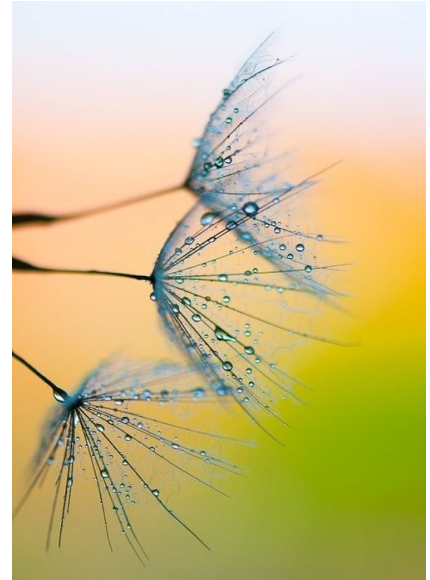


# Anencephaly

This leaflet has been written with the help of parents who have had a pregnancy affected by anencephaly. It includes information that they wish had been available to them at the time of their baby's diagnosis. We hope that you will find it helpful, and if you have any further questions or would just like to talk to us, please do get in touch.

## ***What is anencephaly?***

Anencephaly is the most severe of a group of conditions known as Neural Tube Defects (NTDs). It happens in about 1 in 2,000 pregnancies in the UK, and occurs when an unborn baby's brain doesn't form properly in the womb. All this happens during the first 28 days of pregnancy. Sadly this condition is fatal. Most babies that are diagnosed with this condition will be born prematurely, and will die before, during or very soon after birth. Some babies may live for a few minutes or even a few hours, and **very** rarely for a few days.



## ***What causes anencephaly?***

At the moment, we don't have all the answers to this. We know there are many factors which increase the chances of a baby having anencephaly, such as genetics, diabetes or low levels of folate/B12. Other possibilities are being researched. Unfortunately, this means that it isn't possible to know exactly why it might have happened in this pregnancy.

## ***How is it diagnosed?***

It is possible to diagnose anencephaly by ultrasound scan at the dating scan.

## ***Is there any treatment?***

Unfortunately there is no treatment for anencephaly.

## ***Will my baby be in pain?***

No. Because your baby's brain doesn't develop, there will be no awareness of anything that happens, although there may occasionally be some reflex responses.

## ***Where can I go for more information and support?***

At the moment you may feel like talking only to your family and friends, or a particular professional or faith leader. You may also feel as though you can't talk to anyone at all. It's important to know that you are not alone, and that there are other people and organisations that can provide information and support throughout your pregnancy, loss and afterwards.

**Shine Anencephaly Support** - is a closed Facebook group for anyone dealing with the loss of a child to anencephaly. It is a safe, non judgemental place where you can ask questions and openly discuss your thoughts and fears, with others who share your experience, at any stage of your journey. This group is managed by the Health Team at **Shine**, with the help of volunteers who have first hand experience of a pregnancy affected by anencephaly. Our health team also provide support and important advice on getting ready for a next pregnancy, to help reduce the chances of it happening again. To join the group visit

<https://www.facebook.com/groups/ShineAnencephalySupport/>

For more information email: [marie.mcgonnell@shinecharity.org.uk](mailto:marie.mcgonnell@shinecharity.org.uk)

### ***What happens now?***

Although there is nothing that you, or anyone else can do to change the final outcome, **you do have a choice about what happens next**. Some parents in the UK receiving this diagnosis opt to end their pregnancy early. However, you do have the option of continuing with your pregnancy. **Take time to understand and take in everything that you've been told, so that you don't feel rushed or pressurised into making a decision.**

### ***Opting to end your pregnancy early***

Making the decision to end a much-wanted pregnancy is never easy. Understanding that your baby would not survive in any case, may make this decision easier for some people, but not everyone.

If you are considering ending your pregnancy, it's important to think about whether or not you might want to meet/see your baby. There's no right or wrong way. It's perfectly normal to feel worried about how tiny your baby will be or how they will look. You don't need to make your mind up straightaway, but if you think that you may want to meet your baby you should discuss this with your midwife. As some hospitals may not be able to offer you this option if your baby is under 20 weeks, your care may need to be continued at a different hospital if this is important to you.

### ***Continuing with your pregnancy***

It is important to understand that if you continue with your pregnancy there are higher risks for you. Polyhydramnios (too much amniotic fluid in the womb) may develop, and your baby may not make it to full term.

If you have other children, they will usually pick up how worried or upset you are. When you are ready, it is important to share a little of what is going on and reassure them. A simple but honest explanation is often best.

### ***Organ Donation***

Some parents have continued with an anencephaly pregnancy with the hope of donating some of their baby's organs. If this is something that you are considering, it is important to discuss this carefully with your doctor. However, the chances of donating successfully are **very** slim, owing to prematurity and low birth weight.

### ***Preparing for your baby's delivery***

Use the time before delivery to make plans and preparations for delivery and afterwards. There is no right or wrong way; it is important that it is just as your family chooses it to be. This can include choosing a name, and buying or making an outfit, shawl and little hat. Keep a camera handy for your photos, maybe choose a frame for your picture or your scan. If you have other children, they may wish to draw a picture for the baby. It may also help to arrange to meet some of the midwifery team who will be involved in the delivery of your baby closer to your due date.

### ***Keepsakes of your baby***

This may not be something you think of immediately, but parents often tell us how they gained comfort from having something to remember their baby by.

Examples of this could be:

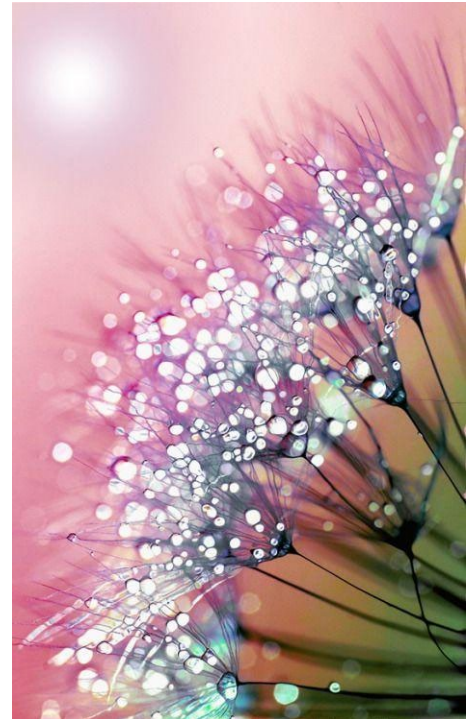
- Scan pictures or photographs
- A recording of your baby's heartbeat (this can be recorded and put into a teddy bear)
- Taking your baby's hand and footprints

Some parents make a memory box for their keepsakes

### ***Planning a funeral for your baby***

Many parents aren't aware that they have choices regarding a funeral. What might be right for one set of parents may not be right for another, and it's so important that you are able to say goodbye to your baby in the way that you want to. Hopefully the following information will help you to understand what's possible, so that you are able to make the best choices for you. It might be helpful to talk to your faith leader and / or a funeral director. **Remember - All babies can have a funeral and it is up to you whether to have one or not.**

Having a burial or a cremation is your choice. Cremation is possible, and if your baby is very tiny, it may be suggested that they are cremated with a cuddly toy of your choosing.



Some hospitals will be able to arrange a funeral for your baby. If you choose this, do check carefully that their arrangements regarding exactly what will happen with your baby are going to be right for you, and that you are comfortable with them. You can choose to arrange and pay for a funeral privately if you prefer (you may be entitled to help with costs if you are on a low income). The first step is to contact a funeral director who will be able to guide you through the process, and help you decide whether you wish to have a service or not.

***What is the likelihood of this happening again?***

Once you've had a pregnancy affected by anencephaly, there is a 1 in 50 chance of it happening again.

Your genes may affect your chances, and small changes to DNA may increase the risk of having another baby with an NTD, so do ask to see a geneticist if you would like to find out if this was the case for your family.

***Is there anything I can do to reduce the chances of it happening again?***

When you are ready, contact **Shine's** Health Team. We can guide you through getting ready for a further pregnancy, and help you identify any changes you can make which might help lower the chance of anencephaly happening again. Also, you can visit our website: <https://www.shinecharity.org.uk/folic-for-life/folic-for-life>



We hope that this information has helped you feel better placed to make the right choices for you and your family at this difficult time. The most important thing to remember is that you are not alone.

For more information email: [marie.mcgonnell@shinecharity.org.uk](mailto:marie.mcgonnell@shinecharity.org.uk) or phone us on **01733 555988**.