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Women diagnosed with fetal anomaly on booking or anomaly USS

Introduction and Aim

To provide a clear pathway for the management of women, when a fetal abnormality is suspected on USS, at either the booking or anomaly USS. This pathway outlines the care from time of scan until the woman is seen in fetal medicine.

Objectives

To minimise distress to pregnant women and their partners. To ensure clear consistent information is conveyed with signposting to accurate resources and preparation for a fetal medicine appointment.

Scope

This guideline is relevant to all healthcare professionals involved in the care of pregnant women including Midwives, Obstetricians and Sonographers.

It is applicable to both sites, UHW and UHL where antenatal care is delivered.

Equality Health Impact Assessment	*An Equality Health Impact Assessment (EHIA) has not been completed.*
Documents to read alongside this Procedure	*FMU referral form and Criteria*
Approved by	*Maternity Professional Forum*

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Disclaimer

If the review date of this document has passed, please ensure that the version you are using is the most up to date either by contacting the document author or the Governance Directorate.

Summary of reviews/amendments			
Version Number	**Date of Review Approved**	**Date Published**	**Summary of Amendments**
1	December 2020	January 2021	New Document

1 Table of Contents

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2 Pathway: -

Majority of initial counselling will fall to the ANC midwives, with the knowledge of backup from the FMU team for difficult and rare cases. Exceptions – some women with extremely poor prognosis who are not required to go to FMU – request medical review by on-call team same day.

1. Anomaly found on USS
2. Information relayed to woman by sonographer
3. Woman referred to ANC to see midwife, partner can stay with her.
4. If the clinic midwife is uncertain about the scan finding or condition, then please speak to someone in FMU unit in person or on the 'phone before approaching woman and her partner.

3 Counselling by clinic midwife: - AIMS

"I am really sorry that your USS has not gone as expected. You will be referred to a specialist doctor and team in the fetal medicine unit for further scans, tests and professional counselling". "The anomaly scan is a screening test and needs to be confirmed."

1. Less is more.
2. Need to see a specialist in FMU and have a rescan.
3. Provide time frame for this (normally within 5 working days).
4. Some findings may be linked with a genetic condition. Testing for this is with a diagnostic test. This is either an amniocentesis or CVS depending on gestation of pregnancy. Provide ASW pink book which outlines both in detail.
5. For some conditions arrange blood tests for a viral screen. "This may be caused by infections –we recommend having a blood test today so that the results will be available when you see the specialists in the fetal medicine unit"
6. Provide local information sheets approved by Cardiff and Vale.
7. Give woman - Patient Information leaflet – "Referral to FMU when your baby has been diagnosed with an anomaly" (on S Drive/ Teams – FMU Guidelines) – has appropriate web sites and telephone numbers

If woman is unduly distressed, please give details to FMU midwife who will telephone woman at earliest convenience.

4 Specific Conditions: -

If the patient wants specific information leaflets they can be found on S-Drive/Teams

or

https://www.gov.uk/search/guidance-and-regulation?parent=%2Fhealth-and-social-care%2Fpopulation-screening-programmes-fetal-anomaly&topic=e883852d-03e7-4490-96d2-7646e82e7745

4.1 BRAIN

4.1.1 *Anencephaly*

Describes a condition when part of the baby's skull and brain does not form properly. A major part of the baby's skull is missing, and this affects the brain development. Babies with anencephaly are unlikely to survive after birth. These women should be referred to see an Obstetrician same day as they do not need referral to FMU. TOP can then be discussed. Woman needs lead consultant for follow up and advice. Esp. for Preconceptual folic acid 5mg from 3 months before stopping contraceptive. (This must be prescribed by the GP)

Information Leaflet available in FMU

4.1.2 *Ventriculomegaly.*

A fluid filled space within the baby's brain is slightly increased. Occurs in around 3/1000 pregnancies. May be caused by infection, so recommended to have a blood test for these today (Toxo, CMV, Rubella IgG/IgM). Needs a rescan with FMU specialists. If confirmed may be linked with a genetic condition. Testing for this is with a diagnostic test. This is either an amniocentesis or CVS depending on gestation of pregnancy. Provide ASW pink book which outlines both in detail. Further investigations may include an MRI for the baby. Prognosis and outcome can be very different, needs further investigation by specialists. (ASW Information leaflet on S drive/ Teams)

4.1.3 *Agenesis of corpus callosum:*

The part of the brain that joins the 2 sides of the brain may be missing. However, needs a rescan in FMU. This may be linked with a genetic condition. Testing for this is with a diagnostic test. This is either an amniocentesis or CVS depending on gestation of pregnancy. Provide ASW pink book which outlines both in detail. If this is normal, many babies, normal development. Further investigations include a fetal brain MRI – Information leaflet available in FMU

4.1.4 *Holoprosencephaly –*

The front part of the baby's brain fails to develop into clearly separate right and left halves. Often associated with facial anomalies. There are varying levels of severity. This may be linked with a genetic condition. Testing for this is with a diagnostic test. This is an amniocentesis. Provide ASW pink book which outlines in detail. ****Alert FMU midwives to this diagnosis as they may make earlier contact with woman.**

4.2 FACE

4.2.1 *Cleft Lip and Palate*

This is a developmental problem in babies when the upper lip or palate (roof of the mouth) is not joined properly. This means there is a gap in either the lip and/or palate. Very occasionally it can be related to a genetic syndrome. Testing for this is with a diagnostic test. This is either an amniocentesis or CVS depending on gestation of pregnancy. Provide ASW pink book which outlines

both in detail. Refer to FMU and please refer directly to the cleft team in Morriston, Swansea who will contact them in 24-48hrs. Also provide details of CLAPA website. https://www.clapa.com.

4.3 NECK

4.3.1 *Increased NT.*

Explain common finding. Requires further scans in FMU and fetal cardiology. This may be linked with a genetic condition. Testing for this is with a diagnostic test. This is either an amniocentesis or CVS depending on gestation of pregnancy. Provide ASW pink book which outlines both in detail. Leaflets & guidelines for Increased NT on S drive/Teams

4.3.2 *Cystic hygroma.*

Common finding on early scans, 1 in 600. Fluid filled spaces at back of, and around baby's neck/torso. Explain further USS required in FMU & cardiology. This may be linked with a genetic condition. Testing for this is with a diagnostic test. This is either an amniocentesis or CVS depending on gestation of pregnancy. Provide ASW pink book which outlines both in detail. Leaflets & guidelines for Cystic hygroma on S drive/Teams

4.4 SPINE

4.4.1 *Neural Tube Defect (NTD)*

There are several types of neural tube defect including spina bifida. An NTD is an anomaly where the spine has not closed over the central nervous tissue. This hole is known as a lesion. If this 'lesion' is at the head, the skull bones do not develop properly. The condition is called anencephaly and means the baby will most likely not survive after birth. If it occurs anywhere lower down the spine it is called spina bifida and results in varying degrees of physical and mental disability. Most NTDs are 'open' which means that there is no skin over the lesion in the spine; about 1 in 7 cases of spina bifida are 'closed' which means that although the spine has not covered the nervous tissue there is a covering of skin. Needs further scans. This may be linked with a genetic condition. Testing for this is with a diagnostic test. This is an amniocentesis. Provide ASW pink book Future pregnancies need Preconceptual folic acid 5mg from 3 months before stopping contraceptive.

4.5 HEART

4.5.1 *Ventricular Septal Defect (VSD)*

This is a defect (hole) in the dividing membrane between the two heart pumping chambers. Needs rescan with specialist. Amniocentesis will be offered. Provide ASW pink book outlining diagnostic testing in pregnancy and Patient information leaflet Referral to FMU when your baby has been diagnosed with an anomaly found on the S drive/teams

4.5.2 *Other Cardiac*

These all need referred for specialist scans to understand further. Provide ASW pink book outlining diagnostic testing in pregnancy and Patient information leaflet Referral to FMU when your baby has been diagnosed with an anomaly found on the S drive/Teams

4.6 CHEST

4.6.1 *Diaphragmatic Hernia*

Sometimes referred to as a congenital diaphragmatic hernia (CDH), a hole in the diaphragm, which the stomach/bowel can pass through. This could affect the development of a baby's lungs as abdominal organs enter the chest cavity and create pressure against the heart and lungs. Need further scans. This may be linked with a genetic condition. Testing for this is with a diagnostic test.

This is either an amniocentesis or CVS depending on gestation of pregnancy. Provide ASW pink book which outlines both in detail.

4.7 ABDOMINAL WALL

4.7.1 *Exomphalos*

Also called omphalocele. This occurs when the abdomen fails to close around the base of the umbilical cord during the early development of the baby. This means some organs develop on the outside of the baby's abdomen. This is usually the bowel but may include the liver and other organs. The sac containing the exposed organs is usually covered in a protective membrane. Needs rescanning. This may be linked with a genetic condition. Testing for this is with a diagnostic test. This is either an amniocentesis or CVS depending on gestation of pregnancy. Provide ASW pink book which outlines both in detail.

4.7.2 *Gastroschisis*

This is a condition where the baby develops a hole in the abdominal wall during development. This is usually to the right side of the umbilical cord. Some of the bowel may slip through this hole and continue to develop outside the baby's abdomen. Needs rescanning by FMU specialist. Not usually associated with genetic conditions. Patient information leaflet Referral to FMU when your baby has been diagnosed with an anomaly found on the S drive/teams

4.8 BOWEL

4.8.1 *Echogenic bowel.*

The bowel looks bright on ultrasound. Found in 1% of USS. Can be caused by infection (1%), associated with cystic fibrosis (0-33%) and Trisomy 21. Testing for this is with an amniocentesis or CVS depending on gestation of pregnancy. Provide ASW pink book, which outlines in detail. Arrange infection screen (CMV). ASW information leaflet on S drive/Teams – provide this and discuss testing for CF (both parents), following sheet. If both parents consent, then take blood and send to genetics (see sample form in blood rooms).

4.9 KIDNEYS

Leaflets & Guidelines can be found in the Kidney folder within FMU on the S drive/Teams

4.9.1 *Duplex Kidney*

Provide local information sheet. Do not require referral to fetal medicine unit if isolated and uncomplicated. Require follow up USS at 30-32 weeks. Scan follow up should be in general consultant ANC with USS on Tuesday pm, Wednesday am/pm, Thursday pm in UHW, In UHL Tuesday pm Cons ANC and Thursday am Cons ANC are appropriate for scan follow up.

4.9.2 *PCD*

Provide local information sheet. Mild 5-9mm, moderate10-15mm, severe >15mm. Mild and moderate scan require follow up at 30-32 weeks. Scan follow up should be in general consultant ANC with USS on Tuesday pm, Wednesday am/pm, Thursday pm in UHW, In UHL Tuesday pm Cons ANC and Thursday am Cons ANC are appropriate for scan follow up.

4.9.3 *Severe PCD*

Hydronephrosis =/>15mm requires referral to FMU.

4.9.4 *Pelvic Kidney*

Assuming isolated finding, and no adverse features to suggest obstruction. Provide local information sheet. Consultant clinic follow up with scan of fetal growth and of renal tract within cons ANC at 30-32 weeks. Scan follow up should be in general consultant ANC with USS on Tuesday pm, Wednesday am/pm, Thursday pm in UHW, In UHL Tuesday pm Cons ANC and Thursday am Cons ANC are appropriate for scan follow up.

4.9.5 *Unilateral Multicystic dysplastic kidney*

Assuming isolated finding, and no adverse features to suggest obstruction. Provide local information sheet. Consultant clinic follow up with scan of fetal growth and of renal tract within cons ANC at 30-32 weeks. Scan follow up should be in general consultant ANC with USS on Tuesday pm, Wednesday am/pm, Thursday pm in UHW, In UHL Tuesday pm Cons ANC and Thursday am Cons ANC are appropriate for scan follow up. Complicated cases to be referred to fetal medicine.

4.9.6 *Unilateral Renal agenesis*

One kidney is missing. Assuming isolated finding and that present kidney looks normal. Provide local information sheet. Consultant clinic follow up with scan of fetal growth and of renal tract within cons ANC at 30-32 weeks. Scan follow up should be in general consultant ANC with USS on Tuesday pm, Wednesday am/pm, Thursday pm in UHW, In UHL Tuesday pm Cons ANC and Thursday am Cons ANC are appropriate for scan follow up. Complicated cases to be referred to fetal medicine.

4.9.7 *Bilateral renal agenesis*.

This is a lethal condition; most babies would die shortly after birth. These women would normally require to see an Obstetrician same day.

4.10 BLADDER

4.10.1 *Large keyhole shaped bladder*

May be a blockage at outflow of bladder needs rescan and likely to be offered karyotype –. Provide ASW pink book which outlines in detail.

4.11FEET

4.11.1 *Talipes* (Unilateral & Bilateral)

Foot rotated inwards or outwards. Needs rescan. If any other abnormality, then may be linked with a genetic condition. Testing for this is with an amniocentesis. Provide ASW pink book, which outlines in detail.

4.12 PLACENTA

4.12.1 *Low lying placenta*

Provide RCOG information leaflet. **If woman has had a previous caesarean section**, refer to ANC at 22 weeks for review (see placental pathway).

4.13 CORD

4.13.1 *Umbilical vein varix*

Needs rescan and follow up in FMU.

4.13.2 *Two-vessel umbilical cord*

(because of a single umbilical artery). Excellent prognosis **if isolated**. Does not need FMU referral. Serial USS as per dept. policy.

4.14 LIQUOR

4.14.1 *Oligo/anhydramnious*

Evaluate for history of SROM. Should see Obstetrician same day. If Oligohydramnios is severe and there is NO history of PPROM to be referred to FMU

4.15 OTHER

4.15.1 Body-stalk anomaly:

Is lethal and can be referred for appropriate pathway for TOP, if patient wants more information or second opinion can be referred to FMU

4.15.2 *Hydrops*

An abnormal build-up of fluid in body tissues or cavities. Should see Obstetrician same day but also refer to FMU.