NHS
The Leeds Teaching Hospitals
NHS Trust

Cystic Hygroma

Information for patients

Leeds
Maternity Care

This leaflet is aimed at pregnant women with a confirmed cystic hygroma in their baby. The leaflet should only be used to supplement a consultation with an experienced obstetrician.

What is a Cystic Hygroma?

A cystic hygroma is a collection of fluid filled sacs known as cysts that results from malformation of the lymphatic system. By the end of the 5th week of pregnancy, the baby's lymphatic tissues form as lymph sacs. The first to appear serve the chest, arms, neck and head. They sprout a network of channels called lymphatic vessels that maintain fluid in the baby's body and carry fats and immune system cells.

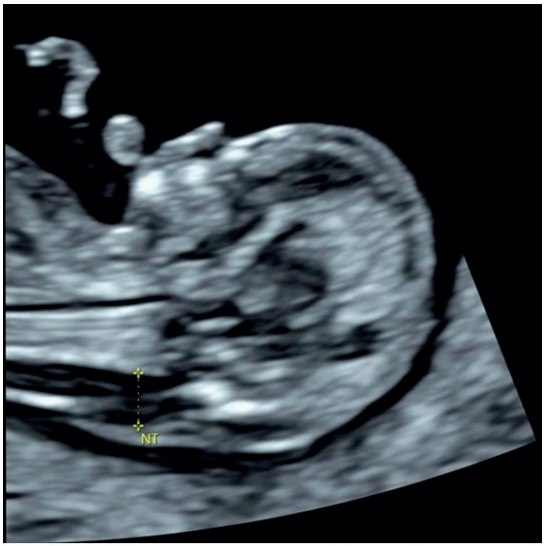
When a problem occurs between the veins and the developing lymph sacs, the sacs expand with fluid and partially or completely block the vessel system.

How is it diagnosed?

At about 10 weeks of pregnancy, ultrasounds show some babies have more fluid than normal at the back of the neck.

This fluid appears as a large, clear space, referred to as an 'increased nuchal thickness' or 'nuchal translucency'

Image of a nuchal translucency at 12 weeks



What does it mean for your baby?

Small cystic hygromas can disappear by themselves, causing no further problems for your baby. However, some cystic hygromas can grow to become very large. This can result in 'hydrops', the formation of extra fluid within the baby's body, which can lead to miscarriage or fetal death. **Hydrops** occurs in 25-75% of cases.

Some cystic hygromas cause additional conditions such as:

- Extra folds of skin on the neck ('webbed neck')
- Tissue swelling
- 'Lymphangiomas', non-cancerous tumours of the skin.

Cystic hygroma may be an isolated problem or it may occur with other abnormalities, such as **cardiac** (heart) abnormalities.

In approximately 60% of babies, the cystic hygroma is part of an underlying problem with baby's chromosomes and we offer a diagnostic test to see if the chromosomes are normal.

A cystic hygroma can be associated with a chromosomal problem called Turner's Syndrome (45X0) in a female baby. It can also be associated with other chromosome problems including Down's Syndrome, Edward's Syndrome and Patau's Syndrome.

Further investigations

- A detailed scan will be arranged with one of the Fetal Medicine Consultants in Leeds
- All women whose baby has a cystic hygroma are offered a test (amniocentesis or chorionic villus sample) to examine the baby's chromosomes in detail
- If an amniocentesis or CVS is performed, a genetic test called a microarray will be done. This test looks at the baby's genetic make up in fine detail but it is not possible to exclude all genetic problems before birth
- A fetal echocardiogram (scan of the baby's heart) will also be offered since there is an association with heart abnormalities in babies with a cystic hygroma
- Regular ultrasound scans are recommended throughout the pregnancy to monitor the baby

If my baby's chromosomes are normal

If your baby has normal chromosomes and the cystic hygroma disappears by 20 weeks of pregnancy, the outlook will probably be good. If the cystic hygroma does not resolve by 20 weeks, the chance of a healthy outcome decreases to less than 10%.

How will a cystic hygroma affect my baby's birth?

Babies with a large cystic hygroma should be delivered at Leeds General Infirmary as the staff and equipment required to support a baby needing specialised care are based here. Your doctor will discuss with you whether a vaginal delivery or caesarean section is best for you and your baby. If the cystic hygroma is large, a caesarean section may be necessary.

A neonatologist (baby doctor) will review your baby after birth.

Treatment after birth

Treatment may be needed if the cystic hygroma starts to interfere with breathing or feeding as the cysts fill the fluid and swell or if infection develops.

How can cystic hygromas be treated?

Sometimes cystic hygromas need to be treated. For babies, where the cystic hygroma is causing functional problems, the treatment options include:

- Surgical removal
- Sclerotherapy

What about future pregnancies?

The risk of having further babies with a cystic hygroma is very small and for the majority of mothers. We usually quote a recurrence rate of the order of 1-2%.

What happens next?

You will have been referred to the Fetal Medicine Unit at Leeds. The Fetal Medicine consultant will discuss and agree the best plan for you and your family, according to your wishes.

You will have the option to continue with the pregnancy and receive the care outlines above or, to end the pregnancy (have a termination).

Where can I get more information & support?

Be sure to ask questions to the doctor supplying you with this leaflet and make a note of any questions you would like to ask at your Fetal Medicine Unit appointment. Your local hospital will also have a specialist midwife who you will be able to contact for further discussion.

Other useful sources of information:

Antenatal Results and Choices

- **www.arc-uk.org**

Questions / Notes

What did you think of your care?

Scan the QR code or visit **bit.ly/nhsleedsfft**

Your views matter

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