Complex Congenital Heart Defects and Pregnancy

What is complex congenital heart disease?
Broadly speaking, complex congenital heart disease is where you are born with several problems with the heart that require surgical repair and life long medication. People who have complex congenital heart disease may also be cyanosed (blue tinge around the lips and fingernails) because of a reduced oxygen supply.

I have a complex congenital heart defect and I want to have a baby. What should I do?
If you have a complex congenital heart defect and are thinking about getting pregnant, it is advisable to talk to your cardiologist. Together you can discuss any possible risks associated with your pregnancy. Careful planning and management of your own health prior to the conception will reduce both you and your baby’s risk of health problems. If you find out you are pregnant and have not already spoken to your cardiologist, you should contact them as soon as possible for an assessment.

What will the cardiologist do?
The cardiologist will assess your condition ideally before you become pregnant. This will mean that any tests you may need, such as X-rays or scans, can be done without potentially harming your baby. It may be that you will need further tests during your pregnancy. Your obstetrician and midwife may wish to liaise with your cardiologist about your cardiac condition so they can better support you.

Will I stay on the same medication during the pregnancy?
Your cardiologist will discuss your medications with you and make any necessary changes. Anticoagulation is one of the biggest issues for most women with congenital heart disease who want to get pregnant. The cardiologist will discuss the associated benefits and risks of the different types of anticoagulation therapy for you and your baby.

Will my baby have a heart defect?
If you have complex congenital heart disease, your baby’s risk of inheriting a heart defect is approximately 10 times higher than that of a baby whose mother does not have a heart defect. The risks are even higher if both parents have a congenital heart defect. Your cardiologist may be able to help you to access your individual risk of having a baby with congenital heart disease and identify the levels of care that may be needed. A scan early in your pregnancy will often detect signs of any congenital problems with your baby. Should a complicated congenital defect be found, your options can be discussed with your obstetrician.

Heart Helpline
For information and support on anything heart-related

0300 330 3311  bhf.org.uk
Phone lines open 9am to 6pm Monday to Friday

This information is not intended to substitute the advice that your doctor or specialist can give you.

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Can women with congenital heart disease have healthy babies?
Women with congenital heart disease can have a safe pregnancy and give birth to healthy babies. Heart defects vary so much in type and severity it is difficult to give an exact number of healthy babies born to mothers with congenital heart defects.

Is there any risk to the mother?
Although it is rare, pregnancy could shorten your own life expectancy if you have certain complex congenital heart defects and it is best to get as much information as possible to help you make an informed choice.

For further information on Congenital Heart Disease, contact:

The Grown up Congenital Heart Patients Association (GUCH)
75 Tuddenham Avenue
Ipswich
Suffolk, IP4 2HG
Tel: 0800 854759
Website: www.guch.org.uk
(Information on “GUCH and Pregnancy” and “Thinking of Motherhood”)

The Children’s Heart Federation
52 Kennington Oval
London, SE11 5SW
Tel: 0808 8085000
Website: www.childrens-heart-fed.org.uk
(Information on “Checking the unborn baby’s heart”, “Feeding for Children with Heart Problems”)

HeartLine Association
Community Link
Surrey Heath House
Knoll Road
Camberley, Surrey
GU15 3HH
Tel: 01276 707636
Email: admin@heartline.org.uk
Website: www.heartline.org.uk
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For information on nutritional needs during pregnancy:

The British Nutrition Foundation
High Holborn House
52-54 High Holborn
London, WC1V 6RQ
Tel: 0207 4046504
Email: postbox@nutrition.org.uk
Website: www.nutrition.org.uk

The Food Standards Agency
Aviation House
125 Kingsway
London, WC2B 6NH
Tel: 020 7276 8000
Website: www.food.gov.uk
Email contact service available through the website

For information on Maternity leave and Entitlements:

Working Families
1-3 Berry Street
London
EC1V 0AA
Helpline: 0800 013 0313
Email: office@workingfamilies.org.uk
Website: www.workingfamilies.org.uk
Working Families is the UK’s leading work-life balance organisation.

For practical information on Disability, Pregnancy and Parenthood:

Disability, Pregnancy & Parenthood International
National Centre for Disabled Parents
Unit F9,
89-93 Fonthill Road
London, N4 3JH
Freephone: 0800 018 4730
Text: 0800 018 9949
Email: info@dppi.org.uk
Website: www.dppi.org.uk

HEART HEART HELPLINE
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For information on Breast Feeding:
La Leche League GB
P.O. Box 29
West Bridgford
Nottingham
NG2 7NP
Helpline: 0845 120 2918
Website: www.laleche.org.uk

For information on benefits and help for lone parents:

New Deal is a Government programme that aims to give unemployed people the help and support they need to get into work.
Tel: 0845 606 2626 - 7am to 11pm, seven days a week
Website: www.newdeal.gov.uk

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