

C: INFORMATION AND SUPPORT FOR PARENTS

Before the scan

1. Information leaflet should be sent with appointment details (or departmental website information) outlining location of clinic, what to expect during the scan and who can attend appointment.
2. Additional support should be considered and provided if required for those with limited English language and those with physical, sensory or learning needs for example: foreign language interpreting service, face to face wherever possible; British Sign Language (BSL) interpreter or support worker.
3. Information should be given regarding consent for scan and data collection

At the time of the scan

1. Ensure parents understand the reason for specialist fetal cardiac evaluation, for example an abnormality has been suspected or deemed high risk.
2. Explain what to expect during scan; it may take some time to gather all the information, and then the scan results will be discussed in a separate room.
3. Explain the limitations of a fetal echocardiogram due to the unique fetal circulation.

Counselling following the identification of an abnormality

Following the detection of a problem, information, counselling and support should be provided.

1. Provision of information with implications and choices for fetal heart abnormalities should be provided by a fetal cardiologist or paediatric cardiologist with experience of fetal congenital heart disease.
2. A separate room should be available for discussion of the scan findings. This should be in close proximity to the scanning room to provide a quiet environment, minimising the potential for interruption (16)
3. Information should be jargon free and delivered in an empathetic and compassionate way (17)
4. Information should include an accurate description of the abnormality, information regarding the need for non-surgical or surgical intervention; potential surgical options available for the condition; timing and number of planned interventions likely to be required; associated mortality and morbidity and the short and longer term prognosis for the child.
5. Discussion and presentation of choices should aim to be in as non-directive manner as possible.
6. When present, the impact of extracardiac structural abnormalities in combination with the cardiac abnormality should be discussed and the potential implications for postnatal management. This may involve joint discussion with the FMU specialist.

7. The potential associations with chromosomal or genetic abnormalities should be discussed and the option of invasive or where appropriate, non-invasive testing, should be offered in a timely manner.
8. The parents should be made aware of all options available to them including, where relevant, information on termination of the pregnancy and relevant time limitations for decision making. Sufficient information and support must be provided to enable them to make an informed decision for their individual circumstances. Pregnancy options should be presented in an unbiased, non-judgemental manner (18)
9. In the presence of certain complex and life limiting congenital heart disease, the option of postnatal comfort care or palliative care should be discussed.
10. A fetal cardiac nurse specialist or specialist fetal medicine midwife should be present during both the primary consultation in accordance with UK National standards. It is also of benefit for the specialist nurse/midwife to be present at follow up consultations. Documentation of information given by the nurse specialist/midwife should be recorded.
11. Clear documentation should be made in the patients records of the scan findings, discussion during the counselling session, appropriate follow up or onwards referral.
12. The individual values and beliefs of patients and the impact of these on decision making should be considered and respected.

Written information/resources

- The cardiologist should provide the parents with a written report summarising the information given during the consultation.
- This can be supplemented with written information on the specific diagnosis including diagrams of the cardiac condition. Signposting to trustworthy, accurate websites may be useful, for example, British Heart Foundation, Childrens Heart Federation or other appropriate resources.
- Contact details should be provided for independent counselling groups, and appropriate patient related support groups. This may include signposting to support groups of relevant faiths when appropriate.
- Parents should be provided with contact names of staff they have met during the consultation and contact details for the fetal cardiac nurse specialist/ specialist fetal medicine midwife who will provide continuing support.
- Written communication regarding the scan findings and consultation discussion should be provided, ideally on the same day, to referring team; GP; patient and other members of the multi-disciplinary team when appropriate

Parent support

- Parents should be given adequate time to process the information that they have been given during the consultation, they should be allowed time to express their grief and be left alone if desired.
- The parents will experience a range of emotions after being told that their baby has a serious heart problem, and this may make it difficult for them understand all the information in one consultation. Support with further information and emotional support is likely to be required. This may be provided by a nurse practitioner/counsellor/specialist practitioner who has been present during the counselling session (19).
- Referral to psychology service can be offered if considered appropriate and this resource is available.

Communication with other teams and ongoing care

1. The family should have appropriate follow up arrangements made.
2. If not already undertaken a referral should be made to an associated feto-maternal medicine unit to identify any extra-cardiac malformations; when appropriate to discuss testing for fetal chromosomal and genetic abnormalities with chorionic villus sampling (CVS) or amniocentesis and more detailed discussion of the option of termination of pregnancy if required.
3. If appropriate, onward referral to psychological services, clinical genetics, palliative care services (20) and bereavement services.
4. Counselling at follow up scans may be undertaken in the presence of feto-maternal medicine obstetrician and/or with other members of the multi-disciplinary team: clinical geneticists; neonatologists; palliative care team or a paediatric cardiac surgeon if appropriate.
5. Cases in which management options are unclear or complex may benefit from multidisciplinary team discussion. In some cases it may be most appropriate that this

is a prenatal MDT involving fetal medicine specialists and fetal cardiologists. In others, particularly where there is uncertainty about the postnatal management course, discussion at a cardiac surgical MDT may be more appropriate. The outcome should be documented and fed back to parents.

6. Discussion should be undertaken regarding the time and place of delivery, for example in local obstetric unit vs. tertiary centre at/close to paediatric cardiology services. This discussion should involve the local obstetric and neonatal teams in addition to the tertiary unit and cardiology team.
7. A meeting, for the parents, with a member of the neonatal team should be considered at third trimester follow up appointments for major CHD
8. Where resources are available, parents may benefit from the provision of antenatal support/ information sessions. These may include information from parents who have previously had a child with a congenital heart defect and practical information such as a tour of the hospital.

Bereavement support

Support and the opportunity for further discussion should be given to parents who have suffered a pregnancy loss whether termination of pregnancy or intra uterine demise. This may be provided by fetal cardiology or, if more appropriate, the fetal medicine team.