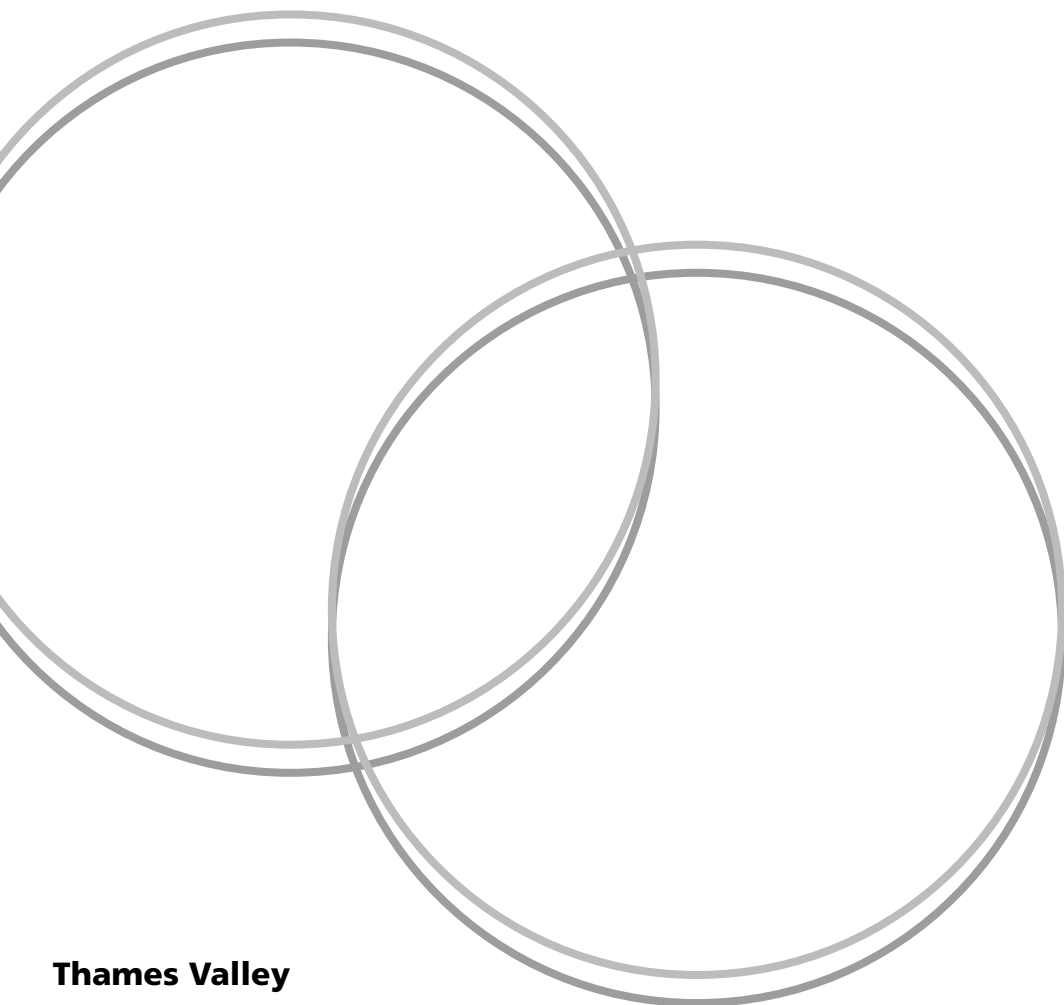




Oxford University Hospitals
NHS Foundation Trust

Perinatal palliative care

Information for parents and carers



Thames Valley

Why have I been given this leaflet?

This leaflet is for women and couples who have received the very difficult news that their unborn baby has a very serious life-threatening health condition that cannot be cured.

You will have already been given some information about options available to you for continuing or not continuing your pregnancy.

This leaflet is to provide some extra information about a form of specialised care for your baby if you decide to continue your pregnancy. This care is called perinatal palliative care.

What is perinatal palliative care?

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

Palliative care is the name given to the specialised form of medical care provided for patients with health conditions that medicine cannot fix, and whose life may be shortened. Although medicine is not always able to cure, there are always things that can be done to care for the patient and their loved ones.

For babies, perinatal palliative care aims to support parents to make the most of the time that they may have with their child. It includes help before, during and after birth to make important decisions relating to birth and the baby's medical care, to make sure baby is comfortable and not in pain, and to provide extra support for the whole family at a very stressful time.

What does it involve?

If you decide to continue your pregnancy, you will be offered the opportunity to meet with a consultant newborn specialist. You may also be able to meet with a specialist in children's palliative care. They would talk with you about what support you need during your pregnancy as well as help make some plans around birth and care of baby after they are born. Those specialists would be able to provide information about other sources of support before and after birth.

Uncertain outcomes and flexible plans

Every baby is different.

Sometimes when baby has been diagnosed with a very serious life-threatening condition, we cannot be sure what will happen. There may be a chance that sadly, baby will die in the womb before they are born. Another possibility is that baby may be born alive, but live for a shorter or longer period of time.

Your doctors will be able to give you more specific information about what could happen for your baby. However, if we are not certain what will happen, sometimes it can be helpful to have a plan that is flexible – depending on what happens, and how baby is at the time.

Choices about birth

Depending on your situation, there can be a range of different choices available. For example, there can be questions about where to give birth (usually this would be in a hospital closer to home or a specialised centre), how to give birth, and how to monitor baby during labour. Your doctors will want to know your views about these, but will also be able to give you some advice about the advantages and disadvantages of different options, both for your own health and for baby.

Decisions about care after birth

There are also important decisions to make about care of baby after they are born. For example, that can include thinking about which treatments would be helpful for baby, which would be unlikely to help, and which might do more harm than good. It will be important for the doctors caring for your baby to know what your hopes are in the care for your child, as well as to know what things are worrying you the most.

One important decision can be about where the best place is to care for baby after birth if it appears that you are going to have little time with baby. Some families prefer for baby to stay in the hospital where baby was born. Others are keen, if possible, to get home with baby as soon as they can. Other families may choose to go with baby to a hospice. In Oxford, Helen and Douglas House provides a home-like environment with access to specialised medical and nursing support for babies who have very serious health conditions that sadly mean they may not survive for a long time.

Next steps

If you decide to continue your pregnancy, the midwives and fetal medicine specialists caring for you can arrange an appointment for you to see a specialist in newborn care. They will usually arrange that after 24 weeks or so of the pregnancy. However, if you would like to be seen sooner, please let them know and if it is possible, they will arrange this for you.

Further information

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/

Oxford Perinatal Palliative Care

Newborn specialists
01865 221355

Helen and Douglas House

Oxford based children's hospice
www.helenanddouglas.org.uk

Thames Valley Network Perinatal Palliative Care Framework

www.patientsafetyoxford.org

Together for Short lives

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

www.togetherforshortlives.org.uk

Helpline: 0808 8088 100

Perinatal Hospice

US based website supporting perinatal palliative care <https://www.perinatalhospice.org>

A Gift of Time. Continuing Your Pregnancy When Your Baby's Life Is Expected to Be Brief – by Amy Keubelbeck, Deborah Davis

This is a book 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.

Author: Consultant Obstetrician and Fetal Medicine Subspecialist
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Oxford University Hospitals NHS Foundation Trust
www.ouh.nhs.uk/information



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Making a difference across our hospitals

charity@ouh.nhs.uk | 01865 743 444 | hospitalcharity.co.uk

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