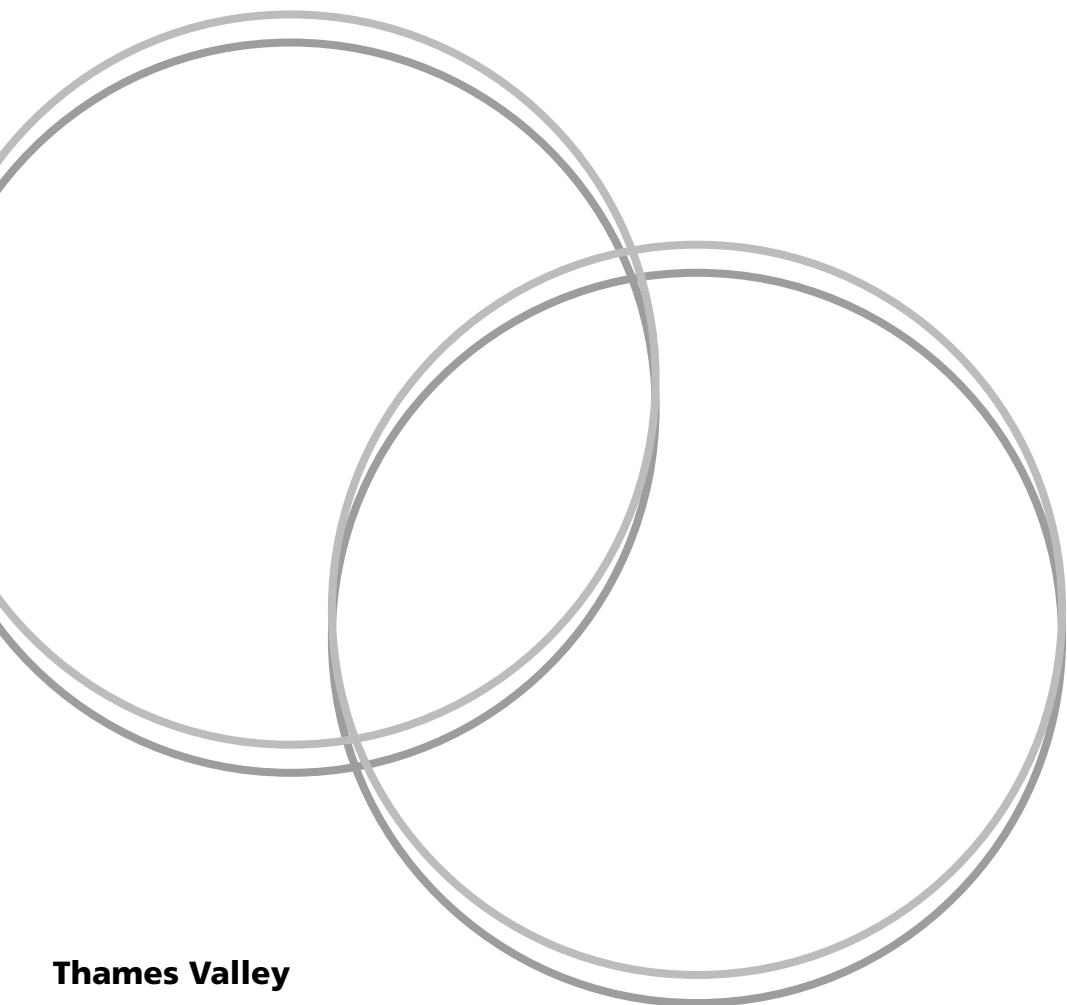


# **Perinatal palliative care**

**Information for parents and carers**



We have created this leaflet for you, because you have received the very difficult news that your unborn baby has a serious life-threatening health condition that we cannot cure.

You should by now have received information about the options available to you.

If you have decided to continue with your pregnancy, we can offer you and your baby a specialised kind of care called **perinatal palliative care**.

**Perinatal** means 'before, during and soon after birth'.

**Palliative care** is the medical care provided for patients with health conditions that medicine cannot heal, and whose lives may be shortened as a result.

There are always things that we can do to care for patients and their families, however long their lives are expected to be.

For babies, this means we support parents to make the most of the time they may have with their baby.

Perinatal palliative care includes help before, during and after birth to make important decisions about the baby's birth and medical care; making sure the baby is comfortable and not in pain; and extra support for the whole family at a very stressful time.

## What is involved

If you decide to continue your pregnancy, we will offer you the opportunity to meet with a consultant newborn specialist.

You may also be able to meet with a specialist in children's palliative care.

You can talk to them about the support you might need during your pregnancy, and how we can help you plan for the birth and caring for your baby after they are born.

## **Uncertain outcomes and flexible plans**

Every baby is different.

Sometimes when a baby has been diagnosed with a very serious life-threatening condition, we cannot be sure what will happen.

It may be that the baby will die in the womb before they are born.

It is also possible that the baby may be born alive, but live for a limited period of time.

Your doctors will give you more specific information about what could happen for your baby.

It is helpful to prepare for a number of possible outcomes – depending on what happens, and how the baby is at any given time.

## **Birth choices**

You may have a choice of places to give birth, depending on your situation.

Things to consider include whether to give birth in a hospital close to your home or in a specialised centre; how to give birth; and how we should monitor your baby during labour.

Your doctors can advise you about the best options, for your own health and for the baby, as well as listening to your views.

## **Care after the birth**

There are important decisions to make about your baby's care after they are born, such as which treatments would be helpful, and which might do more harm than good.

Doctors caring for your baby will want to know what your hopes are for your baby's care, as well as which things concern you the most.

If you are likely to have only a short time with your baby, think about where you would like to spend that time with them.

Some families prefer their baby to stay in the hospital where they were born. Other families choose to go home with their baby, if that is possible.

There is also the option of specialist care in a hospice. Helen and Douglas House in Oxford provides a home-like environment with access to specialised medical and nursing support for babies with very serious life-limiting health conditions.

## **Emotional support**

It is normal to feel a whole range of emotions, including some that you may not expect to feel. If you think it would be helpful for you, we can refer you for psychological support, or put you in touch with local counselling and bereavement charities.

## **Spiritual support**

If you would like spiritual or religious support during your pregnancy or after your baby is born, please let your care team know. There are chaplaincy services and local faith leaders we can contact for you.

## **Memory making and practical planning**

If you would like photographs, hand or footprints, a naming ceremony or the opportunity to make a keepsake box, your midwives or hospice staff will help you to arrange these.

If you want to talk through practical matters, such as registering your baby's birth and death, funeral arrangements and maternity or paternity leave, hospital staff and local charities can help.

## **Sibling support**

If you have other children, the local children's hospice team can help you talk with them in an age-appropriate way.

Some families find it helpful to involve siblings in memory-making or visits, where this is appropriate.

## **Next steps**

If you decide to continue your pregnancy, the midwives and fetal medicine specialists caring for you can arrange for you to see a specialist in newborn care after around 24 weeks of pregnancy.

If you would like this appointment sooner, please let them know and they try to arrange this.

## **Resources**

### **Antenatal results and Choices (ARC)**

Supporting you through your pregnancy: a handbook for parents after a prenatal diagnosis.

**[www.arc-uk.org/for-parents/arc-forum](http://www.arc-uk.org/for-parents/arc-forum)**

### **Oxford Perinatal Palliative Care**

Newborn specialists.

Tel: **01865 221355**

### **Helen and Douglas House**

Oxford-based children's hospice.

**[www.helenanddouglas.org.uk](http://www.helenanddouglas.org.uk)**

### **Petals (bereavement charity)**

**[www.petalscharity.org](http://www.petalscharity.org)**

### **Together for Short lives**

UK-based charity supporting babies, children and young people with life-limiting conditions.

**[www.togetherforshortlives.org.uk](http://www.togetherforshortlives.org.uk)**

Helpline: **0808 8088 100**

## **Perinatal Hospice**

US-based website supporting perinatal palliative care

**[www.perinatalhospice.org](http://www.perinatalhospice.org)**

## **Further reading**

***A Gift of Time. Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief***

by Amy Kuebelbeck and Deborah L. Davis

This book is written by a mother and a journalist offering a practical guide and stories of other parents' experiences.

## Further information

If you would like an interpreter, please speak to the department where you are being seen.

Please also tell them if you would like this information in another format, such as:

- Easy Read
- large print
- braille
- audio
- electronic
- another language.

We have tried to make the information in this leaflet meet your needs. If it does not meet your individual needs or situation, please speak to your healthcare team. They are happy to help.

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[www.ouh.nhs.uk/information](http://www.ouh.nhs.uk/information)



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*Making a difference across our hospitals*

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