Congenital Heart Conditions

A notebook for patients
Congenital Heart Conditions

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This notebook is divided into sections, with an introductory paragraph at the beginning of each section. Feel free to change the order of the sections if a different order works better for you. Please let us know if you have any suggestions to help improve this notebook.

If you need help getting information for your notebook, please ask any of the Adult Congenital Heart Program team members listed on page 3 of the “Regional Heart Center” section.

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Materials developed by Medical Home and the American Heart Association were used in the creation of this notebook. Some information was adapted from materials written by the Adult Congenital Heart Disease Center at the University of California at Los Angeles.

Questions?

Your questions are important. Call your doctor or health care provider if you have questions or concerns.

Regional Heart Center
Adult Congenital Heart Disease Program:
206-598-1764
Regional Heart Center
At University of Washington Medical Center

This section of the Congenital Heart Conditions notebook gives general information about University of Washington Medical Center (UWMC), the Regional Heart Center, your health care team, and helpful contact information.

About University of Washington Medical Center

What to Expect at UWMC
Our program takes an adult-centered, team approach to patient care. That means there is a team of people devoted to your medical care, and that you are part of this team. (For more information about the providers on your team, see page 2.) All final decisions about your cardiac care are made by you and your attending cardiologist.

Throughout your care experience at UWMC, you will meet doctors in various stages of training. You may have an Advanced Registered Nurse Practitioner (ARNP) managing some of your care along with your attending doctor.

Protecting Your Health Care Information
We cannot legally give information about your health and health care to anyone but you without your permission. But, you may name certain family members or friends who are allowed to receive this information.

Insurance Issues
We strongly advise you to avoid any lapses in your insurance coverage. Continuous coverage will protect you from the pre-existing condition policy in many insurance plans. This policy can deny you coverage for a time. Ways to consider keeping your coverage are:

- Working at a larger company that has good medical benefits
- Paying for temporary insurance called COBRA when you have gaps in insurance coverage
• Remaining on your parents’ insurance if you are a student or until you are 26 years old

Tell us if you need help with financial issues. We can connect you with the hospital’s financial counselor or other resources.

**Parking**

You must pay for parking at UWMC. To reduce the cost, have your parking ticket validated in the clinic where you are being seen.

**Local Housing and Hotels**

If you need information about where to stay in the area, please ask about this when you schedule your appointment. Make your hotel reservation well before you come to Seattle for your appointment.

For more information, visit [www.uwmcpatientfamilyhousing.org](http://www.uwmcpatientfamilyhousing.org), where you will find information on:

• Overnight lodging
• Long-term housing
• Transportation
• Maps and directions to UWMC

**Your Care Team**

**Attending Doctor**

Your attending doctor is a cardiac specialist who is responsible for your care. The attending doctor supervises all doctors in training and other staff who are caring for you. This doctor also approves all decisions about your plan of care.

**Advanced Registered Nurse Practitioner (ARNP)**

An ARNP has a Master’s of Science in Nursing and advanced medical training in the assessment, diagnosis, and treatment of patients. Your ARNP is licensed to diagnose and prescribe medicines in Washington state and works with your attending doctor in your care.

**Fellow**

A fellow is a licensed doctor with 3 or more years of experience who is now in training in a specialized area of medicine.

**Resident**

A resident is a licensed doctor in training, with 1 to 3 years of experience.
Medical Student
Medical students are in training to become doctors, but they are not yet licensed as doctors.

Adult Congenital Heart Program Team Members
- Karen Stout, MD – Director, Adult Congenital Heart Service
- Eric Krieger, MD
- Catherine Otto, MD
- David Linker, MD
- Edward Verrier, MD – Director, Adult Congenital Cardiac Surgery Program
- Thomas Jones, MD – Interventional Cardiology
- Stephen Seslar, MD – Electrophysiology
- April Stempien-Otero, MD – Heart Failure and Transplantation
- Mary “Libs” Schlater, ARNP
- Jilian Sachs, Program Operations Specialist

Contact Information
Regional Heart Center
To schedule an appointment (8 a.m. to 4 p.m.) .................. 206-598-4300
To reach a UWMC Regional Heart Center nurse ................. 206-598-0118
To reach the nurse practitioner or doctor during regular clinic hours ................................................. 206-598-4300
To reach the program operations specialist .......................... 206-598-1764
To reach the Regional Heart Center operator (toll-free)...... 800-251-7695
For non-urgent issues only, email ................................... sachsj@uw.edu
For urgent after-hours concerns .............................. 206-598-6190
  Ask for the on-call cardiology fellow on the Cardiology “A” Team to be paged

UWMC
Main hospital operator .................................................. 206-598-3300
Social Work and Care Coordination .................................. 206-598-4370
Anticoagulation Clinic (8:30 a.m. to noon; 1 to 5 p.m.) ....... 206-598-4874
Radiology/MRI (Imaging Services) .................................. 206-598-6214
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Regional Heart Center
Adult Congenital Heart Disease Program:
206-598-1764

Nuclear Medicine .......................................................... 206-598-4240
Pulmonary Diagnostics
(CPET, PFT testing; see “Diagnostic Tests,” page 2)......... 206-598-4265
Maternal and Infant Care Clinic..................................... 206-598-4070
Financial Services......................................................... 206-598-4320

Harborview Medical Center
Operator ................................................................. 206-744-3000
Sleep Disorder Clinic (Sleep Study) ......................... 206-744-4999

Seattle Children’s Hospital
Operator ............................................................... 206-987-2000
Toll-free...................................................................... 866-987-2000
Heart Center Clinic.................................................... 206-987-2015
Heart Center Scheduling.......................................... 206-987-2515
Internet Resources
For congenital heart patients

This section of the Congenital Heart Conditions notebook offers online resources that may be helpful.

Heart Condition Resources
Adult Congenital Heart Association ......................... www.achaheart.org
American Heart Association .................................. www.heart.org
Canadian Adult Congenital Heart Network .............. www.cachnet.org
Congenital Heart Information Network .................... www.tchin.org
Grown Up Congenital Heart ................................... www.guch.org.uk
International Society for Adult Congenital Cardiac Disease ........................................ www.isaccd.org
Marfan Association .............................................. www.marfan.org

Special Needs Resources Washington State
Adolescent Transition Health Project ....................... https://depts.washington.edu/healthtr
Washington State Medical Home ......................... www.medicalhome.org
Washington State Department of Social and Health Services .................................................. www.dshs.wa.gov
Hopelink ................................................................ www.hope-link.org

Americans with Disabilities Act (ADA) Resources
Americans with Disabilities Act ................................ www.ada.gov
Healthy and Ready to Work ..................................... www.hrtw.org
National Center on Workforce and Disability ........... www.onestops.info
Career Counseling Resources

A joint venture of organizations dedicated to addressing Washington state’s employment needs. Includes job search and placement services, job training, and many other job-related services.

Center on Human Development and Disability

Offers assistive-technology resources, such as special-needs keyboards, to help people with cognitive or motor disabilities communicate.

Centerpoint Institute for Life and Career Renewal

................................................................. www1.cpinst.org
Offers workshops, individual support, and resources to guide you through any stage of the career process.

The Work Site/Social Security Online............. www.ssa.gov/work
For those already receiving social security benefits who want to go back to work.

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Regional Heart Center
Adult Congenital Heart Disease Program:
206-598-1764
Lower Your Risk for Endocarditis
For congenital heart patients

This section of the Congenital Heart Conditions notebook explains endocarditis – what it is, how it occurs, its symptoms, and ways to prevent it.

What is endocarditis?
Endocarditis is an infection of the inner lining of the heart muscle. This lining is called the endocardium. The endocardium also covers the heart valves.

How does endocarditis occur?
Bacteria may grow in areas where there is turbulent blood flow (where the flow may speed up or slow down). This can happen where a shunt or a prosthetic heart valve has been placed. The bacteria may settle and increase, and this can damage the tissue. It may also send infection into the bloodstream.

Foreign material, such as valves and tubes, or newly placed patches that may be inserted during heart surgery, may also be sources of infection. Skin infections or dental procedures (especially when mouth care is poor) can also bring germs into the bloodstream.

When endocarditis occurs, it requires a long hospital stay with treatment with antibiotics (germ-killing medicines). You may also need surgery.

What are the symptoms?
Symptoms of endocarditis include:
• Unexplained fever that does not go away
• Paleness
• Night sweats
• Unusual tiredness
• Weight loss
• Muscle or joint pain
• A general feeling of illness

If you have any of these symptoms, tell your doctor.

Tell your doctor if you are unusually tired, or if you have any other symptoms listed here.
How do I prevent endocarditis?

To prevent endocarditis, the American Heart Association recommends using antibiotics before certain procedures, depending on your condition. Talk with your cardiologist to see if you should take antibiotics before you have certain procedures.

To prevent endocarditis, 1 dose of an antibiotic is usually given 1 hour before a dental procedure. With a high level of antibiotic in your bloodstream at the time of your procedure, the likelihood of infection is very small.

You can lower your risk of getting endocarditis by getting regular dental care and taking good care of your skin and nails.

Questions?

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Regional Heart Center
Adult Congenital Heart Disease Program:
206-598-1764
Diagnostic Tests

For patients at the Regional Heart Center

This section of the Congenital Heart Conditions notebook describes some of the diagnostic tests that are done at University of Washington Medical Center. When you come for your clinic visit, your doctor may order one or more of the diagnostic tests listed here.

**Electrocardiogram (EKG)**

The EKG (or ECG) test uses *leads*, which are like stickers. They are placed on your arms, legs, and chest. This test shows the electrical activity of your heart and can help detect abnormalities in the rhythm and structure of your heart.

**Echocardiogram**

This test uses *ultrasound* to produce a picture from the sound waves that reflect from your heart. A hand-held wand is moved around on your chest to produce pictures of the different parts of your heart. This test is useful in checking the structure and function of your heart chambers and valves.

**Holter Monitor**

A Holter monitor has 5 leads that attach to your chest. It records your heart rhythms over a 24-hour period. You will wear the monitor and keep a logbook of your activities and when you did them. Your doctor will then compare this log with the heart rhythms the monitor records.

**Event Monitor**

An event monitor records your heart rhythms when you push a button while you are wearing the monitor. You keep a logbook of your activities and the times that symptoms occurred. Your doctor then compares this log with the heart rhythms the monitor records. An event monitor is usually worn for up to 1 month to record heart rhythms when you feel *palpitations* (racing heart beat), dizziness, shortness of breath, or chest pain.
Stress Testing and Pulmonary Diagnostics

The stress test assesses your heart’s response to physical stress. It shows how the heart muscle responds to increased oxygen needs and the blood flow to the heart. Your heart rate, electrical activity, blood pressure, and respiratory rate are all monitored during the test. An electrocardiogram (EKG) is done before, during, and after the test.

Stress testing can be done with physical exercise on a treadmill or a stationary bike. It can also be done with an echocardiogram before and during stress (stress echo). You may also have a cardiopulmonary exercise test (CPET) or a pulmonary function test (PFT) to evaluate your lungs.

Computed Tomography (CT) Scan

This test uses special X-ray equipment to produce many pictures of your heart and large blood vessels. This test may require an IV for contrast dye to be injected.

Magnetic Resonance Imaging (MRI)

An MRI uses non-X-ray magnetic waves to form pictures of the heart from many different angles. This test may require an IV for contrast dye or sedation. An MRI should not be done for patients with pacemakers, implantable cardioverter defibrillators (ICDs), or certain other implanted medical devices.

Cardiac Catheterization

This procedure uses a small catheter that is advanced from an artery or vein in the top of your leg or in your neck, through a blood vessel, and into your heart. Through this catheter, the doctor measures heart pressures and takes an X-ray video of injected contrast dye as it pumps through your heart.

Electrophysiology Study (EP study)

This test measures your heart’s electrical activity from inside your heart. Narrow catheters are placed into one of the big veins in your leg or your neck and are advanced through the blood vessels into the chambers of your heart to find exact sites of abnormal rhythms. Electrocardiograms (EKGs) and computers monitor your heart’s electrical responses.

An EP study helps us diagnose and treat difficult arrhythmias (abnormal heart beats) and conduction (electrical activity in your heart) problems. These can often be treated with a catheter-based procedure called ablation.
Family Planning
For congenital heart patients

This section of the Congenital Heart Conditions notebook explains what women with congenital heart disease who may want to have children need to consider.

If You Want to Try to Become Pregnant

Many women with congenital heart disease have successful pregnancies. Talk with your provider about your risks during pregnancy.

Parents who have congenital heart disease have a higher risk of having children with congenital heart disease. Women may have an increased risk of cardiac complications during pregnancy, delivery, and beyond.

If you decide you would like to try to become pregnant:

- Talk with your cardiologist before you become pregnant. You may need an evaluation to assure you have the safest pregnancy possible.

- To make sure you and your baby are in the best health possible during the pregnancy and delivery, your health care provider may suggest a care plan that requires frequent visits and careful monitoring.

- Only a few heart conditions would cause your cardiologist to advise you not to have children.

If you are already pregnant:

- Call your cardiologist as soon as possible.

- Your cardiologist may recommend that you see an obstetrician who specializes in managing high-risk pregnancies.

To Prevent Pregnancy

If you decide not to become pregnant, there are many birth control methods available. Talk with your doctor about methods that are safe for you to use.
Adoption

If you are thinking about adopting a child, there are many helpful Internet resources, such as the Northwest Adoption Exchange at www.nwae.org.

Northwest Adoption Exchange is a service that connects families with children who are awaiting adoption.

Questions?

Your questions are important. Call your doctor or health care provider if you have questions or concerns.

Regional Heart Center
Adult Congenital Heart Disease Program:
206-598-1764
How to Read Prescription Labels and Order Refills

This section of the Congenital Heart Conditions notebook tells how to read prescription labels and what to do when you need a refill.

Sample prescription label

Reading Prescription Labels

Match the numbers in the sample prescription label above to the numbers in the table below.

<table>
<thead>
<tr>
<th></th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>The prescription number</td>
</tr>
<tr>
<td>2</td>
<td>The date of your original prescription</td>
</tr>
<tr>
<td>3</td>
<td>The number of refills left on your prescription</td>
</tr>
<tr>
<td>4</td>
<td>Your UWMC patient number, also called your “U number”</td>
</tr>
<tr>
<td>5</td>
<td>The doctor who prescribed the medicine</td>
</tr>
<tr>
<td>6</td>
<td>The expiration date of the drug inside the container</td>
</tr>
</tbody>
</table>
Refills

You may have options for the number of pills in your refills, based on your insurance plan. They are usually given for 30, 60, or 90 days.

If you are close to finishing the pills in the container and:

- The label shows there are refills available, call your pharmacist for a refill.
- The label shows “0” refills, you must talk with your pharmacist or doctor to renew your prescription.

To refill your medicine prescription:

- Allow at least 2 working days for your prescription to be filled.
- If you use an outside pharmacy, ask your pharmacy to fax a refill request to the Cardiology Clinic at 206-598-4669.
- If you use the UWMC Outpatient Pharmacy, call 206-598-4363 for your refill.
- If you need a written prescription faxed to your pharmacy, call the nurse at 206-598-0118. Please leave this information:
  - Your name
  - Your hospital ID number
  - Name of the medicine
  - Name of your pharmacy
  - Your pharmacy’s phone number

Questions?

Your questions are important. Call your doctor or health care provider if you have questions or concerns.

Regional Heart Center
Adult Congenital Heart Disease Program:
206-598-1764
How to Take Your Blood Pressure
For congenital heart patients

This section of the Congenital Heart Conditions notebook tells how and when to take your own blood pressure and how to record the reading.

Blood Pressure Machine

- Choose a blood pressure machine with an arm cuff, not a finger or wrist cuff.
- Make sure that the inflatable part of the cuff is at least as long as the widest part of your upper arm. The size and position of the cuff can affect how accurate the readings are. If the cuff is too large or too small, the readings will not be accurate.
- When you first get your machine, check how accurate it is by comparing its readings with readings that are taken at your doctor’s office.
- Inspect your blood pressure cuff often to make sure the tubing, bulb, valve, and cuff are in good condition. Even a small hole or crack in the tubing can affect how accurate the readings are.

Taking Your Blood Pressure

- Take your blood pressure while you are sitting in a comfortable and relaxed position. Sit with your arm slightly bent and resting on a table so that your upper arm is at the same level as your heart.
- Wrap the blood pressure cuff snugly around your upper arm so that the lower edge of the cuff is 1 inch above the bend of your elbow. Do not put on the cuff over your shirtsleeve; put it on bare skin.
- Try not to move or talk while you are taking your blood pressure.
- Use the same arm every time you take your blood pressure. Your reading may be 10 to 20 points different between your right and left arms.
• Ask your heart doctor if your blood pressure in one of your arms tends to be inaccurate. Know which arm is accurate, and use that arm to check your blood pressure.

• Try to take your blood pressure at the same time every day. Blood pressure readings are usually highest in the morning after you wake up and move around. They decrease throughout the day and are lowest in the evening.

• When you take your blood pressure, you may feel discomfort when the cuff inflates and squeezes your arm.

What to Record
When you take your blood pressure, write down:

• Your systolic (the upper number) and diastolic (the lower number) pressures

• The date and time

• Which arm you used (right or left)

• Your position (sitting, lying down, or standing)

• Your heart rate (pulse), if your blood pressure machine also measures that

How to Get the Most Accurate Readings
To get the most accurate blood pressure readings:

• For at least 30 minutes before taking your blood pressure, DO NOT:
  – Eat
  – Use tobacco products
  – Take medicines that raise blood pressure
  – Exercise

• Plan to rest for at least 15 minutes before taking your blood pressure.

• Do not take your blood pressure when you are nervous or upset.

Questions?
Your questions are important. Call your doctor or health care provider if you have questions or concerns.

Regional Heart Center
Adult Congenital Heart Disease Program:
206-598-1764
How to Take Care of Your Skin and Nails
For congenital heart patients

This section of the Congenital Heart Conditions notebook explains basic ways to protect your skin and nails from infection.

Your skin is a “barrier” against infections that can be serious, such as endocarditis. Your skin is an especially important barrier if you have congenital heart disease.

Protect Your Skin
Avoid doing anything that can break your skin “barrier”:

• Do not pick at cuticles, scabs, or pimples.

• Talk with your cardiologist before you get a tattoo, body piercing, or electrolysis (a procedure that uses an electric current to remove hair).

Tell Your Doctor
Tell your doctor if you have any signs of skin or nail infections, such as:

• Redness
• Swelling
• Discharge

Questions?

Your questions are important. Call your doctor or health care provider if you have questions or concerns.

Regional Heart Center
Adult Congenital Heart Disease Program:
206-598-1764

Taking good care of your skin and nails is an important part of self-care when you have a congenital heart condition.
How to Take Care of Your Teeth

*For congenital heart patients*

This section of the Congenital Heart Conditions notebook tells how to care for your teeth and what to tell your dentist when you have a heart condition.

Good dental habits can help prevent bacteria from entering your bloodstream and causing a life-threatening heart infection. Visit your dentist for cleaning and a checkup every 6 months.

**Daily Dental Care**

In addition to routine checkups, adults with heart conditions should:

- Brush with a soft toothbrush twice a day, once in the morning, and once before going to bed.
- Floss carefully once a day, taking care not to hurt your gums.
- Check with your dentist or doctor if your gums bleed.

**Tell Your Dentist**

Be sure to tell your dentist:

- You have a heart condition
- If you have had any heart or valve surgeries
- If there has been any change in your heart condition
- The names and doses of all medicines you take, especially blood thinners such as warfarin (Coumadin)
- The names and phone numbers of your doctors and other health care providers.

Questions?

Your questions are important. Call your doctor or health care provider if you have questions or concerns.

Regional Heart Center
Adult Congenital Heart Disease Program:
206-598-1764
When to Call, for Patients Taking Warfarin (Coumadin)

This section of the Congenital Heart Conditions notebook tells patients who are taking warfarin (Coumadin) when to call the Anticoagulation Clinic.

University of Washington Medical Center Anticoagulation Clinic
Phone: 206-598-4874
Website: www.uwmcacc.org

Call the Anticoagulation Clinic at 206-598-4874 If:

- You miss a dose of warfarin (Coumadin).
- There is a change in your current medicines. This includes prescription medicines, over-the-counter medicines, herbal or natural products, vitamins, and supplements.
- You eat more or less than your usual amount of foods that contain vitamin K.
- You notice any unusual bleeding or bleeding that lasts longer than usual. This includes red or dark brown urine; red or dark tarry stools; or nosebleeds that last longer than 5 minutes.
- You have a lot of bruising.
- You are scheduled to have a dental procedure, surgery, or other invasive procedure that could cause bleeding.
- Your new warfarin tablets look different than your old tablets when you refill your prescription.
- Anyone tells you to stop or change your warfarin therapy in any way.
- You are pregnant or planning to get pregnant.
- You have any questions about your warfarin therapy.

In Case of Emergency

- Call 9-1-1 right away.

Questions?

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