification from the hospital and they should provide helpful information and contacts. The Miscarriage Association and SANDS (see page 179) can provide further support and information.

If your baby dies after 24 weeks, you will need to register your baby's birth (even if they were stillborn) with the Registrar of Births, Deaths and Marriages. The hospital will offer to arrange a funeral, burial or cremation free of charge, or you may choose to organise this yourself. The hospital chaplain will be able to help you. Alternatively, you may prefer to contact someone from your own religious community, the Miscarriage Association or SANDS about the kind of funeral you want. You do not have to attend the funeral if you don't want to.

Many hospitals arrange a regular service of remembrance for all babies who die in pregnancy, at birth or in infancy. Again, you can choose to attend if you wish.

Many parents are surprised at how much and how long they grieve after losing a baby. Friends and acquaintances often don't know what to say or how to offer support, and they may expect you to get back to 'normal' long before that is possible. You may find it helpful to contact SANDS or the Miscarriage Association so that you can talk to people who have been through similar experiences and who can offer you support and information. You should be entitled to maternity leave if your baby is stillborn or dies after 24 weeks.