

# North West Perinatal/Neonatal Palliative Care

## Useful information when an anomaly has been diagnosed in your baby



*"There is no footprint so small, that it does not leave an imprint on this world"*

**This guideline has been produced in partnership with  
the Northwest Paediatric Palliative Care Network**

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### Useful information when an anomaly has been diagnosed in your baby

#### Introduction

Making a decision about your pregnancy, when your baby has been diagnosed with a severe fetal anomaly, can be very difficult and complex. Every woman has the right to make her own choice about whether to end or continue with a pregnancy, as long as the requirements of the abortion act 1969 are met.

This booklet is designed to provide information to women and families facing this decision.

We encourage you to discuss your pregnancy, the diagnosed anomaly, your options, your concerns, and the risks with your health carer as soon as possible. This booklet is not meant to replace their advice.

Being informed about terminating a pregnancy and your other options will enable you to carefully consider your choices and the decisions that you need to make. This will help increase your confidence in making the right decision for you. At the back of this booklet we have provided details of agencies and people you can speak with. We recommend you contact your preferred health carer; whoever you feel most comfortable with is often the best choice.

#### What are my options?

The decision you make about your pregnancy is very important and should not be rushed. You should allow yourself time to come to terms with the diagnosis and what it will mean for you and your baby. Finding out about the specific type and severity of problems your baby has been diagnosed with, and the impact they might have, will help you with making your decision.

It is important for you to understand, acknowledge, reflect and make your own choice about which option is right for you. Depending on your situation the following are options for you to consider:

- Continue with the pregnancy and try to prepare for the needs of you and your new-born baby
- End the pregnancy - termination of pregnancy.

#### Continue with the pregnancy

If continuing with your pregnancy, childbirth and motherhood is an option you wish to consider, you should discuss how your antenatal care and birth will be managed with your health carer.

Being informed about your baby's possible health complications by a neonatologist or paediatric specialist may assist you in preparing for what the outcome may be. Being provided with information on raising a child with a potential health problem may help you understand what to expect for the future. It may also help you to speak to parents and families of children born with the same condition. (Information on the support groups provided at the end of the leaflet).

It may be helpful to meet with a health carer who cares for children with your baby's condition. During the pregnancy your obstetrician and the baby doctor will sit down with you to discuss and plan care for your baby at birth.

Some families wish to continue the pregnancy even though the baby may have problems that may result in baby not being able to survive once born. Paediatricians and neonatologists can also help with practical support and planning for care following delivery. Support is also available for care at home or in a hospice environment if preferred. Spiritual, Emotional and counselling support is available if you need someone to talk to or help with your decisions regardless of if you have any beliefs or none.

## **End the pregnancy**

A termination of pregnancy is a way of ending a pregnancy. The way in which a termination is managed will depend on your situation.

The earlier you have a termination the safer it is for you.

### **Medical termination**

Medical termination is a way to end a pregnancy using drugs (medication) in the form of tablets. The tablets help to stop a hormone needed for pregnancy and to assist the cervix (neck of the womb) to relax and bring on labour and start the termination. You should discuss any possible outcomes and risks associated with this method with your health carer.

### **Surgical termination**

This method of termination of pregnancy is carried out under general anaesthetic (where you are put to sleep).

Most of the hospitals do not offer a surgical termination beyond 12 weeks of gestation. It is important for you to find out what services are available at your local hospital.

### **Fetocide**

If the delivery is likely to occur after 21+6 week of pregnancy, fetocide (stopping the baby's heart by an injection) is strongly recommended to prevent the delivery of a live baby. The procedure is done at the tertiary fetal medicine unit by the fetal medicine specialist.

### **How will my baby look?**

It is important for you to understand that the appearance of your baby may be different to how you imagined, in size, skin condition or features. How far along your pregnancy was and any fetal anomalies will also determine how your baby will look. If you would like to discuss the appearance of your baby you can do so with your health carer.

## **What happens if my baby dies or I have a termination of pregnancy?**

### **Post mortem examination**

Your health carer may discuss the benefits of a post-mortem and placental examination. This examination will only occur with your consent. A perinatal pathologist (doctor) will examine your baby to identify or confirm any abnormalities. This examination may provide valuable information for you for this pregnancy and future pregnancy planning. Results from the post-mortem are usually sent to your consultant obstetrician within six to eight weeks.

### **Rituals and ceremonies**

Regardless of your religious views, spiritual and emotional support is available for you throughout this difficult time. The bereavement midwife or ward midwife can provide information and advice on funeral options available to you. Where required our health carer will complete the consent forms documenting all appropriate options which may include:

A service of naming or blessing; an acknowledgement of the life of your baby.

A memorial service held in the hospital chapel; these services are provided by the hospital chaplaincy on different hospital sites, three times a year. You will receive written information about this from the ward staff or bereavement midwife.

The ward staff will discuss funeral arrangements with you and; assist with planning what is right for you.

## Registration of your baby

If the gestational age of the baby is over 24 weeks or your baby shows signs of life at birth at any gestation, it is a legal requirement to register the baby with the Registry of Births, Deaths and Marriages. The information will be provided to you before leaving hospital.

## Further information

### Support Groups

You may feel that you need to talk to someone about how you are feeling and there are several support groups who may be able to help.

Local Neonatologist or paediatrician

Paediatric specialist

ARC (Antenatal Results and Choices) Tel 0207 631 0285

[www.arc-uk.org](http://www.arc-uk.org)

SANDS (Stillbirth and neonatal death society) Tel (local help line)

Hospital Trust Chaplaincy Team Tel -----

Child Bereavement UK

[www.childbereavementuk.org](http://www.childbereavementuk.org)

Helpline: 0800 02 888 40

email: [support@childbereavementuk.org](mailto:support@childbereavementuk.org)

Runcorn office: 01928577164

This charity supports parents through pregnancy loss, stillbirth and neonatal deaths as well as other situations. They offer online or telephone support.

Newlifefoundation

Nurse Helpline 0800 902 0095

(Mon-Fri 9.30am - 5.00pm)

**Newlife Foundation:** Tel: 01543 462 777

**Newlife Ltd:** Tel: 01543 468 888

**Newlife Foundation for Disabled Children**

Newlife Centre, Hemlock Way, Cannock, Staffordshire, WS11 7GF