Congenital Heart Disease

Information for health professionals
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The aim of this information sheet is to support staff involved in counselling pregnant women and their partners when a suspected or confirmed diagnosis of Congenital Heart Disease (CHD) has been made, following an ultrasound scan.

All diagnoses of the conditions must be recorded and audited to ensure the effectiveness of the screening programme.

This information sheet is designed to provide only an overview of the screening and diagnosis of CHD and the available resources. The NHS FASP has prioritised work in this area and future work will provide complimentary and comprehensive information.

1. Definition

Major CHD is defined as any congenital cardiac defect requiring immediate cardiac assessment and/or treatment within the first year of a child’s life (Kirwan and NHS FASP 2010).

There is a wide spectrum of cardiac defects, with pathology ranging from mild to severe. Detection of CHD during pregnancy allows parental choice regarding the course and management of the pregnancy.

For those parents who choose to continue their pregnancy prenatal diagnosis facilitates time to prepare for the likely course of events as the pregnancy progresses to delivery. Research evidence has also demonstrated that anticipatory care plans for delivery and immediate neonatal care have the capacity to prevent life threatening clinical deterioration prior to surgery (Franklin et al. 2002).

2. Prevalence

Major Congenital Heart Disease occurs in about 35 of every 10,000 births (National Audit of Treatment for Congenital Heart Disease, NICOR, UCL).

3. Screening

CHD can be detected prenatally using ultrasound, sometimes as early as 13-14 weeks gestation but it is usually detected during the 18th-20th week Fetal Anomaly scan.

The multi-factorial aetiology of CHD results in the majority of significant defects occurring within an unselected population and therefore most defects are detected during the detailed Fetal Anomaly ultrasound scan.
There are a number of identified risk factors for CHD and defects can also be associated with genetic syndromes and chromosomal aberrations. Some fetal cardiology services will offer specialist screening to these women (BCCA 2010). The national fetal cardiology standards can be accessed via the BCCA website www.bcs.com/pages/page_affiliate.asp?PageID=321&NewsCatID=859.

4. Diagnosis

A formal diagnosis is usually made following referral to fetal cardiology and fetal medicine services within a specialist centre. Fetal echocardiography can detect most major structural abnormalities of the heart, functional abnormalities and rhythm disturbances. Referral should also be made to a specialist in fetal medicine as this will involve a careful assessment for additional abnormalities and if appropriate the offer of karyotyping (by CVS or amniocentesis). ¹

5. Treatment and prognosis

Treatment and prognosis are condition specific and vary from complex cardiac surgery in early neonatal life to observation and assessment only. Morbidity and mortality are affected by the type of cardiac abnormality and the presence of extra-cardiac malformations. CHD can be associated with genetic syndromes. Further information regarding treatment and prognosis can be found in the British Heart Foundation booklets about congenital heart disease and also via the National Audit of Treatment for Congenital Heart Disease, NICOR, UCL accessible via http://www.ccad.org.uk/congenital.

6. Prevention

There is no known way to prevent Congenital Heart Disease however there are a number of identified risk factors for CHD and many fetal cardiology services will offer specialist screening to these women (BCCA 2010). Recent research also suggests maternal obesity and smoking may have adverse effects on the development of the fetal heart (Baardman et al. 2012).

7. Referral pathway

Where CHD is suspected, referral should be made to a Fetal Cardiologist for diagnosis, further counselling and additional information regarding the care and management of CHD. A specialist in fetal medicine should also be consulted to undertake a further scan to search for additional abnormalities and, where appropriate, the offer of karyotyping (by chorionic villus sampling (CVS) or amniocentesis) to exclude a chromosomal abnormality should be offered.

A termination of pregnancy should be offered following appropriate counselling. Women should be offered the opportunity to discuss the possible implications of continuing and ending their pregnancy.

¹More information on CVS and amniocentesis can be found in the following leaflets: Chorionic villus sampling (CVS) – information for parents, Amniocentesis test – information for parents. Chorionic Villus Sampling (CVS) and Amniocentesis – for health professionals. These are available here: www.fetalanomaly.screening.nhs.uk/publicationsandleaflets.
Some women choose to continue their pregnancy and these parents will need ongoing care and support.

Women who elect to continue their pregnancy will be seen antenatally by the paediatric team who will care for their baby. Ongoing antenatal care involves ultrasound scans to monitor the fetus.

The NHS FASP is currently developing a care pathway for Congenital Heart Disease.

8. Further Information

Fetal echocardiography screening now forms part of the ultrasound base menu. The fetal cardiac protocol outlines the four intra-cardiac views required, these are; laterality, the four chamber view, the left ventricular outflow tract, the right ventricular outflow tract or the three vessel view.

The use of colour Doppler is not a requirement, but it should be encouraged as it may help provide additional information and improve the detection of CHD. The storage of images of the fetal heart is not currently a requirement of the national ultrasound standards.

NHS FASP – Fetal Medicine Foundation - Fetal echocardiography online training resource

The fetal echocardiography online training resource reflects the Fetal Cardiac Screening Protocol which forms part of the ultrasound base menu included in NHS FASP 18th-20th weeks Fetal Anomaly Scan National Standards.

To access the online resource please click on the link below:
www.fetalmedicine.com/fmf/online-education/04-fetal-echocardiography/

Serious Cardiac Abnormality leaflets provided by the British Heart Foundation (BHF)

The British Heart Foundation have developed and printed a series of booklets about CHD. They are designed for parents of children with CHD and health professionals.

All of these leaflets are available on their website: www.bhf.org.uk.

- C1 Understanding Your Child’s Heart - Aortic Stenosis
- C2 Understanding Your Child’s Heart - Coarctation of the Aorta
- C3 Understanding Your Child’s Heart - Large Ventricular Septal Defect
- C4 Understanding Your Child’s Heart - Pulmonary Stenosis
- C5 Understanding Your Child’s Heart - Tetralogy of Fallot
- C6 Understanding Your Child’s Heart - Transposition Great Arteries
- C7 Single Ventricle Circulation
- C8 Pulmonary Atresia with Intact Ventricular Septum
- C9 Hypoplastic Left Heart
- C10 Tricuspid Atresia
- C11 Double Inlet Ventricle
• C12 Caring for children on anticoagulants
• C13 Common arterial trunk (truncus arteriosus)
• C14 Complete & partial atrioventricular septal defect
• C15 Pulmonary atresia with ventricular septal defect

References


Baardman M, Kerstjens-Frederikse W, Corpeleijn E, de Walle H, Hofstra R, Berger R, Bakker M. Combined adverse effects of maternal smoking and high body mass index on heart development in offspring: evidence for interaction? Heart Online First, published on January 30, 2012 as 10.1136/heartjnl-2011-300822


National Audit of Treatment for Congenital Heart Disease, NICOR, UCL.

This information has been produced on behalf of the NHS Fetal Anomaly Screening Programme for the NHS in England. There may be differences in clinical practice in other UK countries. The leaflets have been developed through consultation with the NHS Fetal Anomaly Screening Programme expert groups.

All of our publications can be found online at: www.fetalanomaly.screening.nhs.uk.

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