Special Care for Your Baby with Congenital Heart Disease

What if my baby’s heart condition was diagnosed during pregnancy?
Your baby will have a direct exam after birth. Even with good evaluations during pregnancy, this exam provides important details. Your care teams will update you and explain any differences found from the prenatal exams.

What type of medical care will my child need?

A cardiologist
Your child will always need a heart doctor (cardiologist) to monitor heart health over time. Pediatric cardiologists specialize in children with heart conditions. Your child’s heart doctor will work with you and the primary care provider to keep your child as healthy as possible.

A primary care provider
Just like any other child, your child needs a regular, primary care provider in your own community. This provider will work closely with you and your child’s specialists. You can expect to take your child to the primary care provider often after you leave the hospital to make sure your child is gaining weight and doing well.

Things to consider in choosing a primary care provider:
• Consider using the same office other family members already use.
• Check with friends and family nearby for recommendations.
• Choose an office close to your home.
• Be sure the office accepts your insurance.
• Be sure the provider is accepting new patients.

If you have trouble finding a primary provider, let us know so we can help.

Immunizations
It is important for your child to get all of the routine childhood immunizations.
• Check with your child’s heart doctor about recommendations for your child. Exactly when your child has them can depend on the timing of surgeries or other procedures.

Seasonal vaccines:
• Your child should get the flu shot each year, starting at age 6 months.
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- Ask your doctor if your child should get a Synagis vaccine. This is a vaccine that protects against another seasonal respiratory virus called RSV (respiratory syncytial virus).

**Medicine**

Many children with heart conditions need to take medicine regularly. You will get information and time to practice with all of your child’s medicine.

**Your baby’s hospital stay after birth**

Babies who need heart surgery as newborns are usually in the hospital for 1 month. It can be shorter or longer, depending upon each baby’s health. It takes time for your baby to have a detailed evaluation, undergo surgery, recover from surgery, and learn to eat well. This is also an important time for you to learn to care for your new baby.

**How will I feed my baby?**

Children with heart disease tend to gain weight slowly and may need more calories to grow.

Babies with complex heart conditions may leave the hospital doing a combination of feeding by mouth and feeding by tube. This combination is to be sure they get enough nutrition and enough rest to grow. The feeding tube is a thin, soft, flexible tube inserted from the nose to the stomach. Breast milk, formula and medicine can be given through the tube. Most babies who need a feeding tube do not need it long term — usually only during the early weeks or months. If your baby needs a feeding tube at home, you will have time to practice and get supplies before you go home.

**Breastfeeding**

Babies with heart conditions can breastfeed. In order to get enough calories, though, some babies need to add other feedings by bottle or by tube. If your baby cannot breastfeed right away due to the health condition, you can pump and store your milk. There are pumps you can use at the hospital, or you can bring your own. Your stored milk can be used as soon as your baby can eat.

Breastfeeding and pumping take lots of time and energy. It is not realistic for everyone to use breast milk, especially during the stress of being in the hospital. For help with breastfeeding, please ask your nurse about Lactation Services and materials.

**What about child care?**

Babies with complex heart disease typically need more time to feed, take medications regularly, and are at risk for complications from common illnesses. For these reasons we recommended a small number of consistent adult caregivers, and limited contact with other kids outside the family. If you need child care, try to find a setting with a small number of children. Small day care centers, in-home day cares, or a paid caregiver in your home can provide
consistent care, and may reduce your child’s exposure to germs and illness. For help finding child care in Washington State, see the Resources section.

What safety issues or play restrictions do I need to know about?

CPR Class
Plan for your family and any of your baby’s main caregivers to learn infant CPR and child safety. We offer free training while you are in the hospital. Ask your child’s nurse for more information.

Car seat
Your baby needs a regular infant car seat. Bring the car seat to the hospital. Before leaving you can practice using it with your baby, and you can get help if you need it.

Activity levels
Kids with congenital heart disease can be very active. There are not many rules about their activity. In fact, being active is important for health. Depending on the heart condition, your child may have trouble keeping up with peers for activities involving speed and endurance. For some kids, the heart doctor may advise against certain strenuous activities or highly competitive team sports. Talk with your child’s heart doctor about specific activity recommendations for your child.

Will my insurance cover these medical costs?
Cost is a common concern for families. Even though health insurance generally covers the medical bills, there are other costs when your child needs frequent check-ups and hospitalizations. These may include transportation, meals, lodging, child care for siblings, and time away from work. Having a child with a serious or chronic illness is expensive.

- Social workers and financial counselors at Children’s can help with financial questions and with applications for resources.
- Even if you already have private health insurance, you can also apply for supplemental Medicaid to cover gaps in coverage.
- Some children are eligible for SSI (Supplemental Security Income) based upon the medical condition and the family income.
- Some families are eligible for financial assistance through Seattle Children’s.
Resources for support
At Seattle Children’s Hospital

Family Resource Center
The Family Resource Center (level 7, River zone) provides hospital and health information, personal care items, computer access, showers, laundry and a gathering place for families. Call 206-987-2201.

Spiritual Care
Spiritual Care provides support to patients and families from diverse faith traditions and cultures 24 hours a day. They can help you find clergy of your faith or denomination. Call 206-987-2273. The Chapel and Meditation Room (level 3, River zone) is open 24 hours a day.

Palliative Care
This team addresses the physical and emotional needs of children and their families with complex or life-limiting conditions. They work with families and providers to make plans and treatment choices that are right for you and your child. When desired, they can help arrange comfort care at the hospital or in the home.

Social workers
Social workers are at Children’s to help support your family. They will talk with you about what might be helpful to your family. They can discuss lodging options, financial support, resources about your child’s condition, and more.

Children’s support groups:

Heart-to-Heart, Congenital Heart Defects Support Group
This support group welcomes families during pregnancy expecting a baby with a heart condition, families of children with heart disease, and families grieving the loss of a child with heart disease. Children and their siblings meet others with similar experiences.

Meetings are once a month at Seattle Children’s. For more info, call Dr. Josephine Young, parent, 425-460-5669 or email heartmom1204@yahoo.com.

Parent Support Program (PSP)
The Parent Support Program offers families of children with special health needs a way to connect with an experienced volunteer parent who has been through a similar situation with their own child. Parent matches are made to provide emotional, practical and informational support. Conversations typically happen over the phone. For more information, contact Maria Cervantes, family support specialist, at 206-987-1119, or send an email to parentsupportprogram@seattlechildrens.org.
Sibshops
Sibshops provide peer support and education for brothers and sisters of children with special health or developmental needs. These are lively events that include activities, special guests, discussion and information. Sessions for different age groups are typically offered on Saturdays every other month during the school year. For more information or to register, call 206-987-4133 or email sibshops@seattlechildrens.org.

Other Resources

Heart resources

Websites
• seattlechildrens.org/clinics-programs/heart/
• heart.org/
• pted.org
• childrensheartfoundation.org/
• Children with Special Health Care Needs cshcn.org/

Parenting

Baby Safe Class
• seattlechildrens.org/classes-community/current-class-offerings/babysafe/

Infant and child CPR
• seattlechildrens.org/classes-community/current-class-offerings/first-aid-cpr-aed/

Finding child care
• childcare.org
• childcarenet.org
**To Learn More**
- Prenatal Clinic
  206-987-5629
- Ask your child’s healthcare provider
- www.seattlechildrens.org

**Free Interpreter Services**
- In the hospital, ask your child’s nurse.
- From outside the hospital, call the toll-free Family Interpreting Line 1-866-583-1527. Tell the interpreter the name or extension you need.

**Grief Support and Bereavement Resources**

**Hospice**
- Stepping Stones is the perinatal hospice program
  providence.org/hospiceofseattle

**Photography services for children and pregnancies with life-limiting conditions**
- Soulumination
  soulumination.org
  206-297-0885
- Now I Lay Me Down To Sleep
  nowilaymedowntosleep.org
  206-399-8233
  425-385-3473
  206-310-9888

**Grief support for parents**
- Compassionate Friends
  compassionatefriends.org

**Grief support for kids**
- Safe Crossings
  safecrossingsfoundation.org

**Financial assistance for bereaved parents (funeral and burial costs)**
- The Tears Foundation
  thetearsfoundation.org

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Seattle Children's offers interpreter services for Deaf, hard of hearing or non-English speaking patients, family members and legal representatives free of charge. Seattle Children's will make this information available in alternate formats upon request. Call the Family Resource Center at 206-987-2201.

This handout has been reviewed by clinical staff at Seattle Children's. However, your child's needs are unique. Before you act or rely upon this information, please talk with your child's healthcare provider.

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