

7-13-2021

Congenital Heart Disease

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Recommended Citation

Furman, Katie; Jaipalli, Suraj; Kulkarni, Sanika; Lalo, Enxhi; Lewis, Elizabeth; Thomas, Rohan; and Ashwin, Shankar, "Congenital Heart Disease" (2021). *Patient Education Projects*. 31.

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COMMUNICATING CHD WITH YOUR CHILD

A diagnosis of CHD can be challenging to navigate for both parent and child. Here are some tips on how to communicate with your child through their diagnosis.

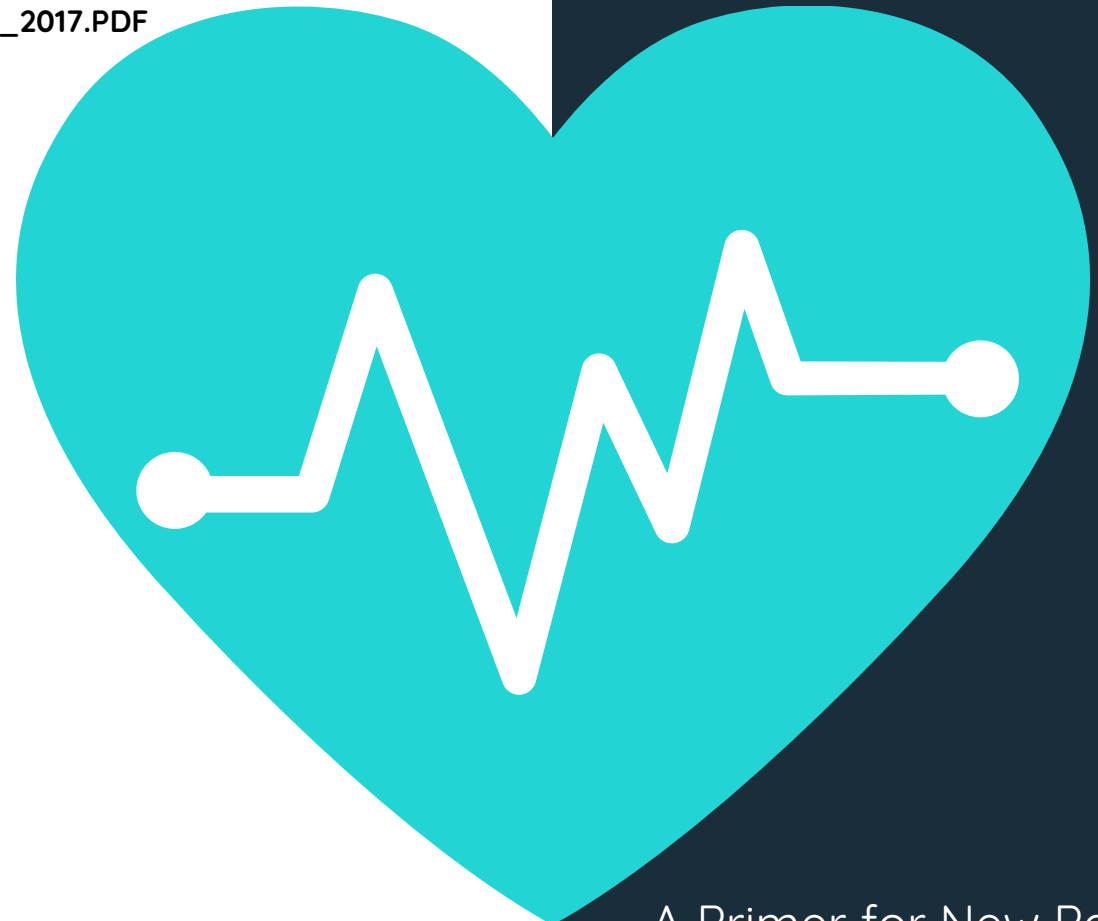
1. Provide information in age-appropriate stages. Use simple language for toddlers such as "heart problem" or "hole in heart" in place of medical terminology.
2. Make hospital visits fun! Connect with social workers, child life specialists, music therapists, and more to make the hospital experience enjoyable for your child and family.
3. Reward your child after completing a difficult procedure (i.e. favorite food, toy, or movie). This is often referred to as a "poke prize" and can be a helpful tool to make it through uncomfortable scans or pokes.
4. As your child gets older, actively engage them in conversations about their diagnosis. This is especially important if your doctor has placed exercise limitations. It can help to communicate that - with proper management - CHD will not stop your child from living a full and happy life!

RESOURCES

FOR MORE INFORMATION:

1. [CDC.GOV/HEARTDEFECTS](https://www.cdc.gov/heartdefects)
2. [CONGENITAL HEART DEFECTS IN CHILDREN- MAYO CLINIC](#)
3. [AMERICAN ACADEMY OF PEDIATRICS- INFORMATION FOR PARENTS AND FAMILIES](#)
4. [MENDED LITTLE HEARTS](#)
5. [CHILDRENSDMC.ORG/SERVICES/CARDIOVASCULAR](https://www.childrensdmc.org/services/cardiovascular)
6. [WWW.NBDPN.ORG/DOCS/NBDPN_FLYER_2017.PDF](https://www.nbdpn.org/docs/nbdpn_flyer_2017.pdf)

CONGENITAL HEART DISEASE (CHD)



A Primer for New Parents

WHAT IS CHD?

CHD refers to defects in the heart that are present before birth. CHD contributes more to infant mortalities than any other congenital disease.



HOW COMMON IS IT?

- 6-13 babies per 1000 live births are affected by CHD
- ~ 1 million children are living with CHD in the United States



MOST COMMON TYPES

- Bicuspid Aortic Valve
- Ventricular Septal Defects
- Atrial Septal Defects
- Tetralogy of Fallot

RISK FACTORS

- Prematurity
- Maternal Alcohol or Tobacco Use
- Maternal Diabetes
- Infections During Pregnancy
- Genetic Syndromes



SYMPTOMS IN CHILDREN

- Abnormal Cardiac Rhythms
- Blue Tinted Skin
- Shortness of Breath
- Failure to Feed
- Swelling



PRENATAL CARE + SCREENING



- **Prenatal Recommendations:**
 - Talk to your doctor about starting prenatal multivitamins + 400 mcg supplement of folic acid (vitamin B9) during the 1st trimester
 - Keep up to date with influenza and rubella immunizations
 - Avoid alcohol and smoking
 - Check with your primary care physician regarding continuing current medications
 - Seek genetic counseling, especially when there is family history of CHD
 - If mother is diabetic, it is important to maintain well-controlled blood sugar levels during pregnancy
 - Adequate nutrition is key! Enrich your diet with fruits, veggies, legumes, whole grains, and fish. Limit intake of dairy, meat, and excess sugar
- **Screening**
 - Fetal echocardiogram, EKG, cardiac MRI, ultrasound

DISEASE MANAGEMENT

***Consult your child's physician for specific management plans**

NEONATAL

- Different procedures are performed based on severity of CHD
- Catheterization - placing a small tube into the heart to fix holes or narrow areas
- Surgeries - surgically opening the chest and using tools to repair advanced complications

INFANCY

- Nutrition - infants with CHD can have difficulty feeding or may follow slower growth progressions
 - Parents can consider using formulas with higher caloric density or increasing feedings
- Immunizations - it's important to keep CHD patients up to date!

CHILDHOOD

- Exercise - physical activity can help strengthen the heart and allow it to work better in the setting of a defect
- Diet- eating heart-healthy, nutritious foods can boost your child's cardiovascular health

ADULTHOOD

- Patients can become their own best advocate by learning more about their CHD.
- Schedule regular visits with PCP/cardiologist, and follow treatments or medication regimens as prescribed.
- If planning for pregnancy or considering birth control, talk with an adult CHD specialist to decide what is right for you!