

Supporting you through
difficult family times

Looking ahead to another pregnancy

“For me this time would best be described as emotionally exhausting, one day full of hope and expectation, the next totally pessimistic and full of despair.”

**Antenatal
Results &
Choices**

**arc-uk.org
Helpline 020 7713 7486**

Introduction

The loss of a baby is a physically and emotionally traumatic experience. Both you and your partner will need time to recover. You will never forget your baby, and you need to grieve in your own way and in your own time.

Deciding to become pregnant again after the loss of your baby can be a source of great hope, but it can also be emotionally complicated and painful. Parents can feel conflict between treasuring memories of the baby who died and wanting to have another, healthy baby. The fact that the loss came after a prenatal diagnosis can make the prospect of scans and other tests particularly daunting.

This booklet has been written to help you think about some of the issues around becoming pregnant again, and some of the questions you might face during another pregnancy. It talks about practical things as well as some of the emotional issues. Throughout we use 'you' to refer to a couple when both are involved or to either one when that is relevant.

Thinking about becoming pregnant again

Doctors often recommend that you wait about three months or a couple of menstrual cycles before trying to conceive again. This is not based on hard evidence – more that it makes it easier for them to date a subsequent pregnancy. Some parents are desperate to try again as soon as possible, while others need more time. For some, trying again is a healing process in itself. It is very individual.

There will be some women who are older and couples with fertility issues who feel the pressure of time. You will need to balance the conflicting desires in a way that suits you. If you feel you want to start trying again before three months then go ahead.

If there is a genetic factor that means you will always have a risk of conceiving a baby with a particular condition, this may play an important part in your decision. If you aren't sure about the cause of your baby's condition and the risk of future pregnancies being affected then NHS genetic counselling may be helpful. Your doctor will be able to advise you and refer you to your regional genetics service if appropriate.

There may be pressure from others to try again, but it's important to concentrate on what is best for you and your partner. Only the two of you can decide what you want to do and it is important that you talk as honestly and openly as you can about how you feel. You may each feel differently about another pregnancy. It can help to take the time you need to come to a decision together. Some couples decide not to try for another baby.

There can be extra challenges ahead if you are a single parent, or if pregnancy will involve assisted conception. ARC has supported many people in these circumstances through a subsequent pregnancy.

Sexual relationships are sometimes difficult after the loss of a baby and your feelings and attitude may change as you go through your grief. This will inevitably have an impact on how you feel about becoming pregnant again. If any of these difficult issues are causing problems in your relationship, you might want to talk to your GP or ARC about accessing counselling.

The unplanned pregnancy

Not all pregnancies are planned. You may conceive unexpectedly or sooner than you had wished. Some women find this loss of control disturbing; others find it as hopeful sign. Partners can also have mixed reactions to an unplanned pregnancy.

Some partners mention the powerlessness they felt in the previous pregnancy and fear finding themselves in the same position again. You might both be shocked and it might take a while to be able to accept your new pregnancy and to work out how you feel about it. This adjustment may be hard and involve complex emotions. Remember you can always offload on the ARC helpline.

Some women have mentioned feeling guilty for not having managed to prepare physically in the way they might have wanted to. It is not your fault that you haven't arranged everything 'perfectly' – very few women do. You might still find some of the information that follows useful in managing your pregnancy, and there is a list of positive and practical things that every pregnant woman can do at the end of the booklet.

Remember you can contact ARC at any stage if you need support and understanding or would like to talk through your worries with someone outside your circle of concerned family and friends.

Preparing for pregnancy

Some couples feel guilty after the loss of their baby and some believe that what happened was somehow their fault. While this is a natural and common feeling, what happened in your previous pregnancy is very unlikely to have been affected by anything you did or didn't do. Some women feel burdened by a desperate need to do everything 'right' next time around. In reality, very few fetal anomalies can be prevented. There are, however some simple things that you can do to keep yourself healthy and give your baby the best chance.

Once you have decided to try for another baby, you might like to make sure you are looking after yourself. Health professionals sometimes describe this as 'preconception care' and you can get more detailed advice from your GP. Your general health before and around conception is important both for yourself during the pregnancy and for your baby.

- You don't need to eat anything special, but it is a good idea to have a healthy balanced diet.
- Exercise and general physical fitness will help keep your body in good condition.
- If you smoke, try to stop before you conceive. Smoking can affect fertility in men and women and may mean you take longer to conceive.
- It is best not to drink too much alcohol. Alcohol can also affect fertility in men and women.
- If you have a condition that requires long term medication or treatment and are planning a pregnancy, talk to your doctor.
- If you are using the contraceptive pill, doctors recommend that you stop at least three months before you try to conceive.

Folic acid

Taking supplements of the vitamin folic acid for three months before and after conception can help prevent neural tube defects, such as spina bifida. The Department of Health recommends that all women planning a pregnancy should take a 0.4 mg folic acid tablet every day and continue for the first 12 weeks of pregnancy. You can buy folic acid tablets in chemists and health food stores. The best advice is to start taking folic acid at least three months before you wish to conceive, but if you are already pregnant, it isn't too late to start now.

For women who have had a previous pregnancy affected by a neural tube defect, there is a higher dose 5mg folic acid tablet that is available on prescription.

Drugs

Some prescribed and over the counter drugs can harm the baby. It is sensible to be cautious about taking any medicines, including homeopathic and herbal remedies, unless a doctor or pharmacist says they are safe. If you are pregnant, or trying to conceive, make sure your dentist or doctor knows before giving you any treatment or medicines.

Illegal or recreational drugs can affect your fertility and the baby's health. If this is an issue for you can talk in confidence to your GP or contact Frank, the **National Drugs Helpline on 0300 123 6600 or visit www.talktofrank.com**

Conception

Whatever advice you follow, some pregnancies are conceived easily and others take longer. Each pregnancy is different and your previous experience won't necessarily tell you what will happen this time. Try not to worry if conception doesn't happen as quickly as you would like.

An average healthy couple can take up to a year to conceive, and this can take longer for women over 30. You may be frightened of failure and find yourself watching for any sign that you are pregnant again. You may find the arrival of your period hits hard and intensifies your grief. You may feel your body is letting you down. These are difficult but very normal feelings.

It can be hard not to let your desire to be pregnant dominate your life. Trying to involve yourself in other things may help you to feel better. Your desperation to conceive can mean that having sex becomes very pressured. Try to make sure you and your partner communicate how you are feeling and be kind to one another. You can always use the ARC Helpline to talk through these difficult feelings if it helps.

It can help your chances of conceiving if you are aware of your menstrual cycle and when you are ovulating. You could chart your cycle in a diary to help you recognise the signs for when you are ovulating. However, it can be unhelpful to get too obsessive about this.

Assisted conception

If you know you have problems conceiving or want to access PGT (pre-implantation genetic testing) because you know you carry a genetic condition, you may be considering fertility treatment such as IVF. Unfortunately, it is not always easy to obtain this on the NHS, so it can be a very expensive option. It is also a very demanding process both physically and emotionally, so you may want to feel ready for this before embarking on it. A genetic counsellor can be helpful in talking you through your options.

Being pregnant again

It can be helpful to contact a midwife or doctor fairly soon after you know you are pregnant. This will help you to plan the best care for you and your baby. It can be very hard if the people

"Many of them would greet me with, 'Hello, first baby isn't it?' I'd have a debate with myself about what to say, if anything... because I knew that if I explained, I'd start to get upset, my blood pressure would go up and I'd start crying etc etc, which I didn't want to do. It may be difficult to tell people, especially when they assume this is your first baby, but if you can tell people it will probably help them understand you better."

– ARC parent

caring for you appear not to know about your previous experience. You will need to think about how you react to this.

This pregnancy is likely to be emotionally difficult for you. You may be full of hope, fear and relief all at the same time. Some parents find that they not only worry about the same thing happening again, but also about miscarriage and other things that may go wrong. You may find that you become extremely over-protective of yourself and your baby. Although these worries are natural, try not to let your anxieties take over.

Please use ARC as a source of support and talk to your midwife or doctor about any difficulties you may have.

Some parents value being cared for at the same hospitals and clinics, and perhaps even by some of the same staff as during their previous pregnancy. You might want to think about whether this is important to you or whether you would prefer to book your care in a different hospital or unit. Your GP can help you access the care you want.

Antenatal Testing

You know better than anyone that antenatal testing is not just there to provide reassurance. Most ARC parents find the whole process of antenatal testing in future pregnancies very worrying. Do raise your concerns with doctors and midwives. It might be helpful to speak to the antenatal screening midwife at your hospital as s/he will have a good understanding of your options. Of course it is up to you to decide which tests, if any, you want. And you can call the ARC helpline to discuss your options around testing.

You will be offered the same tests as every other pregnant woman. You may also be offered different tests, depending on what was diagnosed in your previous pregnancy. We talk about the tests you may be offered in the section below, and raise some of the issues you might want to consider. Whichever tests you decide to have, your previous experience is likely to make the process of having them, and waiting for the results, particularly stressful. You might want to make sure that you have someone with you, both when you are having the tests and when the results are due, to give you support.

The tests you might be offered

Ultrasound scans

All women will be offered a scan early in pregnancy (usually between 11 and 13 weeks) either as part of Down's, Edwards' and Patau's syndrome screening or in order to date your pregnancy as accurately as possible. Occasionally major anomalies can be picked up at this scan, but many anomalies will not be visible at this early stage.

The 'fetal anomaly' scan which specifically looks for structural anomalies in the baby is usually carried out between 18+0 and 20+6 weeks. For some conditions you will be referred to a specialist fetal medicine unit for scans. You are likely to be anxious at any scan, and this will be especially true if your baby's condition was picked up on scan before. You might want to check if staff are aware of your previous experience so that they are sensitive to your anxieties and concerns.

Maternal blood tests

Routine blood tests are offered to all pregnant women to check their blood group, blood count and to rule out certain infections. Most of the problems that these tests identify can be successfully treated to keep you and your baby in good health.

Screening for sickle cell and thalassaemia

Dependent on your ethnic origin you may be offered a blood test to screen for these two conditions. They are both inherited conditions so can only affect a baby if both parents are carriers.

Screening for Down's syndrome, Patau's and Edwards' syndromes

Combined screening (11 – 13 weeks)

At the time of writing this is the recommended screening test by the UK National Screening Committee (UKNSC) and the National Institute for Health and Clinical Excellence (NICE).

It involves a nuchal translucency scan and a blood test. The NT measurement is combined with two pregnancy hormones (PAPP-A, and Free beta hCG) along with the mother's age and the gestational age of the baby to give a statistical chance of the baby having Down's syndrome.

The test will detect approximately 85 – 90% of affected pregnancies.

In England, Scotland and Wales, non-invasive prenatal testing (NIPT) or invasive diagnostic tests are offered to those who have a combined screening result of between 1 in 2 and 1 in 150.

NIPT will detect approximately 99% of pregnancies with Down's syndrome. It is also a good screening test for Edward's syndrome and Patau's syndrome.

If you are not offered NIPT, it is available in the private sector. You can call or email ARC to check what's available in your area. We also recommend reading through the sections on NIPT on our website:

www.arc-uk.org/tests-explained/non-invasive-prenatal-testing-nipt

Quad test (14 – 20 weeks)

For women who are unable to have the combined screening (perhaps because they fall outside the gestational window or the sonographer couldn't get an NT measurement), the Down's syndrome screening test offered is a blood test. Note that the quad test screens for Down's syndrome only as the baby will be checked for indicators of Edwards' or Patau's syndromes at the fetal anomaly scan.

Four substances are measured from the blood test (afp, ue3, hCG and inhibin). These are naturally occurring hormones that have crossed into the mother's blood from the baby. The concentration of these substances is measured and combined with the mother's age and the gestational age of the baby to give a statistical chance of the baby having Down's syndrome. This test will detect approximately 75% – 80% of pregnancies with Down's syndrome.

Parents who have had a previous diagnosis of chromosomal anomalies

If chromosomal anomalies were diagnosed in your previous pregnancy, you may be offered diagnostic procedures, either CVS or amniocentesis whether you have screening or not. Some parents need the definite answer these tests provide but others would rather avoid the risk of an invasive test and choose to go for screening first. Only you know what will help you manage your pregnancy so let your health professionals know what you want.

Invasive diagnostic tests

Even if you are sure that having a diagnostic test is right for you, it can be very difficult to manage your anxieties around the procedure and waiting for results. You should feel able to ask to be referred to a specialist fetal medicine unit and for your tests to be carried out by an experienced clinician if you feel this would help you. It is never an easy decision to undergo one of the invasive diagnostic procedures because of the small but always significant risk of procedure-related miscarriage. Only the CVS or amniocentesis can give a yes/no answer on chromosomal conditions and some women know that they need this clarity to help them manage their anxieties.

CVS (Chorionic villus sampling)

CVS is usually done from 11 to 14 weeks. Using an ultrasound scan as a guide, a very thin needle is used to take a tiny sample of tissue from the edge of the placenta. This fine needle will either be put through your abdomen or in rare cases your vagina. The cells from the tissue

can be tested for Down's syndrome and other chromosomal and inherited disorders. Some women cannot have a CVS because of the position of their placenta.

The sample is then sent to a laboratory to be analysed. Very occasionally the laboratory is unable to get an accurate result from the sample. If this is the case, you will be offered an amniocentesis.

Some women say the procedure feels uncomfortable and it is not unusual to feel some period-like cramping pains afterwards. It is a good idea to take it easy for 48 hours after the procedure and avoid strenuous physical activity such as heavy lifting.

Amniocentesis

Amniocentesis can be carried out from around the 16th week of pregnancy onwards. Under ultrasound guidance, a fine needle is passed through the mother's abdomen into the uterus and a small sample of amniotic fluid surrounding the baby is collected. The fluid contains cells from the baby which can be analysed to check for chromosomal changes. Occasionally, the fluid may be tested for a particular problem such as an infection.

Most women do not describe the procedure as painful but it can feel uncomfortable and it is not unusual to feel some period-like cramping pains afterwards. It is a good idea to take it easy for 48 hours after the procedure and avoid strenuous physical activity such as heavy lifting.

Getting results

Rapid results

Q-PCR and FISH are molecular tests that can be performed on the sample to provide a rapid but accurate diagnosis of Down's syndrome and two other rare but serious chromosomal syndromes called Patau's and Edwards' syndromes. Sometimes the test can look for other specific chromosome conditions. Results take on average three working days.

Full karyotype

A full karyotype means the laboratory use cells from the sample to look at all the baby's chromosomes under a microscope. They check for any major changes in the chromosomes and can tell the baby's sex. It is a longer process than the rapid tests and so results can take up to three weeks.

Micro array

Microarray (sometimes called Array CGH) is an advanced method of testing a sample from CVS or amnio. It can detect more subtle changes in a baby's chromosomes. This means it looks for where there are deletions (bits missing) or duplications (where there are extra bits) in the baby's DNA that would not be identified through the full karyotype. It is now sometimes used instead of or as well as karyotyping.

Whole genome/exome sequencing

It is now technically possible to sequence the whole fetal genome (all of a baby's DNA) or the part of the genome that codes for proteins (the exome). This is sometimes carried out in pregnancy when scan findings indicate a genetic condition that could not be diagnosed by other forms of testing. It can take three to four weeks to get information from this form of testing.

Waiting for antenatal test results

Whichever tests you decide to have, waiting for results is likely to be an anxious time for you after your previous experience. While there are no guarantees, most conditions do not recur. Some parents know they carry a genetic condition and so know they could have another affected baby.

You know better than anyone (perhaps too much!) about what might be diagnosed in a pregnancy and this can make waiting for results agonising.

"For me this time would best be described as emotionally exhausting, full of highs and lows, one day full of hope and expectation, the next totally pessimistic and full of despair. I felt unable to think of anything other than the test result, couldn't sleep much."

– ARC Parent

Many ARC women and partners contact us at this time to talk through their fears and worries. Some have said that they were frightened to allow themselves to become really involved in the pregnancy until after the test results showed all was well.

Telling others about the pregnancy

Some women and couples choose to wait for reassuring news from tests until telling other people, including other children, about the pregnancy.

They often find that this reduces the pressure during early pregnancy. But not being able to talk about your anxieties outside your relationship can also cause stress. Remember, ARC's confidential helpline is always there for you so you don't have to deal with this on your own.

The rest of your pregnancy

For most expectant parents, the testing process will be over by four to five months. Many people think that at this point an ARC 'parent' becomes just like any other expectant parent, looking forward to a happy outcome. This is not always the case, as many women describe periods of anxiety until their baby arrives. However much reassurance you receive, it is quite normal for expectant parents in your situation to be especially anxious.

After the loss of a baby, a lot of women say that they worry much more about all of the other issues and problems that can affect pregnancies. They say they fear losing the baby, stillbirth and cot death. This is completely normal after your previous experience but may be difficult for others to understand. ARC helpline staff and support network volunteers will understand your fears and confusions, so please feel you can share them with us if you need to. Some people have found seeing a counsellor or therapist helpful too.

Remembering

All women compare a pregnancy to their previous experience, and for you this might be particularly painful and poignant. You may feel physically similar to before, or perhaps very different. Whatever your physical health, another pregnancy will be emotionally complex for you. You will probably find yourself remembering your baby as you move forward. Some parents have described feeling guilty because they see themselves as being disloyal to the baby they lost as they look towards a new arrival.

There will be stages, dates and perhaps anniversaries that are significant to you, and it might help if you and your partner can give time to whatever feelings emerge then. Many parents feel a mixture of hope and grief, which can be hard to deal with. Grieving and crying will not harm the baby you are carrying and does not mean that you cannot look forward to the birth.

Another baby

Giving birth to a healthy baby is a dream come true for most ARC parents, and everyone will be delighted for you. Many parents though, have found that their new baby brings difficult feelings along with the joy.

“We are now blessed with a baby son, our rainbow baby, following IVF. I m so lucky to have become a mother and I know he would not exist if our path had been different. However, the sadness I feel over our loss coexists with that joy.”

– ARC Parent

Memories of the baby who died are often very strong at this time and you can't help thinking about what might have been. Some parents feel guilty. Bonding with your new baby may be harder because of your previous loss. Your baby may bring your grief to the surface, bringing back feelings which you hadn't expected. Friends and family may not understand which may cause difficulties for you. If there are other children in your family, this may be a difficult time for them too. Parents and families find that moving forward with a new baby is a help in coming to terms with their loss, but this is not always easy. Lots of ARC parents feel the need for support at this time. Please contact us if you need to – ARC will understand.

Positive and practical things you can do

No-one can guarantee the outcome of a pregnancy, but there are a number of fairly simple things that you can do to help.

Your health care professionals are the best people to give you advice in your individual circumstances, but here are some recommendations that every pregnant woman can follow.

No woman can ever have complete control over the development of a pregnancy; you know that all too well. However, if you follow this simple advice, you will know that you have done everything you can for you and your baby. More detailed information about being healthy in pregnancy can be found at www.nhs.uk/conditions/pregnancy-and-baby/ or from your midwife.

Things you can do

Exercise

Regular, gentle exercise is good for you during pregnancy. You may find it helps you to feel positive and strong. Many pregnant women find swimming relaxing and enjoyable, particularly in later pregnancy. Yoga can also be helpful as it can tone your body and relax you too. Although exercise is beneficial, it is important not to overdo it. Listen to your body and try not to do too much. Ask your doctor or midwife if you have concerns about pursuing a particular form of exercise while pregnant.

Eating well

- You don't need a special diet, but it is sensible to eat a mixture of foods to give you and your baby all the nutrients you need.

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- Eat plenty of fresh fruit and vegetables – at least five portions a day. Make sure you wash them thoroughly before eating.
 - Eat carbohydrates such as bread, potatoes, rice, pasta and cereals.
 - Lean meat (but not liver), fish, pasteurised cheese, eggs, pulses and beans are all good sources of nutrients so aim to have two portions a day.
 - Dairy products (or calcium-rich non-dairy foods) can help your baby's development. You can often find lower fat healthy options.
 - It is recommended that you have two portions of oily fish (mackerel, herring, salmon or sardines) every week. You should limit yourself to one portion of tuna a week.
 - It is a good idea to cut down on sugar and sugary foods as well as high-fat foods as they have no nutritional value.

Things to be careful about

Take special care with some foods

- The safest way to eat eggs is scrambled or hard boiled. This avoids the risk of salmonella.
- It is best to avoid pate and ripened soft and blue veined cheeses (such as brie, stilton etc) because of the risk of listeria infection.
- Make sure all meats are cooked thoroughly (no pink).
- Avoid liver and liver products as they contain high levels of vitamin A which could be harmful to your baby. This is why you should only take vitamin supplements that are designed for pregnant women as others could contain too much vitamin A.
- Don't eat marlin, shark or swordfish. These can contain high levels of mercury, which can damage your baby's developing nervous system.

Alcohol

Light or occasional drinking will not harm your baby, but it is sensible to avoid persistent heavy or 'binge' drinking. Binge drinking is defined as having more than five units at one time. A unit of alcohol is classified as either half a pint of beer or cider, a pub measure of spirits or a small glass of wine.

Smoking

There is no evidence to suggest that smoking causes fetal abnormalities. However, women who smoke while pregnant increase their chances of miscarriage, premature labour or stillbirth. Babies born to smokers tend to be smaller than average, and living with smokers can affect a baby's health. Having said all this, stopping smoking is very hard, especially if you are feeling anxious or stressed. It is important for you and your baby's health that you stop or at least cut down your smoking while you are pregnant. Your GP or midwife can give you help and support or you can get help here: www.nhs.uk/smokefree

Toxoplasmosis

This is an infection caught mainly from undercooked meat or from handling cat poo.

It can cause miscarriage or harm an unborn baby. While you are pregnant, make sure all meat is thoroughly cooked. You don't have to keep away from cats, but avoid their litter trays or make sure you use gloves when cleaning them. It is also sensible to wear gloves for gardening. In general in pregnancy it is a good idea to pay attention to hygiene and wash your hands regularly.

Complementary medicines

Like orthodox medicine, complementary medicines and treatments may be powerful. Just because complementary medicines are labelled as 'natural' doesn't mean they cannot be harmful in pregnancy or when you are trying to conceive. There will be some that could be helpful in pregnancy. Many of the products available in high street chemists and health food shops will be labelled. If in doubt seek expert advice from a doctor or pharmacist.

Scare stories in the media

There are regular articles in newspapers and magazines about what may or may not be good for you in pregnancy. Sometimes the information can be confusing. Not all the stories are based on good medical evidence. If you are worried about something you hear or read, check with your midwife or doctor.

Useful organisations

NHS

www.nhs.uk

For general health advice and information

HFEA

www.hfea.gov.uk

For information on licensed IVF clinics and PGD

British Association for Counselling and Psychotherapy

www.bacp.co.uk

To find an accredited counsellor or psychotherapist in your area – do also ask us at ARC for help with this

Relate

www.relate.org.uk

For relationship counselling

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Need help?

Call our national helpline and speak to a member of our trained team.
Our helpline is open Monday to Friday, 10.00am-5.30pm.

Helpline: 020 7713 7486

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